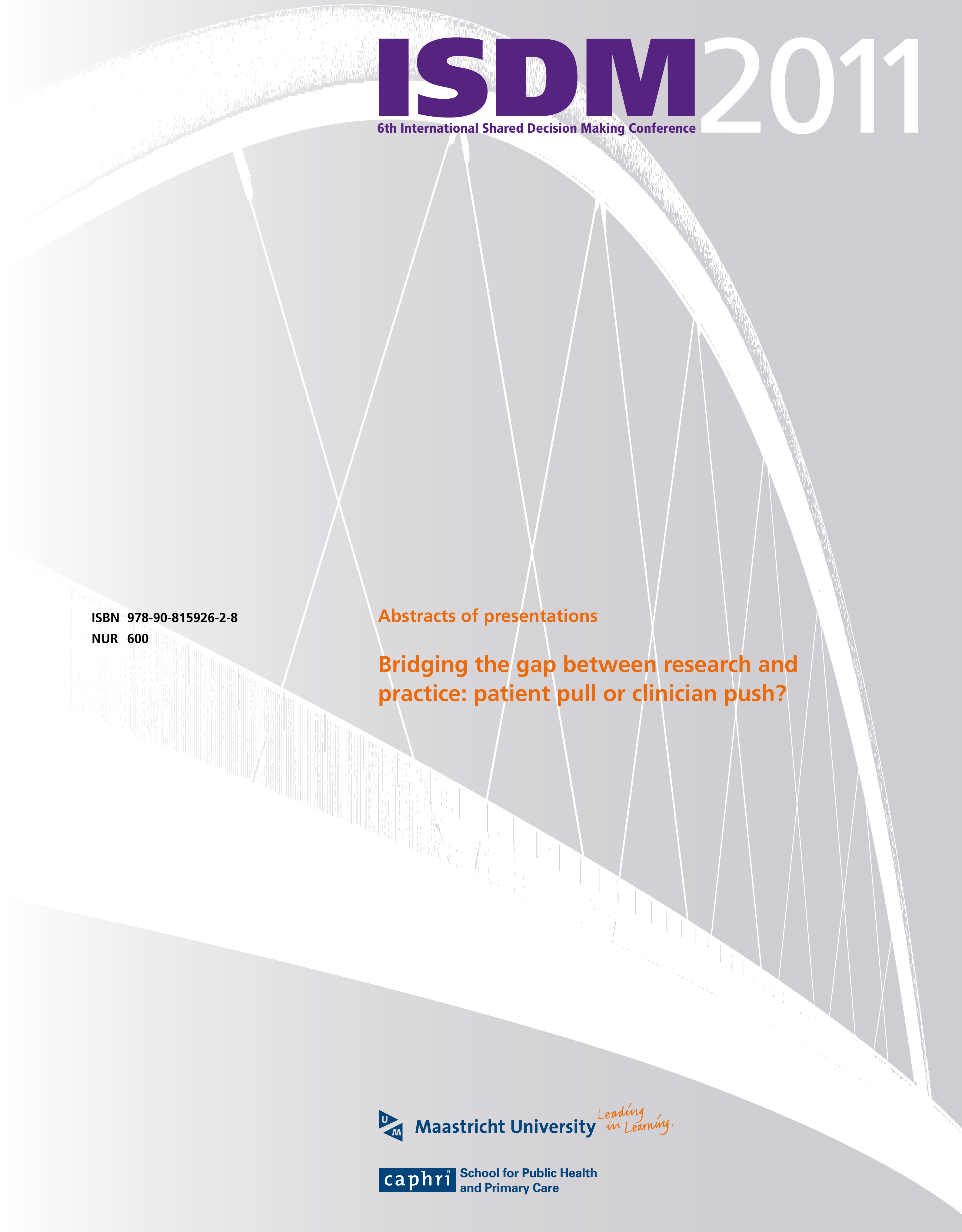

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Abstracts of presentations

Bridging the gap between research and practice: patient pull or clinician push?

Maastricht University *Leading in Learning.*

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43 POSTER SESSION TUESDAY

Patient Reactions to the Offer of Group Support: A Study of Patient Decision Aid Moderating Effects

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BACKGROUND

Research on patient support groups generally reports positive effects. However, some studies find that group support can produce negative outcomes depending on the patient and/or the type of support. These mixed results suggest that offers of group support to patients with a newly diagnosed disease could negatively affect feelings of self-efficacy and desired participation during a subsequent medical consultation. A recent Cochrane review concluded that patient decision aids (PDAs) improve knowledge, reduce decisional conflict, increase risk perception accuracy and lower decision-making passivity. Such positive outcomes lead to the hypothesis that presenting offers of group support with a PDA may counter potential 'side effects' that could occur if the offer of support is presented in isolation. The following study initiates research on this issue using an online panel of 625 respondents broadly representative of US adults.

DESIGN AND METHODS

Respondents were randomly assigned to one of four cells (PDA/Basic Information Only X Support Group Offer/ No Offer). The scenario involved a patient visiting a dermatologist to discuss treatment options for recently diagnosed basal cell carcinoma. Based on standard guidelines that include provision of cost/benefit information and values exploration, respondents evaluated the PDA positively on multiple dimensions. Manipulations worked as intended.

RESULTS

ANOVA identified a positive PDA main effect qualified by a significant interaction on cancer self-efficacy. Respondents advised of group support availability with the PDA had significantly higher self-efficacy scores than those advised of group support with no PDA. Ordinal logistic regression on 'desired treatment control' also found a significant interaction. Group support availability without the PDA resulted in a .73 log odds decrease in desired treatment control.

CONCLUSIONS

The risks of lower self-efficacy and desired participation following an offer of group support may be significantly reduced when the offer is paired with a PDA. Validation awaits field tests in 2011. Mediating pathways will be tested. Even so, it appears prudent for practitioners to consider presenting offers of group support in tandem with a PDA rather than alone.

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110 POSTER SESSION MONDAY

Patients and Physiotherapists Preferences for Patients' Involvement in Clinical Decision Making When Managing Low Back Pain in Saudi Arabia

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BACKGROUND

Low Back Pain (LBP) is a common problem with high socioeconomic costs; it is debilitating and difficult to manage. Various reports suggest that the 'paternalistic"model of decision-making lacks legitimacy as it denies patients' rights to be involved in deciding on their treatment and may consequently impact on management outcomes by not motivating patients to adhere to clinicians' advice and treatment. The few studies that have examined decision-making in patients with LBP suggest that they expect their physiotherapists to communicate with them, individualize their treatment plans and provide them with information. There is no indication whether patients and physiotherapists like to discuss treatment decisions or to share information about managing LPB. This study aimed to explore perceptions and preferences of physiotherapists and patients with LBP on patients' involvement in treatment decisions and sharing information about physiotherapy management of LBP in Saudi Arabia.

DESIGN AND METHODS

A cross-sectional study with 93 physiotherapists and 293 patients with LBP was conducted (December 2009 to May 2010) using self-completion questionnaires developed for this study. Participants were drawn from three cities across Saudi Arabia. Descriptive statistics and chi-square tests were conducted.

RESULTS

Age, gender, education, socioeconomics, and hospital type all had a significant impact on the preferences of subjects in both groups for some aspects of participation in decision making and information sharing ($p < .001$-$.050$). The intensity and location of pain and level of disability in the patient group also demonstrated effects. Patients preferred to participate in making decisions about their home management programs and leave treatment decisions during the clinical encounter to their physiotherapists. Physiotherapists generally demonstrated a paternalistic approach to patient participation when making decisions.

CONCLUSION

This study shows that while both parties sometimes engage in collaborative decision making and wish to share limited levels of information, it is more common for both groups to adopt a biomedical model ensuring that the physiotherapist leads in decision making. It is not known how this compares with approaches in other cultural contexts. This study was limited to literate patients, and further in-depth understanding is required to explore the reasons for the subjects' views.

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25 POSTER SESSION TUESDAY

Barriers and facilitators to participating in a continuing medical education program in shared decision making

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BACKGROUND

In a pilot trial, we showed that DECISION+, a continuing medical education (CME) program in shared decision making (SDM), has the potential to reduce the overuse of antibiotics for treating acute respiratory infections. The objective of the present study was to identify barriers and facilitators to physicians' participation in DECISION+ with a view to applying DECISION+ on a larger scale.

METHODS/DESIGN

We used mixed methods and retrospective and prospective components. For the retrospective component, we consulted research assistants' logbooks, the transcripts of training sessions conducted during the pilot, and participants' evaluations of those sessions. For the prospective component, 18 months after completing the pilot, we invited the five family medicine groups that had participated in the pilot to take part in a semi-structured focus group at their clinic. The interview grid for the focus groups and all analyses were based on an adapted version of the Ottawa Model of Research Use. We used content analysis to study retrospective material and thematic analysis to study prospective material.

RESULTS

A total of 39 physicians had been exposed to DECISION+ during the pilot. For the retrospective component, we collected eight logbooks, the transcripts of 15 training sessions, and 27 participant evaluations. The facilitating factors related by participants consisted of their interactions during the program, DECISION+'s decision support tools, and the subject matter. The participants mentioned no barriers. As for the prospective component, 23 physicians from four of the original five FMGs agreed to participate in the focus groups; of these 23 physicians, 11 had participated in the pilot. The facilitators related by participants consisted of the CME credits awarded for participating in the program, the program's interactive nature, the subject matter and the fact that the program took place at their FMG. They suggested that barriers might be an inconvenient time or location and too long a duration for the program.

CONCLUSION

Participants' identification of facilitators suggests that DECISION+ must be an interactive CME program with a relevant topic, should not last too long and should take place near physicians' place of work.

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26 POSTER SESSION TUESDAY

Determining physicians' intention to take part in a continuing medical education program in shared decision making

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BACKGROUND

In 2007, a pilot study assessing the impact of DECISION+, a continuing medical education (CME) program in shared decision making (SDM), was conducted in five family medicine groups (FMGs) in Quebec City, Canada. The results showed that DECISION+ has the potential to reduce the use of antibiotics for acute respiratory infections. The objective of the present study was to determine physicians' intention to take part in a CME program in SDM similar to DECISION+.

METHODS/DESIGN

Eighteen months after conducting the DECISION+ pilot study, we contacted the FMGs that had participated in the study to inform them of the results and obtain their feedback on DECISION+. During this meeting, we asked all family physicians present to complete a self-administered questionnaire that assessed their intention to take part in a CME program in SDM similar to DECISION+. The questionnaire consisted of four questions about respondents' sociodemographic characteristics and 11 questions based on the main constructs of Azjen's Theory of Planned Behaviour (TPB), measured on a 6-point Likert scale. The constructs were intention, subjective norms, affective attitude, cognitive attitude and perceived behavioural control. We computed descriptive statistics before independently analysing the effect of each construct on intention using Spearman's correlation. Next, we calculated partial correlations to obtain the correlation coefficient between intention and each construct, controlling for the other three constructs.

RESULTS

Of the five FMGs that had participated in the DECISION+ pilot study, four agreed to participate in the research. Of the 23 family physicians who completed the questionnaire, 11 had participated in the pilot study, while 12 were new to their FMG. Physicians' mean intention was 2.57 ± 0.48 (range: 2.00 to 3.00) and the means of all the determinants of intention were positive. Perceived behavioural control and affective attitude were significantly correlated with intention ($r=0.46$ and $r=0.59$, respectively; $p<0.02$). Controlling for other variables revealed that only affective attitude was correlated with intention to a statistically significant extent ($r=0.51$; $p=0.04$).

CONCLUSION

Family physicians from FMGs that had participated in the DECISION+ pilot study intend to participate in a CME program similar to DECISION + in future.

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208 POSTER SESSION TUESDAY

Development of a decision-making educational program related to the health subjects of reproduction in female

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BACKGROUND

As approaches to female, interventional studies related to the decision-making support (DMS) for breast cancer and prenatal tests had just begun in Japan. No engagement related to a comprehensive educational program to the nurse professionals had been made. The purpose of this study is to develop a DMS educational program to the nurses relating to the health in reproductions, with considering the characters of conflicts.

METHODS

This educational program was targeted to those nurses who had two years or more clinical experiences. As the first step, general education goals were set before developing the contents of the program. A 1 to 2-day program was created with considering for future utilization as an e-learning program.

RESULTS

- 1 Setting of the education goals
  - 1 To understand the situations where a decision-making (DM) is needed in an individual's life cycle and the conditions that supports are needed.
  - a To understand the situations where a DM is needed in an individual's life cycle and the conditions that supports are needed.
  - b To understand the character and difficulties of the DM related to the female reproduction.
  - 2 To understand the support based on the common DM and the evaluation approach
  - a To understand the conceptual framework of the [Ottawa DMS] for individual decision-making support
  - b To understand the details of the [decision conflict scale] and the [Ottawa Individual DM Guide]
  - c To understand the necessity and the outlines (concepts) of the common DMS
  - d To provide evidence-based information with the focus on the common DMS anticipatory guidance.
  - 3 To be able to execute and evaluate the DMS. To master the common DM S/communication skills.
  - 4 To be able to examine to obstacles while executing the DMS. To exchange ideas each other to their individual assessments, on the cases that DMS is needed, then execute role-play separating to different groups.
- 2 The total educational program was separated to two days. In the first day, the first two goals were executed through lectures. The remaining two goals including group work and role play were executed in the second day.

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269 SYMPOSIUM PARALLEL SESSION 1

Challenges in measurement of patient decision making tools: how can theory-based evaluation promote learning?

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[2]Harvard University and Massachusetts General Hospital, United States of America

BACKGROUND

The goal of patient decision making interventions, such as decision aids, is to improve the quality of decisions. The measures used to determine the impact of patient decision making tools will vary depending on the theories used and the stage of the process (e.g. development, evaluation or implementation).

METHODS

We will highlight examples of how investigators have used theory to guide measurement across the continuum, from the development of the tools through formal evaluation of the tools in trials through implementation in practice. We will critically review the quality of outcome measures that are commonly used in these areas.

RESULTS

The majority of published measures are used in evaluation studies. Reviews of trials of decisions have found that investigators use many different primary outcomes, and different instruments to measure those outcomes. One systematic review examining the quality of the instruments used in these studies found that the details on the measures used was limited and the quality often inadequate. There has been very little published regarding key outcomes for implementation of patient decision tools. There is, however, a significant evidence base around disseminating and implementing interventions that is relevant for decision aids and other decision making tools.

CONCLUSION

It is important to use theory to guide not only the development but also the evaluation of the tools in order to understand their impact. More attention to development of implementation measures, and strengthening quality of outcome measures used to evaluate decision making tools is needed.

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35 SYMPOSIUM PARALLEL SESSION 1

Using theory pragmatically to guide patient decision making interventions

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Arwen Pieterse, Leiden University Medical Center, NL
Jeffrey Belkora, University of California, San Francisco, USA
Karen Sepucha, Harvard University and Massachusetts General Hospital, USA

STRUCTURE

1 introduction (10 mins), 4 presentations (55 mins),
2 discussants (20 mins), change-over (5 mins).

OVERVIEW TITLE

decision science interventions that meet patient-professional need

BACKGROUND

A challenge for health service researchers is to design, implement and evaluate resources that enable patients' to make treatment decisions well. This requires utilizing evidence from the decision sciences that explain individuals' decision making. One of the challenges for decision scientists is to provide evidence on how to facilitate people's decision making about healthcare choices. The aim of this symposium is to translate evidence informed by theories of individual decision making applied to health that enable services to support their patients' decision making about treatment choices.

METHODS

Three presentations provide an overview of the types of theories and methods used to investigate people's decisions about healthcare options. The presentations focus on: information presentation; value clarification; decision scaffolding.

RESULTS

Enabling choice in healthcare requires a complex intervention that impacts on the patient (and family), health professional(s), patient-professional interaction, and organisation of healthcare. Theory-informed interventions lead to more effective resources but there is a gap between patient-professional need and evidence of which intervention to use in what context and why. A recurring issue is the usefulness of measures to assess improvements in service' provision, and patients' experiences, of interventions to aid treatment decision making.

CONCLUSIONS

The structured discussion of this symposium will focus on issues of measurement raised by the preceding talks and priority areas for further research and practice.

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102 ORAL PARALLEL SESSION 7

A Critical Discourse Analysis of Shared Decision-Making in Palliative Care

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BACKGROUND

It is difficult to accurately infer palliative care patients' preferences for participation in decision-making. Clinical interactions unfold through verbal and non-verbal communication, yet few discourse analyses have explored power relations in consultations about palliative care decisions. The question addressed in this research was: How do patients and their health care providers discursively construct shared decision-making about palliative care options in a hospital-based palliative care team?

DESIGN AND METHODS

This qualitative research study combined ethnography as a research design with critical discourse analysis (CDA) as a method of data analysis in order to explore the power relations that emerge in the clinical encounter and shape the decision-making process. The field research lasted one year and a total of 20 patients were followed longitudinally through the course of their care. Observations and audio-recordings included formal and informal consultations of decisions being made with participating patients and their health care providers. Using Fairclough's three-dimensional CDA framework, the analysis concentrated on the discursive practices used by both patients and health care providers when attempting to bring up decisions and foster patient participation.

RESULTS

Opening up the conversation about palliative care decisions represents the first step to patient involvement. Probing for patients' concerns, understandings and expectations in light of their uncertain future constitute discursive practices that introduce decision-making. Even without explicitly delegating decisions to patients, there exist subtle discourses framing options of care in ways that encourage patients to express their preferences and values. For example, deliberating options in terms of patients' previous clinical experience or quality of life brings their expertise to the fore and shifts the power dynamic.

CONCLUSION

Patients and their healthcare providers seldom address their decision-making roles explicitly. Rather, they discursively construct shared decision-making about palliative care options in a covert manner. Even patients who are seeking active roles subtly express their preferences while exhibiting deference to professional recommendations. Reflecting on these discursive practices promotes awareness of the clinical and ethical stances that are taken everyday when approaching decision-making with patients toward the end of life.

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272 **SYMPOSIUM SESSION 1**

Using the Theory of Critical Reflection to Implement and Evaluate Decision Support in Academic and Community Settings

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BACKGROUND

People vary in their perceptions about the timing, likelihood, and value of treatment outcomes. These perceptions tend to change when outcomes are anticipated and/or with when they are compared with experience. All this variation creates opportunities for mutual learning towards decisions that are informed by well-considered facts and feelings. Theories of critical reflection suggest that people evolve their views by thinking, writing, and talking. Through these social learning processes, people can test and critique their views, leading to more factually-based decisions that also include fuller consideration of feelings.

METHODS

The UCSF Breast Care Center and other collaborating sites, use the FAST critical reflection model of critical reflection to provide a scaffold for shared decision making (SDM) between patients, physicians, family members and others involved in or affected by treatment decisions. There are four iterative stages: Formulate; Analyse; Synthesize; Translate into action. SDM coaches are used to enable patients to engage patients by formulating questions for their doctors after review of decision aid videos and booklets. Coaches then accompany patients to take notes and make audio-recordings of the doctor-patient discussions.

RESULTS

The Decision Services extend the time of critical reflection to include preparation before and reflection after the doctor-patient visit. This service is associated with increased patient knowledge, reduced anxiety, increased self-efficacy, increased question-asking, high satisfaction, and broad use of consultation recordings and summaries. The reach of Decision Services has expanded over the last five years to local, regional, national, and international collaborations. At the UCSF site, 2/3 patients opt in to the services, in a context of universal cooperation among 13 attending physicians.

CONCLUSIONS

The FAST theory of critical reflection has served as a practical basis for integrating stand-alone evidence-based decision and communication aids into a powerful multi-component suite of interventions. We have focused to good effect on the formulation and analysis phases of critical reflection. We now plan to refine our understanding of the synthesis phase, in which patients actually arrive at their decisions after visiting their physicians and reviewing consultation summaries and recordings.

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197 **ORAL PARALLEL SESSION 3**

Effectiveness and economics of telephone-based decision support for rural patients: a randomized controlled trial

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BACKGROUND

Our academic-community partnership implemented Consultation Planning (CP), a form of question-coaching, in a rural, underserved setting. CP was associated with patient decision self-efficacy (DSE) when delivered by trained staff, face-to-face, with patients. We now report on the effectiveness and economics of delivering CP by telephone (Tele-CP). Our study asked:

1 Is Tele-CP as effective as in-person CP in terms of patient decision self-efficacy?
2 Can Tele-CP be delivered at a lower cost than in-person CP?

DESIGN AND METHODS

In a rural, Northern California county we conducted a randomized, controlled trial of non-inferiority between Tele-CP and in-person CP from October 2007 to December 2010. Women with a diagnosis of breast cancer (n=67) were randomized to receive CP in-person (n=32) or by telephone (n=35). The primary outcome, decisional self-efficacy (DSE), is an 11-item Likert scale measuring patients' confidence in their ability to navigate decisions effectively with physicians. Items are averaged resulting in DSE scores ranging from 0 (min) to 4 (max). We used a two-sample t-test to compare post-intervention DSE for tele-CP versus in-person CP. For cost analysis, we added intervention and patient costs together. Patient costs included economic value of patient time.

RESULTS

Mean DSE increased significantly in both in-person (3.15 Pre/3.44 Post) and telephone (3.12 Pre/3.53 Post) groups. The difference in mean post-intervention DSEs was 0.09 in favor of tele-CP, which was not significant [95% CI: -0.15 to 0.33, p=0.47]. The mean cost to society of tele-CP ($160) was $59 lower than in-person CP ($219) [95% CI: $28 to $90, p=0.0003.] This cost advantage for tele-CP was due to the increased time and costs associated with driving for patients randomized to in-person CP. The resource center cost of delivering tele-CP was $169 compared to $186 for in-person CP. This cost includes training ($6/person for both), overhead ($25/person for both) and staff time costs to deliver CP ($139 for telephone, and $155 for in-person).

CONCLUSION

Both in-person and tele-CP were associated with increased levels of decision self-efficacy, and the mean level of DSE attained did not differ significantly. Tele-CP is as effective as in-person CP and costs less to deliver.

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231 WORKSHOP PARALLEL SESSION 2

The SCOPED process and software for guiding people to good decisions

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WORKSHOP CHAIRPERSON'S NAME AND AFFILIATION

Jeff Belkora, Institute for Health Policy Studies, University of California, San Francisco

OVERALL AIM

Share a systematic approach to guiding people to good decisions that has been implemented in academic and community settings in the US and UK. Applications of SCOPED have been associated with improvements in knowledge and participation for people making cancer treatment decisions. SCOPED is also being used with patients making decisions about asthma, diabetes, heart failure, and other chronic conditions.

DESCRIPTION

The format is highly experiential and interactive. Participants should bring two case studies suitable for public discussion, one past decision and one current or upcoming decision. I will briefly present the SCOPED checklist elements (Situation, Choices, Objectives, People, Evaluation, Decisions), and then facilitate participant use of the checklist on their past and current decisions. Participants will leave with the ability to apply this checklist to their own decisions, and some indications of how to use the checklist with other people, including patients. With a little more practice, workshop participants should be able to teach the checklist to colleagues. Participants from the 2009 ISDM workshop may enjoy a refresher and exposure to the new web-based SCOPED software.

LEARNING OBJECTIVES

1. Learn SCOPED Note format (Situation, Choices, Objectives, People, Evaluation, Decision)
2. Use SCOPED software to write a SCOPED Note for 1 past and 1 current decision
3. Reflect on SCOPED with the instructor and other participants
4. Time permitting, review other applications of the SCOPED process (e.g. question-prompting, note-taking)

PRE-REQUISITE KNOWLEDGE OR OTHER REQUIREMENTS FOR ATTENDEES

If possible bring a laptop or smartphone with internet access and come ready to engage in:

- Individual written exercises
- Small and large group discussion
- Simulations or role-plays

Also, to prepare for this workshop, please think of 1 past and 1 current decision (health-related or other is fine):

a Personal - involving you;
b High stakes - involving considerable resources, risks and/or benefits;
c Deidentified - stripped of any private information; and
d Public - you are willing to discuss with anyone at the workshop.

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232 ORAL PARALLEL SESSION 6

Five years of integrating decision and communication aids into routine breast cancer care: an implementation report

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BACKGROUND

Decision aids (DAs) educate patients about treatment options and outcomes. Communication aids (CAs) include question prompts and consultation summaries/audio-recordings. In efficacy studies, DAs increased patient knowledge, while CAs increased patient question-asking and information recall. In 2005 we integrated DAs/CAs into our university-based breast cancer clinic.

DESIGN AND METHODS

From July 2005 through June 2010, we measured:

1 Reach: patients using DAs/CAs annually.
2 Effectiveness: for DAs, patient knowledge and decisional conflict. For CAs, patient questions; decision self-efficacy; and satisfaction.
3 Adoption: patients offered, accepting, and using DAs/CAs.
4 Implementation: Strategies to improve program delivery and staff utilization.
5 Maintenance: Strategies for funding.

RESULTS

1 Reach: DAs grew from 208 to 1,027 annually for a 5-year total of 3,208. CAs grew from 142 to 348 annually for a 5-year total of 1,228.
2 Effectiveness: DA survey (response rate 35%) found increase in knowledge from 45% to 74%; decrease in decisional conflict from 2.61 to 2.09 before/after viewing DAs ($p<0.001$). CA survey (response rate 77%) found increase in patient questions (9 to 24) and decision self-efficacy (6.7 to 8.1) before/after question-prompting ($p<0.001$); satisfaction was 9.1/10. Follow up survey of DAs and CAs (response rate 50%) found satisfaction 8.9/10.
3 Adoption: In 2009-2010 we contacted 83% of 1,355 new patients to offer CAs: 81% responded with 67% of respondents accepting. CA follow-up survey (response rate 50%) found 83% reviewed consultation summaries and 56% reviewed consultation audio-recordings. DA follow-up survey (response rate 57%) found that 76% reviewed DA videos and 93% reviewed DA booklets.
4 Implementation: We employ trainees as highly motivated and high performing but relatively low-cost program staff. We use software, the internet, and telephone communications to track and deliver services to patients.
5 Maintenance: we renewed internal and external funding for 5 consecutive years.

CONCLUSION

We have efficiently and effectively integrated DAs and CAs into routine breast cancer care by employing trainees who use technology to streamline program operations. We meet demand for DAs but can only provide CAs to 33% of new patients due to resource constraints. Next steps: further automate and streamline delivery of CAs.

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233 ORAL PARALLEL SESSION 5

Assessing need for decision and communication aids among breast cancer survivors

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BACKGROUND

A 1994 qualitative needs assessment with 250 breast cancer survivors found they reported suffering, at time of diagnosis, from difficulties with gathering information, asking questions, and remembering doctor responses. In 2010, the Cancer Support Community (CSC) recruited 2,700 breast cancer survivors into an online registry designed to examine the psychosocial impact of breast cancer. CSC surveyed survivors to assess current decision and communication needs and inform future directions for community-based decision support interventions.

DESIGN AND METHODS

In October 2010, 962 registrants answered study-specific questions about their treatment decision process and communications with the medical team. This sample was 99% female, 83% Caucasian. The mean age was 55. 71% had at least a college degree. The average time since diagnosis was 5.5 yrs (mean age at diagnosis was 50). Over half were Stage II + and 13% had a recurrence.

RESULTS

Just over half of the respondents (52%) reported arriving at a treatment decision during the first visit with a breast cancer specialist. Only 14% received informational materials before the first visit and 20% were dissatisfied with the materials they received. 50% brought a written list of questions to the first visit, but 34% forgot to ask questions they had formulated. Some (17%) were dissatisfied with the questions they asked. Of those who were dissatisfied with the questions they asked, 27% were unsure what to ask and 22% were too overwhelmed. On a 10-point scale, a majority of registrants rated 10 on the importance of: gathering information (52%); developing a written question list (58%) prior to the first visit; and taking notes during the consultation (66%).

CONCLUSION

While the majority of patients make their treatment decisions within their first consultation with a specialist, a significant proportion arrive at the meeting unprepared and leave regretting not having asked more questions. These findings suggest the need for decision and communication aids before and during the initial consultation with the breast cancer specialist.

85 POSTER SESSION TUESDAY

A Return on Investment Analysis of Using Health Information Technology in the Course of Shared Decision-Making Processes

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BACKGROUND

In light of the ever-growing importance and usability of medical information systems (IS), the healthcare sector has been investing heavily in these technologies in recent years, with the aim of improving medical decisions and shared decision-making through improved medical processes, reduced costs and integration of medical data. However, the overall contribution of these technologies to the medical field is not obvious, especially, in high-stress environments such as emergency departments (EDs). The objectives of this research are to evaluate the contribution of medical IS to share decision-making and to explore whether investing in health information technology (HIT) in an ED is financially rewarding in evaluating chest pain scenarios.

DESIGN AND METHODS

A cost-effectiveness analysis served as the selected tool for return on investment (ROI) estimations of certain integrative medical IS that support shared decision-making and serves seven main hospitals. The methodology included these stages:

- Developing a theoretical analytical model that represents the admission decision in EDs - We developed our model with decision trees using Markov models.
- Performing a controlled experimental study using the analytical model - We simulated the complicated reality of an ED environment.
- Conducting a cost-effectiveness, by balancing the quality gained from information (retrieved from medical IS) against the costs of providing this information.

RESULTS

The results of the cost-effectiveness analysis show that our specific medical scenarios of chest pain received a clear cost-effective reading since the results (ΔQuality/ΔCosts) were lower than the range of all common threshold values. Furthermore, the use of HIT in the ED improved the quality units (QALY) per patient for all admission decisions and improved the shared decision-making outcomes.

CONCLUSIONS

The use of integrative medical IS during the period of treatment in the ED improves the QALY units per patient and improves clinical shared decision-making in an ED in the course of evaluating chest pain scenarios.

The findings of this study may also contribute to medical technology designers, physicians, patients (by improving healthcare services and their sharing in decision-making) and policy makers in the healthcare sector (regarding the advisability of investing in such systems).

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250 WORKSHOP PARALLELSESSION 1

Do Clinical Practice Guidelines, made by professionals and patients together, stimulate shared decision making?

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In shared decision making patients and physicians discuss together the possibilities for treatment. Therefore an open communication between the physician and the patient is required. The physician suggests options for treatment recommended in the guideline and both, patient and physician, can consider these options including the effects and side-effects. The patient can read this in the patients version of the guideline as well and discuss all with the physician. Together they can reach a shared decision.

This sounds to be an ideal situation! Is it achievable? How is the current reality? Is it possible to have a really good discussion between a healthy professional and a patient? Is it feasible to handle the differences in knowledge about the illness and about diagnostic and therapeutic possibilities? There are not only differences in knowledge but also in physical and mental condition, motivation, discussion capacities, interest etc.

DESCRIPTION OF THE WORKSHOP

10 min. A short introduction on the patients perspective of shared decision-making.

40 min. Discussion in subgroups. Participants are asked to imagine themselves in the role of a patient (with orofacial pain or with migraine at work) or a physician. Some examples are given of situations that may occur in the consulting room. These situations are linked to recommendations in the prospective guidelines.
15 min. Evaluation. Which results can be obtained for patient and physician following the patient perspective procedures of these guidelines?
20 min. Debate How can we stimulate and practise shared decision-making? Can experiences in guideline development from patients perspectives help in clinical situations?

LEARNING OBJECTIVES

- Practising in shifting to a patients perspective.
- Knowledge about different situations about shared decision-making as seen by the patient.
- Understanding of the relationship between guideline development and shared decision-making in clinical situations.

TARGET POPULATION

Professionals applying clinical practice guidelines, developers of clinical practice guidelines and all participants with feelings for the patients perspective in guidelines and treatment are welcome.

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219 EXHIBITION TUESDAY

Is Prenatal Screening Right For You? A decision aid for women considering prenatal screening.

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The American Academy of Obstetrics and Gynecology recommends offering prenatal screening for chromosomal abnormalities to all pregnant women. The practice of using screening tests as tools for risk assessment is time-consuming for providers to explain and difficult for patients to understand. Patients sometimes do not understand that a screening test cannot guarantee a healthy baby or that screening may lead to additional invasive diagnostic testing and difficult decisions about pregnancy management.

A needs assessment, “Is There a Need for a Patient Decision Aid for Prenatal Screening?”was presented at the 2010 SMDM conference in Toronto. This study assessed whether women (n=188) felt informed about prenatal screening, if their stated values matched their screening choice, and if they had any regret about their choice. Although most women reported they felt informed about prenatal screening, some made choices that appeared discordant with what they stated was important to them. In addition, some women were not aware of whether they were screened or could not recall the results of their screening. These results suggest that some women were not making informed, values based decisions about screening.

To address this problem we developed a video decision aid to help women understand the elective nature of prenatal screening and to consider what is important to them in making this decision.

The 30 minute video decision aid includes information about the potential benefits and risks of screening, as well as information about the medical and developmental characteristics of individuals living with the conditions that can be detected via screening. Women and couples share their experiences with prenatal screening, subsequent diagnostic testing, and decisions they made concerning their pregnancies.

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238 ORAL PARALLEL SESSION 3

What’s the use? Assessing Patient Decision Aid Use at an Academic Medical Center

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BACKGROUND

The Center for Shared Decision Making at Dartmouth Hitchcock Medical Center loans about 3,500 patient decision aids (DA) annually. Around 40% of patients return feedback questionnaires with questions about whether they used the program. This study’s aim was to assess DA utilization in patients who did not return DA program materials.

DESIGN AND METHOD

The study design was a 4-cell design of 200 telephone interviews.
Group 1) PSA screening DA mailed with Preventive Health Visit appointment letter. The cover letter states their provider wants them to watch the program before their appointment.
Group 2) Herniated Disc or Spinal Stenosis treatment choices DA prescribed by their spine specialist and picked up in person by the patient.

For each group, interview:
1 50 patients who returned the DA but not the questionnaire
2 50 patients who returned no program materials

The hypothesis was that patients who felt the DA contained useful information would be more likely to watch it.

RESULTS

From July - December 2010, 175 interviews were completed (101 PSA, 74 Spine). 14% of PSA patients did not remember receiving a DA (compared to 0% of the Spine patients). More spine patients felt they received information about why they were prescribed a DA ($p < 0.0001$), and spine patients had higher ‘your doctor thought it was important for you to see the DA’ scores ($p < 0.01$). Not surprisingly, more spine patients reported watching the video/reading the booklet (64%/ 81%) than PSA patients (29% /49%, $p < 0.0003$).

CONCLUSIONS

Patients may be more or less inclined to take advantage of DAs depending on the decision and method of distribution. It is conceivable that patients considering back surgery are more motivated to use these tools than those facing a screening decision. However, these results suggest that patients may be more inclined to utilize a decision aid if presented with clear information about why they are receiving it and if they think their provider feels it is important. In addition, self-reported DA utilization can be high even when programs are not returned as seen in the spine patient group.

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119 ORAL PARALLEL SESSION 3

Quality of evidence informing patients' choice of renal replacement modality in the United States

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BACKGROUND

The quality of evidence informing patients' choice of renal replacement modality (RRM) is unknown.

METHODS

To develop an intervention to improve decision-making about RRM choice, we obtained data from national registries and systematically reviewed studies published after 1987 to summarize evidence regarding differences in RRMs' clinical outcomes. Using modified Grading of Recommendations Assessment, Development and Evaluation (GRADE) criteria, we assessed evidence quality ("very low"(e.g. case series), "low"(e.g. cross-sectional or pre-post observational studies), "medium"(e.g. longitudinal cohort studies or registry data), "high"(e.g. randomized controlled trials (RCTs))) across 12 domains of outcomes identified by patients as important to RRM decisions.

RESULTS

Registries provided evidence on 2 domains (8 outcomes). From 3,384 possibly relevant PubMed abstracts, 105 studies provided evidence on 10 domains (53 outcomes). (Table) There were a few (n=7) longitudinal cohort studies. Most (n=98) studies had qualitative, case-series, cross-sectional, or pre-post designs. There were no RCTs. Most (n=72) studies compared outcomes between hemodialysis (HD) versus peritoneal dialysis (PD) while fewer (n=21) compared HD versus transplant (TX) or PD versus TX (n=3). The quality of evidence was low for the majority of domains [range of GRADE for quality of life domain "very low"to "medium"(article n=14); for cognitive function domain "very low"to "low"(n=11); for mental health domain "low"to "medium"(n=20); for physical function domain "very low"to "low"(n=20); for fertility domain "very low"(n=6); for sexual function domain "very low"to "low"(n=17); for employment domain "very low"to "low"(n=12); for symptoms domain (e.g. pain, cramping) "very low"to "low"(n=39); for body image domain "very low"to "medium"(n=9); for freedom domain "very low"to "low"(n=6)].

CONCLUSION

There is little high quality evidence to inform patients' RRM choice. More rigorous research on preference-sensitive aspects of RRM decisions is needed to better inform decisions.

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127 POSTER SESSION MONDAY

Patients' and their Families' Engagement in Informed Decision Making about Renal Replacement Therapy (RRT) Initiation in the United States

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To inform a culturally sensitive intervention to improve decision-making about RRT initiation, we performed 13 focus groups of patients with end stage renal disease and their family members to elicit their prior experiences with RRT decisions. Patient and family groups (held separately) were stratified by race (African American (AA) or non-African American (non-AA)) and current RRT modality. We asked groups questions to assess: how sick patients were when they [or their family members] first learned about patients' initial RRT modality, whether they felt they had enough time to choose among modalities, whether they learned about other modalities, and whether they understood patients' initial modality prior to initiation.

RESULTS

Patient and family focus groups (N=50 and 43) had experiences with initiating hemodialysis (HD)- (7 and 7 AA; 8 and 8 non-AA), peritoneal dialysis- (9 and 7 AA; 4 and 3 non-AA), and transplant (TP)- (11 and 9 AA; 11 and 11 non-AA, respectively). Most patients initiated RRT on HD. Patients and families often reported patients were very sick at the time of RRT initiation and felt there was "not enough time to make a decision"about what form of RRT to initiate. They also often reported they "did not know about or weren't given another option or choice"about alternative treatment options prior to initiation or felt "rushed into hemo". Many patients who had received TP reported learning about TP while on HD, during which "there was more time to make decisions".

CONCLUSIONS

Patients were often very sick when initiating RRT with little time to make informed decisions. They also lacked knowledge about their initial RRT or other modalities prior to initiation. Efforts to better educate patients and their families about all available treatment options prior to RRT initiation could improve patients' access to optimal therapies, such as early transplant.

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109 POSTER SESSION TUESDAY

Primary care based distribution of hip and knee osteoarthritis decision aids

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BACKGROUND

Decision Aids (DAs) facilitate shared decision making through increasing patient knowledge, clarifying values, reducing uncertainty, and increasing patient participation in decision making. The use of DAs has been shown to reduce the rates of elective surgical procedures by 20%. We sought to create and evaluate the impact of a systematic approach to distribute hip and knee osteoarthritis (OA) DAs in primary care to patients considering orthopedic referral.

DESIGN AND METHODS

Patients at 2 primary care clinics who were referred to orthopedics for hip or knee OA were offered DAs before their orthopedic appointment. Questionnaires were completed before and after viewing the appropriate DA, and after the orthopedic appointment. A subset of patients was contacted by research staff to assess whether they wanted to proceed with the appointment after viewing the DA.

RESULTS

Over the 8 month study period, 58 DAs were distributed and 31 questionnaires were returned. 93% of respondents viewed the entire video DA. The large majority of patients felt viewing the DAs was "very"or "extremely"useful in helping them to understand their condition, treatment options, and personal values, and in helping them prepare for talking with the orthopedist. Patients rated the DAs highly (71% very good or excellent), and unanimously felt that it was important for clinicians to provide patients with these programs. Before watching the DA, 15 of 31 patients (48%) were unsure whether they wanted surgical or non-surgical treatment. After watching the DA, 5 of the 15 unsure patients leaned toward non-surgical treatment, and 1 leaned toward surgical treatment, with 9 remaining unsure. After watching the DA, the number of patients not planning on making an orthopedic appointment increased from 1 to 3.

CONCLUSIONS

The process of distributing DAs to primary care patients considering arthroplasty was successfully accomplished, highly valued by patients, and well accepted by clinicians. The DAs' impact included trends toward decreased intent of patients to schedule an orthopedic appointment and less interest in surgery, although enrollment was too small to reach statistical significance.

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69 POSTER SESSION TUESDAY

Revealing the secret : the dilemma of people disclosing their HIV status. A support workers' perspective.

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BACKGROUND

Living with HIV constitutes an important threat to the psychosocial wellbeing of those who have the disease. The condition of being HIV-positive not only affects physical health, but also it involves a distressing lifestyle including issues with interpersonal relationships, sexual life, treatment and difficult decisions surrounded by stigma and discrimination. The aim was to assess the decision needs of people living with HIV (PLHIV) and to describe these needs in order to consider to what extent they could be met by the development of new services or interventions.

METHODS

A qualitative research study, using phenomenological approach, was conducted. A web-based search strategy was conducted to identify HIV charities/organisations in the UK; inclusion criteria were organisations which provide direct services to PLHIV. The organisations were approached and support workers were invited to take part in the research. Semi-structured interviews were conducted from September to December in 2009. The interviews were audiotaped and transcribed verbatim. Thematic analysis was performed. ATLAS.ti version 6 package was used. Ethical approval was granted.

RESULTS

Access to organisations was very difficult. 13 interviews (7 men, 6 women average age 36 years) were conducted in 5 charities/organisations in London covering PLHIV from different ages, gender, country of origin and sexual orientation. One of the principal emergent themes was revealing the secret; whether or not to disclose is an ongoing conflict for PLHIV; sharing the information can bring social, emotional and medical support, but the negative consequence of being discriminated against makes the dilemma harder. Disclosure constitutes an endless process which involves personal experiences and realities, however little has been done to support PLHIV when facing it.

CONCLUSION

Support workers in the HIV field identified particular decision needs of PLHIV. Revealing their status is a distressing process surrounded by fears of rejection and discrimination; however, it is an essential step to reach social and healthcare support. This process and its potential negative outcomes exemplify the need for social and psychological support for PLHIV. This need may have a large influence on the way care is provided and should be considered in the design of supporting interventions.

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99 WORKSHOP PARALLEL SESSION 4

It Takes 3 (or more) to Tango! Supporting Shared Decision Making among Multiple Stakeholders

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OVERALL AIM

To highlight challenges unique to clinical encounters involving shared decision making with multiple stakeholders and to facilitate discussion of strategies to foster shared decision making in this context.

DESCRIPTION

Family members and/or friends of patients are often present during clinical encounters and contribute to the decision making process. This is true in multiple medical settings (e.g. pediatrics, adult medicine, geriatrics). Successful deliberation between the patient, family members, and the healthcare team can improve decision quality and impact decision process and health outcomes. However, few studies have addressed how best to provide support for decision making when multiple stakeholders are involved.

This workshop will utilize a variety of interactive techniques to engage participants, drawing on their collective experience and expertise. After a short introduction of the topic, participants will generate a list of 1) perceived challenges to shared decision making with multiple stakeholders and 2) perceived benefits that accrue when these challenges are overcome. Participants will then break into small groups to role play clinical scenarios involving clinician, patient, and family member with and/or without use of a decision aid. Small and large group discussion will follow each role play to identify practical strategies that could overcome previously identified challenges. Participants will contribute to an evolving curriculum for decision support training workshops and identify a research agenda in this area.

LEARNING OBJECTIVES

At the end of the workshop, participants will be able to:

1. Describe challenges/benefits to engaging multiple decision stakeholders in a shared decision making process
2. Describe practical strategies to overcome these challenges
3. Practice shared decision making in the setting of multiple stakeholders as a way to explore these strategies.
4. Identify a research agenda for supporting shared decision making among multiple stakeholders, including how best to train clinicians.

Pre-requisites for attendees: None

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230 POSTER SESSION MONDAY

Pilot Testing of Decision Aids to Improve Decision Making in ADHD Care

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BACKGROUND

Guidelines for care of children with Attention-Deficit Hyperactivity Disorder (ADHD) recommend that physicians collaborate with parents to develop a treatment plan. We sought to 1) characterize the degree to which parents were informed about treatment options and involved in treatment planning and 2) pilot test an intervention to improve these outcomes.

DESIGN/METHODS

We video-recorded 39 physician-parent encounters at 7 community-based practices (n=10 physicians). All encounters involved medication decisions for children newly diagnosed with ADHD before (n=27) and after (n=12) implementing a shared decision making intervention including decision aids. After encounters, parents completed a 15-item survey assessing their knowledge of ADHD treatment options and the accuracy of their outcome expectations (range 0 to 100% correct). Physician shared decision-making behavior was coded using the validated 12-item OPTION scale (total score range: 0, no parental involvement to 100, maximal parental involvement). We elicited feedback from parents and physicians on prototype intervention materials and revised to incorporate their suggestions prior to implementation. Materials included: 1) pre-encounter parent decision aid on ADHD treatment modalities (e.g. behavior therapy, medication, or both combined), 2) pre-encounter parent worksheet to inform physician about parent goals/preferences, and 3) ADHD medication choice cards to augment parent/physician discussion of medication options during the encounter.

RESULTS

Pre-intervention (n=27 encounters), parent knowledge was median of 60 out of 100 and physician OPTION score was a median of 27 out of 100, demonstrating much room for improvement. During the first 12 post-intervention encounters, parent knowledge was a median of 80 out of 100 (33% increase compared to baseline encounters) and physician OPTION score was a median of 31 out of 100 (15%

increase compared to baseline encounters). Thus far, only 4 of the 10 participating physicians have used the intervention materials during study encounters, with one physician accounting for 5 of 12 such encounters. Despite coaching on intended use, this physician struggled to use the decision aid to foster parent involvement in decision-making.

CONCLUSION

Preliminary testing of our intervention bundle demonstrates that improving parent knowledge is easier than changing physician behavior. Efforts to optimize the intervention and its implementation are on-going.

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70 ORAL PARALLEL SESSION 6

Patient participation in end-of-life decision-making

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BACKGROUND

Several decision-making models on patient participation exist. The shared decision-making model is often considered ideal. However, results of empirical studies give rise to the question whether this model is the most suitable in all situations or in all patient groups. Overall aim of the study is to investigate which decision-making models (or components) for patient participation can be recognized in practice in end-of-life decision-making and how appropriate these models are for different patient groups.

DESIGN

Qualitative prospective study using observations and interviews.

METHODS

Observation will give insight into actual communication; in-depth interviews into experiences and preferences. The first interview with the patients will take place previous to a decision whether or not to start a life-prolonging treatment. The Control Preference Scale will be used to investigate patient's preference concerning participation in medical decisions. Patient-physician conversations will be observed. After a decision has been made the patient and physician will be interviewed separately to discuss actual participation in decision-making and their satisfaction. The study started with patients who suffer from a malignant brain tumour in whom it has to be decided whether or not to start a life-sustaining treatment (while cure is not possible), but with the disadvantage of burdensome symptoms of chemotherapy. Other patient groups will be determined based on results of the first interviews, eligible departments can be haematology and general oncology.

RESULTS

Preliminary result: 6 patients have been interviewed until December 2010, life-prolonging treatment decisions have not been made yet. All patients are men and between age 37 and 82. Two patients preferred an active role, three patients a passive role and one to share the decision. Passive patients mentioned trust in physician and lack of knowledge as explanations for their preference. There seems to be difference in preference between treatment decisions and minor decisions such as change of medication.

CONCLUSION

Although the results are too preliminary to draw conclusions, it has become apparent that trust in physicians and discrepancy in opinion on best decision between physician and patient are relevant themes to address in future interviews, both in new interviews and in follow-up of current respondents.

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237 ORAL PARALLEL SESSION 4

Improving Shared Decision Making Communication Skills: RCT to Assess Impact of an Educational Intervention

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BACKGROUND

Engaging patients in shared decision making requires specific communication skills. Communicating with patients about uncertainty, risks and benefits, values, and decision conflict are not currently a routine part of medical training. Evidence suggests that physicians' intentions to involve patients in decision making are strengthened by shared decision making (SDM) training workshops. Little data exists on optimal training intensity and impact duration of training interventions. Only one recent study has assessed SDM skills training for resident physicians. Our study goals were to implement and evaluate impact of an educational training program designed to improve SDM skills.

DESIGN AND METHODS

Internal medicine residents (n=41) were randomized to receive a 4-hour educational workshop focused on risk communication, values elicitation and decisional conflict. Control group residents received a concurrent workshop on general teaching methods. We evaluated intervention and control group communication skills utilizing a standardized analysis of audio-taped SDM consultations with a simulated patient. Using a modified Informed Decision Making scale and our own (non-validated) 10 point risk communication scale, we assessed residents' ability to communicate benefits and risks, elicit patient's values, and address decisional conflict. We assessed skills pre-, immediately after and 6 months after the workshop.

RESULTS

There were no statistical differences between control and educational intervention groups at baseline on IDM or risk communication scale scores. Immediately post workshop, risk communication skill scores increased from baseline mean 0.7 (scale of 0-10) to 5.0 ($p< .0001$) At 6 months, the intervention group maintained improvement with a mean score of 4.7. The control group also improved their mean score at 6 months from .0.4 to 3.7. There were no improvements immediately post training on the IDM scale. At 6 months, IDM mean scores (scale 0-22) were minimally higher in both control (15.7->16.7 ($p=.39$)) and intervention (14.7->16.7 ($p=.03$)) groups.

CONCLUSION

The lack of significant improvement in IDM scores is consistent with previous literature regarding impact of educational interventions in changing practicing physicians SDM communication skills. Improvement in risk communication skills is encouraging. Study of more intensive education interventions, including individual feedback, is needed to determine how best to improve critical SDM communication skills.

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264 POSTER SESSION TUESDAY

Determinants of patient-doctor interactions contributing to unsafe situations.

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BACKGROUND

Shared decision making by clinicians and their patients is based upon optimal interaction between both parties. However, individual characteristics of patients and clinicians in health care organisations, may form a poor combination and result in unsafe situations in healthcare.

Insight in determinants of unsafe patient-clinician interaction may provide a basis for improvement of shared decision making.

We designed a conceptual model of patient-clinician interactions and their determinants leading to unsafe situations. The model aims to explain ethnic disparities in patient safety, but in many ways also applies to other patient groups.

DESIGN AND METHODS

Semi-structured interviews on 29 cases were conducted with care providers about unintended events in in-hospital medical care. In addition, semi-structured individual and group interviews were conducted with 22 patients about negative experiences of health care. Interviews were transcribed, qualitatively coded and analysed, using a framework analysis.

A review of literature was used to identify characteristics of patients and healthcare which may increase the risk of unsafe interactions between patients and clinicians.

RESULTS

Unsafe situations occurred because of (1) inappropriate reactions to objective characteristics of minority patients, such as language proficiency, being uninsured or genetic characteristics; (2) misunderstandings as a result of differences in illness perceptions and expectations of care between patient and professional (3) inappropriate care because of providers' prejudices against or stereotypical ideas about minority patients. The unintended events were not only related to human factors, but also to organisational shortcomings. We identified several patient characteristics which may influence the risk of unintended events, such as language proficiency, health literacy, cultural distance, socio-economic status, religion and objective external characteristics. Health care characteristics consisted of organisational aspects at the hospital and ward level, and 'cultural competence' of individual health care providers.

CONCLUSION

Our results indicate that training for care providers to better interact with the immigrant patient and to identify specific patient needs and perspectives is needed. Moreover, health care organisations should be optimized to improve care for specific patient groups. Further research is needed to assess the influence of the determinants we identified and to evaluate the effect of strategies to improve patient-clinician interactions.

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244 ORAL PARALLEL SESSION 1

Causal structure and concurrent validity of the Decisional Conflict Scale in German health insurants

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BACKGROUND

The Decisional Conflict Scale (DCS; O'Connor et al., 1993, 2005) has been developed to assess health-care consumer decision making as an outcome assessment for the evaluation of decision aids and other decision-supporting systems. While there is some evidence for the reliability and aspects of validity for the DCS, studies on the causal structure supporting the underlying theory of the DCS are scarce. LeBlanc et al. (2009) proposed a causal structure with the subdimensions feeling uninformed, unclear values, inadequate support, ineffective decisions predicting personal uncertainty. Aim of the present study is, to investigate the causal structure of the DCS including associated constructs as decision self-efficacy, perceived participation and autonomy preference in a sample of German health insurants.

DESIGN AND METHOD

Data have been gathered in a large postal survey investigating the effects of integrated health care in a rural area in South-West Germany. The Decisional Conflict Scale (16-Item version), Decision Self-efficacy Scale, the Autonomy Preference Index, the Shared Decision-Making Questionnaire-9 as well as sociodemographic data, the participants' current health condition and several single-item measures concerning patients' satisfaction were part of this survey. Using Structural Equation Modeling (SEM), the causal structure of the DCS as well as associations of sociodemographic data and constructs related to decisional conflict were analysed.

RESULTS

Of the 1229 participants responding to the survey, 763 (63 %) were included in the analysis (49 % male, median age 64). Factor loadings (> .6) and goodness of fit of the measurement model (CFI =.95; TLI = .93; RMSEA = .07; SRMR = .04) were acceptable and similar to our previous studies. Analyses regarding the causal structure and concurrent validity of the DCS will be presented at the conference.

CONCLUSION

This study corroborates the stability of the dimensional structure of the DCS in a sample of German health insurants and will provide empirical information to evaluate the validity of the theoretical underpinnings of the DCS.

ACKNOWLEDGEMENTS

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196 POSTER SESSION MONDAY

Comprehension of graphical risk formats among adults with low and high literacy: A think aloud study

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BACKGROUND

Little is known about how individual differences in literacy affect comprehension of graphical formats used in risk communication and decision aids. A “think aloud”method was employed to explore how adults with low and high literacy interpret two different formats: bar charts and pictographs.

METHODS

Eighteen lower literacy (LL) participants were recruited from government funded Adult Basic Education classes teaching basic literacy skills at Technical and Further Education (TAFE) colleges in Sydney and 18 higher literacy (HL) participants were former graduates and first year Psychology students from The University of Sydney. Participants were instructed to verbalise their thoughts (think aloud) while performing a graphs task with either two bar charts or two pictographs. The task involved (a) judging which of the two quantities was bigger (gist task) and (b) estimating the difference between quantities (verbatim task). The audio-recorded data from the task were transcribed and analysed using constant comparison analysis to develop a coding scheme.

RESULTS

Overall, participants correctly answered 142 out of 144 gist task questions (98.6%). When a numerical answer was required (verbatim task), errors were made by participants in both literacy groups but HL participants were more accurate when answering the verbatim task compared to LL participants, and accuracy was higher overall for pictographs compared to bar charts across both groups. Four cognitive strategies were identified to describe how participants interpreted both graphical formats: “*visual perception*“was used in the gist task whereas “*using the scale*“, “*counting*“and “*calculatio*n”were used for the verbatim task. HL participants demonstrated a more systematic cognitive process by employing the cognitive strategies in a logical sequence. Both groups evaluated bar charts as more straightforward and easier to read than pictographs.

CONCLUSIONS

Adults with lower literacy may lack specific graph comprehension skills that adults with higher literacy have acquired. How a format is evaluated may depend upon prior experiences and familiarity with particular formats. Understanding of quantitative risk information presented graphically may be facilitated by providing instruction in graph comprehension to people with low literacy.

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87 ORAL PARALLEL SESSION 4

Informed decision-making about fertility health issues: The validation of the Fertility Status Awareness Tool (FertiSTAT)

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BACKGROUND

Despite a near universal desire for parenthood many young women do not behave optimally when it comes to protecting their fertility (e.g., increase in exposure to fertility compromising risks, increase in age at first birth, delay in infertile people seeking timely medical attention). In addition, many European countries are at below replacement fertility levels (level required to ensure a population replaces itself in size). Therefore, it is clear that more needs to be done to raise awareness about fertility health issues to ensure women are making informed decisions regarding their parenting goals. FertiSTAT is a 22 item self-administered, multifactorial tool that can enable women to get personalized fertility guidance based on their own lifestyle and reproductive profile. The aim of the present study was to assess whether the FertiSTAT items could discriminate between fertile and infertile (trying to conceive >12 or 6 months if >34 years of age) women.

DESIGN AND METHODS

Associations between the 22 risk factors and fertility status were examined in two samples. In the preliminary validation 1073 women (currently pregnant [fertile] versus infertile) completed the survey online or in pregnancy termination, antenatal or infertility clinics in the UK. In the prospective validation women who were currently trying to get pregnant were recruited via an advert in a weekly woman's magazine to complete a series of online surveys at 6 and 12 months (since completion of baseline survey).

RESULTS

Preliminary validation: most risks were independently associated with fertility status in logistic regressions and in the expected direction. Discriminant analysis demonstrated that the set of FertiSTAT indicators could correctly classify whether women were fertile or infertile ($P < 0.001$) with a correct classification rate for the overall sample of 85.8% (326/380), 91.0% (n = 243/267) for the fertile and 73.5% (n = 83/113) for the infertile. Prospective validation data on 207 women will be presented.

CONCLUSIONS

FertiSTAT provides foundational work for public health campaigns to increase personal fertility awareness that could enable women to make informed decisions concerning their parenting plans.

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223 POSTER SESSION MONDAY

Experiential expertise as a crucial patient pull condition for successful SDM.

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TITLE

Experiential expertise as a crucial patient pull condition for successful SDM.

BACKGROUND

According to DVN (Dutch Diabetes Association) the ideal of Shared Care consultation is: the person with a chronic disease and the doctor are two distinct experts who treat one patient together.

In this case the doctor is a medical and the patient an experiential expert (EE). If the patient is not yet an EE, it is essential DVN and the doctor encourage him/her to become an EE. Experiential expertise, which presupposes practical medical knowledge, is a body of expertise that exceeds the boundaries of individual experience, it is tested and adapted continuously in daily life by EE themselves. Having experiences in living with diabetes mellitus (DM), which every (narrative) diabetes patient has, does not mean one is an EE. An EE is trained and certified by the DVN to support peers.

Given the foregoing we have decided to objectify and to systematize experiential expertise. It concerns (reported) successful diabetes-related behavior in order to prevent hypo- and hyperglycemia; from this we have derived guidelines in two life-domains: driving and work.

DESIGN AND METHODS

This exploratory qualitative study used individual in-depth interviews with EE who have DM and use insulin and/or tablets. Validation was based on data-saturation.

RESULTS

In this study on driving 33 EEs, on work 47 EEs were involved. It has resulted in: eleven recommendations for safe driving with 27 guidelines and ten recommendations regarding work with 41 guidelines. Central issues were preventing, anticipating on and handling (on coming) hypo- and hyperglycemia along with fulfilling the public relations role.

