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BOOK OF ABSTRACT

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ISDM 2017

Poster Session 1

Monday 3rd

16:30—18:00

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ISDM 2017

Medication and pregnancy: the need to incorporate shared-decision making into Autoimmune Rheumatic Disease consultations.

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SDM IN CHRONIC CONDITIONS

Background and aims

Autoimmune rheumatic diseases (ARDs) are chronic conditions that affect women's vital organs, joints and muscles. ARDs include conditions such as arthritis, lupus and vasculitis and affect >25,000 women of childbearing age in the UK. Women with ARDs have to consider the benefits of medication use in terms of disease control, as well as the barriers associated with planning a family such as side effects on women's fertility and tetratogenic effects. When facing treatment decisions, shared decision making (SDM) can facilitate discussion of different ARD disease treatment options, their associated pros and cons in terms of disease management and impact on future pregnancies, as well as the incorporation of patient preference into final treatment selection. There is a lack of evidence for SDM in the context of ARD treatment decisions.

Our aim was to explore women's information needs, whether they currently feel involved in decisions and whether they would value opportunity and support to share decisions.

Methods

A mixed-methods design was used. A cross-sectional on-line survey (advertised through social media) of 131 UK women with ARDs aged 18-49 years who are either thinking about getting pregnant, currently pregnant or have recently had a child (<5yrs) was conducted. Measures included the Arthritis Impact Measurement Scale 2 (short form), Educational Needs Assessment Tool, and questions about support received and required. Qualitative interviews were carried out with a sub-sample of women (n=9) to explore their experiences in more depth. Participatory qualitative methods were used, where women completed a pre-interview timeline in order to tell their story. Interviews were audio-recorded, transcribed verbatim, and thematically analysed.

Results

Of the 131 women completed the survey, 38% were thinking of getting pregnant in the next 5 years, 48% had been pregnant in the last 5 years, 7% were trying to conceive, and 7% were pregnant. We found that 41% currently wanted more information about their disease and 51% of women wanted to be more involved in sharing decisions with clinicians about their treatments. In interviews, women reported that they would like to have had a detailed discussion about the benefits and barriers of medications in relation to planning a family. Women felt that clinicians focused on disease management, rather than adopting a more holistic approach. Women expressed a need for more information resources to help them navigate through the different medication options and the impacts they might have on pregnancy.

Conclusion

Women need more information and want to be more involved in treatment decisions. Women want to be involved in treatment decisions that might impact on planning a family. SDM can facilitate this by ensuring that treatment options are presented, risks and benefits in relation to disease management as well as impact on pregnancy are discussed, patient preferences are elicited and preference sensitive decisions are made. Therefore, SDM is an approach that seems particularly suited for application in chronic conditions such as ARD consultations with women of childbearing age. Further research is required to establish how SDM could be supported in this context.

Contextualizing Chronic Care: A pilot study of the ICAN Discussion Aid

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Background

One of four adults, three of four over age 65 have chronic conditions, representing a growing population in primary care. While SDM tools exist for making specific decisions about treatment, tools that contextualize care across decisions and elicit treatment burden for this population are lacking. The ICAN Discussion Aid is an SDM tool that can address these needs and was designed for use during busy primary care encounters. We conducted a pilot evaluation of ICAN in primary care encounters to inform future studies of ICAN.

Methods

We video recorded 100 encounters and administered a brief post-visit survey to patients and clinicians. 81 encounters were evaluable for analyses. The first 39 evaluable encounters used no discussion aid. Clinicians were then trained in the ICAN Discussion Aid and asked to use it during the remainder of the encounters (n=42). The patient survey included the Consultation Care Measure (CCM). CCM quantifies the extent to which patients and clinicians (a) share an understanding of the impact health problems have on the patient's life, and (b) share a decision about the plan of action. The clinician survey used an 8-item (each item on a 4 point scale) version of the CCM to determine the extent to which the clinician felt they had understood and addressed the situation with the patient. We tested for differences in CCM scores between ICAN and control encounters, and for agreement in clinician and patient scores. Videographic analyses of encounters to measure fidelity in the use of ICAN and the amount of contextual and treatment burden information elicited during the consultation with and without ICAN are ongoing.

Results

With and without ICAN, patients gave clinicians favorable (lower) CCM scores [ICAN Adjusted mean 31.5 (95% CI 25, 39) vs. 34.6, (95% CI 29, 43)]. There was low agreement between clinician and patient CCM items, but larger differences after ICAN encounters: with ICAN use, patients felt better understood by their clinicians by almost a point (>0.8) across 6 of the 8 items CCM items, while scores in the control condition were more similar.

Conclusion

Although fidelity assessments are pending, this pilot found that using ICAN in primary care was feasible. Despite little room for improvement from baseline (given the ceiling effect of the CCM in this context), a tantalizing signal suggests ICAN can contribute to patients feeling better understood and better able to share in designing the care plan. It is unclear if ICAN could perform better in other more unfavorable situations (e.g., underserved population, non-salaried clinicians, new patient-clinician relationships, rushed appointments without continuity of care). Ongoing videographic analyses will improve our interpretation of these findings. A hypothesis worth exploring is whether the higher rating of clinicians' behavior compared to clinicians' own perceptions suggests that patients feeling better understood when care is contextualized may come at a cost of making clinicians more uncomfortable with the ambiguity introduced by eliciting this information with the ICAN tool.

What are the attitudes and experiences of adolescents living with chronic conditions towards participation in shared decision making?

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Background and aims:

Chronic conditions are a major source of morbidity, mortality and cost worldwide. Young people with chronic conditions have been found to have poorer educational, vocational and financial outcomes in young adulthood when compared to their healthier peers. Adolescents with chronic conditions have demonstrated poorer illness management than young children or adults. Shared decision making (SDM) is one way to improve care for adolescent patients with chronic conditions, and is actively supported by NHS bodies and patient organisations. Perceived SDM was found to be associated with higher reported illness management competence and fewer treatment problems among adolescents with chronic conditions.

Chronically ill adolescents were found to act as bystanders during consultations, and were rarely encouraged to participate. Clinicians often view the parents as the primary figure in decision-making. Little is known about the adolescent patient perspective regarding SDM involvement with health professionals. The aim of this review is to explore the attitudes and experiences of adolescents (age 10-19) with chronic conditions towards involvement in SDM about their illness management.

Methods:

A systematic review will be performed with the objective of summarising the attitudes and experiences of adolescents with chronic illness regarding SDM about their illness manegement. The following databases have been systematically searched for relevant publications: Embase, Medline, Cochrane Library, CINAHL, PsycINFO and Scopus. A search of grey literature was also conducted, and experts in the field were consulted to identify unpublished or in progress works. Original research studies that describe attitudes and / or experiences of adolescent patients with one or more specified chronic condition, will be included. Descriptions of the sample characteristics, methodology, use of theoretical framework, and relevant findings will be reported. The quality of the reports will be assessed according to the design of each study.

A scoping review identified that qualifying records primarily employ qualitative methodology and are heterogeneous in nature, which precludes quantitative analysis. Therefore, a narrative synthesis will be undertaken. The data extracted will vary according to the methodology of the study. From quantitative studies, the relevant questionnaire or survey data will be extracted. From the qualitative studies, the main focus will be on actual patient quotes and summaries of accounts. Thematic analysis will be used to extract, code, organise and report patterns or themes of the extracted data.

Results:

A total of 6562 records were identified through the searches, of which 11 met the inclusion criteria. These studies included reports of attitudes and/or experiences towards SDM described from the patient patient perspective.

Completion of the systematic review is expected by 31/05/17. Due to the limited literature available on the topic, the findings are predicted to identify research gaps which will be addressed in a subsequent qualitative study. The purpose of the results is to assist in the development of an intervention addressing the barriers which prevent adolescents with chronic illness from SDM participation.

A Novel System for Sharing Patient-Reported Outcomes in ADHD between Parents, Pediatricians and Teachers

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Background

Attention-deficit/hyperactivity disorder (ADHD) is the most common chronic childhood neurobehavioral disorder. Although portals have been developed for pediatricians to collect information from parents and teachers, we lack systems that share relevant information between families, pediatricians and teachers in order to overcome fragmented care that worsens outcomes.

Aims

To co-produce and evaluate innovations to an existing ADHD survey collection system to enable information sharing between families, pediatricians and teachers.

Methods

We conducted a prospective technology development and implementation evaluation, engaging 8 parents, 11 pediatricians and 8 educators in the iterative process. From 9/2015 to 9/2016, we held 2 family advisor, 3 educator, 3 pediatrician and 2 joint parent-educator meetings that set priorities. The original system, which collects information from families and teachers by sending survey links by email following parental consent and presents this information to the pediatrician within the electronic health record (EHR), was implemented in December, 2014 in 31 pediatric primary care practices in 2 US states. Information collected from parents includes treatment preferences and goals and the Vanderbilt rating scales for ADHD symptoms, co-morbidities and performance (validated measures). We described parent willingness to share information with teachers. T-tests and chi-square tests assessed the association of child symptoms, performance and co-morbidities with parents' willingness to share.

Results

The stakeholder-engaged design process prioritized the following features: (1) parents' ability to control which survey components (goals, symptoms, performance, medication side-effects) were shared with teachers and (2) parents' and teachers' ability to receive information entered by each other and retain their own submitted information. These features were added in January, 2017. 209 parents submitted responses within 28 days of the upgrade. Of these, 138 (66%) agreed to share information (114 (83%) sharing all information). Parents of children with greater hyperactivity (p=.03) as well as impaired performance (76% versus 46%, p<.001) were more likely to share than others. We observed a trend toward information sharing among parents of children with ADHD co-morbidities (oppositionality, anxiety, depression) (92% versus 71%, p=.2).

Conclusion

A stakeholder-engaged process developed feasible and acceptable upgrades to an EHR-linked system that support parents' information sharing with pediatricians and teachers for a common chronic condition. Results indicate that parents of children with greater symptomatology and impairments, those likely to benefit most, were most likely to share. This system provides a model for how patient-reported outcomes may be shared between families and interdisciplinary care teams.

First steps in developing a novel decision support intervention for pain management options in juvenile idiopathic arthritis

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Background and aims

Juvenile idiopathic arthritis (JIA) is the most common cause of chronic musculoskeletal pain among youth, and can negatively impact all aspects of health-related quality of life. However, pain is often under-recognized as adolescents with JIA often do not feel comfortable asking questions and discussing their health with their health providers. To address the complexity of pain management options and challenges for youth to engage in in-depth discussions about these options, we propose to develop a decision support intervention for adolescents with JIA and their parents. The overall aim of this research project is to describe the development of this intervention for pain management options in JIA.

Methods

The intervention is being developed using a stepped approach consisting of a systematic review of the evidence for pain management options, a consensus meeting followed by a Delphi survey to gain consensus on the elements to include in the intervention, focus groups to elucidate user profiles, and interviews of youth, parents and health providers to assess decision-making needs. To date, three steps have been completed. First, a systematic review was conducted to summarize the evidence for benefits and risks of pain management options in JIA. Second, a consensus meeting of rheumatology clinicians and researchers with expertise in JIA and pain (n=13), young adults with JIA (n=2) and parents (n=1), as well as a follow-up Delphi survey were conducted to gain consensus on the elements to include in the decision support intervention. Finally, focus groups with adolescents with JIA (n=5) and their parents (n=3) were conducted to elucidate user profiles for this intervention.

Results

A total of 22 randomized controlled trials (RCTs) were included. RCTs were found for massage, splints and orthoses, therapeutic exercises, psychosocial modalities, disease-modifying anti-rheumatic drugs, and biologics. Both pharmacological and non-pharmacological pain management options were effective to varying degrees. Participants in the consensus meeting and the Delphi survey agreed that recent evidence for benefits, risks and inconvenience of both pharmacological and non-pharmacological pain management options for JIA (as well as other evidence for pediatric chronic musculoskeletal pain and adult rheumatoid arthritis) should be presented in a user-friendly manner in the intervention. They also agreed to include an exercise to help clarify adolescents' and parents' values and preferences. Participants involved in all phases of the project felt that the preferred format consisted of an electronic decision aid that could be used on a computer, tablet or smartphone periodically, and that could be discussed with health providers.

Conclusion

The first phases of this research project have shown that a wide variety of modalities can be effective and safe in reducing pain in JIA. According to rheumatology experts in JIA and pain, adolescents and young adults with JIA and their parents, recent evidence for these pain management options, as well as a value clarification exercise, should be included in an electronic decision support intervention and discussed with health care providers trained in decision coaching. Future steps include in-depth interviews to develop the intervention, as well as acceptability and usability testing.

A willingness to consider new options? A qualitative analysis of community-based focus groups on anticoagulation therapies

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Background

Atrial fibrillation (AF) is a common arrhythmia affecting nearly five million Americans and is the cause of one in six strokes. In older adults, the consequences of stroke can be devastating. Patients with AF are at increased risk of stroke and many are advised to take a blood thinner to reduce that risk. Multiple stroke prevention strategies are available to patients, including: aspirin; warfarin; non-vitamin K oral anticoagulants (NOACs); and an implantable device (WATCHMAN, Boston Scientific Corp., Marlborough, MA, USA). Determining an optimal prevention therapy is a preference-sensitive decision appropriate for shared decision making (SDM), where patients and physicians discuss tradeoffs based on evidence and preferences for treatment. Despite emergent calls for SDM in cardiovascular medicine, knowledge gaps in patient preferences for anticoagulation options hinder implementation efforts.

Methods

To identify patient values and preferences around the choice of strategy for stroke prevention in AF, five focus group sessions were conducted in May of 2015. Demographic data were collected and a semi-structured interview guide was used. Transcripts of the audio-recorded focus groups were evaluated to develop qualitative themes.

Results

Five focus groups were completed: two in senior living facilities, one in a community-based senior resource center, and two in anticoagulation clinics. Of the participants, 60% (25 of 42) were women and the mean age was 82 years. A majority of participants (64%) (27 of 42) had a history of AF and 93% (39 of 42) took aspirin or another blood thinner. Qualitative analysis revealed three main themes: 1) Fearing loss of self-control through debilitating stroke; 2) Recognizing uncertainty in the weighing the risks and benefits of new treatment; and 3) Mutual respect supports a willingness to consider new/alternative treatment regimens.

Conclusion

In the context of AF, where uncertainty around stroke and treatment for prevention are high, SDM may provide the scaffolding on which to help patients and their doctors clarify the most appropriate therapy for reducing risk. While fearing loss of self-control due to debilitating stroke was a salient finding, we observed a willingness to consider new stroke prevention options with a trusted physician. The importance of mutual respect to consider new therapies offered by subspecialists highlights an opportunity for evidence-based tools to guide deliberation. Future research is needed around implementation of decision aids for anticoagulation treatment and optimizing trust and mutual respect within a referral practice to facilitate elicitation and integration of patient preferences into decision making.

Reflexion on intervention facilitating shared decision making (SDM) in Haemophilia Treatment Center (HTC)

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Keywords :

haemophilia, shared decision making, patient needs assessment, rare disorders

Sobi provided financial support for this interdisciplinary work

Background

In France, despite health authorities willingness, shared decision making (SDM) faces difficulties to be implemented. And this is the case for haemophilia, too. However HTC are particularly suitable for this implementation: strong relationship between healthcare professionals and patients or families, therapeutic education for patient established for decades, long patient culture partnership with the AFH patient/parent resources in educational program… Furthermore, in this rare disorder (about 6.700 patients in France), first decision boxes have been elaborated in Canada (Laval U and McMaster University). An interdisciplinary study group was created in fall 2016 to implement SDM in haemophilia.

Objectives

Identify the situations that are relevant for SDM in haemophilia. Prioritize medical situations for developing decision tools to help patients and health care providers during intervention.

Develop a strategy for a successful SDM implementation in HTC

Methods

4 phases in 2016-2017:

1) Recruit an expert group: healthcare providers, a patient psychologist, French Haemophilia Society members (patient organization)
2) Identify and prioritize situations. Reflexion on interventions to raise awareness among healthcare providers
3) Do a literature review to elaborate specifics decision tools
4) Apply the implementation strategy
5) During this work, Edusanté provides methodological support (French company working in patient-centered approach).

Results

19 situations emerged after a group brainstorming. 2 were chosen:

(a) Coagulation factor (long acting versus conventional),

(b) Chronic pain treatment choice: medication or no-medication (alternative medicine included).

We put 4 criteria to evaluate if SDM is possible for each 19 situations:

(i) Clinical uncertainty area,

(ii) Repeated situation in HTC,

(iii) Best Evidence available on topic,

(iv) Original topic compared to SDM Canadian work in haemophilia field

Currently, working group analyses best available evidences. The goal is to elaborate new decision tools.

The others healthcare providers awareness has started to raise. A booklet was delivered to HTC which is called “How to enter the shared decision making era in haemophilia?”. Even more, communications are done in bleeding disorders congresses. An interview guide is being drafted to help healthcare providers.

Conclusion

Due to a double will by healthcare providers and patient organization, haemophilia was one of the first field relevant for patient education during the 70’s, and this well ahead of time.

It is not a coincidence if this community seizes, today, this new partnership model as SDM.

Following the decision-making tools elaboration, the next steps will be to choose the way to deliver these tools. Then, we will think about necessary accompanying actions in HTC (training…).

Defining an effective implementation strategy for shared decision-making: a multi-faceted approach

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Background and aims

Active patient participation in shared decision-making (SDM) is becoming an integral part of patient-centered care and its benefits have been established in Cochrane Level 1 randomized controlled trials. However, implementation in clinical practice remains a challenge. Evidence suggests that implementation requires change on multiple levels: individual, organization, and external environment. High-quality SDM depends on clinician-activation and patient-activation. Activation depends on four mechanisms: coordination, ease of SDM, attitudes/beliefs, and knowledge/skills. These mechanisms are impacted by six drivers: organizational culture/structure, resources/clinic environment, workflow, health information technology, training/education, and incentives/disincentives. We develop an implementation strategy for SDM and a patient decision aid (PDA) for prostate cancer patients in the Netherlands that takes into account these mechanisms and contains concrete actions for each driver.

Method

The following themes were explored by means of the Integrated Change (I-Change) model which forms a theory of health intervention adoption:

1) Current decision-making process and the patient pathway.
2) Organizational support.
3) Stakeholder attitudes/beliefs.
4) Knowledge/skills required to practice SDM.

We used I-Change model constructs (awareness, motivation and action) to develop a semi-structured interview instrument to explore these themes from the perspective of former prostate cancer patients (n=19), urologists (n=10), radiation oncologists (n=7), oncology nurses (n=4), general practitioners (n=8) and patient organizations (n=2). Relevant factors were obtained through open coding and axial coding of the interview transcripts.

Results

1) Most treatment decisions were made solely by the clinician. Other healthcare professionals (oncology nurses, general practitioners and social workers) play a significant part in the patient pathway but their roles are not well-defined.
2) Lack of coordination between disciplines meant patients had incomplete information on treatment options and preferred to follow the treating urologist's opinion.
3) Clinicians were positive about SDM but felt that time constraints and patient diversity made it inefficient to practice. In addition, they believed most prostate cancer patients faced a technological barrier regarding PDAs. Patients incorrectly believed that only aggressive treatments such as surgery increase chances of being cured.
4) Clinicians found it challenging to elicit patient preferences and involve patients in decision talks and valued e-learning as a means to learn how SDM principles can be applied in practice.

Conclusion

Our results indicate that greater interdisciplinary collaboration and embedding customized PDAs in the patient pathway can facilitate SDM implementation. Concrete actions include:

- Structure: Joint consultations with urologists and radiation oncologists to enhance collaboration and ensure patients receive balanced information.
- Resources: PDAs developed through user-centered design to enhance quality and ownership.
- Workflow: An expanded role for oncology nurses and general practitioners in delivering information and PDAs.
- Health information technology: Combining PDAs with a patient portal to ensure coordination between visits.
- Effective training based on clinicians' characteristics, educational theories, user-centered design principles, competences for SDM, and technology-enhanced learning.

Incentives: Insurers can stimulate clinicians to take a more collaborative role in treatment decisions, for instance by paying for use of PDAs or making SDM a prerequisite for reimbursement.

This is what I prefer: design of an app to support values clarification and decision making of individuals with mild cognitive impairment

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Background and aims

Known as a precursor of dementia, mild cognitive impairment (MCI) has an unclear prognosis that carries the risk of causing uncertainty and overtreatment of patients with MCI. Decision aids (DAs) can help provide information on treatment options, prognosis, and determinants of its future course; they also support a values-driven decision-making process with healthcare professionals. While advances in research have been made with DAs, and they have had growing exposure on the Internet, little is known about optimal design features and level of detail of DAs that promote understanding of options in the context of MCI and dementia. Thus, the aims of this project were to apply features that best support values clarification and adjust the level of detail of a computer-based DA for individuals with MCI to support shared decision making.

Methods

We conducted a rapid review of the evidence to identify options to maintain/improve cognitive functions in individuals with MCI. We structured the evidence according to IPDAS standards into a novel web application (app) mock-up designed in collaboration with specialists in digital and web-based solutions. We used a qualitative and user-centered evaluation of the app to optimize users' knowledge, values clarification, and adoption of the app in routine clinical practice. Following the CeHRes guidelines, we invited primary care providers (n=15), patients with MCI (n=15) and their caregivers to evaluate the app in five consecutive rounds, with new participants in each round. We verified understanding of the information using a teach-back method, and recorded any usability issues. Results were analyzed and the app was modified to adjust its level of detail and to address issues with usability. Sessions were audio-recorded and transcribed verbatim. To modify the app, we conceptualized the level of detail as a collective measure of adequacy of the app comprising "knowledge" and "action". For patients/caregivers, we defined "action" as "clarifying one's values and making an informed choice" and for professionals, as "adopting the shared decision making app in routine practice". Two researchers conducted an inductive thematic analysis of the factors influencing "knowledge" or "action".

Preliminary findings

The rapid review process required 19 weeks and involved three reviewers (one working full-time). We identified six options to maintain/improve cognitive function of patients with MCI, including watchful waiting. We designed a beta version of the app that allows tailoring of content for use by the patient alone, by the clinician alone, or by both together during the consultation. Informed by recent systematic reviews on values clarification and computer-based DA, and based on specialists' recommendations, we opted for an explicit method of values clarification based on rankings and included features allowing users to add their own concerns. Future findings from the evaluation will allow tailoring the app to meet users' decisional needs better.

Conclusion

This project will result in a promising web app for individuals with MCI that was developed following guidelines from IPDAS and CeHRes. Results will support future development and adaptation of DAs' level of detail to users' needs.

Beta testing of Bladder Explorer: A patient decision aid for men with spinal cord injury

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Background:

Making treatment decisions to choose a method of bladder drainage following a spinal cord injury (SCI) can be difficult. Bladder Explorer (BE) is an iPad-based patient decision aid (PtDA) developed for men with SCI, who have a neurogenic bladder and are considering an alternative method of bladder drainage. The BE presents facts and details about neurogenic bladder, the treatment options, and experiences of other patients using a particular treatment method. It also provides interactive value clarification methods to help patients explore what is important to them when making this decision. Beta testing was performed to assess the usability, utility, acceptability, and feasibility of BE.

Methods:

The study was carried out in three public hospitals in Malaysia that provide SCI rehabilitation. Participants were made up of men with SCI (n=5) who had recent SCI and needed alternative bladder drainage techniques. The participants were undergoing active in-patient rehabilitation and at the stage of making the decision. The researchers observed how participants used the BE and their feedback helped to further refine this PtDA. This study used a mixed-method approach, with the qualitative approach using screen recording, field notes and semi-structured interview, and the quantitative approach used System Usability Scale (SUS) and self-constructed acceptability questionnaires.

Results:

The BE is usable (SUS score ranges from 67.5 - 92.5, average of 75). All the questions of the acceptability questionnaire received predominantly positive responses except for one item regarding balance presentation. The two most useful modules cited were ‘Your Options’ and ‘Making the Decision’. Barriers to effective implementation included determining the entry point into the clinical pathways, lack of privacy, fatigue, and touchscreen illiteracy.

Conclusion:

BE is usable, acceptable and useful for men with SCI who are at the point of making a decision to choose a method of bladder emptying. The identified barriers to implementing BE in real life are modifiable.

Bridging the Age Gap trial of decision support interventions for older women with breast cancer: Preliminary process evaluation

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Background:

A large UK cluster randomised trial is currently assessing the effectiveness of two complex interventions for older women with breast cancer. The interventions support two different treatment decisions: 1) whether to have primary endocrine therapy or surgery with endocrine therapy, 2) whether or not to have chemotherapy. These decisions may be particularly difficult in this older age group as there is little evidence-based guidance specifically on the management of these patients. The decision support interventions (DESIs) consist of an online algorithm (primarily for clinicians, with a patient print-out available) which predicts personalised survival rates with each treatment, a short tool (for use within consultations) and a booklet of information with a values clarification section (for use outside consultations). A process evaluation is being conducted alongside the trial to understand usage of the DESIs and levels of shared decision-making.

Methods:

A mixed-methods approach is being used for the process evaluation including questionnaires and semi-structured interviews with 40-60 patients from a subsample of trial sites (eight intervention and eight control sites), and semi-structured interviews with 12-20 clinicians (surgeons, oncologists and specialist nurses) from intervention sites. Usage data is also being collected from the online component of the intervention and from trial forms and patient questionnaires. Clinical consultations to discuss chemotherapy choices are being audio-recorded and will be analysed using the OPTION scale. Preliminary thematic analyses of the interview data are presented here.

