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BOOK OF ABSTRACT
Oral communications

SUMMARY

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Parallel Session 01
Monday 3rd
10:30—12:30

Chronic disease and SDM	Salle de conférence Médiathèque
SDM and decision aids	Room 106, CIER
SDM and decision aids	Room 107, CIER
SDM and person-centered care	Room Salle du Conseil
SDM and public health policies and pediatrics	Room Amphi Revol
SDM training for healthcare professionnals	Room Amphi B, CIER

ISDM 2017

Barriers and facilitators to implementing shared decision-making in older patients with multiple chronic conditions; a systematic review

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Background
In order to enhance implementation of shared decision making (SDM) in older patients with multiple chronic conditions (MCC), we conducted a review on barriers and limitations that older patients with MCC, their informal caregivers and health professionals.

Methods
Medline, Embase, Psycinfo, Cinahl and Cochrane Central Register of Controlled Trials (Central) were searched covering the period from 1980 to April 2016. We used both keywords and MESH terms for 'shared decision making', 'older people', 'comorbidities', 'barriers' and 'facilitators'. Studies were included if they had an original data collection, both qualitative and quantitative studies were included. Two researchers independently reviewed all data, including a quality assessment. Barriers and facilitators were reported according to an existing taxonomy for predisposing factors, interactional context factors, the SDM encounter, organisational, social and policy factors. We described from which perspective (patient, informal caregiver, health professional) which barriers and facilitators were reported.

Results
We reported only those barriers (b) and facilitators (f) that were not previously reported in reviews about b&f in a general population. Patient reported b & f were mainly about: hectic environment (b), not really allowed to decide (b), bad communication skills professional (b), individual approach (f), forming partnership with professional (f) and feeling invited (f). Health professional reported barriers and facilitators concerned: patient not wanting to participate, thus having to guess (b), organisational constraints (b) and working in a multidisciplinary team (f). Informal caregivers reported barriers and facilitators addressed: having to deal with complex and multiple health organisations (b), stress between own values and interests and patients values and interests (b), being extra eye and ear for both patient as well as health professional (f). The major part of barriers and facilitators was experienced by both patients as professionals.

Conclusions
Older people with MCC, informal caregivers and health professionals caring for them experience particular barriers as facilitators in the SDM process, in addition to general and well known barriers and facilitators. There is consensus between patients and health professionals about most barriers and facilitators, which is a fertile starting point for enhanced implementation of SDM.

A Collaborative Approach to Personalizing Obesity Management in Primary Care: Patient Experience and Self-management Outcomes

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Background and aims

This study explores patient experiences to identify key elements of personalized obesity prevention and management consultations in primary care and their impact on patients' everyday efforts to improve health.

Obesity is a complex condition associated with comorbid diseases and psychosocial drivers. Management requires sustained efforts in the patient's everyday life and support by interdisciplinary primary care clinicians. Despite available resources, patients' needs for strategies to navigate their individual set of drivers and barriers to obesity management are currently not sufficiently met. There is a pressing need for an effective intervention that can guide clinicians to use a collaborative approach and shared decisions to personalize obesity assessment and care planning with the goal to improve health.

We integrate the 5As of Obesity Management with the Collaborative Deliberation model for patient care communication to develop an intervention. We examine how patients perceive the consultation including interpersonal work, communication, and content; and how this experience impacts patients' ability to make changes to improve health as a result.

Methods

This qualitative study is part of the larger research program, which uses collaborative approaches in working with patients and clinicians to improve obesity prevention and management in primary care. We recruited 20 patients living with overweight or obesity through purposeful sampling to ensure a diversity of patient contexts. Video-recorded one-on-one interventions with a primary care clinician, semi-structured patient and clinician interviews immediately after the consultation, and documentation of intervention impact on patients' self-management through diaries and two follow-up interviews over the course of 6-8 weeks. Thematic analysis using inductive and deductive coding in NVIVO11.

Results

Three themes emerged that appear central to achieving a personalized and impactful intervention from the patient perspective: (1) the clinician listened to the story of their obesity and anchored the assessment of root causes and patient context in this story; (2) the story informed a collaborative effort of identifying preferences and strategies to address root causes and barriers that were then integrated into a care plan; and (3) telling and re-telling their story with the clinician helped patients to shift toward increased awareness of the multiple connections between their life context, emotions, thoughts, and health, increased self-efficacy, more positive self-image, and more realistic expectations for weight management. These are interpersonal processes that underpinned several pertinent intervention elements, such as patient story, shared decision-making, and motivational interviewing, and that were decisive for patients to make changes in their everyday lives to improve health.

Conclusions

Preliminary findings suggest that interpersonal processes occurring during collaborative, personalized obesity assessment and care planning are key in supporting patient self-efficacy and self-care as well as for coordinating optimal interdisciplinary clinical care to improve health outcomes. Results will be used to refine the intervention and identify outcome measures in preparation for a future trial.

LEMENTING these tools in routine care.

The DICO study: Decision making In Complex Old populations; an observational study

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Background

Shared decision making (SDM) in older patients is more complex when multiple chronic conditions (MCC) have to be taken into account when deliberating about goals and options. Little is known about older patients' and caregivers perspective on SDM and how clinicians perform SDM during consultations. The aim of this research is to explore (1)what are the preferred and perceived roles of patients, informal caregivers and clinicians to decide together, (2) what is the match between preferred and perceived participation of patients and informal caregivers and (3) what is the actual shared decision making during consultations of the clinician.

Methods

In an observational study fifty older patients and thirty-seven informal caregivers visiting the outpatient clinic for geriatric care in a Dutch academic hospital were recruited for the study. Pre- and post consultation questionnaires were carried out and consultations were videotaped and coded with the OPTION-5. Preferred and perceived participation was measured by Patients' perceived Involvement in Care Scale (PICS).