CONCLUSION

Objectify and systematize of successful diabetes-related behavior resulted in guidelines for safe driving and concerning work. According to EE these guidelines enable peers and doctors to deal with possible limitations of the consequences of DM in daily life.

HYPOTHESES

- EEs are in an optimal position to encourage both less experiential patients and doctors in patient-empowerment.
- Experiential expertise is a crucial condition for successful SDM.

Shared Decision Making presupposes medical expertise and experiential expertise as complementary fields of expertise.

93 ORAL PARALLEL SESSION 7

Integrating Patient Decision Aids into Clinical Care: DHMC Center for Shared Decision Making 2006 - 2010

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BACKGROUND

Patient decision aids (DAs) have been shown to help patients make informed choices for preference-sensitive healthcare decisions (O'Connor et al., 2009). The Center for Shared Decision Making (CSDM) at Dartmouth Hitchcock Medical Center (DHMC) has been providing patients with decision aids since 1999.

Our objective is to summarize the last 5 years of the feedback from patients who have received decision aids as a part of clinical care.

DESIGN AND METHODS

Eligible patients are referred to the CSDM for DAs as a part of clinical care. Several distribution strategies are used, including:

1. Post-visit, take home: providers refer eligible patients to the CSDM to borrow a condition specific DA after their appointment,
2. Pre-visit, mailed: appointment type, new diagnosis, age and gender may initiate a mailing of DA packet prior to an appointment,
3. Walk in, self referrals.

All patients who borrow a DA are asked to: 1) complete pre-DA questionnaire, 2) watch the DA, and 3) complete post-DA questionnaire.

Measures: treatment/screening preference before and after DA, decisional conflict, DA acceptability.

DA* topics include: spine conditions, knee and hip osteoarthritis, breast and prostate cancer, cancer screening, cardiology, OB/Gyn, and chronic conditions.

RESULTS

From 2006-2010 the CSDM distributed 20,543 patient decision aids. Average patient age was 57.8, 43% were female; 37% returned a questionnaire. Similar response patterns were observed across topics.

- Fewer patients were unsure about their decision (pre-DA 28% unsure, post-DA 18%, $p<0.0001$).
- A substantial proportion (23%) of patients switched their treatment intention (pre vs. post DA).
- Patients felt they knew the options (89%) and were clear about what was important (84%).
- Most rated the DAs favorably (94%) and would recommend the programs to others (95%).

CONCLUSIONS

Factors associated with good decision making include understanding the treatment options, the risks and benefits of those options, knowing which benefits are personally important, and feeling confident. These results suggest that systematically including decision aids as a part of clinical care can help patients make quality healthcare decisions.

(*Source of DAs: Foundation for Informed Medical Decision Making/Health Dialog Shared Decision-Making© programs)

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95 WORKSHOP PARALLEL SESSION 6

Yes, I Can! Moving Shared Decision Making From Research to Practice: PART 2

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OVERALL AIM OF THE WORKSHOP

The world of shared decision making is filled with researchers, decision scientists, health policy experts and clinicians who are devoted to studying, testing and establishing guidelines and policies. Over the past 25 years this has been the necessary work to establish a credible basis for the tools and processes that ultimately must be translated to the clinical setting and reach the patients and clinicians who will make use of them. This workshop teaches the use of practical tools and processes to make this translational imperative real.

Workshop Part 1 demonstrates decision support tools; workshop Part 2 demonstrates workflow mapping and clinical integration. This is being submitted as 2 separate 90 minute workshops but can be combined into one if necessary.

DESCRIPTION OF THE WORKSHOP

Module 1

See separate submission of Yes, I Can! Moving Shared Decision Making From Research to Practice: PART 1: WHAT DO I DO?

Module 2

HOW DO I DO IT?: Demonstration of and practice with mapping clinical workflows in your setting, to translate what you want to do into when and how you will do it. workshop includes workflow demonstration and audience participation in small workgroups with debriefing

LEARNING OBJECTIVES TO BE COVERED IN WORKSHOP

Module 2

1 Participants will demonstrate proficiency in constructing a workflow map for their home clinical setting
2 Participants will incorporate understanding of pros and cons of timing of interventions to maximize both workflows and decision support.
3 Participants will demonstrate proficiency with concepts of best practices and potential challenges to implementation: identifying clinical champion, use of project design tool, assembling team, determining scope of project, measurement tools, feedback and reporting mechanisms, measures of success.

Pre-requisite knowledge or other requirements for attendees

Recommended (not required):
1 Center for Shared Decision Making - Decision Support Toolkits (http://www.dhmc.org/webpage.cfm?site_id=2&org_id=844&gsec_id=0&sec_id=0&item_id=43192)

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74 ORAL PARALLEL SESSION 2

The effect of patient participation in health decisions: an evidence-based review

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BACKGROUND

Patient participation in health decisions is widely thought to be positively associated with a range of patient outcomes. We conducted a review of articles published through the end of 2009 to identify the extent to which patient participation about decisions in the medical encounter is associated with patient outcomes.

DESIGN AND METHODS

A Pubmed (Medline) search of English language, non-animal studies using the MeSH headings (Physician-Patient Relations[MeSH] OR Patient Participation[MeSH]) and the terms (decision OR decisions OR option OR options OR choice OR choices OR alternative OR alternatives) in the title or abstract resulted in 7041 citations. We reviewed all available abstracts, rejecting 5579 because they were not: about the topic, empirical, specific to decision making, in the context of physician-patient decisions, or because they lacked either a measure of patient participation or an outcome measure (psychological or biological). We obtained the remaining 1462 articles, of which 83 met the inclusion criteria. As RCTs provide the strongest evidence regarding potential effects of patient participation, we include only RCTs (n=6) in our final sample.

RESULTS

The 6 studies vary widely in measurement of patient participation (e.g., coding of audio recordings; self report of involvement in decision making) and patient outcomes. Patient involvement reportedly increased in each of the intervention groups. However, two studies found no effects of patient participation in decision making on outcomes. Four studies found positive effects: two studies reported less decisional conflict among the intervention group; one study found fewer hospitalizations; and one study reported lower anxiety, although 3 studies found no relationship between anxiety and participation.

CONCLUSION

Few RCTs include a measure of participation in a decision and its relationship to an outcome. Those that exist have little consistency in how these constructs were measured. Importantly, the seminal RCTs by Greenfield, Kaplan et al., which found positive relationships between patient question asking and health outcomes, did not meet our criteria as there was no indication that decision making had occurred. There is a great need for well-designed studies of decision making that include measures of patient participation and clinically relevant psychological and biological outcomes.

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256 ORAL PARALLEL SESSION 4

Parents' knowledge and views of cancer-related fertility effects and fertility preservation options for their daughters

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BACKGROUND

Survival rates for children with cancer have increased tremendously, and approximately 80% of children who develop cancer survive. Fertility preservation has been raised as a matter of priority for survivors of childhood cancer, as cancer treatments lead to infertility or a reduced reproductive time span. Although fertility preservation for post-pubescent males is well established, methods of fertility preservation for girls are still experimental. This study aims to better understand parents' knowledge and views of cancer-related fertility effects and fertility preservation options for their daughters.

DESIGN AND METHODS

Seventeen retrospective interviews about fertility-related concerns and decision making were conducted with 19 parents whose daughters were diagnosed with cancer as minors. Audio recordings were transcribed and examined both with thematic analysis and content analysis.

RESULTS

Parents ranged in age from 37-64, while 12 were white, 3 Latino, 1 Black, and 1 ethnicity not captured. At the time of diagnosis, the children ranged from 9 months to 17 years old, including 6 teenagers. Parents reported that the topic was often not discussed, discussed only if they broached it, or discussed after treatment was complete. Several parents were left with uncertainty about their child's fertility status (e.g., how to monitor, if it can be monitored). Parents strongly felt that the ability to reproduce would help their children to have a "normal"life. However they also expressed that fertility preservations decision making before entering treatment would have been overwhelming, given the necessity to begin treatment quickly. Parents expressed an interest in using data to consider pros and cons of options, although the experimental nature of many options precludes the existence of strong evidence. Despite the fact that several children of parents in our sample were teens, only one parent had a conversation with their child about fertility preservation before treatment.

CONCLUSION

Parents are unprepared for decision making about fertility preservation, and providers do not seem to initiate timely and substantial discussions with parents. Parents are potentially interested in experimental options for their children, but need significant support in order to make such decisions.

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214 WORKSHOP PARALLEL SESSION 7

Teaching essential shared decision making communication skills

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Aim: to teach the essential SDM communication skills to clinicians

Helping patients make informed medical decisions congruent with their values is critical to patient-centered care. High quality decision aids have been shown in over 55 randomized controlled trials to improve patients' knowledge, provide more accurate risk perceptions, increase patient participation in decision-making and reduce the numbers of patients who are undecided. However, clinicians have not been taught the communication skills required to do effective SDM counseling. These skills include eliciting patients' values, helping resolve decisional conflict and providing data about the risks and benefits of different options in a clear and understandable way. This workshop will briefly review the medical literature which has assessed the SDM communication skills of practicing clinicians. The essential communication skills required for effective SDM will be reviewed, including elicitation of patient values, effective risk communication, and identifying and resolving decisional conflict. Participants will observe video clips which demonstrate these skills, then practice skills in dyads.

LEARNING OBJECTIVES

1 Review literature on clinician SDM communication skills
2 Introduce communication skills needed for SDM
  - eliciting patient values
  - doing effective risk communication
  - identifying and helping resolve decisional conflict
3 Practice SDM communication skills in dyads

Pre-requisites for attendees: none

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79 ORAL PARALLEL SESSION 5

Decision Support Needs in Caregivers of Children with Autism Spectrum Disorder

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BACKGROUND

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders characterized by impairments in communication and social interaction, along with restrictive and repetitive behavior. They are relatively common (prevalence 1/110) and frequently associated with co morbid and sometimes lifelong medical and behavioral problems, and intellectual and mental health disabilities. Parents are faced with numerous ongoing decisions regarding medical, behavioral, educational, diet/vitamin and other therapies with limited evidence on risk and effectiveness. Little is known about parental decision-making experiences or decision support needs in ASD.

DESIGN/METHODS

A qualitative content analysis was used to analyze information from focus groups involving parents of school-aged children with ASD.

RESULTS

Themes of need (1) for information and (2) for social connections are consistent with other studies of parents making decisions on behalf of a child. ASD caregivers noted frequent contradictory information, contributing to distress and confusion. They experienced difficulty connecting with others facing similar decisions for multiple reasons, most notably time spent caring for their affected child. Novel themes that emerged included (1) increased complexity of decision making related to the multitreatment options and the controversy associated with many, (2) interconnectedness of traditional medical, complementary, and non-medical treatments, with need for professionals to support caregiver decisions across all intervention types, and (3) the significant role of emotions before, during and for a prolonged time period after decisions.

Parents expressed the need for for easily accessible, accurate information in a variety of formats to help compare treatment options, risks, and benefits. They sought professionals who were respectful of their family with whom they could develop a trusting relationship, and they sought connection with others who have faced similar decisions.

CONCLUSIONS

This study, by assessing parents' past decision making experiences and information and decision-making needs, serves as a first step toward providing decision support to families of children with ASD. Understanding the decisions faced by families who have children with ASD will inform the development of caregiver tools and professional training to implement shared decision making into care of children and families affected by this disorder.

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80 EXHIBITION MONDAY

Medication treatment of Challenging Behaviors in Autism: A Decision Aid for Parents

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Autism Spectrum Disorders affect approximately 1 in 110 children, resulting in impairments in communication, socialization, and behavior. Behavioral symptoms can be significant and can lead families to consider a variety of treatments. Many families consider psychopharmacologic medication as one option, and about 40% of children with ASD in the United States are prescribed medication for behavior. This decision aid was developed to empower parents and caregivers to work with their health care provider in considering this treatment option for their child.

The decision aid was developed in accordance with IPDAS criteria. It includes key points about autism and medication, along with comparison of options, personal stories, clarification of personal values, and a question prompt list. In addition, sections that assist families in identifying problem behaviors that may and may not be helped by medication were included based upon caregiver feedback in the development process. Consideration of personal benefits and risks incorporated a tool to assist families in determining severity of behavioral problem and impact on the child and family. Links to reliable family resources and sources of information are imbedded.

The decision aid is a visually appealing tool that can be utilized electronically or on paper, with reading level below the 8th grade level. This is the first decision aid we are aware of that has been developed for use with patients/families affected by autism.

The materials were developed with the support The Autism Treatment Network/Autism Speaks and US Department of Health and Human Services, Health Resources and Services Administration.

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191 POSTER SESSION MONDAY

Medication for Behavioral Symptoms in Children with Autism: Decision Support Needs of Caregivers

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BACKGROUND

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders characterized by impairments in communication, social interaction, and the presence of repetitive behavior. This group of disorders is relatively common (prevalence 1/110) and is associated with a high rate of mental health diagnoses (anxiety, ADHD) and other challenging behavioral symptoms (irritability, insomnia, tantrums, aggression, self-injury). Poorly controlled behavioral symptoms contribute to academic underachievement and more restrictive educational and residential placements. Approximately 40% of children with ASD take medications including antipsychotics, stimulants and anti-anxiety agents, to treat behavioral and mental health problems, despite high rates of side effects and limited evidence regarding safety and efficacy in ASD. Little is known about the decision making experience or decision needs of caregivers of children with ASD facing these decisions.

DESIGN/METHODS

Caregiver focus groups (semi-structured format) were conducted during the process of developing decision support materials for families considering medication treatment. A qualitative content analysis was used to analyze focus group data.

RESULTS

Consistent with previous studies of parents making decisions on behalf of a child, ASD parents indentified need for information, connection with others, and control over the process of deciding whether and when to use medication for their child's behavioral symptoms. Additional themes specific to this population were identified, including:

1. Inter-relatedness between medication decision, symptom severity and use/effectiveness other treatments (medical, behavioral, educational, complementary). Effectiveness and availability of other treatments often impacted severity of symptoms, which in turn affected the timing and potential benefit of the medication decision.
2. Preference to maximize non-medication interventions that families considered lower risk prior to considering psychopharmacologic treatment, and
3. Chronic emotional distress. Families described strong emotions including guilt and self-doubt during and well after decision making. Distress related to the decision and the impact of the decision on the child's present and future general condition was described.

CONCLUSIONS

The decision of whether to use medications to treat behavioral symptoms in children with ASD is complex. Caregivers of children with ASD facing this decision have specific support needs that must be taken into consideration when developing materials and when planning professional training.

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12 ORAL PARALLEL SESSION 5

Involving Parents in Decisions about Possible Tonsillectomy

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BACKGROUND

Resistance to shared decision making is often voiced by those who cite patients' lack of desire for involvement ' as a barrier. Is this still the case when the patient is your child and where management options include surgical procedures under anaesthesia? We examined the context of tonsillectomies, a controversial elective procedure, to explore the hypothesis that where genuine choice exists, parents value increased involvement in decision making which may reduce the uptake of elective surgery.

METHOD

We recruited 100 children under the age of 16 referred for a possible tonsillectomy to University Hospital of Wales between June and December 2010. Families referred by their GPs for assessment for tonsillectomy were sent a leaflet containing information about the operation and the current national guidelines for referral. The leaflet required parents to consider the criteria for surgery and to decide whether to remain on the list for a specialist opinion or to defer assessment. Quantitative data was collected prospectively about appointment rates and conversion to tonsillectomy rates. Qualitative data was collected about the information leaflet, its content and its placement in the referral pathway.

RESULTS

Conversion rate to tonsillectomy was 45% following introduction of the leaflet. In the previous 5 years it had ranged between 50 & 60%. Non attendance for appointment remained at 30%. 1% chose to defer their appointment without further discussion with a specialist.. Qualitative data revealed that parents appreciated the greater level of information. They felt it would have been most appropriate if delivered by the GP, offering the opportunity to discuss the information and referral criteria with their GP prior to the referral being initiated.

CONCLUSION

Parents of children referred for tonsillectomy value the opportunity to become more involved in decisions about tonsillectomy. This work indicates that whilst the primary-secondary care interface is an under utilized pathway for the introduction of decision tools, how best to provide these tools is yet optimised. Further work is needed to further explore the role of the referral between primary and secondary care in the implementation of shared decision making.

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77 SYMPOSIUM PARALLEL SESSION 3

Adapting and validating a shared decision making approach for work rehabilitation programs involving workers with persistent pain due to musculoskeletal disorders

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BACKGROUND

The objective of this study is to adapt and validate a shared decision making (SDM) approach for interdisciplinary rehabilitation of workers experiencing persistent pain due to a musculoskeletal disorder (MSD). From many empirical and theoretical points of view, the implementation of shared decision making (SDM) in work rehabilitation for an MSD is justified but typically the SDM model applies to a one on one encounter between a health care provider and a patient. This study was designed to develop an SDM approach adapted to an interdisciplinary work rehabilitation program.

DESIGN AND METHODS

A developmental research approach with a descriptive design was used in the study. We adopted a mixed perspective combining a theory-based development and a user-based perspective. The strategies for developing an SDM approach included consulting the scientific literature and holding three group consensus meetings with clinician-experts. A convenience sample of eight OTs, three clinical coordinators and four psychologists all of whom have been working full-time in work rehabilitation focussing on workers with persistent pain due to MSD for more than two years were recruited from four collaborating rehabilitation clinics.

RESULTS

First, the theory-based SDM approach had to be adapted by clinician-experts because the formulation of the objectives did not resonate with their language and clinical practice. Specific objectives were rephrased and two (maintaining a working alliance and ensuring a common understanding among all significant actors in the SDM process) were identified as longitudinal objectives that needed to be present during the rehabilitation program. Activities as well as human and material resources needed to attain the objectives were identified. Finally, consensus was achieved on a minimum of one and a maximum of six indicators per objective. The final version of the SDM approach was validated with SDM and work rehabilitation experts-researchers.

CONCLUSION

An SDM approach applicable to work rehabilitation was completed and is available for implementation. The design and multiple theory-driven basis of this study have helped to ensure clear definition and rigorous development of the approach.

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10 **ORAL PARALLEL SESSION 5**

SDM for special populations: Children with cancer, their parents and attending healthcare professionals' perspectives of SDM.

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BACKGROUND

Although SDM is increasingly valued, children's participation in the healthcare setting is often limited. Research in primary care settings has revealed a variety of ways in which doctors and parents constrain children's participation in triadic interactions but we lack information on the rationale underpinning their behaviour. We lack information on children's preferences and what role children want to play in SDM. We lack information on how the process is managed between child, parent and health professional, with studies mainly conducted in clinic settings. Hence we investigated participation in SDM from the perspectives of children, their parents, and healthcare professionals from one cancer unit in Ireland.

DESIGN AND METHODS

Using grounded theory, we obtained data though in-depth interviews and participatory techniques with hospitalised children aged 7-16 years (n=20), their parents (n=22) and the healthcare professionals (e.g. doctors, nurses, social workers, teachers, play specialists) (n= 40). Data were analysed according to grounded theory principles and managed with the aid of NVivo (version 8).

RESULTS

Children were not included in SDM when decisions were seen as 'major' decisions (e.g. initiation of therapy) as refusal was not an option. Both parents and children perceived that they had no choice in major decisions because the treatment 'had to be done'. Children were seen as having a right to be involved but not necessarily possessing the emotional maturity to make serious or major decisions. When older children were seen as competent, they were allowed to participate more in major decisions, with the guidance and support of parents and health professionals. Children were involved in SDM when decisions were minor, which were decisions about their care that did not compromise welfare in any way. Children were involved in choosing how treatment was delivered to gain their cooperation and adherence to treatment protocols and procedures.

CONCLUSION

Children with cancer were only involved in shared 'minor' decision making and were aware of the difference between choices and actual decisions. Adults were reluctant to include them in SDM when refusal was not feasible.

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249 **ORAL PARALLEL SESSION 2**

Patient Educational Technologies (PET) and their use by patients diagnosed with prostate cancer

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BACKGROUND

Patient education is a vital part of successful shared decision making between health care provider and patient. Conventional educational materials have included pamphlets or non-interactive videos, providing limited feedback to providers as to their use. Information technology (IT), however, offers opportunities for more interactive platforms and a richer understanding of the effectiveness of these tools. The purpose of this study is to better understand how patients interact with Patient Educational Technology (PET) aimed at informing them about their treatment options for prostate cancer .

DESIGN AND METHODS

A PET library was developed for prostate cancer, including separate modules for different treatment options. The PET library content was developed by a committee of urologists using systematic reviews and updated with current evidence as necessary. Content generally includes a description of the intervention, its potential harms and benefits, and any ongoing care needed after the intervention. Data generated from patients' use of PET feed into providers' electronic medical record. The PET library was made freely available to the patient population of two urologists in Calgary, Canada between 2008 and 2011.

RESULTS

Every patient (~700) was referred and given access to the PET library using a unique identifier. Over 50% of those logged-in to the PET library and viewed at least one module for more than 2 minutes. The number of modules that were viewed by patients and the length of time (minutes) they were viewed for were recorded. Data is currently being analysed as to the number of slides viewed within each module; the number of patients that returned to re-view a module; the span of time (days) that the PET library was accessed; and how these relate, if at all, to the ultimate treatment decision.

CONCLUSION

When referred, a number of patients diagnosed with prostate cancer engage with PETs on an ongoing basis between the time of diagnosis and time of treatment. Understanding how patients engage with these types of technologies is an important step in developing more useful PETs; tools that hold the potential to provide an effective and inexpensive means to improve shared decision making on a broad scale.

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21 ORAL PARALLEL SESSION 1

What is Right for Me? An interactive decision aid on antipsychotic medications

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BACKGROUND

Decisions about use of antipsychotic medication are complicated by the vast amount of information about options and alternatives. Multifaceted medication efficacy profiles and risk-benefit trade-offs make a decision aid (DA) a valuable resource for both providers and users of mental health services. This presentation discusses the development and testing of a computer-based interactive DA on antipsychotic medications developed under contract for the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA). It is part of SAMHSA's effort to develop public domain resources to promote shared decision making in mental health services.

This interactive, computer-based DA provides objective information about antipsychotic medications, side effects, and various treatment and service options. It was constructed to help mental health services users express preferences and make informed choices. The DA offers opportunity to prepare and print a personal report that can be reviewed with providers, as well as supplemental worksheets and video stories.

DESIGN AND METHODS

The DA audience tested at multiple points in development. A beta-version was field tested with service users and providers at 3 mental health agencies representing urban, rural, and Veteran clientele. The DA was implemented idiosyncratically, reflecting each agency's structure, workforce, and clinical approach. Multiple focus groups with providers, service users, and coaches using the DA provided qualitative information about impressions, use, and comfort with the DA. These data were evaluated using content analysis. Questionnaires exploring provider and service user satisfaction, increased knowledge, perceived utility, and ease of use were analyzed using SPSS.

RESULTS

Preliminary results show overwhelming support for this information being accessible, opportunity to learn more about antipsychotic medications, and the side effect information and comparisons. Service users and staff report some difficulty learning to navigate the DA. Many service users are new to computers and require considerable assistance from others, often requiring more than one training/support session. Idiosyncratic implementation indicates applicability in diverse settings and contexts, and has revealed multiple practical methods of presentation.

CONCLUSION

Adapting shared decision making approaches and tools for mental health shows exceptional promise. Future work will focus on provider training, developing peer coaches and implementation in diverse settings including inpatient.

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38 POSTER SESSION TUESDAY

Decision supportive strategies for rehabilitation in people with aphasia

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BACKGROUND

People with aphasia are often excluded in decision making in rehabilitation because of their communication impairments, leading to a lack of shared choices. Empowering people with aphasia in their ability to express their wishes in rehabilitation seems very important to facilitate shared choices with regard to chronic disease management. Although some current rehabilitation models address the importance of involvement in a life situation, they do not adequately address issues of the importance of meaning and choice when thinking about life situations.

AIM

To suggest strategies and techniques to empower people with aphasia in their ability to express their wishes facilitating shared choices in rehabilitation. These strategies and techniques are based upon experiences in conducting research in this group of people.

METHODS

We conducted a qualitative study and a quantitative study in people with aphasia concerning their participation in life. In these studies different strategies were developed based upon literature, conversations with people with aphasia, and speech and language therapists, to facilitate the inclusion of people with aphasia, even those with severe communication problems. Several strategies were evaluated. The strategies used and our experiences will be outlined in this presentation.

MAIN CONTRIBUTION

It is possible to include this group in decision making. Several strategies are helpful to make this mission possible: the use of pre-structured diaries, the use of in-depth interviews with attention to non-verbal communication, the use of existing measurements, adjusted for people with aphasia by: using pictograms, placing one question per page, bolding the key concepts in the question, using large font, visualising the answering possibilities in words and in pictures, reducing the question length, and excluding negatives in the question.

CONCLUSION

Models of rehabilitation service delivery need to move to a chronic disease management model that incorporates outcomes that are meaningful to clients, and not the assumed needs or outcomes as defined by rehabilitation professionals. This can be done by using strategies and techniques to empower this population to express their wishes.

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68 POSTER SESSION MONDAY

Integrating the patient's perspective in preventive health consultations: how to communicate about cardio-metabolic health risks?

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BACKGROUND

In preventive health consultations and decision aids, communication about the risks of certain diseases plays a major role. However, risk messages are not always well understood by patients. An important question is how health care professionals can better tailor their information to the knowledge and needs of patients.

DESIGN AND METHODS

To assess focal points for more patient-centered risk communication about cardio-metabolic diseases (diabetes, cardiovascular disease, kidney disease), we compared the conceptions of lay people with those of experts (the 'mental models approach'). We performed 8 interviews with experts (physicians and epidemiologists) and 40 interviews with lay people (people with different socio-demographic background), in which we asked open-ended questions about the risks of these cardio-metabolic diseases.

RESULTS

Although we found substantial overlap between the content of expert knowledge and lay mental models, experts and lay people differed in the value attached to certain causes (e.g. ageing), risk factors (e.g. abdominal obesity), and risk reduction strategies (e.g. losing weight). Lay conceptions were not as coherent as expert conceptions, but were rather superficial, indiscriminate, and fragmented. The identified focal points for risk communication were to: (1) emphasize a coherent total cardio-metabolic risk concept; (2) explain the shared risk factors and the interrelatedness between the 3 diseases; and (3) address certain concepts that lay people mark as important, such as stress and adverse socio-economic circumstances.

CONCLUSION

When health care professionals communicate about cardio-metabolic risks using their expert conception, this will likely not fit lay conceptions and may not be adequately comprehended. In improving risk communication about cardio-metabolic diseases, we suggest to build on the principles derived from our focal points.

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245 ORAL PARALLEL SESSION 2

How does shared decision making affect costs in patients considering total knee arthroplasty?

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BACKGROUND

In addition to the traditional clinician encounter, shared decision making (SDM) provides patients with decision aids summarizing current "best"practices. It is has been shown to improve patients understanding of their treatment options. There have been suggestions that the use of SDM for patients with knee osteoarthritis considering total knee arthroplasty (TKA) could potentially lower costs to the US healthcare system.

DESIGN AND METHODS

Patients with severely symptomatic knee osteoarthritis were enrolled in an observational prospective cohort study to evaluate whether participation in a shared medical decision making process resulted in patients switching treatment preference. Costs of TKA projections were derived based upon historical costs and were combined with published US projections for the demand for TKA. Costs for SDM were estimated using our institution's expenditures.

RESULTS

The study recruited 392 patients; 384 patients completed the questionnaire. The average age of patients was 63 with 67% being female. Prior to SDM, 52 patients leaned towards non-surgical treatment, 253 for surgical treatment and 79 were unsure. Following SDM, 68 patients opted for non-surgical treatment, 261 opted for surgical treatment and 55 patients were unsure. The majority of patients who preferred non-operative or operative management did not change their preference. Nearly half of the "unsure"patients changed their preference (22.8% switched to non-operative vs. 25.3% switched to operative). There was an overall shift towards surgical management (Bowker's Symmetry s3=12.2, p<.007). When "unsure"patients were excluded, a greater proportion of patients changed their preference from non-surgical to surgical management compared to the opposite (10.64% vs. 3.28%, p<0.03). We found that the present value of projected SDM costs were 0.06% of projected present value for TKA over the next 20 years.

CONCLUSION

The majority of patients with severely symptomatic knee osteoarthritis who participate in SDM do not change their initial treatment preference. Patients were more likely to switch from non-surgical to surgical management. Our data finds no evidence that SDM reduces the utilization of TKA, and is therefore not cost-saving. However, the present value of projected SDM costs for TKA is small compared to the present value of projected TKA costs.

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239 SYMPOSIUM PARALLEL SESSION 5

Integrating Decision Aids and Enhancing Shared Decision Making in Rural Non-Academic Primary Care: The Essential Role of Practice Facilitation

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BACKGROUND

Shared Decision Making (SDM) and Decision Aids (DAs) reduce unwarranted variations in care and facilitate patient centered interactions. Studies of SDM and DAs have primarily occurred in academic centers and large health systems, although the majority of primary care is delivered in practices employing five or fewer physicians. Barriers to incorporating new technologies, like DAs, may be more pronounced in these settings. Therefore we undertook this study to identify "Best Practices"for integrating DAs in small, rural non-academic primary care clinics.

DESIGN AND METHODS

Mixed method interim evaluation of a three year SDM/DA implementation project in four member clinics of the Oregon Rural Practice-based Research Network (ORPRN) involving practice facilitation and serial plan-do-study-act (PDSA) cycles. Three data sources were analyzed: 1) focus groups with clinical staff (clinicians, front/back office, administration) pre-intervention and at one year; 2) implementation field notes; and 3) quantitative data on DA distribution, return, and patient satisfaction. Investigators individually reviewed focus group recordings and field notes to identify initial themes then met to reconcile final themes through iterative processing.

RESULTS

91 clinical staff participated in intervention focus groups, 43 pre-assessment and 48 at one year. DAs were distributed to 56% of eligible patients (n=227) over an eleven month period. DA integration varied between the four clinics (e.g., distribution rates between 34% to 98%) and within clinics (e.g., DAs distributed by 17% to 75% of practice clinicians, mean = 48%). Clinic stability was essential to DA implementation. Facilitators to DA integration included developing team based distribution strategies, creating system level protocols, identifying a staff data liaison, selecting DAs for "common"conditions, sharing patient feedback and having external support through practice facilitation. Practice facilitators helped clinics develop implementation protocols, hold regular meetings to debrief and refine distribution processes, provide clinic level data reports and respond to clinic requests (i.e., develop inter-clinic learning community and prepare SDM/DA marketing materials).

CONCLUSIONS

Evidence-based DAs, to facilitate SDM, can be successfully integrated into routine care in rural, non-academic primary care settings. Best practices for implementing DAs include addressing system and individual level factors, supported through external practice facilitation.

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241 ORAL PARALLEL SESSION 4

Perceptions of Shared Decision Making and Decision Aids among Rural Primary Care Clinicians: Implications for Practice Transformation

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BACKGROUND

Many medical decisions are in a "gray"area, where reasonable people might make different choices based on their values and preferences (e.g., treatment for chronic pain, knee osteoarthritis, or PSA testing). For these, shared decision making (SDM) is a key element in applying evidence-based medicine to optimize diagnostic and treatment decisions in primary care practice and patient decision aids (DAs) may supplement patient-clinician discussions. Studies of SDM and DAs have primarily occurred in academic centers and large health systems, but most primary care is delivered in practices of five or fewer physicians. Therefore we undertook this study to describe knowledge, attitudes and practices of SDM and DA use in rural primary care practices to inform a clinic level intervention.

DESIGN AND METHODS

Cross sectional survey administered to primary care clinicians affiliated with the Oregon Rural Practice-based Research Network (ORPRN), September through December 2009.

RESULTS

Surveys were returned by 181 of 231 eligible participants (78%), 174 were analyzed. Participants were 67% physician, 84% family medicine, 55% male. The majority of respondents were unfamiliar with the term "SDM"(65%), but given a definition, 97% reported they found it useful or extremely useful for conditions with multiple treatment options. Although most clinicians preferred that patients play an equal role in such decisions (69%), they reported that this happens only 35% of the time. Time was the largest reported barrier to engaging in SDM (63%) and only 10% of respondents identified lack of patient interest as a barrier. Respondents were receptive to using DAs in printed (95%) or web-based formats (72%) and topic preference varied by clinician specialty and difficulty of decision making.

CONCLUSIONS

Rural primary care clinicians recognized the value of SDM and were receptive to using DAs in multiple formats. Integration of DAs to facilitate SDM in routine patient care requires addressing the barriers of time, reimbursement, and topic relevance based on clinician specialty.

FUNDING ACKNOWLEDGEMENT

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263 **ORAL PARALLEL SESSION 2**

Participatory Medicine in SDM: Contribute and Consider, Not Push or Pull

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Our conference title - "patient pull or clinician push?"- notes the difficulty of pushing clinicians to use SDM and asks if we should teach patients to pull. This question, while valid, overlooks a dimension of SDM's full potential: not all information for SDM exists at the clinician end. Patients' experience and patient communities should be a key input to the decision process.

Today much valid information exists outside the medical establishment, in wise patient communities. As a Stage IV kidney cancer patient I personally experienced the value of their advice, which I brought to my clinicians for consideration. Before treatment began I gathered seventeen first-hand stories, so when my side effects hit, I knew what to expect. Today my oncologist says that although the medication killed the cancer, he's not sure I could have tolerated enough to do the job if I hadn't been so well-informed about the side effects, and thus enabled to push through them.

A second dimension to the "doctor knows all"error is that no doctor can be expected today to know everything relevant, yet non-medical stakeholders can bring new information. How does the clinician cope when the SDM tables are turned?

I propose that SDM be considered not the dispensing of information compiled years ago, but the combining of that information with the latest developments, both clinically and as gathered through social media.* SDM becomes a process of discovery and consultation, constantly evolving as new information comes to light, and especially as we cultivate feedback from previous patients' experience.

Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners. Today as co-chair of the Society for Participatory Medicine I discuss this at conferences of many types - pharma, patient advocates, physicians, safety and quality. A session at ISDM would frame my experience and participatory medicine blogging in the context of SDM, with concrete recommendations for all stakeholders, particularly developers of SDM tools and processes.

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224 **ORAL PARALLEL SESSION 4**

Shared Decision Making in Family Planning Care

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BACKGROUND

Contraceptive counseling is a unique area of medical decision making due to its highly preference sensitive nature, with multiple methods being appropriate for the vast majority of women, and its complex cultural context, which necessitates consideration of sexuality and fertility. Contraceptive decision making is poorly understood, however, and the degree to which research on general health care decision making is relevant to this decision is unknown. This presentation will integrate the results from three studies - a qualitative study, a survey study, and a direct observation study - to explore decision making around contraception and the application of shared decision making to this area of health care.

DESIGN AND METHODS

1. Qualitative study: This study performed semi-structured interviews of women in the United States to assess their values and preferences about contraceptive counseling.
2. Survey study: Women receiving contraceptive counseling at abortion clinics in the United States were surveyed about their decision-making preferences for contraception and for general health care.
3. Direct observation study: Women receiving contraceptive counseling had their visits audiorecorded and completed pre- and post-visit surveys about their expectations and preferences regarding contraceptive care.

RESULTS

Women value greater autonomy over contraceptive decision making than over decision making over their general health care, with 50% of women surveyed indicating that they wished to make an autonomous decision about contraception, compared to only 19% about their general health care. In the qualitative study, however, women indicated that, even when they desired independence in the decision, they valued input from their health care providers, and often felt that they did not receive enough decision support. Preliminary results from the direct observation study (data collection will be complete by May, 2011) indicates that counselors provide extensive information and allow patients to make independent decisions, but infrequently provide active facilitation of decision making.

CONCLUSION

Investigation of this socially complex, preference-sensitive decision draws attention to the need to consider variation in decision making preferences across areas of health care. Our results suggest that while family planning providers appropriately emphasize patient autonomy in contraceptive decision making, there is an unmet need for decision support.

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96 ORAL PARALLEL SESSION 7

A web-based decision support intervention for familial colorectal cancer: a pilot study

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BACKGROUND

For individuals with a high familial colorectal cancer risk (>3 times population risk), genetic counselling is recommended to determine appropriate preventive measures. However, since genetic counselling has both benefits and harms, not everyone wants to be referred. Therefore, a web-based decision support intervention was developed to support colorectal cancer patients in deciding whether or not to be referred for genetic counselling.

DESIGN AND METHODS

The decision support intervention (DSI) is part of a website containing evidence-based information on familial colorectal cancer, a risk calculation tool, and the DSI. The DSI consists of a four-step worksheet, with questions on risk perception and decision making preferences, and a value clarification exercise where patients rate how important the different pros and cons of genetic counselling are to them personally.

To assess utility, acceptability and feasibility of the website, ten patients with colorectal cancer and twelve clinicians (surgeons, gastroenterologists and medical oncologists) reviewed the website and completed a questionnaire in a pilot test.

RESULTS

The majority of patients and clinicians (80-100%) found the website useful and acceptable, and completion of the tools feasible. Pilot testing resulted in several improvements, particularly in the format of the decision support intervention to help patients score the importance to them personally. After implementing the adjustments, patients found the DSI easy to use, and helpful in deciding whether or not to be referred for genetic counselling.

CONCLUSION

This study shows the importance of including users in development processes, in this case of a web-based decision support intervention supporting colorectal cancer patients in deciding whether or not to be referred for genetic counselling. Results from the pilot test support the acceptability of the website and the helpfulness of the DSI in deciding whether or not to be referred for genetic counselling. The website is currently being evaluated in a randomised controlled trial to determine its effectiveness on improving the recognition of individuals at an increased familial colorectal cancer risk.

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62 POSTER SESSION MONDAY

Involving patient in decision of adjuvant chemotherapy for breast cancer. Observation of physicians practices in the French context.

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BACKGROUND

Adjuvant chemotherapy is prescribed postoperatively in breast cancer with the aim of reducing the risk of disease progression to a metastatic state. Its benefit is uncertain. The practices of French oncologists regarding the degree and manner of the involvement of patients in such decisions are poorly documented.

DESIGN AND METHODS

As an exploratory study, qualitative methodologies (information based on observations of physicians-patient encounters and in-depth semi-structured interviews) were selected. We observed 50 consultations where the issue of adjuvant chemotherapy had to be decided.

These observations took place with 11 oncologists volunteers sensitized to the issue of patient participation in decision making. The consultations were classified according to the degree of participation of the patient in the decision, using two tools: the decision-making scenarios proposed by Charles (2004) and the Elwyn's OPTION scale (2005).

RESULTS

Of these 50 visits, 31 were identified by physicians as situations where it was from their point of view, 'possible to involve the patient in the decision'. In these consultations, the scenario of 'shared decision making' defined by Charles is majority (20 visits), but there are also 7 scenarios 'patient decision-maker', 3 'intermediate' and a 'medical paternalism.' Scores on the Elwyn's OPTION scale show recurring weaknesses on the items: "feedback to validate the understanding of information"and explanation by the oncologist 'pros and cons of each option". The period of consultation is significantly associated with the degree of involvement measured by this scale.

The study of interactions, made for all consultations, highlighted the strategies used by oncologists following the objective of participation sought.

CONCLUSION

Our study helps identify the skills and difficulties to a sample of motivated oncologists by the implementation of patient involvement in the medical decision. It shows the discrepancies between the design of medical consultation and shared decision-reality of the consultation. It also highlights the obstacles to widespread use of an approach to systematically involving the patient in the French context.

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86 **ORAL PARALLEL SESSION 6**

Participative Goal Setting in Rehabilitation: Towards 'Smart' Shared Goals of patients with chronic back pain

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BACKGROUND

Evidence in motivation and volition research underline the importance of well defined or "smart"individual, activity related goals in rehabilitation, shared by patient and physician. However, recently several studies suggest that there are serious communication barriers which prevent discussing and defining shared goals (Meyer et al., 2008; Glattacker et al., 2009; Dudeck et al., 2009).

METHODS

"Participative Goal Setting"is a dialogical intervention to decide about rehabilitation goals analogue to a shared decision making process (Dibbelt et al., 2009). Physicians and therapists were trained to accomplish the "goal dialogue"consisting of seven major steps resulting in three specific main goals related to current concerns of the patient. The effectiveness of the intervention with respect to direct and indirect treatment outcomes is currently assessed in a sequential (pre-post) control group design study with patients suffering from low back pain and coronary heart disease. Initial goals were registered on a special form, as well as goal adjustment and goal attainment assessed at an interim and final balance. In this contribution we report results from a descriptive analysis of goal categories and goal processing with patients with low back pain based on 90 documented cases and 168 registered goals.

RESULTS

19% of goals documented were pain related, 24% referred to functioning in general, 11% to work related activities, 11% to information gathering, 11% to control of risk factors and 8% to psychic problems. Measures how to reach the goal were indicated in 82% of goals registered. Indicators for goal attainment were specified for 76% of goals. For 40% of goals at least a desired value was specified. Interim and final assessments of goal attainment were registered in 60% and 62% of cases respectively. In the final balance complete or nearly complete goal attainment was registered 47% of cases.

CONCLUSION

The participative goal setting procedure seems to structure the exchange between patient and physician about goals, concerns and expectations of both, patient and physician as well as specification of health related objectives and necessary action.

186 ORAL PARALLEL SESSION 7

Internet use and information needs of patientswith chronic diseases

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BACKGROUND

The internet is considered as a way of providing interactive health information to patients as a prerequisite for informed or shared decision making. It is recognised as good practice to involve patients' views in the process of the development of internet-delivered systems. The objective of this study was to analyse patients' needs regarding online health information in patients with type 2 diabetes (T2D) and chronic low back pain (CLBP).

DESIGN AND METHODS

A survey was conducted with patients with T2D (N=169) and CLBP (N=167) recruited from cooperating inpatient / outpatient medical centres and self-help groups. Experiences with online information seeking and information needs were assessed.

RESULTS

The results showed that 62% used the internet for searching disease-specific information and use this information for healthcare decisions. Primary reasons were that patients rated the information obtained from physicians as not sufficient or difficult to understand. Patients with T2D searched mainly for general information about the disease and relevant health behaviours, whereas patients with CLBP focused more on where to get treatment (clinics, practices) and on treatment options.

Patients with CLBP were less satisfied and experienced more often discrepancies concerning information obtained from their practitioner or from different web-pages. Therefore, online information about CLBP did less contribute to a better understanding or coping of and coping with their chronic disease than in patients with T2D.

Patients with CLBP frequently indicated starting "physical exercise"(81%) or "oral pain management"(75%) as important decisions and indicated information needs especially regarding "comparative presentation of different treatment options"and "expected impact of treatment options on CLBP"as important. Patients with T2D most frequently stated "glycemic control"(67%) or "oral antidiabetics"(54%) as relevant decisions and wished especially information on "secondary diseases"and "glycemic control". Results differed concerning sub-groups based on sociodemographic and clinical factors, especially with regard to educational level and duration of disease.

CONCLUSIONS

Results showed that patients with CLBP were less satisfied with online health information and subgroups of patients had specific information needs. Therefore, the presentation of information tailord to the needs of the individual patient might be important.

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148 ORAL PARALLEL SESSION 3

Supporting, documenting, and evaluating the patient-centred decision via online multi-criteria analysis

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BACKGROUND

Ensuring that decisions within patient-centred care are of the highest possible quality and safety can be addressed as a generic task, with particularities that vary with setting and context.

DESIGN AND METHODS

We developed an interconnected suite of programs to ensure that these decisions are made in a way that meets the triple requirements of informed consent, patient-centred quality care, and institutional efficiency in terms of decision (as opposed to administrative) documentation. It can be expected to minimise patient complaints as well as legal cases. Integration with electronic record systems will be possible because the outputs are standards-compliant. The portal for MyDecisionSuite filters the route through the 3 component modules depending on time, resources, and literacy and preferences of the patient. Each module is customised to the specific decision, but the generic structure and format provides a common multi-disciplinary, cross-border 'language'. Implemented in Annalisa 2+ software much of the communication is in graphic form. MyDecisionPreparation spells out what is needed for informed consent in respect of any choice made and establishes the criteria by which the quality of the decision about to be made will be judged, including the patient's desired type and extent of participation and control. MyDecisionAid sets out the available options and evaluates them by combining the best available patient-specific evidence with the importance the patient attaches to the various outcomes and other relevant considerations. It is equipped to incorporate any clinical scoring systems. MyDecisionQuality establishes (i) how well the requirements of informed consent have been fulfilled; (ii) how well the earlier decision quality criteria have been met; and (iii) if there is a need or expressed wish to raise the quality, the best means to do so during a resumption of the decision process (i.e. aspects to concentrate on).

RESULTS

The suite has been demonstrated in relation to patient transfer decisions and we report on pilot feedback from three countries and an online survey. Conclusion

A suite of programs that meets the specified requirement of many health care systems has been developed and shown to work at a proof-of-method level.

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261 POSTER SESSION TUESDAY

Training General Practitioners in Shared Decision Making to consult their patients about completing Advance Directives - Experiences of a pilot study

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BACKGROUND

In Germany, an increasing number of people want to take preemptive measures concerning end-of-life decisions including, among others, the completion of Advance Directives. On September 1, 2009, the German Parliament issued the first law concerning the legal bindingness of Advance Directives, thereby strengthening patient autonomy. But completing Advance Directives still remains a difficult task for patients as well as the consulting health care providers. The present study is a pilot study for a project funded by the German Federal Ministry of Education and Research (BMBF) and supposed to examine and improve the form of consultation for completing Advance Directives.

This pilot was aimed at answering the following questions:

1 Whether General practitioners (GPs) are interested in using Shared Decision Making (SDM) for completing Advance Directives with their patients?
2 Whether GPs are interested in using a new computer-based Advance Directive program to create individual Advance Directives for their patients?
3 Whether patients request a consultation service of their GPs?
4 Whether SDM is a suitable approach, as measured in parameters like the patient's decisional conflict and satisfaction with decision?

DESIGN

Observational study.

METHODS

2 GPs were coached in advance care planning, especially in completing Advance Directives, in SDM and in a computer-based Advance Directive program as an instrument to support doctor-patient-communication.

The patients have been informed about the study by means of posters and flyers in the GPs' practices and, if interested, recruited for the study.

After the consultation, the patients were asked to complete a questionnaire including "Decisional Conflict Scale"and "Satisfaction with Decision Scale".

RESULTS

- The GPs were highly interested in being coached in SDM and the new computer-based Advance Directive program.
- 100 patients were enrolled in this pilot study.
- The data show a low extent of decisional conflict and a high extent of patient satisfaction with decision after consultation.
- The GPs asked to continue the program.

CONCLUSION

End-of-life decisions are difficult, especially if anticipated by completing Advance Directives. Our pilot study showed that SDM might be a promising approach to meet the patients' need to complete Advance Directives.

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178 POSTER SESSION TUESDAY

Evaluation of Telephone Health Coaching for chronic diseases

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BACKGROUND

Since 2007 the German health insurance fund KKH-Allianz provides a telephone health coaching (HC) for people with chronic diseases. Using motivational interviewing and collaborative goal setting techniques patients are supported to change risky health behaviours. To date it lacks studies regarding the acceptance and the efficacy of HC in Germany. Therefore two studies were started to analyse a) how patients evaluate the HC [1] and b) the efficacy of HC and its impact on economic outcomes.

DESIGN

To assess how patients evaluate HC, a retrospective first study was conducted in 2008. We included 834 insurants who did participate in the HC and 1.074 insurants who did not. A second study in 2010, a four-year randomized controlled trial (RCT), focuses on the efficacy of HC. Estimated 2.600 insurants are assessed at baseline and three yearly follow-ups. Three groups are compared:
1) participants of the HC, 2) insurants that declined to participate, 3) control group.

METHODS

The first study assessed data with self-rating questionnaires and the HC software. Outcomes included the patients' general evaluation of HC and the process. Additionally to questionnaire- and software-data the RCT collected the information with the routine data of the health insurance fund. In the RCT assessed outcomes include health behaviour, quality of life, clinical parameters and hospital readmission rates. Possible mediating factors like patient activation, health literacy and the stages of change concept are also analysed.

RESULTS

The first study showed that 78.3% of the participants were satisfied with the HC and 82.3% would recommend it to others. 53.3% of the participating probands had learned about new options to influence their state of health. Based on these promising results, the 2010 RCT was initiated to prove long term efficacy. So far 2.005 insurants provided analyzable data. Baseline results and differences between participants and non-participants will be presented and discussed.

CONCLUSION

The 2008 study showed a general positive appraisal of the HC. The current study tries to prove the longitudinal efficacy of HC.

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179 **ORAL PARALLEL SESSION 2**

Translation and Validation of a Health Literacy Questionnaire for chronically ill Patients

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BACKGROUND

Health Literacy (HL) describes the ability of individuals to access health information, to comprehend the facts and to transfer the information into their daily life. HL also seems to influence medical decision-making. Most existing tools to measure HL focus on reading comprehension and numeracy using observer-rated scales. Due to the need of self-rating scales that also reflect a broader range of attributes implied in current definitions of HL, the health literacy scales (HLS) were developed [1] assessing the three scales functional, communicative and critical HL. The objective of this study was to translate the existing English version into German and to examine its psychometric properties.

DESIGN

The HLS were translated into German using translation/back translation methodology and were administered to 1034 probands with chronic diseases contacted via a big health insurance fund.

METHODS

Psychometric properties were assessed including acceptance (percentage of missing values), item difficulties, reliability (internal consistency) and factorial structure. To analyze the factorial structure of the German version of the HLS, it was examined whether the predicted three-factor model fits our data using confirmatory factor analysis.

RESULTS

The acceptance was high (4,7% missing values) and item discrimination parameters were above .4 for each scale for all but one item. Item difficulties ranged between 1.54 and 3.42 on a scale from 0 to 4. The reliability was fair (Cronbach's α =.77). Within a subsample of 534 insurants, the three-factor solution of the original version could not be replicated. Using structural equation modeling an enhanced two-factor structure was developed that showed a fair fit and an internal consistency of a Cronbach's α of .86 for Analytical HL and α =.78 for Functional HL. The enhanced structure was cross-validated with another 500 insurants.

CONCLUSION

The psychometric analyses of the German version of the HLS showed satisfactory results regarding acceptance, item discrimination and reliability. The predicted factor structure of the original English version could not be replicated. A shortened, amended two-factor model is proposed.

REFERENCES

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5 **ORAL PARALLEL SESSION 2**

The Health Literacy Pathway Model: a qualitative study of the development of health literacy and shared decision-making abilities in patients with a long-term condition.

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BACKGROUND

Health literacy is "the ability to find, understand, appraise and communicate information to engage with the demands of different health contexts to promote health across the life-course". Making informed self-care decisions and participating in treatment decision-making are two health contexts where sufficient health literacy is important to empower patients living with a long-term condition in managing their health. Poor health literacy is suggested to be a barrier to the exchange of relevant information and participation in shared decision-making (SDM). The main objectives were to describe how patients with a long-term condition become more health literate, and to facilitators or barriers to the development of health literacy for informed self-care decision making and active participation in health care consultations (including SDM).

DESIGN AND METHODS

A longitudinal qualitative study using serial interviews (total 44) with 18 participants recruited from patient education programmes (diabetes programme, a generic self-management programme, and a cardiac rehabilitation programme) and one community-based group to explore their learning experiences and understand how they draw on their health literacy abilities to manage their condition and participate in healthcare processes. Observations of patient education programmes explored how health literacy may develop during group-based classes. Interview and observation data were analysed using a framework approach to consider existing descriptions of health literacy and emerging themes.

RESULTS

A model is presented describing the development of health literacy along a trajectory including the development of knowledge, health literacy skills and practices, health literacy actions, abilities in seeking options and participating in informed and shared decision- making opportunities. Motivations and barriers to developing and practising health literacy skills were personal to participants' characteristics and also created by health professionals. Participants developed their health literacy to a point where they were able and motivated to make informed and shared decisions through patient education programmes, self-directed learning and social interactions with health professionals and lay informants.

CONCLUSION

The model describes how people can develop health literacy over time to become more involved in healthcare decision-making. The findings have implications for developing health literacy interventions aimed at patient involvement in healthcare processes.

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6 POSTER SESSION TUESDAY

The distribution of health literacy through family, social and health education networks: the role of health literacy mediators in decision making processes

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BACKGROUND

Health literacy is the ability to find, understand, appraise and communicate information to engage with the demands of different health contexts. Making informed self-care decisions and participating in shared decision-making are two health contexts where sufficient health literacy is important for patients living with a long-term condition. Health literacy and shared decision-making are typically described as an individual cognitive activity. The role of one's social network as an influence on the development of health literacy and participation in shared decision-making is not fully understood. Recent research has explored how decision making is distributed over a range of encounters with people and technology. This study aimed at exploring the distributed nature of health literacy and its influence on decision-making.

DESIGN AND METHODS

A longitudinal qualitative interview and observation study of the development and practice of health literacy in people with a long-term health condition. Participants (n=18) were recruited from health education groups and from community education venues. Interviews explored how participants' developed health literacy and how it might have influenced their abilities to manage their condition and participate in decision-making processes. Observations of patient education programmes explored how health literacy might develop during group-based classes. The transcripts and observation notes were analysed using the 'Framework' approach, a both deductive and inductive form of thematic analysis.

RESULTS

Health literacy was distributed through family and social networks. Participants often drew on the health literacy skills of others to seek, understand and use health information to aid their decision-making. During patient education classes participants and tutors facilitated the distribution of health literacy. Friends and family acted as health literacy mediators and supported participants in day to day self-care decisions and influenced participation in shared decision-making in health care consultations.

CONCLUSION

Access to health literacy mediators enabled participants to benefit from distributed health literacy in terms of being informed and motivated to participate in shared decision-making. The findings have implications for the design and implementation of family and community level interventions that might help distribute health literacy through groups of people living with a long-term condition and influence participation in shared decision-making.

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217 POSTER SESSION TUESDAY

Personalization in patient decision aids: state of the art and potential

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BACKGROUND

The concept of personalization is often included in the definitions and descriptions of patient decision aids. Personalization can pertain to several aspects of a decision aid, such as the structure and content of the tool, the decision-making process, and the resulting choice. Although personalization can be accomplished by applying different strategies, it often includes using technology to accommodate the differences between individuals. The evolution in information and communication technology offers new opportunities for personalization, customization, and tailoring in decision aids.

DESIGN AND METHODS

The objective of the study is to identify and describe the current use of personalization strategies in electronic patient decision aids based on a pre-established coding scheme. This coding scheme is based on operationalization of concepts from fields related to shared decision-making, such as interactive web design, computer decision support, genetic medicine, tailored communication, personalized healthcare and personalized education. We plan to analyze a total of 50 electronic decision aids, some of which are included in the Cochrane systematic review of patient decision aids for people facing health screening or treatment decisions.

RESULTS

It has been proposed that technological personalization of patient decision aids has the potential to tailor healthcare and healthcare communication to individuals, by adjusting to the different biological, social and psychological idiosyncrasies of patients. The process of operationalizing the personalization concepts from various fields (e.g. medicine, computer science) results in a coding scheme that can be applied to future work. The current personalization practices in patient decision aids is mapped to this coding scheme and presented in the paper. Results also include an analysis of the possibilities for personalized data exchange between patient decision aids and online electronic medical records.

CONCLUSION

The era of paper provided limited possibilities to diverge from a one-size-fits-all approach. In the digital era, new technologies such as adaptive hypermedia open further opportunities for personalization, including interaction between patient decision aids, online electronic medical records and other resources. The effects of personalization techniques on patient knowledge levels, patient satisfaction with decisions, decision quality, and compliance to treatment plan warrants further investigation.

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4 POSTER SESSION TUESDAY

Walking on a tightrope: Oncologists' perspectives on providing information to women with recurrent ovarian cancer during the medical encounter

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BACKGROUND

Women with ovarian cancer (OC) must make treatment decisions through-out their journey with the disease. The first step in decision making is information exchange. Our objectives were to 1) describe the key issues that are reviewed by the oncologist when a woman presents with recurrent OC (ROC); and 2) understand the extent to which physicians have different methods of giving information to patients.

DESIGN AND METHODS

A qualitative study of 26 gynecologic and medical oncologists was undertaken using a semi-structured interview guide. A thematic analytic approach was undertaken by two reviewers.

RESULTS

Oncologists felt that the process of information giving was a required and important part of the medical encounter. The four themes that emerged were: 1) Oncologists vary in their approach to giving information about the disease and management; 2) Most oncologists feel giving management choices to the patients engages patients in dealing with their disease and moves the decision making process forward; 3) It is really important to keep patient's hope alive; and 4) Oncologists struggle with the extent to which they give patients outcome information.

CONCLUSIONS

Although physicians articulate that it is important to be upfront and clear about treatment options and giving treatment choices to keep hope alive for the patient, this is usually done in the context of vague or no survival information.

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183 ORAL PARALLEL SESSION 1

Measuring 'readiness to decide': using the DelibeRATE scale in an online evaluation of a decision support tool for women facing breast cancer surgery options (Bresdex)

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BACKGROUND

Debate continues about how best to measure 'good' decision making. A promising approach, advocated by Sepucha et al, proposes measuring the alignment of informed preferences with intentions. Another complementary approach is to focus on decision process (deliberation), where high deliberation would indicate a greater 'readiness to decide'. We describe how a measure of deliberation (DelibeRATE scale) captured the effect of using an online patient decision support intervention to support women facing surgery options for early breast cancer (www.bresdex.com, BresDex).

DESIGN AND METHODS

A conceptual analysis by Elwyn, Miron-Shatz (2009) led to the generation of a set of scale items. After pilot work, a prototype scale was developed comprising 9 items (7-point 'strongly disagree' to 'strongly agree' scale) with scores summed and rescaled 0 to 100, where the higher the score, the greater the 'readiness' to make a decision. DelibeRATE was included in an online evaluation of BresDex. Participants were asked to use BresDex after receiving a diagnosis of breast cancer. Online questionnaires were completed before and after use of BresDex, using the DelibeRATE scale, knowledge scale (about breast cancer) and treatment intentions.

RESULTS

70 women with breast cancer consented to participate in the study, of which 52 completed the DelibeRATE and knowledge items (mean age 53; range 29-80 years). The mean total scores increased from 65.1 (sd=26.3) pre-BresDex to 78.0 (sd=22.8) post-BresDex (F [1,51]=22.4, p<0.000). The mean scores of all but one item improved post-Bresdex. See figure. There were non-significant improvements in knowledge scores. Changes in treatment intentions are associated with an increase in deliberation scores (F[1,48]=21.6, p<0.000).