Results:

Interviews with 38 patients and with six surgeons have been completed to date. Patient experiences of discussing treatment options varied, both depending on their own case (what options were available) and on the consulting clinician. Most women felt involved in the decision-making process, but to varying degrees; some reported being given a choice of treatments, whereas others were recommended treatment plans. Most women reported receiving a lot of information about treatments, both written and verbal. Written information included booklets produced by charities, locally provided leaflets and the DESI materials. Some women from intervention sites had not received any elements of the DESI. The DESIs received positive feedback from the small number of clinicians interviewed, in particular the online component. However, clinicians reported less use of the booklets and short tools, with some suggesting that perhaps the breast nurses or research staff have used these or provided them to patients. Potential bias in the clinician sample so far is noted as a number of clinicians have not volunteered to participate and non-responders may view the DESIs less favourably.

Conclusion:

While preliminary results suggest positive feedback about the DESIs, lack of usage is also apparent from the interview data. Once data collection is complete, results from the interviews will be analysed along with further intervention usage data (from questionnaires, the online component and trial forms) and OPTION scoring of consultations and integrated using Normalization Process Theory to provide more insight into how the interventions have been used. The findings from the process evaluation will aid in the interpretation of the trial results and will be available for presentation in July.

The Development of a Decision Aid with a Multi Criterial Analytic Approach for Women with Pelvic Organ Prolapse

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Background and aims

In Denmark app. 4-5000 women annually have surgery for their pelvic organ prolapse (POP). More than one treatment option for symptoms from POP exists, and it can be challenging to establish to what extent these symptoms fully originate from the objective prolapse and what impact other components may have on the symptoms. Both objective as well as subjective components are important in order finding the best treatment choice. In this multicriterial context, women may need support to prepare and empower them to participate in a shared decision making about choice of treatment. It is important to support participation in the decision making process for these women in order to individualize the treatment choice making and to systematize the way these women's preferences are included in the decision making. Decision aids (DA) are used to support an informed choice and patients' participation in decision making.

The aim of this study is to develop a DA for women with POP based upon a multicriteria decision approach in an online program. The DA is built by and based upon identification of criteria important for women with POP and for health care persons involved in the decision making process.

A brief description of methods

The DA is developed through conceptualizing the users' needs and through pretesting of the DA in a participatory design process. Furthermore the development follows international standards for DA (IPDAS). The data derive from literature search, field observations, thematic text analysis of patient interviews and of workshop outputs from clinicians (doctors, nurses and physiotherapists). Clinical comprehensibility, feasibility and acceptability of the DA in the clinical decision making process during consultation are alfa- and beta tested by patients as well as clinicians during the development phase.

The DA is developed and tested at five gynecological clinics – from both urban and rural hospitals in Denmark.

A brief summary of results to support conclusions

Data collection from patients and clinicians revealed important aspects of relevance for choice of treatment. The aspects can be divided into six main symptom criteria of importance (i) bowel function, (ii) micturion function, (iii) symptoms of vaginal bulging and pressure, (iv) body awareness (v) problems with sexual function, (vi) side effects. Besides these criteria patients reported more emotional aspects related to anxiety, uncertainty about treatment options, pro and cons (trade-offs) with different treatment options, and the 'investment' (such as time investment e.g. sick leave) in each treatment.

Conclusions

Three overall domains are important for Danish women with POP; 1) symptom relief in the light of variation and intensity of symptoms and coherence of symptoms 2) sufficient information to assure emotional stability and 3) impact of treatment on short as well as long-term life quality.

The online DA with a multicritial approach and reconceptualized for women with POP will be pilot tested in a hospital setting at the point of decision during clinical consultations to ensure feasibility and acceptability of the DA before final adjustments and prototyping (summer 2017).

Patient and health care professionals' perspectives on shared decision making for radiotherapy treatment in breast cancer patients

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Background and aim:

Guidelines on breast cancer treatment show grey areas on radiotherapy (RT) indications. Some guidelines recommend to discuss the treatment of choice with the patient. Other recommendations are clear, but the multidisciplinary team decides, based on the latest literature, that different options should be discussed with the patient. The question then rises of which pros and cons should exactly be discussed. This qualitative study aims to investigate the patients and professionals perspectives on shared decision making (SDM) and informational needs when deciding on RT for breast cancer.

Methods:

Semi-structured interviews were hold with 15 breast cancer patients, all confronted with a decision on their RT at least 5 weeks prior to the interview, as well as with 15 professionals, selected from different hospitals in different regions of the country. Interviews were transcribed verbatim and independently coded by two researchers, who agreed upon relevant issues by consensus.

Results:

The interpretation of SDM varies between professionals. Some leave the choice completely to the patients after giving neutral information, others leave the choice to the patients after framing the options colored by their own perspective, while some try to share the decision making with the patient. All professionals report to explain the pros and cons. The pros being risk reduction of a local recurrence and survival benefit, although there is uncertainty around the exact benefits. Some professionals frame the estimates as percentages including the uncertainty while others do not dare to mention numbers. The side effects are discussed by mentioning the most common and most important side effects, with various subjective interpretations of what is viewed as 'important '. Patients reported various different ways of decision making. Only some used specific attributes such as recurrence risk, not always taking into account the uncertainty, while others try to prevent overtreatment, or are open to take any chance of improving survival. While most patient are aware of the side effects, only a minority mentioned them as the most important attribute to their decision. On the patients interviews saturation was reached. No saturation was reached on the professionals' interviews.

Conclusion:

We found valuable perspectives of patients and professionals on shared decision making and informational needs on deciding on RT. These data will be used to develop a personalized decision aid to assist deciding on RT, eligible for broad implementation. We expect to find saturation in the professionals' opinions during the first testing period of this decision aid.

Comparative effectiveness of encounter decision aids for early stage breast cancer across socioeconomic strata: study protocol

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Background

Breast cancer is the most commonly diagnosed malignancy in women. Although breast conserving surgery (BCS) is the recommended treatment for early stage breast cancer (stages I to IIIA), research confirms equivalent survival between mastectomy and BCS. Currently, both options are offered to patients, yet the options have distinct harms and benefits, and are valued differently by patients. Women of lower socioeconomic status (SES) diagnosed with early stage breast cancer experience poorer doctor-patient communication, lower satisfaction with surgery and decision-making, and higher decision regret compared to women of higher SES. They often play a passive role in decision-making and are less likely to undergo BCS. There is no evidence that women of lower SES have distinct preferences that explain lower uptake of BCS and limited engagement in decision-making.

Aims

Our first aim is to assess the comparative effectiveness of two encounter decision aids against usual care on decision quality, shared decision-making, treatment choice, and other secondary outcomes across socioeconomic strata. The first decision aid is a validated pictorial encounter decision aid (Picture Option Grid). The second decision aid is a validated text-based encounter decision aid (Option Grid). Our second aim is to explore the effect of the Picture Option Grid on disparities in decision-making and treatment choice. Our third aim is to explore strategies to promote the decision aids' sustained use and dissemination.

Methods and Analysis Plan

We will conduct a three-arm, multi-site randomized controlled superiority trial with stratification by SES (Aims 1 and 2) and randomization at the clinician level. The three arms of the trial will be (1) Intervention 1: Picture Option Grid, (2) Intervention 2: Option Grid, and (3) usual care. We will recruit 1,100 patients (half higher SES and half lower SES) from four large cancer centers in the United States. We will use interviews, field-notes, and observations to explore strategies that promote the interventions' sustained use and dissemination using the Normalization Process Theory (Aim 3). Community-Based Participatory Research will be used throughout the trial (with continuous patient and stakeholder involvement). We will include women aged 18 and 75 years with a confirmed diagnosis of early stage breast cancer (I to IIIA) from both higher and lower SES, provided they have a basic command of the English, Spanish, or Mandarin Chinese language. We will recruit about 367 patients per arm. Our primary outcome measure is the 16-item validated Decision Quality Instrument.

We will use a regression framework and mediation analyses to examine the data. We will also use multiple informants analysis to measure and examine SES and multiple imputation to manage missing data. Heterogeneity of treatment effects analyses for SES, age, ethnicity, race, literacy, language, and study site will be performed.

Conclusion

This study is highly relevant to patient-centered care as we seek to promote the involvement of women of low SES in breast cancer treatment decisions and address disparities in this area. This study hopes to identify solutions that effectively improve outcomes across socioeconomic strata and reduce disparities in quality of care.

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Decisions near the end: An environmental scan of life-sustaining treatment decision aids for patients approaching death

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Introduction

People approaching the end of their lives face difficult decisions, especially concerning extent of medical intervention. Given the inherent difficulty and complexity of these decisions, the care they ultimately receive often does not align with their preferences. Patient decision aids that educate individuals about options and help them construct preferences when decisions about life-sustaining care are imminent can reduce the mismatch between the care people say they want and the care they receive. The quantity, quality and use of decision aids for patients at or near the end-of-life, however, is unknown.

Objective

Our objective was to develop an inventory of all patient-facing life-sustaining treatment decision aids currently available, along with information about the tools' content, quality, and known use.

Methods/design

We identified decision aids using a three-step approach: 1) mining previously published systematic reviews; 2) systematically searching online and on two popular app stores; and 3) undertaking key informant outreach and survey. We screened and assessed the quality of the decision aids identified using the National Standards for the Certification of Patient Decision Aids. Additionally, we assessed readability via readability.com and content via directed content analysis. We also queried key informants about their knowledge of tool use.

Results

Preliminary results indicate there are at least 25 decision aids concerning life-sustaining treatment decisions. The vast majority of these tools, however, have not been formally evaluated. We anticipate we will have detailed results to share by the time of the conference.

Conclusion

We found there are many more decision aids available to patients than those that are formally assessed in the academic literature, suggesting environmental scans provide more appropriate landscape assessments than systematic reviews. In an effort to acknowledge that patients and their families may be more likely to find tools via Internet search, in addition to publishing our findings in an academic journal, we plan to post our inventory online in an easy-to-read format for public consumption.

Effect of a Skills Training for Oncologists on Shared Decision Making about Palliative Chemotherapy in Simulated Encounters

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Background/Aims

Systemic treatment for advanced cancer offers uncertain and sometimes limited benefit while the burden can be high. Hence, applying the premises of Shared Decision Making (SDM) to these treatment decisions is recommended. This paper reports on the effect of an SDM skills training for medical oncologists on observed SDM about palliative systemic treatment in simulated encounters (standardized patient assessments).

Methods

Thirty-one oncologists and oncology residents were randomly assigned to receive an SDM training or continue providing care as usual. The training was based on a 4-step model of SDM, including (1) setting the SDM agenda, (2) informing about options, (3) exploring patient values, and (4) making a decision. The training focused on SDM about palliative systemic treatment and consisted of a reader, two 3.5h group sessions using modelling videos and role play, a booster session including individual feedback on a audio-recorded consultation in clinical practice, and a consultation card with the SDM steps and example phrases.

Oncologists participated in a video-recorded simulated encounter at baseline (T0) and after 4 months (T1, post-training). Two male actors were trained to play the patient role in a standardized way. The primary outcome was observed SDM as assessed with the OPTION12 (Observing Patient Involvement). Secondary outcomes were observed SDM per step (self-developed instrument), general communication skills ratings (providing information and anticipating/responding to patient emotions) and oncologists' satisfaction with communication (PSQ). After training and reaching sufficient interrater agreement (ICC's and M weighted kappa's > .60; interrater differences <=1 point), the consultations were coded by two researchers. The effect of training was statistically tested by General Linear Modelling for repeated measures.

Results

Observed overall SDM (OPTION12) in the simulated encounters significantly improved over time in both groups. The improvement in trained oncologists was significantly larger than in the control group (time x group, $p<.01$, Cohen's $f = 0.62$). At T1,mean OPTION scores were M=64 (SD = 9) in trained oncologists, and M=44 (SD = 11) in the control group. Next to overall SDM, the training significantly improved observed SDM behavior in each of the four steps of SDM ($p<.05$; Cohen's f 0.39-0.72). The training seemed least effective in improving skills required to explore patients' values (step 3). Lastly, the training significantly improved the quality of information provision ($p<.001$; $f = 0.77$) and of anticipating/responding to emotions ($p=0.03$; $f = 0.42$); as well as oncologists' satisfaction with the consultation ($p=0.01$; $f = 0.77$).

Conclusion

Training medical oncologists in SDM about palliative systemic treatment improves SDM behavior in simulated encounters. This was demonstrated for all steps of SDM: SDM agenda setting, informing about options, exploring patient values and making (or deferring) a decision. The next step is to examine the effect of such training on SDM in clinical practice and on patient outcomes.

A systematic review of strategies to evaluate health care provider trainings in shared decision-making

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Background and aims

How to successfully implement shared decision-making (SDM) in clinical practice is of great interest to the scientific community as well as policy makers. Health care provider trainings in SDM are promising means to achieve implementation. However, evidence on the efficacy of SDM trainings remains unclear. Therefore, we sought to systematically review and critically appraise health care provider trainings in SDM.

Methods

We adapted and followed the PRISMA guidelines and registered the study in PROSPERO, the international prospective register of systematic reviews. A primary systematic search of the databases Medline, CINAHL and PsycInfo was performed. A secondary search consisted of reference- and citation tracking, consultation of experts in the field and a scan of the Canadian inventory of SDM training programs for health professionals. Title- and abstract screening was performed by two reviewers who double-screened 300 references to calibrate inclusion and exclusion criteria. Full texts were double-screened by two reviewers against inclusion and exclusion criteria. In case of disagreement, two other reviewers were consulted to make a decision. Data extraction (currently in progress and performed by two reviewers independently) includes characteristics of studies, characteristics of SDM trainings, outcomes used to evaluate the trainings (and their references, if applicable), measurement points and application of an evaluation framework. Two reviewers currently independently analyze the quality of included studies using the integrated quality criteria for review of multiple study designs (ICROMS) tool. We will summarize and critically appraise strategies to evaluate health care provider trainings in SDM using Kirkpatrick's four level evaluation model (reaction, behavior, learning, results). We will categorize identified outcomes in the model and provide an overview of evaluation strategies.

Preliminary results

A total of n=6179 references were screened, n=81 articles were full-text analyzed and n=33 articles were included in the study. Included articles reported on n=13 clustered randomized controlled trials, n=10 randomized controlled trials, n=1 controlled pretest-posttest study, n=4 non-controlled pretest-posttest studies, n=2 posttest studies and n=3 qualitative studies. A preliminary overview of the outcomes used in the studies show a great diversity of measures (many of them self-developed by the authors) that cover different levels of Kirkpatrick's model. Outcomes were mainly self-reported outcomes for health care providers and their (standardized) patients. Final results will be available at the time of the conference.

Conclusion

Preliminary results show that evaluation studies of health care provider trainings in SDM follow very different evaluation strategies. This makes the comparison and synthesis of study results on the efficacy of training health care providers in SDM difficult. This review will provide important and needy orientation in choosing adequate evaluation strategies and may be a first step towards achieving consensus on an evaluation framework for future SDM training studies.

A mixed methods pilot study of the acceptability and feasibility of a virtual community of practice to improve primary care professional attitude towards the empowerment of patients with chronic diseases (e-MPODERA trial)

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Background

Virtual Communities of Practice (vCoP) are based on the idea of learning through the participation of a group of interested people via the exchange of experiences and knowledge. The e-MPODERA project aims to assess the effectiveness of a vCoP in improving attitudes of primary care health professionals on the empowerment of patients with chronic diseases.

Objective

We pilot tested a virtual platform of CoP in primary care professionals (PCP) to evaluate the acceptability and feasibility of the intervention and make adjustments for the implementation of a cluster randomised control trial.

Methodology

A mixed methods pilot study was conducted using surveys and two discussion groups to determine professional's experience and platform use. Three primary care centres were selected to participate in the pilot test.

Intervention

The intervention consisted in a vCoP including an online platform with activities, forums and gamification methods for some of the activities. For the activities design, a competence framework was used including four learning objectives and twelve core competences. Contents were developed considering patient health literacy, self-efficacy, coping with the disease, shared decision-making, self-monitoring, etc. Contents were included gradually during a three-month test period.

Results

Twenty-nine PCPs accepted to participate in the pilot test, 15 nurses and 14 general practitioners (GPs). All of them entered vCOP and 31% contributed with comments. Topics with most comments were health literacy, shared decision-making and communication.

Fourteen PCPs answered the survey. Satisfaction and impact evaluation showed low to moderate results mainly due to issues of access to the platform and lack of time.

Six PCPs participated in the two discussion groups (one with GPs and one with practice nurses), who expressed technological issues, lack of time, and work-overload as the most important barriers. Nurses also considered as a barrier that some of the material was only available in English.

The existing disagreement between hospital and primary care and some organizational issues that hinder a better communication with patients were two of the barriers mentioned by the participants for the implementation of patient empowerment strategies.

Participants expressed great interest for learning how to engage patients to be more active in their care, and related concepts including patient education, communication techniques, shared decision-making and practical tools. They also considered this type of learning methodology interesting because they were able to learn from other participating professionals experience and they could do it at home and in any moment. In addition we found some insights regarding learning methods and about the facilitator role.

Conclusion

vCoP have the potential to facilitate learning and create professional awareness about patient empowerment; however, in order to be successful, strict attention is needed for technological issues, accessibility issues and time requirements for professionals. Based on the pilot test, several recommendations for further work are given and an updated training program for patient empowerment is presented.

Trial registration:

ClinicalTrials.gov Identifier NCT02757781, May 2016.

Keywords

Patient centred care, patient empowerment, primary health care, professional education, e-learning, healthcare professional attitudes, communities of practice.

Tailoring a smoking cessation intervention to patient's needs and gender specificities

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Background and aims:

The relationship between smoking and diabetes is complex. On one hand smoking increases micro- and macro-vascular complications and mortality. On the other hand smokers with diabetes might have more difficulties quitting because of specific barriers linked to weight gain at cessation and consequences on diabetes control. Men and women might have different perceived risks and concerns about quitting smoking and its metabolic consequences. The aim of the DISCGO study (Diabetes and Smoking Cessation: a Gender Oriented study) is to design a gender specific smoking cessation intervention, which acknowledges gender norms and considers women and men's specific needs, in a population of people with type 2 diabetes and to test the efficacy of this intervention.

Methods:

In a preliminary phase, we used mixed qualitative and quantitative approaches to understand the beliefs and needs of type 2 diabetic smokers. Ten in-depth semi-structured individual interviews and 5 focus groups have been performed, including a total of 33 participants (14 women and 19 men, mean age 60 years old), using the Information-Motivation-Behavioral Skills Model. Based on the findings of the qualitative study, we designed a survey which was submitted to 250 smokers and ex-smokers with type 2 diabetes.

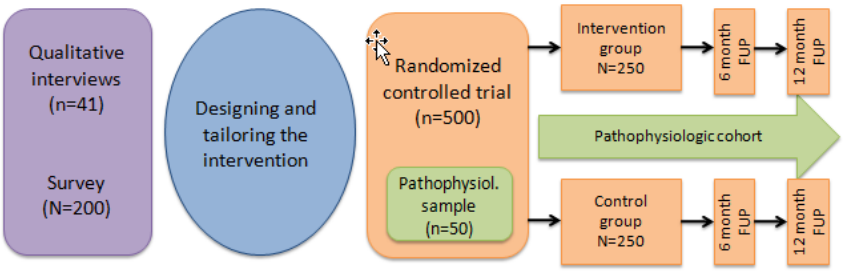
Results:

The main themes found using the qualitative approach revealed that smokers were globally unaware of the association between smoking and diabetes and did not know the specific risks on diabetes associated with smoking. Participants reported that they did receive few or no advice to quit smoking from their healthcare providers. They were globally not very concerned about weight gain following smoking. The survey showed that type 2 diabetic smokers had on average strong nicotine dependence. Women were more motivated to quit than men. Confidence in cessation was however low in both men and women (4.5 on average on a 0-10 scale). Reasons that motivated diabetic smokers to quit were mostly related to health and women were more likely to report reasons related to their health and the protection of other's health as reasons to quit than men. Weight or diet management was not reported as an important reason to smoke although women were more likely than men to report smoking to manage their weight. Regarding aids for smoking cessation, most smokers did not report wanting aid for smoking cessation. If they mentioned being interested, they favored help by a health professional, use of nicotine replacement therapy and acupuncture or group sessions with other diabetic smokers. They were not interested in mobile phone application, internet based help or text messages. They were also not interested in evidence-based treatment for smoking cessation or e-cigarettes. Former smokers reported that they quit smoking without help for the majority of them. Men were more likely to have quit "cold turkey" whereas women were more likely to have set a quit date before quitting.

Conclusion:

Using a participatory design to integrate gender specificities and special needs of type 2 diabetic smokers in a behavioral smoking cessation intervention could increase the uptake, acceptability and efficacy of the intervention.

Figure: Study design



Assessment of Patient-Centeredness through Patient-Reported Experience Measures – A Study Protocol

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Background and aims

Patient-centeredness has become increasingly important in health care research and in health policy. However, the assessment of patients' perspectives on experiences with different aspects of patient-centeredness has been neglected in German health care for many years. Yet, it is a crucial step towards forming a patient-centered health care system. To overcome inconsistencies in the definition of patient-centeredness, an integrative model from experts' perspective including 15 dimensions (including shared decision making) was developed[1]. Currently, it is unclear how patients value these dimensions. It has also been shown that there is a lack of psychometrically sound measures to assess patient-centeredness in German language. Thus, the aims of this study are: 1) to assess the relevance of different dimensions of patient-centeredness from patients' perspectives; 2) to develop and psychometrically test a core set of German patient-reported experience measures (PREM) that assess dimensions of patient-centeredness; and 3) to investigate the feasibility of implementation of the developed core set in routine health care. Therefore, the development of the PREM core set to assess different dimensions of patient-centeredness aims to make the level of patient-centeredness in routine care structures experienced by patients measurable.

Methods

The prospective study will be conducted within three study phases using a mixed-methods approach. The study will target patients from different chronic disease groups (cancer, cardiovascular diseases, mental disorder, and musculoskeletal disorders). In Phase 1 patients' perspectives on dimensions of patient-centeredness will be assessed using a Delphi study in a sample of 200 participants. In Phase 2, the core set of measures will be developed (with several steps of stakeholder involvement, including several rounds of cognitive interviews with patients) and psychometrically tested in a large patient sample (N=2,000). In Phase 3 the use of the developed measures core set in routine care will be assessed. A subsequent national expert workshop will be held to discuss ways of implementing the measurement of patient-centeredness through the core set in routine clinical practice and as a quality indicator.

Expected results and implications

The main result of this study will be a consistent PREM core set assessing patient-centeredness in German language, which is not available at the moment. This will close an important gap and allow assessing the degree of patient-centeredness in German health care. The resulting PREM core set can be used as a performance, benchmarking or quality improvement measure. The results of the last project phase will generate important insights into how to best implement the developed PREM core set into routine practice. Thus, the results of this study will provide the opportunity to foster the implementation of patient-centeredness in routine practice and can contribute significantly to a more patient-centered health care in Germany. The results of this study will certainly also be of international interest, as the use of PREMs to assess patient-centeredness has also received relatively little attention in other countries.

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Validation of a search filter for studies on patient's values and preferences

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Background:

When making decisions, it is important to incorporate patient preferences regarding how they value health outcomes. There is a growing body of evidence on this topic and its incorporation in the development of systematic reviews, guidelines, and decision aids can be complex and time consuming due to difficulties when retrieving articles from medical databases.

Objectives:

To develop and validate a search filter (Pubmed/MEDLINE) previously designed by our group for the retrieval of studies addressing the patients' values and preferences.

Methods:

We constructed a "gold standard" set of articles on patients' values and preferences by handsearching high-volume journals that are sensitive to this topic and a random sample of MEDLINE articles. Eligibility and classification of relevant articles was performed in duplicate; discrepancies were solved by consensus. We performed term-by-term searches in MEDLINE (via PubMed) using terms from a previously developed filter and other terms provided by experts in the field. We used the diagnostic test accuracy assessment framework to calculate sensitivity, specificity, precision, and accuracy of each term comparing the search results from the database with the articles included in the "gold standard". Furthermore, we combined the search terms in multiple permutations in order to identify the combination with the best sensibility, specificity and balance within specificity and sensibility. These filters were later evaluated using a validation subset with sensitivity, sensibility, precision and accuracy re-calculated.

Results:

We are currently conducting the term-by-term searches and we will present the advances of this project. We will present the full characteristics of the gold standard and the filters with their corresponding sensitivity, specificity, precision, and accuracy at the Global Evidence Summit.

Conclusions:

The filter we are validating will fill an important gap in research. The filter we propose will facilitate the retrieval of studies on how patients or other affected by decisions value the different outcomes. This, in turn, will facilitate the use of this evidence and its incorporation in developing strategies for shared decision making.

Oncologists and hematologists' experiences with second opinions

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Background and aims

Second opinions are increasingly sought by patients in oncology. As such, clinicians are increasingly confronted with patients broaching their wish, or visiting for a second opinion. The value of patient-initiated second opinions has been debated, but little empirical evidence exists on this topic. The multiple parties involved in the second opinion process, i.e., two different oncologists, the patient and partners or family, may pose specific challenges to oncologists' communication. Yet we do not know how oncologists experience the second opinion process, and what communication difficulties they perceive.

Methods

Semi-structured qualitative face-to-face interviews were conducted with 25 Dutch oncologists and hematologists, varying in years of experience, type of hospital and geographical region. Topics discussed were: 1) communication within second opinions, 2) communication about referral for second opinions, 3) inter-collegial communication, and 4) communication about and after back-referral, with specific focus on personal experiences, emotions, difficulties and personal opinions. Interviews were transcribed verbatim and double coded. Analysis was inductive, using the constant comparative method. Open coding was followed by axial coding and subsequently the identification of overarching themes.

Results

Strong differences were present in both clinicians' opinions of and their experiences with second opinions. Most found the vast majority of second opinions to be medically unnecessary, but saw psychological benefits to the patient. Some found these psychological benefits worthwhile and enjoyed contributing to them, whereas others did not think these benefits weighed up against the high costs and work load they entailed. Many clinicians responded open to patients broaching the idea of a second opinions, but felt hurt or irritated if patients arranged the second opinion without their knowing. Inter-collegial communication was sensitive, especially in case of discrepancies between first and second opinions. Clinicians experienced most difficulty with patients expecting to stay in treatment with the institute performing the second opinion. For most, this was not desirable. Convincing patients to return to their referring specialists required a large effort.