CONCLUSION

The DelibeRATE scale registered a statistically significant change in score after the use of BresDex. Further work is required to validate the ability of this scale to assess patients' 'readiness to decide' and to correlate this construct to other measures, such as shifts in informed preference and option intention.

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64 POSTER SESSION MONDAY

Implementation and Evaluation Roadmap Selfmanagement

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CONTEXT

Supporting patients in the tasks of managing their own chronic condition(s) calls for more than education, in which patients gain knowledge about their condition. Patients need to have the skills and confidence to effectively manage the condition on their own. Professionals need to have the skills to support patients in doing so. They need to turn into coaches and show patients how to do so in stead of being a caregiver and tell patients what to do. That's still a difficult job for professionals.

Since every patient with a chronic condition is a self-manager, responsible for most of his or her own care, support of self-management is an ongoing activity for the health care team.

For professionals and patient to support self-management to a structural part of care, Vilans develop with professionals, patients and experts an 'selfmanagement roadmap'. This roadmap can help selfmanagement to be not longer an individual event between patient and professional, but a group activity with consideration of all relevant disciplines.

METHODS

Vilans developed a roadmap, in consultation with patients and professionals, with 10 steps, to make it easier for patients and professionals into work with self management in daily care. Each step involves background information en questions for professionals to help them to make a teamplan for their own daily practice.

DEEL 1: PREPARATION

1 develop teamvision
2 identify and develop skills for professionals
3 make appointments and task distribution
4 use individual care-plan
5 use successful Methods

DEEL 2: IMPLEMENTATION

6 before consultation
7 during consultation
8 after consultation

DEEL 3: EVALUATION AND UPDATING

9 evaluate self-management
10 adjust teamplan where necessary

RESULTS

In 2010 we started a project with professionals in primary health care to help them with making a plan for implementing selfmanagement in the care of patients with heart disease or risk at it. In January 2011 we start a new project to build more experience with this roadmap.

CONCLUSIONS

The roadmap is a valuable tool to plan all kinds of actions needed to make selfmanagement a goal for professionals and patients.

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67 POSTER SESSION MONDAY

Implementation and Evaluation Individual care plan

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BACKGROUND

Self-management is an important part of the care standard Cardio Vascular Risk Management (CVRM). The standard aims to ensure that the care by professionals is based on self-management of patients with vascular risk. Shared Decision Making (SDM) is an essential condition to achieve self-management. Professionals note down the results of SDM in an individual care plan. This care plan is based on personal goals of the patient and defines what professionals and the patient themselves contribute to achieve this.

RESEARCH QUESTIONS

- What are the effects of using a care plan on the degree of self-management by patients and type/frequency of contact with professionals?
- What are the effects of using a care plan on professionals, such a the degree of support, content/type/frequency of contact, sharing responsibility with the patient, collaborate with colleagues, time investment?
- Are the developed tools and trainings for professionals and patients sufficient to support in the use of the care plan?

DESIGN AND METHOD

In order to support professionals in working with an individual care plan is the project ‘ implementation and evaluating Individual care plan’ started.

In this project Vilans supports thirteen general practices in starting with the Individual care plan. There is a Manual created, the care plan Vital Vessels is available, conferences with professionals are organized and questionnaires for research are developed. Vilans supports the individual general practices by phone or on-site visit in the application of the Individual care plan.

In January and February 2011 takes the first data collection place in patients and professionals in September and October the second data collection in patients and professionals place.

RESULTS

The results of the first data collection are available in March 2011. Than we know which patients use a care plan and which don’t. Also is visible what tools or training professionals still need to have Shared Decision Making in using the Individual care plan.

CONCLUSIONS

The initial conclusions about the use of the Individual care plan come available in March 2011.

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276 POSTER SESSION TUESDAY

Issues of trust and responsibility in the promotion of patients’ contributions to patient safety

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BACKGROUND

Increasing interest in encouraging patients and their family members to act to help ensure their safety as they use health services has been accompanied by concerns about the appropriateness of some safety-oriented patient activation initiatives and the limited circumstances in which they can be effective. Ideas about relationships between healthcare staff and patients, including issues of trust and the allocation of responsibility, are emerging as particularly important for understanding the promise and the pitfalls of activating patients for the sake of their safety. The purpose of this presentation is to examine insights relating to patient-staff relationships derived from studies of patient involvement in patient safety to facilitate consideration of their implications for efforts to involve patients in decisions about their healthcare.

DESIGN AND METHODS

Critical interpretive assessment of key findings from research into patient involvement in patient safety.

RESULTS

Patients’ and family members’ capabilities to contribute to their safety are strongly shaped by features of healthcare provision, especially interpersonal relations with healthcare staff.

Patients and families are often unable or unwilling to adopt recommended safety-promoting behaviours such as monitoring their care and speaking up about concerns because such behaviours appear to involve them challenging rather than collaborating with healthcare staff. This problem arises particularly when staff behave in ways that indicate they are disinterested in or distrustful of those patients, and when they do not routinely engage patients in discussions and decision-making.

Attempts to involve patients to ensure their safety as they use health services risk shifting responsibility inappropriately to patients if the interventions used do not suffice in the circumstances to enable patients to act confidently and achieve the intended effects. While most patients may need more support than is currently given, this issue is particularly acute for people whose personal and social circumstances generally limit their capabilities for autonomy and agency.

CONCLUSIONS

Shared decision making could tend to facilitate patients’ contributions to their safety. The exchange of insights from work on patient involvement in patient safety and insights from work on patient involvement in healthcare decision making could benefit both domains.

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106 POSTER SESSION TUESDAY

Sharing decisions about childbirth: experiences of service users and providers with woman-held maternity records that invite women to record birth preferences

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BACKGROUND

The Scottish Woman-Held Maternity Record (SWHMR) invites pregnant women to record salient information, questions, and preferences about their care. One section, commonly called the birth plan, focuses on preferences for labour and childbirth.

As part of a study of how the SWHMR might affect woman-centred care, we considered how the birth plan might influence shared decision-making during delivery.

DESIGN AND METHODS

A longitudinal qualitative study. Semi-structured interviews with 24 clinicians (midwives, obstetricians, GPs) and 42 women (sampled for socio-demographic and obstetric diversity) explored experiences of the SWHMR and woman-centred care. Women were interviewed pre- and post-natally. Data were analysed thematically using a Framework approach.

RESULTS

Clinicians were generally positive about the SWHMR inviting women to record their labour/childbirth preferences but noted that not all women were inclined and able to do this. Clinicians appreciated the quick introduction the birth plan could give them at delivery to a woman and her preferences.

Women had varied experiences of being encouraged and enabled (or not) to consider, discuss and document their labour/childbirth preferences antenatally, and not all completed birth plans. Some felt insufficiently informed or were reluctant to record preferences that might not be attainable. Several noted preferences to be flexible and to follow clinicians' advice to ensure good outcomes.

Postnatally, most women who had recorded preferences said these had been followed where feasible - sometimes without them re-stating them at the time. They had diverse recollections of how the SWHMR was used during labour, and talked more about direct communication with delivery clinicians. Several commented that clinicians' initial acknowledgement and discussion of what they had written helped establish a good rapport. Several women received interventions they initially not wanted, but found this unproblematic because clinicians took their preferences seriously and offered both explanations and alternative options. (Prior discussions about possible interventions were also appreciated).

CONCLUSION

An invitation to complete a birth plan can facilitate shared-decision making by: normalising an expectation of attention to women's preferences, helping ensure pregnant women know and can think about possible interventions in advance; familiarising clinicians with women's (initial) preferences; and helping develop a clinician-woman rapport.

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34 POSTER SESSION MONDAY

The involvement of children in decision making: development and implementation of a novel method for assessing actual and preferred involvement in treatment decisions for squint.

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BACKGROUND

Decision-making in the treatment of children implies a three-way partnership between clinician, parent and child. Whilst this has received attention for severe or life-threatening illnesses (e.g. diabetes, cancer), little is known about actual or preferred involvement of children in decisions for less serious conditions. Intermittent distance exotropia (X(T)) is a childhood squint with several treatments, but with no clear evidence as to the best option. We describe the development and implementation of a novel method for assessing actual and preferred involvement of children (4-12 years) in decision making about treatment of (X(T)).

DESIGN AND METHODS

Families attending two ophthalmology centres in northern England were recruited. Interview schedules employed interactive, participative techniques to engage the child. Children were asked to 'draw-and-describe' people important to them, providing contextual relationship information. Coloured stickers were used to introduce the concept of sharing decisions between parties. A quantitative technique ('pots and corks'), adapted from Thomas and O'Kane (1999) was used to assess actual and preferred involvement in consultations. Using illustrations provided, children indicated preferred degree of involvement for the parties in making treatment decisions, and quantified this using coloured stickers.

RESULTS

Home interviews took place with 20 children (mean age 5.6 years). The introductory drawing exercise worked well with all children. Children across the age range described their clinic and treatment experiences. Older children were better able to complete the 'pots and corks' activity than younger ones. The concept of "influence"was not well understood by young children. Early results suggest that children would prefer less input from adults and would like to contribute more verbally themselves in consultations. Even very young children could indicate their preferred involvement of parties in decision making, using a combination of pictures and discussion. Children acknowledged that the views of parents and professionals were important when deciding on treatment, with a majority wanting to participate in this process themselves.

CONCLUSION

The method enables direct, quantifiable capture of children's involvement in clinical consultations, and capture of their preferences about the roles of those involved in decision making.

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270 SYMPOSIUM PARALLEL SESSION 1

Using theory to guide presentation of the risks and benefits of treatment

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BACKGROUND

Four major theoretical approaches can be used to influence strategies for presenting risks/benefit information to patients making medical decisions. These include the information-processing that stress reducing cognitive burden; 2) evolutionary approaches that stress natural quantitative processing as illustrated by frequency effects; 3) dual-process approaches that contrast intuitive (or affective) and analytical processing in which errors are due mainly to intuitive processing; and 4) fuzzy-trace theory, another dual-process theory, but one that stresses gist-based intuition as an advanced mode of processing and contrasts it with verbatim-based analytical processing. These methods suggest strategies for communicating risk information.

METHODS

Experimental studies conducted in both general public populations and in clinical contexts have tested a number of methods for communicating risk and benefit information. Factors investigated include use of graphical formats, order of presentation of risk and benefits, use of frequencies vs. percentages, presenting less information (vs. more), as well as many other topics. This talk will review a number of experimental studies that address these topics and how they have (or have not) been influenced by theoretical approaches.

RESULTS

Results suggest that reducing cognitive burden and presenting information that communicates both gist and verbatim knowledge results in better understanding and better decision making.

CONCLUSIONS

While research has given us many recommendations of how to best present information, there are significant areas that need additional research. Furthermore, more studies need to consider theoretical rational for their testing.

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257 ORAL PARALLEL SESSION 2

If you give them tailored information, will they believe? The impact of a web-based, tailored decision aid on women at high risk for breast cancer

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BACKGROUND

There is an emphasis on providing tailored risk/benefit information to patients who are making preference sensitive medical decisions. While many studies have shown that tailoring influences decision making and behavior, little research has assessed patients' perception of the accuracy of the tailored statistics.

DESIGN AND METHODS

Guide to Decide (GTD) was a randomized trial designed to evaluate the impact of a personally-tailored, web-based decision aid for breast cancer chemoprevention. 690 women from two health care organizations, Henry Ford Health System (Detroit, MI) and Group Health Cooperative (Seattle, WA), and who were at high risk of future breast cancer (Gail score $\geq 1.66\%$) received an online decision aid (DA). The DA presented individually tailored feedback about their 5-year breast cancer risk and personalized risk/benefit information about tamoxifen and raloxifene chemoprevention. Afterwards, they completed a post-test survey. Of note, participants were asked to indicate their actual risk of breast cancer with and without taking a chemoprevention drug. Those who gave incorrect numbers were asked why they give incorrect numbers (Forgot, rounded, disagreed with the numbers). Those who disagreed with the numbers were asked to provide an explanation for their disagreement.

RESULTS

22/690 (3%) disagreed with at least one number and 131/690 (19%) disagreed with both numbers. The primary reasons were family history, own medical history, and preventative actions they have undertaken. Disbelief in the numerical information presented was correlated with gist knowledge regarding the risks and benefits of raloxifene ($R = .11$, $p<0.04$), but was not correlated with Gail model score (actual breast cancer risk), anxiety (baseline or following reading of decision aid), subjective numeracy, need for cognition.

Furthermore, those who were specifically told how the information was calculated did not have greater belief in the numerical information.

CONCLUSIONS

People may be skeptical of tailored risk/benefit information. Further work needs to be done to find methods to insure patients that the statistical information provided is scientifically and personally relevant.

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114 **POSTER SESSION TUESDAY**

Attributes affecting treatment choice for early-stage prostate cancer: many changes and wide differences produce stable results

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BACKGROUND

A multi-centre randomized controlled trial assessed the impact of values clarification exercises (ValEx) in a patient decision aid (DA) for treatment of early-stage prostate cancer. Results showed that, after actual decisions were made, those randomized to ValEx felt they had been better prepared to make the decision, and experienced less post-decisional regret. The ValEx included identifying attributes affecting the decisions at several times during DA. The attributes of this group could be compared to those of patients who completed an earlier version of the DA ~10 years ago.

PURPOSE

To determine the range and stability of attributes that affected patients' decisions, and compare attributes across 2 patient groups who made their respective decisions ~10 years apart.

METHOD

The ValEx patients identified attributes that affected selection of their most preferred option up to three times during DA: before presenting information (pre-info), after it was presented (post-info), and for those offered >2 options, when they were choosing between their two most-preferred options (most-preferred).

RESULTS

The 81 ValEx patients identified medians of 11 (range 0-15) and 7 (0-15) attributes in the pre- and post-info lists, respectively; 80 (99%) made changes (adding, dropping and/or shifting relative impact) between lists. Fifty-one patients (those offered >2 options) completed the most-preferred list identifying a median of 5 (range 0-15) attributes; 48 (94%) made changes from their previous list. Across all 81 patients, 32 different attributes were identified on final lists, but only 2 (bladder and sexual functioning) affected the decisions of half (or more) patients. The distribution of final attributes was highly correlated to that of the patients who made their decisions ~10 years ago (Pearson r = 0.72, p<.001).

CONCLUSION

Almost all patients were actively differentiating their choices during the DA, with large differences in final attributes amongst the patients. The final attributes, however, were very similar to those of the previous group of patients showing that the changes are not random.

IMPLICATION

Patient decision aids should be designed to accommodate wide inter-patient differences in attributes that affect their decisions, and expect patients to differentiate the options slowly.

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29 **ORAL PARALLEL SESSION 6**

Implementing Shared Decision Making for Human Papillomavirus Vaccination

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BACKGROUND

Little work has been done to understand how best to implement shared decision making (SDM) with multiple decision makers. Beginning in 2006, human papillomavirus (HPV) vaccination was recommended for all US adolescent girls, yet rates remain low. We sought to understand (1) how vaccination decisions were made among adolescent girls, their mothers, and clinicians at the point of care and (2) the link between the decision making process and vaccine receipt.

DESIGN AND METHODS

Between March and June, 2010, we conducted semi-structured interviews with 20 purposively sampled adolescent-mother-clinician triads (60 individual interviews) directly after a pediatric preventive visit with HPV vaccine due. Questions in the interview guide, developed after an extensive literature review, focused on the decision making process. Data from the audio taped interviews were analyzed within and across triads using NVivo software based on a modified grounded theory approach. Interviews continued until saturation of our primary themes was achieved.

RESULTS

Nine out of 20 teens received the HPV vaccine. We identified 3 themes: (1) Parents delayed, rather than refused vaccination, and when they expressed reluctance to vaccinate, clinicians were hesitant to engage them in discussion. (2) Clinicians used one of two distinct strategies to present the HPV vaccine, either presenting it as a routine vaccine with no additional information or presenting it as optional and highlighting risks and benefits. Those that used the former approach believed they had more success delivering the vaccine. Neither elicited negative responses from families. (3) Teens considered themselves passive participants in decision making, even when parents and clinicians reported including them in the process.

CONCLUSIONS

Although we conceptualized HPV decision making as a multi-party process, adolescents were passive and clinicians were often not able or willing to engage reluctant parents in discussion. To optimally implement SDM for HPV, our results suggest that clinicians must believe that SDM is warranted and may benefit from decision aids that engage reluctant parents as well as passive teens. Findings also suggest that the impact of SDM versus paternalistic decision making styles on vaccine receipt should be examined.

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75 ORAL PARALLEL SESSION 3

Development and Testing of a Computerised Decision Support and Risk Communication Tool for Thrombolytic Treatment in Acute Stroke Care

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BACKGROUND

Thrombolysis (clot-busting treatment) improves outcomes from acute ischaemic stroke (AIS) but may produce bleeding complications. Decision support during the emergency period of stroke is warranted to expedite appropriate clinical eligibility assessment for thrombolysis and communication of risks/benefits to patients/families, including where appropriate engaging them in decision-making.

DESIGN AND METHODS

Informed by development work (interview study; literature review; international survey of available examples; a decision analytic model; ethnographic study; group workshops with clinicians and patients/family members), we designed a prototype computerised decision support and risk communication tool. This is presented on a tablet computer and expresses outcomes for AIS (independence [none/slight disability], dependence [moderate/severe disability] and death at six months), and risk of bleeding complications, with and without thrombolysis, as a function of 11 patient characteristics. Outcome probabilities are presented using a pictograph, bar graph and flowchart diagram. Interactive usability testing was undertaken with ten stroke clinicians (five stroke consultants, three A&E physicians, two stroke nurses) and nine patients/family members (five patients, four family members) to determine acceptability and usability of the prototype.

RESULTS

Clinicians reported potential benefits in enhanced decision-making on eligibility (e.g. patients at the extremes of the licensing criteria for thrombolysis) and informed consent (provision of personalised information); and improved clinical governance (record of thrombolysis decision-making discussions). The tool was also considered to be a valuable educational/training resource and a potentially useful adjunct to the telemedicine model of acute stroke care. Interruptions to clinical flow (e.g. delay of treatment), data security, medico-legal issues (e.g. data mis-entry) and patient/clinician acceptability of the outcome probabilities were highlighted by clinicians as barriers to use. Both groups reported preference for the pictograph as a risk presentation/communication tool. Patients/family members considered the information provided by the tool to be valuable and expressed preference for paper-based risk presentations, with outcomes presented in the order of independence, dependence and death.

CONCLUSION

The prototype was well-received by clinicians and patients/family members. Additional functionality (e.g. save/print), strategies for minimising data mis-entry and impact on clinical flow, including transparent communication of the evidence used to generate the outcome probabilities are required to augment acceptability/usability in clinical settings.

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3 POSTER SESSION MONDAY

Pediatric Fundoplication and the Surgeons' Decision Making Process

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BACKGROUND

The pediatric surgical literature has no consensus as to one objective test to determine which child needs a fundoplication, and therefore subjective factors may play a role.

DESIGN/METHODS

To examine subjective and objective factors influencing the decisions of pediatric surgeons a pre-operative self-administered survey questionnaire was completed by one of 6 pediatric surgeons on three groups of patients who were being considered for a primary fundoplication procedure: those having a fundoplication, those having a gastrostomy without a fundoplication, and those having a gastrostomy and fundoplication.

RESULTS

From July 1, 2009 through June 30, 2010, 197 patients met eligibility criteria and 189 surveys were completed (RR 96%) by the surgeons. The mean age of the patients was 3.8 years, 61% were male, and the median LOS was 9 days. Of the patients, 14% (n=27) had a fundoplication only, 42% (n=79) had a gastrostomy only and 44% (n=83) had a fundoplication and gastrostomy performed by one of the hospital's pediatric surgeons. Of the cohort, 59% were referred to the surgeon as an inpatient and the balance as outpatients.

For 87% of cases the surgeons stated that the input of another physician had somewhat or a lot of influence on their decision. Specifically they mentioned the input of several specialists: Neonatologist (21%), Hospitalist (21%), Pulmonologist (20%), Primary Care Physician (19%), and Pediatric Gastroenterologist (18%). The opinion of the parents contributed somewhat or lot to the decision making 75% of the time. Among the 89% of the cohort that had an upper GI contrast study, surgeons stated that the results had a lot of influence 38% of the time. Only 13% of the cohort had a pH probe and the surgeons reported that this study had a lot of influence 44% of the time.

CONCLUSIONS

Most decisions to perform a fundoplication occur in the inpatient setting and are impacted by objective and subjective factors, including the opinions of other physicians. The high level of parental input suggests that the decision regarding fundoplication would be amenable to the development of a shared decision making tool which clarifies the preferences of the family.

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216 POSTER SESSION MONDAY

Designing visual and verbal cues to communicate genomic risk: A user-centric qualitative exploration.

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BACKGROUND

Although genomic information may refine estimates of coronary heart disease (CHD) risk, how people will perceive these estimates and their mutability through intervention is unclear.

OBJECTIVE

To assess the effect of novel verbal and visual cues on communication of 10-year CHD risk estimates computed using both traditional coronary risk factors and genomic information.

STUDY DESIGN AND METHODS

As an exploratory effort to better understand patients' perceptions and understanding of presentation of risk for developing CHD in the next ten years we organized two focused discussions with members of the community. In cooperation with the research team, a design team prepared several different scenarios for presenting CHD risk estimates to the study groups. The first group received four different scenarios and based on the results the scenarios for the second group were modified. In the first group we explored more what should be presented and in the second group how it should be presented.

RESULT

It was not important to either group to explore at length what goes into calculations of CHD risk as long as the physician presenting the risk deemed those test results reliable and useful. Feedback from the second group indicated that language matters a great deal to patients and can influence how the information affects them. The key insight from this group was the difference in personal interpretation of risk that came with the formulation "out of 100 people like you..."vs. "out of 100 possible lives you are living now...". Participants reported that the latter presentation conveyed the CHD risk in an impactful manner and was difficult to dismiss. They also reported it being more difficult to grasp and convey to others.

CONCLUSION

Not only the visual depiction of risk, for instance using a 100-people pictograph, is important in CHD risk communication in decision aids, but also the accompanying language formulation. Tradeoffs involved include clarity, interpretation, and cognitive burden. Attention to the language of risk in decision aids remains an understudied area of great importance in the genomic era.

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42 ORAL PARALLEL SESSION 2

Encounters with 'gods on their high thrones in heaven': Patient perceptions of what it takes to participate in shared decision making

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BACKGROUND

This study explored a critical gap in shared decision making research - patient perceptions of what it takes to engage in the communication behaviors necessary for shared decision making.

METHODS

We conducted a focus group study. Discussion centered on participants' perceptions of communicating with physicians (e.g., asking questions, expressing preferences, disagreeing with a recommendation) in the context of preferences sensitive decisions. Participants (N=48) were primary care patients who were at least 40 years old (Mean = 64.7, SD = 12.1). We conducted a total of 6 focus groups, which were transcribed and analyzed thematically.

RESULTS

Participants' experiences and perceptions were grouped around four major themes, each with further subthemes:

1. Protecting the doctor and protecting oneself from the doctor:
   a. Participants talked of wanting to conform to normative definitions of the patient role, wanting to be deferential, not 'displeasing' or 'disappointing' the doctor, by asking too many questions, or disagreeing with a recommendation.

   b. Fearing retribution for being a difficult patient, participants described a high dependency on the good will of the clinician and concern that they will be dismissed as non-compliant and receive worse care if perceived as too assertive.
2. Picking up the slack
   a. Participants described researching their medical issues on their own in various sources to deliberate their choices, with little support from the physician.
3. Bringing in the reinforcements:
   a. Some participants talked about bringing family members or friends to consultations in an effort to make the most of limited time with the physician.
4. System barriers to patient involvement in decision-making:
   a. Lack of time limited the ability to ask questions, voice their concerns and seek guidance in deliberating.
   b. Clinic staff sometimes blocked access to physicians, serving as gatekeepers who protected them.

CONCLUSION

Consistent with Thomas Kuhn's argument that paradigm shifts require considerable time, these findings highlight some of the medical-cultural barriers that stand in the way of broader adoption of shared decision making in clinical practice.

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45 ORAL PARALLEL SESSION 7

A randomized controlled trial evaluating a behavior support intervention for patients with poorly controlled diabetes

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BACKGROUND

There is growing interest, as part of broader implementation of patient centered care, in using telephone coaching to support behavior change for patients with chronic diseases. However, few rigorous evaluations of such interventions have been reported to date. This study evaluated an intervention targeted at economically disadvantaged ethnic minority patients with poorly controlled diabetes.

METHODS

We conducted a two-group randomized controlled trial (N=200) comparing an intervention package consisting of a video behavior support intervention (BESI) about diabetes self-care (developed by the Foundation for Informed Medical Decision Making), combined with 5 telephone coaching sessions from a diabetes nurse, to usual care. Participants (18% African American, 53% Latino) were drawn primarily (89%) from a community-based free clinic. The intervention focused on supporting participants in identifying and implementing behavior change goals. Participants completed assessments, including hemoglobin A1c, blood pressure and lipids, at baseline and six months. An interim survey was conducted 1-month post-enrollment.

RESULTS

The majority of participants assigned to the experimental group (94%) reported viewing the video BESI and 73% completed 5 sessions of telephone coaching. Average baseline hemoglobin A1c was 9.67% (SD = 1.99). There was a significant overall reduction at 6-months (p<.001), but non-significant differences between groups (p=.642), as both groups improved over time. Similarly, there were no significant differences at 6-months between groups for blood pressure (p=.268) or lipids (p=.865). Diabetes knowledge improved modestly in both groups, but neither increases over time nor differences between groups were significant (p=.310). Behavioral measures also showed modest changes over time, but neither overall increases nor differences between groups at 6-months were statistically significant. In-depth interviews conducted with a randomly selected subset of participants suggested that the impact of the economic recession lowered the priority given to diabetes care among the study participants.

DISCUSSION

We found no significant effects for a video BESI combined with telephone coaching for improving diabetes management among economically disadvantaged ethnic minority patients. These results suggest that more intensive interventions may be necessary for disadvantaged patients with poorly controlled diabetes.

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116 SYMPOSIUM PARALLEL SESSION 6

Creating a paradigm shift in health care practice: Lessons learned facilitating culture change to implement patient decision support interventions

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BACKGROUND

There is still limited recognition that implementing shared decision making (SDM) requires culture change, both at the level of providers and patients, as well as at higher levels within health care organizations. We describe a case study from a large private health care organization in the US.

DESIGN AND METHODS

The Palo Alto Medical Foundation (PAMF) is a multi-specialty physicians group serving 750,000 patients in the San Francisco Bay Area. As part of a demonstration project focused on patient decision support implementation we are working in 5 primary care practices and 3 Community Health Resource Centers to raise awareness of SDM and provide decision support interventions (DESIs) to eligible patients at the point-of-care. Ethnographic field notes document day-to-day experiences facilitating culture change and implementing SDM and DESIs for patients.

RESULTS

The “Partners in Medical Decision Making”(PMDM) program has taken a multi-tiered approach to facilitating culture change by developing a structured social marketing campaign targeted at all levels of the organization. Patient outreach includes brochures, posters, and newsletters to raise awareness of SDM and the availability of DESIs for a range of conditions. Patient and health care provider outreach materials are organized around slogans intended to capture the primary benefits of using DESIs, specifically: “Prescription strength information for better decisions”and “Better decisions, together”. Outreach to health providers takes several forms. The project team worked with each clinic to develop individualized plans and workflows to implement distribution of DESIs to patients. Regularly scheduled academic detailing ensures that clinics and providers have frequent interaction with PMDM as well as opportunities for trouble-shooting, problem-solving, feedback and reinforcement. Contests were used successfully in some sites to help staff develop the habit of providing DESIs to patients, while earning nominal rewards branded with the program’s promotional slogans. Outreach to the organizational leadership includes semi-annual newsletters, presentations to administrative committees and grand rounds presentations.

DISCUSSION

Implementing SDM requires culture change, which in turn requires sustained engagement at multiple levels of an organization.

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247 ORAL PARALLEL SESSION 6

Measuring Dissonance between Patient Preferences & Surgery for Breast Cancer, Prostate Cancer & Cardiac Disease

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BACKGROUND

This paper explores some of the consequences and origins of dissonant decisions. In a mail survey funded by the NIA, Medicare patients were asked to describe the decision-making process for 5 of the most common and important surgical interventions in the U.S.: lumpectomy and mastectomy for breast cancer, insertion of stents and CABG for coronary artery disease, and radical prostatectomy for prostate cancer. Each of the surgery-specific survey instruments included a series of items about how important a set of goals and concerns were that patients have reported are relevant to the particular treatment decision they had faced.

DESIGN & METHODS

Dissonance scores were created by summing responses to the goals and concerns that would lead a patient to avoid each of the procedures. We then looked at whether there were lingering regrets associated with dissonant goals using responses to questions that asked: “how do you feel about how things turned out?”and “if you had the decision to make over again, would you still choose surgery?”

The 5 surgery samples were selected using Medicare administrative data. After following a standard 4-contact data collection protocol, with a prepaid $5 cash incentive, a total of 2,709 completed questionnaires were returned for an overall response rate of 79% (Range: 74-86%).

RESULTS

Overall, the majority of people were pleased with the way things turned out and say they would “definitely”choose the same treatment again. However, almost without exception, the more important one of the dissonant concerns was to the respondent, the less pleased they were with the outcome and the less likely they were to say they would choose surgery again. Many of these relationships are statistically significant; in prostatectomy, all are highly statistically significant.

CONCLUSION

We present evidence that dissonance associated with surgical decisions across diverse procedures can be measured by patient self reports.

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11 POSTER SESSION TUESDAY

DEcision making in breast Cancer; pre-Implementation of a Decision-aid for fErtility preservation (DECIDE)

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BACKGROUND

Information provision about fertility preservation is not always sufficient for informed decision making, and often late. To improve information provision we developed a webbased decision-aid (DA). A pre-implementation study is carried out to reach consensus between different end-users of the DA regarding their attitude towards implementation of the DA.

DESIGN AND METHODS

Delphi expert panel consisting of three rounds. In round 1 and 2 respondents complete a questionnaire, in round 3 respondents take part in an online focus group. We will assess attitudes towards fertility preservation, the procedure of informing patients, and the (implementation of the) DA. Answering categories in the questionnaire range from 1 (totally disagree) to 5 (totally agree). Consensus is considered significant when at least 80% of the participants score either the lowest or the highest two categories. The online discussions will be analyzed qualitatively. Study population (n=24) exists of 8 (ex)patients who have received information on fertility preservation at the time their treatment started, 4 medical oncologists, 2 breast cancer surgeons, 2 radiotherapists, and 4 gynecologists, from different parts of the Netherlands.

RESULTS

Data collection will take place from January-February 2011.

(EXPECTED) CONCLUSION

Consensus on the way of implementing a DA to improve information provision about fertility preservation, and on the procedure of introducing it to patients. In case of no consensus we will have important information on heterogeneity of procedures. We expect increased motivation for all end-users to provide or use the DA.

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24 POSTER SESSION MONDAY

Is it better to present dialysis treatment choices in an option or attribute format? An experimental study

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BACKGROUND

This study is part of a project evaluating the components that make up the Yorkshire Dialysis Decision Aid (YoDDA). A prerequisite of informed decision making is that patients have a clear, full and unbiased representation of the decision information. The way information is structured affects people’s judgments and choices. This study provides evidence on how best to structure details about dialysis treatment options.

DESIGN AND METHODS

A 2*2 between-subject experimental design was employed to test the following:

- Information structured by option versus by attribute: treatment information is usually presented in a sequential or linear format, i.e. one option is described fully followed by the description of another option (by-option). Information can be presented by making explicit the attributes of the options, i.e. descriptions of the characteristics within each option (by-attribute).
- Even versus uneven categorisation: many treatment choices involve several options which can be classified or nested under broad categories. In the dialysis context choices can be classified so that an even or uneven number of options occur within categories: categorising by dialysis type (haemodialysis and peritoneal dialysis) results in even options; categorising by treatment location (medical centre and patient location) results in uneven options.

Participants: 200 students participated in an on-line survey in January 2011.

Measures included: information utilised during decision making; treatment choice; decision quality; knowledge; values; acceptability of resource.

RESULTS

Most services are providing information about dialysis in a by-option structure and classifying individual treatment options under broader categories. These findings provide evidence that the way details about dialysis options are structured affects people's judgments, choices and quality of decision making.

CONCLUSION

The information content of patient resources can be structured in a way that encourages patients' active engagement with the treatment details and reduces the likelihood of biasing their final representation of the decision problem.

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192 POSTER SESSION TUESDAY

Patient pull: who pulls and how?

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BACKGROUND

Our understanding of patient pull, its predictors and behavioural manifestations is limited. While we know that some patients, for example, women and the highly educated are more likely to seek an active involvement in decision making, we do not fully understand why this might be. And going beyond simply mapping SDM preferences little research has been published that examines the tactics patients use to influence decisions about their health care. This paper provides important insights into patients' behaviours and preferences in situations where decisions about their health are being made.

DESIGN AND METHODS

We report on an online survey of approximately 200 general practice patients. The research was conducted in New Zealand and the sample was predominantly of European origin, female, middle aged, healthy and well educated.

RESULTS

Structural equation modelling techniques were used to investigate the predictive power of demographic, attitudinal and dispositional variables. Need for cognition, doctor-patient trust, perceived health care competence and health locus of control were found to have predictive power in determining patient SDM preferences and pull. Patients reported using a range of tactics to influence decisions about their health care, and these too could be predicted from attitudinal and dispositional differences. The relationship between influencing tactic use and SDM preferences is explored.

CONCLUSIONS

Our results support the notion that SDM preferences reflect underlying psychosocial and attitudinal differences and we successfully identify some important predictive variables. We argue that efforts to increase patient pull need to operate on and through these underlying causal variables.

Our results confirm that general practitioners are exposed to a range of patient influencing tactics. We describe these tactics and provide insight into when and why patients adopt particular tactics. We argue that efforts to increase patient involvement in decision making must be attuned to the range of tactics patients use in their efforts to influence.

We anticipate that this work will be of practical relevance within general practice, with the ambition being to elevate patient pull. The research could not only be used to inform medical practitioners but also to empower patients.

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53 ORAL PARALLEL SESSION 2

Developing decision boxes to facilitate shared decision making in primary care

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BACKGROUND

Healthcare professionals have difficulty interpreting evidence and translating it to patients. These skills are nevertheless essential for shared decision making. Decision boxes summarize the most important benefits and harms of diagnostic, therapeutic and preventive health interventions. They are intended for use by healthcare professionals before they meet their patient. The objective of this study was to provide a framework for developing decision boxes.

DESIGN AND METHODS

Step one: A panel of seven researchers (including four practicing family physicians) selected 10 clinical topics in a 3-round web-based Delphi survey. Criteria for selection of topics were relevance to primary care practice and availability of evidence. Step 2: Decision box prototypes were developed in French and in English for each selected topic, based on risk communication literature, and on an iterative process involving collaboration between graphic designers and researchers.

RESULTS

The 10 topics covered screening (n=5), preventive (n=3) and treatment (n=2) interventions. Each decision box is a single-page document divided in two sections. Section one describes the intervention, the patient population and the decision to be considered. Section two presents research-based information on the probabilities associated with each option using numbers, graphics and narrative statements. At the bottom of the box, a statement of confidence in these probabilities is used to report consistency of results, indirectness of evidence, study limitations, and imprecision using an approach adapted from the GRADE Working Group.

CONCLUSIONS

Decision boxes will prepare clinicians to help patients make informed value-based decisions. By acting as primers, the boxes should enhance the application of evidence-based practice and increase shared decision making during the clinical encounter. This study produced a preliminary framework for developing decision boxes. Future research should explore perceptions of patients and physicians regarding the content and format of each prototype, and trials to determine the effects on shared decision-making.

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225 POSTER SESSION TUESDAY

Development of PRIDe based on the Script Concordance Test to assess physicians preferred role in clinical decision making

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BACKGROUND

Shared decision making (SDM) training programs targeting clinicians should increase their preference for a more active role of patients in the decision-making process. Our objective was to assess item quality and explore the validity and reliability of a new tool measuring role preference of clinicians trained in SDM.

DESIGN AND METHODS

This study was embedded within a pilot clustered randomized controlled trial that assessed the feasibility of a larger trial of a SDM training program (DECISION+) in the context of antibiotics use for acute respiratory infections. Family physicians exposed to DECISION+ either immediately (n=18) or 6 months later (n=21) completed seven items based on the Script Concordance Test model at baseline and follow-up. Clinicians rated their preferred role in decision making on a scale ranging from -2 (decision taken by the patient alone) to +2 (decision taken by myself alone). Responsiveness to change of each item was assessed with histograms of the frequency distributions of participants' answers before and after the training program. Consistency, reliability, and discriminant validity of the tool were also explored. Our a priori hypothesis was that an exposure to DECISION+ would change the preferred role of clinicians towards a more active participation of patients in decisions.

RESULTS

Thirty-nine clinicians completed the questionnaire at baseline, 32 after 6 months and 27 after 12 months. For five of the seven items, frequency distributions of participants' preference shifted towards a role where patients are more active in decisions after training. The combined items showed limited internal consistency (Cronbach's alpha = 0.41), significant test-retest reliability (P=0.03 in the immediate group; P=0.008 in the delayed group), and significant discriminant validity with a preferred role for more active involvement of patients in decision making after training (Fisher exact test; P = 0.02).

CONCLUSION

Of the seven items evaluated, five were kept based on their responsiveness to an exposure of participants to training in SDM. Additional items based on these will be added before further development and evaluation of the PRIDe (**P**referred **r**ole **i**n **de**cision making).

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32 ORAL PARALLEL SESSION 4

Shared Decision Making and Other Variables as Correlates of Satisfaction with Health Care Decisions in a U.S. National Survey

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BACKGROUND

Patient satisfaction with health care decisions has been shown to be associated with improved clinical outcomes. If modifiable correlates of patient satisfaction, such as shared decision-making (SDM), can be identified, these variables can be targeted for improving clinical outcomes. The objective of this analysis is to model variables associated with satisfaction with a health care decision.

DESIGN AND METHODS

A stratified (race, ethnicity, gender) randomly-selected age-proportionate national sample of adults aged 21-70 years (N = 488) was recruited from the U.S. National Institutes of Health ResearchMatch health research volunteer registry. Participants completed a secure online survey (45.7% response rate) that included the SDM-Q-9, sociodemographic, health, and other standardized decision-making measures. Measures were completed based on the respondent having had an interaction with a health care provider during the3 months prior to survey completion for diagnosis, treatment, or referral related to a personally-experienced health issue. Enter method multiple linear regression was used to model correlates of satisfaction with decision (SWD). The independent variables were standardized measures of SDM (SDM-Q-9 scale), autonomy preference, decisional conflict (Decisional Conflict Scale; DCS), and selected sociodemographic variables.

RESULTS

After controlling for socioeconomic variables, SDM-Q-9 total score remained as a highly significant predictor of satisfaction with decision ($t = 15.173$, $p < .000$). Sociodemographic variables were not associated with SWD, and DCS and autonomy preference were marginally significant. The final model accounted for 36.2% (adjusted R2) of the variance.

CONCLUSION

By identifying variables such as SDM that are significantly associated with satisfaction in a health care decision, the public health and medical communities can be enabled to target potentially modifiable variables to enhance decision satisfaction and clinical outcomes. Further analysis could examine the specific aspects of SDM that are most highly associated with decision satisfaction, to inform the design of interventions to improve decision satisfaction.

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167 ORAL PARALLEL SESSION 5

Breast cancer patients' informative needs and shared decision making preferences during a first oncological consultation.

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BACKGROUND

Patients desire to be involved in the medical consultation and those who shared decisions with their doctors are more satisfied and show greater treatment adherence (Butow et al. 2002).

Aims of this study are to observe the natural trend of the frequency and type of questions asked by patients with breast cancer in a first consultation and to evaluate their preference regarding the decision making process and satisfaction with the decision.

DESIGN AND METHODS

We conducted an observational study on patients with breast cancer at their first consultation with the oncologist. To assess the preferred level of participation we administered the Control Preference Scale (CPS) before the consultation. Consultation was audio-recorded and the frequency and type of questions asked by patients during the interview were noted. After the interview we administered the Shared Decisions Making Questionnaire (SDMQ) to and the Satisfaction with Decisions (SWD).

RESULTS

We recruited 70 patients. The mean age was 59 (range 30-75). Most of patients (67%) attended with relative who participated at the consultation. Patients asked a mean of 18 questions, mainly about administrative question (eg. Where to collect the exams results) and about treatment, less about prognosis and etiology. The majority of patients (84 %) showed a preference for shared treatment decision, stated that the oncologist helped them to understand all the information (97%) and made clear that a decision needed to be made (79%). They also felt to have reached an agreement with the oncologist on how to proceed (79%). Moreover most patients show a high degree of satisfaction with the decision made about treatment (87%).

CONCLUSION

The majority of Italian patients affected by breast cancer preferred to be involved in the decision-making process. Their informative needs are similar to what observed in the same context in other countries (Clayton et al. 2007), although they asked more questions. The factors that may affect the number of questions and patient involvement such as the presence of the relative or the role of the oncologist during the consultation, will be explored in the future.

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171 POSTER SESSION MONDAY

The involvement of breast cancer patients in the informative and decisional processes during oncological consultations. The study protocol of a clinical multi-centre randomized control trial.

G.C. Goss[1], A. Ghilardi[2], G. Deledda[1], C. Buizza[2], F. Chiodera[1], A. Bottacini[1], M.A. Mazzi[1], C. Zimmermann[1]
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BACKGROUND

Not all patients desire the same type of information on their illness and physicians have to adapt information to patients' informative needs and understanding. Such achievement seems to be associated with greater treatment adherence and better coping skills (Joosten et al. 2008). Different methods to encourage the active participation of patients have been described in literature (Butow et al. 1994, Clayton et al. 2007), but similar studies with Italian patients are lacking. Moreover Italian patients frequently attended the consultation with a family member. To our knowledge studies on the informative needs of family members and their role in the decision-making process are few. The aim of this study is to assess the effects of a pre-consultation intervention in determining a major patients' involvement during the consultation and to explore the role of the family member if present.

METHODS

All first patients with breast cancer at an early stage, aged 18-

75 years who attend the Oncology Out-patient Services are asked informed consent to participate the study.

The intervention consists in the presentation of a list of relevant illness-related questions. The main outcome measures are: a) the number of questions asked by patients during the consultation, b) the involvement of the patient, c) patient's perceived achievement of her informative needs.

The intervention study was preceded by an observational phase to explore the information exchange between patient and oncologist.

RESULTS

The observational phase has been completed. We recruited 70 patients (mean age of 59). The majority (67%) attended with relative. They asked a mean of 18 questions. We considered an intervention efficacious if it increases the number of questions by 30%. The sample size required in order to demonstrate such difference would therefore require at least 45 control and 45 experimental patients (Pocock 1983).

CONCLUSIONS

It is expected that the use of a list of printed questions of potential relevance facilitates the participation of the Italian patients with breast cancer in the information exchange and decisional processes. Considering the informative needs of the family members may open new and interesting perspectives.

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169 POSTER SESSION MONDAY

'To Be or Not to Be (Operated)' ? A quantitative decision model for the dilemma of an IPF patient when facing a transplantation surgery

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The present paper analyses the decision making process of a lung-disease-patient facing the dilemma whether to accept or decline a lung-donation and a transplantation surgery, when offered. The authors focus on data regarding an IPF patient and suggest the rational Von-Neumann-Morgenstern decision process as a benchmark both for the transplant-candidate as well as for the medical team involved.

BACKGROUND

Although previous studies have shown various data for the survival of lung-transplant patients, right after surgery and throughout the following years, none has touched the subject of the patient's decision process prior to the surgery with the emphasis on the patient's preferences and possible insights for the medical team. This process is highly important for those lung-transplant-candidates that are terrified by surgery and tend to decline the offer of transplantation.

METHOD

The authors focus on the point of view of the transplant-candidate, modeled by his revealed Von-Neumann-Morgenstern risk- preference, using existing data of survival probability and the conditional probabilities derived from them. The resulting decision model may help surgeons assess the benefit, to the patient, of the surgery compared to the assessed value of a possible negative answer by the candidate.

RESULTS

The model suggested is examined through the personal case of the first author, with a concave utility versus survival curve, where the 'accept' alternative is shown to be preferable to the 'decline' or 'delay decision' alternatives. The model was also checked for a convex utility function. The authors suggest an interactive computerized computational model to examine the sensitivity of the decision to changes in surgery-success probabilities, survival probabilities or patient's personal risk-preferences.

CONCLUSION

The introduction of the patient's life-span horizon and his revealed risk-preferences make it possible to present the Rational decision-making process which results , in many cases, in a positive 'accept' answer. Such an analysis may serve as a bench mark for both the patient and his surgeons

KEYWORDS
medical decision making, lung transplant

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154 ORAL PARALLEL SESSION 5

Pilot Decision Navigation Intervention for Prostate Cancer Management

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BACKGROUND

The Healthcare Quality Strategy for NHS Scotland aims to provide 'mutually beneficial partnerships between patients and those delivering healthcare', promoting shared decision-making (SDM) in medical consultations. The Decision Navigation (DN) intervention aims to promote this objective by increasing patient participation and SDM in cancer consultations.

DESIGN AND METHODS

Newly diagnosed Prostate Cancer (PCa) Patients attending the Edinburgh Cancer Centre were invited to participate over 20 months. Patients were randomized to intervention or usual care (control).

The intervention involved a 'decision navigator' creating a 'consultation plan' with patients prior to a key medical consultation, to elucidate their personal questions, concerns and objectives regarding treatment. The navigator accompanied patients to their medical consultation. The patient was supplied with an audio-recording and written summary of the consultation.

To evaluate the efficacy of the intervention, decisional self efficacy (DSE) was measured at baseline (T1), immediately after the consultation (T3), and 6 months later (T6); decisional conflict (DCS) at T3 and T6, and anxiety and depression (HADS) at T1 and T6.

RESULTS

113 PCa patients participated in the study (63 intervention; 60 control).
At T1 there were no statistically significant differences in the levels of depression and anxiety between intervention and control, nor at 6 month follow up indicating that the intervention did not impact mood.
At T1 there were no statistically significant differences between the groups in DSE. After the consultation, the scores reached significance in the intervention group (t=2.58, df 106, p=0.01). This was not sustained at 6 month follow up.

However, intervention patients scored significantly lower on the DCS compared to the control group (t = -2.0, df 109, p=0.05) post-consultation. At 6 months post medical consultation , it remained to be significant (t = -2.6, df 77, p=0.01).

CONCLUSIONS

The differences in DSE post consultation suggest the intervention increases patient's confidence in their ability to effectively make decisions about the management of their cancer. At 6 months the intervention patients also experienced less decisional conflict than control patients. The intervention is supported by clinical staff due to improved communication in consultations with enhanced preparation.

51

Arriba-lib: electronic library of decision aids. Results of a feasibility study.

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BACKGROUND

Evidence based medical decision aids have the goal to enable the patient to make an informed decision together with the physician. The aim of our project was to create an electronic library of evidence based, interactive, and transactional decision aids on the basis of the shared decision making (SDM) concept which cover the spectrum of coronary heart disease. Such a comprehensive library of decision aids has rarely been field tested, especially not in the primary care context.

DESIGN AND METHODS

We created an electronic library of evidence based decision aids including cardiovascular prevention, atrial fibrillation, coronary heart disease, diabetes type 2, and depression. We conducted a feasibility study with 29 general practitioners recruiting 192 patients. Patients were included when there was a decision to be made in the treatment of the above mentioned diseases. Counselling was based on the concept of SDM (definition of the problem, individual risk calculation, change of individual risk due to treatment options, discussing pros and cons of treatment options, plan for further action). Questionnaires, personal and telephone interviews, and focus groups were used to measure attitudes of patients and physicians. To account for the cluster structure of our data, we mainly used generalised estimation equations for statistical analyses.

RESULTS

Almost two thirds of the patients prefer a shared decision, 75.1% were very satisfied with counselling. Elder patients were more likely to implement the decision in a period of 2 months. The wish to be counselled again with arriba-lib was independent from age, gender, and educational level but it was dependent on the competence of the GP in SDM.

Three quarters of the GPs said that there was an acceptable extension of the consultation. In their opinion, a detailed discussion of therapeutic options promotes reaching a decision, not so much the discussion of individual risk.

CONCLUSION

There was a high acceptance of arriba-lib by patients and GPs, independent of patient characteristics. This makes a broad application possible. However, with regard to sustainable implemention of the electronic library GPs need ongoing support and further training in SDM.

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234 **ORAL PARALLEL SESSION 3**

Decision Aid Gone Viral? The Six-Year History of 'Making the Choice….'

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BACKGROUND

Use of Patient Decision Aids (DAs) in the public domain is more the exception than the rule. “Making the Choice: Deciding What to Do About Early Stage Prostate Cancer”, received funding from the US Centers for Disease Control, and is maintained by the Michigan Department of Community Health (MDCH) in booklet and audio format (printed copy, PDF, audio CD, mp3) and electronically at www.prostatecancerdecision.org. Six years of uptake suggests routes of dissemination and influence.

DESIGN AND METHODS

The prostate cancer DA was a public health initiative intended for Michigan. It was designed using plain language, emphasizing shared decision making. Statistical data describe treatment risks and benefits, and evidence is updated annually. PDFs and MP3 files are free on the internet; booklets are either free or at cost to individuals and clinical entities. All primary care and urology providers in Michigan received one copy with more available on order. Distribution volume is estimated from hits on the Internet site and vendor order records. MDCH received requests for translation into versions sensitive to culture and language. English, Spanish and Arabic versions are available.

RESULTS

Three printings totaled 40,000 English language booklets. Orders appear to be driven by clinical site orders and by patient support groups internationally. The most common website access is to download the entire PDF. Revision requests for cultural sensitivity and language have been received from Hawaiian and North American First Peoples groups and for a Russian translation. Internet use has grown 20-fold; the most recent year (July, 2009-June, 2010) experienced 1,111,081 hits. The American Society of Clinical Oncology (ASCO) has indicated preferential attachment through a link on their Internet site. Distribution receives MDCH staff support and fees from booklet orders. Evaluation in the State of Washington followed passage of DA supportive legislation and the booklet is currently being tested in 5 hospitals across the U.S.

CONCLUSION

DA distribution shows both sustained growth and preferential attachment by professionals, with supportive recognition from research and evaluation, suggesting influence on public education and clinical practice. Future development of the public health importance of DAs remains an opportunity.

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89 POSTER SESSION MONDAY

Patient participation in treatment decisions for stage I non-small cell lung cancer.

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BACKGROUND

Presently, surgical resection of stage 1 non-small cell lung cancer (NSCLC) offers a reasonable possibility for cure, with five years survival rates ranging from 50% to 77%. However, older patients are less likely to undergo curative treatment because of co-morbidities, frailty, higher operation risks, personal choice or a perceived lack of benefit of treatment. A new curative approach, stereotactic body radiotherapy (SBRT) was recently introduced in stage 1 NSCLC. SBRT delivers very high doses of radiotherapy in an outpatient setting and in 3-8 treatment fractions. A recent analysis in patients with staged I NSCLC revealed similar rates of local recurrence and disease-specific survival in patients treated with surgery compared with SBRT. An analysis of the overall survival outcomes of patients living in the province north Holland who were treated for a stage 1 NSCLC has revealed that SBRT produces the same survival outcomes for elderly patients diagnosed with early-stage lung cancer as surgery. At present, patients can choose between these two curative treatment options. The aim of this study is twofold: 1) to study the decision-making process regarding the treatment of patients for stage 1 NSCLC and 2) the involvement of patients in this decision-making process.

DESIGN AND METHODS

In order to study patient participation in treatment decisions and patient-physician perspectives in the process of shared decision-making, we will use the methods of observation and interviews. Study 1: A total of 20 patients will be recruited who have made the decision in the past between SBRT and curative surgery. Retrospective, semi-structured interviews will be held with the patient. Study 2: Observations of the physician-patient interactions during consultation and semi-structured interviews with patients who are confronted with a choice. The OPTION scale en Control Preference Scale will be used. Observations and interviews will be audio-taped, transcribed literally and will be coded with Atlas.Ti. The interviewer will keep field notes in which the context of the observation/interview and condition of the patients will be described. Reflections will be made on the content of the observation/ interview.

RESULTS

Data collection is ongoing and will be available at the time of the meeting.

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215 POSTER SESSION MONDAY

Occurence of health professionals initiating Shared Decision Making in gynecological oncly practice

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BACKGROUND

Previous studies show that SDM is still scarcely practices. However, SDM in patients with gynecological cancers has not yet been subject of study. Furthermore, many previous studies have assessed the application of SDM in single consultations, whereas SDM practices can be spread over several consultations and do not necessarily occur in every consultation. Therefore, we aimed to assess the extent to which health professionals involved in gynecological oncology facilitate patient involvement in the episode of treatment decision making.

DESIGN & METHODS

Medical consultations from gynecological oncology patients (N=11) of seven health professionals from two hospitals in the south of the Netherlands were observed and audio taped. Duration of decision making stages was measured and patient involvement in decision making was assessed using the OPTION-scale.

RESULTS

Consultations lasted on average 24 (SD 10.5) minutes. A quarter of the consultation time (24.3%) was devoted to deliberation related to patients' queries and concerns. Relatively little time was taken for equipoise (0.2%) and decision making (6.5%). The overall OPTION-score per patient was 21.8 (SD 10.8, scale 0-100). Health professionals regularly referred to previous or future encounters, indicating an episodic nature of decision making practices.

CONCLUSION

Low levels of patient involvement as initiated by the health professional were observed in the gynecological oncology setting. Equipoise and explicit decision making, prerequisites for shared decision making, were infrequently observed. Results show that decision making transcends single consultations. Health professionals involved in gynecological oncology can improve patient participation in treatment decision making by incorporating SDM facilitating behaviors, especially equipoise and decision making.

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50 ORAL PARALLEL SESSION 2

Patient and professional perceptions of trust: exploring the negative consequences of patient pull.

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KEYWORDS

Patient involvement, patient engagement

BACKGROUND

Current trends worldwide encourage patients to take a proactive role in making decisions about their care and treatment. More recently the notion of "patient pull"has been extended to improving patient safety, with patients encouraged to monitor their care and to intervene if they perceive their safety may be compromised. Such co-determination of treatment and safe care necessitates change in the traditional dynamics of patient-healthcare professional (HCP) interactions. However, little is known about the potential negative consequences of a "patient pull"approach.

DESIGN & METHODS

As part of a project to develop a patient-mediated intervention to improve safety, HCPs (pharmacists, doctors, nurses and health care assistants), patients and relatives or carers were involved in semi-structured interviews, exploring how patients, relatives and carers could contribute to improving patient safety whilst in hospital. Respondent perceptions of the consequences of different approaches were also explored. Respondents were recruited from general acute medical and surgical wards in two hospitals in north east England. Data coding was done using NVIVO 8 and emergent themes identified using grounded theory.

RESULTS

Eight patients, two relatives/carers (mean age (sd): 61years (12); six female, four male) and 39 HCPs (nine pharmacists, 11 doctors, 12 nurses, seven health care assistants) took part. Initial analysis suggests that, whilst respondents identify positive consequences of involving patients in their healthcare and in improving patient safety, some approaches elicit feelings of suspicion and reduced trust. For example, patients feel speaking up might appear rude or disrespectful, and are concerned about upsetting HCPs and worry that their care might be compromised. HCPs generally welcome patient questions but sometimes worry about the motive for questioning. Patients who ask many questions and/or make written records of their care may be perceived as more likely to complain.

CONCLUSIONS

Initial analysis suggests that some "patient-pull"approaches to improving healthcare and patient safety may create negative tensions in the patient-HCP relationship. This has implications for approaches to improving care that require mutual respect and collaboration between patients and HCPs.

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100 POSTER SESSION MONDAY

Development of an online decision aid for self-testing on glucose and cholesterol.

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BACKGROUND

Self-tests, tests on body materials that can be performed without the involvement of a doctor, are increasingly available. A survey among Internet users in 2008 showed that eighteen percent of the respondents had ever used a self-test, the most frequently used tests being those for diabetes (5.3%), kidney disease (4.9%) and cholesterol (4.5%). Self-testing can make people more conscious of risk factors and promote self-management. On the other hand, the negative sides of self-testing should not be ignored: for example the risk of false positive or false negative results, or giving a 'certificate of health' when the test result is negative. Since these tests are available, consumers should have access to information about self-testing, to promote an informed decision when they are considering doing a self-test.

DESIGN AND METHODS

Input for the decision aid was derived from qualitative and quantitative research. In these studies, the experiences of self-testers were explored, the quality of the currently available instruction leaflets was assessed, and expert opinion was obtained. After a first prototype of the website had been developed, the contents and usability of the website were assessed by professionals as well as end-users. Semi-structured interviews were held with experts, and end-user usability tests were performed using Morae software. Changes to the website were made in an iterative process.

RESULTS

The usability tests with end users showed that changes in the lay-out of the website were necessary, and a clearer explanation on the goal of the website was needed. Technical errors were found. The use of our tool to weigh personal preferences was not clear, and had to be adjusted. The comments of the experts were similar to the comments of the end-users: they mainly concerned the goal of the website and the lay-out . Furthermore, the experts provided feedback on on the medical contents of the website.

CONCLUSION

The usability testing of an online decision aid for self-testing provided valuable information for the development of the website. Further research should focus on the effect of the website on informed decision making.

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150 POSTER SESSION TUESDAY

Patient Decision Aids Software in Breast Cancer

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BACKGROUND

There is a paternalistic attitude in Spain within the context of breast cancer. Laín Entralgo Agency's Health Technology Assessment Unit (UETS) in Madrid (Spain) has detected a need to develop a national PDA, as there are no available Patient Decision Aids tools. Our aim is to develop a PDA for breast cancer to improve the quality of decisions for therapeutic options and to promote shared decision making.

DESIGN AND METHODS

A systematic review (SR) of Decision Aids in breast cancer was performed in UETS during 2010. Search includes main databases as well as websites of institutions working with PDAs. Additionally, qualitative research (QR) techniques were conducted: semi-structured interviews and a focus group with stakeholders (patients, family members and health professionals). The SR provides the available evidence and the QR contributes information regarding the needs of this collective when decisions have to be made from amongst various options and the most appropriate format of the PDA. For its development, the IPDAS and the Ottawa Decision Support Framework criteria have been observed.