Conclusion

These results indicate that the second opinion process is fraught with communication challenges for oncologists involved. Training may be beneficial to assist oncologists and hematologists in inter-collegial communication, optimally performing second opinions, and proper collaborative decision making on whether to pursue a second opinion and about back-referral. Additionally, discussion is needed that leads to an improved second opinion process.

Understanding what matters most: Exploring older adults' priorities for experiences with inpatient care.

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Background

There is increasing interest in measuring patient-reported experiences of inpatient care. The Canadian Patient Experience Survey – Inpatient Care (CPES-IC) is a Patient-Reported Experience Measure (PREM) used by national and provincial policy-makers to monitor health system performance. The CPES-IC includes experiences of shared decision-making, such as communication with the healthcare provider and involvement for both the patient and family in treatment decisions. Routine data collection with the CPES-IC is used to indicate how well (or poorly) hospitals are performing, however it does not capture which experiences of care are prioritized most (and least) by patients.

Aims

To: a) determine the most appropriate method to elicit priorities for experiences of care described by the CPES-IC, b) derive preliminary priorities, and c) explore differences in priorities between frail and non-frail individuals.

Methods

Best-worst scaling (BWS) was used to ask adults with recent inpatient experiences to select what they view as most and least important among a set of experiences. A subset of 25 different experiences from the CPES-IC was selected. We developed a survey which asked participants to complete the CPES-IC, questions about their health and frailty status (PRISMA-7), and then 10 BWS tasks (see Figure 1). We first explored the most appropriate mode of administration by conducting one-on-one interviews, designed to mimic phone, online, and in-person interviews. We then ran online surveys on a larger sample of individuals aged 60+ who reported being hospitalized within the last 5 years. Data was analyzed using simple count, conditional logit, and latent class conditional logit models by frailty subgroup.

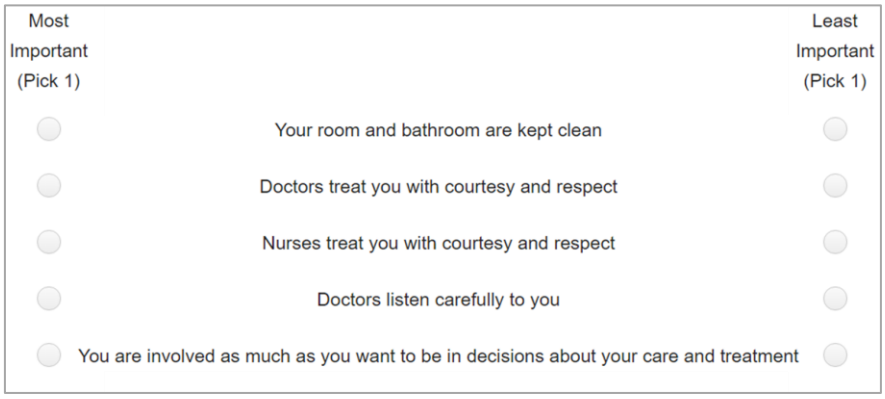
Results

One-on-one interviews were conducted with 10 individuals aged 72 to 94 of which 7 were classified as 'frail'. Administration of the BWS survey using a phone interview was deemed too difficult in our interviews. While participants preferred in-person to online administration as it offered the opportunity to ask questions, it was considered too resource intensive to produce sufficient numbers of responses. Integrating feedback from the interviews, we implemented online surveys. Preliminary results suggest *being involved as much as you want to be in decisions*, and *having doctors explain things in a way you can understand* were the most important experiences, while *having your room and bathroom kept clean* and *family and friends involved in decisions* were least important. However, this varied depending on the individual's level of frailty.

Conclusions

BWS appears to be feasible approach for determining priorities in a heterogeneous population. Participants preferred in-person interviews, however, online administration was deemed adequate for providing fast and relatively inexpensive responses. We have been able to identify frail individuals using an online panel, however this has an important selection bias. Preliminary results suggest involvement in decision-making is the biggest priority for patients, however there are important differences in priorities by frailty status.

Figure 1. Example BWS task



Randomized controlled trial on the effectiveness of a web-based decision aid for colorectal cancer screening in Spain

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Background

Colorectal cancer is one of the most common forms and the second leading cause of cancer mortality. However, early detection has proved to reduce its mortality. Participation rates in screening programs vary widely by country, but in general they are not considered optimal. The application of decision aids (DA), tools designed to inform users about diagnostic and therapeutic procedures and to promote their active participation in decisions concerning their health, could improve the decision-making process of people at risk of developing colorectal cancer, through their participation in a screening program.

Methods

We performed a randomized controlled trial on the effectiveness of a web-based DA for colorectal cancer screening. We included participants between 50-69 years old who had never been screened (n = 125), including a subsample that in the past had been invited and refused to participate in the Spanish population screening program (n = 32), which consists in a Fecal Occult Blood Test (FOBT) followed by colonoscopy if FOBT positive. Sixty-three participants were randomized to the DA and 62 to control group. Outcome measures were knowledge about the disease and the screening procedure, decisional conflict, intention to undergo the screening tests and concordance between users' preferences (importance attributed to different characteristics of the screening program) and intention to undergo the tests.

Results

There was a significant effect favoring the DA in knowledge ($p<0.001$). In the decisional conflict instrument, the total score and all its subscales also were significantly improved (p values < 0.015), but only in the subsample that had not been invited to participate in the screening program. In this subsample the effect of the DA was also significant at increasing the percentage of participants who stated an intention to undergo FOBT (100% vs. 89.5%, $p = 0.016$) and colonoscopy (96.2% vs. 81.6%, $p = 0.021$). In the total sample the effect was significant only for FOBT (98.4% vs. 88.3%, $p = 0.023$). None of the program's characteristics whose importance was rated by participants significantly predicted their intention to undergo the tests, and therefore a measure of concordance could not be calculated.

Conclusion

The DA evaluated improved the quality of the decision-making process about participation in a colorectal cancer screening program, especially in those users who never had been invited. Participants who had been invited (and refused) in the past did not show improvements in decisional conflict (possibly due to a floor effect, since conflict was low in the control group), but they also improved their knowledge significantly. Future studies should examine other characteristics of the screening program that significantly predict not only intention but actual behavior regarding the uptake of the screening tests.

Iterative evaluation and adaptation of communication material for the public with a group of simulated patient. A pilot project.

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Introduction

Guidelines recommend developing decision aids and communication materials (CM) with the participation of target populations. Iterative cycles of evaluation and adaptation have an advantage over focus groups (where comment is often reserved for the final CM), since users can shape early versions of CM and can see if suggested changes improved the next version. We aimed to test the feasibility and yield of involving a group of simulated patients in a patient advisory group to improve CM developed in a statewide colorectal cancer (CRC) screening program.

Methods

We invited the participation of simulated patients, aged 50-69, who already helped teach medical students from the University of Lausanne. We excluded those with a personal history of CRC. We planned 2h meetings every 3 months and used a cyclical approach. We shared the CM before meetings, collected the comments during group discussions, decided on the adaptations, updated the CM, and then sent the newest version to the group for further comment and changes. Participants received a $ 50.- voucher per meeting.

Results

Of the 20 eligible simulated patients invited, 5 (25%), 4 women and 1 man, accepted the invitation. They came to 4 meetings every 3 months, over a 12-month period. Their comments helped identify discrepancies between the intended and perceived tone of messages in CM, test proposed solutions, and revise based on repeated evaluation. Participants commented on overall presentation, vocabulary, formulations, and the character of the message. They also suggested developing new CM for people with special needs. All participants said they would recommend that others participate in these groups and approved of including patients in development of CM.

Conclusion

The participatory approach of having a patient advisory group review CM improved the CM, helped us identify critical elements, and avoid discrepancies in the CM. The cyclical approach helped us understand the comments of participants. This pilot project highlighted the willingness of participants to be part of the process of evaluating medical CM. The method should now be rigorously tested, especially in populations with special needs.

Randomized Trial of a Patient-Centered Decision Aid for Promoting Informed Decisions about Lung Cancer Screening: A Study Protocol

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Background

Lung cancer is the leading cause of cancer deaths in the United States. Screening with low-dose computed tomography (LDCT) can reduce lung cancer-related mortality, but screening is associated with potential harms. Professional societies encourage high-risk smokers be presented with information about the benefits and harms of lung cancer screening before making a screening decision.

Specific Aims

The aim of this study is to compare the impact of a video decision aid to standard educational materials on lung cancer screening decisions. We hypothesize that high-risk smokers eligible for lung cancer screening who receive the decision aid will: a) be more prepared to make a decision about lung cancer screening; b) feel more informed about the screening decision, c) have more clarity on their values regarding the benefits and risks of lung cancer screening with LDCT, and d) be more knowledgeable about lung cancer screening than patients receiving the standard educational materials. We will also collect data about screening intentions and completion of screening for exploratory purposes.

Methods

The study, funded by the Patient-Centered Outcomes Research Institute (PCORI), reflects the importance of patient-centeredness through its conceptualization, execution, interpretation, and dissemination efforts. High-risk smokers from state-based tobacco quitlines will be randomly assigned to receive the decision aid “Lung Cancer Screening: Is it right for me?” or educational materials presenting facts about lung cancer screening. Patients will be followed up to 6-months after receiving the intervention. A Patient Advisory Group will provide input about the intervention materials and study outcomes. A Stakeholder Advisory Group of clinicians and quitline service providers will provide guidance on execution of the study and dissemination planning.

Results

To date, 516 quitline clients have been randomized to the patient decision aid or control materials. Patients from 13 states and four quitline service providers have been enrolled. Recruitment accelerated with the inclusion of more state quitline providers, and use of prospective and retrospective strategies for identifying patients. Engagement of quitline service providers has been key to successful recruitment and dissemination planning.

Conclusions

This project will provide high-risk smokers with information they find important about lung cancer screening, and the tradeoffs between the potential benefits and harms of being screened, so they can be prepared to make values-based screening decisions.

This work is supported through a Patient-Centered Outcomes Research Institute (PCORI) Award CER-1306-03385. All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

Motivating factors influencing women on performing mammograms for breast cancer screening

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Background and objectives

Systematic screening of breast cancer using mammography carries the risks of false positives and overdiagnosis. Some scientific societies recommend the use of an individual approach by providing information about screening and engaging patients in their decision through a shared decision making process. The objective of this study is to understand women's motivations and explore their preferences regarding mammography screening tests.

Methods

We conducted a qualitative research study in Buenos Aires in 2016. We performed semi-structured individual interviews to 16 middle-class literate women (40 to 75 year-old) from a private healthcare system. Convenience sampling was used and data analysis was based on Grounded Theory methodology.

Results

We found the following semantic constructions: 1) the mammography procedure itself produces negative feelings in the vast majority of women, nevertheless many consider it necessary to detect anomalies on time; 2) even though the doctor is regarded as a knowledgeable authority, the patients seem interested in engaging a dialogue that takes into account their individuality; 3) mammography is positively valued as a prevention tool, however some women do not consider it harmless and question their limitations; 4) mammography is highly regarded in the media and is well-established in society; 5) the participation in screening is conceived as a responsibility and a duty towards self care, sometimes motivated by fear or by the need of reassurance or tranquility.

Conclusion

In this population mammography is a highly regarded procedure with a great impact on their perception of health. Despite the discomfort experienced during the procedure it is perceived as a duty of self-care. Some women question this practice and point out the need to strengthen the individual relationship with the doctor. The incorporation of this views could aid in the decision making process.

Keywords:

Qualitative research, screening mammogram, breast cancer, shared decision making, quaternary prevention

Shared decision – Making at the general internal medicine outpatient clinic of the Philippine general hospital: patient's perspective

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Background:

Shared Decision Making (SDM) is an active and collaborative process of clinical decision making involving the patient and healthcare professional. It is a prototype of current models of patient-centered care, and emphasizes the special role of the patient as a manager of his or her own health. The goal of SDM is to ensure that patients and health practitioners arrive at medical decisions that are consistent with the former's values and preferences. Presently, there is a paucity of published studies on this subject in the Philippines. The objective of the study was to utilize a Filipino version of the SDM Q-9 questionnaire to evaluate the extent to which a shared decision-making process is implemented in the General Medicine outpatient clinic of the Philippine General Hospital from the patient's perspective.

Methodology:

The English version of the SDM Q-9 questionnaire was translated into Filipino and validated through focused group discussions (FGDs). The validated questionnaire was then fielded to 236 patients who were consulting at the General Medicine outpatient clinic of the Philippine General Hospital.

Results:

Majority of the participants agreed that the different steps of the shared decision-making process were being practiced in the General Medicine outpatient clinics. Notably, the domains involving identification of preferences, negotiation and shared decision showed weaker trend towards agreement, indicating that among the nine items of the SDM Q-9, these areas required the most strengthening.

Conclusion:

In this study, the investigators were able to observe that patients agreed that shared decision-making was being practiced in their clinical encounters with their respective physicians.

Concurrent Validity of CollaboRATE in a Pediatric Setting

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Background:

CollaboRATE is a valid and reliable 3-item measure of the shared decision making (SDM) process that was developed for report by adult patients. We sought to determine the concurrent validity of a CollaboRATE version adapted for report by parents of pediatric patients.

Methods:

Data is drawn from 143 parents of children with autism spectrum disorder (ASD) who participated in a randomized controlled trial of an intervention to facilitate shared decision making about treatment of challenging behaviors. Prior to their encounter, parents reported the behavior that was most important to address (i.e. primary treatment priority). We video recorded encounters where parents and clinicians discussed treatment options (with or without the SDM intervention based on their group allocation) and used the OPTION scale to measure the amount of parent involvement. After their visit, parents completed CollaboRATE and the decisional conflict scale. For each parent, we determined whether their primary treatment priority was addressed by the treatment plan documented by their clinician after the visit. We have presented results of the randomized trial elsewhere. For the current analyses, we pooled all parents in one group. We summarized the measures using descriptive statistics. To assess concurrent validity, we compared top score on CollaboRATE (i.e. 9 on all 3 items) to 1) mean score on the OPTION scale and 2) mean total score on the decisional conflict scale using bi-serial correlations and to 3) receipt of a treatment plan that addressed their priority using a t-test.

Results:

75% of parents reported the top score on CollaboRATE, mean score on the OPTION scale was 26.9 (SD=13), mean total score on the decisional conflict scale was 19.4 (SD=17.2), and 72% of parents received a treatment plan that addressed their priority. CollaboRATE top score was not related to OPTION score (r=0.06; p=0.56), but was related to total score on the decisional conflict scale (r=-0.41; p<.0001). The proportion of parents reporting top score on CollaboRATE was higher for those who received a plan that addressed their priority (78%) compared to those who did not (68%), but this difference wasn't statistically significant (p=0.3).

Conclusions:

The proportion of parents of pediatric patients with ASD who report a top score on CollaboRATE is similar to the proportion of adult patients who report a top score. The absence of a correlation between patient perceptions of SDM (as measured by CollaboRATE) and observed assessments (as measured by OPTION) is consistent with past research. The strong inverse relationship between CollaboRATE and decisional conflict provides evidence of concurrent validity with lower conflict relating to higher perceptions of SDM. Additional studies are needed to examine the validity of CollaboRATE among parents of children with a range of conditions

Danish Translation and Cultural Adaption of the 9-Item Shared Decision Making Questionnaire (SDM-Q-9) patient version.

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Background and aims

Measure instruments that measure the extent to which patients are involved in the process of decision-making are developed and validated and being used worldwide. So far, no validated self-report instrument for the shared decision making (SDM) process is available in Denmark.

The German 9-item Shared Decision Making Questionnaire (SDM-Q-9, patient version) is used to measure the extent to which patients are involved in the process of decision-making. The questionnaire can be used in both research and clinical practice. It can be used when there are several treatment options for a particular disease and can be implemented for purposes of evaluation and quality improvement in health care. It has been translated into 17 languages, thus it can be suitable for comparing results internationally.

The aim was to translate and cultural adapt a Danish translation of the SDM-Q-9 patient version to the context of Danish women with pelvic organ prolapse and patients with cruciate ligament injuries in the Outpatient Gynecology Clinic and the Department of Sports Traumatology.

A brief description of methods

In accordance with and acceptance of the German authors the original SDM-Q-9, patient version was translated from German and cultural adapted into a Danish context following WHO's four phased recommended process; (1) Forward translation (2) Expert panel discussion – Back translation (3) Pre-testing and cognitive interviewing and (4) Final version and documentation.

A brief summary of results to support conclusion

A forward and backward translation were completed by four different translators and followed by an adjustment made by the expert panel. The expert panel included the three of the four translators, experts in health, instrument development and translation and an expert in the field of gynecology. Minor changes to the first Danish draft was made based on results from a cognitive pretest among six women with pelvic organ prolapse and five patients with knee injuries recruited from the outpatient clinics. The final Danish version was approved by the German author.

Conclusion

A Danish translated version of SDM-Q-9patient version, is now available and is currently undergoing psychometric testing for further validation.

Development of a core outcome set for the EvaLuation of Interventions for informed Consent for RCTs.

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Background

The process of obtaining informed consent for participation in randomised controlled trials (RCTs) was established as a mechanism to protect participants against undue harm from research and allow people to recognise any potential risks, or benefits, associated with the research. A number of interventions have been put forward to improve this process. Outcomes reported in trials of interventions to improve the informed consent process for decisions about trial participation tend to focus on 'understanding' of trial information and recruitment to the parent study. Yet there is a lack of clarity regarding whether these are the 'right' outcomes to measure and which outcomes matter (to whom) and why.

The ELICIT project aims to develop a core outcome set (COS) for the evaluation of interventions intended to improve how people make decisions about whether to participate in RCTs of healthcare interventions.

Methods

The ELICIT project will adopt and adapt methodology previously developed and used in projects developing COS. Specifically, the work will consist of four stages: 1. A systematic methodology review (which is reviewing both evidence from explanatory, exploratory and philosophical literature) of existing outcome measures of trial informed consent interventions; 2. Interviews with key stakeholders (including trial participants, trialists, research nurses, ethicists, philosophers and researchers with an interest in trial communication) to explore additional outcomes relevant for trial participation decisions; 3. A Delphi study (with stakeholder groups listed above) to refine the COS for evaluation of trial informed consent interventions; and 4. A consensus group meeting to finalise the COS.

Results

This presentation will discuss the key issues relevant for this work and present data generated to date from the systematic literature review and the interviews with stakeholders. In brief, the literature review included 149 eligible studies, from which 1006 verbatim outcomes relating to informed consent for trials were recorded. Forty two individual outcomes were identified following de-duplication and further refined through reduction to a shorter list which contained minimal overlap. Number of outcomes reported per paper ranged from 1 to 35. Outcomes could be grouped into specific domains relating to 'Informedness'; 'Decision making process components'; 'Behaviour'; and 'Protection'. Results from the interviews with stakeholders will be presented alongside the findings from the review of outcomes identified from the literature.

Discussion

ELICIT will be one of the first COSs to be developed within the field of trials methodology. The development of a COS in this methodological area aims to improve the conduct, interpretation and comparison of past and future studies by minimising heterogeneity across studies and reducing the potential risk of outcome selection and reporting bias in studies of this type. Determining which outcomes to measure for evaluation of RCT recruitment processes and interventions will also require further reflections on how to measure these core outcomes and will provide key areas for future research.Specific challenges relating to the development of COS in this context will also be discussed.

What is shared decision-making in oncology from patients', healthcare professionals', healthy individuals' and experts' perspective?

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Background

There is growing recognition that shared decision making (SDM) is important, particularly in oncology. However, ideas about what constitutes an SDM-process seem to differ significantly among patients, clinicians, and observers. The aim of this qualitative interview study was to further clarify the construct of SDM for oncology.

Methods

Cancer patients (N=22), their treating clinicians (N=16), nurse practitioners (N=6), members of the general population (as potential future patients, N=16), disease-free patients (N=8) and SDM-experts (N=6) were asked in interviews: "If I say 'Doctors and patients making decisions together about cancer treatment', what does this make you think about?". Ideas were further solicited by presenting 19 cards each describing an SDM-element, based on earlier qualitative studies among cancer patients and oncologists, and current definitions of SDM.

Results

Preliminary results from the patient and clinician interviews show that from the participants' perspective, clinicians as well as patients have specific responsibilities to make SDM happen.

SDM involves that clinicians determine the possible treatments for a particular patient, based on medical and personal patient factors. In the consultation, clinicians state that a) there is a choice, b) the patient's opinion is important, and c) the patient decides. Clinicians give information about the disease and present the treatment options, which may include pros and cons and probabilities of these. Clinicians do more than only mention treatment outcomes, they explain these in some detail at least. Clinicians are open and honest, and information is accurate, clear and complete. Clinicians determine patients' level of understanding, and clarify any issues, if necessary. Clinicians make efforts to get to know patients, for example by asking what matters to them in their life. Also, clinicians ask about patients' views and preferences regarding the treatment options. Importantly, clinicians coach patients throughout the decision process and provide a treatment recommendation. Their expertise, the fact that they have knowledge and experience, lends them the authority to do so.

Patients, on the other hand, ask questions if something is not clear. They think about the options, consider what is most important to them and offer their opinion on the treatment options. They express their thoughts and feelings to clinicians. Patients decide, they accept or reject the treatment proposal and clinicians respect their choice. However, when patients do not want to decide, clinicians will decide for them. Patients may further search for information, prepare questions, take time to think and consult others (family members, friends, GP) outside of the consultation, as part of the SDM-process.

In many interviews, clinicians formulated responsibilities for clinicians, and patients for patients. The behaviors thus described often complemented each other; the clinicians, for example, put emphasis on clinicians' responsibility to get to know the patient without forcing patients to be open, while the patients stated that patients should express their thoughts and feelings openly.

Conclusion

This study suggests that clinicians have a prime role in the SDM-process but that SDM requires responsibilities from cancer patients as well. These findings will guide the development of an oncology-specific SDM-questionnaire.

Large-scale implementation of shared decision making; action needed from tumor board to consultation room

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Background and aims

Implementation of Shared Decision Making (SDM) faces many challenges; lack of knowledge and self-efficacy among clinicians, negative attitudes towards SDM in general or towards the contents of patient decision aids. There may be barriers on organizational level; the best timing and procedures for bringing patient decision aids (PtDA) in the process is as yet unknown.

In the first two years of this project a PtDA was developed according to state-of-the-art procedures with a best practice team in mamma care. The aim of this study was to develop an implementation strategy, based on empirical findings from a pilot implementation study, for effective integration of SDM and the PtDA in the clinical pathway.

Methods

The best practice is about women diagnosed with early stage breast cancer who face a preference-sensitive decision: the choice between breast conserving therapy, always including radiotherapy, or a mastectomy. The two options are equally effective in terms of survival, but differ in treatment burden. Between May 2015 and March 2017 we performed a mixed method formative process evaluation among mamma care teams in 7 Dutch hospitals, all dedicated to implement SDM for this patient group. We collected data among 20 professionals and 105 patients by audio taping clinical encounters, interviewing patients and professionals and auditing patient files.

Results

The implementation strategy consisted of:

- a state of the art developed PtDA,
- a prescription pad that enables patients to personalize the PtDA,
- a 4 minute video for patients and professionals explaining the PtDA,
- advice tailored to the needs of the team on: to set the indication for the use of the PtDA in the tumor board ,to systematically register the indication, and to timely deliver the PtDA to the patient (by whom, how, when),
- an on-the job training session for professionals on the use of the PtDA,
- a 10 minute video for professionals on the model of SDM.

Preliminary results indicate:

Specific facilitators to accomplish SDM :

- the tumor board determines and registers treatment options instead of a treatment plan ;
- register delivery of the PtDA in the patient file;
- a more distinct role for nurses involved in breast cancer care.

Barriers to implement SDM and the uptake of the PtDA are:

- amount of information patients receive;
- structure of the breast cancer pathway.

Conclusion

The implementation of SDM takes more effort than just disseminating a Patient Decision aid.

An evidence-based online content to inform the public on cancer risks linked to environmental factors exposure: www.cancer-environnement.fr

Nicole Falette[1], Mélissa Moucheboeuf [1], Nora Moumjid-Ferdjaoui[1,3], Thierry Philip [1], Béatrice Fervers [1,2], **Julien Carretier[1,3]**

1. Cancer Environment Department, Comprehensive Cancer Centre Léon Bérard, Lyon, France
2. Cancer Research Center of Lyon UMR INSERM 1052-CNRS 5286 team « oestrogen signaling and breast tumor », Lyon, France
3. University of Claude Bernard Lyon 1, Health Services and Performance Research (HESPER) EA 7425, Lyon, France

Background and aims
Cancer risks associated with environmental, occupational exposures and nutritional factors represent growing concerns for the public, cancer patients, family members, and healthcare professionals. The Centre Léon Bérard has developed an evidence-based online content to improve access to up-to-date reliable information on cancer linked with environmental, occupational or nutritional factors dedicated to users. This website provided recommendations regarding cancer risk and environmental factors since October 2010. It currently represents the French public reference website on this topic.

Methods
Cancer-environnement.fr provides information synthesis of available evidence based on five steps. 1/ To identify and collect primary information sources by the Cancer Environment team, including the International Agency for Research on Cancer (IARC) monographs (especially reviews of human carcinogens), synthesis in plain language of reports from international, European and national health agencies. Besides. Particular attention is paid to propose understandable and accessible information and contents in order to take into account the diversity of users (patients, health professionals, scientists etc). 2/ To validate the information synthesis by external proofreading (expertise from patient associations, environmental health professionnals, healthcare profesionals…). 3/ To endorse the final version by an interdisciplinary editorial committee (Environmental health experts, healthcare professionals, researchers, users) according to quality criteria for public health information. 4/ To publish information factsheets on the website 5/ To update by the team the data available on the basis of a bibliographic monitoring and the main reference websites concerned by this thematic.