RESULTS

The SR shows that PDAs in breast cancer increase patient knowledge on the illness and generates more realistic expectations. PDAs also reduce passivity in the decision-making process to find the option that best suits their preferences and values. Analysis of QR reflects that both patients and professionals agree that surgery, adjuvant treatments and breast reconstruction are most important decisions to face. Patients' experience of the illness is related to anxiety but also to optimism and confidence in professionals. Final selected format was a PDA software which offers an interrelated treatment sequence and includes general information, treatment descriptions, benefits and risks (with visual aids explaining probability of risk), information regarding body image, glossary, experiences of other people who've lived similar situations, and decisional balance sheets with which to reflect on the pros and cons of each option, with statistical and animated graphics and resources.

CONCLUSION

This PDA for breast cancer allows patients to access information and to make shared decisions regarding treatment. It also provides patients and professionals the opportunity to acquire additional knowledge and to exchange experiences.

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16 POSTER SESSION MONDAY

Implementing a web based decision aid for MMR (combined measles, mumps and rubella vaccine) into everyday practice within primary care: An exploratory study

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BACKGROUND
Decision aids are evidence-based tools that can support informed patient health decision-making. We tested the impact of a web based MMR decision aid on parental decision-making within a stratified cluster RCT. The decision aid was found to be effective in reducing decisional conflict. The next step is, therefore, to make it available to parents. In the UK primary healthcare centres deliver the Childhood Immunisation programme and so provide an appropriate setting for this dissemination. As part of the RCT, we investigated primary healthcare professionals' views on implementing the web based decision aid for MMR into their everyday practice.

DESIGN AND METHODS
Normalization Process Theory (NPT) informed this component of the RCT. Sixteen telephone interviews and one focus group were undertaken with health professionals from seven primary healthcare centres in the north of England. We explored key issues in terms of implementing the decision aid into practice using the four components of NPT. Interviews were recorded, fully transcribed and content analysed. These data informed the development of a postal questionnaire which was sent out to 150 health professionals across 51 primary healthcare centres. Data collection will be completed by end February 2011.

RESULTS
The interviews revealed many facilitators (e.g. baby clinics, practice commitment) and barriers (e.g. short consultation times, focus on uptake targets, costs of sending out the decision aid to parents) to implementing the decision aid. To date 56 questionnaires have been returned. All items were scored 1=definitely not to 7=definitely. Preliminary analysis has revealed that health professionals believe the decision aid would improve the support they provide to parents for MMR (M=5.91,SD=1.16). They anticipate making it available to all parents (M=5.36,SD=1.73). Supporting informed decision making (M=6.36,SD=0.85), increasing vaccine uptake (M=6.62,SD=0.65) and not using consultation time (M=5.52,SD=1.64) would encourage their use of the decision aid. The decision aid is seen as creating extra work for receptionists (M=5.60,SD=1.17).

CONCLUSION
This parent-centred approach is consistent with National Health Service policy and might also improve MMR uptake rates. By identifying barriers and facilitators to its implementation, supportive strategies can be developed.

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159 WORKSHOP PARALLEL SESSION 5

How to 'do' shared decision-making: structuring the consultation around choice, option and preference talk

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OVERALL AIM OF WORKSHOP
Shared decision-making (SDM) is gaining prominence in health care policy and practice. However, there is little support or guidance available on how to achieve this in practice. The workshop will focus on how to 'do' SDM in clinical practice and provide participants with the opportunity to practice the skills required, using a range of simulated consultations.

DESCRIPTION OF WORKSHOP
Participants will be introduced to the guiding principles that underlie the skill set required to do SDM, and they will be guided through some short preparatory exercises. We will then introduce a model for doing SDM in clinical practice. The three key steps of the model, and the skills that are required for each step, will be described in detail:
Choice Talk: indicating that a legitimate choice exists.
Option Talk: Listing the options, describing the options, explaining the harms and benefits of the options, and offering decision support tools when necessary.
Preference Talk: Guiding patients to think about what is important to them and how the information has helped form their preferences.

Short presentations of each step will be complemented by small group work sessions, where the participants will practice the skills using a range of clinical scenarios. Group facilitators will provide feedback throughout. Participants will be provided with workshop support materials.

LEARNING OBJECTIVES

Participants will have:
- Understood the 3-step model to achieving SDM in practice
- Had the opportunity to practice the key skills involved, including:
  - Introducing the idea of choice during a consultation
  - Portraying the options available
  - Supporting a patient to deliberate about the options
  - Guiding the patient to focus on personal preferences
  - Introducing decision support tools when appropriate
- A better understanding of how to achieve a SDM consultation and support patients through the SDM process.

PRE-REQUISITE KNOWLEDGE

Participants must have an understanding of SDM and patient decision aids/support tools. Preferably, the participant should be someone who is in contact with patients and would be involved in the decision making process.

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193 POSTER SESSION TUESDAY

Adaption of a decision quality measurement for use in routine NHS settings: interest in assessing patients involvement in deliberation

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BACKGROUND

MAGIC (MAking Good decisions In Collaboration) is a Health Foundation funded implementation project to determine how best to implement SDM in practice. Part of the implementation includes the development of tools to measure decision quality for preference sensitive decisions. Sepucha et al. have studied the best ways to measure decision quality in breast cancer patients. Decision quality measures explore patients' decision-specific knowledge and the concordance between their preferences and choice of treatment. It is not known whether specific measures can be standardised for use across settings to provide comparable data. We describe the approach to testing and modifying decision quality measures to two NHS settings in the UK.

DESIGN AND METHODS

We considered the applicability of Sepucha et al.'s decision quality instrument (DQI) to two breast care clinics in the UK (Cardiff and Newcastle). Knowledge questions were reviewed in relation to the decision aid currently used in the two settings (Bresdex). Preference and process questions were assessed in relation to different clinical care pathways. Extensive consultation with the breast care teams was conducted in an iterative process of development and revision.

RESULTS

Many aspects of the DQI required local adaptation. Knowledge questions were changed to reflect information provided in Bresdex. Preference questions were adapted to elicit the importance patients placed on specific consequences of surgery options. DelibeRATE was used to ensure applicability to a variety of clinical pathways. Consultation with the breast care teams led to further revisions to the order and wording of questions, and an overall reduction in the length of the measure, including the removal of questions about breast reconstruction. Differing clinical processes in Cardiff and Newcastle require different processes of administration.

CONCLUSION

Measuring decision quality appeals to clinical teams because they see the relevance of the measure, especially when used pre and post the process of providing information and deliberation support. Each measure needs to be matched to the specifics of the information context and tailored to the local clinical pathways. This will be a challenge for standardisation and comparison across different studies.

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201 ORAL PARALLEL SESSION 1

Towards minimum standards for patient decision support interventions: a correlation analysis and Delphi process

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BACKGROUND

The IPDAS collaboration has developed a quality criteria checklist and an instrument to assess the quality of patient decision aids (PDAs). Further work is needed to examine the relationship between IPDASi scores and the outcomes achieved in RCTs. Additionally, we need to respond to the recent demand for PDA certification. The study aims were to:

1. Correlate IPDASi quality scores with outcome measurements achieved in RCTs included in the Cochrane review of PDAs.
2. Conduct a Delphi consensus process for expert agreement on certification criteria for PDAs using IPDASi.

DESIGN/METHODS

Study aim 1: PDAs were identified using the Cochrane review of PDAs. Available tools were included if the trial(s) measured at least one of the following: knowledge, accurate risk perceptions, value congruence with choice (attributes of decision); participation in decision-making, satisfaction with decision-making process (attributes of decision process). IPDASi quality scores were produced (two independent raters per PDA). Correlation analyses were conducted using adjusted mean IPDASi scores and effect size.

Study aim 2: Two-stage Delphi voting process on inclusion of current IPDASi items as certification item. Mean scores and qualitative comments considered, followed by expert group discussion.

RESULTS

Study aim 1: 30 PDAs were included in the sample. A significant correlation was found between quality score (global) and accurate risk perceptions ($p = 0.02$, $P < .05$). No other correlations were significant, but the positive direction of all but one correlation indicates reasonable support for PDA quality (global), as judged by IPDASi, is associated with better outcomes in RCTs.

Study aim 2: 101 people voted in round 1; 87/101 (88%) voted in round 2. 47 items (IPDASi v3.0) were reduced to 45 items (3 items combined) across 3 new categories, namely: Qualifying criteria (6); Certification criteria (11); Quality criteria (28).

CONCLUSION

To ensure minimum standards for the protection of patients, this study provides a set of certification criteria for PDAs, to be tested and ratified. Correlation between IPDASi scores and outcome measures would be facilitated by greater consistency in measurements used in RCTs.

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98 ORAL PARALLEL SESSION 3

Is what is important to patients incorporated into current clinical guidelines for implantable cardioverter defibrillators?

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BACKGROUND

Implantable cardioverter defibrillators (ICDs) are used to treat patients with heart failure and/or ventricular arrhythmias at risk of sudden death. Although ICDs increase survival in these patients, they are associated with a number of adverse effects including device complications (e.g. infection); psychosocial effects (e.g. anxiety, depression, panic disorder); and quality of life implications (e.g. driving restrictions). It is unclear to what extent patients are engaged in the decision to opt for an ICD, alongside evidence that decisions for individual patients do not match current guidance. We set out to determine how current guidelines incorporate what is important to the patient in decision making about ICDs.

DESIGN AND METHODS

A literature review was conducted to determine how known adverse effects of ICDs and patient perspectives about ICDs more generally are incorporated into current professional society guidelines on ICD implantation.

RESULTS

Existing national guidelines for ICDs are traditionally evidence-based and largely unambiguous, but there is little mention of the patient perspective. Review of both North American and European guidelines highlights an absence of guidance on patient-centred risks/benefits. For example there is no explicit consideration of the possible psychosocial effects of ICDs, despite evidence of increased incidence of anxiety and depressive disorders in ICD recipients.

CONCLUSION

Influential North American and European national guidelines lack reference to key patient centred elements that might be critical in engaging patients in high quality preference sensitive treatment decisions. This contrasts with guidelines for other conditions such as breast or prostate cancer where potential diagnostic/treatment effects on quality of life are well rehearsed. Uncritical application of these guidelines might lead to decisions that fail to take adequate account of what is important to individual patients. This raises the question as to how much the mismatch between current guidelines and their application reflects failure to implement guidance or appropriate decision making taking account of the patient perspective. It also further emphasises the need to incorporate the patient perspective into the development and application of guidelines.

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126 ORAL PARALLEL SESSION 5

Improving shared decision making in ovarian cancer: the development and evaluation of two decision aids

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BACKGROUND

Women with ovarian cancer (OC) face difficult treatment decisions at different stages of the disease, with uncertain quality of life and survival outcomes. Patient Decision Aids (DAs) have been shown to facilitate informed decision making in such situations, but there are currently no DAs available for women with OC. The aim of the following studies is to address this gap, by developing and evaluating two DAs to help women with OC understand their options and make an informed treatment choice.

DESIGN AND METHODS

The DA booklets were developed in accordance with IPDAS guidelines, and reviewed by an expert panel of clinicians. They contain evidence-based information about the risks and benefits of each treatment option, using both written and graphical formats, as well as values clarification exercises to help patients consider what is most important to them.

Study 1 involves a randomised controlled trial to evaluate the effectiveness of a DA for asymptomatic women with rising CA-125 following initial treatment for OC. This DA helps women decide whether to start immediate treatment or wait for further evidence of cancer recurrence. One hundred and seventy-eight women are being randomised to receive either the DA or a general Cancer Council booklet, and complete standardised measures at baseline and 4-month follow-up.

Study 2 involves a pilot study to assess the acceptability of a DA for women with resistant or refractory recurrent OC who have completed at least 3rd line chemotherapy. This DA helps women decide whether or not to continue active treatment. Twenty women are providing feedback on the newly developed DA via a questionnaire and telephone interview.

RESULTS

Overview and current progress on both studies will be presented.

CONCLUSION

This research program addresses a neglected area in the management of women with OC. It is anticipated that the two DAs will lead to improved understanding of treatment options, reduced decisional conflict and regret, and increased satisfaction with the decision making process. If effective, this relatively simple intervention has the potential to improve the clinical care, and ultimately quality of life, of women with OC.

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253 POSTER SESSION TUESDAY

Without 'pushing' or 'pulling': Deep exploration of the values guiding shared decision making

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BACKGROUND

Though both patients and healthcare professionals advocate for and agree about the importance of shared decision making (SDM) in theory, its implementation and scientific measurement is challenging. A major source of difficulty stems from the fact that no simple recipe for sharing decisions has been deemed suitable for all - neither for choosing the 'best' care, nor for choosing and identifying preferred level of involvement. In an attempt to further understand and reflect upon this complexity, this presentation explores the values on which the SDM process is based, the dilemmas that arise in applying them and the skills necessary for their implementation.

METHOD

In searching for discussions of the values underlying SDM, seminal manuscripts and books were reviewed, focusing on SDM in physical and mental health. Each value was analyzed, with attention to four main goals: 1. Identifying the value's origin from within the principles of SDM; 2. Defining each value; 3. Recognizing the complexities of applying these values in healthcare settings; and 4. Pinpointing the communication skills required to implement them.

RESULTS

SDM stems from various values, such as freedom of choice and autonomy, mutual respect, reciprocity, empowerment, quality of life, responsibility and commitment. In order to apply these values, they must be fully understood and necessary skills must be acquired: assessing preferences for involvement and knowledge, sharing information and compromising, as well as employing flexibility to address the needs and wishes of each patient.

DISCUSSION

Exploring the values of SDM, and professionals' and patients' attitudes toward them, is an important step toward being able to truly share decisions. For example, the value related to acceptance of patients choice, including their decision over the extent to which s/he will be involved/informed may lead to the implementation of a SDM practice, corresponding to the patient's personal preference. Understanding the values may help professionals and patients relate better to the task of decision-making - without creating a dynamic in which one side is pushing or pulling the other.

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166 POSTER SESSION TUESDAY

Using the theory of planned behaviour to analyse immunotherapy choices in persons with multiple sclerosis

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BACKGROUND

Decision support technologies aim at helping patients to make informed choices (IC). Measures of IC have been developed comprising risk knowledge, intention (towards therapy uptake) and actual uptake. To evaluate our efforts to support decisions about immunotherapy in multiple sclerosis, we aimed at developing an instrument to provide insight into the cognitive processes of decision making based on the theory of planned behaviour.

METHODS

We developed the 30 item 'Planed Behaviour in multiple sclerosis (PBMS) questionnaire' particularly addressing the inherent processes of planning a decision on immunotherapy. Following the theory, the questionnaire covers three components: attitude, subjective social norm, and perceived behavioural control and 2 subscales each assessing expectancies regarding the expression of a component and its individual value. A model-coefficient ('pb-estim') was built multiplying expectancy and value and adding up components. After piloting and pretesting (N=50), PBMS was used in a randomized trial (N=192) evaluating the efficacy of a patient education programme for patients with multiple sclerosis. The PBMS was administered twice, at baseline and after the intervention. Item properties and mean values for each subscale were analysed, also the questionnaire's predictive power regarding intention to use immunotherapy using regression analyses. Demographic and disease related data as well as risk knowledge (RK) were surveyed.

RESULTS

All but one item showed acceptable difficulty and variability (mean=1.62, meanSD=0.9, range 0-3). As expected, patients in the intervention group (IG) had less positive attitudes towards immunotherapy and less motivation to comply with social norm than control group patients (CG). At baseline variance of intention was explained by 45% (CG 39%) using 'PB-estim' and by 49% (CG 39%) using the three components, and by 53% (CG 52%) using the six sub-scales as predictors. After the intervention predictive power of PBMS was higher in the IG (69/74/78% for IG and 56/57/64% for CG) and in patients with better RK (64/78/72% for better RK and 55/55/64 for lower RK).

CONCLUSION

The PBMS shows excellent model fit and interesting indications of construct validity. The results show that MS treatment decisions can be monitored and methods to support such decision evaluated.

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213 ORAL PARALLEL SESSION 3

Arriba-lib: electronic library of decision aids - GPs' perspectives

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BACKGROUND

The present study is part of a qualitative approach to explore patients' and physicians' views on and experiences with an electronic library (arriba-lib) of evidence based, interactive and transactional decision aids based on the shared decision making (SDM) concept during consultation in primary care. Arriba-lib is an extension of arriba™, a decision aid on cardiovascular prevention that has been implemented and evaluated according to the guidelines of the British Medical Research Council (MRC) for complex interventions. Such a comprehensive library of decision aids has rarely been field tested, especially not in the primary care context. The present study focuses on the identification of internal and external factors directly initiating the regular use of such an intervention in daily routine.

DESIGN AND METHODS

We conducted a feasibility study with altogether 29 general practitioners recruiting 192 patients. In a qualitative approach, personal interviews (patients), and focus groups (physicians) were used to obtain relevant information about suitability for application in general practice. This presentation focuses only on implementation issues that arose during the group discussions. Two focus groups comprising 12 general practitioners took place. The sampling strategy was stratified and purposive. A semi-structured interview guide was used to generate discussions about the applicability of arriba-lib in routine general practice. The sessions were audio-taped, transcribed and analysed according to the principles of "pragmatic variant"grounded theory.

RESULTS

Initial analysis classified the data into two major categories. The first category included individual factors like attitude (readiness for innovations, motivation, acceptance), competences and skills (prior use of the precursor module, knowledge of and experience with SDM as well as with the diseases) and valuation (complexity, effort, practicability). The second category covers superior aspects related to the occupational area (team, colleagues, patients) and the relevant health system (culture, statutory framework, budget).

CONCLUSION

Their was a high acceptance of arriba-lib by the participating physicians. However, our results suggest that such complex decision aids on the basis of the shared decision making (SDM) concept need to be offered as an integral part of the communication and counselling process in order to be used most effectively.

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73 ORAL PARALLEL SESSION 3

Shared Decision Making: Piloting an implementation model in primary care for stable coronary artery disease (CAD)

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BACKGROUND

In the US, high cost technologies have become an area of focus to reduce overuse while ensuring appropriate patient care. Engaging patients in shared decision- making using patient decision aids may improve appropriateness, and reduce excessive utilization. Estimates suggest this strategy should save the US Medicare program $20.5 million annually. We developed an implementation model, Shared Decision Making Guidance Reminders In Practice (SDM-GRIP), to provide primary care practices with tools for shared decision making about stable CAD early in the diagnostic and therapeutic process.

DESIGN AND METHODS

Feasibility pilot to test implementation of CAD shared decision-making in 2 primary care practices in Michigan with 29 primary care providers (PCPs), and 193 patients with a diagnosis of stable CAD. Model components: decision aid, patient encounter guide, grand rounds presentations, provider training in communication and disease specific content, patient group visit, and SDM consultation visit. Formative evaluation was designed to test the feasibility of provider training, patient group visit, and office practice protocols. Evaluation used patient and physician pre-post surveys.

RESULTS

21/29 PCPs attended 90-minute education workshops (didactic material, role play demonstrations, and performing role plays with feedback). 21/193 patients attended 90-minute group visits (didactic material and open discussion). Patients valued education about treating stable CAD and the opportunity to discuss treatment experience with other patients, but were concerned about cardiology interface. Main incentives for providers appeared to be relevance to the Patient Centered Medical Home, and the focus on one clinical problem in the encounter. Required model improvements: a trigger to initiate the implementation of SDM-GRIP at the stress test when active decisions are underway and interaction with the cardiologist would begin; EMR integration; specified treatment and referral decision-making. Extension to joint cardiology/primary care implementation is in process.

CONCLUSION

The physician workshops and use of patient decision aid are feasible within the primary care patient workflow and current billing practices. Improving the communication between PCPs and cardiologists will be essential for addressing the concerns about cardiology interface. SDM-GRIP appears to hold promise as a basic mechanism to implement SDM. Further evaluation is needed to establish both reach and effectiveness.

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180 ORAL PARALLEL SESSION 6

Barriers to use comparative performance information during referral in general practice

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BACKGROUND

In the Netherlands, general practitioners (GP) act as a guide and gatekeeper for their patients. Patients heavily rely on their GP's advice when deciding where to go when referral to secondary care is warranted. Therefore, to enhance the implementation of comparative performance information (CPI) as a decision support intervention, the strategy should target GPs as well. Ultimately, GPs should incorporate CPI in their referral advice and decision support when providing a referral to secondary care.

DESIGN AND METHODS

In this study, the GP's perspective on the use of CPI in their referral process was considered, as well as the way they support their patients making the decision for a particular healthcare provider. We held 15 in-depth interviews with GPs in October and November 2009. The data were analyzed using ATLAS.

RESULTS

Currently, GPs do not use CPI as a decision support strategy when referring their patients. Their referral is based on established routines, expectations and organizational norms; e.g. previous experiences with a healthcare provider, personal relationships with professionals, skills of specialists or medical diagnosis, as well as previous experiences and preferences of their patients.

GPs expressed many barriers to use CPI as decision support such as fearing that CPI is causing uncertainty for patients, having doubts about the usefulness and pointing out practical implications as the continuity of care. Facilitators and promising implementation strategies were indicated, as well. GPs consider it as being an ethical norm to help patients in a best possible way to select a healthcare provider. If CPI support this objective, GPs are willing to use this. Regarding strategies for implementation it is important to raise attention to reliable information sources for CPI and to offer GPs detailed and up-to-date information.

CONCLUSION

This qualitative study demonstrated that in current practice CPI has no influence on referral decisions. There are barriers to overcome before GPs actually use CPI as a decision support intervention. On the other hand GPs also listed promising facilitators and strategies which could enlarge the role of CPI in general practice.

113 POSTER SESSION MONDAY

Can patients who present to the emergency department with chest pain engage in shared decision making? A videographic analysis of patient-physician interactions nested in a randomized controlled trial.

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BACKGROUND

Patients who develop an acute medical condition are often under emotional duress, and their ability to participate in decisions regarding their care may be limited. We hypothesized that use of a decision aid in patients presenting to the emergency department with chest pain would increase participation in decision making.

DESIGN AND METHODS

In a previous study, we developed and tested in a randomized trial Chest Pain Choice, a decision aid that communicates the individual pre-test probability of an acute coronary syndrome (ACS) and makes management options explicit to the patient (emergency department observation unit admission and cardiac stress testing, 24-72 hour follow-up with a cardiologist, follow up with their own primary care physician, or deferment of the decision to the physician). We obtained video and audio recordings of patient-physician interactions and analyzed the degree of patient participation using a validated scale (OPTION scale). We analyzed the videos using the following methodology: 30 videos were collaboratively scored by 2 observers to calibrate OPTION scoring, 30 were viewed independently and interobserver reliability (kappa) assessed, and one independent observer scored the remaining videos. The Wilcoxon rank sum test was used to test for the difference in OPTION scores between study arms.

RESULTS

Of 205 patients enrolled in the trial, 201 had video recordings (101 decision aid, 100 usual care). 118(59%) of the patients were female, and 87(43%) had family present to support them in decision making (44(44%) decision aid, 43(43%) usual care). Kappa values for the 12 individual OPTION items varied from 0.29 to 1.00, and the interobserver reliability for the overall score was 0.95. The overall OPTION score was significantly higher in the decision aid group [51.4 (8.2) versus 32.0 (5.5), absolute difference = 19.3, 95% CI 17.37-21.25, $p<0.0001$]. The mean score in the decision aid group was significantly higher ($p<0.05$) in 7 of the 12 items, with no significant difference in the remaining 5 items.

CONCLUSION

Although patients who present to the emergency department with chest pain may be in emotional distress, use of a decision aid can increase their engagement in decision making.

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185 ORAL PARALLEL SESSION 7

Enhancing clinicians' perspectives of the effects of decision aids by relating patients' decisional conflict scores to everyday behavior and emotions.

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BACKGROUND

The effects of patient decision aids are often evaluated by their ability to decrease patients' decisional conflict. This is a rather abstract concept, because the impact of decisional conflict in daily functioning remains unclear. This study aimed to enhance the understanding of decisional conflict by relating decisional conflict scores to patient-reported behaviors and emotions during treatment decision making.

DESIGN AND METHODS

First, aneurysm patients and healthy volunteers provided statements considering their behavior or emotions experienced, while having to make any difficult decision. Similar statements were grouped and the investigators selected one representative statement, for example: “I become nervous whenever I think of the decision”.

Second, another group of patients and volunteers judged each of these statements for its intensity of decisional conflict on a one to ten scale. Only statements with unambiguous median rankings passed on to the third phase.

These statements were prospectively tested in aneurysm patients who were confronted with a decision about elective surgery and in cancer patients deciding about adjuvant radiotherapy. They completed the Decisional Conflict Scale and reflected whether or not they actually displayed the behavior or experienced the emotion as specified.

RESULTS

Sixty aneurysm patients and healthy volunteers generated 363 statements. From these, 28 representative items were derived and presented to 79 patients and volunteers. After elimination due to lack of agreement in their judgments, nine items remained which were tested among 93 aneurysm patients and cancer patients during treatment decision making.

Logistic regression analysis showed a significant association between a rise in decisional conflict score and four out of nine items: fretting regularly (OR 1.05), postponing the decision (OR 1.04), getting anxious when thinking of the decision (OR 1.03) and a decreased odds of making the decision immediately (OR 0.96).

CONCLUSION

Although not all of the identified behaviors and emotions during treatment decision making are associated to the concept of decisional conflict, exemplifying that a decrease in decisional conflict score in real terms leads to less patients fretting and putting of decisions, might help clinicians and patients appreciate the effects of decision aids in daily practice.

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248 ORAL PARALLEL SESSION 3

How to integrate patient values and preferences in clinical practice guidelines?

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BACKGROUND

Clinical practice guidelines (CPG) are largely conceived as tools that inform health professionals' decisions rather than foster patient involvement in decision-making. Our objective was to assess stakeholders' opinions and ideas on how CPGs should be adapted to elicit patient preferences and to support SDM.

DESIGN AND METHODS

Stakeholders' ideas were explored through an 18-month qualitative study, with data collected from in-depth individual interviews. We selected a purposive sample of key-informants among three groups of stakeholders: 1) health professionals using guidelines; 2) guideline and decision aids developers, policy makers, and researchers; and 3) patient representatives. We analysed the interviews by directive content analysis. The recommendations expressed by stakeholders were prioritized by nominal group technique in expert meetings.

RESULTS

From 25 individuals contacted 20 accepted to participate. Six stakeholders in group 1, 9 in group 2, and 5 in group 3, spread over 7 countries. In total 30 strategies were mentioned by the interviewees, that we describe in 4 categories. 1) Transform or adapt a specific recommendation, to increase option awareness for professionals by improving the representation of options for a specific recommendation. 2) Provide patient support tools within or as add-on to the CPG, clearly linked to a specific recommendation, to support the option awareness for professionals and patients, elicitation of preferences and deliberation about options. 3) Prescribe, on the level of a recommendation, the decision making process for a specific clinical recommendation, to facilitate the process of deliberation about the options. 4) Generic strategies to support option awareness, preference elicitation or deliberation not specific for one recommendation.

CONCLUSION

The stakeholders had rich ideas on how CPG should be adapted to elicit patient preferences and to support SDM. The time now seems right to adapt CPG, with these strategies as valuable tools to foster patient involvement in decision making on top of involving patients in the development of CPGs. We recommend to elaborate further on these ideas and explore the effect of the prioritized strategies on the level of SDM in practice in rigorous study designs.

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84 ORAL PARALLEL SESSION 2

Patient education program on diagnosis, prognosis and early therapy for persons with early multiple sclerosis - outline and first results of a multi-centre randomized controlled trial (ISRCTN12440282)

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BACKGROUND

A number of immunomodulatory drugs have been licensed for treatment in early or suspected multiple sclerosis (MS). In parallel, new diagnostic criteria were developed to allow for earlier diagnoses and treatment. Uncertainty remains about long-term efficacy of early MS treatment. There is ongoing discussion about possible benign courses of MS. Therefore, evidence-based patient information on diagnosis, prognosis and early therapy is a prerequisite to allow for informed treatment choices and shared decision making. Based on the results of pre-studies, we developed a patient education program to facilitate informed choice in persons with early MS.

DESIGN AND METHODS

The intervention group (IG) received a comprehensive 60 page information brochure and a 4-hour interactive educational program based on the current evidence about significance of prognostic factors, accuracy of diagnostic procedures and efficacy of drug therapies. The control group (CG) received a 4-hour stress management and coping training and a standard information leaflet on diagnosis, prognosis and early therapy. Patients with suspected or definite MS diagnosed within the last 2 years were included in this 12-months study and randomly assigned to the two groups using concealed allocation. Participants and data assessors were blinded to participants' group allocation. Primary outcome measure was "informed choice"after 6 months. Further outcomes comprised decision autonomy, anxiety and depression and risk knowledge.

RESULTS

Recruitment was completed in October 2010. 192 patients from 6 academic centres in Germany were included (IG=93, CG=99). Baseline data were comparable between groups. Results from the first evaluation two weeks after the intervention shows a significant difference between groups concerning risk knowledge ($p<0.0001$). There were more participants preferring autonomous decisions or informed choice in the IG (78%) compared to the CG (66%), but this difference was not significant. Also there were no significant differences for intention to use immunotherapy, anxiety, and depression.

CONCLUSION

The program is feasible and increases relevant risk knowledge as a basis for informed choice directly after the program. Other than expected there were no significant differences for autonomy preferences or intention to use immunotherapy. Data for the primary endpoint will be available in late 2011.

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172 SYMPOSIUM PARALLEL SESSION 3

Beyond the Dyad: Shared Decision Making with Interprofessional Collaboration and in Complex Environments

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Shared decision-making (SDM) is not routinely implemented in clinical practice and effective interventions, such as decision support, educational materials, professional trainings are necessary to facilitate SDM. Most of these interventions are limited to the patient and/ or physician/ provider, but effective development, implementation and evaluation requires considering the context. Health care systems are complex and mostly interprofessional, and these are often the barriers to successful implementation of SDM. Organizational structures are important elements in facilitating the delivery of SDM within the processes of health care.The aim of the symposium is to present frameworks and current research initiatives for considering the contextual factors and interprofessional collaboration important in development, implementation and evaluation.The 4 presentations focus on contextual variables of complex environments and interprofessional collaboration. They originate from 4 different research groups from Germany, the United Kingdom and Canada. **Presentations:(1) Implementing a conceptual framework for interprofessional shared decision making in home care: A feasibility study** Dawn Stacey[1], Nathalie Brière, Sophie Desroches, Serge Dumont, Kimberley Fraser, Mary-Anne Murray, Anne Sales, Denise Aubé and France Légaré; *[1]University of Ottawa*, Canada; **(2) Interprofessional training for shared decision-making in medical rehabilitation** Mirjam Körner, Heike Ehrhardt, Anne-Kathrin Steger, *Department of Medical Psychology and Sociology, Medical Faculty, Freiburg University, Germany*; **(3) Adapting and validating a shared decision making approach for work rehabilitation programs involving workers with persistent pain due tomusculoskeletal disorders** Marie-France Coutu, France Légaré, Marie-José Durand, Marc Corbière Dawn Stacey Patrick Loisel, Lesley Bainbridge; *CAPRIT and School of Rehabilitation, Université de Sherbrooke, Longueuil, Québec, Canada;* **(4) Decision support in complex settings - the challenge of context** Richard Thomson, Joanne Lally, Joan Mackintosh, Darren Flynn*Institute of Health & Society, Newcastle University,UK*

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173 SYMPOSIUM PARALLEL SESSION 3

Interprofessional training for shared decision-making in medical rehabilitation

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BACKGROUND

Shared decision-making (SDM) is increasingly advocated as an ideal model for patient-provider interaction. In order to implement this approach successfully in rehabilitation clinics it is necessary to reach all those involved, particularly the different providers. The university-designed interprofessional train-the-trainer program is used to educate key providers such as nurses, physical therapists, psychotherapists, dieticians, etc. in leading positions. These multipliers then train their staff, considering a participative approach. The aim here is to present the two modules of the training program and the first results of the training evaluation.

DESIGN AND METHODS

A survey is used at the end of each training module to evaluate acceptance, implementation and success. The survey items refer to SDM competencies, satisfaction with training content and with the trainers, and overall impression of training session.

RESULTS

Executives/providers in leading positions in six clinics were trained, with a total of 74 participating (41% female, 59% male) in module 1 and a total of 68 in module 2. The evaluation sheets were distributed to 47 persons in module 1 (one clinic did not take part in the evaluation), with a rate of return of 39 questionnaires (83%). In module 2 all 68 persons were asked to participate in the evaluation, 50 questionnaires came back (rate of return of: 74%).

Evaluation of the general training for both modules (module 1: M=1.89, SD=0.59; module 2: M=1.96, SD=0.71) is very good (rating scale: 1 = best and 6=worst). Satisfaction with the trainers is appraised best of all the measured aspects (module 1: M=1.56, SD=0.55; module 2: M=1.65, SD=0.53). The providers are also satisfied with the content of the training (module 1: M= 2.48, SD=0.43 ; module 2: M=2.41, SD=0.66). Self-appraisal of the SDM competencies is acceptable (module 1: M=2.04, SD=0.40; module 2: 2.1, SD=0.50).

CONCLUSION AND PERSPECTIVES

Both training modules were evaluated very positively. It seems appropriate to design and implement SDM training in rehabilitation in the form of interprofessional training. Further evaluation of the training program with a patient and a staff survey is currently being conducted.

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174 POSTER SESSION TUESDAY

Shared decision-making in an interprofessional context

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BACKGROUND

SDM is mostly assessed for physicians and medical decisions. Other occupational groups relevant in an interprofessional treatment context have not been taken into consideration for the SDM approach until now. However, it can be supposed that other occupational groups also have to make decisions with their patients and that interprofessional training enables the patients to receive a professionally coordinated comprehensive plan of care.

DESIGN AND METHODS

The present study is cross-sectional with a descriptive-explorative design. The SDM-Q-9 surveys were completed by patients and staff members.

RESULTS

17 rehabilitation clinics participated in the survey of patients (N=1279 patients, rate of return n= 666 (= 52 %), complete data file: n = 580). And 15 rehabilitation clinics took part in the staff survey (N= 658 employee, total rate of return n= 275 =41 %). The sample here consisted of 275 providers (49 physicians, 48 nurses, 67 psychotherapists and 67 physical therapists, 37 other occupational groups, 9 are not specified and 12 have more than one profession.

The results of the SDM-Q-9 for the patients as well as for the providers show values in the middle (somewhat disagree/ somewhat agree). The appraisal of the providers is better (M=67.2, SD=20.96) than the appraisal of the patients (M=58.3; SD=26.23). There is a significant difference between the different occupational groups (F=16.48, df=4, p<.001, η^2=.0211):

- Physicians (M=78.54; SD=13.87)
- Nurses (M=50; SD=20.76)
- Psychotherapists (M=72.5; SD=14.69)
- Physical therapists (M= 64.58, SD=20.89)
- Others (M=58.26, SD=28.22)

CONCLUSION

These results show that the providers perceived patient participation to be better than the patients themselves did. It could therefore be difficult to reach the through a SDM-training. Physicians and psychotherapists in particular are convinced that they involved their patients in decisions, while nurses and physical therapists are less confident. That might be explained by less experience as well as by fewer possibilities for decision making with patients.

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135 ORAL PARALLEL SESSION 3

Balance between evidence based guidelines and shared decision making in preventive care

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BACKGROUND

Use of evidence based guidelines is one of the applications of evidence based medicine (EBM) in clinical decision making in primary health care (PHC). In Australian PHC there is currently a great emphasis on prevention, patient-centeredness and adherence to best practice guidelines published by various professional bodies. While GPs provide preventive activities, they often facing ethical dilemma of involving the patient, or just implementing the guidelines, regardless of patient wishes. From a shared decision making (SDM) perspective, we need to accept that patients may not want to do what the ‘evidence’ says they ‘should do’.

DESIGN AND METHODS

This study is based on a project aiming to develop an implementation approach for preventive guidelines in Australian PHC. Face to face interviews with 16 general practice staff were conducted in 8 GP practices from two divisions of general practice in Sydney. Patients’ interviews are underway to explore patient perspectives about prevention of chronic diseases. All interviews were audio recorded and transcribed. Transcripts are coded using Nvivo 8.

RESULTS

The study suggests that PHC providers are not homogenous and have range of values, attitudes, and approaches to preventive health. They fall into four categories across the two dimensions guideline adherence and patient centredness a) adhere to preventive guidelines and are patient centred (balance between EBM and SDM); b) do not adhere to guidelines, but are patient centred (patient responsive); c) adhere to preventive guidelines but are not patient centred (rigid); d) don't adhere to guidelines and are not patient centred (ad hoc, non-responsive). Patient perspectives about prevention are still to be collected.

CONCLUSION

From an implementation perspective, one could argue that the more involved the patient is, the more likely they are to do something positive about their future risk. There are risks in both dimensions from poor adherence to poor quality. In practice, most providers would provide patient education by informing patients and getting them more committed to change rather than truly involving them in deciding whether to do it. The main struggle for providers is the balance between maintaining patient autonomy and beneficence by trying to protect their health.

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194 POSTER SESSION TUESDAY

A Qualitative Study of Family Involvement in Decisions about Life Support in the Intensive Care Unit

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BACKGROUND

Evidence suggests that proactive communication during the decision-making process increases agreement between healthcare professionals and family members about using life support interventions for critically ill patients. Although a shared decision making approach seems optimal, it is not always used in practice. The purpose of the study was to explore family involvement in decisions about life support with patients' families and healthcare professionals in the Intensive Care Unit.

DESIGN AND METHODS

A critical incident technique was used to interview family and healthcare professionals from the Intensive Care Unit of a large Canadian tertiary care teaching hospital. Participants were asked how the decision about life support interventions was conceptualized, the key values used to construct a preference for the options, their roles in the decision-making process and the barriers to an interprofessional approach to involving family members. Directed content analysis of interview transcripts was guided by the research questions and the Interprofessional Shared Decision Making conceptual model.

RESULTS

Six family members and nine healthcare professionals were interviewed. Participants conceptualized the decision as having two options, life support or comfort care. Their key values used to construct a decision preference were: maintaining quality of life, surviving critical illness, minimizing pain and suffering, not being attached to machines, needing adjustment time, and judicious healthcare resource use. Participants identified three roles which included the leader role of the physician, support role of other healthcare professionals, and the patient advocate role of the family. Barriers to family involvement included not being offered alternative options, no specific trigger to initiate decision-making, dominant influence of professionals' values, and families lacking understandable information and getting inconsistent messages from the team.

CONCLUSION

Identified roles for family members and healthcare professionals in the process of deciding about life support interventions in the Intensive Care Unit are consistent with an interprofessional shared decision making approach. However, the family could be better involved in the shared decision making process if the decision was made explicit and other barriers were minimized.

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195 ORAL PARALLEL SESSION 1

Field Testing a Patient Decision Aid to Engage Families in Decision Making about Life Support in the Intensive Care Unit

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BACKGROUND

The patient decision aid (DA) "Understanding your options: Planning for a family member's care during their critical illness"was developed to help family members become more actively involved in making decisions about life support for a critically ill relative admitted to the Intensive Care Unit (ICU). The study purpose was to field test the DA with families and healthcare professionals who were actually involved in making the decision.

DESIGN AND METHODS

The field test of the DA was conducted with families and their healthcare professionals who were facing the decision in the ICU of a large Canadian tertiary care teaching hospital. Five criteria identified by the International Patient Decision Aid Standards were examined: a) feasibility, b) acceptability, c) balanced presentation of information, d) clarity, and e) potential to clarify patient values.

RESULTS

Nine family members and 5 healthcare professionals associated with 8 index patients were recruited. Of 9 family members, 8 used the DA and completed all measures. Families felt moderately prepared for discussing the decision and checked 69% of shared decision making criteria on the OPTION scale. Exposure to the DA did not appear to further augment family member's level of distress. Of 11 who completed the acceptability survey, 11 would recommend it to others, 10 rated it helpful, 8 agreed it had the right amount of information, and 8 rated it as very good or excellent. Of 11 participants, 9 thought it was completely balanced and 2 family members thought it was a little slanted to comfort care. Most things or everything in the DA was clear. Family members were able to rate and communicate patient values regarding the features of the options.

CONCLUSION

Field testing indicated the DA was used by family members and professionals in the ICU setting. It was rated as acceptable and balanced, appeared to present information that families were able to understand, and helped family members identify and share what is known about the patient's values. Further research is needed to determine the effect of the DA on the decision-making process and outcomes such as distress.

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246 POSTER SESSION TUESDAY

DECISION+2 Web-Based Tutorial on the Use of Antibiotics for Acute Respiratory Tract Infections Increases Knowledge on SDM.

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BACKGROUND

DECISION+2 is an educational program in SDM regarding the use of antibiotics for acute respiratory tract infection (ARI). Part of the program consists in a 2-hour web-based tutorial. The objective of this study was to evaluate the effect of completing the web-based tutorial on participant's knowledge on SDM.

DESIGN AND METHODS

This study was part of a cluster randomized trial conducted in the network of the 12 family medicine teaching units (FMU) of Laval University, Quebec City, Canada. Five FMU were randomised to the DECISION+2 program and five to a non-intervention control group. In this study, the population is limited to all residents and teachers assigned to the experimental group and who completed the DECISION+2 wWeb-based tutorial. The tutorial was divided in four main modules structured according to the Decision+ framework (diagnosis of ARI, benefits and risks of antibiotic treatment, benefits and risks communication, patient participation in decision making process). Pedagogical methods include audio-video presentations and interactive exercises using written/video clinical scenarios and feedbacks. All participants had to complete the same 10 multiple choice item online questionnaire before and after completing the tutorial. Knowledge on diagnostic probabilities (four items), antibiotic treatment benefits and risks (3 items) and patient involvement in decisional process (3 items) was measured.

RESULTS

A total of 124 physicians (77 residents and 47 teachers) completed the pre- and post-tutorial questionnaire. The mean global knowledge scores (/10) increased significantly after completing the tutorial, from 3.8±1.4 to 6.8±1.5 (paired t-test, $p<0.0001$). The effect of the tutorial was similar in residents (3.6±1.2 to 6.8±1.5) and teachers (4.1±1.7 to 6.8±1.5). The effect was significant ($p<0.0001$) across all three components of knowledge: diagnostic probabilities (1.5/4 ± 0.8 to 2.5±1.0) antibiotic treatment benefits and risks (1.4/3 ± 0.7 to 2.8± 0.4), and patient involvement in decisional process (0.9/3 ± 0.7 to 1.5 ± 0.8).

CONCLUSIONS

Teachers and residents in family medicine who completed the DECISION+2 web-based tutorial increased their knowledge on SDM regarding the use of antibiotics for ARI. Impact of the DECISION+2 program on SDM practice and use of antibiotics will be clarified in the randomized trial.

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152 ORAL PARALLEL SESSION 4

How can we best support shared decision making in childbirth: the example of pain relief?

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BACKGROUND

Evidence is growing that shared decision making (SDM) is having a positive impact on health care, and there is mounting pressure to implement in more clinical areas. Recent UK NHS policy demands that SDM become "the norm not the exception". Decision making about pain relief in childbirth is distributed over time, beginning during pregnancy, whilst the implementation of these decisions is often taken in the urgent setting of childbirth. The challenge is to provide appropriate information and decision support. We explored this in a qualitative study.

DESIGN AND METHODS

Four focus groups and 48 semi-structured interviews were conducted with women (whilst pregnant and shortly after delivery) and professionals These were recorded, transcribed and analysed using the constant comparative method.

RESULTS

Midwives found it difficult to describe labour pain to women. The women were not sure what to expect, with conflicting information making it difficult to achieve realistic expectations.

Decisions about aspects of childbirth, such as place of delivery, often have consequences for the choice of method or the combinations of pain relief which may be available e.g. you can't have an epidural in a midwifery led unit, you can have a water birth and Entonox, but you can't have Pethidine and a water birth. It is clear that decisions about pain in labour are not made at a single point in time, and the available options are not independent.

Although women can and do make plans for pain relief antenatally, with support from their midwives, these plans often change due to the urgency and unexpected events experienced during labour

CONCLUSION

There are challenges in supporting pregnant women in making good quality decisions about pain relief in labour, and in preparing them for an event that may differ from their prior expectation or experience. Our qualitative data suggest that we need to rethink how we support pregnant women to make pain relief decisions. We argue that, as well as providing appropriate information, we should focus our efforts on helping women early in pregnancy to acquire skills that will prepare them to make decisions in childbirth.

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111 ORAL PARALLEL SESSION 5

Knowledge-to-action: development and implementation of decision support service in a pediatric hospital

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BACKGROUND

The Children's Hospital of Eastern Ontario (CHEO), a large tertiary academic pediatric center, is developing and implementing a decision support service to target the needs of children, their families, healthcare providers, and policy-makers. Multifaceted knowledge translation (KT) interventions are being developed to close knowledge-practice gaps in shared decision making (SDM).

DESIGN AND METHODS

A five step multilevel systematic approach is being used to implement a hospital-based pediatric patient decision support program: (1) assessment of patients', families' and providers' information and decision making needs using surveys and focus groups; (2) review of patient decision support tools and identification of those relevant to pediatrics; (3) identification of education/training needed to enhance providers' decision support skills; (4) development and implementation of patient decision support strategies tailored to the pediatric setting; and (5) development of tools to monitor the quality of decision support provided. The challenges and successes encountered during implementation are described.

RESULTS

Key stakeholders at CHEO were identified and consulted. Senior decision-makers were engaged early as partners. Needs assessment results identified time and a lack of awareness of decision support tools as barriers. Feedback consistently indicated that a hospital-based support system model was preferred for the integration and uptake of decision support tools at CHEO. An inventory of pediatric decision aids was reviewed by CHEO expert providers and made available on the CHEO Web site (www.cheo.on.ca/en/DecisionServices) for all stakeholders. To facilitate training, workshops were designed to develop SDM skills and will be offered to providers, patients and their families. Implementation and evaluation of the generic Ottawa Family Decision Guide and decision coaching is being conducted. Investigation of quality monitoring tools and methods for including them in the healthcare system remains a priority.

CONCLUSIONS

The development and implementation of CHEO decision support service is an integrated KT project engaging key stakeholders. Our multilevel approach has resulted in increased awareness of pediatric SDM, improved availability of pediatric decision aids, and increased interest in pediatric SDM research. Continued efforts will focus on implementing decision support tools in the processes of care, sustaining knowledge use and evaluation.

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115 POSTER SESSION MONDAY

Clinical decision-making in a pediatric hospital: Patient and family perspectives

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BACKGROUND

Ensuring that family preferences and values guide decision-making is a critical component of family-centred care in pediatrics. Little is known, however, about families' perceived experiences with the decision-making process. The present study investigated families' perceptions of, and satisfaction with, involvement in clinical decision-making about their child's health and their decision support needs.

DESIGN AND METHODS

The Children's Hospital of Eastern Ontario (CHEO) is a tertiary academic pediatric center, with over 200,000 patient visits per year. A survey was developed using items from the Decisional Conflict Scale and CHEO's mission statement on family-centred care. The survey was administered to families after an outpatient consultation with their health care provider in a variety of settings in CHEO.

RESULTS

541 individuals completed the survey (39.6% response rate). 48% of respondents reported not being offered treatment choices and 23% indicated not knowing the benefits and harms of the option(s) presented. Compared to families who reported being offered options, those who did not were more likely to report: not knowing the benefits and harms of the option(s) (41.9% vs. 3.6%, $p < 0.05$); feeling unclear about the benefits and harms that mattered most to them (8.3% vs. 3.0%, $p < 0.05$); that the provider failed to consider the values that mattered most to them (10.3% vs. 2.2%, $p < 0.05$); insufficient support and advice to make a choice (5.2% vs. 1.3%, $p = 0.01$); uncertainty about the treatment decision (13.2% vs. 4.4%, $p < 0.05$); and dissatisfaction with their level of involvement in decision-making (9% vs. 5%, $p < 0.05$).

CONCLUSIONS

Nearly all clinical encounters include a treatment choice, even if it is watchful waiting, continuing the same plan or determining no further follow-up is required. Despite this, many respondents reported not being informed about treatment choices for their child and the associated benefits and harms. When families reported being offered choices, they experienced less decisional conflict and were more satisfied with their level of involvement. Initiatives, such as pediatric decision support services, are needed to support family involvement in clinical decision-making and uptake of effective decision-making interventions.

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251 ORAL PARALLEL SESSION 7

Do General/Family Physicians Correctly Estimate the Benefits and Harms of Common Therapeutic and Preventive Interventions?

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BACKGROUND

Sharing information with patients about benefits/harms of therapeutic and preventive options is essential to the practice of evidence-based medicine and shared decision making. To determine the extent to which practising physicians and residents in general/family medicine accurately perceive the probabilities of benefits and harms of interventions commonly prescribed in family practice.

DESIGN AND METHODS

Teachers and residents in general/family medicine from one university in Quebec City, Canada and one in Paris, France, and participants to a conjoint France-Quebec continuing professional development meeting held in Tignes, France were invited to complete an anonymous 36-item questionnaire before attending a class or meeting. Ten clinical scenarios, presenting 33 questions, covered common therapeutic/preventive interventions in primary care. Each question sought the physician's best estimate of the probability of a clinical event occurring within a specified time frame, with/without intervention, in a hypothetical population (N=1000). Based upon systematic reviews of RCTs, responses were deemed correct if they fell within the 90% confidence limits of the exact answer. Three more questions tested the participants' statistical literacy.

RESULTS

A total of 265 physicians (122 from Quebec, 116 from Paris and 27 participating to the Chamonix meeting) completed the questionnaire. The mean score was low (23% ± 13%, range 0% to 52%) and varied significantly according to status and country of respondents (practicing physicians-Quebec 32%, practicing physicians-France 24%, residents-Quebec 24%, and residents-France 17%; ANOVA, $p<0.0001$). On average respondents better estimated the risk difference (benefits/harms) with intervention than baseline risk (practicing physicians-Quebec 45% vs. 17%, practising physicians-France 33% vs. 14%, residents-Quebec 33% vs. 14%, and residents-France 24% vs. 10%). The 176 respondents (66%) who correctly answered and the 89 (34%) who failed to correctly answer the three statistical literacy questions had similar mean scores.

CONCLUSIONS

The physicians' poor estimates of the probabilities of benefits and harms of commonly prescribed interventions in family medicine are a barrier to the implementation of shared decision making in primary care practice. Strategies to improve physician access to balanced clinical information, and tools to help them clearly translate this information to patients could foster better shared decision making in general/family practice.

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258 POSTER SESSION MONDAY

A Systematic Development Process for Entertainment-Based Decision Aids

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BACKGROUND

The International Patient Decision Aids Standards Collaboration offers guidance to developers and adopters of patient decision aids regarding their content, the development process, and evaluation. Despite standards recommending the use of a systematic development process, including needs assessments, peer review, and user testing for acceptability, surprisingly little attention has been given to explicating the steps in such a process. Entertainment-based decision aids are found to be acceptable by a wide range of users and are especially helpful for lower-literacy audiences. We describe a systematic process for development of entertainment-based decision aids, including the use of telenovelas, and provide examples from an aid on colorectal cancer screening.

DESIGN AND METHODS

We draw on experience from prior studies in development and evaluation of decision aids, concepts from the Edutainment Decision Aid Model, and concepts from Intervention Mapping, in proposing a systematic strategy for development of entertainment-based decision aids.

RESULTS

The development process comprises formative, production, and refinement and review phases. The formative phase consists of the following steps: 1) specifying design requirements for the aid; 2) performing a decisional and informational needs assessment; 3) determining desired decisional outcomes; 4) developing learning objectives and key messages; and 5) mapping key messages to strategies for achieving learning objectives (i.e., factual learning modules, dramatic scripts). The production phase consists of the following steps: 1) developing the program flow and architecture; 2) drafting and expert review of dramatic scripts; 3) storyboarding; 4) cognitive testing with users and revisions; and 5) production of the prototype aid. For the colorectal cancer screening aid, a playwright drew from the learning objectives and key messages in preparing dramatic stories of a couple making decisions about testing. Finally, the refinement and review phase consists of 1) user testing, 2) external peer review, and 3) modifications to create the final decision aid.

CONCLUSION

A systematic development process is useful in guiding the development of entertainment-based aids by describing the phases of production and providing a strategy for mapping learning objectives and key messages to entertaining stories of patients making difficult health decisions.

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218 ORAL PARALLEL SESSION 4

Impact of decision aids on patient involvement in the clinical encounter: an encounter-level meta-analysis of OPTION scores

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BACKGROUND

Effective decision aids (DA) should improve patient involvement in clinical decision making. The OPTION scale can validly and reproducibly assess in video recordings of clinical encounters the extent to which the clinician was able to involve the patient in making decisions. We sought to (1) determine the extent and manner in which DAs designed for use exclusively during the clinical encounter impact patient involvement, and 2) identify factors affecting the magnitude of DA effect.

DESIGN AND METHODS

Encounter-level meta-analysis of the OPTION scores of videotaped clinical encounters from 4 completed randomized control trials (3 primary care/ 1 specialty setting) at a single major health care facility. We used generalized linear models stratified by study to estimate the differences in overall and item-level scores between patients and clinicians participating in encounters with (DA arm) and without the DA (usual care arm). Age and level of education of patients, type of provider, and gender of patients and providers were explored as possible predictors.

RESULTS

A total of 243 OPTION scores of videotaped encounters were pooled. Mean age (SD) of patients involved in these encounters was 65 (10). The majority (71%) of patients were women. Large and significant improvement was found across studies for total OPTION score in percentage (DA arm: 40% vs usual care: 24%, absolute mean difference: 16% CI 12, 20) when adjusted by arm and clinician type (consultant vs. fellow/resident vs. nurse), stratified by study. Significant improvement was also observed for all 12 items. Improvement in total and item-level scores were greater in trials conducted in the primary care setting than in the specialty setting.

CONCLUSION

DAs designed for use during clinical encounters caused large and significant improvements across all items of the OPTION score when compared to usual care. This justifies ongoing work to routinize their use in practice as a tactic to engage patients in their care.

Factors clinicians believe important for themselves and parents in treatment decisions for childhood exotropia

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BACKGROUND

Intermittent distance exotropia (X(T)) is a form of childhood squint, exacerbated when the child focuses on distant objects, is tired or daydreaming. Management includes observation, orthoptic exercises, occlusion, minus lenses and surgery, yet evidence for superiority of any of these is sparse. With surgery there is a risk of over-correction sometimes leading to further surgery. We wished to explore with clinicians the factors they believe important in treatment decision making for themselves and for parents.

DESIGN AND METHODS

This is a qualitative study. In-depth interviews were conducted with orthoptists and consultant ophthalmic surgeons in four ophthalmology centres in the north of England. Data were analysed using a constant comparative method.

RESULTS

Eight ophthalmic surgeons and 13 orthoptists were interviewed. Most children are monitored regularly in the clinic by the orthoptists; occlusion and minus lenses are offered when the child has problems controlling the squint and as means of ‘buying time’ and delaying surgery. Factors important for clinicians’ surgical decisions included: clinical features of the squint (e.g. squint manifest for longer periods); parents’ views (e.g. the cosmesis of the squint); and accurate measurement of the squint. Clinicians listed a number of factors important to parents’ treatment decision making that included: concerns about the impact of the squint cosmetically or on visual acuity; understanding of the condition and of treatment; and the opinions of others. Most clinicians felt that very few children were bothered or even aware of the squint. Whilst some clinicians stated that surgery would only be conducted for clinical reasons, it was clear that parents’ views could influence this decision.

CONCLUSION

Clinicians’ decision-making about surgery is frequently influenced by parental anxiety rather than clinical factors. Parents concerns about the cosmesis of the squint and that their child would be subjected to bullying once they attend school could be a driver for treatment.

“Sharing a decision” vs “Shared Decision Making”: What’s the difference? - Perspectives of Healthcare Professionals in Malaysia

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BACKGROUND

There are different definitions of shared decision making (SDM). However, most of these definitions are derived from a western perspective. The SDM concept has not been explored much in the Asian context. Using insulin initiation in Type 2 diabetes as an exemplar, this study aimed to explore the perspectives of healthcare professionals from Malaysia, a multiethnic Asian country, which has a public-private dual healthcare system.

DESIGN AND METHODS

In depth interviews and focus group discussions were conducted in 2010 with healthcare professionals consisting of general practitioners (n=7), diabetes nurses (n=3), government policy makers (n=1), family medicine specialists (n=1) and endocrinologists (n=1). A topic guide was used to guide the interviews which explored healthcare professional’s roles and views about healthcare decision making. The interviews were transcribed verbatim and analysed using Nvivo software using a grounded theory approach.

RESULTS

The participants viewed shared decision making as a process that involved: listening, negotiation, information-giving, offering options, giving time, patient’s consent and making decisions together.
When helping patients to make decisions, the healthcare professionals attitudes varied from being ‘very serious’, wanting the patients to ‘be on our side’ to ‘not forcing’ the patient to make a decision. During the decision making process, the healthcare professionals played different roles. Some would try to ‘convince’ patients to start insulin, while others would ‘guide’ them through the decision making process. A few would even try to push or ‘threaten’ the patients. The attitudes and roles of healthcare professionals in the decision making process depend on the clinical settings. Those from the private sector expressed a fear of losing patients if they forced the patient to initiate insulin. This was because patients from the private sector paid for the service and could decide which treatment options they preferred.

CONCLUSION

Healthcare professionals in Malaysia viewed shared decision making as the process of providing information and persuading patients to choose a medically-preferred option. Patient’s values or perspectives were not highlighted by the healthcare professionals.

14 POSTER SESSION TUESDAY

What is needed to ensure the quality of continuing professional development in shared decision-making? Perspectives from an international collaborative workshop

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BACKGROUND

Little is known about continuing professional development (CPD) in shared decision-making (SDM). This workshop aimed to: identify knowledge gaps based on the preliminary results of an environmental scan about CPD for SDM; discuss the current knowledge; and create a research agenda.

DESIGN AND METHODS

In November 2010, 35 participants from 6 countries (Canada, France, Germany, Switzerland, the United Kingdom, and United States) attended a 2-day workshop in Quebec City, Canada. The workshop included keynote presentations from a large healthcare organisation that train their health professionals in SDM, and the state of knowledge on CPD. Representatives from each country provided brief presentations on a synthesis of their country's experience implementing SDM in clinical practice and training clinicians in SDM. Preliminary results of the environmental scan were presented and discussed; including ways to improve the environmental scan. Participants subsequently identified a research agenda during two 1-hour discussion sessions in small groups, each followed by a 1-hour plenary session.