Results
This website was certified by the Heath On the Net Foundation, in partnership with the National Health Authority since its launch in 2010. Nowadays, more than 300 factsheets have been published into the six main sections of the website: general information (classifications, regulations…), cancers, environmental exposure, occupational exposure, nutrition and physical activity and IARC monographies. French translations of summaries of evaluations of human carcinogens by IARC are available exclusively on this website. An increased traffic with 62795 visitors/month in 2016, being 680 395 visitors in 2016 year (+72% compared to 2015) traduced an increased interest for this website by the visitors. In 2016, factsheets on 'e-cigarette' and 'endocrine disruptors' were the most viewed topics of interest.

Discussions
This website allows different target user groups to access to evidence-based information on cancer risks linked to exposure to environmental factors. With the flow of heterogeneous information available from different media that could influence inadequate health behaviors, this website can be used to provide an independent and impartiality validated environmental health information for the French public and improves SDM in this domain. A national online survey conducted in 2016 helped the team to better characterize the information search behavior of Internet users and their expectations (publication in preparation). Such an online content can be used regularly to improve this website and SDM tools according to the evolution of French users' needs. In a complementary and important way, better understanding cancer environment risks perceptions could help to develop, implement and assess SDM tools for cancer environment prevention and support national health organizations to enhance heath information strategies.

Keywords: evidence-based; website; cancer risk; environmental factors; prevention; methodology

Poster Session 2

Tuesday 4th

16:00—17:30

Salle des pots de thèses

ISDM 2017

Testing a Shared Decision-Making Protocol for Youth Psychotherapy: A Case Series

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Background and Aims:

Conducting shared decision-making (SDM) with families and youth to address mental health concerns raises challenges distinct from standard barriers to SDM, such as 1) addressing disagreement between parents and youth, 2) accommodating youths' varying developmental levels, and 3) providing information on treatment options that may be difficult to understand (e.g., the differences between therapeutic approaches).

Methods:

Following a mixed-methods assessment of parent and youth perspectives on treatment planning and consultation with content experts, a 1-session SDM protocol was created to guide clinicians, parents, and youth through a collaborative treatment planning process that incorporates research findings into a discussion that addresses three questions: 1) what will be the target problem(s) for treatment, 2) who will participate in treatment, and 3) what skills will be the focus of treatment. The protocol was then used across five cases with children ranging in age from 7 to 15 years old with presenting problems of depression and anxiety. The assessment battery included measures of decision self-efficacy, treatment motivation, treatment preferences, treatment outcomes expectations, decisional conflict, and decision satisfaction, in addition to measures of symptoms, impairment, and diagnoses. If accepted, this poster or oral presentation will focus on describing the components of the SDM protocol and the quantitative results of the aforementioned measures.

Results:

The SDM protocol resulted in a clear treatment plan in each of the five cases, with each participant in the treatment planning process agreeing to the treatment plan by the end of the SDM session. Parents and youth were generally favorable about the SDM protocol, with scores on decisional conflict remaining low, and scores for expectations of treatment outcome, motivation for treatment, and satisfaction with decisions remaining high. Target problems decided upon in the SDM session were consistent with the problems that parents and youth reported individually during the initial assessment, and the degree to which parents were planned to be included in treatment was consistent with the initial preferences of parents and youth.

Conclusions:

The SDM protocol was both feasible and acceptable in its current format. After participating in an SDM session, parents and youth reported satisfaction with their decisions regarding the treatment plan. Furthermore, the treatment plan was consistent with the preferences parents and youth endorsed prior to the SDM session (even when parent and youth disagreed), suggesting that the SDM protocol facilitated compromise and the creation of a treatment plan that balanced the preferences of different stakeholders.

Theoretical development of an integrated model of shared and supported decision making for mental health settings

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[2] *Melbourne Social Equity Institute, The University of Melbourne, Victoria Australia*

Background

Despite the moral imperative to include individuals in making decisions about their own mental healthcare, there is no single approach capable of addressing the contextual complexity of these decisions. 'Shared decision making' has become prominent in clinical practice, applied in a variety of settings for a diverse range of treatment decisions with mixed success. 'Supported decision making' may help in this regard, which is a concept that has become prominent in developments in mental health policy and international human rights law. Legal tools such as advance statements and powers of attorney are commonly referred to as forms of supported decision making, but the term is also used to promote an ethos of autonomy with support in decisions across the life, such as housing, finances and lifestyle. These two approaches have been developing largely in parallel with little thought given to the similarities, differences and possible ways they can complement one another.

Aims

To describe the similarities and differences between shared decision making and supported decision making in the mental health context, and to propose a theoretical model to integrate the two approaches.

Methods

Narrative review to inform the exploration of the theoretical underpinnings of these approaches.

Summary of results

Although both approaches have the shared goal of providing tools and resources for an individual to make choices, there are historical, structural and theoretical differences. The field of shared decision making has largely been clinician-led, influenced by evidence-based practice. The idea of supported decision making has been largely consumer-led, stemming from efforts to promote the rights of persons with disabilities. Although these differences should be acknowledged, there are points of overlap. While shared decision making may be perceived as conceding decision-making power in part to the clinician, this fails to recognize the focus on the decision-making processes (e.g. information sharing, deliberation) rather than on who ultimately makes the decision. Conversely, supported decision making may be perceived as abandoning the individual to their expressed wishes no matter the consequences, but this fails to recognize the range of ways individuals may be supported to make decisions.

Conclusion

The two concepts aim to strengthen the choice and control of individuals. Supported decision making can offer legal grounds for a person to make decisions with support (e.g. via advance statements and representative powers), and more broadly offer an ethos for strengthening a person's human right to make choices about how they want to live. Shared decision making can provide guidance for how to make evidence-based, preference-informed decisions about mental healthcare once these legal mechanisms are in place. Each approach has unique elements that can inform the other to ensure support for people in making decisions about their own healthcare. The conceptual thinking for mental health settings may be transferable to other settings in which decision making, capacity and legal decisions are at play.

Treatment preference and choice in shared decision making: creating a decision aid for young people with attention deficit hyperactivity disorder (ADHD) and their families

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[2] *The Tavistock and Portman NHS Foundation Trust*

[3] *University College London*

Background & aims

Experience of shared decision making (SDM) in young people's mental health care has been associated with better psychosocial outcomes (Edbrooke-Childs et al., 2015). However, a recent CYP IAPT rapid internal audit in the United Kingdom showed that while 83% of clinicians felt that they usually or always discussed the range of treatment options available with service users, only 30% of young people felt that they were given enough information to make a choice about the treatment they received (Edbrooke-Childs et al., 2015). A Cochran review indicated that use of decision aids could improve SDM in practice. These tools are associated with multiple positive effects, including increasing knowledge, lowering decisional conflict, decreasing passivity in decision making, increasing accurate risk perceptions, increasing satisfaction with the decision and increasing the likelihood that patients will choose an option that is congruent with their values (Stacey et al., 2012). While the use of decision aids in adult physical and mental health is now common, there is a growing need for these tools to be developed in the field of child and adolescent mental health. An intervention with medication choice cards for ADHD successfully increased parents' shared decision making and knowledge of treatment options without increasing visit duration (Brinkman, 2013), however there are other treatment and support options for ADHD that could be explored. This paper will cover the process of creating two paper-based decision aids exploring community, psychosocial, and medication support options for young people with ADHD and their families.

Methods

The researchers conducted a scoping review of the literature around patient preference for treatment of ADHD. Using the process laid out by Barr et al. (2016) in creating a depression Option Grid™ decision aid for adults, the researchers compiled a list of frequently asked questions relating to treatment or support for ADHD. These questions were then entered into an online questionnaire-building system (SurveyMonkey), and respondents were asked to rate how important each question was to them when considering treatment or care.

Results & conclusion

75 parents of children with ADHD participated in our survey. The top five most important questions for respondents were included in the first draft of our decision aid for ADHD, and we determined the available treatment options from What Works for Whom (Fonagy et al., 2002), the NICE Guidelines for ADHD (NICE, 2016), and expert clinical consensus. The resulting decision aid is currently being refined in North London CAMHS using quality improvement methodology. It will be freely available for anyone to use from July 2017.

‘If I could see on a piece of paper options for treatment that would just be insane’: Shared decision making in mental health

Magenta Simmons[1]

[1] *Orygen, The National Centre of Excellence in Youth Mental Health, Centre for Youth Mental Health, The University of Melbourne, Victoria Australia*

Background

Implementing shared decision making is challenging in youth mental health for a number of reasons, including the age and developmental stage of the young person; the legal and structural context of their care; perceived and actual decisional incapacity; the varying involvement of caregivers; and the paucity of relevant, high quality research available to communicate probabilities of treatment benefits and harms to young people and their families. In an attempt to address these complex issues, a suite of studies have been undertaken. When considered together, this research provides a blueprint for how to maximize treatment decision making in youth mental health.

Aims

To describe a series of studies investigating optimal ways to support young people with emerging or established mental disorders to be involved in shared decision-making processes. Specific study aims included:

1) To explore the experiences of young people, caregivers and clinicians about treatment for: a) major depressive disorder; b) young people at increased risk of developing a psychotic disorder; and c) first episode psychosis;
2) To measure decisional capacity in young people diagnosed with major depressive disorders, with first episode psychosis, and those with no history of mental disorder;
3) To develop and pilot test a generic, multi-purpose decision aid for any youth mental health treatment;
4) To develop and pilot test an online decision aid for young people at risk of developing a psychotic disorder;
5) To develop and evaluate an online decision aid for young people diagnosed with major depressive disorders;
6) To evaluate a combined peer work and shared decision making intervention.

Methods

A variety of qualitative and quantitative methods were used.

Results

Qualitative data revealed enthusiasm for shared decision making across a number of treatment decisions. This included the consideration of how decision aids and advance statements could be combined. The online decision aids that were tested were all feasible and well received; the only decision aid to be tested using a full evaluation demonstrated promising results in terms of decision support (e.g. reduced decisional conflict, perceived involvement) and outcome (e.g. helping young people to choose a guideline concordant treatment option, depression scores). It was possible and beneficial to combine peer work and shared decision making. However, the assessments of decisional capacity highlighted that some young people diagnosed with major depressive disorder, and many young people with first episode psychosis will need significant support to be fully involved in decision-making processes.

Conclusion

Shared decision making is desired and feasible for a range of young people with emerging and established mental disorders. However, feasibility testing of online decision aids does not provide adequate data to ensure the young person is fully involved in the decision-making processes. Future decision aids should address the complex needs of young people who suffer from cognitive deficits related to the emergence of mental ill health. Additional research is needed to more comprehensively understand treatment decision making within the legal and structural context of youth mental health services.

Behaviour Change Techniques (BCT's), Shared Decision Making, and Outcomes in Child and Youth Mental Health?

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[2] *University College London and Anna Freud Centre*

Background

A recent review of approaches and tools to facilitate SDM in child and youth mental health identified six different categories of approaches being used. These included: therapeutic techniques, psychoeducational information, decision aids, action planning or goal setting, discussion prompts, and mobilising patients to engage (Cheng et al., in press). Seven included studies had an evaluation component attached to them, and the majority suggested SDM could be associated with at least one positive outcome, though this varied by study, with some similar approaches finding different or conflicting results. Variability in outcomes may be linked to different Behaviour Change Techniques (BCT's) being used within interventions. BCT's are defined as the smallest components of behavior change interventions that can bring about change (Michie et al., 2013). Identifying these active units of change is important in establishing how an intervention works (Craig et al., 2008; Michie & Abraham, 2004). The aim of this review is to examine what BCTs were associated with better outcomes in child and youth mental health.

Method

This review considers studies with a quantitative evaluation component to examine which behavior change techniques may be contributing to better outcomes in SDM. Data was considered from 21 records retrieved from the Cheng et al., (in press) study which the first author of this paper co-authored. Included records were published between 1994 and September 2016 and were searched from databases (PsycINFO, EMBASE, Medline, PubMed, Web of Science, Cochrane Libraries, the Ottowa Decision Aids Database), and grey literature. An updated search was conducted to January 2017 but no additional papers were found that met inclusion criteria.

Results

7 studies met inclusion criteria. Included studies ranged from having 0 to 7 BCT's with a mean of 2.71 BCT's. The most commonly associated BCT was adding objects to the environment, followed by discussing pros and cons, information about health consequences, and problem solving. BCT's were most commonly aimed at parents of young people, followed by BCT's aimed at clinicians, as few studies had included young people as the target population. It is also unclear which BCT's, or specific combinations of BCT's are associated with better outcomes in child and youth mental health, though adding objects to the environment without other BCT's may not be associated with better outcomes. A quality assessment of included studies ranged from weak to moderate.

Conclusion

There is a lack of high quality, rigorous studies that include young people as their target population within this area. Intervention developers should clearly outline all active BCT's being used, and measures need to be developed to capture SDM in young people.

Power Up App for Parents: A comparative RCT to promote Shared Decision Making (SDM)

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University College London, UK

Background

Many researchers agree that stress can be a barrier to SDM (Hofstede et al., 2013; Légaré & Thompson-Leduc, 2014; Peek et al., 2009). In addition, making decisions for young people (YP) with mental health can be challenging as evident by low levels of parental SDM and agreement between parents, YPs and clinicians for example, on reasons for attending services (Koller, 2017; M. B. Simmons, 2011; M. B. Simmons, Hetrick, & Jorm, 2011; Magenta B. Simmons, Hetrick, & Jorm, 2013)This research is typically based on the premise that parents in addition to the young person accessing mental health service is involved in SDM and therefore the parent can be considered as another service user. Therefore, parents need support in managing parental stress when their child is experiencing difficulties in order to be involved in the SDM process.

Objective

This research will be conducted in phases that will eventually lead to a cluster RCT. The general research question addressed will be to find out whether an evidence-based app for parents can promote SDM for parents of children in therapy.

Methodology

Phase I

A systematic review of parental involved interventions that aim to promote SMD will be conducted to identify how effective they are and potential moderators that may be used to develop stronger effects. This will highlight specific components, such as modes of delivery, formats and techniques that are more effective among various populations to predict levels of parents' SDM behaviour in their child's therapy.

Phase II

A survey to identify parent's interest in being involved in SDM for their child's mental health and subsequently their interest in using a SDM app will be conducted. This survey can be email based for convenience and ease of accessing data from two geographically apart areas which will identify clusters of parents who are more or less likely to engage in SDM for their child accessing mental health services.

Phase III

A pilot study of the app will be conducted at the affiliated clinics/hospitals to examine interrelationships between the app intervention and SDM.

Phase IV

Interviews will be conducted to get feedback on the app use, then materials will be refined and retested.

Phase V

A pilot RCT would then be conducted and delivered to make comparisons among different cultures and to examine potential generalizability of the Power Up app.

Significance

The findings of this proposed study will lead to informed support to promote SDM and enhance the overall lifestyle of children and adolescents accessing mental health services, by providing parents with opportunities to be involved in SDM for their child's physical, mental and social well-being.

References

(in-text citations can be found in the appendix)

Healthcare Options for People Experiencing Depression (HOPE*D)

Paul Barr[1], Rachel Forcino[1], Michelle Dannenberg[1], Manish Mishra[1,2], Eric Turner[3], Yaara Zisman-Ilani[1], Jim Matthews[4], Michelle Hinn[5], Martha L. Bruce[1,2,6], Glyn Elwyn[1]

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Background and Aim

Individuals with depression report low levels of shared decision making (SDM). There is also a lack of decision aids outlining first line treatment options for depression. The aim of this study was to develop and pilot an encounter-based decision aid for people with depression for use in primary care.

Methods

We developed an encounter-based tool called an Option Grid™ decision aid (OGDA). We refined the OGDA through a series of cognitive interviews with patients, the general public, and clinicians. We then piloted the OGDA using a single group pre-intervention, post-intervention design with patients at risk for depression (PHQ-9 score of ≥5) of four primary care clinicians. Feasibility, fidelity of OGDA use, and acceptability were assessed using recruitment rates and semi-structured interviews with patients, medical assistants, and clinicians. Differences in treatment choice and SDM were also assessed using CollaboRATE and SDM-Q-9.

Results

During the OGDA development, three stages of cognitive interviews were conducted with 28 individuals. Changes to the format and layout of the OGDA for depression included moving the combination therapy information and access to treatment information, adding color, and modifying the pictogram. Clinicians suggested edits to the talk-therapy description. Clinician concerns about patient literacy were not reflected in patient interviews. In the OGDA pilot test, of the 59 patients who reviewed study information, 56 were eligible and agreed to participate in the pilot; however, only 29 could be reached for follow up assessment by telephone. The OGDA for depression was widely accepted, though clinicians did not always use it as intended. We found no impact of OGDA use on SDM. Patients in the OGDA group chose a wider range of treatment options.

Conclusions

Achieving greater alignment of treatment with patient preferences through a process of SDM in the treatment of depression is a goal of primary care. For the first time, patients and clinicians have a widely-accepted tool, developed with key stakeholders, that outlines common first-line approaches to treating depression: the OGDA for depression. Creating an electronic encounter-based version of the tool, linked to real-time screening for depression, may improve its fit in clinic. Further research is needed to increase fidelity with which the OGDA is used and to assess it's impact on SDM and related health outcomes.

ABSTRACT FOR ISDM CONFERENCE IN LYON, FRANCE

Shared decision making and care planning within collaborative mental health care:

A SYSTEMATIC REVIEW

Matthew Menear, Michèle Dugas, Emmanuelle Careau, Joyce Dogba, Marie-Pierre Gagnon, Guylaine Cloutier, Michel Gervais, Hervé Thchala Vignon Zomahoun, & France Légaré

Background and aims

Collaborative mental health care is an evidence-based model of care for treating depression and anxiety disorders in primary care and has been the focus of widespread dissemination efforts in North America and Europe. There is a growing consensus that service users and families should be active partners in collaborative care teams, yet how to best engage them remains less clear. We thus aimed to identify and describe in detail the strategies used to engage service users and families in collaborative care programs for depression and anxiety disorders. The current presentation focuses on ongoing work to describe engagement strategies specifically related to shared decision making (SDM) and care planning.

Methods

Our team of researchers, service users, clinicians and policymakers performed a systematic review update of a previous Cochrane review on collaborative care programs for depression and anxiety disorders in primary care (Archer et al. 2012) and then descriptively analyzed the service user and family engagement strategies within all programs (2012 review + update). The search for the update was conducted in the Cochrane Collaboration Depression Anxiety & Neurosis (CCDAN; 2011 to present) and CINAHL (2009 to present) databases and three clinical trial registers. An exhaustive list of search terms related to depression, anxiety disorders, and collaborative care was used. Articles were eligible if they described RCTs or clinical controlled trials of collaborative care programs meeting the same eligibility criteria used in the 2012 Cochrane review. Five independent reviewers were involved in the process of screening and assessing articles' eligibility. Two review authors are independently performing the data extraction guided by a structured extraction form and codebook. Data extraction is ongoing but will be completed by April 2017. Details of SDM being extracted include SDM processes (information exchange, presenting options, discussing pros/cons, etc.), participants involved in SDM, supports for SDM (e.g. use of decision aids), and evaluation of SDM. Details of care planning extracted include care plan components (e.g. assessment, goal setting, action planning, documenting, etc.), care plan format and goals, participants in care planning, and care planning period (in months). Results will be summarized descriptively.

Results

The systematic review update yielded 4643 unique citations. Initial screening of titles and abstracts led to the exclusion of 4339 articles, leaving 304 citations. After reviewing full-texts, 69 publications describing 55 collaborative care programs were included in the review. These programs were added to the 79 programs identified by the 2012 Cochrane review (total = 134 programs). To date, extraction has been completed for 28 programs, yielding 16 programs that have incorporated care planning and 7 programs that have described efforts to engage service users in shared decision making.

Conclusions

Improving access to evidence-based mental health services in primary care is a shared priority for governments, care providers, researchers and service users. The findings of this systematic review will provide valuable information about how to better integrate shared decision making and care planning within collaborative mental health care, thus making these programs more effective and more person- and family-oriented.

Design and user-testing of a decision aid comparing medications for smoking cessation

Jakob J, Cornuz J, Auer R, Jacot-Sadowski I, Cardinaux R, Selby K

Introduction*:*

Approved medications for smoking cessation, such as nicotine replacement, bupropion and varenicline have comparable efficacy, but different advantages, side effects and costs for patients. Decision aids help physicians present options to their patients and elicit patient preferences. While multiple brochures focusing on motivational approach are available in French-speaking Switzerland, there is no decision aid independent from pharmaceutical companies to help patients and physicians compare smoking cessation medications

Methods:

We incorporated medication images, cost data from local pharmacists and recommended dosing from national guidelines. Comparative effectiveness, side effect and weight change data were taken from systematic reviews and meta-analyses. We tested the decision aids through direct qualitative observation techniques of smoking cessation consultations and applied recommended methods from the user-centered design and option grids approaches. The decision-aid was further refined using three PDCA cycles (Plan-Do-Check-Act) based on user-testing by staff and resident physicians during consultations.

Results:

The first PDCA cycle consisted of validation of content by four smoking cessation experts and the rapid development of several prototypes without patient testing. Based on previous experience we followed national guidelines, restricting the choices to medications and not e-cigarettes or alternative therapies. We chose a tabular concept to permit easy comparisons during consultations. In the second PDCA cycle, five resident physicians pilot-tested the decision aid during 15 patient consultations. They reported the density of information to be too high, so we removed information about weight change and contraindications. In the third PDCA cycle, the updated tool was used by the same doctors with different patients. Doctors and patients requested clearer indications on pricing and a graphic artist specialized on medical multimedia presentation participated.

Discussion:

User-testing and multiple feedback loops have enabled us to create a tool that incorporates the best evidence, fits patient and health care provider expectations and is useful during consultations. The decision aid is freely available and should be further tested in different settings, as the tool has been used in one ambulatory clinic only and with a restricted number of patient consultations. The methodology used for its development could be employed for other decision aids for preference-sensitive decisions.

Shared Decision Making in Catalonia: a new step forward in improving decision making process

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[2] *Catalan Patient Advisory Council*

Background and aims

Over the past few decades there has been increasing interest in the concept of shared decision making. In this context, the Catalan Patient Advisory Council was created and requested to lead a strategic plan aiming to promote patient-centered care which has been associated with improving self-management, patient satisfaction and responding to patients, families and patient associations' needs. As part of this strategic plan, the shared decision project started by designing and developing specific patient decision aids (PDA) for shared decision making and encourage patients in discussing with their doctors reasonable treatment and decision options.

Methods

A web based PDA was designed and elaborated with the participation of patients from the Catalan Patient Advisory Council and health care professionals representing different scientific societies The PDA aimed to provide patients with the best scientific evidence through the following content: information of the health condition, appropriate options of management, pros and cons of each alternative, a test on patient's values and preferences, and frequently asked questions.

Results

Five patient decision aids are available at the moment on clinically localized prostate cancer, chronic kidney disease, abdominal aortic aneurysm, carpal tunnel syndrome and breast reconstruction after mastectomy. All PDAs include stories of patients from the frontline, preference tests, patient resources such as video demonstration on dialysis with the final aim of helping the patient on the decision about treatment or therapeutic choice.

Conclusions

While the web based PDAs were reviewed by experts, some contents of PDAs can still remain subject of discussion since every doctor participating in the process for example the case of localized prostate cancer (nephrologist, radiotherapist or oncologist) can see the health condition from their own perspective, and all can have their own preference on presenting for instance treatment options. However, good shared decision making in this process should recognize the complementary areas among the experts and lead in this case to improve de quality of decisions.

The shared decision project was designed to address the challenges to improving decision making process. The PDAs educates patients and emphasizes the availability of multiple treatment options and the role of the patient in this process. In order to facilitate this process, it includes a test of preferences that prepares patients to discuss with their doctor their values, opinions and preferences.

All these PDAs will help to ensure that patients start being involved in the management decision making with their doctors and this might have an impact in the future in increasing patient empowerment, compliance and satisfaction and decreasing inappropriate treatments. But there are still some challenges to cope with in the future such as the metrics needed to evaluate their impact at different levels as well as their main barriers and facilitators to overcome for its successful implementation in the decision making process.

How is ambiguity in risk estimates being presented to patients? A review

James Hicklin[1], Nick Bansback[1]

[1] *University of British Columbia, British Columbia, Canada*

Background and aims

Interventions designed to help people deliberate and participate in their healthcare choices frequently describe uncertainty in terms of potential benefits and harms. This uncertainty can be conceptualized into two dimensions. The first dimension, termed aleatory or first-order uncertainty, can be represented by risk estimates, and arises due to an inherent variability in the population. The second dimension, called epistemic or second-order uncertainty, is represented by imprecision or ambiguity around the risk estimates, and originates from a lack of precision, reliability, credibility, or adequacy of information. The aim of this study was to review how second-order uncertainty has previously been described to patients.

Objectives

To review how patient decision support interventions (PDSIs) and existing literature describe epistemic uncertainties, in order to determine an optimal representation of ambiguity with regards to patient decision-making.

Methods

We searched for patient decision aids available online in 5 repositories, and searched 2 databases for peer reviewed literature using search terms previously developed for identifying risk communication, combined with terms including “ambiguity”, “imprecision”, “quality”, “credibility”, and “uncertainty”. We followed the PRISMA approach to systematically identify relevant literature and decision aids. Our search was widespread in that we did not restrict ourselves to presentations of uncertainty within a single disease, but instead investigated across the entire patient health domain. Eligibility was determined by screening texts for patient-directed descriptions of ambiguity.