RESULTS

Participants included 14 researchers, 11 trainees, 5 research professionals, 3 CPD managers and 2 representatives of a large American healthcare organisation. Of 6 country presentations, all 6 had some training initiatives. The environmental scan identified 53 SDM-CPD programs from 14 countries. The clients of those programs were mostly physicians (n=34) and/or nurses (n=13). There was considerable heterogeneity in the programs' duration (3 hours or less to more than 3 days) and in teaching methods. Participants suggested ways to improve reporting of findings, such as scoring programs' quality, identifying programs' main successes and extracting more information, such as the type of conceptual model used (SDM vs. educational model). They asked that CPD programs be appraised against CDP accreditation standards and suggested having the program developers validate the data extraction. Research agenda items included establishing international consensus on core competencies in SDM and identifying criteria for certifying SDM CPD programs based on SDM competencies and CPD accreditation standards.

CONCLUSION

Participants' presentations, preliminary results of an environmental scan, and discussion of research priorities indicated the need for an international consensus on core competencies in SDM with the identification of criteria for certifying SDM-CPD programs.

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18 ORAL PARALLEL SESSION 4

EXACKTE2: Assessing the factorial validity and reliability of dyadic measures for the study of shared decision-making

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BACKGROUND

The study of shared decision making (SDM) requires dyadic measures, i.e., standardized measures that apply to both clinicians and patients. Our objective was to assess the factorial validity and reliability of existing dyadic measures for SDM.

DESIGN AND METHODS

We conducted a longitudinal study in 17 primary care clinics in London, Ontario and Québec City, Quebec, Canada. We enrolled physicians and one of each enrolled physician's patients and asked them to independently complete a self-administered questionnaire after the consultation. We measured five components of SDM: i) defining/explaining the problem, presenting options, and discussing benefits and drawbacks (information-giving subscale, Medical Communication Competence Scale (MCCS)); ii) clarifying the patient's values and preferences (values clarification subscale, Decisional Conflict Scale (DCS)); iii) discussing the patient's ability/self-efficacy (self-efficacy scale, Theory of Planned Behaviour); iv) discussing the doctor's knowledge and recommendations (doctor's recommendations subscale, Patient-Physician Discordance Scale); and v) checking/clarifying the patient's understanding (feeling uninformed, DCS and information verifying subscales, MCCS). We also measured physicians' and patients' personal uncertainty (uncertainty subscale, DCS). We assessed the measures' reliability with Cronbach's alpha and factorial validity using exploratory factor analysis followed by confirmatory factor analysis. We confirmed the measures' dyadic potential using equality of correlation structure (root mean square error of approximation (RMSEA)) and equality of loading (Chi-square).

RESULTS

Of 382 eligible physicians, 274 participated. Physicians' mean age was 36.6 +/- 10.7 years. Of 430 potentially eligible patients, 276 participated. Patients' mean age was 49.4 +/- 17.7 years. We analyzed the responses of 264 physicians and 269 patients. In both physicians and patients, all measures except the doctor's recommendations subscale showed adequate reliability (Cronbach's alpha= 0.70 to 0.93) and factorial validity (RMSEA= 0.031 to 0.056). We confirmed the dyadic nature of three measures: the values clarification subscale (RMSEA= 0.011; chi-square: 0.106); the self-efficacy scale (RMSEA: 0.051; chi-square: 0.371); and the uncertainty subscale (RMSEA= 0.049; chi-square 0.666).

CONCLUSION

Of six dyadic measures of SDM, only the values clarification subscale, the self-efficacy scale and the uncertainty scale were reliable and valid. More research is needed to develop adequate scales for the SDM components not measured by these three scales.

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103 SYMPOSIUM PARALLEL SESSION 4

Measuring Decision Quality: State-of-the Science for Research, Implementation in Clinical Practice, Performance Measurement and Quality Improvement

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How do you know when a good decision has been made? How do we know if patients have the information they need to make an informed decision? How can we ensure that patients' goals and concerns have been addressed during their decision making process? How do we measure the extent to which the patient/provider interaction informs and involves patients in the decision making process? Measures of decision quality assess patients' decision making experiences and often include the following components: an objective measure of patient knowledge, match of patient preferences to their treatment goals and concerns; patient involvement in the decision making process; and patient assessment of the quality of the decision. Measures of decision quality can be used in research projects, clinical practice; and for performance measurement and quality improvement.

This symposium reports new empirical findings from three initiatives that measure decision quality: 1) Dr. Karen Sepucha will discuss findings regarding the development and testing of measures of decision quality; 2) Dr. Dawn Stacey will present results from a large scale Canadian project that implemented decision aids with summary reports of decision quality measures to inform clinical practice in for all men with localized prostate cancer; and 3) Dr. Lawrence Morrissey will describe a quality improvement project to assess the effect of context (e.g., specific condition versus in general) on the measurement of patient experience with decision making.

The goals of this symposium are to:

1. Discuss components of decision quality for different purposes (including both research projects and clinical situations).
2. Explore ways of measuring decision quality
3. Share lessons learned
4. Engage symposium attendees in broader discussion of the state of knowledge on measuring decision quality and future directions for research, clinical practice, performance measurement and quality improvement.

Chair: Carrie A Levin, PhD: Foundation for Informed Medical Decision Making

Presenters:

1 Karen Sepucha, PhD: Massachusetts General Hospital
2 Dawn Stacey, PhD: University of Ottawa
3 Lawrence Morrissey, MD: Stillwater Medical Group

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55 POSTER SESSION TUESDAY

Decision support and individualized decision making for colorectal cancer screening in the elderly

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BACKGROUND

Individualized decision making with providers is recommended for adults age 75 and older because the potential net benefit of colorectal cancer (CRC) screening decreases with increasing age and co-morbidity. Our purpose was to provide decision support to patients and physicians then examine physicians' and patients' perceptions of screening and assess visit outcomes regarding CRC screening.

METHODS

We recruited a convenience sample of 6 physicians and their elderly patients who were not up to date with CRC screening. Prior to the visit, we provided patients with decision support targeted to elderly patients and for physicians a bar graph showing life expectancy estimates divided by quartiles of health state targeted to the patient's age and gender. We analyzed audiotapes of the visit to determine visit outcome.

RESULTS

At baseline, 8 of the 20 patients preferred to undergo screening, 3 preferred no screening and 9 were unsure. After decision support, 10 patients changed their screening preferences resulting in 6 who preferred screening, 9 preferred no screening, and 5 were unsure. After the visit, 12 patients thought the benefits outweighed the risks, 5 thought they were equal, and 2 thought risks outweighed the benefits, while physicians responded that for 11 patients benefits were greater than risks, for 7 they were equal, and 2 the risks were greater. Eleven physicians thought that screening would likely prolong the patient's life, 3 reported it unlikely, and 6 assessments were neutral. Audiotapes revealed 8 visits with no discussion, 7 visits in favor of screening, 5 visits where screening was discussed but the decision was deferred, and no decisions against screening. The patients' post decision support preference was not associated with the visit outcome (p=0.443) or the patients perception of decisional balance (p=0.135). However, the visit outcome was associated with the physicians' perception of benefit (0.015) but not with physician decisional balance (p=0.62)

CONCLUSION

Patient decision support changed patient CRC preferences but these preferences do not appear to influence visit outcomes; however, physicians' perceptions of benefit may influence visit outcome.

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56 POSTER SESSION TUESDAY

Patient and Physician discussions after decision support for colorectal cancer screening in the elderly

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BACKGROUND

The potential benefit of colorectal cancer screening decreases with increasing age and co-morbidity. Individualized decision making between elderly patients and their providers has been recommended to maximize the benefits and minimize harms. Our purpose was to provide decision support and examine individualized decision making between physicians and elderly patients.

METHODS

We recruited 6 physicians and their patients who were age 70 and older, not up to date with CRC screening, and were scheduled for an upcoming appointment. Prior to the visit we provided patients with a decision support booklet targeted to elderly patients. Physicians were given a bar graph showing life expectancy estimates divided by quartiles of health state and targeted to the patient's age and gender. Visits were audio-taped, transcribed and coded for elements of individualized decision making.

RESULTS

20 of 71 patients (28%) agreed to participate. Twelve of the 20 encounters (60%) had discussions of CRC screening defined as 3 verbal exchanges between physician and patient. The average discussion time was 6 minutes. Two discussions were initiated by the patient. The patient's health status was discussed in 7 encounters and in 3 screening was discussed in the context of the patient's other health issues. In 4 encounters, the USPSTF recommendations that screening is not routinely recommended for older adults were discussed. Decisions in favor of screening were made in 7 encounters (6 for FOBT; 1 colonoscopy); no decisions were made explicitly to discontinue screening but 3 patients preferred not to get screening at the current visit and for 2 the decision about screening was deferred. In 6 encounters, the physicians assessed patient understanding, 2 discussed the potential benefits and harms of screening , and 2 physicians discussed uncertainty in the decision.

CONCLUSION

Decision support triggered discussions in over half of participants but was initiated primarily by physicians. Most discussions included considerations of limited life expectancy and an assessment of patient understanding but fewer discussed other elements of informed decision making.

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118 SYMPOSIUM PARALLEL SESSION 5

Delivery, Uptake, and Satisfaction with Decision Support Interventions in a Primary Care Clinic

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BACKGROUND

Implementation of decision support interventions in primary care poses a number of challenges. Our purpose was to implement decision support interventions for a wide variety of health conditions in a primary care practice and to test the effectiveness of this program in terms of patient uptake and satisfaction.

DESIGN/METHODS

We employed health information technology to identify patients who were eligible for decision support and coupled it with continuous quality improvement methodology to deliver decision support, determine use by patients, and assess patient perceptions of decision support interventions.

RESULTS

From 8/10 - 11/10 we delivered decision support to 433 eligible patients for screening (236 for colorectal cancer (CRC) and 5 for PSA), symptomatic conditions (46 for hip and 42 for knee osteoarthritis, 46 for chronic pain, 2 for depression, 9 for menopause, 9 for benign prostatic hyperplasia), and chronic conditions (28 for diabetes and 10 for weight loss surgery). Over this period, clinic staff followed-up on 532 patients who had been provided decision support within 6 months of their clinic visit. Of these patients, 363 (68%) indicated that they had received a decision aid. Among these 363 patients, 302 (83%) liked receiving the decision aid, 295 (81%) found the information useful, 209 (58%) watched some or all of the DVD, and 239 (67%) read some or all of the booklet.

Patients were more likely to report they liked receiving decision support (88% vs. 79% p=0.03), more likely to watch the DVD (66% vs. 51% p<0.01) or read the booklet (72% vs. 59%; p=0.02) for symptomatic conditions (n=134) compared to screening (CRC) (n=197). Similarly, those who received decision support in clinic (n=168) were more likely to report they liked getting it (90% vs. 77% p<0.01) more likely to watch it (67% vs. 50%; p<0.01) and more likely to read the booklet (74% vs. 58%; p<0.01) than those who were mailed decisions support (CRC screening) before their upcoming visit.

CONCLUSIONS

We were able to deliver a wide variety of decision support interventions and the majority of patients reported receiving them. Uptake and satisfaction appeared to vary by topic type and delivery method.

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221 ORAL PARALLEL SESSION 6

Impact of a Previsit Colon Cancer Screening Decision Aid

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BACKGROUND

Colorectal cancer (CRC) is the third most common cancer for both men and women in the United States. US Preventive Services Taskforce 2008 recommendations conclude there is fair to good evidence that benefits from screening substantially outweigh potential harms (USPSTF, 2008), yet evidence suggests that less than half of age eligible individuals are adherent with current screening guidelines (Subramanian, 2004).

Prior studies have demonstrated that a lack of appropriate communication between providers and patients about cancer screening is associated with lower screening rates. Prior trials of decision aids to improve colon cancer screening rates are limited (Pigone, 2000; Ruffin 2007). We hypothesize that activating patients to make informed shared decisions will improve screening rates.

DESIGN AND METHODS

A total of 307 non guideline adherent patients presenting to a primary care clinic for a preventive visit were randomly mailed one of two letters; one recommending accessing CRC screening information on the AAFP website, the other recommending accessing a website with a CRC screening video decision aid (FIMDM). An historical control group of non-guideline adherent patients was utilized for comparison. Each patient was individually tracked for the following six months to assess ordered and completed CRC screening as well as DA utilization.

RESULTS

A total of 137 patients received a letter directing them to a website with a video-based decision aid and 131 to a website to view information about CRC screening. Visit based DA prescription rates in the historical group (n=245) were 9%. Order rates for CRC screening was higher in both the DA group (46%) and website group (53%) compared to controls (13%). Guideline adherence at follow-up was 24% in the website group, 25% in the DA group, and 11% in the historical group. Viewing rate of the DA was 17% among the pre-visit group, while none of those prescribed the DA by their physician viewed it. Of patients who viewed the DA, guideline adherence was 36%.

CONCLUSIONS

A pre-visit distribution model increases DA use compared to a visit based distribution model. Patients who view a DA had the highest rates of CRC screening guideline adherence.

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222 POSTER SESSION MONDAY

Increasing self-management in chronic illness: Using decision aids and coaching to engage patients

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BACKGROUND

Diabetes is a leading cause of death in the United States. Research demonstrates that activating the patient and increasing self-management skills can improve patient outcomes in diabetic patients. Decision aids (DA) can help improve patients' self-management skills , yet underutilization limits optimal patient outcomes. A collaborative care approach may increase use of DAs to more effectively increase patient self-management.

DESIGN AND METHODS

Physicians at three primary care clinics with collaborative care therapists were randomly assigned to the intervention group (n=11) or usual care group (n=10). Physicians in the intervention group met with a collaborative care therapist (i.e., "coach") to identify diabetic patients to be mailed a letter inviting the patient to watch FIMDM's diabetes decision aid (DA). Therapists, available by phone, could coach a patient to create a self-management plan. Each intervention period involved a coach working with a physician for 60 days. The primary outcome measured was viewing rate of the DA. Secondary outcomes included clinic visits, use of other self-management programs (i.e., Group Medical Visits), and ordering of relevant lab tests.

RESULTS

A total of 270 patients, identified by intervention physicians, were mailed letters and telephoned by coaches (i.e., Full Intervention), were compared to 294 patients sent letters with no follow-up phone calls (i.e., Lite Intervention), and 350 patients seen by usual care physicians. Patients in the Full intervention were nearly three times as likely to watch the video (22%) compared to those in Intervention Lite (7%) or control groups (< 1%). Patients in the Full intervention group presented to the clinic and receive diabetes-related lab tests more than the other two groups (p <.05). Patients who viewed the decision aid were more likely to present to clinic than those that did not view the decision aid (46% vs. 35% p<0.5) and have a Hemoglobin A1C checked (43% vs. 26%, P<0.5).

CONCLUSION

Collaborative care therapists are uniquely qualified to increase the use of DAs and improve patient self-management. The skills of therapists improve upon traditional approaches to improve activation of patients with diabetes resulting in increased visit frequency and ordering of relevant lab markers.

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59 ORAL PARALLEL SESSION 7

Promoting Use of Patient Decision Support Interventions in a Large Community-Based Group Practice

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BACKGROUND

Widespread use of patient decision support interventions (DESIs) has yet to occur in the US. We describe implementation of DESIs into a large, community-based, multi-specialty group practice setting.

DESIGN AND METHODS

Working with five primary care practices and the Community Health Resource Centers associated with the Palo Alto Medical Foundation in northern California, we implemented DESIs tailored to each department's specific needs. The implementation process included identifying physician and staff champions, designing clinic-specific workflows for distribution, continuous social marketing of the program to physicians, staff, and patients, and program promotion amongst organization leadership. We identified barriers to and facilitators of successful distribution through rapid Plan, Do, Study, Act cycles, which included calculation of distribution rates and analysis of feedback from key stakeholders.

RESULTS

Different strategies for DESI distribution resulted in variable success. Successful strategies included using a patient self-screening questionnaire for colon cancer screening (weekly average distribution of 29 DESIs), and in-clinic, in-room distribution of four back pain DESIs by medical assistants (weekly average distribution of 14 DESIs). A direct patient outreach strategy, where eligible patients were identified and mailed a personalized letter inviting them to obtain and watch the DESI, was less successful, with only 2.9% (22/790) of patients requesting the DESI via mail. Overall DESI distribution rate over a 10-month period was 33.3% (290 of 897 eligible patients) for colon cancer screening and 22.4% (411 of 1878 eligible patients) for back pain. DESI distribution increased with a social marketing campaign in all clinics that included patient oriented brochures and posters, academic detailing for clinic physicians and staff, and performance incentives for staff. Highest DESI distribution rates were seen in clinics that had active physician and staff champions raising the visibility of the programs.

CONCLUSION

Distribution of DESIs in primary care clinics was variable and highly dependent on distribution strategy as well as physician and staff enthusiasm. Successful strategies include recruiting physician and staff champions, non-physician based distribution, increasing program visibility with social marketing, and frequent contact with clinics to increase awareness and adjust workflows.

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170 ORAL PARALLEL SESSION 7

Option Grids: a solution to over engineered patient decision support interventions

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BACKGROUND

MAGIC (MAking Good decisions In Collaboration) is a Health Foundation-funded implementation project to determine how best to implement SDM in practice. Part of the implementation includes working with clinical teams to identify and use appropriate decision aids. Although decision aids are considered optimal, they are not widely available for all clinical areas. In particular, the development and implementation of decision aids for head and neck cancer has been sporadic and limited. Key barriers include lack of resources, lack of time to invest in the development of lengthy tools, absence of ownership, and issues of applicability to local situations. We describe the approach to developing and modifying simplified decision aids for head and neck cancer in an NHS setting.

DESIGN AND METHODS

An extensive process of consultation was conducted with the clinical team. Data on patients' use of online decision aids were used to explore patient preferences for the depth and format of information on treatment options. Focus groups with a panel of head and neck patient representatives were conducted to explore specific preferences.

RESULTS

In order to respond to patient preferences and to circumvent common obstacles to the development of extensive decision aids, we agreed to present information on treatment options in an Option Grid. Consultation with the clinical team resulted in the decision to focus on four key areas of head and neck cancer. Clinical team members were allocated responsibility for gathering evidence on treatment options. Draft Option Grids were disseminated to team members for discussion. Feedback from focus groups ensured the data reflected key factors that are important to patients, and that information was presented in a suitable format.

Conclusion

Option Grids can be developed in a short time-scale (2-3 months) and the process of development has important implications for the implementation of SDM. Involvement of clinical teams raises awareness of the importance of presenting treatment options. Reaching agreement on the information included ensures the tool is applicable to local settings, facilitates standardisation of verbal presentation of treatment options, and encourages implementation. Involving patients in the development of Option Grids ensures the information is applicable and relevant.

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121 ORAL PARALLEL SESSION 5

Need assessment of advanced chronic kidney disease patients when facing the preference-sensitive decision of choosing a renal replacement therapy.

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[2]University of Ottawa, OTTAWA, Canada

BACKGROUND

Patients with advanced chronic kidney disease (ACKD) at stage 5 face many choices regarding future renal replacement therapy (RRT). Decision making is difficult for patients and nurses are not trained for decision support. We propose to develop and evaluate a decision support intervention which includes a decision aid for patients and training in decision support for nurses. Guided by the Ottawa Decision Support Framework (ODSF), their development requires beginning with a decisional need assessment. Objective: To describe the decision-making needs from the perspectives of ACKD patients, professionals and others involved in the decision.

DESIGN AND METHOD

A qualitative study using key informants interviews and focus group was conducted. Key informants were: 18 patients who had the experience of choosing a RRT, 7 health professionals and 5 individuals who have the experience of guiding patients to choose a RRT (2 peer patients and their carer and 1 member of a patient advocacy group). The participants to the focus group were 7 predialysis educator nurses and their head nurse. The interview guides and the content analysis were based on the ODSF.

PRELIMINARY RESULTS

The results highlight the complexity of choosing RRT. Manifestations of decisional conflict were expressed by a profound emotional distress and a constant questioning about whether or not to start dialysis. Major factors affecting decision making are: stage of the decision, unrealistic expectations, perceptions of the others, personal characteristics and resources. In addition to these factors, the patient's representations of RRT have emerged. To facilitate decision-making, participants suggested: a compassionate and caring approach, provision of patients experiential knowledge about RRT, utilization of strategies to improve patient self-confidence and support for carer, better timing of dialysis education and more guidance in planning the next steps of decision making especially for the frail elderly with multiple comorbidities. Credible testimonies are helpful for the acceptance of the disease and for the choice of a RRT.

CONCLUSIONS

These findings demonstrate the complexity of developing a decision intervention support in the context of RRT. They will be addressed in the patient decision aid and the coaching intervention to be evaluated.

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76 POSTER SESSION MONDAY

The Effects of Communicating Uncertainty in Quantitative Health Risk Estimates

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BACKGROUND

It is increasingly argued that scientific uncertainty in quantitative health risk estimates should be disclosed to consumers to ensure complete understanding of risk information. However, there is concern this may negatively influence consumers' understanding and perceptions of risk information.

DESIGN AND METHODS

This study examined the impact of communicating uncertainty using a numerical range (e.g. 16 to 24 /100) compared to a single point risk estimate (e.g. 20/100), and examined the effect of varying the source of the risk information. A 2 (source: doctor or pharmaceutical company) by 3 (uncertainty: small range, large range or point estimate) mixed design was used. Three outcomes were examined: understanding of risk information, perceived personal susceptibility and perceived credibility of the source communicating the risk estimate. A sample of 120 students were presented with three hypothetical scenarios containing a risk estimate of acne medication side effect.

RESULTS

Communicating uncertainty (as a numerical range) resulted in significantly poorer understanding of the risk information ($F(1,118) = 161.54$, $p<.001$) and a greater perception of personal susceptibility ($F(1,118) = 10.50$, $p=.002$). Furthermore, the risk information source (doctor or pharma) was largely seen as less credible when a range was presented ($F(1,118) = 19.94$, $p<.001$). However, for the doctor this reduction in credibility only occurred when a large range risk estimate was presented.

CONCLUSION

Communicating uncertainty in the form of a range was found to be detrimental to effective risk communication, reducing understanding, increasing perceptions of personal susceptibility and reducing perceived credibility of the source of the information.

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181 ORAL PARALLEL SESSION 3

Shared decision making and management of cardiac electrophysiological disease.

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[2]University of Newcastle on Tyne, NEWCASTLE UPON TYNE, United Kingdom

BACKGROUND

Clinical consultations with patients should be informed by the evidence-base and involve shared decision making (SDM). Commissioners require quality in decision making. We aimed to determine the quality of delivery of SDM by clinicians with patients referred for invasive treatment of cardiac electrical disease and to establish whether decisions made corresponded with patient and referring physician expectations.

DESIGN AND METHODS

Forty nine outpatient consultations with two consultant cardiologists in one large tertiary centre were audio-recorded. Demographic data, diagnosis, reasons for referral and decision reached were compared directly with patient and referring physician expectations. The OPTION instrument was used to measure quality of SDM. Patient expectations and satisfaction were elicited.

RESULTS

Quality of SDM was good and there was broad patient satisfaction. Whilst all patients were suitable for invasive treatment according to guidelines, and the majority (80%, n=39) had been explicitly referred for it, only 59% (n=29) opted to proceed with invasive treatment. Consultation quality with respect to SDM was significantly greater for patients choosing a less invasive option (54% vs 45% $p=0.015$).

CONCLUSION

The study demonstrated that tertiary consultations are crucial to engaging patients and often change expected management. Patients were satisfied with their consultations. Although referrals were generally appropriate, following discussion of options, decisions differed from those suggested by the referring physician and were less invasive. These disparities may be linked to a high level of patient involvement and positive patient perception.

255 POSTER SESSION MONDAY

Development and field test of a webbased patient decision aid about fertility preservation for breast cancer patients

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M. Baas-Thijssen, C. Hilders, A. Stiggelbout
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Development and field test of a webbased patient decision aid about fertility preservation for breast cancer patients

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BACKGROUND

According to the recommendations of the American Society of Clinical Oncology, options of fertility preservation should be considered early after the diagnosis of breast cancer. To inform patients about such options and the consequences of their choice, a web based patient decision aid (pDA) was developed by the authors. A values clarification exercise with online summary is part of the pDA . The pDA was next revised by medical oncologists, gynaecologists, nurse practioners, and a textwriter. Before the start of an evaluation study, a field test was conducted to investigate acceptability and to get suggestions for improvement.

DESIGN AND METHODS

The field test of the pDA consisted of semi-structured interviews with 12 patients, selected from the database of patients with breast cancer, who had been informed about fertility preservation options in the past. Every paragraph of the website was evaluated for understanding, length of information, relevance, and use of pictures, graphics and tables, using questions with open answers or answers on a five-point scale. Every comment was registered. The interviews were audio-recorded, transcribed, and coded by two independent researchers.

RESULTS

All patients were enthusiastic about this type of information. They found the website to be informative, useful, worth reading and easy to understand. They suggested to shorten some text parts. Patients stated that the website was a source of information that they had missed at the time of diagnosis, when they had to decide about options for fertility preservation. The website will be presented.

CONCLUSION

The positive evaluation of this webbased pDA has led to improvements. According to this small group of patients webbased information can be of great help for newly diagnosed breast cancer patients in decision making about fertility preservation options. Our research group is preparing a nation wide study to compare the webbased pDA and usual care.

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139 ORAL PARALLEL SESSION 7

Understanding 'good' decisions: Are decision process measures associated with quality of life and patient satisfaction 12 months after a Decision Aid supported choice?

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BACKGROUND

Decision making quality in Decision Aid trials is commonly assessed using measures of decisional conflict, knowledge and informed choice. However, there is little evidence to indicate how these process measures relate to longer-term patient outcomes once a decision has been made.

Design: We carried out a randomised trial of women (n=318) considering different management options for a mildly abnormal Pap smear and measured long-term psychosocial and quality of life outcomes (at repeated intervals) over 12 months following management.

METHODS

We assessed the quality of the decision process among women in one arm of the trial receiving a decision aid (n=106) using measures of decisional conflict, anxiety (6-item STAI), knowledge and informed choice. We compared scores, using linear regression and ANOVA, on each process quality indicator to the long-term psychosocial outcome measures, QoL (SF36) and patient satisfaction.

RESULTS

There were no statistically significant associations between decisional conflict and QoL over 12 months. However, patients with lower decisional conflict were more satisfied over the 12 months of follow-up with decisional conflict analysed both as a continuous scale, with a one point increase in decisional conflict associated with a 0.069 decrease in satisfaction (β=-0.069, 95%CI -0.127,-0.011, p=0.021); and using thresholds commonly used to categorise decisional conflict as 'low' 0-<25, 'moderate' 25-36 and 'high' ≥37 (satisfaction: L=15.4, M=13.8, H=13, ANOVA F=3.34, df=2, p=0.042). Anxiety at the time of decision making was significantly associated with QoL, with a one point increase in anxiety associated with a decrease of 0.919 in QoL (β=-0.919, 95%CI -1.505,-0.332, p=0.003). Higher anxiety was also associated with lower satisfaction (β=-0.228, 95%CI -0.429,-0.026), p=0.028). There were no significant associations between measures of knowledge and informed choice on psychosocial outcomes over 12 months.

CONCLUSION

In this DA trial, measures of decision process quality (decisional conflict and anxiety) were associated with improved long term psychosocial outcomes for patients. This suggests that these commonly used indicators of decision process quality may also potentially indicate quality in patient outcomes. Future research is needed to understand the relationship between decision process measures at the time of decision making to patient outcomes.

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88 ORAL PARALLEL SESSION 3

Development of a Decision Analytic Model (DAM) to Support Decision-Making and Risk Communication for Thrombolytic Treatment in Acute Stroke Care

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BACKGROUND

Thrombolysis with Recombinant Tissue Plasminogen Activator (rt-PA) has improved the prognosis for acute ischaemic stroke (AIS), but it must be administered within 4.5 hours of onset of symptoms. Decision support during the emergency 'hyperacute' period of stroke is warranted to expedite appropriate clinical assessment of eligibility for rt-PA, and communication of risks and benefits to patients/families.

DESIGN AND METHODS

A literature review identified robust sources of evidence for prediction of outcomes for treatment of AIS with and without rt-PA. A DAM was constructed to establish the likely balance of benefits and risks of thrombolytic treatment in individual patients. Probability of independence (absence or minimal disability) three months post-stroke was based on a predictive equation reported in the literature (Stroke-Thrombolytic Predictive Instrument [S-TPI], derived from large scale trials) calibrated using data from stroke patients treated in routine practice in the UK (Safe Implementation of Thrombolysis in Stroke [SITS-UK] database). Probabilities for death at three months were derived from analyses of SITS-UK data; whereas, probability of symptomatic intracerebral haemorrhage (SICH) were calculated using an equation derived from SITS data.

RESULTS

The DAM expresses probabilities for short-term (SICH, death, independence and dependence at 6-months) and long-term outcomes (QALYs), with and without rt-PA, as a function of 11 patient characteristics: (age, gender, diabetes, previous stroke, stroke severity, systolic BP, onset time to treatment, weight, aspirin use, blood glucose and signs of current infarction on baseline imaging). The prediction accuracy of the model for independence was improved by the addition of blood glucose and signs of current infarction to the S-TPI predictive equation (area under the curve for the calibrated S-TPI model for independence increased from 0.728 to 0.741). The DAM identifies sub-groups of patients with a different balance of likely risks and benefits from rt-PA, including no benefit and likely harm.

CONCLUSION

Outcomes generated by the DAM show improved discrimination between stroke patients who may and may not maintain their independence. The DAM has been embedded within a computerised tool for supporting clinical decision-making on rt-PA and risk communication (including where appropriate engagement of patients/family members in decision-making) within the hyperacute stroke period.

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266 ORAL PARALLEL SESSION 6

The role and limits of legislation to promote Shared Decision Making: a Legal, Ethical and International perspective

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Washington was the first state in the U.S. to pass legislation designed to expand the use of shared decision making for preference sensitive conditions. The legislation authorized a multi-provider and payor pilot and evaluation coupled with changes to the state's laws governing informed consent. Several of the state's leading health care providers have participated in this groundbreaking initiative, along with the largest state healthcare purchasing agency and the University of Washington. Group Health Cooperative, a nonprofit consumer governed integrated health plan and delivery system, has played a leading role in this effort. Group Health has now implemented widescale use of patient decision aids for twelve conditions ranging from hip and knee replacement to benign prostate disease. Ms. Merrikin will describe Group Health's approach to shared decisionmaking, including both the decision to seek and support state legislation as well as Group Health's implementation activities in the context of the statewide collaborative. She will explore the survey results from the patients and providers who participated, review what conditions were the focus of the preference sensitive study and what the impact, if any, has been on decision quality, patient satisfaction and provider standard of care. In addition she will talk about the work underway at the other state collaborative implementation sites. She will also discuss the rationale for seeking supportive state legislation, the practical limits to state action, as well as insights gained via the collaborative approach and the pilot study.

120 ORAL PARALLEL SESSION 2

Mind like a Sieve: patient recall and adaptation of genetic risk information

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BACKGROUND

Clinical literature and SDM practices rarely take into account the sinuous path genetic risk estimates for conditions such as Alzheimer's Disease (AD) travels in the patient's mind. Two crucial stops along this path are recall of the communicated risk estimate as delivered by the healthcare professional, and one's incorporating the risk estimate in their subjective risk assessment. This work uses the rare opportunity provided by the REVEAL study to follow people when receiving a risk assessment, and thereafter.

DESIGN

In this non-experimental design, we followed 273 people whose parent or sibling had been diagnosed with AD. The participants agreed to undergo genetic testing for the disease and completed questionnaires six weeks, six months and twelve months following consultation.

METHOD

We recorded objective risk assessments for AD, then measured recall of risk information by asking "what was the risk estimate the doctor gave you", and adoption of risk information by asking "what do you believe your risk is?"Current work in the project is examining whether the length of time the relative has been ill with AD is associated with reduced adoption of objective risk assessment.

RESULTS

Sixty percent of the participants accurately recalled their objective risk assessment for AD. The remaining participants divided equally between remembering the risk as higher or lower than the actual number. Females and older participants were less likely to recall accurately overlapped the subjective one. A mere 40% of the participants adopted the objective risk information and incorporated it as their subjective assessment. Interestingly, this does not present an optimistic bias: 40% of participants had subjective risk assessments that were higher than the objective risk, and 20% had lower subjective risk assessments.

CONCLUSION

Providing patients with risk information does not necessarily involve their accurate recall of the information and its incorporation in the person's subjective risk assessment.
In order to facilitate SDM, it is important to recognize the hurdles to recall and adoption of risk information.

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273 POSTER SESSION MONDAY

Differences in Patient Preferences for Chronic Hepatitis B Treatment Outcomes: a cross-sectional survey in five countries

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BACKGROUND

Currently recommended oral antiviral medicines for first line treatment of chronic hepatitis B (CHB) have demonstrated potent viral suppression and a low resistance profile. Clinical guidelines may not always reflect patient value and preferences. The aims of this study were to elicit patient preferences for outcomes associated with CHB treatments and to determine which treatment features are most important to patients.

DESIGN AND METHODS

Adult patients with a self-reported physician diagnosis of CHB in five countries (France, Germany, Spain, Italy, and Turkey) completed a web-enabled, discrete-choice experiment survey. The survey presented patients with 12 treatment-choice questions. Each treatment-choice question included a pair of hypothetical CHB medication profiles. Medication features included how long the medication has been studied (weight of evidence), probability that viral load is undetectable at 5 years (long-term efficacy), 5-year treatment-related risk of fracture, 5-year treatment-related risk of renal insufficiency, and personal monthly cost. Treatment-choice questions were based on a predetermined experimental design with known statistical properties. A nested-logit model was used to estimate preference weights for all attribute levels and the mean relative importance of each attribute after controlling for scale differences across countries.

RESULTS

560 patients completed the survey. 5-year risk of renal insufficiency and probability that viral load is undetectable at 5 years were the most important outcomes for Germany, France, Spain, and Italy. Weight of evidence and risk of renal insufficiency were the most important outcomes for patients in Turkey, while patients in Germany ranked risk of a fracture above weight of evidence, and patients in France, Spain, and Italy ranked weight of evidence above risk of a fracture in importance. For an increase in probability from 70% to 95% that viral load is undetectable at 5 years, mean maximum acceptable risk of renal insufficiency for all five countries was approximately 8.0% (4.9%-11.1%).

CONCLUSIONS

This study shows that patients are willing to make tradeoffs between efficacy, side-effect risks, and weight of evidence among CHB treatments. The relative importance of these treatment features varied across the five countries. The impact of (Dis)concordance between patient and clinical-decision makers preferences on patient outcomes warrants further research.

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151 WORKSHOP PARALLELSESSION 1

Designing decision aids patients and clinicians (really) want to use during clinical encounters: Insights from a participatory development process

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Workshop chairperson's name and affiliation:
Victor Montori, MD, MSc, Knowledge and Evaluation Unit, Mayo Clinic, Rochester, MN

Name of co-presenters and affiliations:
Maggie Breslin, Annie LeBlanc, PhD, Mayo Clinic, Rochester, MN

OVERALL AIM OF THE WORKSHOP

Our decision aids are focused on facilitating a conversation between health professionals and patients. We feel that the conversation is critical to dealing with the enormous amount of ambiguous information and the unique personal circumstances that surround most decisions. As such, our decision aids are really conversation tools intended for use in a clinical setting. Because the intent of our decision aids is different, our process is different. We use a participatory development process in which iterations of the decision aid are tried in actual clinical encounters to gauge their effectiveness in generating conversations.

DESCRIPTION OF THE WORKSHOP

Learning activities throughout this workshop will include didactic lectures, scenarios, videos, and discussions about: understanding what is known from the literature, designing tools that engage patients, and practice-based evaluation of this process. Participants will be walked through the unique process of designing a decision aid and experience some of the challenges and opportunities that comes from using a different process. The workshop will be facilitated by the multidisciplinary team (physician, designer, researcher) which developed the approach 5 years ago.

Learning objectives to be covered in workshop. After the completion of this workshop, participants will be able to critically appraise and reflect on the 1) steps required to design decision aids that best meets the users' (patients and health professionals) needs, 2) value of direct clinical observation, 3) advantages of early low fidelity prototyping in actual settings prior to formal evaluation in this same settings, and 4) importance of the evaluation process in practice-based settings.

Pre-requisite knowledge or other requirements for attendees. There is no pre-requisite for this workshop. However, presenters may have assumptions regarding understanding of basic principles of risk communication, shared decision making, and sense of humour of the attendees. Intended audience includes researchers and healthcare professionals interested in creating practical decision aids for use within the clinical encounters.

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36 POSTER SESSION MONDAY

The development of a decision aid for prospective orthognathic patients

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BACKGROUND

Evidence indicates patients are more satisfied when they are actively involved in their treatment decisions. Shared decision-making is a key health policy objective but is under-researched in dental contexts. Patients who have severe dentofacial deformity (SDD) require orthognathic (combined orthodontic and surgical) treatment. Previous studies in the orthognathic setting have found that patients need to be better supported throughout their course of treatment; treatment takes place over a two-year period and has serious consequences. Recent studies have highlighted shortcomings in current information for dental patients. Decision aids are likely to be effective resources for patients making orthodontic and orthognathic treatment choices.

DESIGN AND METHODS

A cross-sectional pilot study employing questionnaire and interview methods to elicit data about the acceptability of a newly developed decision aid leaflet. The leaflet included explicit reference to the decision being made, quality of life related exercises to help patients' clarify their values about treatment consequences as well as risk and benefit information about treatment options summarised within a decision-attribute table. Prospective orthognathic patients (n=40) completed two questionnaires about their socio-demographics, levels of psychopathology, knowledge, decisional conflict, anxiety, risk perception and expectations; 15 patients were interviewed either face-to-face or by telephone.

RESULTS

All patients considered the decision aid to be more useful than current information. Their knowledge about the risks and benefits of treatments was good but some dental terms need more explanation to help patients' understanding. Most patients expressed strong emotions when talking about the treatment options. Patients found the leaflet helped them think about the decision in a different way, enabling them to reason more fully about how the consequences may impact on their personal and family life. Although patients found the leaflet useful, they did not complete all the exercises within the leaflet.

CONCLUSION

Variation in the completion of tasks within the decision aid existed. Interviewed patients had thought about the implications of the questions and had increased their reasoning but had not always put their thoughts down in writing. Overall, prospective orthognathic patients felt that the decision aid presented the required information in a more "patient friendly"and useful format.

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107 ORAL PARALLEL SESSION 6

The Minnesota Shared Decision Making Collaborative: A case study of a community wide effort to study and encourage shared decision making.

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BACKGROUND

Minnesota has a history of community-wide quality improvement initiatives. In November 2008, we added the Minnesota Shared Decision Making (SDM) Collaborative to spread and improve the quality of SDM across our State.

DESIGN AND METHODS

This is a case study of the process used to establish a state-wide multi-stakeholder collaborative, including health plans, medical groups, other health organizations, policy makers, academics, individual clinicians, and patients.

RESULTS

We began by organizing a day-long workshop on SDM specifically aimed at attracting a wide spectrum of participants that concluded with agreement to develop an organizational structure that would sustain the original interest. This included a diverse steering committee and subgroups focusing on the key goals of the collaborative:

1. Identify best practices for implementing and measuring SDM
2. Implement identified best practices Minnesota-wide
3. Improve SDM to reduce unwarranted variation in preference-sensitive care

Next we established five measures of success:

1. learning collaborative defined and implemented
2. number of SDM program implementations in clinical practice
3. resources to support the initial work of the collaborative
4. research grant(s) obtained to fund SDM work related to the collaborative
5. annual symposia held to provide an update on the work of the Collaborative, gather input from other community members, and educate the community about SDM.

Finally, we monitored outcomes over two years. Original administrative support from one health plan made a successful transition to a regional quality improvement collaborative. There has been a steady increase in the number of SDM-related programs being developed in the state from 10 to 18 including several cross-institutional projects and significant expansion of many initial programs. To build capacity for implementing and measuring SDM, we held a pre-conference workshop with 100 attendees and our first symposium with 70 attendees. Consensus priorities were identified at the symposium that will guide the next stage of work.

CONCLUSION

We successfully developed a sustainable infrastructure in our state to support the process of implementing and measuring SDM for health care decisions. This model and process can serve as a template for other communities who desire to improve SDM.

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108 SYMPOSIUM PARALLEL SESSION 4

Being specific: The effect of context on the measurement of patient experience.

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BACKGROUND

There is increased interest in patient experience surveys to assess the delivery of healthcare services. Provider scores on these surveys are often high with minimal variation. The effect of the context of the questions asked is unknown.

DESIGN AND METHODS

We analyzed the simultaneous administration of surveys of patient experience with the same group of providers over the same period of time. The Consumer Assessment of Healthcare Providers and Systems -Clinic and Group adult primary care survey was sent to a randomized sample of adult male patients who had visits with a primary care group over a 3 month time period. This survey is a standardized tool for the measurement of patient experiences in healthcare developed by the Agency for Healthcare Research and

Quality. A topic specific survey about Benign Prostatic Hyperplasia (BPH) containing 4 CAHPS-CG questions was sent to patients who saw the same primary care providers for BPH during a 6 month time frame that overlapped with the baseline survey.

RESULTS

All 4 questions assessed patients' perception of how well the providers communicated and focused specifically on whether they explained things in a way that was easy to understand, listened carefully, showed respect for what the patient had to say, and spent enough time with the patient. There was a significantly lower score for the questions asked in a visit specific context compared to those questions asked in a general context.

CONCLUSIONS

Asking questions about patient experience in a visit specific context can have a significant influence on outcomes. Patients asked questions about their experience gave significantly lower scores when asked in a topic specific context. Further study is needed to understand the reasons behind this variation.

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122 SYMPOSIUM PARALLEL SESSION 5

Decision support for benign prostatic hyperplasia

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BACKGROUND

Little research has been done on the clinical implementation of Shared Decision Making (SDM) and Decision Aids (DAs) in primary care practice environments. Our goal was to assess the impact of a new program to provide better SDM support to men with Benign Prostatic Hyperplasia (BPH).

DESIGN AND METHODS

Patients who saw their primary care provider for BPH during a 15 month period received a mixed-media (video and printed booklet) DA explaining treatment options for BPH at a face to face decision support visit. Patients completed questionnaires to asses their experience 1) before and after exposure to the DA. (PPQ) and 2) after a subsequent visit. (PVQ)

We identified a "natural control group"of 296 patients seen by their primary care providers for BPH within the 6 months prior to the start of the DA implementation. All were sent a questionnaire similar to the PVQ their experience during their last visit for BPH (response rate=39%).

RESULTS

82 patients referred by their primary care provider participated in the program. 44 completed the PPQ, and 25 completed the PVQ successfully. Patients were more likely to have made a decision about treatment after participation in the program. (Percent of patients responding they chose an option: Control=60% vs. post Intervention=79%, p=0.046; prior to intervention 28% vs. post intervention=79%, p=<0.05). While the demeanor of the physicians was similar, reports from patients who experienced the decision support process indicate that a higher degree of SDM occurred during their visits than during the visits of patients who did not go through the program. (Clinician explained there are choices for treatment: (82% vs. 100%, p=0.019); Discussed surgery: (23% vs. 40%, p=0.058); Discussed non-surgical options: (74% vs. 92%, p=0.044); Provider listened carefully: (82% vs. 96%, p=0.048) Clinician asked which treatment patient wanted (58% vs. 72% p=0.168)

CONCLUSIONS

Patients who received decision support were more likely to 1) choose a treatment option, 2) understand there were choices, 3) discuss treatment options and 4) feel the provider listened to them. Patients who experience structured decision support with a DA may able to participate more fully in their treatment decisions.

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132 ORAL PARALLEL SESSION 6

How do video-based decision aids affect treatment choice in patients considering Total Knee Arthroplasty (TKA)?

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BACKGROUND

Shared decision making (SDM) provides patients with decision aids (e.g. booklets, videos, etc.) summarizing current "best"practices which supplement traditional clinician education regarding treatment options. This is expected to increase a patient's knowledge, thereby improving understanding of potential risks and benefits associated with treatment options.

DESIGN AND METHODS

Patients with severe knee osteoarthritis were enrolled in a prospective cohort study to evaluate the usefulness of a 50-minute video decision aid to assist with treatment choices. Patients completed a questionnaire before and after viewing the video. Changes in knowledge, treatment preference, concordance in treatment preference with values, and decision readiness were evaluated.

RESULTS

Eighty patients were recruited into the study; average age 63 years with 61% female. Basic knowledge increased after the video (59.5% vs. 77%, p<.0001), however an improvement in complication risk knowledge was not statistically significant, (68% vs. 69%, p<.54). The majority of patients (85%) reported a treatment preference prior to seeing the video and these patients demonstrated no significant treatment preference shift, (Bowker's Symmetry s3=3.83, p<.28). However, 67% of patients who were unsure of their treatment decision pre-video had a treatment preference post-video. Although 80% of patients reported that the video prepared them to discuss their values, pre- to post-video concordance between treatment choice and both importance of symptom relief (r=.26 vs. r=.40 p<0.20) and wishing to avoid surgery (r=.-0.47 vs. r=-0.57,p<0.83) were not improved. In contrast, post-video decision readiness was significantly improved as 50% of patients reported greater decision readiness after viewing the video compared to 6.6% of patients reporting lower decision readiness (p < .0001). Interestingly, despite pre- to post-video preference shifts, the overall distributions of pre- and post-video treatment preferences were quite similar.

CONCLUSION

In patients with knee osteoarthritis SDM improved basic knowledge but did not significantly improve complication knowledge. Improved preparedness to discuss their values and decision readiness did not translate into greater concordance between patient values and treatment choices. Patients with an initial treatment preference were not likely to change their preference while those who were unsure about their treatment preference were more likely to report a preference after watching the video.

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133 ORAL PARALLEL SESSION 6

How do video-based decision aids affect treatment choice in patients considering Total Hip Arthroplasty (THA)?

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BACKGROUND

Shared decision making (SDM) provides patients with decision aids (e.g. booklets, videos, etc.) summarizing current "best"practices which supplement traditional clinician education regarding treatment options. This is expected to increase a patient's knowledge, thereby improving understanding of potential risks and benefits associated with treatment options.

DESIGN AND METHODS

Patients with severe hip osteoarthritis were enrolled in a prospective cohort study to evaluate the usefulness of a 50-minute video decision aid to assist with treatment choices. Patients completed a questionnaire before and after viewing the video. Patient knowledge, concordance in treatment preference with values, decision readiness, and preferred role in treatment decision were evaluated.

RESULTS

Forty-three patients were recruited into the study; mean age was 63 years with 54% male. Both basic knowledge and knowledge about complications increased after viewing the video, (71% vs. 81%, p<.028) and (73% vs. 94 %, p<.0001), respectively. The majority of patients (88%) reported a treatment preference prior to seeing the video and these patients demonstrated no significant treatment preference shift, (Bowker's Symmetry s3=1.00, p<.81). Although 79% of patients reported the video prepared them to discuss their values, pre- to post-video concordance between treatment choice and both importance of symptom relief (r=..09 vs. r=.39 p<0.28) and wishing to avoid surgery (r=.-0.54 vs. r=-0.49,p<0.76) were not improved. In contrast, post-video decision readiness was significantly improved as 83% of patients reported greater decision readiness after viewing the video compared to 18% of patients reporting lower decision readiness (p < .0005). Females preferred the shared decision-making process to include both them and their physician more so then men (70% vs. 30%, p < .012), who preferred being the sole decision maker. As would be suspected with minimal pre- to post-video preference shifts, the overall distributions of pre- and post-video treatment preferences were quite similar.

CONCLUSION

In patients with hip osteoarthritis SDM improved patient's basic knowledge, enhanced understanding of possible complications, and prepared them to discuss their values, but did not significantly affect treatment preference nor improve concordance between patient values and treatment choice.

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267 ORAL PARALLEL SESSION 6

The role and limits of legislation to promote SDM: a legal, ethical and international perspective.

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BACKGROUND

There has been no analysis of US legislation to promote shared decision making.

DESIGN AND METHODS

A survey of the current US legislative activities both state and federal

RESULTS

In 2007 Washington state passed legislation to promote shared decision making through a pilot project. The pilot is concluding the first quarter of 2011. Other states including Vt. have initiated pilot projects. Several are considering filing legislation.

PPACA contains several sections that advance shared decision making within the context of clinical practice. Benjamin Moulton will provide an overview of the legislation and its relevant SDM sections. Section 3021 creates a CMS innovation center which is funded and charged with testing several models of which shared decision making is one. Section 3506 contains language for certification, best practices and national resource centers and the placing of federally supported decision aids into the public domain. This section awaits appropriations. Finally Section 931 of the act calls for giving priority to certain quality measures including those that would allow assessment of the experience, quality and use of information provided to and used by patients to inform decision making.

He will review the key policy reasons why state and federal policy makers are interested in shared decision making to promote quality and patient centered care. He will discuss the differences between shared decision making and traditional informed consent and other policy reasons for SDM legislation including the ethical tension between patient autonomy and physician beneficence.

CONCLUSIONS

There are several policy reasons advanced for adopting shared decision making. Both state and federal law makers are intrigued by the promise of patient centered care and how SDM may be a catalyst for change. Physician training and acceptance of shared decision making are barriers. Using the informed consent process is one promising way to introduce shared decision making into clinical practice. The ethical tensions between physician beneficence and patient autonomy need to be closely examined.

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210 ORAL PARALLEL SESSION 5

Eliciting patients' preferences for local medical management versus centralized technical support using a computerized decision aid based on contingent valuation survey: an innovative method tested in cancer

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BACKGROUND

Technical support centres specialized in cancer care are expensive and geographically concentrated, making access difficult for some patients. Home care, designed to relieve the pressure on hospitals, is only one of several possible solutions. For some interventions, local structures like local hospitals or nursing homes already exist or are being developed to offer proximity healthcare.

OBJECTIVES

To elicit and analyse patients' preferences for home or proximity care versus technical support centres (hospital care) by developing a computerized decision aid based on a contingent valuation survey (willingness to pay method, WTP) using a payment card.

RESULTS

- Content of the tool and its ergonomics were pre-tested among healthcare professionals and experienced patients. Both groups found the tool user friendly, pleasant to handle, informative and easy to understand but they encountered some difficulties with the presentation of the WTP method. They thus suggested some improvements.

- A survey was conducted among 117 cancer patients of the Rhône-Alps Comprehensive Cancer Centre in Lyon, France. For heavy care, either blood transfusion or chemotherapy, the majority of patients (respectively 72% and 79%) would prefer to be treated at the hospital (technical support centre). Moreover, patients with previous experience of heavy care at home (local medical facilities) and patients living with a partner would prefer to be treated at home rather than at the hospital. Concerning willingness to pay, 38% of the patients were not able to propose a monetary amount and were thus classified as protest responses. No specific demographic or medical differences were noted between these patients and those who proposed a monetary amount. The link between income and WTP was not established due to the low number of observations.

CONCLUSION-DISCUSSION

This is the first study conducted in France or worldwide using a computerized decision aid based on a contingent valuation survey to elicit patients' preferences for local facilities versus technical support centres in cancer. Because of the large number of protest responses we need to rework the contingent valuation survey and notably to propose different methods to elicit patients' preferences: payment card versus bidding game. We will further conduct a cost-benefit analysis.

Concept Mapping to Elicit Men's and Partners' Views of Active Surveillance vs Active Treatment for Early Stage Prostate Cancer

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BACKGROUND

There is no consensus on the best option for men facing a diagnosis of early stage prostate cancer; active treatment often causes side effects, e.g., incontinence, and does not extend life. Active surveillance is an option that is not currently included in decision aids. Methods
Using concept mapping, a qualitative, participatory method, we produced a framework for viewing active surveillance and active treatment: 54 statements about what men need to make a decision were derived from focus groups with African American, Latino, and white men and partners in Houston and El Paso who had screened negative (n=80) and from journal articles; 86 similar participants (55 from the focus groups and 31 new participants) sorted the statements and rated their importance.

RESULTS

Multidimensional scaling and cluster analysis yielded an 8 cluster map based on the data for the 3 ethnicities. Clusters were labelled Doctor-patient information exchange, Finding out about active surveillance and active treatment, Weighing the options, Seeking and using information, Spirituality and inner strength, Access to active treatment, Side effects of active treatment, and Family considerations. There is a major cluster, rated somewhat more important overall, concerned with obtaining information and weighing options in decisions. The other major grouping concerns family, faith, and considering the side effects of active treatment. Average cluster importance ratings varied in Finding out about active treatment and active surveillance (less important by Hispanics), Access to active treatment and Spirituality (more important for African Americans). Women saw weighing options and seeking information from physicians active surveillance more important than men. There were no differences by gender in clusters about family considerations or spirituality.

CONCLUSIONS

Our next step is interpretation by participants and advisers. The results are contributing to the development of educational messages that include active surveillance.

Whose Choice: Patient, Healthcare Professional or Family? - Views of Malaysian Healthcare Providers

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BACKGROUND

Patients, family and healthcare professionals are the main stakeholders in decision making. Traditionally in Asia, family units are close-knit and are often actively involved in the care of the patient. However, their role in making healthcare decisions has not been studied. Using insulin initiation in Type 2 diabetes patients as an exemplar, this study aimed to explore the healthcare professionals views of the stakeholders' roles in decision making in Malaysia, a multiethnic Asian country, which has a public-private dual healthcare system.

DESIGN AND METHODS

In-depth interviews and focus group discussions were conducted in 2010 with healthcare professionals consisting of general practitioners (n=7), diabetes nurses (n=3), government policy makers (n=1), family medicine specialists (n=1) and endocrinologists (n=1). A topic guide was used to guide the interviews which explored healthcare professional's views about healthcare decision making roles. The interviews were transcribed verbatim and analysed using Nvivo software using a grounded theory approach.

RESULTS

This study found that the key stakeholders in making decisions about insulin initiation included the patients, their families and doctors. In this study, healthcare professionals viewed the patients as the main decision maker.

The families had a significant influence on the decision making process. In some instances the decision was made solely by the spouse or the children, in particular amongst patients who were elderly or visually impaired, requiring assistance with insulin injections. There was an observed trend that domestic helpers were becoming the main caregivers and this might influence the decision making process.

Doctors' role in decision making varied widely. Some would make decisions for the patients while others would leave it to the patients to decide. Their preferred role was influenced by the clinical settings of their practice (Private vs Public) and doctor-patient relationship. Nurses and diabetes educators were less involved in the decision making process.

CONCLUSION

In Malaysia, doctors and patients' families played an important role in making decisions about insulin initiation. The role of domestic helpers in influencing the decision making process needs to be further explored.

176 POSTER SESSION TUESDAY

Evaluation of a patient decision aid and a training program for improving oncologists' shared decision making skills

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BACKGROUND

Many patients with cancer prefer an active or shared role in medical decision making. Patient participation in treatment decision making has been shown to result in increased patient satisfaction, treatment adherence, and improved psychological status. However, despite the acknowledged benefits of Shared Decision Making (SDM), most of the patients do not achieve their desired level of participation in treatment decision-making. To facilitate SDM in clinical practice a combination of physicians' training and patient decision aids has been shown to be effective. In this study such a combined SDM intervention for the use in the treatment of colon cancer will be developed and evaluated.

DESIGN AND METHODS

The intervention will be evaluated in a cluster-randomized controlled trial with 25 oncologists and 200 patients diagnosed with colon cancer. Relevant medical consultations will be audiotaped and evaluated by independent raters. A triangulation will be reached by assessing the views of patients, physicians, and independent observers. Patients' preferred level of participation, decisional conflict, satisfaction with the decision, perceived level of involvement in decision making, and level of anxiety and depression will be assessed directly after the consultation and after three months.

EXPECTED RESULTS

It is assumed that after the training physicians' SDM skills will be improved. The involvement of the patient in the decision making process might be associated with greater patient satisfaction and reduced emotional distress.

CONCLUSION

The triangulation of data from three different sources provides a comprehensive test of the effects of the intervention. An in-depth analysis of the audiotaped medical consultations will also shed light on the process of SDM applied by physicians in the daily routine.

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177 ORAL PARALLEL SESSION 5

Development and evaluation of a patient decision aid for colon cancer

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BACKGROUND

According to the German S3-guidelines, risks and benefits of adjuvant chemotherapy for stage II colon cancer should be discussed with each patient individually. Although, many patients want to be involved in treatment decision making, most patients do not achieve their desired level of participation. To facilitate shared decision making (SDM) in clinical practice decision aids (DAs) have been successful. The objective of this study was to develop and evaluate a new DA for patients regarding choices in stage II colon cancer with respect to adjuvant chemotherapy. Design and Methods We utilised the criteria set out for the development of DAs, according to the Cochrane Systematic Review of Patient Decision Aids. Focus groups with oncologists led to the identification of adjuvant chemotherapy for stage II colon cancer as a situation for SDM. The DA was reviewed by experts and patients. After adaptations, the DA was sent to all members of the German Association of Resident Gastroenterologists working with colon cancer patients and members of the Scientific Institute of office-based haematologists and oncologists. Fifty-four physicians provided detailed written feedback.

RESULTS

The DA on stage II colon cancer will be presented. The majority of physicians (86%) reported that the DA is useful in providing an overview on information difficult to obtain, in facilitating communication, and in preparing patients for potential difficulties. Some (14%) had concerns about the framing of information and patient's cognitive load. Patients found the DA acceptable, but noted that they prefer the delivery of the DA by their clinician during the visit.

CONCLUSION

Since no DA for stage II colon cancer exists in Germany, most physicians applauded the development of the DA. However, concerns about the complexity of the information and patients' capacity to understand the information remain. Our results show that patients generally like the presentation of the information as a guide during their consultation. Despite shortcomings, the DA was valued as useful.

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242 ORAL PARALLEL SESSION 4

Patient and coach ratings of physician shared decision making behaviors

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BACKGROUND

Prior studies have used patient reports to determine whether shared decision making (SDM) happened in patient-physician interactions. To explore the validity of this approach, we compared patient reports with those of SDM coaches who were present for patient-physician interactions.

DESIGN AND METHODS

Between May and December of 2009, 180 patients newly diagnosed with breast cancer obtained SDM coaching as part of an ongoing decision support implementation in a university-based clinic. Ten premedical interns acted as SDM coaches and accompanied patients to visits with physicians (5 surgeons and 8 medical oncologists). The coaches took notes and made audio-recordings of the consultations for the patient. After each visit, the coaches rated physician SDM behaviors on 6 items and surveyed patients for their ratings. The items probed the degree to which the doctor presented multiple treatment options, answered patients' questions, presented treatment benefits and risks, asked about the patient's preferred treatment, and made a recommendation. We calculated the frequency with which patients and coaches reported SDM behaviors (i.e. responded yes, all, or a lot) for each item, using Binomial and Chi-square tests to compare frequencies.