Results

We identified 11 different approaches, which were further separated into 3 distinct categories. Textual approaches presented uncertainty using simple qualitative descriptions (e.g. “about/around a 40 in 100 chance”). Combination approaches provided point estimates alongside additional textual information about the quality of the estimate (e.g. “we are very confident that the true effect”, “low quality evidence”, “based on the observations of 220 people”). Integrated approaches incorporated ambiguity/imprecision within the risk estimates, using numerical confidence intervals or ranges, and more sophisticated visuals including gradients, violin plots, and box plots that better represented the probability distributions around the point estimates.

Conclusions

Since nearly all risk estimates have second order uncertainty, there is a tension between the perceived ethical imperative to communicate this type of uncertainty, and people’s well-described difficulty and negative psychological responses to second order uncertainty. We find considerable variation in approaches used to describe this ambiguity. It is unclear how its provision influences trust, credibility in the information presented, decisional conflict, and worry. This variation is a possible consequence of the lack of evidence surrounding the relevant point estimates and the absence of consensus regarding optimal representation, and highlights the need for more empirical research to understand if and how second order uncertainty should be presented.

Analysis of the Extent of Shared Decision Making in Consultations between Australian General Practitioners and Patients with Acute Respiratory Infections

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Background

There is a trade-off between the benefits and harms of antibiotic use for acute respiratory infections (ARIs), hence consultations for ARIs are ideally suited to shared decision making (SDM). However, there has been little exploration into the extent to which this occurs, including what and how benefits and harms are discussed.

Aims

To 1) analyse the extent to which SDM occurs between general practitioners (GPs) and patients with ARIs, including if and how benefits and harms are discussed; 2) explore the use of patient decision aids in ARI consultations.

Methods

Nested within a cluster randomised trial of three decision aids (for acute otitis media [AOM], sore throat, and acute bronchitis) and a brief GP SDM training package, we audio-recorded a convenience sample (of consenting patients and GPs) of consultations for ARIs involving GPs who had been provided with the decision aids. Two raters independently analysed the recordings using the OPTION scale (maximum score of 100) and 5 items (about communicating evidence) from the Assessing Communication about Evidence and Patient Preferences (ACEPP) tool (maximum score of 5) and also noted any antibiotic benefits and harms discussed.

Preliminary Results

Twenty-four consultations, involving 8 GPs, were recorded; 12 for bronchitis; 8 for sore throat; and 4 for AOM. The total mean OPTION score was 29.8 (SD=14.3). The two highest scoring items were Item 12 (clinician indicates need to review the decision) (M=2.7, SD=1.6) and Item 5 (clinician explains pros and cons of options) (M=2.6, SD=1.7). The two lowest scoring items were Item 8 (clinician checks patients' understanding) (M=0.08, SD=0.4), and Item 10 (clinician elicits patient's preferred level of involvement in decision making) (M=0.2, SD=0.4). The total mean ACEPP score was 2.6 (SD=1.7), with Item 1 (clinician describes benefits of the treatment) the highest scoring (M=0.7, SD=0.5).

In consultations in which a decision aid was used (n=15), the mean OPTION score was 38.9 (SD=6.6), significantly higher than those (n=9) in which an aid was not used (M=14.6, SD=9.7) - a mean difference of 24.3 (95%CI 17.5 to 31.2). Similarly, the mean ACEPP score was significantly higher in consultations which used an aid (M=3.8, SD=0.5) than those which did not (M=0.6, SD=0.6); a mean difference of 3.2 (95%CI 2.8 to 3.7).

Of the 15 consultations in which decision aids were used, at least one harm was mentioned in 14 consultations, two harms in 13 consultations and 3 in 12 consultations. Diarrhoea, rash and antibiotic resistance were the three most commonly discussed harms. No harms of antibiotics were mentioned in any of the consultations in which decision aids were not used.

Conclusion

The extent of SDM in consultations between GPs and patients with ARIs is low, although use of specific decision aids was associated with higher scores on SDM tools. Without aids, antibiotic harms were not mentioned; this improved when aids were used. Brief decision aids about common ARIs may improve the extent of SDM in GP consultations including better discussion about benefits and harms, and further evaluation in a randomised trial is needed.

Women's change in decisional outcomes after using breast cancer screening patient decision aids: a systematic review

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Background and aims

Shared decision making is recommended by several organizations for women entering (40's) and exiting the screening window (70's) (World Health Organization 2014, American Cancer Society 2015, United Sates Preventive Task Force Services 2016, BreastScreening Australia 2015) In these age groups, decisions for screening mammography should be based on women's values and personal preferences. Shared decision-making has been shown effective for reducing patient decisional conflict, increasing patients' knowledge and patient satisfaction for patients who are facing complex health decisions. However, the effect of breast cancer screening patient decision aids (BCS-PtDAs) on women's screening decisions and perception remains unclear. The purpose of this systematic review was to identify the effect of BCS-PtDAs on women's knowledge of the benefits, risks, anxiety, decisional conflict, informed choice, and clarity of values.

Methods

A search for evidence was performed using the following databases (updated on August 24, 2016): Scopus, MEDLINE Epub Ahead of Print (OvidSP), MEDLINE In-Process & Other Non-Indexed Citations (OvidSP), MEDLINE(R) Daily (OvidSP), and MEDLINE (OvidSP), Cochrane Central Register of Controlled Trials (OvidSP), PsycINFO (OvidSP), Health and Psychosocial Instruments (OvidSP), Health Technology Assessment (OvidSP), and PsycARTICLES Full Text (OvidSP). All retrieved records and full-text articles were assessed for eligibility by two reviewers independently. Disagreements were resolved by a third reviewer. The data that reflect women's knowledge of the benefits, risks, decisional conflict, informed choice, and clarity of values were pooled.

Summary of results

Of 422 studies initially identified, six were eligible for inclusion in the systematic review. Three randomized controlled trials (RCTs) (see Table) and three before-after studies included 2100 women facing a decision whether or not they should begin (women aged 38–50 years) or discontinue (women aged 69–89 years) breast cancer screening. Two RCTs showed that the use of a BCS-PtDA, resulted in significantly more women (aged 48–50 and 69–79) who made an informed choice about undertaking breast cancer screening (326/718 [45%] *vs.* 199/687 [29%]; difference 16%, $p<0.01$) compared with usual care. Women (aged 38–50) in two RCTs and aged 75–89 in one before-after study) were more knowledgeable after using a BCS-PtDA ($p<0.001$). The use of a BCS-PtDA did not affect the level of anxiety in women age 48–50 and 69–72 ($p=0.93$ and $p=0.76$, respectively in two RCTs) BCS-PtDA use also led to a fourteen percent decrease in woman (age 48-50) that reported a positive attitude toward starting breast cancer screening ($p<0.0001$, one RCT). All three before-after studies (women aged 38–49 and 75–89) reported a reduction in overall decisional conflict in the BCS-PtDA group ($p<0.001$). Two before-after studies involving125 women (aged 38–49 years) showed a reduction in feeling unclear ($p<0.001$) and uncertainty about screening values ($p<0.001$).

Conclusion

The use of BCS-PtDA is more likely to increase women's knowledge, help them to make an informed choice, without affecting women's anxiety.

Table

Effect of breast cancer screening patient decision aids identified in RCTs

Outcomes	**Group**	**Randomized Controlled Trials**										
		Mathieu 2007 (women aged 69–71)				**Mathieu 2010 (women aged 38–45)**			**Hersch 2015 (women aged 48–50)**			
		N	**Mean**	**n**	***p***	**N**	**Mean**	***p***	**N**	**Mean**	**n**	***p***
Knowledge	Control	–	–	–	–	189	6.27	<0.001	419	–	71	<0.0001
	BCS-PtDA	–	–	–		113	7.35		419	–	122	
Attitude	Control	313	83.53	–	0.07	–	–	–	408	–	340	<0.0001
	BCS-PtDA	321	81.37	–		–	–		409	–	282	
Anxiety	Control	315	29.34	–	0.76	–	–	–	419	29.6	–	0.93
	BCS-PtDA	321	29.61	–		–	–	–	419	29.7	–	
Informed choice	Control	279	–	136	<0.001	–	–	–	408	–	63	0.0017
	BCS-PtDA	309	–	227		–	–	–	409	–	99	

N – number of women in the group; n – number of women who developed an outcome

Strategies to Support Women and Clinicians to Engage in Shared Decision Making about Timing of Hospital Admission in Labour

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Background and Aims

Up to two thirds of women are admitted to hospital in early labor, reducing risk of unplanned out-of-hospital birth and expanding pain management options, but increasing risk of obstetric intervention, adverse maternal and infant outcomes, and health service costs compared to admission during active labor. There is limited evidence about the extent to which current admission decision-making incorporates patient preferences, the impact of interventions to support shared decision making about timing of admission (particularly any simultaneously supporting both women and clinicians), and very little evidence on the potential of decision support tools in pragmatic trials. We evaluated the uptake of a suite of patient- and clinician-directed interventions in a tertiary hospital and estimated potential effects on rates of early labor admission and clinical outcomes.

Methods

The suite of interventions was developed in collaboration with local stakeholders and comprised: (a) a patient decision aid on where to spend early labor, provided antenatally to all pregnant women planning vaginal birth and available online, designed using local data and refined through user testing with consumers and their partners (n=7); (b) two mandated clinical decision support tools to guide labour diagnosis and preference elicitation when women telephoned/presented at hospital, (c) implementation training for relevant staff, and (d) promotional materials to prompt use in the hospital setting and with community-based physicians. We used an interrupted time-series design with a random sample of 335 eligible women before (n = 177) and after (n = 158) implementation to assess intervention uptake and estimate potential impact on rates of admission in early labour, obstetric intervention, maternal and infant clinical outcomes and use of hospital resources. Data was extracted from medical records. Postnatal interviews were conducted with 12 women to explore acceptability of the hospital admission process and tool use.

Results

The patient decision aid was provided to 48.1% of eligible women. Clinical decision support tools were used for 56.7% of women with telephone presentations and 7.1% of hospital presentations. We observed no significant change in rates of admission in early labour, obstetric intervention, or clinical outcomes after implementation in intention-to-treat analyses, and no association between intervention use and outcomes in treatment received analyses, but were insufficiently powered to detect changes of their estimated magnitude. After implementation, women made fewer telephone calls to hospital in late pregnancy (OR=0.75, 95%CI 0.6-0.93, p<0.05). Women commented favorably on the patient decision aid for enhancing sense of control in managing early labor and consistency with clinician-sourced guidance.

Conclusion

Uptake was suboptimal, despite co-creation, user-centered design, locally relevant information and integration into standard care pathways. Reduced telephone calls to hospital may indicate an effect of the patient decision aid on care-seeking behavior attributable to women's increased sense of control. Future pragmatic trials need to more rigorously evaluate impact on women's perceptions of being informed, in control, and satisfied with decisional outcomes, and pay further attention to implementation challenges. Research exploring factors contributing to poor uptake and subsequent evaluation on clinical and shared decision-making experiences in adequately powered pragmatic trials is planned.

Evaluation of Patient Information Leaflets in Japanese Clinical Research with reference to Decision Quality

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Background and aims

From an ethical viewpoint, the voluntary decisions of patients are necessary for clinical trials. However, some patients participate in trials with an incomplete or false understanding of treatments. The patient-physician relationship in Japan predominantly follows the paternalistic model. This greatly influences patients' trial participation decisions, making patient-centred decisions with value-judgment difficult. Though many Japanese studies have examined patient information leaflet comprehension, none have focused on patient-centred decisions. Conversely, Western studies have developed and implemented patient information leaflet (PIL) evaluation tools that are based on the shared decision making (SDM)-based International Patient Decision Aid Standards instrument (IPDASi), with indications that PILs insufficiently include the content necessary for quality patient-centred decisions. This study was the first to evaluate Japanese PILs using the IPDASi. It also compared the present findings with those of previous research.

Methods

The study evaluated 20 PILs used in Japan, after securing permission, using 32 items from the tool created by Brehaut et al. that was based on the IPDASi, and using the Ideas, Concerns, and Expectations instrument (ICEi) developed by Gilles et al. An evaluation using a four-point scale was carried out independently for the two inventories. A final evaluation using a two-point scale was decided upon following discussion among the authors. In addition, two Japanese language assessment tools were used to evaluate readability.

Results

The overall score ratio was under 50% for all PILs, with an average of 12.4%. The overall score and sub-section ratios did not differ significantly between the regulations followed or the diseases examined. Four of the twelve "Providing Information about Options in Sufficient Detail to Make Decision" items, one of the eight "Presenting Probabilities items, both Clarifying and Expressing Value" items, both "Structure Guidance in Deliberation and Communication" items, and two of the four "Using Evidence" items scored zero across almost all PILs. Adequate mention of Good Clinical Practice (ICH-GCP) and ethical guideline requirements was made. The kappa coefficient for inter-rater validity was 0.535, with a significant difference observed for overall scores when compared to previous studies. Readability was either difficult or very difficult for all PILs, with content ranging between Grade 9 to University level in terms of reading difficulty.

Conclusion

As many ICH-GCP-based international joint clinical trials are being implemented, there is a need to investigate PIL improvements and decision support at an international level. As with previous studies in the West, the results of this study show that Japanese PILs do not sufficiently include the content needed for quality decision-making and are not at the recommended Grade 8 reading level. Therefore, patients may not be able to make decisions appropriate to their own values and based on information sufficient for participation in clinical trials. Accordingly, there is a need for research regarding ideal methods for IPDASi item-based and patient-centred support in Japan. Further, given the low inter-rater validity when compared with previous studies, future research must aim at increasing accuracy in Japanese-language PIL evaluations.

Pregnant women's perceptions of effective behaviour change techniques for an intervention to promote the use of patient decision aids for Down syndrome prenatal screening

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Background

The decision about whether to undergo prenatal screening for Down syndrome (DS) is not an easy decision for pregnant women. Patient decision aids (PtDAs) can help them make an informed decision in keeping with their values and preferences. But PtDAs are rarely used in this context. We aimed to elicit pregnant women's perceptions of effective behaviour change techniques (BCTs) for an intervention to promote the use of patient decision aids for DS prenatal screening.

Methods

We used the Theory of Planned Behaviour to identify the determinants of pregnant women's intention to use a PtDA. We correlated these determinants with the domains of the Theoretical Domains Framework, and used Michie's Behaviour Change Wheel methods to choose BCTs and develop an intervention. This process allowed us to define 25 BCTs that we grouped into eight following categories: information, support, consequences, others' approval, learning, reward, environmental change and mode of delivery. We conducted an exploratory qualitative study. We recruited pregnant women in three different sites (a birthing centre, a family practice teaching unit and an obstetrical ambulatory care clinic) in Quebec city, Canada. Eligibility criteria were: pregnant women over 18 years old, with a low-risk pregnancy, 16 weeks pregnant or more or who had just given birth, having already decided about prenatal screening for their current pregnancy, who spoke French and consented to participate in the study. We divided women according to their parity because it is a factor that influence pregnant women decision. Then a moderator conducted three focus groups, the first with primaparous women, the second with both primaparous and multiparous women, and a third with multiparous women only.

Results

As of February 26, 2017, we have conducted one focus group with five primaparous women, and another with five primaparous women (one of them had recently given birth) and two multiparous women. The third with multiparous women only is ongoing. There were some differences across the groups about suitable strategies for the intervention. The preliminary results of our study suggest that goal setting, problem solving, social support, information about others' approval, adding objects to the environment and prompts/cues are the BCTs that will most likely induce change in women's intention to use the PtDA for DS prenatal screening. The women did not value other types of BCTs such as information about consequences and rewards. Overall, they considered that the two best delivery modes of the intervention to reach pregnant women would be: (i) its publication on a credible website, and (ii) posters in the waiting rooms.

Conclusions

We elicited pregnant women perceptions about techniques to be used to deliver an intervention that would increase pregnant women's intention to use PtDA in the context of DS prenatal screening. Further work is needed to develop the full intervention.

Perceived barriers and facilitators of patient participation in shared decision making: A focus group interview of therapists

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Background and aims:

Patient participation in shared decision making is known to enhance patients' satisfaction with (Turner-Stokes et al, Int J Ther Rehabil, 2015) and motivation for (Leach et al, Disabil Rehabil, 2010) rehabilitation. Few therapists in Japan, however, implement and facilitate patient participation; rather, they tend to fall into paternalism. This study aimed to assess the perceived barriers and facilitators of patient participation in shared decision making with a focus group interview of Japanese physical and occupational therapists.

Methods:

Seven Japanese clinical therapists (5-8 years' experience) participated individually in two daily focus group interviews. The focus group interview was conducted using semi-structured interview protocols by a sufficiently trained and prepared interviewer. The protocol questions were as follows: 1) What do you think of patients' participation? 2) What are some barriers to patients' participation? and 3) What are the facilitators of patients' participation? The qualitative content analysis was used to summarize and label these questions.

Results:

The facilitators included patients' autonomy in decision making, patients' literacy, patients' knowledge, the sharing of knowledge between patients and therapists, and taking evidence into practice. The barriers included patients' delegating attitudes, lack of therapists' accountability, and therapists' paternalism. Some commonalities were observed between the facilitators and barriers.

Conclusion:

Physical and occupational therapists thought patients' literacy and knowledge facilitated their participation in decision making regarding their treatment. Facilitators of and barriers to patients' participation included aspects of both the therapist and the patient.

Perceptions from health professionals and patients regarding participation in Shared Decision Making process. A protocol study

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Background

Shared Decision Making (SDM) improves treatment adherence, patient satisfaction, health care standards and promotes patient autonomy. However, SDM is not always applied in our daily practice; certain characteristics of health professionals and patients have a strong influence in different aspects of the SDM process. Population that attends to San Pantaleon Health Community Center (SPHCC) have low socioeconomic status, low educational level, and poor health literacy. Studies show that these characteristics predict less patient interest in participating in SDM.

Aims

Main: To explore perceptions from health professionals and patients that attend to SPHCC regarding participation in SDM process.

Secondary: To understand how the SDM process works in SPHCC and patient involvement in SDM; assess level of interest that patients have in participating in SDM and level of interest that health professionals have in involving patients in SDM; explore barriers and facilitators perceived by health professionals and patients to carry a SDM process; explore influences from family context, social relationships, media and other possible factors involved in the acquisition of medical information used to participate in SDM.

Methods

Cross-sectional observational descriptive study using a qualitative research methodology.

First stage: Observation and Participant observation to collect information and generate an interview guide to be used on the second stage.

Second Stage: Semi-structured interviews to patients and health professionals.

Results (Expected Impact)

In order to promote SDM in our daily practice we must know the perspectives and necessities perceived by patients and health professionals, and design strategies that help us improve the process.

Our results will provide basis to generate new programs, services, redefine problems and create alternative solutions, establishing levels of priorities. They will allow us to involve, inform, stimulate and empower patients and health professionals to participate in SDM.

Adapting a novel consumer SDM training program for a maternal health setting

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Background:

Efforts to diffuse existing evidence-based SDM interventions in diverse community settings have been limited. In order to implement SDM interventions that account for specific community needs and capacity, adaptations of existing programs is needed.

Aims:

To adapt an existing SDM consumer training program to a specific maternal patient group with lower literacy in such a way that core elements of the original SDM program were maintained while allowing for local adaptation.

Methods:

The original SDM program was developed for implementation in an adult education setting with consumers with lower-literacy. The program focused on knowledge and question-asking, with the AskShareKnow questions (Shepherd et al., 2011) incorporated as a generic tool to support decision-making across healthcare contexts.

To adapt the existing program for a maternal patient group with lower literacy, we followed the principles and processes for conducting research-based program adaptation (Solomon, Card & Malow, 2006):

1) **Know the target population and community context:** Literature reviews were conducted to assess (a) the needs and assets of adults with lower-literacy in the decision-making context, and (b) existing SDM interventions for this group. Collaborations with service providers and maternal health experts helped to better understand the target population and community capacity for program delivery.
2) **Select the program that best matches the population and context:** The original SDM program is an empirically-validated intervention. It provided the best possible match for the new maternal health context given the target population's literacy level, the delivery format and the availability of materials.
3) **Retain fidelity to the "core program":** The adaptation process maintained the theoretical foundation of the program and the tools/techniques used to target the determinants of behavioural change. For example, the AskShareKnow questions remained a core component of the program, as did the inclusion of modeling to build self-efficacy. Content modifications (Stirman, Miller, Toder & Calloway, 2013) included:
    - Tailoring/tweaking/refining: Minor changes were made to make the program more applicable for a maternal context (e.g., modifying handouts to contain relevant examples [e.g. options for pain relief during labour instead of options for treatment of sustained ear pain]).
    - Removing elements and condensing: The program was modified from a 6-h to 1.5-h program. Particular elements of the original intervention were not included (e.g., some numeracy-based activities removed), and some concepts (e.g. benefits and harms) were covered more quickly without skipping material.
4) **Systematically reduce mismatches between the program and the new context:** Observation of the intervention and qualitative interviews with teachers and students were conducted across 3 sites to evaluate the acceptability of the program ensure the content and delivery format was appropriate for the new target group.
5) **Document the adaptation process and evaluate:** The adaptation process has been documented and the final version of the program will be evaluated in a larger randomised trial.

Results:

The research-based program adaptation has resulted in a modified consumer SDM program, appropriate for a maternal patient group with lower-literacy.

Discussion:

Adapting existing SDM interventions for local contexts provides a more efficient use of research funding and resources.

Interventions to improve participation in healthcare decisions with patients from non-Western cultural backgrounds: A systematic review

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Background and aims

Patient participation in decision-making is an important component of patient-centred healthcare. However, there is often uncertainty about its applicability and feasibility with people from non-Western cultural backgrounds.

The aim of this systematic review is to provide an overview and assessment of interventions which aimed to improve patient participation in decision-making with people from non-Western cultural background.

Brief description of methods

Eight electronic bibliographic databases were searched from respective inception to 07 July 2016. Studies were included if they were (i) randomized controlled trials, before and after studies and interrupted time series studies (ii) included patients entirely from non-Western cultural backgrounds or separate outcome analysis for this sub-group is provided (iii) aim to improve patient participation in dyadic decision-making (iv) report outcomes relevant to patient participation in decision-making. Studies were excluded if they included children, were about triadic decision-making or solely focused on information provision without reporting outcomes related to patient participation.

Summary of results to support conclusion/s

A total of 27 studies, 14 RCTs and 13 non-RCTs, were included. Among these studies, 16 were from the USA and 11 were from non-Western countries. Intervention strategies ranged from decision aids, question prompt materials, patient and/or provider communication skills training, to information plus activation strategies. Whilst the majority of studies reported increased patient participation, those interventions which did not require provider endorsement or did not provide interactive or interpersonal coaching or training seemed to be less effective.

Conclusion

Our results suggest that patient-participation, within the context of dyadic decision-making, with patients from non-Western cultural backgrounds can be achievable in a supportive environment with positive endorsement from providers and interactive activation strategies for patients.

Factors Affecting Patients' Perceived Communication about Coronary Artery Disease Treatment: A Latent Profile Analysis

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Background and aims

To be able to fully participate in a shared decision-making process, patients should be sufficiently knowledgeable about the risks and benefits of all available options, such that they can state informed preferences for care. Communication between patients and providers is a key component of the shared decision-making process; however, less is known about how distinct profiles of perceived communication may relate to the decision-making process. We sought to determine whether perceived communication can be used to differentiate patients who are participating in a decision-making process for coronary artery disease.

A brief description of methods

Cross-sectional survey of 212 patients from four U.S. hospitals who were referred for cardiac catheterization for evaluation for coronary artery disease. Survey questions elicited the patients' knowledge about heart disease treatment, perceived communication about the decision-making process, and preferences for decision-making and treatment. The perceived communication section included 7 questions asking how much communication about the risks and benefits of different heart disease treatments was perceived by the patient (responses included "A lot", "Some", "A little", and "None"). Latent profile analysis (LPA) was used to extract classes from the patients using these 7 communication items.

Once classes were extracted, the classes were compared on the following items: 1) communication (7 items), 2) demographics (sex, marital status, age, education), 3) cardiac history (8 items including prior myocardial infarction and cardiac procedures), and 4) knowledge (8 items on the risks and benefits of treatment).

A summary of results to support conclusion/s

The LPA extracted 2 latent profiles. The first profile was composed of 91 individuals, while the second profile was composed of 121 individuals. The profiles were found to differ on all 7 of the communication items, such that Profile 2 perceived much better communication than Profile 1. However, on the other variables examined, only a history of coronary artery bypass surgery differed between the groups. Specifically, for Profile 1, 44.6% of patients had a history of coronary artery bypass surgery, while only 10.0% of those in Profile 2 had such a history.

A conclusion

We found 2 latent profiles associated with perceived communication by patients with coronary artery disease. However, we found that no other factors in our study group, such as demographics, medical history, and patient knowledge, were able to further differentiate the groups. Thus, perceived quality of communication does not appear to be significantly influenced by such patient characteristics. Future work is needed to determine what factors may be associated with optimal communication between doctors and patients

Adapting the Decision Quality Instrument for breast cancer surgery: Semi-structured interviews with women of lower socioeconomic status

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Background

Nearly one in eight women will be diagnosed with breast cancer in their lifetime. Despite significant improvements in overall breast cancer survival, disparities associated with breast cancer treatment, communication in healthcare, long-term health outcomes and mortality persist. Research suggests that women of low socioeconomic status (SES) diagnosed with early stage breast cancer have poorer communication with their clinicians, lower knowledge of breast cancer surgery, higher mastectomy rates, and worse cancer-related and patient-centered health outcomes compared to women of higher SES. The Decision Quality Instrument (DQI) measures the extent to which patients are informed about and involved in medical decision making and receive surgery that is aligned with their goals and preferences. This measure was primarily developed and evaluated with women of higher SES. There is limited data on the performance of the DQI is women of lower SES and lower health literacy. Our aim is to examine the usability, readability and acceptability of the DQI, and explore whether it captures the factors that are important to women of lower SES when deciding about early stage breast cancer treatments.

Methods

The DQI adaptation is occurring at three of the four cancer centers involved in a randomized controlled trial of breast cancer encounter decision aids across socioeconomic strata, currently underway in the USA. We are in the process of recruiting up to 45 women (assigned female at birth) of low SES (government insured or uninsured and 138% of the federal poverty level or below) between the ages of 18 and 74 years old. We are using purposive sampling and targeting women who have completed treatments for early stage breast cancer in the past three years.

Results

Preliminary results suggest that small word changes are needed to improve the readability and usability of the DQI instructions and items. In the 'what matters most to you' subscale, some patients suggested describing key words, such as radiation. The item 'how important is it to you to avoid having radiation' may not be meaningful if the patient does not fully understand what having radiation means.

Conclusions

Ensuring the usability, readability and acceptability of patient reported outcome measures, irrespective of literacy and health literacy levels, is essential yet overlooked. The DQI adaptation among women of lower SES suggests that the readability and usability of a measure that was primarily developed and validated in women of higher SES could be improved.

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A systematic review of measures of informed consent for randomised controlled trials.

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Background

The subjective assessment of informed consent for clinical trials, and the potential difficulties associated with it, has led several studies to develop objective measures of informed consent for clinical trials. These objective measures of informed consent are often specific to a particular population or clinical condition and largely focus on understanding of (some or all of) the key elements of informed consent, namely: capacity, disclosure, understanding, voluntariness and permission. Many of the developed tools are study-specific, but some validated measures exist. Whether these objective tools conceptualize and measure informed consent in the same way is not known. As such, it is not clear whether meta-analyzing data from studies reporting different tools is worthwhile. The aim of this systematic review was to critically appraise the evidence on the conceptualisation and item content of validated questionnaire based measures of informed consent for randomised controlled trials.

Methods

A systematic search of the literature was conducted to identify relevant articles that described the development, and/or validation, of measures of informed consent for RCTS. General data extraction categories were split into those relating to the context of the included study and those relating to items included in the instrument. Data was synthesised by coding of the items identified into domains and sub-domains which were determined by nomenclature defined in included studies. Both for descriptions of included studies and of the instruments reported in those studies, descriptive statistics were used to describe general information and instrument detail. A narrative synthesis of the instruments and their inter-related domains and subdomains was conducted to identify areas of both convergence and divergence.

Results

The search identified 6669 citations. After screening titles and abstracts, 16 complied with our pre-specified inclusion criteria. The included studies report 16 separate instruments whose aim is to measure an aspect of informed consent for RCTs. Four of the included instruments report development of a tool to assess competence of research subjects to consent to participation in RCTs i.e. was set amongst participants who may have diminished decisional capacity (e.g. early stage Alzheimer's, schizophrenia, etc). Of the 16 instruments, 3 explicitly reported a theoretical or conceptual framework underpinning their development, a further 3 implicitly refer to the 'conceptual dimensions of informed consent' or 'principles of research ethics' as informing their development and 10 reported no guiding theoretical framework. Linked to this, some instruments were explicit with regard to which constructs they were measuring while others were more vague. Finally, only 3 of the 16 studies reported patient or public involvement in the development of the tool. Findings from the narrative synthesis of individual constructs will also be presented.

Discussion

This presentation will discuss the key issues relevant for this work specifically relating to the issues surrounding the heterogeneity of existing measures of informed consent to RCTs. The results from the narrative synthesis will be discussed with explicit considerations regarding the conceptualisation of informed consent and inclusion of constructs and items that matter to potential trial participants.

Protocol for implementing shared decision making-Q in Japan

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Background

In Japan, more than 25% of the population is comprised of the elderly, and this is expected to exceed 30% in 2025. Because of this situation, the promotion of shared decision making (SDM) between patient and physician is very important to support many people in experiencing a better end of life. However, methods assisting SDM have not been established, and no tool abiding to this aspect exists. Therefore, a project aiming to promote SDM among medical staff is required in Japan.

Aim

The aim is to enlighten medical personnel on the necessity and methodology of SDM in Japan. No version of SDM currently exists in the Japanese system. Therefore, we have created a protocol for implementing SDM-Q to spread the concept and practice of SDM in Japan. As the first step, we developed a measurement tool (Japanese version SDM-Q-Doc) to visualize SDM.

Methods

1. Verification of validity of face and content of Japanese SDM-Q-Doc

i) Approval by Hamburg University that created the original version of SDM-Q-Doc
We verified the validity of the concept using the Delphi method with native English speakers who had medical experience outside Japan and Japanese doctors who were associated with a study on decision making. Subsequently, we twice translated and back-translated between the original and Japanese versions of SDM-Q-Doc prior to obtaining approval by a copyright holder.

ii) At the same time, using the Delphi method, we verified the parameters being measured by and the Japanese expressions used in the Japanese version of SDM-Q-Doc with doctors familiar with primary care in Japan and other countries.

2. Verification of construct validity and concurrent validity of the Japanese version of SDM-Q-Doc

Because the systematic education of medical consultation skills is performed only in family medicine education courses in Japan, we conducted this examination with the cooperation of doctors eligible for practicing family medicine.

Object (doctor): 40 doctors eligible for practicing family medicine

Object (patient): 400 patients (planned)

Setting: adult outpatients with chronic disease on initial diagnosis

Term: from May 2016 (ongoing)

Evaluation

Questionnaire regarding attributes, SDM-Q-Doc, physician confidence in the medical interview

Expected effect

We created a protocol implementing SDM-Q in Japan and have just launched this project. Using this protocol, it is expected that the importance of the practice of SDM will achieve greater recognition in Japan. This project will enable active communication between patients and medical staff and promote patient-centered medicine in Japan.

Conflict of interest declaration

We declare that there are no conflicts of interests associated with this study.

Acknowledgments

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Personalized prognostic information to support person-centered end-of-life care in the community: a qualitative study

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Background

People in the community who are frail may receive fragmented care in many jurisdictions — especially as they near the end-of-life — due to poor prognostication. One challenge is a lack of tools to identify people across a spectrum of care needs. RESPECT (Risk Evaluation for Support: Predictions for Elder-life in the Community Tool) is a prognostic tool developed using population-level data. The purpose of our study was to explore the acceptability and usefulness of a personalized risk prognostic tool to identify community-dwelling people nearing end-of-life and its' potential role in improving advance care planning discussions and end-of-life care.

Methods

We developed a mortality-risk prediction model (RESPECT) for people who are frail (nearing the end of life) that can be used in the community setting by home care clients, as well as their informal and/or formal caregivers. The risk prediction model was developed using survival analysis and data from 560,000 Ontarians who received a structured home care assessment between January 1, 2007 and January 1, 2014. To assess the value of the prognostic tool in community care, we conducted semi-structured qualitative interviews and focus groups with patients, caregivers, and home care practitioners, using maximum variation sampling. Additionally, the focus groups are being used to evaluate the preliminary online tool, potential metrics and additional communication information. The interviews and focus groups were recorded and transcribed; thematic analysis along with a constant comparative approach is being used to analyze data.

Results Preliminary results from pilot-phase interviews and focus groups suggest that risk stratification instruments play an important role in community care planning. Online implementation of this prognostication algorithm with an adaptive design enables its ease of use by health care providers, the patients, as well as their caregivers and is perceived to be a valued feature in knowledge translation and risk communication. Analysis is ongoing and additional themes regarding the type of information people want, feelings around having risk of deteriorating health identified, and support required for individuals who receive personalized risk information from the tool are emerging.

Conclusion

Initial results suggest on-line implementation of RESPECT presents a valued opportunity for person-centered care. Results of this qualitative study will enable a comprehensive assessment of the implications of end-of-life identification in the community setting and will support implementation of prognostic algorithms in ways that facilitate sensitive and responsive identification, assessment, care planning, and improvement of quality of life

A field-test of peer support shared decision-making with First Nations, Inuit and Métis people in cancer care: Initial results

Jull J, Kewayosh A, Prummel M, Sheppard A, Steiner R, Graham I

Objectives

An approach to health decision-making called “shared decision-making” has been found to improve peoples’ participation and outcomes in healthcare. The purpose of this study is to tailor and field test, by and with First Nations, Inuit and Métis communities, a peer support shared decision-making strategy for use in cancer care.

Approach

This project has 2 theory-driven phases and will be led by a core research team from the Aboriginal Cancer Control Unit of Cancer Care Ontario and academic researchers from the Ottawa Hospital Research Institute, with an experienced Advisory council. In **phase 1**, a previously developed peer support shared decision-making strategy will be tailored and training developed to meet the needs of cancer care system providers and users. During **phase 2**, community members and support workers will use the strategy and their experiences assessed. Data on health systems’ factors related to the strategy use will be collected.

Results

Preliminary results will be presented to describe 1) the approaches used to engage with cancer care system stakeholders (Advisory council; First Nations, Inuit and Métis communities and health workers), 2) processes to tailor and develop training in the peer support shared decision-making strategy to facilitate participation of people in their care, and 3) responses to the strategy training.

At completion of the project, the research will 1) inform further development of peer support shared decision-making strategies to facilitate participation of First Nations, Inuit and Métis people in decisions about their cancer care, 2) advance the science of knowledge translation, and 3) produce data to support a proposal to conduct a multi-site implementation trial of peer-supported shared decision-making, the next stage in this program of research.

Conclusion

First Nations, Inuit and Métis people face increased cancer risks in relation to general populations and experience barriers to health service use. This study proposes to address these barriers to care and tailor and then field test a peer support shared decision-making strategy for use in cancer care.

Co-design of the ambulatory care to improve the quality of life of cancer patient at home

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Context

Ambulatory in the organization of care represents an opportunity for change of model in cancer patient care. Indeed, 1 million people are living with a cancer at home, one third of the patients undergoing treatment in France.

It is essential to integrate all stakeholders' perspectives: patients, loved ones, health professionals, non-medical professionals, city professionals and hospitals and relay structures. Two associations of cancer patients' defence, "Cancer Contribution" and the "Multiple m yeloma French patients association (AF3M)", have responded in a call for projects on "Health democracy" proposed by the General Direction of Health to co-develop an innovative approach for patient care.

Objectives

CancerAdom project aims to foster the emergence of new inspiring ideas to improve the lives of patients cared at home. The main objective is to develop a participatory approach anchored on the expression of all stakeholders, in taking into account their expectations and questioning in a strategy of actions which can be modelling beyond cancer for other chronic diseases. Operational objectives of CancerAdom are to:

- Identify health practices and reaffirm the importance of users' expertise.
- Promote and develop health democracy (patient representatives and patient involvement) in cancer care.
- Allow the expression of users in the development of a new model of care at home.
- Establish a modeling and reproducible approach for all chronic diseases.

Method

CancerAdom chose a new form of citizen consultation, using the methodology of service design. Made-to-measure, it is embodied in meetings and interviews with all actors of the healthcare system, patient and professionals in a dynamic of co-construction from different expertise and perspective.

Three areas have been selected: Ile-de-France, Haut-de-France and Auvergne-Rhône-Alpes, where a dozen of cancer patients and relatives and a dozen of professionals have been interviewed individually. In a second time, they met for a workshop to confront their point of views, needs, proposals, and enrich them in order to prioritize them. The proposals then were submitted to a less initiated target for exchange table in public places.

First results

Seven themes have been identified: 1/Preparation: how I went from hospital to home; 2/Hospital at home: bring care home; 3/My care: my medical care at home; 4/Daily life: m y new routine; 5/The coordination and training of professionals; 6/My interlocutors ; 7/My independence

About 50 proposals have emerged and have been prioritized and documented. Their feasibility has been assessed. A W hite Book of these proposals is ongoing and will be published and discussed during a national public meeting in June 2017. These results will be presented to politicians and institutions to move towards a realization of a maximum of them. They could be presented at ISDM conference. The French National Cancer Institute, which has closely followed the project, is already ready to take into account these proposals and work with patient associations in line with the measures of the national cancer plan. The healthcare network of Ile-de-France is also ready to experience some of them.

Better Conversations, Better Decisions: Choosing Wisely UK

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Background and aims

Current healthcare models are undergoing challenging times as the demographics of the population changes and technical expertise surges in the face of financial and resource constraints. Matching the right patient to the right treatment option has never been so imperative through aligning decisions with a patient's values, preferences and goals. At the heart of better decisions lies better conversations.

In 2012, the American Board of Internal Medicine launched an international programme to promote better conversations between providers and patients entitled 'Choosing Wisely'. Sixteen countries subsequently joined the programme, of which the UK arm is one of the most recent. Led by the Academy of Medical Royal Colleges, which governs all the UK Royal Colleges and subspecialty faculties, we aimed to make the focus of our programme embedding shared decision making into healthcare through a public facing initiative promoting better conversations.

Methods

We asked all the Royal Colleges and subspecialty faculties we represent to identify five areas of care which could benefit from improved shared decision making. The recommendations were examined by a team of expert clinicians and policy makers alongside lay and patient representatives to ascertain appropriateness and relevance to the UK healthcare model.

Results

Twelve responded producing recommendations, which were examined by the Choosing Wisely team of clinicians and policy makers alongside patient liaison representatives. We noticed variability amongst the royal colleges in the focus of recommendations. Some chose to identify five areas of practice which we 'should not' do, for example a head CT in the event of minor head injury. Others chose to challenge traditionally controversial, yet increasingly relevant, decisions broaching the topic of end of life care. For example, the Royal College of Radiologists recommended reviewing the use of chemotherapy in advanced cancer where it is unlikely to be beneficial and the Faculty of Intensive Care Medicine recommend life support not to be offered where there is a high risk of death or severely impaired functional recovery. The Royal College of General Practitioners urged in those approaching end of life or frail, for a review of medications decreasing to only those which offer symptom relief.

Engagement has been impressive with the website – www.choosingwisely.co.uk - receiving widespread media attention. Overall with recommendations have been widely accepted, with the exception of the advisory on prostatic sensitive antigen. Interestingly end of life care has been highlighted as a healthcare priority for public, patients and professionals alike.

Conclusion

We are now planning implementation of the recommendations through quality improvement initiatives and education and training. Central to this will be developing and disseminating education and training in shared decision making. Our aspiration is Choosing Wisely UK will be a timely national initiative to promote and engage public and professionals to improve conversations through the practice of shared decision making.

How do Iranian Clinical Residents Deal with Uncertainty in Making Diagnostic Decisions?

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Background and aims

Diagnostic uncertainty plays an important role in clinical setting in teaching hospitals and also primary care. New progresses in treatment and management of diseases result in uncertainty. The sources of uncertainty have been studied but its effect on diagnosis and treatment of diseases are unknown. Since this issues has been lees paid attention in Iran, we sought to identify and evaluate how patients deal with uncertainty.

A brief description of methods

We used the Persian version of PRU (Physician's Reaction to Uncertainty) which has been validated in other studies to evaluate residents' diagnostic uncertainty. The questionnaire was completed by training residents in internal medicine, pediatric, gynecology and surgery in Iran University of Medical Sciences teaching hospitals. This questionnaire included demographic information and PRU questions. Demographic data was containing sex, marital status, field of residency and number of year's works as a physician. The PRU questionnaire contained 10 questions in four subscales ("Anxiety due to uncertainty", "Concern about bad outcomes"," Reluctance to disclose uncertainty to patients" and" Reluctance to disclose mistakes to physicians").

A summary of results to support conclusion/s

In this study, 119 residents filled the questionnaires. Of these, 45.5% were men and mean age of residents were 31±3 years. Residents' field was divided in four major groups; Internal medicine (39), Pediatrics (37), surgery (24) and gynecology (19). The mean year of clinical experience as a GP was 3±2 years. There was not statistical significance between PRU questionnaire subscales and sex, married, residents' field and year." Reluctance to disclose mistakes to physicians" was correlated with age (P-value=0.014) and years of clinical experience as a GP (P-value<0.001).

Conclusion

Although this study didn't show any major difference in dealing with uncertainty among residents in terms of gender, marital status, educational level and residency field, higher scores in all PRU scales than other studies indicating that dealing with uncertainty in clinical decision making should be considered in curriculum in residency program in Iran.

Poster Session 3

Wednesday 4th

11:00—12:30

Salle des pots de thèses

ISDM 2017

The effects of decision aids for involving patients in Asian

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Background

Shared Decision Making (SDM) is the ideal model for medical decision making in the medical process by allowing medical staff and patients to share the available empirical results before making medical decisions, and to provide patients all the possible choices, and support the patients to make treatment decisions in line with their preferences. In Asian, many countries have advocated, but not yet been widely adopted in practice.

Aims

The aim of this study was to assess effects of decision aids for involving patients.

Methods

We conducted this study at a medical center in south Taiwan from 1 Nov to 31 Dec in 2015 and used the Likert Scale to assess the effects of decision aids when patients faced the medical decisions.

Result

We involved 111 patients. The proportion of patients feeling choose the accurate decision with their values, getting adequate knowledge and accurate benefit and risk perceptions were 77.3%, 86.4%, and 86.5%. After exposing the decision aids, the patients felt more anxious than before ($p < 0.01$). Furthermore, the proportion of feeling chooses the accurate decision between different education status was no significant difference ($p=0.572$). When patients' age were above 65 years old, they had the lower rate to feeling choose the accurate decision ($p=0.007$).

Conclusion

The decision aids help patients make the more suitable decision with their values, improve people's knowledge regarding options, but after making the decision patients still felt concerned. Our decision aids may need to modify more simple to let older patients understand.

Decision-making about breast reconstruction and information needs: preliminary results of patients and professionals

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Background

Women with breast cancer who are surgically treated with a mastectomy can opt for breast reconstruction to restore their breast shape. Decision-making about breast reconstruction is complex and a substantial number of women regret their decision. To support the decision-making process, we are developing an online patient decision aid (pDA) for broad implementation in The Netherlands. To ensure this pDA is in line with patients' and professionals' needs, this study aims to investigate the experiences with the decision-making process about breast reconstruction and the information needs.

Methods

Semi-structured interviews were conducted in 17 women that had considered breast reconstruction due to breast cancer or being at high-risk for breast cancer. By purposeful sampling, women varying in age, educational level and choices about breast reconstruction were recruited by physicians from 5 hospitals. Interviews were transcribed verbatim and thematic analysis was performed. Additionally, 44 professionals involved in decision-making about breast reconstruction were sent an online study-specific questionnaire. Descriptive analyses were performed.

Results

While deciding about breast reconstruction, women felt emotional and were overwhelmed by information about breast cancer and its treatment. Women at high-risk for breast cancer without a diagnosis of breast cancer felt less emotional and overwhelmed. While most women reported that they immediately knew whether or not they preferred to have breast reconstruction, some experienced substantial conflict. Motivations for or against breast reconstruction were personal and diverse. Women placed a high value on the feeling of being heard by their surgeon. They expressed a need for reliable and personalized information and a clear overview of available reconstructive options. Furthermore, women reported a strong need for experiences of other women and information about what to expect as a result of breast reconstruction and the potential impact of breast reconstruction on their daily life (e.g. How will it look and feel like? How long will I need to recover?). Professionals (n=33) varied in their levels of satisfaction with current information provision. Most agreed that well-informed patients facilitate decision-making (90%). Decisions about breast reconstruction should be shared by the patient and her surgeon or by the patient herself (respectively 55% and 45%). Most professionals (94%) agreed that a pDA would be of added value to current information provision.

Conclusion

The experiences with decision-making about breast reconstruction vary. Furthermore, information focusing on the impact of breast reconstruction on patients' daily life is needed. These findings are guiding the development of a pDA that is expected to improve decision support.

Comparative Analysis of Evidence Synthesis Methods by Organizations that Produce Patient Decision Aids

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Background and Aim

Patients need access to relevant, unbiased information based on high-quality evidence to make informed choices about their care. However, methods that patient decision aid developers use for reviewing and synthesizing clinical evidence are not well understood. The aim of this study was to evaluate how patient-facing decision aid developers synthesize evidence for these tools.

Methods

We identified patient decision aid developers by mining online inventories, publications, academic networks, email groups, conference proceedings, and social media groups. We invited representatives from 23 organisations to complete an online survey. The survey addressed how developers determine what evidence to include on patient decision aids, including: evidence synthesis, evidence quality assessment, handling insufficient evidence, outcome selection, and evidence update. We also asked developers about the overall challenges associated with synthesizing evidence for patient decision aids. Only organizations that self-identified as producing, updating, and maintaining five or more patient decision aids were eligible for inclusion.

Results

To date, 14 respondents have completed the survey, of which 10 met the inclusion criteria. The current eligible sample includes seven nonprofit organizations, one for-profit organization, one university-based volunteer organization, and one university hospital. Nine organizations offer open access to decision aids; one requires paid subscription. Preliminary findings indicate six organizations have evidence synthesis process documents. Surveyed organizations use multiple approaches for synthesizing evidence. All organizations use published systematic reviews to aid in evidence synthesis. Four organizations reported using and updating existing systematic reviews, three reported conducting entirely new systematic reviews, and two reported conducting new reviews using non-systematic methods. Additional approaches include using clinical guidelines (eight organisations), literature reviews (six organisations), empirical studies (five organisations), and clinical consensus or group/clinical panels (four organisations). Half of the organizations reported systematically assessing evidence quality for all decision aids they produce. In the absence of scientific evidence, developers report seeking expert advice (two organisations), excluding the information (two organisations), and indicating an evidence gap on the decision aids (eight organisations). All organizations report including outcomes from both existing reviews and stakeholder judgement (e.g., patients, clinicians), eight organizations also include outcomes based on developer judgement. Evidence update timing varies; two organizations update evidence annually, two update bi-annually, and others update as-needed. Findings suggest developers are challenged by limitations in the availability evidence (e.g., the breadth of data and relevance for specific patient populations) and the amount of time and effort required to conduct rigorous evidence synthesis.

Conclusions

Preliminary findings reveal developers have unique approaches to synthesizing evidence for decision aids, although most rely on existing systematic reviews and clinical guidelines. Developers use between three and eight approaches for evidence synthesis, demonstrating commitment to comprehensiveness. This is preliminary data; further responses will reveal a more complete picture.

Process Evaluation of a Decision Aid with Patient Narratives Regarding Surgery Choice among Women with Breast Cancer

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Background and aims

Patient decision aids (DAs) are evidence-based tools designed to help people make informed decisions among treatment, or testing options. Although many DAs include narratives of others' experiences with decision-making, it is not yet clear how acceptable for patients' with breast cancer decision making. This study aimed to evaluate the acceptability and perceived usefulness of a DA with patient narratives regarding surgery choice among Japanese early-stage breast cancer patients for implementation to usual care.

A brief description of methods

The process evaluation was conducted as part of a three-armed randomized controlled trial (RCT) that evaluated the effect of a decision aid with patient narratives regarding surgery choice among early-stage breast cancer patients. Participants were 210 women with early-stage breast cancer randomly assigned to two intervention groups and one control group. Group 1 received standard information and a DA with patient narratives and information on how to use patient narratives in the decision-making process and its advantages and disadvantages, Group 2 received standard information and a DA without patient narratives, and Group 3 received standard information (control). We assessed demographic data at baseline (T1) and the acceptability of DAs, perceived level of usefulness of the DAs with or without narratives, at post-intervention after the decision (T2) for the intervention groups. Satisfaction with decision making was assessed using the effective decision-making subscale of the Decisional conflict Scale. The subscale consists of four items on satisfaction with decision making at T2. Data were analyzed using Pearson's correlation to analyze the correlation between the satisfaction with decision making scores and level of usefulness of DAs with or without patient narratives.

A summary of results to support conclusions

56 participants in Group1 and 61 participants in Group 2 were included in statistical analyses. More than 90% of the participants in Group 1 and 2 rated "Strongly agree" or "Agree" when asked if the information in the DA was clear and understandable. More than 80% of the participants in Group 1 and 2 rated "Strongly agree" or "Agree" when asked if they would recommend the DA to someone making a decision about treatment options for breast cancer. 75% of the participants in Group 1 rated "about right", 14% of them rated "too long" when asked the length of the DA. 84% of the participants in Group 2 rated "about right", 2% of them rated "too long" when asked the length of the DA.

Conclusions

Patient acceptability of both intervention groups was high. The DAs with and without patient narratives can be used in clinical practice for women with early-stage breast cancer. However, the patient information needs and preference of using patient narratives in decision-making process may affect the level of usefulness of the DA with patient narratives.

A three-staged alpha test to develop the Bladder Explorer prototype: A patient decision aid for men with spinal cord injury

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ABSTRACT TEXT HERE:

Background:

People with spinal cord injury (SCI) often have concomitant bladder dysfunctions that require the use of an alternative bladder drainage method. Making such decisions can be difficult when there are various choices that come with advantages and disadvantages. The researchers developed the Bladder Explorer (BE), an iPad-based patient decision aid (PtDA), which helps men with SCI choose a method of bladder drainage.

Methods:

The researcher used the following tools to build the content, design and overall development process: International Patient Decision Aid Standard (IPDAS) quality framework, cognitive theory of multimedia learning, and iOS guidelines for application development. The scientific content was based on the integration of IPDAS guidelines, needs assessment results, steering committee feedback, and scientific information obtained from the literature. The steering group reviewed the PtDA draft in alpha test I, low fidelity prototype in alpha test II, and high fidelity prototype in alpha test III. These alpha tests were iterative; the review-revision cycle was repeated until both the researchers and steering committee members were satisfied with the results.

Results:

The prototype development went through seven iterations. The alpha test I provided feedback for the scientific content, alpha test II for the design, whilst alpha test III provided feedback regarding the usability aspect. The resulting prototype consists of five modules: 'It's Your Choice', 'The Urinary System', 'Your Options', 'Stories', and 'Making the Decision'. It is a highly interactive program with videos and pop-ups available for optional information. The module 'Making the decision' features two-dimensional values clarification exercises; the users need to state their values based on attributes of treatment options and their personal and social factors.

Conclusion:

The prototype was developed through a rigorous process that involved multiple versions of BE. The alpha tests played a significant role in defining the content and design of this prototype.