RESULTS

SDM coaches collected 131 post-visit surveys (response rate = 69%). Patients reported doctors making recommendations more than soliciting their preferred choice (91% versus 66%, p<0.001). Patients heard benefits discussed "a lot"more often than they heard risks and side effects discussed "a lot"(78% versus 56%, p=0.003). Overall agreement between patients and coaches was 75%. In the 25% cases of disagreement, patients more frequently perceived SDM behaviors than did coaches (18% vs 7%, p<0.001), suggesting a possible bias. However, on the question of whether the physician solicited the patient's preferred treatment, more coaches said yes than patients (91% versus 74%, p=0.001).

CONCLUSION

We found possible measurement bias, in both directions, for patient reports of physician SDM behaviors. More work is needed on the psychometric properties of these items for reporting SDM behaviors. Some trends were consistent across raters, such as the tendency of physicians to discuss benefits more than risks, and to make a recommendation more often than asking for patient preferences.<br type='_moz' />

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37 POSTER SESSION TUESDAY

Evaluation of the Statin Choice decision aid in Spain

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BACKGROUND

The aim of this study was to assess the acceptability and suitability of a decision aid (DA) on perceived risk of heart attacks developed by the KER Unit (Mayo Clinic-USA) to promote shared decision making (SDM) in Spain.

DESIGN AND METHODS

Sample consisted of Spanish patients (n=11), health care providers (n=18), and Spanish health care experts (n=5). Qualitative (focus groups and semi-structured interviews) and quantitative (questionnaire) techniques were used to assess the reactions of participants to the Statin Choice DA. Research questions included a general appraisal of the DA and the exploration of adaptation needs for use in Spain.

RESULTS

Overall ratings of the DA were quite positive in all groups. The aim of involving patients in medical decisions was widely accepted for all participants as a way to improve health care.

Many patients find challenges in gaining a clear understanding of the options before them and the consequences associated with those options, particularly when that understanding involves the numerical probabilities of different outcomes. Participants considered that the Statin Choice DA provides useful information and can be helpful for patients to present accurate and unbiased information about the benefits and harms of the available treatment options in a transparent, easily understood fashion, and thus facilitates SDM.

However, some potential barriers for implementing these DAs in clinical practice were considered. The most often barriers identified were the time constraints, lack of applicability of the SDM based on patient characteristics and some health providers' resistances to implement SDM in the "real world".

CONCLUSION

In overall terms, participants show a great interest on patient centred care and SDM, and consequently on the use of KER Unit DAs in the Spanish National Health Service. Participants considered that the Statin Choice DA can enhance communication about the risks and benefits of statins and can improve patient risk perceptions. The interaction and discussions in the focus groups and semi-structured interviews have helped to identify key elements that could help to develop, assess and implement similar DAs in Spain.

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Evaluation of FIMDM shared decision-making programmes in Spain

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BACKGROUND

The aim of this study was to assess three programs developed by the FIMDM to promote shared decision making (SDM) on patients with type 2 diabetes, breast cancer, and herniated disc, respectively, for suitability in the Spanish National Health Service (NHS).

DESIGN AND METHODS

Sample consisted of Spanish patients (n=85), health care providers (n=77), and Spanish health care experts (n=13). Qualitative (focus groups and semi-structured interviews) and quantitative (questionnaire) techniques were used to assess the reactions of participants to the programs.

RESULTS

Overall ratings of the programs were quite positive. The aim of involving patients in medical decisions was widely accepted for all participants as a way to improve health care. Patients showed a great interest for being well informed about their diseases, and consider this type of materials as useful tools that should be implemented in the NHS.

More specific remarks about the programs focused on their clarity, and its reliable information. The inclusion of real patients who share their experiences was highly valuated by all participants. However, the need for a cultural adaptation of the material was a topic that arose in all groups, although not always there was consensus about it. Generally, health care providers were more critical about this issue.

Beyond specific features that must be reconsidered to implement these decision aids (DAs) in Spain, participants remark the need for an individualized approach, in which patient' attitudes, informational needs, and cultural or socio-demographic characteristics must be carefully assessed to optimize the SDM process.

CONCLUSIONS

In overall terms, participants show a great interest on patient centred care and SDM, and consequently on the use of DAs in the NHS. However, they think that some modifications are needed to improve the acceptability and usefulness of these materials. On the other hand, several barriers to its implementation have been considered, not only concerning the paternalistic view of the doctor-patient relationship still predominant in Spain, but also economic and organizational aspects of the functioning of the Spanish NHS.

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65 POSTER SESSION TUESDAY

Barriers and facilitators to implementing shared decision making in clinical practice: a systematic review

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BACKGROUND

The shared decision making (SDM) model between patient and health professional is gaining importance within the healthcare system. Despite the positive assessment that is given to SDM, this model has not been broadly implemented in clinical practice. This review aims to provide knowledge on the barriers and facilitators influencing the implementation of SDM in routine clinical practice, existing or not a decision aid (DA).

DESIGN AND METHODS

A systematic review was developed using the Medline, Embase, Cinahl and PsychInfo electronic databases, from December 2006 to June 2010. It was considered studies with quantitative and qualitative methods, excluding economic evaluations, narrative reviews, case studies and expert consensus.

Studies with an intervention based on a SDM program (with or without a DA) were included. Regarding outcome measures, studies that assessed perceived barriers and/or facilitators to SDM were included. In order to classify barriers and facilitators it was considered the taxonomy used by Légaré et al. (2008).

RESULTS

A total of 8553 references were considered, and nine articles were eventually included. The most often barriers identified were 'lack of applicability of the SDM based on patient characteristics', 'time pressure' in clinical practice, 'complexity' to understand and implement the SDM process, 'lack of resources', 'lack of familiarity', 'lack of applicability based on the clinical situation', 'lack of expectations based on the health care process', and 'patient preferences'. In relation to the facilitators were identified more often the expectations regarding the 'process of health care", the 'compatibility' within the 'factors related to the SDM as an innovation', and facilitators related to 'saving of time'.

CONCLUSIONS

The results obtained in this review are in line with Lègarè et al. (2008), especially those related to "patient characteristics"and the "lack of time"as major barriers to the SDM implementation.

It is necessary to take into account the constraints of time available for some professionals, which is a widespread problem in health care, especially in public services.

271 SYMPOSIUM PARALLEL SESSION 1

Using theory to guide the design and evaluation of value clarification techniques in healthcare

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BACKGROUND

Patients facing consequential decisions, where different options serve conflicting goals (e.g., lengthening survival versus minimizing side effects), are expected to have labile or non-existent preferences. Consequently, preferences need to be constructed or further clarified in the process of treatment decision making if they are to be incorporated in treatment decisions. To date, interventions to support preference construction or specifically, values clarification exercises (VCE), have often been designed without explicit reference to theory. Informing the design of VCEs is helpful in at least two ways. First, theories aim to explicate the mechanisms by which outcomes are achieved and the mechanisms postulated help to shape the design of the VCE. Second, the postulated mechanisms help the researcher to know what outcomes are relevant to assess, in order to assess the impact of VCEs.

METHODS

This talk will review a number of descriptive process theories of lay individual decision making and theories which describe the valuation process in decision making. The selection of theories was conducted regardless of whether these were stated to have been used in designing interventions to facilitate preference construction.

RESULTS

A number of theories were identified which share commonalities but also differ in how they conceive the process of preference construction. These theories suggest the early selection of a promising alternative, the relevance of the perspective one takes towards the options on offer, and the timeline for evaluating the effects of the intervention.

CONCLUSIONS

The impact of the theoretical stance one takes in the design of values clarification exercises will be discussed as well as its effect on one's choice for evaluative measures.

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48 POSTER SESSION MONDAY

Shared decision making: prostate cancer patients' appraisal of treatment alternatives and oncologists' eliciting and responding behavior, an explorative study

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BACKGROUND

Patient appraisals, i.e. utterances that reflect an evaluation of treatment aspects or alternatives, constitute a core element in definitions of shared decision-making (SDM). The aim of this study was to explore type of appraisals and radiation oncologists' preceding and responding utterances.

METHODS

Two coders independently rated videotaped initial visits of 25 consecutive early-stage prostate cancer patients to one of ten radiation oncologists. Coders labeled appraisals (type) and surrounding radiation oncologists' utterances using qualitative methodology. The Decision Analysis System for Oncology (DAS-O) was used to reflect radiation oncologists' essential SDM skills.

RESULTS

With 19/25 patients, a decision was reached. Treatment benefits were discussed with 15/25 patients and treatment side effects with 20/25.

Patients voiced 67 appraisals (median/visit=2; range, 0-11). Half of appraisals were favorable and a quarter was unfavorable toward treatment options. One-fifth of appraisals referred to explicit tradeoffs between benefits and side effects of options.

One-third of appraisals followed explicit or implicit clinician invitations; 58% followed clinician information. Clinicians approved almost half (43%) of appraisals, or contested, ignored or highlighted them.

CONCLUSIONS

Patients do not often voice appraisals. More fully informing patients about options may help them weigh better the information and increase the number of appraisals they express. Radiation oncologists did not usually explore appraisals. They most often legitimized appraisals, thereby helping patients to feel good about the decision. Exploring appraisals may help patients in forming more stable preferences, thus benefiting patients in the long run. Clinicians should actively elicit patient appraisals and ascertain whether these seem well-informed before making a treatment recommendation.

128 ORAL PARALLEL SESSION 4

Triadic consultation communication: A systematic review of doctor-patient-companion communication and decision-making within medical encounters

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BACKGROUND

Patient companions can have a considerable impact on the dynamics and outcomes of medical encounters. Despite this, there has been a paucity of research into the doctor-patient-companion (triadic) relationship, and the impact of companions in medical decision-making in particular. The current systematic review aimed to elucidate and evaluate the nature of doctor-patient-companion communication, the roles of companions in medical encounters, and their influence on the medical decision-making process.

DESIGN AND METHODS

Relevant studies were identified via Medline, CINAHL, and PsycINFO databases (1950 to September 2010), reference lists of articles and reviews, grey literature databases, and consultations with experts in the field. Studies were included if they explored any aspect of doctor-patient-companion communication and/or decision-making in a medical encounter. Studies were excluded if the patients were unable to fully participate in the consultation (e.g. paediatrics). Two authors independently assessed study quality and extracted data.

RESULTS

A total of 6725 titles and 220 abstracts were identified with 50 studies included in the systematic review, which revealed five primary themes: 1) triadic consultation characteristics; 2) preferences and perspectives of triadic communication (patient, physician, and companion); 3) the roles of companions; 4) factors, processes, and patterns of triadic decision-making; and 5) the consequences of triadic participation. Sub-group analyses were conducted to determine differences across varying: consultation types; cultures; and patient/companion relationships. Any strategies to facilitate optimal triadic participation highlighted in the research literature were also noted.

CONCLUSION

Despite numerous triadic communication research studies; there is limited evidence regarding the role of companions in the decision-making process for life threatening illnesses such as cancer. Of the limited decision-making studies to date, most have been of exploratory nature with small sample sizes. This review found differences between various consultation types (e.g. general practice vs. oncology), across diverse cultures, and among different patient-companion relationships. Further research is needed to explore the roles, patterns, and optimal communication strategies for medical decision-making within the doctor-patient-companion triad.

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130 POSTER SESSION TUESDAY

Triadic decision-making within cancer consultations: Exploring the nature, role, and impact of companions

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BACKGROUND

Patient companions can have a considerable impact on the dynamics and outcomes of cancer consultations. However, there is very little known about the doctor-patient-companion (triadic) relationship, particularly the impact of companions within medical decision-making. Research into medical decision-making has focused almost exclusively on interactions between the doctor and patient (doctor-patient dyad), essentially ignoring the influence of the family (doctor-patient-family triad). The current study aimed to explore the nature of doctor-patient-companion participation in triadic communication, the roles of companions in medical encounters, and their influence on the medical decision-making process.

DESIGN AND METHODS

In-depth focus groups were conducted with homogeneous groups of cancer patients/survivors (n=30), companions (e.g. spouse, adult child, friend; n=30), and oncology nurses (n=10). Semi-structured interviews were conducted with oncology physicians (n=10). All participants had experience in cancer consultations which include a doctor-patient-companion triad. During the focus groups/interviews, participants were asked to describe their preferences for triadic decision-making and its patterns, and any strategies/recommendations for improved triadic communication and decision-making. All focus groups/interviews were audio-recorded, transcribed verbatim and managed using NViVo8 software. Main qualitative themes for each stakeholder group were identified using thematic analysis.

RESULTS

An in-depth qualitative description of the triadic communication and decision-making of patients, companions, oncology nurses, and physicians will be presented. Implications for clinical practice and decision-making theory will be discussed.

CONCLUSION

This study will provide preliminary qualitative data to further explain the influence of companions on medical decision-making within cancer consultations. The findings will inform the development of a triadic decision-making interaction analysis coding system, a triadic shared decision-making conceptual framework, and future interventions to improve doctor-patient-companion decision-making.

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147 POSTER SESSION MONDAY

Choosing The Best Treatment For Locally Advanced Non-Small Cell Lung Cancer (LA-NSCLC) With Two Patient Decision Aids Developed Using Different Multi-Criteria Decision Analysis (MCDA) Approaches.

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BACKGROUND

For selected patients with Stage IIIA3 (T2N2M0) LA-NSCLC, who have limited tumour metastasis in the mediastinum, deciding whether or not to undergo surgery is a complex decision with multiple dimensions. MCDA is an appropriate technique to help these patients and their doctors, within the context of hospital consultations, to 1) quantify the evidence available about these different dimensions, 2) quantify the patient´s preferences for them, 3) combine evidence and preferences into a unique score for each treatment alternative, 4) rate and rank the treatment alternatives from best to worst.

DESIGN AND METHODS

We developed, with two teams of clinicians from two hospitals of the Spanish National Health Service (SNHS), alternative MCDA models to help Stage IIIA3 LA-NSCLC patients choose between surgical and non-surgical treatment strategies. The first was an Analytical Hierarchy Process (AHP) model run on Expert Choice software, high in analytical content but also high in cognitive and elicitation effort. The second was a less effort-intensive and analytical decision matrix model implemented in Annalisa 2+ software. We evaluated the use of both models in proxy clinical consultations.

RESULTS

We will present both models in full. These models contain a hierarchy of criteria and sub-criteria, with the following main top-level dimensions: maximizing life expectancy, maximizing health-related quality of life, maximizing non-health related quality of life, optimizing the medical care process, and minimizing the financial difficulties associated with the disease/treatments. We will also present the judgmental ratings for 30 decision criteria and sub-criteria elicited from the medical doctors, weight elicitations from proxy patients for the top-level criteria, overall ratings and rankings of the decision alternatives, and results from the evaluation of the feasibility of developing and using these two different models in clinical practice.

CONCLUSIONS

To be presented at the conference.

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40 POSTER SESSION MONDAY

PRISMS: An intervention to promote patient participation in decision-making for self-management in long term conditions: development and feasibility testing

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BACKGROUND

Current policy emphasises self-management and supporting patient participation in decision-making as ways of improving patient outcomes and reducing costs in the management of long term conditions. However, achieving genuine patient participation in decisions is difficult. We describe the development of an intervention (PRISMS- Patient Report Informing Self Management Support) intended to promote participation by focusing the consultation on the patients agenda and support needs. PRISMS is a patient completed questionnaire that the patient shares with the health professional. It was developed to be used as part of a whole system approach to improving self-management (the WISE approach) and is a tool introduced as part of the WISE training package

DESIGN AND METHODS

The development of PRISMS was informed by the literature and piloted and evaluated using a range of qualitative methods, including focus groups of stakeholders; individual ‘think aloud’ and qualitative interviews; observation of training and transcripts of consultations in WISE pilot.

RESULTS

The formative evaluation informed the further development of PRISMS and its use as part of an intervention in an RCT. The main themes that emerged from the data related to content, process, operationalising and outcomes. A number of different functions of PRISMS were identified by patients including its use as an aide-memoire, providing a focus to consultations, giving permission to discuss certain issues, and providing greater tailoring for the patient. During the WISE training, clinicians identified how PRISMS could help them provide appropriate self care support and developed innovative ways to incorporate the tool in consultations.

CONCLUSION

There was evidence that patients and professionals found the PRISMS form acceptable and potentially useful. Tools like PRISMS may function as a platform for patients and practitioners to engage in exploration of the patients priorities within the consultation and it does encourage patient participation in decisions, which complements the more ‘task focussed’ aspects of consultations resulting from introduction of clinical guidelines and financial incentives.

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49 ORAL PARALLEL SESSION 2

The importance of Shared Decision Making (SDM) for various patient groups

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BACKGROUND

Though SDM is regarded as a central aspect of care, not all patients regard it as equally important. The aim of this presentation is to identify to what extent the importance that patients attribute to SDM varies according to the health problem at issue and/or demographic characteristics.

DESIGN AND METHODS

Analyses (t-test, analyses of variance) were undertaken on survey data regarding patient priorities on a wide variety of quality aspects in health care for the following groups: patients that underwent hip- or knee surgery, patients suffering from rheumatoid arthritis, spinal disc herniation, congestive heart failure or breast abnormalities (N’s 144 - 596). The data were collected with the Consumer Quality-index, a standardized instrument for measuring patient priorities and experiences.

RESULTS

In general patients regard SDM as more important than other quality aspects, except for the patients with breast abnormalities who score higher on all quality aspects. Overall, female patients and patients with a higher education level regard SDM significantly more important compared to men and lower educated patients ($p<.01$ and .05). Age and level of self-rated health did not lead to significant differences in the importance rating of SDM.

CONCLUSION

SDM is of substantial importance for all patients, although differences between patient (sub)groups are present. Gender and education level have a significant impact on the importance of SDM.

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112 POSTER SESSION TUESDAY

A Design Process for SDM: The PANDA Case

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BACKGROUND

The potential contribution of SDM to the improvement of the quality of decision making places it at the forefront of current Medical Decision Making (MDM) research. A primary objective of SDM is the elicitation of patient preferences in order to find the best treatment for a specific patient. However, recent findings show that patient preferences cannot be easily or accurately judged on the basis of communicative exchange during routine office visits. Thus, the motivation for this study is to improve SDM by facilitating the quality of patient-physician communication through decision support tools.

DESIGN AND METHODS

We develop a novel SDM design process, which integrates normative models and empirical evidence to support MDM. We demonstrate the applicability and value of the proposed process through the PANDA model, which addresses the specific medical context of prenatal testing.

The PANDA model is an analytical framework to recommend strategies for selecting prenatal screening (NT, early ultrasound, TT/QT and late ultrasound) and diagnostic tests (CVS or amniocentesis) and for deciding whether to terminate a pregnancy based on Down syndrome and NTD disease results. We empirically tested the model with structured interviews and questionnaires of pregnant women.

RESULTS

We successfully applied the proposed design process in the case of the PANDA model. The empirical test showed that (1) patients take more tests than recommended by the PANDA model - while most of the patients actually underwent almost all available tests, PANDA recommends no more than two tests per patient; (2) the test sequence has a significant effect on the model’s recommendation.

CONCLUSION

The proposed design process advances research and practice by offering a structured methodology for bridging context-normative-descriptive gaps, thus providing an avenue for developing decision support tools for specific contexts based on normative models.

In the specific medical context of prenatal testing, the identification of alternative tests is part of the physician’s task.

Choosing among alternatives and planning of the pregnancy supervision is the primary role of SDM, which can be assisted by the PANDA model.

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44 POSTER SESSION MONDAY

Shared decision making : observation of prostate cancer screening practices in family medicine.

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BACKGROUND

since the mid-1990's, the concept of shared medical decision making has imposed itself in anglo-saxon countries as an ideal to reach, particularly in cases of scientific uncertainty. In France the advantages of this model have been put forward by the High Authority on Health for example in the case when a practitioner suggests a prostate cancer screening.

How do French general practitioners suggest this screening ? Do they get involved in a process of sharing medical decision making with their patients ?

DESIGN AND METHODS

Direct observation of the interaction between doctor and patient. It was carried out by 13 students who observed GPs during their training session in general practice surgery. The trainees had to observe and note down in a grid 24 indicators characterising patient, screening modality, given information, and the nature of the dialogue preceding the decision to begin a prostate cancer screening.

RESULTS

Out of thirteen consultations observed, only one shows an obvious sharing of medical decision making. In the other consultations, the information provided is often too fragmented for the patient to make the decision his decision, thus, only four of them ultimately expressed their preferences. As for the doctors, five gave no information at all about cancer or its detection during the consultation. Only one asked his patient if he had understood the pieces of information which had been explained to him. There was no tool used to help the decision.

PERSPECTIVES

It would be interesting to see if some training on how to communicate the benefits and the risks would be agreed by practitioners, as well as the diffusion of techniques favouring the active participation of patients in shared decision making.

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105 SYMPOSIUM PARALLEL SESSION 6

Shared Decision Making as Significant, Potentially Disruptive Organizational Change

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BACKGROUND

Facilitated by the research and demonstration team at the University of Washington Department of Health Services, the clinical and administrative leadership of three major multi-specialty group practices (The Everett Clinic, MultiCare Medical Group, and Virginia Mason Medical Center) have piloted the implementation of shared decision making (SDM) and use of patient decision aids within one or more of their ambulatory care clinics.

DESIGN AND METHODS

Realizing that SDM involves significant cultural and organizational change, the organizations' leadership teams are using a set of conceptual principles to guide SDM implementation - shaped by the principles of behavioral economics. (1)

SDM implementation focuses on four critical processes in organizational and individual change-making:

- Signaling the commitment of clinical and administrative leadership to implement and sustain SDM over time (what Heath and Heath term "guiding the rider")
- Motivating behavioral change through improving the efficiency and satisfaction of provider-patient interactions ("motivating the elephant")
- Organizing the work to facilitate consistency and integrate SDM within daily clinical and administrative practice ("shaping the path")
- Re-framing the day-to-day work to overcome inertia ("status quo bias") in the organizational culture

The demonstration is based on a multiple case series. Documentation was conducted using semi-structured key informant stakeholder interviews, standardized patient questionnaires, and document review.

RESULTS

All three provider organizations have implemented SDM in varying degrees, and their differential progress on the four critical processes helps explain much of that variance.

CONCLUSION

For SDM to reach its full potential, SDM must receive visible priority within the strategic plan, be backed consistently by organizational leadership "champions,"and be integrated within daily clinical work routines. Value-based payment, rather than fee-for-service reimbursement, might also speed SDM implementation.

(1) Two scholarly contributions have been particularly influential in shaping implementation and the development of work flows and process maps for the clinics: (1) Heath C, Heath D. Switch: How to change things when change is hard. New York: Broadway Books, 2010. (2) Thaler RH, Sunstein CR. Nudge: Improving decisions about health, wealth, and happiness. New Haven, Yale University Press, 2008.

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117 SYMPOSIUM PARALLEL SESSION 6

The Impact of Organizational Culture on the Implementation of Shared Decision Making

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Symposium Title: “The Impact of Organizational Culture on the Implementation of Shared Decision Making”

Session Chairperson’s Name and Affiliation: Anne Renz, MPH, Department of Health Services, University of Washington, Seattle, WA 98195, USA

Number of Individual Talks: 3

Name & Affiliation of Presenters:

1. Anne Renz, MPH, University of Washington, Seattle, WA
2. Dominick Frosch, PhD, Palo Alto Medical Foundation Research Institute, Palo Alto, CA
3. Leigh Simmons, MD, Massachusetts General Hospital, Boston, MA

Titles of Abstracts From Each Presenter:

1. Shared Decision Making as Significant, Potentially Disruptive Organizational Change - A. Renz
2. Creating a paradigm shift in health care practice: Lessons learned facilitating culture change to implement patient decision support interventions - D. Frosch
3. Overcoming Inertia: How Physician Training and Feedback on Performance Can Increase Use of Decision Aids - L. Simmons

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63 POSTER SESSION MONDAY

Effectiveness of strategies to communicate cardiovascular risk to patients and general population: A systematic review

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BACKGROUND

Cardiovascular disease (CVD) is the leading cause of death worldwide. Among the risk factors for developing CVD identified by medical research are the levels of blood lipids, hypertension or the presence of diabetes, and those modifiable behavioral factors such as diet, insufficient physical activity or consumption of tobacco and alcohol. Health recommendations prioritize implementation of primary prevention programs that promote risk reduction, which could significantly reduce prevalence of CVD and associated mortality.

The objective of this review is to identify studies evaluating the effectiveness of strategies to communicate cardiovascular risk to patients and general population, in order to produce changes in lifestyle and the application of appropriate medical treatment towards reducing such cardiovascular risk.

METHOD

Electronic databases and lists of references were consulted up to June 2010. Randomized controlled trials (RCTs) or comparative studies were included, that evaluated interventions consisting of cardiovascular risk communication in a personalized manner, either alone or in conjunction with decision aids or behaviour change programs.

RESULTS

After adding the references identified by manual search, 23 references were finally included, referring to 19 RCTs (seven of them were clusters RCTs).

The included studies show mixed effects on cardiovascular risk reduction, with about half of the studies obtaining statistically significant effects for intervention in risk communication. Regarding risk factors, the most consistent finding has been found in the reduction of blood lipid levels. All these effects were of low intensity. For the remaining outcomes (blood pressure, BMI, risk perception, beginning and / or adherence to medical therapy, changes in lifestyle and variables related to decision making, emotional reactions) the results are inconsistent.

CONCLUSIONS

Interventions in cardiovascular risk communication show inconsistent results. Positive findings are restricted to primary prevention interventions, and seem more intense in participants with higher baseline risk. There have been no negative effects on health outcomes, emotional responses or decision-making processes of the participants.

More research is needed to conclude to what extent positive effects are due solely to the assessment process and risk communication, or to the implementation and intensity of additional educational or counselling interventions on changes in lifestyle.

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184 POSTER SESSION TUESDAY

Why do women opt for or refuse external cephalic version in breech position

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BACKGROUND
External cephalic version (ECV) is a relatively simple and safe maneuver and a proven effective approach in the reduction of breech presentation at term and consequently, the number of cesarean deliveries. There is professional consensus that ECV should be offered to all women with a fetus in breech presentation, but only up to 70% (range 20-70%) of women undergo an ECV attempt. The aim of the study was to determine arguments women use to opt for or refuse an ECV attempt and to identify facilitating factors to help deciding for an ECV attempt. The study was done as part of a major study to determine factors associated with a substandard implementation of ECV in the Netherlands in order to develop a new implementation strategy to stimulate more women opt for an ECV attempt.

DESIGN AND METHODS
To identify determinants at a client level, semi-structured interviews were held with women eligible for an ECV attempt. The answers were structured and analyzed in MAXQDA, a validated software program for qualitative data analysis. Both clients who had opted for an ECV attempt as clients who refused an ECV attempt, were interviewed. Clients were recruited in primary as secondary care and from all parts of the Netherlands.

RESULTS
A total of 24 women, eligible for ECV, were interviewed. The patient characteristics are shown in table 1. The main reasons to opt for an ECV attempt were the ability to give birth vaginally, the ability to give home birth and positive stories from friends and family. The main reasons to refuse an ECV attempt were fear in the broadest sense, the preference to have a planned Caesarean, cultural backgrounds, influence of religion, stories on the Internet about serious harm to the fetus during breech delivery and a lack of knowledge. Women indicated that they would like to receive more objective information about ECV.

CONCLUSION
Women eligible for an ECV attempt form their decision to opt for or to refuse an ECV attempt on, not always evidence based, information they receive. Women want to be better informed.

KEYWORDS
breech presentation; external cephalic version; determinants; implementation.

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189 POSTER SESSION TUESDAY

Implementing a Breast Cancer Treatment Patient Decision Aid in a Medically Underserved Population in Texas

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Implementing a Breast Cancer Treatment Patient Decision Aid in a Medically Underserved Population in Texas

BACKGROUND
Most patient decision aids rely heavily on written information and require patients to have above average literacy skills, a potential barrier for the medically underserved. Individuals with limited literacy are restricted in their ability to make appropriate health decisions and to act on health information. We developed the “A Patchwork of Life”(PLife) patient decision aid to assist medically underserved women with limited literacy in making a breast cancer treatment decision. The PLife is computer-based, culturally and linguistically appropriate learning environment that involves two key components, soap opera segments and related learning modules designed to support breast cancer (Stages I-IIIA) surgery decision-making and to encourage communication about treatment decision with providers, relatives and friends. Specific aims of the project are to: 1) implement and evaluate the PLife program at one of the National Community Cancer Center Program (NCCCP) sites, in Austin Texas; 2) determine the effectiveness of PLife in assisting patients make informed breast cancer treatment decisions, and; 3) evaluate patients’ perceptions of the usefulness of the intervention for aiding in their decision-making.

DESIGN AND METHODS
We will recruit 48 patients diagnosed with Stage I-IIIA breast cancer. Patients will be identified through pathology, medical records, and physician referrals. Those who consent will complete all baseline assessments in English or Spanish before implementation of PLife. Measures to be collected at baseline and 2-week follow up include breast cancer

knowledge, decisional conflict, and treatment preferences. A Patient Navigator will arrange for a convenient time for the patient to view the program. Immediately after viewing the program, patients will answer a questionnaire rating the program. Follow-up data collection with patients will take place via phone 2-weeks after viewing the program.

EXPECTED RESULTS AND CONCLUSIONS

The proposed project will enable the NCCCP site to significantly enhance breast cancer education, awareness and navigation for the underserved breast cancer patients who currently do not receive education or navigation services utilizing a tool that has been proven to assist patients with limited literacy in making informed breast cancer treatment decisions.

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129 EXHIBITION MONDAY

Shared Decision Making National Resource Center

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Mayo Clinic, ROCHESTER, United States of America

Name and affiliation of exhibitor:
Shared Decision Making National Resource Center, Mayo Clinic, Rochester, Minnesota, USA

Name of decision support material:
Wiser Choices Program decision aids and Mayo Clinic patient and provider education material

Short description of decision support material:
The Shared Decision Making National Resource Center is a new initiative at Mayo Clinic, spearheaded by the Wiser Choices Program at the Knowledge and Evaluation Research Unit and the Mayo Healthcare Delivery Research Program. The primary objective of the Center is to advance patient-centered medical care by promoting shared decision making through the development, implementation, and assessment of patient decision aids (DA) and shared decision making interventions. We propose to exhibit all DAs we have designed at the Center, many of which have been tested in usual clinical settings in the context of randomized trials and are at various stages of implementation. Examples include: Diabetes Medication Choice cards, which help patients compare and choose among available diabetes medicines using issue cards; the Chest Pain Choice DA, which uses a pictograph to provide information about risk so patients and clinicians can decide whether a low-risk patient presenting to the emergency department with chest pain should stay in the hospital for observation and testing or go home and follow up with a primary care or cardiology provider; and decision aids that present risk of outcomes using pictographs without and with intervention to prevent coronary events (Statin Choice, Aspirin Choice, Rosiglitazone Choice), death after myocardial infarction (AMI Choice), postoperative complications (Periop Smoking Choice), and fragility fractures (Osteoporosis Choice). We will also exhibit the website of the Center in which we highlight the range of shared decision making interventions we support, the institutional partners involved and their contributions (patient education, clinician communication training, social media, innovation, and health policy), the Center's involvement in the Minnesota Shared Decision Making Collaborative, and the role of patient advisory groups. Attendees will be able to review the materials, meet and discuss with Center staff, become familiar with the website content and Center offerings, and arrange to visit and collaborate with the Center.

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165 POSTER SESSION TUESDAY

Conducting a multi-site cluster-randomized practical trial of decision aids: Lessons learned

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BACKGROUND

There has been a recent increase in legislation and policy promoting patient participation in decision making and use of decision aids into practice; however, there has been little practice-based research focused on how to embed decision aids into the routine of busy clinical practices. A pilot study was conducted to assess the feasibility of a multi-site cluster-randomized practical trial within rural clinical practices. We present lessons learned from challenges encountered in the study. We aim to increase awareness of necessary facets for recruitment in this type of trial.

DESIGN AND METHODS

Our aim for the study was to obtain an estimate of the impact of patient decision aids versus usual care on measures of patient involvement in decision making and diabetes control. We randomized eight participating practices to implement either Statin or diabetes medication decision aids with eligible patients; each site also practiced usual care. Adult patients of participating clinicians were considered eligible if they had type 2 diabetes with stable but inadequate glycemic control (HbA1c > 7.3) and were on maximum dosages of current medications. Central study coordinators screened for eligible patients from listings of participating clinicians' upcoming appointments with diabetic patients. Since the study sites were small rural clinics, we did not have staffing capabilities to recruit eligible patients at their appointments. Study coordinators contacted potential patient participants by telephone and traveled to sites to consent patients.

RESULTS

Our goal was to enroll 240 patients over a nine-month period. After screening a total of 671 patients, 121 were found to be eligible for the study, with 48 patients (20% of goal) enrolled. Of the 73 eligible patients who were not enrolled, 36 declined to participate, 25 were not contacted, and 12 were not consented.

CONCLUSION

To be successful in reaching enrollment goals, studies to investigate translation of research into practice should prepare for potential obstacles according to site demographics. A close look at eligibility criteria in comparison with patient population of clinics is needed to anticipate how the criteria will impact patient recruitment. Consideration should be given to study coordinator availability and logistics for recruitment at sites.

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164 EXHIBITION TUESDAY

Using the Patient Decision Aids Web site to Support Implementation

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Successful adoption of shared decision making (SDM) requires interventions such as patient decision aids (PtDAs), training of healthcare professionals, and SDM performance feedback. The Patient Decision Aids Web site (http://decisionaid.ohri.ca) provides access to these resources and more to facilitate implementation of patient decision aids and enhance patient involvement in health decisions. In 2010 the site had nearly 49,000 unique visitors, over 654,000 page views and over 192,000 downloads.

The purpose of this exhibit is to display some of resources available on the Web site and discuss their use in facilitating implementation of SDM.

Patient Decision Aids: search for publicly available PtDAs using the A to Z Inventory, find decision aids in development using the Complete Inventory, or register PtDAs in the Decision Aid Library Inventory (DALI).

The Ottawa Personal Decision Guide is a generic decision aid that helps people assess their decision making needs, plan the next steps, and track their progress in decision making for any health-related and/or social decisions (available in English, French, Spanish and Japanese). It can also be used by health professionals when supporting patients making a decision.

Training for health professionals: access to the Ottawa Decision Support Tutorial (ODST) and information on workshops. The ODST is an online training program based on the Ottawa Decision Support Framework (ODSF) and supported with evidence from client and practitioner needs assessments and trials evaluating patient decision aids (available in French and English). Since May 2007 it has been completed by over 1000 people, many of whom have provided positive feedback and recommend it to others.

Performance feedback: the Decision Support Analysis Tool is a valid and reliable instrument for appraising the quality of the patient-practitioner interactions (available in French and English). Findings can be used to audit the quality of decision support and provide feedback to practitioners for enhancing their skills.

The Web site also includes a PtDA development toolkit, an implementation toolkit, evaluation measures (e.g. decisional conflict, preparation for decision making, self-efficacy), the International Patient Decision Aid Standards (IPDAS) Collaboration, the Cochrane Systematic Review of Patient Decision Aids, and links to collaborators, news, and events.

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61 POSTER SESSION TUESDAY

Shared Decision Making: What clinician-level factors positively and negatively influence incorporation into practice?

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BACKGROUND

Although Shared Decision Making (SDM) is a clinically, ethically, and legally relevant model for the clinician-patient interaction, healthcare professionals have not widely adopted its use. We describe a means of evaluating clinician-level factors which influence physician receptivity to SDM through: 1) qualitative content analysis of video recordings of clinical interactions, and 2) qualitative interviews with physicians who have participated in SDM in the context of two randomized trials (Montori 2011, Pierce 2010).

DESIGN AND METHODS

This study evaluates factors which influence physician receptivity to SDM in both acute and chronic care settings. Through qualitative content analysis, fifty video recordings (25 acute) of clinical interactions randomly selected from the experimental (SDM) arm of two randomized clinical trials will be analyzed. Independent observers will 1) assess dynamics associated with/without the occurrence of SDM, and 2) identify barriers and promoters to SDM. Additionally, physicians who participated in each of the two trials will be randomly selected and approached to be individually interviewed by a study investigator. These semi-structured interviews will be audio-recorded, transcribed, and de-identified to preserve physician anonymity. Video stimulated recall will be used to enhance physician recall of thoughts, feelings, and perceptions pertaining to SDM. Two investigators will review the transcriptions, then code and analyze for themes. Using the Normalization Process Theory we will seek to identify factors which add or detract from the adoption of SDM. Approximately 10-12 consenting physicians from each of the two randomized trials will be interviewed. Thematic saturation will define the true number of interviews conducted.

RESULTS

We will present results from ongoing analysis of fifty video interactions between clinicians and patients enrolled in two clinical trials. In addition, we will interview approximately 20-24 physician providers who have participated in SDM and summarize preliminary themes.

CONCLUSION

Clinician-level factors contribute to physician receptivity to SDM. Here, we will present themes from 50 clinical interactions and 20+ interviews with physicians who have participated in SDM trials which predict SDM incorporation and resistance.

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92 ORAL PARALLEL SESSION 6

A comparison of patient derived versus researcher generated attributes for an electronic decision aid on prostate cancer screening

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BACKGROUND

We conducted a pilot study with General Practitioners on the usefulness of using an interactive computer based decision aid, based on Annalisa 2.0, to assist patients in deciding whether to have a PSA test for prostate cancer. The next stage of the research was to evaluate this approach with patients. The overall objective of the study reported here was to assess the usefulness and quality of decision making using MyProstScreenAL amongst a group of men eligible for prostate cancer screening.

METHODS

The Survey

The decision to have a PSA test will be based on a range of factors that include the benefits, potential harms, costs and other factors associated with the process of screening. This study tested two different approaches to generating the electronic decision aid: the first approached fixed the attributes contained in the decision aid based on the published literature and expert opinion; the second approach offered respondents the same 5 attributes included in the first approach plus additional attributes, providing respondents with a much wider choices of attributes. Respondents were then asked to choose up to 8 attributes that were most important to them. The patient's selection of up to 8 attributes then formed the basis of the decision aid.

Setting and participants

A cross sectional survey of men's' preferences for prostate cancer screening was conducted using a random sample of men living in NSW. Half of the study sample was randomly allocated to the fixed attribute decision aid approach and the other half received the 'pick your own' attribute decision. All other aspects of the survey, including the assessment of decision quality, were identical.

RESULTS

This study is still in progress. Results will be reported and compared for each of the two study groups with respect to their screening choices and their self reported quality of decision making.

1. Cunich M, Salkeld G, Dowie J, Henderson J, Bayram C, Britt H and Howard K. Integrating evidence and individual preferences using a web-based Multi-Criteria Decision Analytic tool: an application to prostate cancer screening. The Patient - Patient Centred Outcomes Research (In Press - Accepted January 2011)

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187 ORAL PARALLEL SESSION 4

Training general practitioners in enforcing patients' own expectations in order to maximize health benefits: observed effects on communication in consultations.

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BACKGROUND

Shared decision-making (SDM) enhances patient participation in medical consultations. SDM is especially suitable in situations of clinical equipoise, i.e. when several treatment options exist and none of those has clear clinical preference above the others. Using SDM, patients are most likely to opt for a treatment of which they have positive expectations, which can be reinforced by the healthcare provider. Since enhancing positive outcome expectations leads to better health-related outcomes, combining SDM and positive reinforcement is likely to lead to improve patient outcomes. Although healthcare providers generally have favorable opinions about SDM, the actual use of this method in daily practice is still rare. In fact, training healthcare providers to use SDM in daily practice has been found to be difficult.

This study aims to test whether training for GPs on using SDM and positive reinforcement in situations of clinical equipoise does lead to changes in actual communication.

DESIGN AND METHODS

A training course to use SDM and positive reinforcement (PR) in a situation of clinical equipoise (non-chronic low back pain) was developed for a RCT in general practice, consisting of two training session of 2½ hours and feedback on videotaped consultations. Half of all participating GPs were randomly assigned to take part in the training. Twenty-eight GPs videotaped their consultations. Trained behaviors were systematically observed using an adopted OPTION-scale added with global measurement for patient participation. Both patient and doctor behaviors were taken into account. Comparisons were made between the trained group and the control group and between the trained group after the first and after the second training .

RESULTS

First analyses show that trained GPs more often use SDM and PR after the first training. Analyses of consultations after the second training is in progress and will be finished at the time of the conference.

CONCLUSION

The training of SDM and positive reinforcement leads to changes in GPs' communication, but not all trained behaviors were (consistently) used. We will discuss possible causes for these results, focusing on both GPs' skills or more to possible underlying motives in respect to using SDM and PR during the training.

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7 POSTER SESSION TUESDAY

Development and psychometric properties of the Shared Decision-Making Questionnaire - Physician Version (SDM-Q-Doc)

I. Scholl[1], L. Kriston[1], J. Dirmaier[1], A. Buchholz[2], M. Härter[1]
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BACKGROUND

Several instruments have been developed that measure the shared decision-making (SDM) process in a medical encounter from the expert observer's or the patient's viewpoint. Despite the call for measurement of both the patient's and the physician's perspective on SDM [1], there is still a lack of psychometrically sound self-assessment instruments to measure SDM from the physician's perspective. The objective of this study was to develop and psychometrically test a brief instrument for measuring Shared Decision-Making (SDM) in clinical encounters from the physician's perspective.

DESIGN AND METHODS

We adapted the patient-report 9-item Shared Decision-Making Questionnaire (SDM-Q-9, [2]) to a physician version (SDM-Q-Doc). The adaptation was performed by two of the authors (IS, AB). This physician version was tested in medical encounters between 29 physicians and 324 patients in German outpatient care. Analyses of acceptance, reliability, and factorial structure were performed.

RESULTS

The SDM-Q-Doc showed high acceptance by the physicians (proportion of missing values <7%). Item discrimination parameters were above .4 for all but one item. Item difficulties ranged between 3.52 and 4.34 on a scale from 0 to 5. Internal consistency showed a Cronbach's α of 0.88. Confirmatory factor analysis supported a one-dimensional structure of the construct.

CONCLUSION

The results of this study corroborate reliability and acceptability of the SDM-Q-Doc in measuring the physician's view on the SDM process in medical encounters.This is, to our knowledge, the first psychometrically tested scale to measure the physician's point of view.

REFERENCES

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[2] L. Kriston, I. Scholl, L. Hölzel, D. Simon, A. Loh, M. Härter (2010). The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. Patient Education and Counseling, 80:94-99.

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8 ORAL PARALLEL SESSION 1

Construct validity of the 9-item Shared Decision-Making Questionnaire (SDM-Q-9)

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BACKGROUND

The 9-item Shared Decision-Making Questionnaire (SDM-Q-9) measures Shared Decision-Making (SDM) in clinical encounters from the patient's perspective. It was developed and revised in a theory-driven process with several steps. It has been shown that the SDM-Q-9 is a reliable and well accepted instrument, with both high face and factorial validity [1]. The aim of this study was to analyse the construct validity of the SDM-Q-9 by comparing it to the OPTION scale. We expected a moderate correlation between the two instruments.

DESIGN AND METHODS

Data were collected in a cross-sectional study in 21 outpatient care practices in Hamburg (Germany). 63 consultations were audio-taped, transcribed, and evaluated by two trained raters using the OPTION scale. Patients completed the SDM-Q-9 after the consultation. To analyse the construct validity of the SDM-Q-9 the correlation (Spearman's Rho) between the patient (SDM-Q-9) and expert ratings (OPTION Scale) was calculated. In addition, subgroup analyses were performed.

RESULTS

The correlation between the total scores of both instruments was weak with a Spearman correlation of r =.19 and did not reach statistical significance (p =.138). Subgroup analyses (regarding health problem, age, sex, education) revealed no correlations in some subgroups (e.g. consultations on type 2 diabetes) and small to moderate correlations in other subgroups (e.g. patients above the age of 65) without reaching statistical significance.

CONCLUSION

The hypothesis of a moderate correlation between the SDM-Q-9 and the OPTION scale could not be confirmed. Construct validity of the SDM-Q-9 could not be established by the use of the OPTION-Scale. Possible reasons are low variance due to ceiling effects of the SDM-Q-9 and floor effects of the OPTION scale that may inflate correlation analyses. Furthermore the correlation may be weaker then hypothesised. However the study was underpowered to test for a small correlation. The study results can also be interpreted as indicator that patients and external observers have substantially different perspectives on SDM in clinical encounters.

REFERENCE

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9 **ORAL PARALLEL SESSION 4**

Comparison of patients' and physicians' views on the decision-making process in medical encounters

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University Medical Center Hamburg-Eppendorf,
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BACKGROUND

The interaction between physician and patient is one of the basic requirements for shared decision-making in medical encounters. Up to date, only few studies have focused on the agreement between physicians and patients on the content, the process or the outcomes of clinical encounters, indicating discordance of perceptions. Little research examines and compares physicians' and patients' perceptions of the decision-making process in particular. The aim of this study was to investigate the concordance between patients' and physicians' views on the decision-making process in medical encounters.

DESIGN AND METHODS

Data were collected in a cross-sectional study in 29 outpatient care practices in Hamburg (Germany). 324 outpatient medical encounters were assessed with the 9-item Shared Decision-Making Questionnaire (patient version [1], physician version [2], total scores range from 0-100). Mean and median scores for both instruments were calculated and groups were compared using Wilcoxon-test. Spearman correlation coefficients were calculated for the total scores of the scales and for corresponding items.

RESULTS

A comparison showed a statistically significant difference with the average physicians' rating being inferior to the average patients' rating (means 77.18 vs. 83.80; medians 80 vs. 90).The interrelation between physicians' and patients' overall rating of the decision-making process was weak with a Spearman correlation of r=.254 (P<.001). Correlation between single items proved to be similarly low with sometimes not even reaching statistical significance. The agreement was highest regarding item 1 ("made clear that a decision needs to be made", r=.310) and lowest regarding item 8 ("selected a treatment option together", r=.058).

CONCLUSIONS

The results indicate certain, but low agreement between patients and physicians on how they perceive the decision-making process in the consultation. High total scores indicate that both physicians and patients consider the decision-making process to be shared.

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205 **ORAL PARALLEL SESSION 6**

Internet use and the use of web-based decision aids by general practitioners in Flanders

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BACKGROUND

An increasing number of patients are using the Internet to search for health-related information. Patients who use the Internet feel empowered in managing their health, ask more questions, are more involved in the consultation and in the decision making process about their treatment. Internet use has also raised some concerns. Patients may misinterpret information they find on the Internet or they might come across misinformation. This will result in new communication needs in practice.

DESIGN AND METHODS

The objective of this study is to explore the experiences and attitudes of general practitioners in Flanders with regard to patients' health related Internet use. In addition, we explored how often general practitioners directed their patients to health-related Internet sites, online support groups and online decision aids.

Fifty general practitioners were recruited through an umbrella organization and surveyed before a training session. The questionnaire included questions concerning demographics, experiences with patients' health-related Internet use, attitudes toward patients Internet use, use of web-based decision aids and referral to websites and online support groups.

RESULTS

All GP's give additional information to patients in the form of brochures, booklets or websites. Eighteen GP's direct patients to specific websites more than four times per month and another nineteen refer patients once or twice per month. This number is respectively eight and seventeen for referral to online support groups. Their main concern is the reliability of online health information. GP's find that web-based decision aids are ideal tools to fulfill patients' information needs through evidence based information and guide them in their decision making process. Web-based decision aids are not being used in Flanders because of the lack of availability but forty-two GP's are motivated to use online decision aids in the future.

CONCLUSION

Despite positive attitudes of GP's directing patients to online health information is not yet current practice in Flanders. A decision aid is an ideal tool to offer reliable evidence based information and the use should be promoted. Considering the on demand availability of the Internet, it is the perfect medium to facilitate the implementation of decision aids in practice.

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206 ORAL PARALLEL SESSION 5

Implementation and evaluation of a web-based decision aid in the decision making process of newly diagnosed patients with localized prostate cancer

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BACKGROUND

Different treatment options are available for patients with early-stage localized prostate cancer, including radical prostatectomy, external beam or interstitial radiotherapy, and for some patients 'watchful waiting' or 'active monitoring'. However, the optimal management remains controversial since efficacy and complication rates vary widely, even within one treatment modality. 'Preference-sensitive' choices such as these - so called because the best choice depends on the patients' personal values or preferences - call for a 'shared decision-making' style of counseling. This implies that both the practitioner and the patient exchange information and collaborate in the decision. To facilitate this process a web-based decision aid was developed.

DESIGN AND METHODS

The early-stage localized prostate cancer web-based decision aid contains information on the prostate, prostate cancer, the various treatment options and the probability of side-effects. The decision aid also guides patients through the different steps of the decision making process and stimulates them to make an explicit value clarification.

Newly diagnosed patients with localized prostate cancer, their partners and health care professionals were questioned about the quantity and quality of the information and the impact of the decision aid on the consultation, on the shared decision making process and on the treatment choice.

RESULTS

The information in the decision aid is judged helpful and the amount of information is found to be sufficient. Patients, partners and physicians indicate a positive effect on the consultation. Patients consider the decision aid as a perfect tool to prepare for the decision making process and to make a good choice in deliberation with their physician and family. Patients and partners feel more involved in the decision process. Finally there is more dispersion in treatment choice.

CONCLUSIONS

To conclude, this study showed that the use of the decision aid had a positive impact on the consultation and thus on the patient-physician interaction. This change of strategy, by which patients are more actively involved in the decision-making process, should be further implemented in daily practice.

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33 POSTER SESSION TUESDAY

Informed Consent for Clinical Trial Participation: what can be learnt from the IPDAS?

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BACKGROUND

Informed consent (IC) is regarded as a cornerstone of ethical healthcare research and is a requirement for most clinical research studies (ICH GCP 2009). Guidelines suggest that prospective clinical trial participants should understand a basic amount of information about trials in order to provide valid IC. However, poor participant understanding of the research processes, a lack of knowledge about the expectations and demands of trials and insufficient support when faced with the decision has been demonstrated across a range of clinical areas (Prescott 1999, Flory 2004). As such, the existing approach to obtaining IC for clinical trials is not optimal. We propose that the process could be improved by drawing on existing research in the fields of decision making and decision support interventions.

DESIGN AND METHODS

A systematic search was conducted for guidelines that pertain to IC for clinical trials. Using content analytic techniques, documents were analysed for content on information provision and decision support for clinical trial participation. The results were then systematically compared against the domains of the International Patient Decision Aid Standards (IPDAS) to identify areas of convergence and areas of divergence.

RESULTS

There was considerable overlap identified between the IPDAS and IC guidelines with respect to informational concepts e.g. describing the condition and describing procedures, and their positive and negative features etc. However, there were significant areas of divergence e.g. presenting probabilities in an unbiased way and ways to identify what matters most to prospective participants. Also, the development and effectiveness IPDAS concepts had negligible overlap with the guidelines.

CONCLUSION

The IC process for clinical trials needs to be improved and lessons could be learnt from the IPDAS and the decision making literature. Patients need to be better supported to make more informed decisions about their clinical trial participation, which are in line with their personal values and preferences. Better informed decisions about participation may result in patients being retained throughout the duration of the trial, as their decisions will be linked to more realistic expectations and be more in line with their personal values and preferences.

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81 POSTER SESSION MONDAY

How Do Patients and Clinicians Discuss the Burden Imposed by Treatment? A Videographic Analysis from the Diabetes Medication Choice Decision Aid Trial

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BACKGROUND

Optimal evidence-based care may overwhelm patients and contribute to poor therapy adherence. In particular, diabetic patients must enact new activities that may exceed their capacity to implement treatments. Failure of these therapies to fit into patients' lives leads to poor treatment fidelity and loss of healthcare value. Opportunity arises during the clinic visit for clinicians and patients to discuss the burden of treatment and engage in shared decision-making regarding options to lessen this burden.

DESIGN AND METHODS

We conducted a videographic evaluation of encounters in a randomized trial of decision aid for diabetes medications vs. usual care. These video recordings of primary care visits were analyzed to determine how often burden of treatment is discussed in the clinic visit and the efficacy of these discussions. Two reviewers independently reviewed eligible video recordings of encounters in both arms of the trial, classifying discussions of burden of treatment, the nature of the conversation, and the outcome of these discussions.

RESULTS

Of 46 video recordings (27 with the decision aid) available for analysis, 43 (93%) contained some discussion of burden of treatment. We identified 120 individual discussions of treatment burden (69% inter-observer agreement) with the most common regarding treatment effects and administration. Patients initiated the conversation about burden 55% of the time. Patients were more likely to bring up issues of administration (71%) and monitoring (75%), whereas clinicians were more likely to bring up issues of treatment effects (58%) and access (58%). Decision aid visits averaged 3 discussions per visit compared to 2.1 for control visits. Of these, 67% control and 71% decision aid-mediated discussions ended without clearly addressing ways to lessen or cope with burden of treatment.

CONCLUSIONS

Patients often bring up issues regarding burden of treatment with their clinicians. However, these concerns are rarely addressed in an effective way during the visit. Currently available decision aid tools enhance the ability of both patients and clinicians to initiate discussions, but additional tools may be required to help clinicians effectively address patient concerns.

204 POSTER SESSION TUESDAY

Why do at-risk women reject bisphosphonates for osteoporosis? A videographic study from the Osteoporosis Choice Decision Aid trial

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BACKGROUND

Despite access to effective, safe, and affordable treatment that can reduce the risk of osteoporotic fracture, many women at high risk for fractures choose not to initiate therapy, and, of those who do, up to 50% discontinue treatment in less than one year. This study sought to understand why at-risk women reject bisphosphonates even after being properly informed by their clinicians of the elevated risk of fractures and about the benefits, adverse effects, and costs of bisphosphonates using a decision aid.

DESIGN AND METHODS

We conducted a videographic evaluation of encounters of women with high risk (>20%) for fractures in a randomized trial of decision aid about bisphosphonates vs. usual care. Two reviewers independently reviewed eligible video recordings and verbatim transcripts in both trial groups, classifying patient expressed views about bisphosphonate use, clinicians reponse to those views, the overall nature of the converation, and relationship of these with final decisions and patient adherence at 6 months post visit.

RESULTS

Eighteen video recordings (12 with the decision aid) were eligible for analyses. We identified 39 patient reasons for and against bisphosphonate therapy (interobserver agreement, 78%, with complete agreement by consensus). Eleven patients rejected treatment offering 9 (average of 2 per patient) unique reasons against initiating bisphosphonates (most common: side effects 39%, distrust of medicines in general 33%); 10 of these patients did not offer any positive views on these medicines. Fifty eight percent of decision aid and sixty-six percent of control patients rejected treatment. When physicians conceded to patient views the final outcome was no bisphosphonate use.

CONCLUSION

Patients who participate in an informed shared decision making process sometimes express unfavorable views toward treatment with bisphosphonates even among patients at high risk of osteoporosis fractures. The use of a decision aid does not seem to significantly alter the frequency at which patients reject treatment. Patient centered osteoporosis care to reach these at-risk women may require a change in focus from drug programs to nonpharmacological strategies.

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104 SYMPOSIUM PARALLEL SESSION 4

The development and performance of decision quality instruments

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BACKGROUND

The importance of decision quality on the conceptual level is well established and has been validated by the IPDAS group. There is not consensus, however, on how to operationalize this construct into a reliable and valid survey instrument. Here we present the development process for a series of decision quality instruments (DQIs) and discuss their performance.

METHODS

The DQIs include two sets of decision-specific items that result in two scores: 1) decision specific knowledge (items are summed to produce a knowledge score); and 2) goals and concerns (items used to calculate a concordance score, or the percentage of patients who receive treatments that match their goals). To generate the concordance score we developed a multivariate regression model to predict treatment using the goals as independent variables and controlled for clinical characteristics. The model predicted probability is used to determine whether patients received treatments that "matched"those predicted by the model. There is no gold standard for these constructs, so the performance of the DQIs needs to be evaluated through hypothesis testing. We conducted three field tests (breast cancer surgery, hip and knee osteoarthritis, and herniated disc) with patients and providers to evaluate key criteria, including reliability, validity, acceptability and feasibility.

RESULTS

We report results for breast cancer surgery (patients n=440, providers n=88), hip and knee osteoarthritis (patients n=489, providers n=77), and herniated disc (patients n=183, and providers=98). In general, the instruments were acceptable to patients, with good response rates, and were feasible to complete, with low missing data. The knowledge scores had good retest reliability (intraclass correlation coefficients 0.70-0.81). The knowledge scores were able to discriminate between providers and patients, and between patients who had seen a decision aid and those who had not. The retest reliability of the individual goals and concerns varied (ICC=0.55-0.87). The concordance score varied by decision (73% to 89%). A brief version of each instrument demonstrated high reproducibility.

CONCLUSION

The development process resulted in DQIs that meet many criteria for high quality patient-reported outcome measures. Additional work is needed to improve the reliability of the goals and to further validate the concordance score.

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140 SYMPOSIUM PARALLEL SESSION 7

Impact of Implementing shared decision making for routine care in diverse settings

D. Shah
Mayo Clinic, ROCHESTER, United States of America

Symposium Chairperson: Nilay Shah, Mayo Clinic
Number of Individual Talks: 3
Presenter 1: Erik Hess, MD, Mayo Clinic
Presenter 2: Henry Ting, MD, Mayo Clinic
Presenter 3: Victor Montori, MD, Mayo Clinic

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141 SYMPOSIUM PARALLEL SESSION 7

The Chest Pain Choice trial: a pilot randomized trial of a decision aid for patients with chest pain in the emergency department

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BACKGROUND

Patient involvement in the choice of whether to undergo emergency department observation unit (EDOU) admission and urgent cardiac stress testing or follow-up with a physician on an urgent basis could increase knowledge, satisfaction with the decision-making process and safely decrease resource use.

STUDY DESIGN AND METHODS

We developed and tested Chest Pain Choice, a decision aid (DA) that communicates the pre-test probability of an acute coronary syndrome (ACS) within 45 days and makes management options (EDOU admission and stress testing or 24-72 hr follow-up with a physician) explicit to the patient. Patients with a primary complaint of chest pain and no known coronary artery disease who were being considered for EDOU admission were eligible. Patient-clinician pairs were randomized to intervention (DA plus risk estimate) or usual care (no DA, no risk estimate). We used patient surveys, videotapes of the encounters, and 30-day phone follow-up to assess the primary outcome (patient knowledge regarding their short-term risk for ACS), patient satisfaction, patient involvement in the decision-making process, safety outcomes (delayed or missed ACS defined as acute myocardial infarction, ventricular arrhythmia, cardiogenic shock, or cardiac/unknown death), and resource use.