Patients' beliefs about antibiotic use for acute respiratory infections: a clear need for shared decision making

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Background:

In the fight against the global crisis of antibiotic resistance, focus has increased on improving the appropriateness of antibiotic prescribing for acute respiratory infections (ARIs). Shared decision making may be an ideal approach to use in this situation as the benefits and harms are in near equipoise, and drivers of the inappropriate use of antibiotics include patients' and clinicians' inaccurate expectations about the benefits and harms of antibiotics for these conditions.

Aims:

To 1) quantify patients' expectations of the benefits of antibiotics for common ARIs (sore throat, acute bronchitis, acute otitis media); 2) explore patients' beliefs about antibiotic necessity and preferences for shared decision making in consultations about these conditions; and 3) develop and evaluate patient decision aids to support informed decision-making for these conditions.

Methods:

For aims 1 and 2, we conducted telephone interviews using a nation-wide survey of a community sample (using computer-assisted random digit dialing) of adults who were primary caregivers of children 1 to ≤12 years old (as these ARIs are a leading reason for primary care medical consultations for children). For aim 3, we developed three decision aids (one for each target ARI) informed by the survey findings, a parallel qualitative study and a systematic review. We then recruited a community sample of parents (n=120), randomised them to receive a decision aid or fact sheet, and asked them to self-complete baseline and post-intervention questionnaires that assessed: informed choice (a composite primary outcome measure of knowledge, attitudes, and intention-to-use), decisional conflict, decisional self-efficacy, and material acceptability.

Results:

In the survey, 401 participants were interviewed. Most believed antibiotics provide benefits for common ARIs; grossly over-estimating the mean benefit of antibiotics on symptom duration by 5-10 times, and believing they reduce the likelihood of complications. However most (78%) recognised antibiotics may do harm, although inaccuracies in knowledge were common. Most (75%) wanted more involvement in future decisions. In the randomised trial, significantly more participants given a decision aid made an informed choice (57%) compared to participants given a fact sheet (29%); a difference of 28% (95% CI 11% to 45%, $p<0.01$). Decision aid group participants also had higher total knowledge (mean difference (MD) 2.8, 95% CI 2.2 to 3.5, $p<0.01$); conceptual knowledge (MD 0.7, 95% CI 0.4 to 1.1, $p<0.01$) and numerical knowledge (MD 2.1, 95% CI 1.6 to 2.5, $p<0.01$). Participants liked the aid format and found the information understandable. Between-group differences in other outcomes were not significant.

Conclusions:

Some people have misperceptions about antibiotic use in ARIs and our findings highlight a strong need, and desire, for shared decision making. Brief decision aids that incorporated benefit and harm data assisted parents to make an informed choice about antibiotic use for ARIs in a hypothetical situation. Their effect within consultations with a doctor now needs to be evaluated in a randomised trial.

The assessment for the quality and effectiveness of patient decision aids by International Patient Decision Aid Standards (IPDAS) criteria

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Background and aims

Shared decision making (SDM) is the leading trend of patient care model, especially in the grey areas of medicine. It is a process that a patient and their health professional reach a healthcare choice together. Therefore, lots of decision aids are designed to help people to make decisions about difficult clinical options. In Taiwan, there has been increasing interest in SDM since 2015, decision aids has emerged among many medical centers. In order to enhance the quality of decision aids, the International Patient Decision Aid Standards (IPDAS) Collaboration produced internationally-accepted criteria for the assessment. As the decision aids made by developers to assist in sharing information with patients, our study aim is to determine whether our aids meet IPDAS criteria.

Methods

We conducted a descriptive analysis of decision aids available from our hospital since 2015. All decision aids could be downloaded from official website of the ministry of health and welfare in Taiwan. (http://sdm.patientsafety.mohw.gov.tw/AssistTool/Category?sn=24).We extracted the information about aids including title, objective, type, tool, number of page/time of video, clinical context and specialty. Each aid was assessed according to IPDAS checklist for qualifying and certifying, and the discrepancies were discussed with the developer.

Results

There were total 13 aids, which were presented by the form such as paper, video, power point or website. 12 of them were medical treatment. Most aids were presented by paper and three of them provided video to assist. Lots of specialties were included: one for ICU, one for emergency, three for surgical medicine, two for nutrition and six for internal medicine.

The content part contained the disease, clinical choice and preference. The second part evaluated how the aids be developed. The last part assessed the evidence of these aids. In the content part, only three aids met all the criteria (14/14). All aids compared possible clinical choices, including positive and negative features but most of them did not provide the “non-treatment” as a choice. Seven aids show the information about outcome of each option by incidence rate. Three aids just described the symptoms or outcome without any data. Only four aids provided the incidence in a specific period time instead of the extent of risk. Five of the 13 aids use the same denominator as presentation. All aids tried to find out the preference factors by questionnaire. In the second part as development process, only two aids provided information about what should be knew before making decision. All aids were modified and evaluated by experts before using and did not be pre-test by clinical patient. In the final part that focused on effectiveness, these aids did not be used or published ever.

Conclusion

We evaluated 13 decision aids developed by medical center to determine whether they met the standards. The results show that most aids shared the information about advantage and disadvantage of option, but without the choice of non-treatment. Besides, the pre-test and preparation were lack during the development process.

Can EMR improve shared decision making?

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Background and Aims

The aim of this study is to evaluate the relationship between patients' perception of access to their health records electronically and their engagement in shared decision making. Studies have shown that actively involving patients in decisions about their health improves health outcomes because the treatment option is specifically tailored to the patient. Despite this evidence, a majority of patients are not actively involved in their clinical decision making process. A study showed that about 64% of men who had PSA test were not actively involved in the decision making process. The first step in shared decision making (SDM) is information sharing. Most providers complain that time constraint is a major determinant against the routine practice of SDM. One way to overcome this constraint is by sharing information electronically via the patient portal of an electronic medical record (EMR). The patient portal of an electronic medical record is an information sharing tool where patients can access their vital signs, medication list, problem list, review test results, send secure messages to their providers and make appointments from this portal. Thus, this portal may have the potential to stimulate increased patients engagement in shared decision making.

Methods

This study was guided by the Principal Agent economic theory, with the physician as the agent and the patient the principal. Data from the Health information National Trends Survey (HINTS, 2014 cycle) a cross-sectional household survey of non-institutionalized respondents in the United States aged 18 years and older was used for this study. The primary data analysis was descriptive with percentages and chi-square for univariate analysis, 95% confidence intervals, Odds Ratios and associated *P* values for bivariate and multivariate analysis.

Results

Most patients (87%) were interested in shared decision making, but only 55% of them had actually made a medical decisions while 41.8% had never made a medical decision. 62% considered access to their health records electronically as important, 25% thought it was somewhat important and only 8.1 % thought it was not important. People who considered access to their health records electronically as important had 1.9 times the odds of making a medical decision compared to those who did not consider access as important.

Conclusion

This study shows that patients who consider access to their health records electronically as important are more likely to make medical decisions compared to those who did not consider access as important. Thus, one way to involve patients' in their clinical decision making process is to share their health records with them electronically.

Mixed Messages: Competing Discourses About Information, Choice and Control Affect Women's Engagement in Shared Decision-Making in Antenatal Care

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Background and Aims

Shared decision-making is understood as a discrete episode within a clinical encounter involving information exchange, deliberation and decision. Yet there is growing awareness that shared decision-making occurs in a broader context that is shaped by complex social, political, legal and economic realities whose impact on decision-making in practice we do not fully understand. Antenatal care serves an important educational function for women over many months of pregnancy. The larger social context of antenatal care therefore may be framed as one of informal 'teaching and learning'. Re-casting interaction between antenatal care providers and expectant women as informal education offers a novel perspective to investigate contextual factors affecting decision-making that may not have been considered before. We critically explored the content of women's reflections after birth on the information and support they received in their recent pregnancy and how it related to their sense of decision-making responsibility and empowerment.

Method

We undertook qualitative content analysis of women's open text responses on a statewide survey of mothers who had recently birthed in Queensland, Australia. Of the 706 women who completed the survey, 499 provided at least one open text response to questions about the information and support they received in their antenatal care. Major concepts in data were identified and frequencies noted within our coding schema. These concepts were then critically analysed to explore what women had learned in pregnancy and how this learning impacted their engagement in decision-making in care and sense of empowerment.

Results

There was evidence that women had learned competing discourses about the nature of information, choice and control. Women whose care providers overtly involved them in decision-making in care learned to believe they were in control. Yet they also described learning to accept that they had to 'go with the flow' because pregnancy and childbirth were inherently unpredictable and uncontrollable processes. Women were explicitly taught facts about the risks of various care choices and accepted information and recommendations offered by care providers as value-neutral. Yet they described their choices in dichotomous pairs, value-laden as 'right' and 'wrong', and believed that it was their responsibility to make the 'right' choice. Many women appeared critically unaware of how these competing discourses around information and control may have impaired their productive engagement in decision-making and ultimately influenced the choices they made. Some women, in confronting conflicting information or negative past experiences of pregnancy or childbirth, developed critical consciousness of the limitations of the education received from care providers and the likely impact this had on their decisions and care outcomes.

Conclusion

Women's uncritical acceptance of information and felt pressure to make 'right' choices as opposed to choices that were 'right for them' may impede their productive engagement in shared decision-making. These findings demonstrate the need to consider a far broader educational context for shared decision-making than just information exchange in the decision-making episode. Continued exploration of antenatal care as informal education has potential to improve our understanding of contextual factors impacting patient empowerment and shared decision-making in practice.

Encouraging patients to discuss what is important to them: Values clarification in rectal cancer care

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Background

Pre-operative radiotherapy in rectal cancer increases the probability of local control but also probabilities of fecal incontinence and sexual dysfunction. This study aimed to examine the effect of a values clarification method (VCM) on 1) how often patients express preferences for treatment/treatment outcomes during clinical encounters, and 2) patient-reported outcomes regarding the decision-making process. Secondary outcomes were extent to which treatment harms negatively impact participants' quality of life.

Methods

In a pre-intervention/intervention study, consecutive first and generally only pre-treatment encounters of radiation oncologists and rectal cancer patients eligible for pre-operative radiotherapy were audiotaped. The patients completed a pre-encounter, post-encounter and six-months follow-up questionnaire. In the intervention phase, patients were additionally offered access to a computer-based pre-encounter VCM, at first randomly but due to slow recruitment later to all intervention participants. The VCM asked participants to tradeoff probabilities of benefit and harms, each varying in a clinically-realistic range. The oncologists were asked to complete a post-encounter questionnaire; we did not notify them of whether patients had gone through the VCM or not. Two raters reliably coded the audiotape transcripts using an adapted version of the 'Assessing Communication about Evidence and Patient Preferences' (ACEPP)-coding scheme (kappa=0.88).

Results

Thirteen radiation oncologists participated. Sixty-four patients were recruited in the pre-intervention, and 42 in the intervention phase of whom 33 were offered access to the VCM; 29 (88%) completed the VCM pre-encounter and one (3%) post-encounter. The 29 patients in the VCM arm did not significantly differ from the 77 patients in the control arm regarding age, gender, or education. Median number of treatment outcome-related preferences that patients voiced did not significantly differ between intervention and control arms (Md=1 vs. Md=0.5), nor did the number of encounters in which the patients expressed a treatment preference (30% vs. 21%). The patients in the VCM vs. control arms did not significant differ in how prepared they felt to make a treatment decision (Preparation for Decision Making scale, Mds=67) or were unclear about their values (three Decisional Conflict Scale-items, Md=25 vs. Md=33), or, at six-months follow-up, how much regret they reported (Decisional Regret Scale, Md=10 vs. Md=18) or how much they felt bothered by side-effects although scores were lower for incontinence in the VCM-arm (Incontinence Impact Questionnaire, Md=110 vs Md=148). Twelve (41%) patients reported that the VCM had helped them to gain insight into treatment pros/cons and 13 (45%) reported it had not (4 unknown). The radiation oncologists indicated that the decision had already been made pre-encounter in 98% of cases; either by multidisciplinary teams and/or referring clinicians (94%), or patients (with referring clinicians) (6%).

Conclusion

Although scores point to better outcomes, there is no clear evidence that the VCM helped patients to voice their preferences or clarify what is important to them. It is doubtful how much room patients felt to participate in the decision making process in the first place. The results point to a significant role for referring clinicians and multidisciplinary teams in determining choice of treatment.

Digital Health Literacy in Europe

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Citizens' digital health literacy is an essential element for successful eHealth deployment. However, citizens often do not have the necessary skills to find, understand and appraise online health information and apply their knowledge to make health decisions. Digitally health literate citizens are empowered to play a more active role in their health self-management, resulting in improved prevention, adherence to a healthier lifestyle and better health outcomes.

The aim of the presentation will be to present the objectives, activities and results so far achieved by the IC-Health project, a project funded by the European Commission. The project aims at providing support for the improvement of digital health literacy (DHL) in Europe. In particular, it will develop 35 open access online courses (MOOCs) for different population cohorts including children, adolescents, pregnant and lactating women, elderly and people affected by type 1 and type 2 diabetes.

The identified population cohorts, along with health professionals and academics, will be organised in Communities of Practice (CoP) and involved directly in the co-creation of the MOOC content and structure. Once the courses are designed, they will be tested by members of the CoP and by other users. MOOC use and impact will be monitored and assessed in order to ensure their uptake and sustainability beyond the duration of the project.

IC-Health started in November 2016 and, so far, the key outputs of the project relates to the set-up of the methodological and operational framework within which the co-creation process and the development and test of the MOOCs will happen. By June 2017, project partners will: 1) create a knowledge base on digital health literacy in Europe addressing drivers, barriers, trends and uses; 2) draw a profile of the target groups in each country of intervention in terms of needs, level of digital literacy, health literacy and digital health literacy; and 3) develop an engagement strategy to approach those groups and engage them.

The first results emerged from literature review and target group profile compiling have shown that there is still a need to better define the concept of DHL, requiring more robust measures of DHL covering the different faucets and aspects of the construct. Recently, there has been an increase in the use of digital health information for all age groups; moreover, the importance of the Internet is increasing when looking for health-related information. In this sense, there is a need to support actions aimed at increased awareness of the opportunities of eHealth tools and at empowering citizens with enhanced skills on how to use ICT for health-related purposes.

One of the barriers for deployment of eHealth solutions is the lack of awareness and confidence in eHealth solutions. IC-Health seek to overcome this constraint by improving the capacity of the selected target groups to deploy the Internet as means that facilitates the provision of health information and services. 780 people will be directly involved in the process of co-creation of the MOOCs and at least 624 in the MOOCs.

The Decision Aid Factory (DAfactory) – between prototype and series production

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Background and aim

DAfactory is a standard for development, design and implementation of decision aids (DA) purposing at producing DAs more efficiently, quality assured and adjusted as far as needed to the respective target group. DAfactory has been modelled during development of the first six DAs for the Norwegian platform, *Mine Behandlingsvalg* (my treatment choice). All components are justified either empirically or by theory and pass evaluation both separately and incorporated in the entire intervention. Five additional DA are currently under development. We aim at answering the question, whether our approach is suitable.

Methods

DAfactory is a virtual production site consisting of 9 divisions providing guidance by detailed descriptions of quality concepts and procedures to pass during the development: Implementation, evaluation, user involvement, structure information generation, presentation, didactics, design and prioritization. A superior project plan organizes single proceedings from various divisions with regard to time schedule and responsibility. Developments employ experts of process management, medicine, systematic review, medical writing, communication and film. We will report on an observational study applying DAfactory to the production of five additional DA. The idea of a production standard will be critically reflected.

Results:

In June 2017, the new DAs shall be accessible on the Norwegian national platform helsenorge.no. Production and final product comply with the DAfactory standard, which, however, needed to be slightly refined. High emphasis was given to qualify the internal produces in EBM basics, project management and medical writing. The task to explore the medical experts in the initial phase to structure the decision and to inform the systematic review turned out to be a particular challenge. Production of a DA is currently lasting 5 months, still longer than expected.

Conclusions:

DAfactory is not yet fully self-explanatory, but the generic approach proved practicable. Operating the factory needs further manualisation and a curriculum to qualify producers. Automatization and transparency of the procedures are clearly contributing to implementation right from the start.

Is it all about the money? Organizational- and System-level Factors that Influence the Implementation of Shared Decision-making in Cancer Care in the Unites States

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Background and aims:

Shared decision-making (SDM) is poorly implemented in routine care, despite its inclusion in many clinical practice guidelines and the Affordable Care Act. Recently, we conducted a scoping review around organizational- and system-level factors that influence the implementation of SDM in routine care. A broad range of organizational- and system-level characteristics were found to influence implementation of SDM in routine care. However, it is unclear how important these characteristics are in a specific health care setting. Thus, the aim of this study is to discuss the importance of different organizational- and system level factors in the implementation of SDM in cancer care in the US.

Methods:

We are conducting semi-structured interviews with a different stakeholders in the field of cancer care in the US. We used a purposive sampling strategy with a maximum variation approach, with the aim of interviewing experts with different roles (e.g. clinicians, cancer center leadership, researchers, health policy representatives, patient advocates), different backgrounds (e.g. different specialties), different workplaces (e.g. academic and community cancer centers), as well as different demographic characteristics. The final sample size will be determined by theoretical saturation, with approximately 20-30 interviews needed to reach saturation. Potential participants were invited by email. Interviews are mainly conducted over the telephone. Interviews are audio recorded, transcribed, and anonymized. Data is analyzed in Atlas.ti software, drawing on conventional content analysis, using an integrated approach of inductive and deductive coding.

Preliminary results:

31 invitations were sent to a broad range of stakeholders in January 2017; y now 27 agreed to participate (87% response rate). 18 interviews have been conducted with a mean duration of 39 minutes (SD 14). The participants' main roles were evenly distributed with four researchers, four patient representatives, three clinicians, three persons from cancer center leadership, two federal agency officers and two other stakeholders being interviewed. The current sample has a mean of 26 years (SD 10) of experience and 33% are female. A preliminary analysis indicates that the role of money in the US health care system and the fact that physician and hospital revenue is often related to the delivery of certain cancer treatment options is seen as an important barrier in the implementation of SDM in routine cancer care in the US. Alternative payment models (as value-based care) were discussed as possible solutions. Furthermore, the implementation of multidisciplinary clinics, where all clinicians discuss treatment options with the patient in one single visit, was seen as a way to better implement SDM in cancer care. Final results will be available at the time of the conference.

Conclusion:

While it is too early to draw final conclusions from these preliminary analyses, they do show that the aspect of revenue seems to have a considerable impact on SDM implementation efforts in US cancer care. This aspect, as well as other organizational- and system-level characteristics should be taken into account in SDM implementation efforts, which up to now too often focused solely on interventions on the individual patient-clinical level.

Valuing shared decision-making in end-stage knee osteoarthritis: a discrete choice experiment

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Background

Increasing shared decision-making (SDM) is a priority for many health systems. Moves to greater us of SDM will likely require investments, e.g., disseminating decision aids to patients, training clinicians or decision coaches, or increasing the number or length of clinical consultations. Cost-effectiveness analysis is widely used in health care to determine whether investments provide value. To determine the value of SDM in this paradigm requires evidence that patients are willing to trade-off health outcomes for greater SDM. Otherwise, the argument will be that the limited healthcare resources could have been spent on other activities that provide health benefits.

Aims

To elicit societal preferences for the trade-off between health outcomes and SDM in a manner that allows the value of SDM to be incorporated in a cost-effectiveness analysis.

Methods

We conducted a discrete choice experiment (DCE) in the context of end-stage knee osteoarthritis (OA), where patients must choose whether to undergo total knee arthroplasty (TKA). SDM can play an important role in treatment decision-making, with guidelines stating that patients are appropriate for TKA when "the patient and surgeon agree that the potential benefits to the patient of joint replacement surgery outweigh potential surgical risks." An online panel of Canadians aged 60+ were asked to imagine they had been diagnosed with knee OA and presented with 12 binary hypothetical choices of consultations with two different arthritis specialists to make a treatment decision (see Figure 1). Consultations were described using four attributes: waiting time (24 weeks, 30 weeks, 36 weeks), two SDM attributes based on the CollaboRATE scale: information/listening and decision-making (some effort, every effort), and health outcomes characterized as the chance of improvement to no pain or discomfort one-year following the consultation (50%, 60%, 70%). A condition logit model was estimated to determine the marginal rate of substitution between the two SDM attributes and the chance of improvement in pain or discomfort.

Results

A total of 115 older adults completed the survey. All four attributes had a statistically significant impact on choice of consultation and attribute coefficient signs met a priori expectations (preference for shorter waiting time, specialist who made a greater effort to engage in SDM and whose patients had better outcomes). Results suggest that having a specialist who made every effort (compared to some effort) to help inform and listen to the patient was equivalent to a 5% increase in the chance of improving to have no pain or discomfort. This was similar for a specialist who made every effort (compared to some effort) to include what mattered most to the patient into treatment decision-making.

Conclusions

While previous studies have shown that individuals value SDM, this study provides evidence in the context of knee OA that people were willing to accept a lower chance of improvement in pain or discomfort (health outcome) for greater SDM. This potentially provides further justification for the investment in interventions that promote SDM.

Figure 1. Example DCE question

	Specialist A	Specialist B
Waiting time for consultation *How long you must wait for an appointment.*	24 weeks	36 weeks
Information / Listening *Effort made by the specialist to help you understand your health issues and to listen to the things that matter most to you.*	Some effort	Some effort
Decision-making *Effort made by the specialist to include what matters most to you in choosing what to do next.*	Every effort	Some effort
Chance of improvement in pain/discomfort *Number of patients who improve to no pain/discomfort one-year after their consultation*	60 out of 100 (60%) of patients improve	70 out of 100 (70%) of patients improve
I would choose:	○	○

Evaluating medical students' knowledge of and attitudes towards shared decision-making: a multinational cross-sectional study

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Background and Aims

Shared decision-making (SDM) has received national attention but it is not yet fully integrated into clinical care in Canada, the Netherlands, the United Kingdom (UK), and the United States (US). Despite evidence confirming the role of SDM in patient care and outcomes, we know little about SDM undergraduate medical education. Therefore, we sought to conduct a multinational assessment of students' attitudes towards, knowledge of, and experience in SDM.

Methods

A mixed methods, two-phase study was conducted among undergraduate medical school students and relevant stakeholders in Canada, the Netherlands, the UK, and the US. Phase 1 (September 2016 - May 2017) was an online cross-sectional survey distributed via a convenience sample of four medical schools in Canada, the US, and the Netherlands (n=12), and all medical schools in the UK (n=32). Social media was also used for dissemination. The survey included 23 close-ended questions and assessed students' attitudes towards SDM, knowledge of SDM, and previous SDM training. We also devised three clinical scenarios using expert consensus and clinician input. Two scenarios asked students to (a) indicate how they would expect experienced clinicians to involve the patient in the presented scenario and (b) how the student would involve the patient should they face the same scenario tomorrow. The third scenario asked how students would communicate risk. Phase 2 (February 2017 – June 2017) included a series of audiotaped, semi-structured interviews with a subsample of students from the phase 1 survey, and with medical school course coordinators and curriculum stakeholders identified using a snowball strategy. We applied simple descriptive and multivariable analysis to quantitative data and thematic analysis to the verbatim interview transcripts. We triangulated the quantitative and qualitative data.

Results

As of 20 February 2017, 608 surveys have been recorded across all four countries. We anticipate 1,000 completions by the conclusion of data collection. Average respondent age was 24 years and 68% were female. In the clinical scenarios, just under half (47%) of students felt that they see other clinicians utilize SDM, whereas more than half (69%) felt that they would utilize SDM. Seventy-four percent of students said they had received either theoretical or practical SDM training in their medical education. Ninety-two percent of students had heard of SDM before completing the survey. Seventy-two percent of students believed engaging in SDM would increase the length of a clinical encounter; 59% of those students believed it would increase it by more than five minutes. A majority of students answered over 90% of the basic SDM knowledge questions correctly. We are currently collecting qualitative data.

Conclusion

Any conclusions should be interpreted carefully as data collection has not yet finished. Full results will be available at the time of the conference. Data from the phase 1 survey suggest that the concept and basic principles of SDM are well-known among medical students. Students' knowledge of SDM is strong although the nuances of SDM strategies (i.e., risk communication) are less well understood.

What is the impact of a shared decision making workshop on healthcare professionals' behavioral intention in Iran?

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Background

Healthcare professionals (HCPs) need a unique set of knowledge and skills in order to be able to implement shared decision making (SDM) in practice. However, although there are numerous training programs in North America, Europe and Australia, few are available in Asia. Therefore, this study evaluated the impact of a one-day educational workshop on the knowledge and the behavioral intentions of HCPs in various specialties in Iran.

Methods

We developed a one-day workshop curriculum for HCPs to promote SDM in treatment decisions. The workshop was in Persian and held in Tabriz University of Medical Sciences, Iran. The content of the workshop was partially based on programs developed by the Canada Research Chair in Shared Decision Making and Knowledge Translation. It included an introduction to SDM concepts and decision aids, group discussions, two videos, and written evaluations. One video showed SDM taking place in the context of a decision about knee replacement surgery and the other in the context of a decision about taking a Down syndrome prenatal screening test. To evaluate the impact of the workshop, we invited participants to complete a questionnaire (10 open-ended and 2 close-ended questions, to evaluate workshop's content, design, instructor and results), and a theory-based instrument designed to assess the impact of continuing professional development activities on clinical professional behavioral intentions (the CPD-Reaction questionnaire, with 12 close-ended questions).