RESULTS

There were 205 patients with a mean age (SD) 54.7 (11.8) enrolled in the trial. Compared with usual care patients (n=104), patients receiving the DA (n=101) less frequently decided to be admitted to the EDOU for cardiac stress testing (58% vs 77%, absolute difference=19%, 95% CI 6, 31), had a lower rate of stress testing (74% vs 90%, absolute difference=16%, 95% CI 6, 26), greater knowledge of their exact pre-test probability of ACS (25% vs 1%, absolute difference=24%, 95% CI 15, 33), reported greater satisfaction with the decision-making process (strongly agree: 61% vs 40%, absolute difference=21%, 95% CI 7, 33), and were more involved in the decision-making process (OPTION score: 51% vs 32%, absolute difference=19%, 95% CI 17, 21)

CONCLUSION

Use of a DA in low risk ED chest pain patients increased knowledge, increased satisfaction, and safely decreased resource use.

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142 SYMPOSIUM PARALLEL SESSION 7

Use of a Decision Aid for Patients Hospitalized with Acute Myocardial Infarction (AMI). A randomized control trial

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BACKGROUND

Patients are typically not provided with enough knowledge about their medications after a acute myocardial infarction. This often leads to patients making uninformed decisions about continuation of their medications. The goal of this study was to develop and evaluate the effectiveness of a decision aid for patients hospitalized with acute myocardial infarction (AMI) to promote shared decision making about the benefits and risks of taking evidence-based cardiac medications.

DESIGN AND METHODS

This trial was conducted in patients hospitalized with AMI. Patients (n=106) with AMI were randomized to the AMI Choice Decision Aid versus usual care. The decision aid described individualized risk of dying at 6 months using the GRACE risk score with and without a bundle of cardiac medications (Aspirin, ACE Inhibitor, Beta blocker and Statin). Patient demographic and clinical variables were prospectively collected. Surveys and videotaped patient-clinician encounters in the hospital were utilized to assess knowledge transfer, decisional conflict, patient involvement in the decision-making process (OPTION scale), and medical and pharmacy records to assess adherence to medications at 6 months, readmissions, and death.

RESULTS

Patients in the decision aid and usual care group had comparable age, 91% (n=48/53) of patients who received the decision aid found the tool helpful in reducing decisional conflict, compared to 87% (n=46/53) of usual care patients. Patients who received the decision aid were also more likely to be able to predict their 6-month risk of death within 20% of the correct value compared to those in the usual care group (77% vs 28% respectively). Patients in the decision aid group were highly involved in the decision-making process (OPTION score: 53%). All patients in both arms decided to take the AMI bundle of medications. Six-month adherence and readmission data collection is ongoing.

CONCLUSIONS

An innovative decision aid effectively engaged patients following AMI in shared decision-making about their cardiac medications through reduction of decisional conflict and improving patient knowledge.

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143 SYMPOSIUM PARALLEL SESSION 7

Use of a decision aid to improve treatment decisions in osteoporosis. The OSTEOPOROSIS CHOICE randomized trial

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BACKGROUND

Poor adherence to therapy, perhaps related to unaddressed patient preferences, limits the effectiveness of osteoporosis treatment in at-risk women.

DESIGN AND METHODS

We conducted a parallel patient-level randomized trial. Postmenopausal women had bone mineral density (BMD) T-scores of <-1.0, and were not receiving bisphosphonate therapy were eligible to participate in this trial. In addition to usual primary care, intervention patients received a decision aid (DA) -- including a pictographic tailored 10-year fracture risk estimate, absolute risk reduction with bisphosphonates, side effects, and out-of-pocket cost -- and control patients received a standard brochure. The main outcome measures for the trial were knowledge transfer, patient involvement in decision making, and rates of bisphosphonate use and adherence. Data came from medical records, postvisit written and 6-month phone surveys, video recordings of clinical encounters, and pharmacy prescription profiles.

RESULTS

100 patients (range of 10-year fracture risk of 6 to 60%) were randomly allocated to receive DA (n=52) or usual care (n=48). DA patients were more likely to identify their 10-year fracture risk (relative risk 1.8, 95% CI 1.03, 3.2) and their estimated risk reduction with bisphosphonates (relative risk 2.7, 95% CI 1.3, 5.7). Patient involvement improved with the DA by 23% (95% CI 13.6, 31.4). Bisphosphonates were started by 44% of DA and 40% of usual care patients. Adherence at 6 months was similarly high across both groups; the proportion of patients with >80% adherence was higher with DA (n=23 (100%) vs. n=14 (74%); P=0.009).

CONCLUSION

A decision aid improves the quality of clinical decisions about bisphosphonate therapy in postmenopausal women at risk of osteoporotic fractures by improving knowledge transfer and patient involvement. While the decision did not affect start rates, it may have improved medication adherence.

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82 ORAL PARALLEL SESSION 6

Evaluation of FIMDM shared decision-making programs for implementation in the Australian healthcare system

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BACKGROUND

The Foundation for Informed Medical Decision Making (FIMDM) has developed evidence-based patient decision programs, comprising a DVD and booklet, to help patients become involved in healthcare decisions. Use of these programs in other countries would represent significant cost and time efficiencies. We evaluated two programs: Living with diabetes: making lifestyle changes to last a lifetime; and Herniated disc: choosing the right treatment for you, to explore their relevance for people with these health conditions in Australia. We sought views on usefulness, content, format and implementation.

DESIGN AND METHODS

Semi-structured focus groups and interviews were held with convenience samples of health professionals and patients. A stakeholder workshop was then held with health professionals, consumers, policymakers and researchers with interests in diabetes, herniated disc or health information and communication.

Participants completed written surveys, providing individual feedback on the programs. They were then asked questions according to a discussion guide, with prompting as required until all ideas had been discussed. Focus groups, interviews and workshop discussions were audio-recorded and analysed thematically.

RESULTS

In total 48 people participated in the study. Eight health professionals and 10 patients provided feedback on the diabetes program. Six health professionals and 9 patients provided feedback on the herniated disc program. Fifteen participants attended the stakeholder workshop.

Overall, program content was viewed positively. Inclusion of patient stories and the information reliability were rated highly. Feedback suggested that the booklet and DVD are useful, addressing differing information preferences by patients. In general, the booklets were rated higher than the DVD, particularly the diabetes booklet, which was seen to contain more practical information than the DVD.

Patient feedback suggested a preference for reviewing the program individually and using the content as a prompt for discussion with a health professional. All groups emphasised the importance of ensuring that the programs do not replace direct contact and education from a health professional.

CONCLUSION

There is support for resources to assist patients making informed decisions about their healthcare. The need for FIMDM resources in Australia is likely to vary by program; availability of existing resources should be reviewed in order to avoid duplication.

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243 ORAL PARALLEL SESSION 7

A Decision Aid Intervention to Improve Decision Making and Intent for Coronary Heart Disease Risk Reduction.

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BACKGROUND

Promoting use of and adherence to efficacious medicines is integral to reducing coronary heart disease (CHD) events. However, it raises challenges for patients and physicians. To address these challenges, we developed a CHD prevention intervention that includes a decision aid (DA) and computerized tailored message library. In addition to testing the overall effects of the intervention on adherence and CHD risk, we tested the effect of the DA alone on several decision making outcomes.

DESIGN AND METHODS

To determine the effects of our intervention, we performed a randomized trial at one university internal medicine practice. After collecting baseline measures, we centrally randomized patients to either the intervention or usual care and saw them for two additional study visits over 3 months. At the second study visit, intervention participants presented 45 minutes early to a previously scheduled clinic visit, viewed the decision aid, and filled out a survey assessing their knowledge, accuracy of risk perception and decisional conflict. Control participants did not present early and received usual care (UC) from their physician. After their clinic visit, participants in both groups completed surveys assessing their discussions with their physician and intent for CHD risk reduction.

RESULTS

We enrolled 160 patients into our study (81 intervention, 79 control) and followed 96% to study completion. Mean age of participants was 63. 28% were female, 10% black, and 86% white. Mean predicted 10-year CHD risk was 11.3%. Immediately following the DA, participants' knowledge of effective CHD prevention strategies increased from 54% to 82% (+28%, adjusted p<0001) and their accuracy of their risk perception increased from 34% to 67% (+33%, adjusted p<.0001). The DA also decreased decisional conflict from 2.57 to 1.94 (-0.63; adjusted p<.0001). Compared with UC, the DA increased CHD prevention discussions with physicians (UC: 58%, DA: 89%; difference +31%, 95% CI 15% to 45%) and participants' intent to perform risk reducing strategies (UC: 43% DA: 63%, difference +21%; 95% CI 5% to 37%).

CONCLUSIONS

A computerized decision aid improved CHD decision making and patients' intent for CHD risk reduction. Its effects relative to more traditional adherence counseling interventions should be studied.

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23 ORAL PARALLEL SESSION 7

Supporting parental decision-making for MMR (combined measles, mumps and rubella vaccine): Evaluation of a web based decision aid

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BACKGROUND

In the UK public concern about the safety of the MMR vaccine continues to impact on coverage. Whilst the sharp decline in uptake has begun to level out, uptake rates remain short of that required for population immunity. Research consistently shows that parents lack confidence in making an informed MMR decision. We adapted a web based MMR decision aid developed in Australia for UK parents. This study aimed to test whether the MMR decision aid when compared with an MMR information leaflet and usual care improved informed parental decision-making and vaccine uptake.

DESIGN AND METHODS

A stratified, cluster RCT. 250 parents of a first child aged 3 to 12 months were recruited via 58 primary healthcare centres in the north of England. Healthcare centres were randomised to MMR decision aid or MMR information leaflet or usual care. Primary outcome (decisional conflict, scored 1 to 5) and secondary outcome (e.g. knowledge, attitudes) data were collected by postal questionnaire at baseline (T1) and 2-weeks post intervention (T2). Vaccine uptake for first dose

MMR is being collected from primary healthcare centres (to be completed March 2011).

RESULTS

194 parents completed both questionnaires. We analysed decisional conflict using ANCOVA. At T1 parents in all three arms reported levels of decisional conflict close to/above 2.5, associated with 'decision delay'. At T2 mean decisional conflict had decreased for both intervention arms to below 2, associated with 'implementing decisions'. Compared to the control and leaflet arms, decisional conflict at T2 was significantly reduced in the decision aid arm ($p<0.001$). Parents with higher decisional conflict at T1 had higher decisional conflict at T2 ($p<0.001$). Parents with higher anxiety at T1 had higher decisional conflict at T2 ($p<0.05$). Parents with more positive attitudes to MMR at T1 had lower decisional conflict at T2 ($p<0.05$). Analysis of the vaccine uptake data will be completed April 2011.

CONCLUSION

Decision aids are typically used to support decision-making for 'preference sensitive' decisions. MMR is an 'effective' decision yet the web based decision aid was found to be effective in supporting decision-making. The impact on vaccine uptake will be known in due course.

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134 SYMPOSIUM PARALLEL SESSION 6

Overcoming Inertia: How Physician Training and Feedback on Performance Can Increase Use of Decision Aids

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BACKGROUND

Since 2005, primary care providers at Massachusetts General Hospital in Boston, MA, have been able to "prescribe"patient decision aids (DAs) to their patients through the electronic medical record. The DAs include 23 DVD/booklets produced by the Foundation for Informed Medical Decision Making. The use of the DAs has been varied, with some providers using them often and others never using them. The purpose of this project was to evaluate the impact of a provider training session on utilization of decision aids in primary care.

DESIGN AND METHODS

The key components of the course are 1) an overview of shared decision making concepts, 2) a review of prescribing data at the group and clinician level, and 3) a viewing of a DA. Physician providers received one unit of continuing medical education (CME) credit. We examined two metrics: overall group rates of DA use and the number of providers who had prescribed at least one decision aid in the four weeks before and four weeks after the session.

RESULTS

We conducted training sessions with 15 primary care practices with over 200 physicians. We have baseline data for all practices and complete follow-up data for seven practices. For these seven practices, overall utilization increased significantly, from 57 prescriptions prior to and 113 prescriptions after the session ($p<0.001$). Six out of seven practices demonstrated an increase in their overall prescription rates after our intervention. The number of providers who prescribed at least one program also increased from 26/130 (20%) to 45/130 (35%) ($p<0.001$). Thirty-six providers increased their prescription rates, with the most significant increases noted for providers who had joined the practice within the prior year, and for providers previously known to be high prescribers. The increase in use was spread across several decision aids, not just the program used in the session.

CONCLUSION

A CME course that is designed to enhance provider understanding of shared decision making and to give personal feedback on usage of decision aids was successful in increasing overall prescribing rates, and in attracting more users. Whether the short term increase will be sustained needs to be evaluated.

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160 ORAL PARALLEL SESSION 5

Evaluating the use of an interactive, online decision aid (BresDex) to support women faced with surgery choices for early breast cancer.

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BACKGROUND

BresDex is a web-based decision aid (www.bresdex.com) for UK women choosing between mastectomy and breast conservation surgery (BCS) for early breast cancer. We evaluated the effects of BresDex on knowledge, deliberation and surgery choices, based on observations of its use in practice.

DESIGN AND METHODS

Observational web-log analysis of BresDex usage by women aged 29-80 years, newly diagnosed with early breast cancer from 4 UK breast clinics. Women were invited to use BresDex as they considered their surgery options. Online questionnaires (pre- and post-BresDex) assessed knowledge of breast cancer and the treatment options, readiness to make a decision (DelibeRate scale) and surgery intentions. One-way ANOVAs assessed knowledge, DelibeRate scores and intentions, pre- and post-BresDex.

RESULTS

62 women participated in the study, of whom 46 (74%) completed both questionnaires. Preliminary analyses showed wide variation in the use of BresDex; total length of time ranged from under 1 minute to 87 minutes (median 22 minutes). A statistically significant increase in DelibeRate scores was observed ($p<0.000$). Knowledge scores were high pre- and post-BresDex, with a small, non-significant increase ($p=0.168$). The number of women with no surgery preferences halved from pre- to post-BresDex ($n=10$ vs. $n=5$); a non-significant increase in the proportion intending to choose BCS and decrease in the proportion intending to choose mastectomy was observed.

CONCLUSION

BresDex may facilitate women's readiness to make a decision for surgery, supporting those unsure about which surgery to choose. Although not statistically significant, pre-existing high levels of knowledge improved after using BresDex, a pre-requisite for quality decision-making.

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161 POSTER SESSION MONDAY

Theory-based design and field-testing of a web-based decision aid to support women choosing surgery for breast cancer: BresDex

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BACKGROUND

BresDex (www.bresdex.com) is a web-based decision aid for women in the UK choosing surgery for early breast cancer, its design informed by the Theory of Planned Behaviour (TPB) and the Common Sense Model of Illness Representations (CSM). Usability and field-testing evaluation were undertaken using qualitative methods. Usability testing evaluated non-patient users' interaction with BresDex to identify necessary improvements. Field-testing evaluated use of BresDex with patients facing the decision.

DESIGN AND METHODS

Testing was carried out across 3 cycles of iterative development of BresDex with a total of 25 women; 8 women who had previously undergone breast cancer surgery, 6 women with no personal history of breast cancer and 11 women newly diagnosed with breast cancer. After each woman had used BresDex, semi-structured interviews were undertaken to explore ease of use, whether users felt able to consider the relevant information, and whether BresDex could support informed decision-making consistent with personal preferences. Framework analysis was used, guided by the extended TPB and the CSM. Data from each cycle was used to refine the prototype ready for the next stage.

RESULTS

BresDex appeared an effective support to decision-making and useful source for further information, particularly in clarifying attitudes, social norms and perceived behavioral control, and presenting consequences of decisions.

CONCLUSION

This study illustrates the use of the extended TPB and CSM in designing a decision aid to support women choosing breast cancer surgery, and how BresDex could support decision-making and serve as an additional information source to complement clinical team care.

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162 POSTER SESSION TUESDAY

Factors influencing the surgery choices of women using a web-based decision aid for early breast cancer (BresDex): the predictive utility of an extended Theory of Planned Behaviour and the Common Sense Model of Illness Representations.

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BACKGROUND

Many factors are known to influence women's surgery choices for early breast cancer, but few studies examine the influence of procedural, disease status and health outcomes simultaneously. The Theory of Planned Behaviour (TPB) and Common Sense Model of Illness Representations (CSM) are reported to be effective in predicting other health-related behaviours and provide a useful framework for understanding women's surgery choices for early breast cancer, providing complementary perspectives. We explored the predictive utility of an extended TPB and the CSM when applied to decisions to undergo mastectomy or breast conservation surgery (BCS) by women using a web-based decision aid (BresDex: www.bresdex.com) for early breast cancer.

DESIGN AND METHODS

Observational study of BresDex usage by women aged 29-80 years, newly diagnosed with early breast cancer. Women were invited to use BresDex as they considered their surgery options. Online questionnaires assessed views about treatment options (extended TPB) and breast cancer (CSM) post-BresDex and surgery intentions pre-and post-BresDex. The breast clinics provided data on the surgery the women underwent.

RESULTS

46 women completed the questionnaires. Logistic regression analysis will examine the utility of the independent variables specified by the extended TPB and the CSM to predict whether: i) women diagnosed with breast cancer intend to

have a mastectomy or BCS; ii) their intentions predict the surgery they go on to have. Data to follow.

CONCLUSION

The analysis will indicate the extent various procedural, disease status and health outcomes influence the surgery decisions of women with early breast cancer.

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90 ORAL PARALLEL SESSION 5

Parent-professional engagement and collaborative decision-making in acute care encounters

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BACKGROUND

Hydrocephalus is a long-term condition managed by the insertion of a shunt. Shunt malfunction can be life threatening. Identifying shunt malfunction requires effective parent-professional collaboration: parents need to recognise and respond to the symptoms of shunt malfunction in their child; health professionals need to recognise and integrate parents' information about their child's symptoms during clinical decision-making. This study investigated shared decision-making between parents and professionals during the diagnosis and treatment of suspected shunt malfunction in acute hospital admissions.

DESIGN AND METHODS

This survey employed mixed methods: audio-tape recording of the admission consultation; completion of a shared decision making questionnaire post consultation one-week post consultation; interviews one-week post consultation. In total there were 21 consultations involving 26 family members and 14 health professionals. Analyses employed were conversational analysis to explore the characteristics of parent-professional interactions, framework analysis to classify participants' perceptions of the interaction, descriptive analyses to assess variations between observed and perceived shared-decision making by participant type.

RESULTS

When a child with hydrocephalus is ill, parents and professionals focus on ruling out shunt malfunction as a possible diagnosis rather than making a choice between treatment options. Parents and professionals perceive effective collaboration as central to this task. However, parents and professionals differ when and how this collaboration should occur. Parents wanted to contribute to decisions about the likely cause of illness symptoms in their child but perceived their expertise was not always valued by health professionals. Professionals' orientated themselves to collaborating when eliciting illness symptoms and planning care. Evidence from the analysis of parent-professional interactions suggested there was some collaborative practice but tensions were evident within the interactions when parents disagreed with professionals' judgments. Health professionals were satisfied with the level they involved parents in care decisions, parents satisfaction was more variable.

CONCLUSION

The shared decision-making paradigm, where parents and professionals exchange treatment preferences to reach an agreement on a plan of care, is not useful to guide interactions in this clinical context. A model of collaboration is more appropriate where professionals engage and involve parents in decisions about the likely cause of illness symptoms.

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226 SYMPOSIUM PARALLEL SESSION 2

Shared decision making in people with dementia, their informal and professional caregivers

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BACKGROUND

People with dementia and their relatives are continuously faced with changes relating to care arrangements, housing, daily activities, financial and legal management etc. Up until now little attention has been paid to shared decision making (SDM) in the field of dementia care. The present study aims to gain insight into decision making processes within care networks of people with dementia in order to improve SDM within this setting.

DESIGN AND METHODS

Five members of 20 care networks of people with dementia are individually interviewed during three measurement cycles (six months intervals). A care network includes a person with dementia, two family caregivers and two professional caregivers. Interviews are semi structured addressing the following topics; changes in the situation, information needs, decisions made, persons involved, involving the person with dementia, considerations and implementation of decisions. Interviews are audio taped, transcribed verbatim and analyzed using Atlas.ti software.

RESULTS

Analyses of the first five networks (24 interviews) illustrate various aspects that affect decision making processes within networks of people with dementia. 1) Decisions are often taken in crisis situations, partly due to postponement of decisions by family caregivers and people with dementia trying to continue their usual life. 2) Professional caregivers tend to act upon scenarios they foresee from their professional experience. 3) Family caregiver burden is an important consideration for professionals in decision making. 4) Professional and family caregivers act strategically in informing the person with dementia to avoid stress in the person with dementia and the family caregiver.

At presentation the results of the first measurement cycle (20 networks, 100 interviews) are described.

CONCLUSION

Analyses of five networks show that decision making is often not shared. Shared decision making is complicated by stress in the person with dementia, caregiver burden and lack of anticipation on future decisions. In deciding what is best informal and professional caregivers form strategic coalitions around the person with dementia. Insight into common ways of decision making within this particular setting may be helpful to professionals in improving SDM in their daily practices.

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209 SYMPOSIUM PARALLEL SESSION 2

Symposium: Shared decision making in care networks of persons with dementia

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PRESENTATIONS

1. Shared decision making in people with dementia, their informal and professional caregivers
2. Involvement of people with dementia in the development and implementation of supporting ict applications: a systematic review of the literature
3. Developing a decision aid for people with dementia and their relatives: a study into Shared Decision Making in care networks

ABSTRACT

People with dementia and their relatives are continuously faced with changes relating to care arrangements, housing, daily activities, financial and legal management etc. Up until now little attention has been paid to shared decision making (SDM) in the field of dementia care. People with dementia and their family carers experience little involvement in the decisions that are taken over time. Professionals, particularly case managers, find it difficult to implement shared decision making in this patient group. The symposium focuses on decision making processes within care networks of people with dementia in order to improve SDM in this setting. The presentations describe the design and results of three studies of a research program on shared decision making in dementia care networks: (1) a qualitative longitudinal study involving semi-structured interviews with care network members on decision making processes (2) a review on the involvement of people with dementia in the development and implementation of supporting ict applications (3)development of a decision aid for people with dementia and their relatives and its implementation in shared decision making processes.

The research program will result in a dementia decision aid and provideSDM tools for care professionals and professional education relating to the care of people with dementia. Finally, the data will be used to improve theoretical models on shared decision making in care networks.

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229 SYMPOSIUM PARALLEL SESSION 2

Developing a decision aid for people with dementia and their relatives: a study into Shared Decision Making in care networks

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BACKGROUND

People with dementia and their informal caregivers are faced with various problems and decisions during many years. The decisions they have to make concern issues that affect housing, daily care, activities, social relationships, legal and financial matters etc. As informal caregivers often represent the person with dementia, the experiences of people with dementia are being neglected. For a better understanding of the experiences and preferences of people with dementia it is important to include them in shared decision making processes.

The current project focuses on the development of a decision aid to support shared decision making in persons with dementia and their informal caregivers. The decision aid aims to comprehend various life domains and to be of use to both persons with dementia and informal caregivers.

DESIGN AND METHODS

Data collection takes place by semi structured interviews during three measurement cycles (six months intervals). Interviews are held with 20 care networks (person with dementia, two informal caregivers and two professional caregivers). Furthermore websites, telephone services and helpdesks on dementia are studied and screened for Frequently Asked Questions. Finally the Dutch multi disciplinary guideline of dementia is used.

RESULTS

The results of the first measurement cycle will be presented. Preliminary data of five care networks (24 interviews) highlight the importance of the timing, content and form of information on dementia and care alternatives. All network members have their individual considerations regarding care and housing issues. The professionals focus on aspects of care, safety and autonomy with limited considerations of social context and life course.

The considerations and preferences of informal caregivers and persons with dementia often differ, but they share a focus on personal, relationship and normal consumer matters such as apartment characteristics.

CONCLUSION

Conclusions on the content of the decision aid will respect the perspective of all network members, in particular the person with dementia. Besides disease specific matters, people with dementia are concerned about similar consumer matters as healthy people. The decision aid should therefore take account of such daily life issues instead of focusing exclusively on disease and care related issues.

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227 **SYMPOSIUM PARALLEL SESSION 2**

Involvement of people with dementia in the development and implementation of supporting it applications: a systematic review of the literature

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BACKGROUND

People with dementia and their informal caregivers have to make many decisions on treatment, housing, daily care, activities, relationships, legal and financial matters etc. Most decisions are made for people with dementia rather than with them.

Research shows that people with dementia are able to express their preferences consistently, even in an advanced stage of dementia. The participation of people with dementia in the development process and implementation of supporting it applications may facilitate their usability and effect. Although various digital applications have been developed to support people with dementia and their (informal) caregivers an inventory of the experiences with the involvement of people with dementia is missing.

Our presentation addresses a systematic review of the involvement of people with dementia in the development and implementation of supporting it applications.

DESIGN AND METHODS

A systematic literature search is performed using the databases Pubmed, CINAHL, EMBASE, PsycINFO and Communication Abstracts. Reference lists are cross-referenced (backward, forward). Quantitative, qualitative and mixed methods studies are included with no restriction in date of publication or language. The methodological quality of the studies is independently reviewed by two researchers using criteria of the Cochrane Collaboration Back Review Group.

RESULTS

A preliminary analysis of the 226 abstracts show 44 potentially relevant studies that are screened on full text. Family caregivers and client representatives (e.g. representatives of a patient organization) were more often consulted in the process than people with dementia themselves. Further analyses focus on the strategies used to involve persons with dementia themselves and the results of these strategies.

CONCLUSION

Conclusions will focus on the strategies used to involve people with dementia in the development and implementation of supporting it applications and the results of these strategies. The results will be used in the development of a decision aid for people with dementia and their informal caregivers.

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156 **ORAL PARALLEL SESSION 1 / POSTER SESSION MONDAY**

1. Development of a multidomain decision aid for autochthonous and migrant clients with schizophrenia and their relatives

C.H.M. Smits, D. Meije, L. Hulsbosch

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BACKGROUND

Persons with schizophrenia have to take numerous decisions during many years. These decisions relate to various life domains, such as physical and mental health, housing, relationships, work, education and legal matters. Usually, relatives are heavily involved in the lives of their kin. The presentation describes the development of a web based decision aid that can be used by both clients and relatives. This new type of decision aid may facilitate the decision making processes by for example client and health care professional by providing information on the disorder, its effect on all life domains and available evidence based treatments and services (including self management and client driven care). Furthermore, users are facilitated in expressing their personal considerations concerning the available options.

In the Netherlands the prevalence of schizophrenia is high in some migrant groups (eg. Moroccan migrants). Cultural differences are thought to be the main explanation for the underrepresentation of migrant clients with schizophrenia in mental health care. For this reason the new decision aid takes cultural aspects into account.

DESIGN AND METHODS

A working group with representatives of professionals, scientists, clients and relatives develops the decision aid on the basis of (a) semi-structured interviews with clients, professionals and relatives (b) frequently asked questions in mental health help desks (c) multidisciplinary guidelines. The concept decision aid is tested in a laboratory setting (ten respondents) and in a field study in two mental health care setting (eight clinical situations).

RESULTS

At the time of abstract submission the concept decision aid has been tested in a laboratory setting. After adaptation, it will be tested in two mental health care settings (March April 2011).

CONCLUSION

The presentation will describe the development of the decision aid and the results of both evaluations. Current conclusions are that the concept decision aid appears to be feasible and is appreciated by its users.

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157 ORAL PARALLEL SESSION 1 / POSTER SESSION MONDAY

2. Development and evaluation of a decision aid for Turkish and Moroccan migrant clients with depression

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BACKGROUND

The prevalence of depression is high in Turkish and Moroccan populations in the Netherlands. Although many second generation depressed Turkish and Moroccan migrants are seen in mental health care, professionals indicate problems in providing appropriate care to these client groups. Research demonstrates a dissatisfaction with mental health care in these migrant clients. Information and interpretations of the disorder and the available treatment options in clients and professionals do not match. The present study describes the development of a web based decision aid for Turkish and Moroccan clients with depression. The decision aid aims to offer evidence based information on depression and treatment alternatives, highlighting topics that are of special interests to the user groups. Furthermore, a separate section stimulates the expression of personal considerations relating to treatment options.

DESIGN AND METHODS

A working group with representatives of professionals,researchers and clients developed the decision aid on the basis of (a) semi-structured interviews with professionals and Turkish and Moroccan migrant clients (b) frequently asked questions in mental health help desks (c) multidisciplinary guidelines. The concept decision aid was tested in a laboratory setting and in a field study in a mental health care setting.

RESULTS

The research data show that migrant clients have concerns relating to depression and treatment options that are both similar to and distinct from those of their autochthonous peers. The decision aid was implemented in 2009. A research trial focusing on the relationship between care professional and client, drop-out and depressive symptoms is in progress.

CONCLUSION

Our research data show that Turkish and Moroccan migrants with depression have some distinct information needs and considerations relating to depression and treatment options. A decision aid was shown to be feasible and was welcomed by clients in a pilot setting. The results of an ongoing effect study will show whether a decision aid has a significant impact on the relationship between professional carer and client, drop-out and depressive symptoms.

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168 POSTER SESSION MONDAY

3. Implementation of decision aids for migrant clients with mental health problems

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BACKGROUND

Decision aids aim to stimulate shared decision making in clients. Although there is evidence that they may increase involvement in and satisfaction with treatment, the level of implementation and actual use of decision aids appears to be lower than may be expected. Information on the factors facilitating and limiting the implementation of decision aids is missing. The presentation will focus on the results of several projects involving the implementation of web based decision aids for migrant clients with mental health problems.

DESIGN AND METHODS

Thus far, the implementation of a decision aid for Turkish and Moroccan migrants with depression and a decision aid for migrant and autochthonous clients with schizophrenia involved two strategies (1) publication on a national health information website funded by the Dutch government (2) dissemination of research findings in and training of mental health professionals. A third strategy involves dissemination amongst client (driven) organizations, training of client representatives (volunteers).

RESULTS

Publication of a decision aid on the internet does not guarantee actual use by clients. The relevant website is unknown to the user group and the exact internet pages are difficult to find. Furthermore, although second generation migrants have adequate Dutch language skills, they may still overlook language and culture specific information in Dutch language decision aids. Similarly, informing and training mental health professionals does not automatically lead to the use of decision aids in everyday care. Some professionals think they already use a shared decision making approach. Furthermore, mental health clients, particularly migrants, often do not expect to have treatment choices. The implementation involving client organizations is currently in preparation.

CONCLUSION

Implementation of decision aids for migrant clients with mental health problems demands more attention from those managing public information websites, mental health professionals and management. A long term strategy is needed that focuses on client demands and shared decision making at all levels involved: migrant communities, professional education, mental health professionals and organizations, public information support and client organizations.

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13 POSTER SESSION MONDAY

Decision Making strategies of French physicians and prescription of adjuvant chemotherapy in breast cancer

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BACKGROUND

Adjuvant chemotherapy is prescribed postoperatively in breast cancer with the aim of reducing the risk of disease progression to a metastatic state. Its benefit is uncertain, however. To manage this uncertainty, oncologists use various strategies to support the decision.

DESIGN AND METHODS

We have observed 50 consultations where adjuvant chemotherapy could be prescribed. These observations took place in 5 different cancer institutions, with 11 oncologists volunteers sensitized to the question of patient participation in decision making. Those observations were supplemented by 41 interviews with physicians to analyze their decision making strategies and compare their speeches to the practice observations'.

RESULTS

We have noticed an evolution from an individual decision-making form to a collective form, especially during multidisciplinary comities meetings called RCP in French. Those comities are based on national and international validated referentials. They also incorporate informal dimensions as the history of institutions and the symbolic capital of these individuals whose medical opinion shall prevail. In the event that RCP would not lead to a decision, several strategies are observed. Using statistics, referring to AOL , seeking to other medical opinions or discussing with the patient are the main ones. In this latter case, it is not only the decision that is shared between patients and physicians. Most of all, it is uncertainty which is said to be shared. This situation causes deep dissatisfaction among physicians and patients.

CONCLUSION

In analyzing the barriers to sharing medical decision, our research highlights the problems that have French physicians to manage risk and uncertainty. This issue should be linked to the French 'social ideal of zero risk' (Peretti-Watel, 2000). This ideal is well reflected in the injunctions of certainty set out by the patients to physicians during consultations.

Peretti-Watel P. Sociologie du risque, Armand Colin, 2000.

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54 POSTER SESSION TUESDAY

Better Decisions... Together: An Online, Social Media-Based Learning Lab

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BACKGROUND

The Foundation for Informed Medical Decision Making is a nonprofit organization created to ensure that health care decisions are made with the active participation of fully informed patients. In pursuit of this mission, we fund eleven primary care demonstration sites across the United States. These sites deepen our understanding of how to integrate shared decision making and decision aids into routine clinical practice.

In working with this geographically dispersed group, traditional communication approaches have been largely successful, impacting both policy and practice. At the same time, new technology has made it increasingly simple to take advantage of real time information sharing and a more global exchange with others who champion the ideas of shared decision making. With this in mind, the group created a publicly accessible community blog, called Better Decisions Together (www.betterdecisionstogether.org).

DESIGN AND METHODS

It was critical to choose a platform that met the following requirements:

- Simple to use
- Ability to support multiple contributors
- Option to have both private and public entries

After reviewing multiple options, Posterous was selected and a Foundation staff person was assigned the responsibility of supporting participants and encouraging use. Training was conducted to teach participants how to use the platform.

RESULTS

Since launching on August 5, 2010, we have observed:

- 20 posts by contributors at different sites
- Comments often posted in reaction to posts, creating a conversational forum
- 987 visits from 856 unique visitors in 15 countries
- 48% of visitors referred from other social networking tools

Initial months saw the most frequency in posting; fully adopting the new behavior has been challenging. Still, there has been a beneficial knowledge transfer of tools, experience, and approach.

CONCLUSION

A project-specific blog can act as an effective mechanism for both connecting geographically distant groups as well as informing external parties of daily activities. The transparency in development work is unique - often this is kept close to the vest, or is simply unavailable due to geographic dispersion, thus making this application of social media a potentially transformative tool. We believe the value extracted is worth additional efforts required to promote use.

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46 SYMPOSIUM PARALLEL SESSION 4

Prostate cancer decision support in a regional program: Implementing a decision aid for all patients

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BACKGROUND

Men with prostate cancer experience difficulty choosing between surgery, radiotherapies, and watchful waiting. Patient decision aids (DAs) are not routinely used. The purpose was to explore the process of implementing a DA for all men diagnosed with localized prostate cancer within a regional program.

METHODS

A descriptive evaluation of a systematic process for implementing DAs involved: a) appraising available prostate cancer DAs using international standards; b) identifying factors perceived to influence use of specific DAs in practice using 2 focus groups with prostate cancer survivors and interviews with 8 health professionals (surgeons, radiation oncologists, manager, nurse, social worker, cancer society representative); c) designing and implementing a database system to create summaries of patients' clinical and decisional information; and d) monitoring DA use.

RESULTS

Of 7 DAs, 2 had higher quality ratings. Participants in the focus groups and those interviewed agreed that these 2 DAs would be useful and rated them positively for: simple language, visual appeal, helping men consider values, being self-paced, and able to share with family. Concerns were: non-Canadian origin and need for more information on sexual effects and brachytherapy. Most recommended use of a DA at diagnosis; while some men suggested at biopsy. Perceived factors influencing their use were: men's preferred level of involvement, clinical trials recruitment, staff time to distribute, physicians' own agenda, accessibility, and physician/manager buy-in.

Since Fall 2010, one DA is used with all men newly diagnosed with prostate cancer. The first 20 men had 83% median knowledge and 19 felt informed, 17 clear values, 14 adequate support, and 10 felt sure. Eight preferred surgery, 6 radiation, 3 watchful waiting, and 3 were unsure. Six patients requested more information on brachytherapy, surgery, MRI, radiation, physician success rates. Barriers during implementation were challenges making changes to existing health information systems and physician concerns about probabilities in DAs given their perspective on outcomes experienced by their patients.

CONCLUSIONS

A DA was implemented using a systematic process to engage potential users and monitor barriers to its use. Despite barriers, the implementation is successful and lessons learned can be applied to other large-scale implementation projects.

125 SYMPOSIUM PARALLEL SESSION 3

Implementing a conceptual framework for interprofessional shared decision making in home care: A feasibility study

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BACKGROUND

A new interprofessional shared decision-making (IP-SDM) conceptual model was developed to conceptualize SDM beyond the client-physician dyad and recognize care being increasingly delivered by IP teams. Our purpose was to determine the feasibility of establishing an IP approach to SDM in homecare.

METHODS

Guided by the Knowledge-to-Action Framework, we are conducting a case study focused on a single IP homecare team in Quebec City. Sources of data include: one-on-one interviews with patients, family caregivers/surrogates and significant others, and administrators; a focus group with homecare health professionals; organizational documents; and government policies and standards. The interview guide for the interviews and the focus group explores current practices and clinical problems addressed in homecare; factors that influence the implementation of the proposed IP approach to SDM; the validity of the approach; and interventions to facilitate its implementation and evaluation. Based on the Theory of Planned Behaviour, a survey is being administered to 300 health professionals working in the homecare health services organization at baseline and end of the study. It measures the intention of health professionals to engage in an IP approach to SDM. Individual interviews and focus group are analyzed using content analysis and survey data will be entered into a database for comparative analysis.

RESULTS

When the study and our IP-SDM model was introduced to the team of 17 managers, there was strong interest in establishing an advisory team with 8 managers to facilitate the study. The managers fully approved the study and were enthusiastic about its success. Additionally they advised us on the target IP group for the case study and the example decision (placement versus remaining at home for aging patients losing their autonomy). Managers facilitated the administration of the TPB survey. Survey findings will be available by the end of February with case study data collection ongoing.

CONCLUSIONS

Wide-scale implementation of an IP approach to SDM within a homecare health service organization required active participation of managers from the organization to advise the research team. Findings will be used to inform a toolkit for implementing an IP approach to SDM in homecare.

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131 ORAL PARALLEL SESSION 7

Updated Cochrane Review of Patient Decision Aids: 86 trials show increased participation and higher likelihood of achieving informed, values-based decisions

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BACKGROUND

Patient decision aids (PtDA) prepare people to participate in health decisions that involve weighing benefits, risks/harms, and scientific uncertainty. The purpose was to update an earlier synthesis of evidence on effectiveness of PtDAs for people facing treatment or screening decisions.

DESIGN AND METHODS

Systematic review to December 2009 for MEDLINE, EMBASE, PsycINFO, Cochrane databases and September 2008 for CINAHL. Included were randomized controlled trials (RCTs) of PtDAs for treatment or screening decisions compared to usual care and/or alternate interventions. Two reviewers independently screened abstracts and extracted data. Results were pooled - mean differences (MD) and relative risks (RR) - using a random effects model.

RESULTS

This update added 31 RCTs for a total of 86. Compared to usual care, patients exposed to PtDAs showed: a) greater knowledge (MD 13.8/100; 95% CI 11.4, 16.2; n=26); b) lower decisional conflict related to feeling uninformed (MD -6.4/100; CI -9.2, -3.7; n=17) and unclear about values (MD -4.8/100; CI -7.2, -3.7; n=14); and c) reduced proportions of people who remained undecided (RR 0.6; CI 0.4, 0.7; n=9) and passive in decision making (RR 0.6; CI 0.5, 0.8; n=11). These relative improvements were smaller for simpler versus more detailed PtDAs. Exposure to PtDAs with expressed probabilities resulted in higher proportion of people with accurate risk perceptions (RR 1.7; CI 1.5, 2.1; n=14). Exposure to PtDAs with explicit values clarification resulted in a higher proportion of patients achieving choices that were informed and consistent with their values (RR 1.3; 95% CI 1.1, 1.5; n=8). Compared to usual care, exposure to PtDAs reduced rates of PSA screening (RR 0.85; 95% CI 0.74, 0.98; n=7). Eleven studies involving six different elective invasive surgeries showed that PtDAs compared to usual care reduced surgery rates (RR 0.80; CI 0.64, 1.00). The impact of PtDAs on other decisions was variable. PtDAs are similar to comparisons in affecting satisfaction with decision making, anxiety, and health outcomes.

CONCLUSION

PtDAs increase people's involvement, improve knowledge, foster accurate risk perceptions, and improve informed values-based choices. PtDAs may reduce the use of discretionary surgery without affecting health outcomes or satisfaction. Their cost-effectiveness needs further evaluation.

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203 POSTER SESSION MONDAY

Perimenopausal women's perception of decision making needs related to body weight changes during the transition to menopause

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BACKGROUND

Women transitioning through menopause are at higher risk of abdominal fat mass gain and associated health problems. Little is known about effective and sustainable ways to inform perimenopausal women's decisions about body weight changes. This study explored factors influencing perimenopausal women making and implementing decisions about achieving and/or maintaining healthy body weight.

DESIGN AND METHODS

A descriptive study using an interview-guided survey with women aged 40 to 65 years who are perimenopausal. The survey was adapted from the Population Needs Assessment Tool that is based on the Ottawa Decision Support Framework and customized for the study. Descriptive analysis was conducted and thematic qualitative analysis for open questions.

RESULTS

Preliminary findings as of December 2010 are based on 21 women who were typically: 50 years of age (range 41-61), married, with a university degree or college diploma, and a BMI of 27.7 (range 20.4-44.9). Of the 21 women, 18 (86%) identified the decision: changing behaviour to lose weight. Common options: continuing current behaviours versus increasing physical activity, changing food intake, and/or other (e.g. eliminating alcohol, obtaining advice from specialist, joining weight loss group, taking supplements). Women perceived decisions as being difficult due to a lack of support from others (n=7), not enough time (n=6), and low motivation or not feeling ready to make the decision (n=5). Ways for obtaining information and support for making decisions included: getting information on choices (n=13), other's decisions/advice (n=5), self-motivation (n=5), considering pros/cons (n=4), support from others (n=4), and 'common sense' (n=4). Preferred sources of information were: information materials (n=20), counseling (n=20), face-to-face discussion (n=16), and social networking websites (n=11). Factors identified as facilitating implementation of their decisions were: self-motivation (n=8), encouragement from others (n=4), and feeling good about oneself (n=4). Barriers to implementation included: lack of time (n=7), fatigue (n=4), too busy (n=4), and working full-time (n=4).

CONCLUSION

Preliminary findings identified many factors that influence making and implementing decisions about weight loss in perimenopausal women. Findings will be used for the development of effective knowledge translation tools for informing women about emerging evidence related to body weight changes and supporting their decisions.

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262 POSTER SESSION MONDAY

Impact of an evidence-based leaflet on 'risk knowledge' of human papillomavirus (HPV) vaccination in disadvantaged pupils: a randomised controlled trial

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Background In Germany the implementation of HPV vaccination for young women 12-17 years of age was accompanied by various campaigns. However, evidence based information was not provided. Confidence in childrens' ability to deal with numerical data is low, especially in disadvantaged pupils. The British General Medical Council explicitly demands the participation of adolescents in decision making. The aim of the present study was to compare the effects of an evidence-based leaflet with standard information on 'risk knowledge' in HPV vaccination in disadvantaged pupils of vocational schools.

DESIGN AND METHODS

Randomized-controlled short-term trial. A total of 108 female pupils were asked to participate and 105 agreed. Participants were vocational school pupils who were preparing for grade 10 graduation and who were members of the target group for HPV vaccination. The control group was asked to read a standard leaflet on HPV vaccination of the German Working Group on Women's Health. The intervention group received the same leaflet, but the leaflet was supplemented with numerical information on cancer risk and benefit of the HPV vaccination.

As baseline characteristics we surveyed: age, vaccination status, attitude towards HPV vaccination and aspects regarding migration Background
The primary end point was 'risk knowledge'. Questionnaire surveys were performed under experimental conditions within the same classes (n=7). Individual randomisation, participants and data analyses were blinded. The study was approved by the Ministry of Education and Culture and the ethics committee.

RESULTS

We analysed 'risk knowledge for all 105 randomised participants. Baseline characteristics of the two groups were comparable. Evidence-based information recipients were much more likely to give correct answers compared to standard information recipients: Mean value of risk knowledge score: 4.6 ± 1.0 v 2.6 ±1.2 (score 0-5) (difference 2.0; 95% CI 1.6-2.4; p<0.001). Further distractor analyses of single items were performed. Incorrect answers of control participants showed that risks of cervical cancer morbidity and mortality and also benefit of HPV vaccine were highly overestimated, whereas risk of cancer in general was underestimated, which also adds too much weight on cervical cancer risk.

CONCLUSION

Evidence-based information on HPV vaccination improved risk knowledge in disadvantaged pupils attending vocational schools.

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182 ORAL PARALLEL SESSION 1

Old wine in new skins? Are positive outcomes of shared decision making mediated by other (already known) factors?

A.K. Steger, M. Körner
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BACKGROUND

Patient participation has been widely shown to improve medical encounters and sometimes even treatment results. Still there is an ongoing discussion whether patient participation as a factor in itself drives these positive outcomes or whether shared decision making is only old wine in new skins. The later rational is supported by the fact that positive outcomes of shared decision making like higher patient satisfaction, an increase in compliance and better treatment outcomes can also be explained by different factors e.g. empathy, information exchange or self-efficacy expectations. The purpose of this study was to better understand which factors and to which extent drive the positive outcomes. Based on literature review of empirical studies and theoretical models several factors had been integrated into a conceptual framework that was empirically tested.

DESIGN AND METHODS

A cross-sectional study was performed in 17 rehab hospitals of different indications in South Germany. Of the 1392 patients who had been asked to participate 662 patients (48% response rate) completed the questionnaire. 580 questionnaires could be used for analysis. The questionnaire included validated instruments e.g. the German version of the consultation and relational empathy measure (CARE), Man-Son-Hing-Scale, the shared decision making questionnaire (SDM-Q) as well as self-developed instruments e.g. for self-efficacy concerning treatment. Half of the data set (n = 280) was used for a first examination of the model using structural equation modeling.

RESULTS

Preliminary analysis showed a reasonable fit of the original framework and supported the hypothesis that e.g. empathy, information exchange and self-efficacy are important mediating factors between shared decision making and positive outcomes like higher patient satisfaction and compliance. Furthermore the initial analysis step resulted in an adapted version of the conceptual framework initially proposed. After modification of the initial model, the final model will be evaluated with the other half of the data set.

CONCLUSION

The preliminary results indicate that positive effects of shared decision making can be explained by other factors partially but that shared decision making comprises more than just those factors.

41 POSTER SESSION MONDAY

Development of a structured interview to identify care needs and parenting problems in preventive child health care

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BACKGROUND

Preventive child health care in the Netherlands has to make a change from uniform care for all children to care suited to each child within its family. In our opinion this individualized care requires a careful assessment, in dialoque with the parents. We developed a structured interview to identify parenting and developmental problems and care needs in toddlers, using the perspectives and experience of both the parent and the professional, followed by a joint decision on the amount and content of care.

DESIGN AND METHODS

We adapted and expanded a structured interview on need for parenting support into the Structured Problem Analysis of Raising Kids (SPARK) in close cooperation with an expert group of child health nurses. The SPARK consists of 16 subject areas, ranging from somatic health to family issues. The SPARK uses a 3-step model: 1) detection of problems and concerns; 2) clarifying the characteristics and seriousness of problems and concerns in dialogue with the parents; 3) analysis and a joint decision on what to do next. The SPARK was tested in daily practice for feasibility and discriminative capacity. The sample consisted of all toddlers aged 18 months living in Zeeland, a province of the Netherlands, during the study period (n=1140).

RESULTS

The response rate was 97.8%. Although the median level of support needed according to both parents and professionals was low, 4.5% of the toddlers and their parents required intensive help or immediate action. The risk assessment showed 2.9% high, 16.5% increased and 80.6% low risk for parenting and developmental problems. 16.6% of the children required additional care. The SPARK provides relevant information about parent concerns, problems and care needs, which can immediately be put to use. Both agreement and disagreement between scores of parents and professional are useful for deciding which follow-up actions to take.

CONCLUSION

This study shows that a structured interview, named the SPARK, is feasible in daily practice, is discriminative, and clarifies concerns, problems experienced and care needs, which can immediately be put to use in preventive child health care.

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52 WORKSHOP PARALLEL SESSION 3

What's the Story? A workshop on the Use of Patient Testimonials in Decision Aids

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AIM

To update participants on the 'state of the science' regarding patient testimonials (or narratives) in patient decision aids (pDAs) and other forms of health communication and to foster discussion around theory and taxonomy, with the goal of drafting a research agenda to better understand the effect of these potentially powerful elements.

DESCRIPTION

This workshop will include presentations on: 1) the current state of research on the use of patient testimonials in pDAs; 2) relevant cognitive, communications, and other theories that can facilitate understanding of the means by which testimonials exert their effects; 3) outlining a taxonomy of patient testimonials (content, purpose, format, context). We will then moderate a discussion aimed at outlining a research agenda to explore key questions suggested by these presentations.

LEARNING OBJECTIVES

- To understand the current state of knowledge regarding use of patient testimonials in pDAs;
- To describe the contributions that could be made by various theoretical frameworks for better understanding the effects of patient testimonials;
- To work toward consensus on a taxonomy of patient testimonials, informed by theory and the available research base;
- To build a research agenda for patient testimonials in pDAs.

Prerequisite knowledge: Familiarity or interest in the use of patient testimonials in pDAs; interest in conducting research on their impact and use.

83 ORAL PARALLEL SESSION 7

Development and rapid testing of patient experience questionnaires in a national shared decision making (SDM) implementation project.

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[2]Cardiff University, CARDIFF, United Kingdom
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BACKGROUND

MAGIC (MAking Good decisions In Collaboration) is a Health Foundation-funded implementation project to determine how best to implement SDM in practice. Implementation includes use of rapid comparative feedback of patient experience data collected by brief questionnaire. No such questionnaire is available for use currently. We describe the approach to developing and initial testing.

DESIGN AND METHODS

Questionnaires were drafted following wide review of currently available instruments and questions. We agreed that the content should: be simple, easily collected, and sensitive to change; if possible, be embedded within routine NHS practice (or capable of being so); have strong face validity, and be reasonably valid and reliable; ideally be based in a clear theoretical model of SDM; support action learning, continuous feedback and rapid quality improvement; show potential for embedding in performance management and review. After initial piloting concerns arose about length, social acceptability bias, question order and mode of distribution. These were rapidly tested across both sites, and in primary and secondary care, using questionnaire variants in parallel. Questionnaire variants were tested in long (26 questions) and short (13 questions) formats. Common questions addressed involvement in the consultation, with the longer version including the DelibeRATE and control preference scales.

RESULTS

Questionnaires were distributed to 236 patients, either in clinic or by mail. Overall response rate was 79%. The longer format took around five minutes to complete. The questionnaire pilots showed that: increasing response options for questions added discriminant potential; question order affected responses, with reduced ceiling effect on the question, “Were you involved as much as you wanted to be in decisions about your care and treatment?”, if preceded by more specific questions exploring elements of the consultation; good response rates when distributed at clinic (88%) but very poor, and delayed, when mailed post-clinic (38%); and naming the consulting clinician had no marked impact on ceiling effects.

CONCLUSION

The approach to rapid testing allowed quick redesign of questionnaire structure, content and mode of delivery. We have developed brief questionnaires to measure patient experience and commend this pragmatic approach to developing short and practical questionnaires for use in routine service improvement.

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124 SYMPOSIUM PARALLEL SESSION 5

Implementing Shared Medical Decision Making in the Real World: Four Case Studies: Decision Aid Integration and Shared Decision Making in the Primary Care Medical Home

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BACKGROUND

Mercy Clinics has a unique approach to clinician push for Shared Decision Making (SDM) by using Health Coaches. Rather than relying on physician memory, Coaches are nurses on the clinic team who distribute Decision Aids (DAs). Decision support remains the provider’s responsibility at the DA post-viewing visit.

DESIGN AND METHODS

We engaged teams in five primary care clinics, including a clinician champion, clinic manager, and Health Coaches, and began distributing DAs. Clinician champions are leaders in generating provider participation and Health Coaches make the process work. Coaches use pre-visit chart review to identify patients, and flag charts to suggest to the provider a DA. Coaches team with clinic staff to identify and target potential patients, meet with patients, distribute DAs and encourage viewing. The provider closes the loop at the post-viewing visit, and decision support is provided by the physician or Coach, depending on the DA topic. Coaches run distribution reports specific for their clinic. Sharing data and successes at our monthly champion/team meeting with project leaders in clinic administration supports and motivates the teams as they compete in providing the best quality of care.

RESULTS

726 DAs have been distributed August 2009-December 2010. Besides having the Health Coaches in a pivotal role, frequent reminders to providers by champions, such as academic detailing, increased distribution. The total ranking by patients of the quality and importance of DAs has trended up along with the distribution numbers.

CONCLUSIONS

Integrating SDM has been effective in our primary care medical home, which is based on the IOM’s Six Dimensions of Quality and Wagner’s Care Model. Health Coaches are key in making this work. Having no electronic medical record, eligible patient identification has been the biggest challenge. The warm hand-off and having patients watch DAs in the clinic have been our most successful delivery modes. For productive interactions, DAs inform and activate our patients, and they help prepare and make proactive our practice teams.

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Learning how to share: Challenges in implementing decision aids in routine maternity care

R. Thompson, Y.D. Miller, C. Gallois
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BACKGROUND

Despite evidence that decision aids are valued by patients and effectively increase patient knowledge, reduce decisional conflict and promote shared decision-making, far less is known about their efficacy in real-world settings, or about factors that impede or enable their implementation in routine health care.

DESIGN AND METHODS

We have recently undertaken research to identify effective methods of promoting shared decision-making between maternity care consumers and their care providers. In consultation with maternity care stakeholders (consumer groups, clinicians and policy-makers), we developed a suite of decision aids for pregnancy and birth. While both the implementation and impact of these decision aids are currently undergoing evaluation in a randomised controlled trial, the process of decision aid development provided key insights into barriers to shared decision-making in maternity care.

RESULTS

Consultation with maternity care stakeholders revealed diverse perspectives on the value of decision aids in routine maternity care. While the vast majority of stakeholders endorsed the concept of consumer involvement in decision-making, people differed considerably in (i) their assumptions about women's capacity to comprehend health information and to make 'reasonable' decisions about their care, (ii) their views about the types of options that can 'safely' be included in decision aids, and (iii) the extent to which they support unbiased and non-directive provision of information about care options to maternity care consumers. Due to inadequate opportunities for addressing more fundamental barriers to the implementation of decision aids within this project, a number of compromises were made to maximise acceptability of the decision aids (e.g., removing a decision aid on infant feeding, when widespread disapproval of non-directive information about infant feeding options was predicted to undermine acceptability of the suite of decision aids).

CONCLUSIONS

Overall, we found that the prevailing culture in maternity care in Australia does not readily facilitate the practice of shared decision-making or the routine implementation of decision aids. Our learnings substantiate and extend existing knowledge of barriers to the implementation of decision aids in health care more broadly and underscore the importance of focusing efforts on promoting the benefits of shared decision-making among health care providers and other key stakeholders.

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278 ORAL PARALLEL SESSION 4

Learning how to share: Challenges in implementing decision aids in routine maternity care
R. Thompson, Y.D. Miller, C. Gallois
Queensland Centre for Mothers & Babies, BRISBANE, Australia

BACKGROUND

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198 SYMPOSIUM PARALLEL SESSION 3

Decision support in complex settings - the challenge of context

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BACKGROUND

There is growing demand for, and development of, decision support to enhance engagement of patients in decisions about treatment options (including patient decision aids). These are complex interventions and, as such, merit robust development and evaluation. To stimulate more effective development and evaluation of decision support it is important to take account of the context of the particular index decision for which support is required.

DESIGN AND METHODS

We set out to develop a framework for considering decision context in order to help those seeking to develop and evaluate decision support. This was initially drawn up from experience of exploratory research into decision making and developing/evaluating decision support in a range of clinical decisions and settings. These ranged from chronic disease in the elderly, through hyperacute treatments (such as thrombolysis in acute stroke care), and pain relief in labour to engaging children and parents in decisions about treatment for squint. An initial framework of contextual factors was drafted and tested with workshops in two international conferences, with subsequent refinements based on feedback from attendees.

RESULTS

A framework has been developed that incorporates five categories of contextual variables including: patient factors (e.g. age, co-morbidities, capacity); other actors (e.g. parents, carers); decision variables (e.g. acute/chronic, severity, number of options); organisational variables (e.g. multidisciplinary team, care pathway, health system design); and delivery variables (e.g. face-to-face by clinician, on-line). Variables subsumed within (and between) the five categories interact with one another, which further captures the intricacies and context dependent nature of decision support, and highlights the need for a multidisciplinary and inter-professional approach to development, delivery and evaluation.

CONCLUSION

We have developed a framework that might help those involved in developing and/or evaluating decision support. This has been constructed with reference to a range of experience and further validated through discussion within expert workshops using a range of index decisions. We next plan to operationalise this framework into specific guidance for developers and researchers.

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199 POSTER SESSION MONDAY

Development and usability testing of a shared decision support tool for cardiovascular risk reduction in primary care

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[3]St Georges University of London, LONDON, United Kingdom
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[6]Independent researcher, BILLINGHAM, United Kingdom

BACKGROUND

The UK NHS is implementing cardiovascular (CVD) risk screening in primary care for everyone aged 40-74 to initiate lifestyle changes or other interventions for those at raised risk. We developed and tested the usability of a computerised risk communication and shared decision support tool.

DESIGN AND METHODS

This incorporated three elements:1) software development; 2) relevant predictive equations, including the Framingham equation for CVD risk, and the effectiveness of interventions and their adverse effects; and 3) a period of iterative development with clinicians and patients. We drew upon the literature and experience with previous software development to design a prototype that included a range of risk and benefit presentations using pictograms and text. We tested this version in demonstrations and interviews with eight primary care professionals and ten patients with known cardiovascular risk.

RESULTS

Clinicians felt that it: was useful to address a need and replace current less sophisticated tools; was easy to use; included relevant details, functions and interventions consistent with current clinical practice; would support risk calculation and communication; and included alternative risk presentations to meet the needs of different patients. Improvements were suggested: to simplify presentation of adverse effects; allow print out; more on lifestyle interventions; and minor improvements in text and presentation. Some were concerned that the presentations would affect the communication of their (practitioner) desired patient behaviour change and hence would use components of the tool selectively. Patients reported that previous discussions with their GP had not involved any visual information and the tool would provide a welcome addition to consultations. They particularly welcomed the adverse effects function; it would help make a decision as to whether or not they wanted to take a particular medication and whether alternative approaches were available. Some felt that the tool should be more 'hard hitting' by providing information on the consequences of not taking/following interventions

CONCLUSION

We have produced a prototype risk communication and decision support tool that has been well received by clinicians and patients, and adapted in light of usability testing. We are now starting in-clinic service evaluation and will have details of this by June.

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252 POSTER SESSION MONDAY

USE OF THE ANALYTIC HIERARCHY PROCESS TO PRIORITIZE PATIENT-RELEVANT ENDPOINTS OF ANTIDEPRESSANT TREATMENT

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[1]University of Twente, ENSCHEDE, Nederland
[2]IQWiG, KÖLN, Germany

OBJECTIVES

In deciding about coverage of new medical technology, multiple clinical outcomes are used to support reimbursement claims. Neither the real world value nor the relevance of these outcome measures for patients is systematically assessed. Hence, there is growing interest in the use of patient-reported outcome measures. Multi-criteria decision analysis, like the analytic hierarchy process (AHP), is a technique to elicit patient preferences. In the present study we used AHP to prioritize patient relevant endpoints related to the use of antidepressants in major depression. Methods Patient relevant endpoints of treatment (remission of depression, response to treatment, no relapse, serious adverse events, adverse events, social function, anxiety, pain, cognitive function) were prioritized using pairwise comparisons of these outcomes. In two separate groups, twelve patients and seven experts judged on a 9 point scale the relative importance of pairs of two outcome measures. The geometric mean of these judgments was used to derive weighting factors for the outcome measures (scale 0-1).

RESULTS

Of all outcome measures, patients rated response to treatment highest (0.32), while experts rated remission of depression highest (0.48). Adverse events were all rated lowest by patients as well as by experts, and disease-specific quality of life domains such as social function (0.11 & 0.09), anxiety (0.12 & 0.05) and cognitive function (0.13 & 0.06) were rated in between.

CONCLUSIONS

The most important outcome measures according to the patients are, in order of decreasing importance: response, cognitive function, no anxiety, social function, no relapse, no adverse events, and remission. The AHP appears to be suitable in gaining an overview of the importance of patient relevant outcome measures. An additional advantage of AHP is that the group discussions offer insight in the question why the endpoints are important.

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254 ORAL PARALLEL SESSION 2

The effect of numerical and graphical risk formats on perceived likelihood and choice.

D.R.M. Timmermans, J. Oudhoff
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BACKGROUND

Quantitative risk information plays an important role in daily decision making about health and care. It is, however, information that is difficult to comprehend. In practice, various numerical and graphical formats are being used for risk communication. Past research and theoretical views provide different explanations about which risk formats may yield more meaningful perceptions of likelihood for choice and why. The current study aims to provide conceptual understanding of the effects of different numerical and graphical risk formats on risk perception and choice preference.

DESIGN AND METHODS

An experiment was developed that used a mixed 3x2x2 design with two between factors and one within factor. The between factors comprised the use of 3 different numerical risk formats ('1 in X', 'X in 100/1000', and 'X%') and the 2 graphical formats (barchart or icon chart). Whether a graphical format was added to the numerical information or not, was manipulated across tasks within participants (within factor). Dependent variables were perceived likelihood and choice preference. One-hundred ninety two students from the Free University of Amsterdam participated.

RESULTS

The results of our experiment show that the perception of numerical risk information depends both on the degree to which the format refers to concrete and imaginable numbers of events and on the simplicity with which the format conveys a numerical relative risk ratio. Simple numerical formats that use small numbers ('1 in X') yield more impressive perceptions of likelihood and have an according effect on choice preference, suggesting a stronger role for intuitive and affective processing of information than less concrete or more complex formats (percentages or 'X in 100'). The effect of graphical information formats in risk perception is limited, but it is slightly more pronounced among persons with low numerical aptitude and it may be stronger for more complex situations.

CONCLUSION

When presenting risk information in practice, consideration is needed about which format is most concrete and which is the simplest given the purpose the information serves.

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200 ORAL PARALLEL SESSION 3

Association between patient rated amount of participation in Decision-Making and clinical outcome in patients with hypertension in General Practice

I. Tinsel, A. Buchholz, A. Pfaff, T. Schardt, C. Bollmann, W. Niebling, K.G. Fischer, A. Loh
University Medical Center Freiburg, FREIBURG, Germany

BACKGROUND

Hypertension is one of the key factors causing cardiovascular diseases and therefore one of the most important determinants of mortality. There is evidence that SDM may have positive effects on clinical outcomes of patients with high blood pressure (BP). However, study-designs and instruments vary and results are inconsistent [1-4]. To our knowledge associations of the extent of patients' participation, measured by SDM-Q, BP level, and cardiovascular risk (CVR) have not been investigated yet. These relations will be examined in the present study by analysing baseline data of a RCT (WHO Clinical Trials Registry DRKS00000125).

DESIGN AND METHOD

A total of N = 1254 antihypertensive treated patients were recruited in 36 GP practises in Southern Germany. Patients with a mean of blood pressure, measured by Ambulatory Blood Pressure Monitoring (ABPM), being above 130/80 mmHg and/or with a diagnosed cardiovascular comorbidity were targeted in the study (n = 1034). Besides ABPM's, patients completed questionnaires which queried socio-demography, health behaviour, and the extent of patients' perceived participation, measured by SDM-Q-9 (0 = lowest, 100 = highest extent of SDM) [5].

RESULTS

Data of 872 patients could be included in the analyses. 53 % of the patients were female. The age ranged from 18 to 91 years (Median = 66). The mean of blood pressure (ABDM) was 132/81 mmHg (SD 13/10). According to European Guidelines [6] 13 % of the patients showed 'normal' BP, 21 % of the patients were characterized as having borderline hypertension, 36% mild, 22 % moderate, and 8 % severe hypertension. Total cardiovascular comorbidity amounted to 43 %. Patients' perceived participation was high with a mean score of SDM-Q-9 = 72 (SD 19).

CONCLUSION

Detailed associations between patient's participation, BP level, CVR, and other relevant covariates will be presented at the conference. Findings of this study will shed light on the potential of SDM in hypertensive treatment.

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202 ORAL PARALLEL SESSION 4

SDM training for General Practitioners in the Treatment of Arterial Hypertension: Results of a randomized controlled trial to evaluate the training effects

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University Medical Center Freiburg, FREIBURG, Germany

BACKGROUND

The Prevalence of arterial hypertension in Germany is the second highest in Europe. Although high blood pressure entails high cardiovascular risk (CVR) with elevated rate of morbidity and mortality, only 40 % of German patients treated for hypertension are classified as 'controlled treated'. Shared Decision-Making (SDM) has been shown to improve patients' adherence and health behaviour. The objective of this Cluster-RCT was to evaluate a training program for General Practitioners (GP) treating patients with arterial hypertension. Primary outcomes were optimization of blood pressure level and enhancement of patients' participation. Aim of the first follow-up was to examine patient-based outcomes.

METHOD AND DESIGN

In this prospective Cluster-RCT (WHO Clinical Trials Registry DRKS00000125) including baseline and three follow-up assessments, a total of N = 1254 patients in treatment for arterial hypertension were recruited in 36 GP practices in Southern Germany. Patients characterized as "not controlled treated"(Mean of 24h Ambulatory Blood Pressure Monitoring (ABPM) above 130/80 mmHg) and/or patients diagnosed as having cardiovascular comorbidity were targeted in the study (N = 1034). Besides ABPM's, patients completed questionnaires which queried demographic data, health behaviour and the SDM-Q-9. The intervention consisted of a 6h-training program for GPs, the use of patient decision boards and patient information material. In the present study, effects of the intervention on the SDM-Q-9 at first follow-up are investigated.

RESULTS

Data of 621 patients from 36 GP's were included in the present analyses (drop out n = 240, incomplete data n = 173). The Intervention Group (IG) consisted of 17 GP's and 305 patients. The median age was 65 years (18 to 92). The mean scores of the SDM-Q-9 (0 = lowest, 100 = highest extent of SDM) at baseline were 73 (SD = 17) in the IG and 71 (SD = 20) in the CG. At first follow-up, mean scores were 73 (SD = 18) for the IG and 67 (SD = 20) for the CG.

CONCLUSION

First results show that SDM-training for GP's has positive effects on patient's participation in hypertensive treatment. Detailed results will be shown at the conference.

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91 POSTER SESSION TUESDAY

The effect of a decision aid on the treatment choice for prostate cancer; preliminary results.

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BACKGROUND

For primary localized prostate cancer different treatment options are available, of which the most common are prostatectomy and radiotherapy. These treatments offer comparable tumor control, but differ in their profile of side effects. Prostatectomy is associated with a higher risk of urinary incontinence and erectile dysfunction, whereas radiotherapy is more likely to cause persistent bowel problems. In this choice, patients often rely on the advice of the specialist. However, the recommendations of specialists tend to be variable and influenced by their specialty. We studied whether an increase in patient involvement, by means of a decision aid, affected the treatment choice.

DESIGN AND METHODS

In a prospective randomized controlled trial, 226 patients with localized prostate cancer were recruited in three different hospitals. They were randomized, in a 1 to 2 ratio, to usual care (treatment choice discussed with urologist as usual, n=73) or a decision aid arm (usual care plus a decision aid, n=153). The decision aid was presented by a researcher in a separate consultation. It contained information on two or three treatment options, i.e. prostatectomy, external beam radiotherapy and, for eligible patients, also internal radiotherapy (i.e. brachytherapy). The information was based on an extensive literature search and referred to cure and serious side effects such as urinary, bowel and sexual problems.

RESULTS

Overall, prostatectomy was chosen most frequently. Compared to the usual care group, the decision aid group chose less prostatectomy (68% vs. 77%) and more brachytherapy (16% vs. 4%). However, treatment choice varied substantially between hospitals. Multinomial logistic regression analysis showed that the treatment choice was affected by both the decision aid (p=0.02) and the hospital (p<0.001).

CONCLUSION

The decision aid for prostate cancer reduced the preference for prostatectomy and increased the preference for brachytherapy. However, practice variation between hospitals had a large impact on treatment choice. The use of the decision aid did not reduce this practice variation.

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144 POSTER SESSION MONDAY

Doctor's Perception of Men's Receptivity to Sexual Health Inquiry Determines Doctor's Decision in Inquiring about Sexual Dysfuntion

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BACKGROUND

Perceived men's receptivity to sexual health inquiry may affect Malaysian primary care doctors' decisions to initiate sexual discussion with their male patients. This paper quantifies the impact of doctors' perceptions of men's receptivity on male sexual health inquiry. Sexual health inquiry is one of the five areas in a study on the determinants of offering preventive health checks to Malaysian men.

DESIGN AND METHODS

This was a cross sectional survey among primary care doctors in Malaysia. The questionnaire was based on the empirical model recently published which defined the determinants of primary care doctors' intention to offer health checks. The questionnaire measured: 1) perceived receptivity of male patients to sexual health inquiry, 2) doctors' attitudes towards the importance of sexual health inquiries, 3) perceived competence and, 4) perceived external barriers. The outcome variable was doctor's intention in asking about sexual dysfunction in 3 different contexts (minor complaints visits, follow-up visits and health checks visits). All items were measured on the Likert scale of 1 to5 (strongly disagree/unlikely to strongly agree/likely) and internally validated.

RESULTS

198 doctors participated (response rate 70.4%). 78% of respondents were unlikely to ask about sexual dysfunction in visits for minor complaints to their male patients, 43.6% in follow up visits and 28.2% in health checks visits. In ordinal regression analysis using the regression scores, positive perception of men's receptivity to sexual health inquiry significantly predicted the doctors' intention in asking sexual dysfunction in all three contexts; i.e. minor complaints visits, follow-up visits and health checks visits (logit coefficient (B)=0.237, p=0.013; B=0.806, p<0.0001; B=0.288, p=0.002 respectively). Perceived competence in sexual health inquiry predicted their intention in the follow-up visits and health checks visits (B=0.482, p=0.006; B=0.383, p<0.001 respectively). Lower cost to health checks only predicted their intention in the follow-up visits (B=-0.360, p=0.010).

CONCLUSION

Whilst sexual health inquiry should be initiated in an appropriate context, 'perceived receptivity' to sexual health inquiry significantly affected doctors' intention in initiating sexual health inquiry to their male patients. Malaysian men's health may be substantially improved by strategies that assist doctors to identify patient 'receptivity'.

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66 **POSTER SESSION TUESDAY**

Intervention study on method of delivery using decision-aid program for Japanese pregnant women with prior caesarean section experience

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BACKGROUD

The caesarean rate of Japan is lower compared with that of other advanced nations, but it is rising every year and has reached twice as high in 20 years. Once a primary caesarean section has occurred, women face a choice about birth methods in future pregnancies. The decision-making is not easy for women since it involves personal values, medical opinions, and individual factors such as previous caesarean experiences, family circumstance, and perceptions of safety. Health professionals have to examine the method of giving information and the support of decision-making on birth choice after caesarean, considering such a situation.

Design and methods This quasi-experimental study aims to research and evaluate the prior and post interventional effects on the decision-aid program which was designed to provide the researcher with sufficient data from those Japanese women. The decision-aid program was evaluated with quantitative and qualitative data analyses. The quantitative data included decisional conflict scale (DCS) score, level of knowledge, and women's preference of delivery methods. The qualitative data analyses were resulted from the data retrieved from the interviews held with the program subjects.

RESULTS

Evidence from this intervention study including 33 Japanese pregnant women found that the decision-aid program improved the level of knowledge, assisted the women with one previous caesarean experience to learn the risks and benefits of birth options after caesarean, and to reach more precise decisions based on their preference and personal values. DCS score was decreased (p<0.001), particularly in the category of feeling uninformed. The women in the program obtained "emotional stability"through close communication with the researcher, and reached "understanding"of an unexpected situation during the delivery, which could be led to caesarean section even though VBAC was tried.

CONCLUSIONS

The usefulness and necessity of decision-aid support was well-recognized and confirmed through this intervention study. The decision-aid program will be expected to be furthered in the clinical settings in the future. Moreover, it is important that we provide the women with more opportunities of making decisions in various phases of maternity care, and that its support system should be built in collaboration with physicians.

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136 **ORAL PARALLEL SESSION 7**

A randomised controlled trial on the effect of 'My Health Check', a web-based decision tool, on the adoption of health preventive behaviours in volunteers aged 30-69 years

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INTRODUCTION

Practitioners and their patients have an increasing list of preventive health options to reduce mortality and morbidity. Ranking these options for an individual based on demographic, health characteristics and preferences should allow them to prioritise and tailor preventive health care. 'My Health Check' (MHC) is a web-based multi-criteria decision analysis tool populated by age and gender-specific burden of disease data for YLL and YLD. Individual demographic and health data entered by the patient provides a personalised list of relevant options whilst preferences can be interactively adjusted using a slide bar. Prior qualitative work derived the four key attributes/utilities for preventive health decisions as 'avoiding premature death', 'avoiding chronic illness/disability', 'avoid difficulty/loss of enjoyment' and 'minimising financial costs'. This trial tests the effect of MHC on preventive healthcare decisions.

METHOD

1000 Australian participants aged 30-69 years recruited nationally via random-digit dialling and randomised by computer to the self-administered 'My Health Check' (MHC) which provides personalised ranking of relevant preventive health options and links to information; or the control site which comprises a portal with the same information links but does not include the personalised ranking of relevant options. The design is double-blind. The primary outcome is the proportion of people who have undertaken at least one of their top 3 self-identified preventive behaviours 3 months after MHC compared with the control.

RESULTS

To date, 585 participants have been recruited with 91.2% completing the initial survey. Estimated recruitment completion is March 2011. Our pilot data shows that in both arms of the trial about two-thirds of people changed their priorities after viewing the websites. However, of note is that 89% of the intervention participants had their top priority consistent with their MHC output. The remainder put their MHC top priority as second choice. Half changed towards the MHC output and around 40% correctly predicted their top priority and maintained it.

CONCLUSION

Multi-criteria decision analysis appears to be a promising method for personalising and prioritising a range of healthcare options. It allows patients to tailor population-level evidence to individual clinical factors and combine with personal preferences

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20 POSTER SESSION TUESDAY

EXACKTE2: Exploring the association between shared decision-making components and patients' uncertainty

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BACKGROUND

A factor that may predict the success of shared decision-making (SDM) initiatives is the degree to which SDM makes patients' uncertainty explicit. Our objective was to explore the association between SDM components and patients' uncertainty.

DESIGN AND METHODS

We carried out a longitudinal study in 17 primary care clinics in London, Ontario and Québec City, Quebec, Canada. We enrolled physicians and one of each enrolled physician's patients and asked them to independently complete a self-administered questionnaire after the consultation. We measured five SDM components from patients' perspective: i) defining and explaining the problem, presenting options, and discussing benefits and drawbacks; ii) clarifying the patient's values and preferences; iii) discussing the patient's ability/self-efficacy; iv) discussing the doctor's knowledge and recommendations; and v) checking/clarifying the patient's understanding. Based on systematic reviews, we mapped existing dyadic measures onto each SDM component and assessed the reliability and validity of the measures. We also measured patients' personal uncertainty: i.e., their uncertainty about the personal significance of the risks associated with the decision. We used structural equation modeling to explore how the SDM components were associated with patients' uncertainty. We assessed model fit using the chi-square, the comparative fit index (CFI), and the root mean square error of approximation (RMSEA). We calculated sample size according to the method proposed by Kline, 1998. We compared structural equation modelling estimates to regression correlation coefficients.

RESULTS

Of 430 potentially eligible patients, 276 (64%) agreed to participate. Patients' mean age was 49.4 +/- 17.7 years and 69% of patients were female. We analyzed the responses of 269 patients. We found the model fit to be adequate (RMSEA: 0.108; CFI: 0.829). Three SDM components were associated with patients' personal uncertainty: clarifying the patient's values and preferences, discussing the patient's ability/self-efficacy, and checking/clarifying the patient's understanding ($P<0.001$). The amount of variance in patients' uncertainty that was attributable to regression was 0.49.

CONCLUSIONS

To decrease patients' uncertainty, physicians should check patients' understanding, discuss patients' ability/self-efficacy, and clarify patients' values and preferences. Although the explained variance in patients' uncertainty was acceptable, a larger sample could produce better results.

22 POSTER SESSION TUESDAY

EXACKTE2: Exploring the association between shared decision-making components and physicians' uncertainty

S.T. Turcotte[1], F. Légaré[1], H. Robitaille[1], M. Stewart[2], D. Frosch[3], J. Grimshaw[4], M. Labrecque[1], M. Ouimet[1], M. Rousseau[1], D. Stacey[5], T. Van der Weijden[6], G. Elwyn[7]

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BACKGROUND

A factor that may predict the success of shared decision-making (SDM) initiatives is the degree to which SDM makes physicians' uncertainty explicit. Our objective was to explore the association between SDM components and physicians' uncertainty.

DESIGN AND METHODS

We carried out a longitudinal study in 17 primary care clinics in London, Ontario and Québec City, Quebec, Canada. We enrolled physicians from participating clinics and one of each enrolled physician's patients and asked them to independently complete a self-administered questionnaire after the consultation. We measured five SDM components from the physicians' perspective: i) defining/explaining the problem, presenting options and discussing benefits and drawbacks; ii) clarifying the patient's values and preferences; iii) discussing the patient's ability/self-efficacy; iv) discussing the doctor's knowledge and recommendations; and v) checking/clarifying the patient's understanding. Based on systematic reviews, we mapped existing dyadic measures onto each SDM component and assessed the reliability and validity of the measures. We also measured physicians' personal uncertainty: i.e., their uncertainty about the personal significance of the risks associated with the decision. We used structural equation modeling to explore how the SDM components were associated with physicians' uncertainty. We assessed model fit using the chi-square, the comparative fit index (CFI), and the root mean square error of approximation (RMSEA). We calculated sample size according to the method proposed by Kline, 1998. We compared structural equation modelling estimates to regression correlation coefficients.

RESULTS

Of 382 eligible physicians, 274 (72%) agreed to participate. Physicians' mean age was 36.6 +/- 10.7 years and 64% of physicians were female. We analyzed the responses of 264 physicians. We found the model fit to be adequate (RMSEA: 0.059; CFI: 0.914). Clarifying patient's values and preferences was the most important SDM component to be associated with physicians' personal uncertainty ($P<0.001$). The amount of variance in physicians' uncertainty that was attributable to regression was 0.23.

CONCLUSIONS

To decrease physicians' uncertainty, policymakers should find ways to help physicians clarify patients' values and preferences. The explained variance in physicians' uncertainty was modest for a behavioural study. A larger sample could produce better results.

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175 POSTER SESSION MONDAY

'One picture is worth a thousand words'- Shared decision making within the clinical encounter using visual models to empower the patient

L. Turetsky

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BACKGROUND

Within the clinical encounter as family physicians we often explain to our patients how diseases express themselves , why different treatments are used , what can be the final outcome, and what to look out for. In addition we discuss the different options of tests or treatments available and come to a final decision together with the patient. By using visual models , aids , metaphors and diagrams this process is much enhanced often shortening the need of detailed explanations and rapidly improves patients' deep understanding of their situations or choices .

DESIGN AND METHODS AND RESULTS

Models of illnesses , physiology and anatomy of the body, metaphors and possible CBT treatments were developed in graphic and visual form. These visual aids were presented to patients during the discussion about a particular illness and utilized to further the patients understanding and ability to help himself or change his perception of his illness . In addition he was often able to make a more informed choice of treatment once he saw the options visually displayed in front of him. For example a patient suffering from obesity and high blood pressure is shown a diagrammatic spectrum of different aspects of the metabolic syndrome including diabetes , IHD, obesity, hypertension , lipids and CVA which shows future risks. This improves the patients understanding the context of his illness and may promote more active care on the patient's part

CONCLUSIONS

These visual aids are presented as a package for individual doctors consultations and for health organizations to empower their patients understanding of their health and illnesses . In addition it can help train doctors , specialist trainees and students to improve communication skills with their patients and facilitate shared decision making that is often lacking in practice . I would like to present these visual models as an oral presentation showing the important impact of visual aids on deep learning within the clinical encounter

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28 POSTER SESSION MONDAY

Living with untreated prostate cancer: The impact on quality of life of active surveillance

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BACKGROUND

Patients with likely indolent prostate cancer (PC) may be managed with active surveillance (AS), which implies close monitoring of the disease and switching to active treatment if progression occurred. We aimed to study whether AS led to feelings of anxiety and distress while living with 'untreated' cancer.

DESIGN AND METHODS

We prospectively included 150 Dutch PC patients on AS. Patients received questionnaires at inclusion (t=1), 9 months after diagnosis (t=2), and 18 months after diagnosis (t=3). We assessed changes in scores on decisional conflict (DCS) about their treatment choice, generic anxiety (STAI-6), depression (CES-D), PC specific anxiety (MAX-PC), physical health (SF-12 PCS), and self-estimated risk of progression, between t=3 and t=1. A non-response analysis was performed to assess whether non-responders and men who discontinued AS for non-medical reasons differed significantly from those who continued AS.

RESULTS

The t=1, t=2 and t=3 questionnaire were completed by 86% (129/150), 90% (108/120) and 75% (81/108), respectively. 9 men discontinued AS between T=1 and T=2. T=1 anxiety and distress levels were generally favourable compared to reference values and other treatment groups. Levels of anxiety and distress at t=2 were mainly predicted by scores at t=1 and remained favourable low during the first 9 months of surveillance. Comparing t=3 with t=1 revealed small but statistically significant decreases in the mean scores of DCS ($P < 0.001$), CES-D depression ($P = 0.001$), STAI-6 ($P < 0.001$), PC specific anxiety (MAX-PC) ($P < 0.001$) and SF-12 PCS ($P < 0.001$). Between t=2 and t=3 thirty-three men switched from AS to active therapy; but only 4 due to non-medical reasons.

CONCLUSIONS

After a follow-up of 18 months on surveillance, levels of anxiety and distress remained favourably low for men on AS. Further studies need to validate these results and study the medical outcomes of alternative treatments for low risk PC.

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300 SPECIAL WORKSHOP PARALLEL SESSION 7

Sharing decisions on written communication: a short course in writing English articles

A. Visser
Rotterdam University, the Netherlands. Editor Patient Education and Counseling

It is not an easy task for young researchers to write articles in the English language and to get them published. This is even truer for researchers from countries with a less strong tradition in an international publication policy.
In the interactive workshop lessons will be shared about how to improve the chance to get a manuscript published: basic advices and top lessons. Also your main problems during writing an article will be discussed, based on articles you are writing. The opinion will be shared about a distributed article, as an exercise article. Closing remarks about raising your possibilities to publish internationally. Supervision after the workshop is possible. The workshop will last 90 minutes.

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228 ORAL PARALLEL SESSION 3

Factors associated with adherence to the guideline recommendation for external cephalic version in women with a breech presentation at term.

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BACKGROUND

External cephalic version (ECV) is a relatively simple and safe manoeuvre and a proven effective approach in the reduction of breech presentation at term and consequently, the number of caesarean deliveries. There is professional consensus that ECV should be offered to all women with a foetus in breech presentation, but only up to 70% of women are counselled, prohibiting a shared decision making for the treatment of breech presentation. The objective of the study was to determine which factors are associated with substandard application of ECV, in order to develop a national implementation strategy to improve the adherence of professionals with the guidelines.

DESIGN AND METHODS

Key recommendations from the national guidelines were discussed in focus group meetings with midwives and gynaecologist to detect potential facilitators and barriers. These determinants were categorized relating to characteristics of; 1. the guideline (e.g. complexity, outcome expectations), 2. the professional (e.g. attitude, task orientation, self-efficacy), 3. the organisation (e.g. preconditions of ECV) and the socio-political environment (e.g. patient preferences). The determinants were quantitatively analyzed in a national, web based questionnaire among gynaecologists and midwives. A factor analyses was performed to improve reliability of the constructs. We explored which constructs were associated with reported proportions for adherence to the key recommendations of the guidelines: counselling for ECV, advising ECV, referring for ECV and performing ECV.

RESULTS

Although 90% of respondents considered ECV as an effective treatment to prevent caesarean deliveries, only 30% agreed on the item ‘every client should undergo ECV’. Time was identified as a barrier for counselling by 56% of midwives and 24% of gynaecologists. The outcomes ‘counselling for ECV ‘ and ‘recommendation of ECV’ were positively influenced by the constructs ‘self efficacy’ and ‘attitude towards ECV’. Performance of ECV differed among specialists and was dependent of the construct ‘task orientation’. Referring a patient for ECV was more often stated by obstetricians or midwives who had a positive expectation of the facilitating determinants.

CONCLUSIONS

Attitude towards ECV and self-efficacy seem the most important determinants. Therefore, to improve adherence to the guidelines on ECV the national implementation strategy will focus on these constructs.

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211 ORAL PARALLEL SESSION 1

Updating the IPDAS Collaboration’s Background Document: Current Status

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BACKGROUND

In 2006, the International Patient Decision Aids Standards (IPDAS) Collaboration published the IPDAS Collaboration Checklist”’a checklist of quality criteria for patient decision aids. The checklist’s criteria, organized into 12 quality dimensions, were originally identified using a Delphi process. To help the Delphi voters formulate their ratings, they were provided with the 12-chapter 2005 IPDAS Collaboration Background Document, which summarized the theory and evidence underlying each dimension. It is now time to update this Background Document.

DESIGN AND METHODS

There is no extramural funding for this updating effort. Volunteers were identified through listserve postings, at the 5th ISDM in Boston, and in direct solicitation. A leader and co-leader for each of the 12 writing teams was identified; they were provided with rosters of volunteers. Each team is charged with updating their chapter in 4 sections: a) the definition of their dimension, b) its theoretical rationale, c) the relevant empirical evidence, and d) dimension-specific emerging issues in theory, measurement, and future research. In each of these 4 sections, the focus is on reviewing literature directly specific to decision aids; literature from the larger field of health care in general and from other non-health-related fields may also be reviewed, as appropriate.

RESULTS

Overall, more than 80 volunteers from 8 countries were identified. A leader and co-leader have been recruited for each of the 12 chapters, and interdisciplinary team memberships have formed. [The scope of 2 chapters has expanded: “Best Practice in Implementation of Decision Aids”(previously “Delivering Aids on the Internet”) and “Addressing Health Literacy”(previously “Using Plain Language”)]. Each team is reviewing the relevant literature for all 4 chapter sections, and preparing drafts of their updated chapter.

CONCLUSIONS

The 2011 IPDAS Collaboration Background Document will support the current Checklist with an updated overview of dimension-specific definitions, theories, and evidence. It will also highlight emerging issues. Developers, certifiers, and adopters of patient decision aids will want to consider these issues; furthermore, these issues will point to the ways in which the IPDAS Collaboration Checklist itself may need to be revised.

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259 POSTER SESSION TUESDAY

Identifying Clinician Competencies for Shared Decision Making

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[3]Texas Tech Health Sciences Center, EL PASO, TEXAS, United States of America

BACKGROUND

Although research suggests that many patients prefer an active role in decisions about their healthcare, clinicians generally do not have the skills to routinely promote a shared decision-making-process in practice. The goal of this work was to identify skills clinicians need to develop, and key behaviors they should exhibit, for promoting shared decision-making (SDM) with their patients.

DESIGN AND METHODS

An extensive literature search was performed to identify clinician training programs in SDM. Medline, Scopus, and Cochrane library databases were searched. We also reviewed presentations at recent research conferences on SDM. The search was further expanded to coding systems and conceptual models. To supplement the literature search, we contacted several leaders in the field of SDM to identify additional training programs.

RESULTS

The review resulted in 199 unique competency statements being identified. Five members of the research team then sorted the competencies into 24 broader thematic areas. These thematic areas were further reduced into 6 macro-level behaviors for achieving SDM, roughly corresponding to the flow of a clinical encounter: 1) describe the health issue the patient faces and the need for a decision; 2) discuss with the patient the options, including the pros and cons, the likelihood of important outcomes, and assess the patient's comprehension; 3) explore what is important to the patient in making a decision; 4) assess the patient's desired role in making the decision; 5) assess the patient's readiness to make a decision, preferences for options, and negotiate a mutually agreed upon course of action; and 6) make plans for follow up and providing support. In addition, the following across-theme competencies were identified: 1) encouraging patient questions, 2) providing guidance in the decision making-process, 3) tailoring information to the patient, and 4) establishing a partnership with the patient.

CONCLUSION

This content review of training programs, conceptual models, and measurement/coding systems identified key behaviors a clinician should exhibit in promoting a shared decision making-process with patients. These clinician competencies are being used to identify learning objectives for use in an online training program on SDM.

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97 POSTER SESSION TUESDAY

Selecting men with prostate cancer for active surveillance using a risk calculator: a prospective impact study

H.A. van Vugt, M. Roobol, C. Bangma, I. Korfage, E. Steyerberg
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BACKGROUND

Prostate cancer (PCa) prediction models designed to differentiate aggressive from potentially indolent cancer can support in treatment decision-making. The European Randomized study of Screening for Prostate Cancer (ERSPC) risk calculator (RC) predicts the probability of potentially indolent PCa, using serum prostate specific antigen (PSA), prostate volume and pathological findings on biopsy. We assessed urologists' and patients' compliance with treatment recommendations based on the RC, the reasons for non-compliance, and differences between compliers and non-compliers.

DESIGN AND METHODS

Eight urologists from 5 Dutch hospitals included 213 patients with PCa (55-75 years), in 2008-2010. Inclusion criteria were PSA <20ng/ml, clinical stage T1, T2a-c disease, <50% positive sextant biopsy cores, ≤20 mm cancer, ≥40 mm benign tissue and Gleason ≤3 + 3. If the calculated probability of indolent PCa was >70% active surveillance (AS) was recommended, and active treatment (AT) otherwise. Reasons for non-compliance of both urologists and patients were assessed. After the treatment decision was made, patients completed a questionnaire about treatment choice and related (dis) advantages, knowledge about PCa, self-related health (SF-12), anxiety (STAI-6, MAX-PC), depression (CESD), personality (EPQ), and decision-making measurements (DCS).

RESULTS

Overall both urologists and patients were compliant with the RC recommendations in 155/213 cases (73%). AS was recommended in 50 of the 213 cases and most patients (42/50, 84%) were compliant with this recommendation. Another 49 choose AS, in contrast to the AT recommendation (49/163, 30%). The most common reason of urologist for non-compliance with AT recommendations was that their patients preferred AS (n=27). The most reported advantage of AS by patients was the delay of physical side effects of AT (n=18). Compliers with AT recommendations had higher PSA levels (mean 8 vs.7 ng/ml, p=0.03), more tumor tissue in their biopsies (mean 7 vs. 3 mm, p<0.001), lower probabilities of indolent PCa (mean 38% vs. 53%, p<0.001) and higher general anxiety scores (mean 42 vs. 38, p<0.05) than non-compliers.

CONCLUSIONS

The AS recommendations of the RC were followed in almost all patients. One third of the men with an AT recommendation chose for AS. Research is needed to further improve insight into the development of patient's motives.

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145 POSTER SESSION TUESDAY

The influence of social demographic and psychological factors on patients' involvement in decision making on the need of a prostate biopsy

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Erasmus Medical Center, ROTTERDAM, Nederland

BACKGROUND

Patients expect increasingly to be involved in health care decisions. However, the extent of patients' involvement in decision-making varies substantially. We assessed levels of participation in decision-making about the need of a prostate biopsy in men suspected of prostate cancer (PCa) and assessed the influence of social demographic and psychological factors on men's participation in decision-making.

DESIGN AND METHODS

From October 2008 to August 2010, 291 men (55-75 years) were included in 5 Dutch hospitals. Urologists used a risk calculator (RC) in the presence of men to calculate the probability of a positive prostate biopsy (www.prostatecancer-riskcalculator.com). After decision-making to undergo a biopsy or not, men completed a questionnaire about social demographic status (age, marital status, job status, educational level), general health and anxiety (SF-12, STAI-6), PCa-specific anxiety (MAX-PC), decision-making (DCS), knowledge about PCa and the extent of their participation. Levels of participation were measured with a self-developed item 'Who was most influential in the treatment choice, you or your urologist?', with five response options. These were recoded in three decision categories: patient-based, shared-decision and urologist-based. Spearman rank correlation and Contingency coefficients were used to relate social demographic and psychological factors to levels of participation.

RESULTS

288 men assessed their participation in the decisional process about the need of a biopsy. Their mean age was 64 years, 82% were married/cohabiting (235/288), 56% retired (106/288), 37% highly educated (106/288), 70% choose for a biopsy (201/288) which was according to the RC recommendation in 81% of the cases (163/201), 17% considered their decision patient-based (48/288), 46% consider it shared (133/288) and 37% urologist-based (107/288%). Patients' participation in decision-making was not significantly related to patient's age (0.02, $p=0.74$). The influence of urologists in decision-making was positively related with higher decisional conflict scores (0.168, $p<0.01$). Urologists were more influential if men made a 'no biopsy' decision compliant with the RC recommendation (0.160, $p=0.02$).

CONCLUSIONS

Most men considered their decision on prostate biopsy a shared-decision or urologist-based. Research is recommended into reasons for higher decisional conflict scores in men whose decision was mainly based on the urologist's opinion.

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47 ORAL PARALLEL SESSION 6

Shared decision making in end-of-life care for people with intellectual disabilities?

A.M.A. Wagemans[1], H.M.J. van Schrojenstein Lantman[2], I.M. Proot[3], J. Metsemakers[4], I. Tuffrey-Wijne[5], L.M.G. Curfs[3]
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BACKGROUND

The aim of this study was to investigate the process of decision-making in end-of-life decisions regarding people with intellectual disabilities, from the perspective of doctors.

DESIGN AND METHODS

This qualitative study involved nine semi-structured interviews with doctors after the deaths of patients with intellectual disabilities. The interviews were transcribed verbatim and analyzed using the grounded theory procedures.

RESULTS

We identified the core category of "Shared decision-making", which characterized the process of decision-making and the participants involved. People with intellectual disabilities themselves were not involved in the decision-making process. Relatives and professional care providers both contributed to the decisions, although doctors felt they were ultimately responsible. Part of the decision-making process is "Knowing the patients and their vulnerability". Doctors were supported in their decision-making tasks by "Satisfactory professional relationships"with relatives and professional care providers. "Delegating the evaluation of quality of life"was a process in which doctors left it to relatives to evaluate quality of life. Doctors seemed to base end-of-life decisions on health issues and gave patients' representatives the opportunity to evaluate the quality of life of their loved ones. Doctors sought consensus with representatives and professional care providers.

CONCLUSION

In order to take the leading role in the process of decision-making, doctors would have to evaluate the subjective interests of their incompetent patients as part of their professional standards. Doctors should be trained to describe more explicitly the reasons for their medical decisions and should train themselves in discussing ethical issues. Shared decision-making and striving for consensus require trained professionals and a clear decision-support instrument.

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What do representatives need for shared decision making in end-of-life care for people with intellectual disabilities?

A.M.A. Wagemans[1], H.M.J. van Schrojenstein Lantman[2], I.M. Proot[3], J. Metsemakers[4], I. Tuffrey-Wijne[5], L.M.G. Curfs[3]
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BACKGROUND

The aim of this study was to investigate the process of decision-making in end-of-life decisions regarding people with intellectual disabilities, from the perspective of representatives.

DESIGN AND METHODS

This qualitative study involved ten semi-structured interviews with representatives after the deaths of patients with intellectual disabilities. The interviews were transcribed verbatim and analyzed using the grounded theory procedures.

RESULTS

at this moment the interviews with representatives are being analyzed and results will be presented at the congress. The first outcomes would seem to indicate that representatives were uncertain about who had the responsibility to decide in medical end-of-life decisions, but they were not uncertain about what to decide for their loved ones. They had very firm ideas about the quality of life of their loved one.

CONCLUSION

In the process of end-of-life decisions representatives do not strive for consensus contrary to doctors. A clear decision-support instrument could probably help representatives and doctors in the process of end-of-life decisions for people with intellectual disabilities. This will clarify roles and will support a process of shared decision making.

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163 POSTER SESSION MONDAY

The Effect of Cardiovascular Risk Representation Formats on Intentions, Understanding and Emotional Affect: Results of a web-based Randomised Controlled Trial.

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BACKGROUND

The future risk of heart disease can be predicted with increasing precision. However, more research is needed into how this risk is conveyed and presented. This study compared the effects of different cardiovascular risk representation formats on individuals' intention to change behaviour to reduce risk, understanding of risk information, Emotional Affect (e.g. PANAS) and worry about future risk of heart disease.

DESIGN AND METHODS

A web-based RCT comprising two intervention groups and two control groups, to account for a potential Hawthorne effect. The first control group completed a pre-intervention questionnaire on cardiovascular risk perceptions. The sample comprised adults aged 45-64 years without existing heart disease. A website was developed with a risk calculator (Personal Heart Score) and questionnaires. It predicted 10-year future risk of having a coronary heart disease event and categorised risk as low (<10%), moderate (10-20%) or high (>20%).The risk categories were presented in one of three formats: bar graph, pictogram and metonym (image depicting seriousness of having a myocardial infarction).

RESULTS

903 respondents completed the trial. 83% were categorised as low risk, 62% were female, and 53% were educated to university degree level or higher. No significant main effect of cardiovascular risk representation formats was found. However, there was a significant decrease in positive and negative affect and worry about future risk of heart disease, after viewing cardiovascular risk across all the formats. The pictogram format significantly reduced positive affect and worry about future risk of heart disease the most. Whereas, the bar graph format reduced negative affect the most.

CONCLUSION

No significant main effects of cardiovascular risk representation formats were found in this trial. One reason for the lack of effect could be the biased sample, which is a concern for web-based studies. Therefore, the true effects of risk representation formats should not be underestimated. This trial was successful in reducing inappropriate negative affect and worry about future risk of heart disease in the 'worried well', demonstrating the importance of risk prediction tools in better informing individuals, leading them to have more realistic risk perceptions.

260 POSTER SESSION MONDAY

Web-based Cardiovascular Risk Prediction: A Critical Appraisal of the quality of risk communication used by publicly available tools most likely to be retrieved using Google.

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[2]Maastricht University, MAASTRICHT, Netherlands

BACKGROUND

Tools that predict future cardiovascular risk are freely available on the internet. Therefore, it is important to assess how risk is being portrayed in these tools, to find out whether it adheres to evidence-based best practice. The aim of this study was to: (1) determine which web-based cardiovascular risk prediction tools are most likely to be found on the internet when people seek on-line cardiovascular risk assessment, (2) assess the quality of the risk communication portrayals, and (3) examine how and to what extent cardiovascular risk reduction is encouraged.

DESIGN AND METHODS

Cross-sectional criterion-based critical appraisal of web-based cardiovascular risk prediction tools was conducted using hypothetical patient profiles. The top ten most commonly retrieved tools were identified by entering tailored search terms into Google.com. Searches were conducted over 5 consecutive days in May 2010. The tools were critically appraised against best practice criteria for risk communication (e.g. previous research findings and guidelines on risk communication) and on the number of features employed to facilitate decision making about cardiovascular risk reduction.

RESULTS

38% of the tools were from a university/research setting. There was variation in the quality of risk communication employed by the tools. Percentages were used to present risk information by all tools except one. 46% used graphical representation to accompany the numerical risk information. Nearly all tools calculated absolute 10-year risk; three tools provided alternative risks such as relative or comparative risk. Some tools were more helpful than others in assisting with decision making about risk reduction through behaviour change and/or treatment options. One tool stood out by providing 12 features to assist cardiovascular risk reduction. Generally, the tools that scored lower on risk communication also scored lower on their focus on risk reduction.

CONCLUSION

Developers of web-based cardiovascular risk prediction tools could improve their tools by incorporating the findings from the research evidence and guidelines on risk communication, as well as offering more features that help with the decision making process of cardiovascular risk reduction.

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188 POSTER SESSION TUESDAY

Collision or collaboration? The relation between clinical practice guidelines and patient decision aids.

T. van der Weijden[1], A. Boivin[2], J. Burgers[2], H. Schünemann[3], G. Elwyn[4]

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BACKGROUND

Clinical practice guidelines (CPGs) and patient decision aids are well-recognized decision support tools that should facilitate uptake of best evidence in clinical practice in a patient-centered manner. However, these tools support different audiences. This article charts the landscape of CPGs and patient decision aids.

DESIGN AND METHODS

We used material from a qualitative study as starting point to draft a model on CPG and patient decision aids. The qualitative study consisted of in-depth interviews with stakeholders to explore ideas on how clinical practice guidelines could be used to facilitate shared decision making. We interviewed 20 participants from 7 countries face-to-face or by telephone by using open questions. Using the findings from the interviews, we drafted a model on CPG and patient decision aids. The model was refined after discussions among the authors, representing opinion leaders in the area of CPGs and patient decision aids.

RESULTS

The final model include two dimensions for mapping decision support tools for medical practice. 1) The target user and his or her level of decision making; either for groups of patients (e.g. by policy makers) or for an individual patient in a specific context (e.g. by medical professionals, patients, or both). 2) The level of uncertainty related to the option(s) available: either supporting more directive decision making (behavior support) in the case of strong recommendations with one single best option, or supporting dialog (deliberation support) on the pros and cons of different options in the case of conditional (or weak) recommendations.

CONCLUSION

We conclude that it is important to establish closer links between CPGs and patient decision aids, and to encourage collaborative and parallel development of both, taking the different dimensions into account. Such collaboration will encourage the design of decision support tools that share the same evidence but are designed for specific, mutually valid aims, and facilitate their implementation in clinical practice.

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207 SYMPOSIUM PARALLEL SESSION 5

Implementing Shared Decision Making in the Real World: Four Case Studies

R.M.W. Wexler[1], J. Currey[2], C. Lewis[3], L. Morrissey[4], D. Swieskowski[5], M. Gassert[1]
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Session chairperson: Richard Wexler, MD - Foundation for Informed Medical Decision Making

Number of individual talks: 4

- "Integrating Decision Aids and Enhancing Shared Decision Making in Rural Non-Academic Primary Care: The Essential role of Practice Facilitation"- Jill Currey, MPH - Oregon Rural Practice-based Research Network, Oregon Health & Science University
- "The UNC Experience"- Carmen Lewis, MD, MPH - The University of North Carolina at Chapel Hill
- "Decision Support for Benign Prostatic Hyperplasia"- Larry Morrissey, MD - Stillwater Medical Group
- "Decision Aid Integration and Shared Decision Making in the Primary Care Medical Home"- Dave Swieskowski, MD, MBA - Mercy Clinics, Inc., Des Moines, IA

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30 POSTER SESSION MONDAY

Randomized Pilot-test of a Patient Decision Support Intervention for Depressive Symptoms in Type 2 Diabetes Mellitus

C.E.W. Wills, C. Hechmer, K. Glass, C. Holloman, J. Olson, C. Miller, M. Belury, A.M. Duchemin, W. Miser
The Ohio State University, COLUMBUS, United States of America

BACKGROUND

Mild-moderate depressive symptoms occur in 30-50% of adults who have diabetes and substantially impair diabetes self-management and health outcomes. Depressive symptom prevalence is increasing within an epidemic of Type 2 diabetes affecting over 23.5 million (20.7%) of the U.S. adult population. There are multiple options for managing mild-moderate depressive symptoms and choices about the options are driven by patient preferences. The primary aim of this study is to evaluate if a DSI with decision coaching and shared decision-making training components to support making choices about managing depressive symptoms results in improved decision and depressive and diabetes outcomes over a 6-month time period, as compared to usual care only. A secondary study aim is to evaluate DSI feasibility and costs.

DESIGN AND METHODS

A stratified (gender, depressive symptom severity) randomized block design is being used to assign 60 adults with Type 2 diabetes and depressive symptoms to either usual care (N=30) or to the DSI plus usual care (N = 30). Data are being collected at 5 time points: baseline (pre-intervention), mid-point of the intervention (2 weeks), and post-intervention at 6 weeks, and 3 and 6 months.

RESULTS

Recruitment and implementation of the intervention are in process and updated results will be presented at the conference. A sociodemographically diverse sample is being recruited from an urban area in the Midwestern U.S. Initial results show trends for activation of decision-making and improved depressive and diabetes outcomes at post-intervention.

CONCLUSION

Improving decision outcomes is a promising but currently understudied approach to improving clinical outcomes for mental health conditions. This study addresses two nationally-prioritized health problems (diabetes and depression) within a randomized trial of a decision support intervention to improve clinical outcomes for which shared decision-making (SDM) and patient decision support tools are likely to make a significant impact. The results of this study will add to new knowledge about the effects of DSIs for supporting effective decision-making about managing mental health conditions.

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31 ORAL PARALLEL SESSION 1

Validation of the Shared Decision Making Questionnaire-9 (SDM-Q-9) in a Stratified Age-Proportionate U.S. Sample

C.E.W. Wills, K. Glass, C. Holloman, C. Hechmer, J. Olson, C. Miller, M. Belury, A.M. Duchemin, W. Miser
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BACKGROUND

The Shared Decision Making Questionnaire-9 (SDM-Q-9) is a brief self-report measure of patient perceptions of shared decision-making in health care consultations that was recently validated in a German adult-age primary care sample (Kriston, 2010), but has not yet been validated in a

U.S. sample. The purpose of this study was to validate the SDM-Q-9 in a U.S. sample.

DESIGN AND METHODS

A stratified (race, ethnicity, gender) randomly-selected age-proportionate national sample of adults aged 21-70 years was recruited from the National Institutes of Health ResearchMatch research volunteer registry. The obtained sample (N = 488; mean age 41.4 years) was 14.9% non-white, 8.6% Hispanic, and 34.8% male. Respondents completed a secure online survey (45.7% response rate) that included the SDM-Q-9, other decision-making measures, and sociodemographic and health conditions questionnaires. Decision-making measures were completed with reference to a consultation with a health care provider within the past 3 months for diagnosis, treatment, or referral for a personally-experienced health issue.

RESULTS

The SDM-Q-9 demonstrated high internal consistency reliability ($\alpha = .94$) and a unidimensional factor structure that was not significantly improved by item deletion. Concurrent validity was demonstrated via expected patterns of correlations between the SDM-Q-9 and two other well-validated measures of the decision-making process: Satisfaction With Decision scale (.59, $p < .001$), and the Decisional Conflict Scale (- .10, $p < .03$). Sampling strata and level of education were not significantly associated with the SDM-Q-9 or other decision-making measures, but a majority of the respondents reported having a college degree and health insurance. A wide variety of decisions were reported related to diagnosis, treatment and referral for current health issues.

CONCLUSION

The results show that the SDM-Q-9 is a reliable and valid measure in a general U.S. sample. Overall results were consistent with the original German primary care validation study. The generalizability of the results is limited by use of a predominately white and relatively well-educated sample drawn from a national research volunteer registry. Additional research should evaluate the SDM-Q-9 with larger and diverse samples, as well as assess the SDM-Q-9 for sensitivity to change in clinical trials of decision support interventions.

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17 POSTER SESSION MONDAY

Choosing dialysis modality: decision making in a chronic illness context

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INTRODUCTION

Patients with End Stage Renal Failure are encouraged to make an informed decision when choosing between peritoneal dialysis and haemodialysis. Survival rates for both options are equivalent yet there is wide variation in peritoneal dialysis uptake in the adult UK population. It is unclear how much of this variation is attributable to variations in patients' preferences. This study describes patients' decision making about dialysis options.

METHOD

A survey employing interview methods was employed to explore 20 patients' views and experiences of making their dialysis choice. Patients were at different stages of the decision making process. Data were analysed using a thematic framework analysis to develop data driven themes and provide descriptive accounts of how patients managed their illness and made treatment decisions.

RESULTS

Although patients' kidney disease was deteriorating, most were still asymptomatic. Patients talked about the challenges of living with chronic kidney disease and had strong emotions about commencing renal replacement therapy. Patients were provided with an abundance of information about treatment options in different formats including booklets, one-to-one counselling and workshops with other patients. Patients tended not to distinguish between the different types of dialysis and/or to have an in-depth knowledge about the options.

DISCUSSION

Patients did not perceive choosing between dialysis options to be a significant decision. Further, they did not seem to have considered the impact of the different options on their illness management and lifestyle. It may be that patients perceived the dialysis decision to be choosing (not) to have renal replacement therapy rather than thinking actively about which dialysis option would suit them best. Additionally, as patients are asymptomatic, they may feel that they did not yet need to engage with the information. Finally, patients were provided with a lot of information about both dialysis options but there was some evidence that there were more opportunities to encounter positive information about haemodialysis. It seems unlikely that patients are able to make an informed decision between dialysis options.

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15 POSTER SESSION MONDAY

Developing a model of decision support needs for women at increased risk of breast/ovarian cancer

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BACKGROUND

Women at increased risk of breast/ovarian cancer in the UK are offered prophylactic oophorectomy, which decreases ovarian cancer risk by up to 90%, but results in infertility and surgical menopause. These women face difficult decisions for managing their cancer risk and have to balance a number of complex emotions. Such emotions influence how women interpret 'risk' and can affect their decision making and coping strategies. Despite the existence of a wealth of cognitive decision making theories, there appears to be a lack of theories specifically concerned with information and emotional decision support needs of women in this specific situation.

DESIGN AND METHODS

Reviews of decision support interventions were initially used to identify decision making and coping theories which had been referred to in this context. Subsequently, a snowballing approach was employed to identify further relevant theories. Communication models were identified through a title search for the terms "Shared Decision Making"and "Communication"in databases (Embase, Medline and PsycInfo), as well as manual searches of the Journal of Health Communication, Quality and Safety in Health Care (BMJ) and Health Communication. Drawing on principles of meta-theorizing, main ideas were extracted through in-depth reading to synthesize a preliminary model.

RESULTS

A total of 21 (11 decision making and 10 coping) theories and 6 communication models were included in the final review. A lack of theories specifically addressing the various information and emotional needs of women faced with cancer risk reduction decisions was found. To address this deficit, a preliminary model was synthesized which integrates aspects of decision making, such as the theory of decision avoidance and the model of affective forecasting, with coping theory, such as the transactional theory of stress, appraisal and coping, as well as various aspects of communication models.

CONCLUSION

A preliminary model has been developed which is specifically concerned with decision support needs of women facing decisions on breast/ovarian cancer risk reduction. The model will guide the design of a decision aid to help women understand their 'risk' status and make informed, value-adjusted choices. Ultimately, the model could also be applied to similar 'risk' reduction decisions.

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146 POSTER SESSION MONDAY

Decision support for choosing urinary diversion with radical cystectomy: a literature review

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BACKGROUND

Selection of how to divert urine when the bladder is removed for cancer (radical cystectomy) can constitute a preference-sensitive choice. The two main methods of urinary diversion are 'ileal conduit diversion' (ICD) and 'orthotopic neobladder formation' (ONF). ICD results in a 'stoma', an opening on the abdomen, whilst ONF results an internal substitute bladder. These methods give very comparable clinical outcomes but each carries its own disadvantages which can affect each individual patient differently. Some patients are suited to either option and face a choice, prompting the question of whether there is decision support for this choice - the focus of this review.

DESIGN AND METHOD

A systematic electronic database search was conducted. Access to specialist shared decision making (SDM) websites, SDM researchers and hand-searching article references were also pursued. Primary research articles which reported on decision support or aspects of SDM for choosing between stoma and non-stoma forming therapeutic options in three conditions were included: radical cystectomy for bladder cancer; inflammatory bowel diseases (IBS); and colorectal cancer.

RESULTS

No article reported on decision support interventions for any of these conditions. However, a structured-interview study reported over half of colorectal cancer patients treated with stoma or non-stoma forming surgery would like more information prior to surgery. A cross-sectional survey revealed that half of patients with stoma for IBS or colorectal cancer were dissatisfied with the information provided prior to surgery by healthcare professionals, and over half of the patients did not feel sufficiently involved in decision making about their medical and personal care. Another cross-sectional survey showed that only half of Asian patients with ileostomy for IBS recalled seeing a stoma care nurse pre-surgery and few remembered discussion on employment, education matters and marital problems.

CONCLUSION

There is a clear lack of decision support for making the life-changing decision on therapeutic options not only in the context of cancer cystectomy, but also on other comparable decisions, with pre-surgery counselling far from optimal. Before developing such support, a detailed insight is needed into the process of opting for or against stoma formation.

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158 ORAL PARALLEL SESSION 6

What constitutes consent when parents and daughters make different decisions about having the HPV vaccine? Qualitative interviews with stakeholders.

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Cardiff University, CARDIFF, United Kingdom

OBJECTIVE

The UK Human Papillomavirus (HPV) vaccine programme commenced in 2008 for 12-13 year-old school girls. The UK government's sexual health strategy has promoted accessibility of sexual health services to under-16s, and the administration of the HPV vaccine is one area where confusion is likely to occur over whose rights prevail. In the UK, although competence to consent is assumed in those over 16 years, in 1985 Lord Fraser established in the Gillick ruling that children under 16 years who can demonstrate their capacity to sufficiently understand the proposed intervention will have the capacity to consent. We examine how health professionals handle consent in relation to the HPV vaccine when there is a difference of opinion between daughters and parents/guardians.

DESIGN AND METHODS

Qualitative study using semi-structured interviews with a sample of 25 stakeholders: 14 professionals involved in the development of the HPV vaccination programme, and 11 professionals involved in its implementation.

RESULTS

Over-riding parents' wishes was perceived as problematic and could damage relations between school and parents. A number of practical problems were raised in relation to establishing whether parents were genuinely against their daughter receiving the vaccine. Although many respondents recognised the Gillick guidelines (and other guidance) were relevant in establishing whether a girl could provide consent herself, they still felt that there were significant problems in establishing whether girls could be assessed as Gillick competent. In some areas school nurses had been advised not to give the vaccine in the absence of parental consent. None of the respondents suggested that a girl should be vaccinated against her consent even if her parents wanted her to have the vaccine.

CONCLUSIONS

While the Gillick guidelines provide a legal framework to help professionals make judgements about adolescents consenting for medical treatment, in practice there appears to be variable and confused interpretation of this guidance. Improved legal structures, management procedures and professional advice, are needed to support those who are assessing competence and establishing consent to vaccinate adolescents in a school setting. Conflicting consent for this vaccine, and others like it, requires a negotiated process between parents, adolescents, and the vaccinators.

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27 ORAL PARALLEL SESSION 2

Does Adding Motion to Icon Array Risk Graphics Help?

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BACKGROUND

Pictographs/icon arrays can improve comprehension of risk statistics, especially among the less numerate. Prior research has examined static graphs, but few studies have considered interactive applications. Computer-based communications (e.g., online decision aids) could accommodate animated visual images to reinforce risk messages. To our knowledge, no studies have rigorously examined whether animated graphics with motion cues could improve comprehension of risk statistics.

DESIGN AND METHODS

4,243 members of a demographically diverse Internet panel read a scenario about two hypothetical treatments for thyroid cancer. Each was described as equally effective but varied in side effects (with one option slightly better than the other). Participants were randomly assigned to receive all risk information in one of 10 pictograph formats. We compared a control condition of static grouped icons with a static scattered icon display and with 8 Flash-based animated versions that included (a) building the risk 1 icon at a time, (b) having scattered risk settle into a group, and/or (c) having scattered risk shuffle itself (either automatically or by user control). We assessed participants' ability to choose the better treatment, their gist knowledge, and their risk recall, controlling for subjective numeracy and need for cognition.

RESULTS

When compared against static grouped icon arrays, no animations significantly improved any outcomes, and most showed significant performance degradations. Static scattered-icon displays performed poorly as well. However, participants who received animations of grouped icons in which at-risk icons appeared one at a time performed as well on all outcomes as the static grouped-icon control group. Participants who saw sequentially-built scattered icons that then settled also performed as well as the static grouped-icon control group on all measures except recall. These animations were the only two with preference ratings similar to those for the static grouped-icon control condition.

CONCLUSIONS

Many combinations of animation, especially those with scattered icons that shuffle randomly, appear to inhibit comprehension. Static pictographs that group risk icons, however, perform very well on measures of comprehension and choice. Animations that build icon arrays one unit at a time or settle scattered icons into an at-risk group may be helpful under certain circumstances.

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