Results

Out of about 100 invited HCPs affiliated with Tabriz University of Medical Sciences, 41 participated in the workshop (41%). Twenty three of the participants were female (57%). There were 16 family and emergency physicians (39%), six orthopedic surgeons (14.5%), three infectious disease specialists (7%), three anesthesiologists (7%), two obstacologists (5%), two gynecologists (5%), two internal medicine physicians (5%), an otolaryngologist, a general surgeon, a pathologist, a radiologist, a dermatologist, a neurologist and a psychiatrist. The mean age was 37.5 ± 8.6 years old and mean clinical experience was 8.1 ± 7.8 years. Seventeen HCPs responded to the workshop evaluation questionnaire (41% response rate) and all 41 participating HCPs responded to the CPD questionnaire (100% response rate). Most of the participants (90%) rated the workshop as excellent or very good, and 95% said that they would change their practice based on what they had learned. Based on the results of the CPD-Reaction questionnaire, 87.8% of HCPs thought that using SDM would be beneficial, 83% thought that using SDM would be useful, and 83% of HCPs agreed that they planned to engage in SDM.

Conclusion

To the best of our knowledge, this was the first SDM training program given to HCPs in Iran. Most evaluated the workshop as beneficial and useful and indicated they intended to incorporate SDM into their practice. Although we obtained promising results for this first step, additional studies is required to determine to what extent they put their new skills into practice.

Training health professionals in shared decision making for prenatal screening: An international environmental scan

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Background

Prenatal screening is routinely offered to pregnant women in many countries. Whether or not to undergo screening is a sensitive decision that involves personal values and important evidence. Health care professionals need new skills to engage pregnant women in shared decision making about prenatal screening. However, we know little about shared decision making training programs in this area. Therefore, we conducted an environmental scan to identify and analyze training programs for health care professionals in shared decision making for prenatal screening.

Methods

We searched the Canada Research Chair in Shared Decision Making and Knowledge Translation inventory of shared decision making programs for healthcare professionals. This inventory lists shared decision making training programs targeting health care professionals that were produced between 1996 and 2017. Programs in the inventory were identified in a Cochrane systematic review in the field of shared decision making performed by our team members (twice updated), structured GoogleTM searches and our social media networks (Facebook and Twitter). One author identified programs and another validated their eligibility. We explored the content of training programs, their accessibility and if they were evaluated or not. We aimed to assess training effectiveness according to Kirkpatrick's four levels which measure: 1) participants' satisfaction; 2) participants' knowledge, skills, or attitudes; 3) transfer of learning to practice (i.e. behaviour); and 4) organisational outcomes such as productivity and quality. Using a standardised data extraction form, the third author extracted data on the training program's name, authors/developers, country, language, clinical context, targeted users, general objectives and format. The other author then validated the completed extraction forms.

Results

We found three eligible programs among a total of 169 produced from 1996 to February 2017. Two of these three programs targeted licensed health care professionals, and one targeted licensed and pre-licensed health care professionals. One of the programs was in German and targeted physicians, nurses and midwives. Its program format was a group course with various additional educational activities, and its context was in primary care/prenatal screening. Another was in Japanese and targeted nurses with experience in reproduction and women's health. It focused on gene therapy and prenatal diagnosis, and was also given in the form of a group course. The third was in French, developed by the Quebec Ministry of Health and Social Services in 2010. It was provided online, and its general objectives were to describe the trisomy 21 prenatal screening test, teach how to interpret and communicate prenatal screening results, describe the informed consent process, and present an overview of ethical issues concerning trisomy 21. None of the programs included any information on the new non-invasive prenatal screening test (NIPT).

Conclusions

We identified only three shared decision making training programs that focus on prenatal screening. Given the importance of implementing shared decision making in this context, there is an urgent need for producing and evaluating accessible, up-to-date training programs for health care professionals in shared decision making about prenatal screening.

Ready to SDM - Modelling and pretesting a training module in shared decision-making addressing health professionals

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Background

Internationally, several shared decision-making (SDM) training programs for health professionals have been developed. In Norway, however, no proven effective SDM training for health professionals exists. A multidisciplinary training module has been drafted based on the doktormitSDM training approach. Within a multi-center randomized controlled trial (IT'S SDM), the latter has recently proven effective to improve communication after minimal training time.

Aim of the study

The present study aimed at testing the draft's feasibility in terms of comprehensibility, relevance to clinical practice and knowledge gain. Based on our findings we planned to consider needs for adjustment with regard to particular health care professions, settings, and time conditions.

Methods

We tested two variants of the module with varying duration (1 or 2 h), the first comprising two, the other three components: 1st component: Lecture introducing SDM, 2nd component: Teaching particular SDM communication skills and the consultation structure of the six steps to SDM, 3rd component: Interactive training including a face-to-face feedback based on communication analysis. Using a mixed methods design, the first draft passed a series of test applications in a variety of settings and groups. Convenience sampling was used to recruit participants. The sample was heterogeneous with regard to previous knowledge, health professions and the educational context (internal education, master program or further education). Knowledge was tested before and after the lecture using five multiple-choice items. Comprehensibility, attitudes and feasibility were addressed using a questionnaire provided after the course and by a focus group conducted with a small sample of the participants.

Preliminary results

Within 11 courses, 429 participants were trained in total. Results on feasibility are based on a response rate of 83% (n=356) and 4 focus group participants. Results on knowledge gain are based on 59% (n=251) valid pre-post pairs. Percentage of correct answers within the five single tests significantly increased by 13 to 59%, from pre-test 25 to 78% to post-test 84 to 95% ($p<=.001$). The training was evaluated as easy to understand, attractive and relevant. The study revealed the need for some revision, e.g. using examples with regard to particular health professions to allow for better knowledge transfer.

Conclusions

The findings in the present study will inform the ongoing revision of the two modules, which are about to be tested in a randomized trial. The development contributes to a comprehensive curriculum called "*klar for samvalg*" (ready to SDM), which uses generic methods and provides guidance to tailor SDM training for health professionals to particular needs.

Shared Decision Making – global pilots in Bupa

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Bupa's purpose is helping people live longer, healthier, happier lives. One of Bupa's three cornerstone pillars is to be loved as a true customer champion in health and care. We are leading a Shared Decision Making (SDM) programme with the ultimate aim to embed SDM into our services to deliver outstanding, personalised customer experiences and better outcomes.

The SDM programme has three projects

- Building our evidence base by getting clinicians and customers involved in SDM
- Raising awareness & engaging all Bupa clinicians, care assistants & other employees of SDM
- Skilling our clinicians and care assistants to practice SDM every day

Our presentation will focus on the pilots. We are running 5 pilots in 5 different countries across 3 different continents – Hong Kong, Chile, Poland, UK and China

The first pilot, now completed, was in Hong Kong. Bupa's primary care service in Hong Kong, Quality Health, piloted SDM for people at risk or with type 2 diabetes. Dr Winston Lee, our lead physician, and 2 GP Surgeries, embraced SDM in a pilot using 3 Emmi® SDM decision aids:

- Diabetes and the importance of early diagnosis – for all patients
- Lifestyle Modifications – for those classified as "at risk" but not diabetic + those diagnosed with diabetes
- Medications and self-care – for patients diagnosed with diabetes

The customers treated in the intervention group had increased their patient engagement, empowered themselves to take a more active role in managing their health and were more satisfied with Quality Health and Bupa. The Net Promoter Score (NPS) for the 501 customers in the pilot was +56, compared to the organization average of +4.

For the patients that returned for the 6 month follow up there was an improvement in

- HbA1C result
- Reducing sugar
- Reducing saturated fats
- Reducing alcohol assumption

The patient experience of the SDM process itself was measured using the SDMQ9 questionnaire. The average score was 'very strong' 80% with quite a tight concentration of SDM scores meaning all patients received a similar experience.

The results of the pilot in Chile, for patients with Diabetes, are just becoming available. Again, there is a significant improvement in NPS score - twice as high in the intervention group (+39) than in the control group (+25).

The outcome of the pilots with LuxMed will be available from March 2017. This pilot is a partnership with Dartmouth University. The project aim is to evaluate the impact of using Option Grids and CollaboRATE on patient engagement in routine clinical settings in Poland.

The UK pilot will also test the use of Emmi® SDM decision aids in Bupa's Musculoskeletal services (intending to reach 10,000 customers), as well as end those requiring End of Life Care in our care homes. Finally, the pilot in China will take place starting later in 2017 for children with asthma.

Bupa has begun its journey of embedded SDM into our services to deliver outstanding, personalised customer experiences and better outcomes.

Improving SDM in hypertrophic cardiomyopathy: What should family members know about cascade genetic testing?

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Background:

Hypertrophic cardiomyopathy (HCM) is a genetic heart disease, which can result in sudden death at a young age. Affected families are offered clinical surveillance and may also undergo cascade genetic testing. If gene testing is negative, ongoing screening can be avoided, while those who test positive will be closely monitored. These asymptomatic family members who are gene positive represent a new group of 'patients' who may develop HCM, but are likely to remain silent gene carriers with no symptoms or disease. This study explored experiences of HCM genetic testing, to identify potential benefits and harms to communicate to family members considering cascade genetic testing.

Methods:

Thirty-two individuals with an established family history of HCM and who had been offered genetic testing were recruited from a specialist cardiology clinic. Semi-structured interviews were conducted face-to-face or by phone, as preferred by participants. Transcribed audio-recordings were coded using Framework Analysis.

Results:

Participants thought the main benefit of genetic testing was for the next generation, as they hoped to rule out the need for clinical screening of their children/grandchildren. Those who received a positive result stated directly that it had minimal impact on their lives, but described subtle ways it did affect them and their families, including anxiety, increased uncertainty, peer pressure to get tested, and restriction of physical activities for themselves and/or their children. There were also misconceptions about whether they had been diagnosed with a heart condition, if their genetic risk meant that they would definitely develop symptoms at some point in the future, and uncertainty over their need to continue regular clinical surveillance.

Conclusion:

While genetic testing has the potential to benefit those who receive a negative result, half of those tested will receive a positive result. The meaning of such a result in the absence of physical symptoms or prevention strategies is often unclear, and can lead to misconceptions about disease status and management. The sometimes subtle effects this may have on an otherwise healthy individual should be clearly communicated prior to testing to enable informed, shared decision making.

Is there a need for a Patient Decision Aid in a Danish Spine Surgery Clinic?

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Background

Lumbar disc herniation (LDH) is a condition with large impact on general health, function and social aspects for the person involved. Most people improve spontaneously, but some patients are offered surgical assessment. However, apart from a positive MRI finding, with concordant symptoms, on patients with no neurological deficits, there are no exact indications defined for surgery. Few existing studies show that even though surgical patients show a more rapid relief of pain and earlier return to regular activities, the long-term difference in treatment results between surgical and non-surgical treatment is unclear.

The choice of having surgical or non-surgical treatment for LDH, should therefore be informed and preference sensitive. The aim of this current study is to examine if shared decision making (SDM) is performed in a Danish Spine Center.

Methods

Data were collected using field observations and semi-structured interviews with patients seen in the Spine Center. Observational notes and transcripts of the interviews were used for analysis. A model proposed by Elwyn G. et al. for clinical practice, were used to categorize the collected data and to identify if SDM was performed. The model suggests doing a choice talk, an option talk and a decision talk during the consultation, and to use decision support to initiate SDM. A meaning condensation method was used where relevant units of meaning were highlighted and categorized into the pre-defined themes.

Findings

Most patients felt they had a good relation to the health care professionals and that they took the time needed to see the patient. All patients found that there was room for asking questions.

Options of having or not having surgery were often briefly mentioned; however in many cases no well-defined choice or option talk took place. Patients mainly remembered being introduced to benefits and harms of surgery, whereas benefits and harms of not having surgery were rarely discussed.

The observations showed different ways of communicating the risk and outcome of surgery. Different percentages of benefits of surgery are mentioned to different patients. A few patients are not presented to any numbers at all.

Often surgery is offered as a recommendation, not a choice where preferences and values for or against surgery are discussed. The treatment decision is often indirectly made early in the consultation, before an option talk is done, and without a distinct decision-talk being made.

No material on decision support was used in the consultation. Patients, who were recommended surgery, got a leaflet about surgery.

Conclusion

This study shows that good relationships, with a great deal of trust, are made in the clinical encounter in a Danish Spine Center. However SDM is not always achieved. Taking in to account that there are no clear indications of when to do spine surgery in patients with herniated disc, SDM is evident. Developing and using a decision aid, could hopefully facilitate this.

Implementing shared decision-making (SDM) and time-out for breast cancer patients in six Dutch Hospitals

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Background and aims

Most women with newly diagnosed breast cancer face multiple treatment options and many describe to be overwhelmed by the diagnosis. The decision how to treat breast cancer is difficult and healthcare professionals should offer support to patients in order to achieve an informed decision.

We investigated whether the introduction of time-out periods and an participation in implementation programme for SDM increases the involvement of breast cancer patients in decision-making, as perceived by patients and observed in hospital consultations.

Description of methods

We conducted a pre-post implementation evaluation of health professionals (physicians, nurses, nurse practitioners) of six breast cancer teams within six Dutch hospitals.

In a learning collaborative, the teams in the hospitals were supported to implement:

1) 'Time-out': an explicit time break between discussing diagnoses, treatment options and the eventual decision, allowing time for deliberation and reflection.
2) SDM in the consultations through applying four steps: (1) informing the patient that a treatment decision is to be made and that the patient's opinion is important; (2) discuss the treatment options and their pros and cons; (3) discuss the patient's preferences and support the patient in deliberation; (4) discuss the patient's wish to make or defer the decision, and discuss follow-up.

The hospitals participated in a tailor-made implementation programme consisting of:

1) Feedback on the performance regarding SDM and time-out, using the OPTION-5 instrument and SDM-Q-9 questionnaire, and on the barriers and facilitators for implementation.
2) Participation of hospital teams in four collaborative training sessions aiming at process redesign, applying SDM, time-out, and tools for SDM.
3) A local team training on applying SDM and time-out in consultations.
4) Support for the application of tools, such as decision aids, that enhance SDM.

A total of 120 consultations of breast cancer patients were audio-taped and analysed using the OPTION-5. Perceived patient participation in decision making was measured using the SDM-Q-9 (n=120). Total scores, scores per item and scores per hospital were compared before and after implementation. Barriers and facilitators for implementation regarding the implementation programme, health professional, and patients, the organisational context and the socio-political context, were analysed using questionnaires, interviews and a focus group.

Summary of results

Hospitals actively participated in the implementation programme. The implementation programme supporting time-out periods and SDM for breast cancer patients ran from April 2016 to June 2017. The pre-test mean score (n=80) for the Option 5 was 38.5 out of 100 (SD=14.6) and 5.6 out of 6 for the SDM-Q-9. In July 2017, an overview of the actual implementation activities within the six hospitals will be available, including the barriers and facilitators for implementation.

Conclusion

The pre-test mean scores for the Option 5 and the SDM-Q-9 indicate considerable room for improvement on endorsing partnership, supporting deliberation and making the choice for improvement for the six Dutch hospitals that participate in an implementation programme aiming at the application of time-out periods and SDM for breast cancer patients.

Gain-loss framing and personalised presentations in health information: evidence and recommendations

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Background and aims

Evidence-based health information is a prerequisite for informed choice. To expand the evidence based guideline for the development of evidence-based health information (http://www.leitlinie-gesundheitsinformation.de/) we addressed two more questions and assessed the effects of “gain-loss-framing” and “personalised presentations” in health information on cognitive and affective outcomes. In addition to the predefined outcomes, we included persuasiveness as outcome of possible harm.

Methods

Two authors searched the Cochrane Central Register of Controlled Trials, PubMed, CINAHL, PsycINFO, PSYNDEX, and DIMDI up to October 2016. Also the reference lists were reviewed. Randomised controlled trials incorporating the interventions “gain-loss-framing” and “personalised presentations”, and reporting cognitive or affective outcome measures were included. Searches were restricted to English and German language.

Two authors independently assessed included trials for risk of bias. Evidence tables according to GRADE were created. Due to the complexity of the interventions, analyses were descriptive.

Results

We included 14 (gain-loss-framing) and 4 (personalised presentation) studies, respectively. The quality of the evidence was very low (gain-loss-framing) and moderate (personalised presentations).

Personalised presentations had a positive effect on cognitive outcomes in one out of three studies: 78% vs. 66% correct answers, $p<0.001$ (knowledge) and differences in three categories 4% vs.13%; 26% vs. 47%; 70% vs. 40%; $p<0.0001$ (risk perception). Two studies showed no difference. Personalised presentations had a positive effect on readability in one of two studies but no difference regarding attractiveness.

Combined gain-loss framing compared to gain or loss framing only showed a positive effect on cognitive outcomes (% correct answers): 55% (95% CI 37-72) vs. 24% (95% CI 6-42) (gain-framing only) vs. 49% (95% CI 33-65) (loss-framing only); $p=0.003$. The effect on affective outcomes is based on one qualitative study only. Two out of three studies showed a positive effect for the combined presentation in avoiding persuasiveness. Study 1: 1.73 (95% CI 1.63-2.00) vs. 1.43 (95% CI 1.24-1.62) (positive framing) and 1.82 (95% CI 1.55-1.90) (negative framing) (5 point scale); study 2: combined gain-loss framing vs. gain-framing only: OR 0.45 (95% CI 0.35-0.58), $p<0.001$ and combined gain-loss framing vs. loss-framing only: OR 4.40 (95% CI 3.05-6.43), $p<0.001$.

Conclusion

We found a tendency that personalised presentations might have some positive effects on relevant outcomes. Therefore, they could be applied to health information. Based on limited evidence, the use of gain- or loss framing only should be avoided. A neutral framing combining gain and loss in health information may be recommended.

Causal interpretation of correlational results – analysis of news on the website of the official journal for German physicians

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Background and aims

Health information is often framed in the media. Inappropriate causal statements are drawn from observational studies, or conclusions for patient care are based on non-validated surrogate outcome measures or even animal research. Medical writers routinely extract information from medical journals or press releases. However, accidental observations indicate that misinterpretation and exaggeration of study results also prevail on the website of the German Medical Association's official science journal (Deutsches Aerzteblatt, DÄB). The weekly journal is distributed to all physicians in Germany. Therefore we aimed to systematically analyze the reporting of study results of the News section of the DÄB.

Methods

Retrospective quantitative content analysis of randomly selected news and related original journal articles and press releases. News' headlines were selected if they comprised at least two linked variables, e.g. cholesterol levels and heart attack. A master student and a senior researcher independently rated the following parts of each "News": headline, text body, conclusions of the related journal article (abstract and text), and related press release. We adapted and piloted a validated and published assessment instrument comprising a five point scale (range from 'neutral' to 'unconditionally causal'). Inter-rater-reliability (IRR) was κ=0.97. Headlines were additionally rated by a third researcher; IRR was κ=0.69 indicating substantial agreement. Main outcome measure was the degree of matching between 1) headlines and the conclusion of the journal article, 2) headlines and text body of the news, 3) text body and conclusion, and 4) headlines and press releases. Additionally, we analyzed whether headlines rated as causal were based on randomized controlled trials (RCTs).

Results

From April 2015 until May 2016 a total of 1087 news were published. The final random sample comprised 177 eligible news and 101 related press releases. Degree of matching: 45% (79/177) for headlines and conclusions, 55% (97/177) for headlines and text body, 53% (94/177) for text body and conclusions, and 46.5% (47/101) for headlines and press releases. Exaggerations were detected in 46% (81/177) of the headlines compared to the conclusion of the related journal article. 138 headlines were categorized as 'unconditionally causal' although only 52 (38%) of the related articles reported RCTs.

Limitations of our study

Understanding of headlines was not tested with the target user group of physicians. We did not check the correctness of the conclusions in the original research articles or the reporting of the press releases.

Conclusion

Reporting of health related scientific publications in the News section of the official German Medical Journal is frequently misleading. The majority of the headlines implying causal associations were not based on RCTs. Unreliable reporting of research studies interferes with informed medical and shared decision making. Medical writers should follow standards of reporting scientific study results. In order to avoid exaggerations and misunderstanding they should use a neutral wording for their headlines.

‘A Tale of Two Clinics’: Implementing a patient decision aid at two public health clinics in Malaysia

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Background and aims

Patient decision aids are effective tools in engaging patients in shared decision making (SDM). However, its implementation remains variable across different settings. In Malaysia, several patient decision aids (PDAs) have been developed to promote SDM; however, implementation of these PDAs remains fragmented. This study aimed to compare the views of healthcare professionals (HCPs) from two public health clinics regarding implementation of a diabetes PDA. Both clinics are under the Ministry of Health and they have similar diabetes policies, staff composition, resources and facilities.

Methodology

A qualitative methodology was used to explore the HCPs’ views. The two clinics were located in Kuala Lumpur, the capital of Malaysia, and they were sampled purposively to represent different patient profiles in terms of ethnicity, language and socio-economic status. A total of eight in-depth interviews and one focus group discussion were conducted with family medicine specialists (n=2), doctors (n=4), nurses (n=5) and pharmacists (n=2) between July and August 2016. The interviews were conducted with the aid of a semi-structured interview guide. They were audio-recorded, transcribed verbatim and analyzed using thematic analysis. The transcripts of each clinic were analysed separately and the themes were constantly compared to identify similarities and differences in the PDA implementation between the two clinics.

Results

The study found three themes that contrasted the distinct challenges faced by ‘A’ and ‘B’ Clinics: health literacy, language, leadership, and staff motivation.

In ‘A’ Clinic, the HCPs felt that implementing the PDA might be challenging because most patients were elderly with low literacy and they tended to rely on others such as the doctors or family members to make health decisions for them. In addition, majority of the patients were Chinese-speaking while most of the HCPs were non-Chinese and could not communicate with patients in their preferred language. This made implementing the PDA challenging as it required effective communication to delivery SDM.

On the other hand, healthcare professionals in ‘B’ Clinic did not perceive health literacy and language as barriers to implementing the PDA as most of their patients were educated and could speak either English or Malay fluently. The patients in this clinic were more empowered and would like to be more involved in decision making. However, ‘B’ Clinic management did not consider diabetes as their clinic’s health priority. There was a lack of diabetes champion in ‘B’ Clinic and, as a result, the diabetes team, though in place, was less motivated to implement the PDA.

Both clinics viewed top-down approach as effective to implement the PDA; according to the HCPs, this approach had been used successfully to implement other projects previously.

Conclusion

This study identified important factors such as patient profile and leadership, which could influence the outcome of the implementation of PDAs in the Malaysian public primary care setting. This has significant implication as the Ministry of Health is currently finding effective strategies to implement patient-centred interventions, particularly in chronic disease management.

Can Informed Consent Doctrine Enhance Shared Decision-Making? A Québec Law Perspective

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Background and aims

The informed consent doctrine was first adopted by judicial courts to enhance and foster patients' autonomy and engagement in the medical decision-making process. This can be identified as the expected effectiveness of the informed consent legal standard. Although it has been the legal standard for several decades, can we conclude that informed consent is effective, in practice, at enhancing shared decision-making between physicians and patients?

Methods

As law differs from one State to another, we focused on the province of Québec, Canada, in order to assess how effective the informed consent doctrine can be at enhancing shared decision-making. We used a legal effectivity analysis approach to identify 1) the judicial process used to enforce the informed consent doctrine, 2) its constituent legal elements and the burden of proof, and 3) the judicial interpretations of the constituent legal elements. We then critically appraised the judicial process and its constituent elements by systematically comparing them to the expected effectiveness of the informed consent doctrine – namely enhance and foster patients' autonomy and engagement in the medical decision-making process. This legal effectivity analysis was done through a review of Québec' legal doctrine and jurisprudence.

Results

In the civil law province of Québec, the informed consent doctrine is mainly enforced through physicians' professional liability in torts cases. Briefly, in torts law cases, plaintiffs have to prove 1) a fault, 2) a prejudice and 3) causation between the first two. Our critical analysis of informed consent doctrine's legal effectivity through torts cases enforcement revealed that the burden placed on the plaintiffs – the patients – is difficult to overcome, resulting in physicians being rarely held liable for a patient's misinformed consent. As for the fault, the plaintiff must prove that his physician did not disclosed the information that a competent and diligent physician would have disclosed. This "professional standard" thus places in the hands of the physicians the entire responsibility to choose the information that patients deserve to know. As for the prejudice, our analyze shows that only physical prejudices are *prima facie* recognized by the courts, moral or material prejudices being dependent on the latter. Finally, the causation standard that a plaintiff must meet in order for its physician to be held liable for a misinformed consent is that: if the patient had received the undisclosed information, he would not have consented to the care. This last constituent element is the harder to prove and most torts cases for a breach in the informed consent process fail at this point. The general result of our analyze is that physicians' professional liability through torts cases is very hard to prove, and this produces a low effectivity of the informed consent doctrine to enhance shared decision-making.

Conclusion

Law can certainly be a powerful tool for furthering behavioral changes and rebalancing relationships between individuals having inequitable inputs. As for medical decision-making, unfortunately, the judicial process used to enforce the informed consent doctrine does not seem to achieve such changes and enhance shared decision-making.

Development of Patient Decision Aids for Plaque Psoriasis and Acne

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Background

Patient decision aids are lacking in dermatology, despite proven benefits in other specialties. The current study aimed to update a patient decision aid (PDA) for plaque psoriasis, incorporating recent treatment options and providing an interactive, online design; and to develop a similar comprehensive and accessible PDA for acne.

Design & Methods

These PDAs were developed in accordance with International Patient Decision Aid Standards (IPDAS). Content was extracted from current practice guidelines and primary research and formatted for an 8th grade reading level. Throughout development, feedback was collected through focus groups with 15 psoriasis patients, online survey with 34 acne patients, and online survey with 51 physicians. Each round of data collection informed changes to the decision aid content and format.

Results

Psoriasis and acne patients demonstrated a need for decision support and greater information about their disease and treatment options. Physicians reported interest in using the PDAs in practice. Satisfaction with content and format of both PDAs was high among patients and physicians.

Conclusion

Effectiveness of the PDAs for treatment decision making will be pilot tested. The final PDAs will be rated by IPDAS and hosted at www.informed-decisions.org/beta. Results will contribute to the empirical research on the development, implementation, and effectiveness of these tools to informed shared decision making in dermatology.