Results

The mean age was 75,0 years, and 51,0% was female. Informal caregivers mean age was 63,7 years, and 68,4% was female. In 61% of the consultations an informal caregiver was present, 54% was either a partner of a daughter/son. Five clinicians performed all consultations. In 90% of the consultations a decision was made. 22 % of the patients preferred to decide by themselves, 29% with the clinician, or with informal caregiver and clinician (33%). 7% of the patients did decide by themselves, 44% with the clinician, or with informal caregiver and clinician (9 %). Informal caregivers preferred to decide with patient and clinician (70%), 41% did decide with patient and clinician. Clinicians preferred to decide with the patient (50%), or with the patient and informal caregiver (35%). After consultation they actually had decided with the patient (57%) or with the patient and informal caregiver (16%). Patients and informal caregivers preferred a higher level of participation but perceived a lower level of participation (PICS range 0-8: patients preferred 6.6, perceived 5.1, informal caregivers preferred 7, perceived 5). The mean OPTION 5 score was 2.5 (range 0-4), indicating that a moderate level of SDM was observed.

Conclusion

Older patients with MCC, their informal caregivers and clinicians most often prefer a SDM process. Informal caregivers were less involved than they wanted. In addition the participation of patient and informal caregiver in the SDM process is lower as they preferred initially. There was especially a gap between the preferred and perceived role of informal caregivers. To illustrate, 70% of the caregivers wanted to be involved in the decision making, but only 41% felt that they took part in the decision making process. Clinician experienced no difference between preferred and perceived roles (57% vs 50% preference) in taking the decision together with the patient caregiver. The OPTION 5 score shows that SDM is applied, however there is still much room for improvement. Interventions to enhance implementation of SDM should target to empower both patients and informal caregivers and aim at improving clinicians competencies in SDM.

More dissonance than harmony? A qualitative study of patient goals for treatment of rheumatoid arthritis

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Background
Patient and clinician goals for treatment often diverge and may result in suboptimal communication, degradation of trust, and dissatisfaction with care. Goal concordance between patients and clinicians has been shown to improve outcomes in diabetes, but has yet to be explored in rheumatoid arthritis (RA), a chronic condition that requires significant self-management. The objective of this study was to explore goal conceptualization among patients with RA and their clinicians using focus groups to collect qualitative data.

Methods
Patients and clinicians from four participating rheumatology clinics were recruited to participate in one of eight focus groups. Trained focus group moderators led the sessions using a standardized guide developed by study team members. At each session a trained observer took field notes that contained both descriptive and reflexive information about the setting, non-verbal behaviors, and discussion as it unfolded, which supplemented the focus group's verbal data. An inductive-deductive hybrid approach to data analysis was used, in which the identification of areas of goal concordance or discordance guided analysis; this approach allowed for flexibility in the observation of relevant patterns in the data and emergent themes.

Results
A total of 19 patients (mean age 55, 26% Spanish; 74% female; 32% nonwhite) and 18 clinicians (44% trainees, 44% female, 28% nonwhite) participated in 7 focus groups and one semi-structured interview. Two overarching themes were identified. First, both patients and clinicians viewed patient receipt of RA knowledge as an important goal; however, the conceptualization of this goal differed between patients and clinicians. Patients connected knowledge to informed choice and empowerment, while clinicians identified knowledge as necessary for adherence and medication safety. Among clinicians, there was noted variation in how participants viewed the role of knowledge in the patient-clinician encounter. In focus groups, more senior clinicians discussed knowledge (i.e., their medical knowledge) as a tool to enable physician control over treatment plans and as key to their autonomy. Second, both patients and clinicians viewed RA as stressful. Clinicians acknowledged that patients are fearful and experience psychosocial stress; patients reported generalized anxiety, grief (for their former health state and status) and sadness. Clinicians noted that in this setting of stress and fear, communication is difficult. Patients reported desire for, and appreciation of patient-clinician relationships characterized by in-depth communication, trust, and openness to discussing non-clinical aspects of RA.

Conclusion
Knowledge is a shared goal; however, patients and clinicians hold divergent attitudes towards knowledge and RA treatment. While education and knowledge are integral to patient self-management and effective engagement in shared decision making, the mismatch in attitudes towards the goal of knowledge between patients and clinicians may lead to suboptimal communication and lack of trust, which ultimately undermines shared decision making. Given that both groups viewed RA as stressful and clinicians identified this stress as having a negative impact on communication, tools to support and facilitate conversation around patient goals in RA may lead to greater goal concordance and help improve care through reduction in disparities for people living with this chronic, debilitating condition.

A systematic review of decision-making among CALD adults with chronic disease: Barriers, facilitators, and interventions

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Background

Culturally and linguistically diverse (CALD) patients experience not only a genetic predisposition to certain chronic diseases but also higher hospitalization and mortality rates. Improving CALD patients' capacity for shared decision-making (SDM) holds potential to improve outcomes, but little is known of effective strategies to facilitate this. An understanding of cultural beliefs and attitudes and the multifaceted social and cultural influences on decision-making is essential to the implementation of targeted and tailored SDM interventions.

Aims

To understand the barriers and facilitators of SDM for CALD adults and evaluate existing cultural competency frameworks and interventions across the chronic disease spectrum. This research will form part of the formative evaluation process in the creation of a novel SDM training program that aims to support low-literacy CALD adults currently receiving haemodialysis for chronic kidney disease (CKD) to participate in healthcare interactions.

Methods

A search strategy was created and refined and a comprehensive search was conducted on 30th November 2016 using MedLine, PubMed, Embase, Cochrane Central Register of Controlled Trials, CINAHL, Informit Online and PsycInfo. Duplicates were removed and articles screened by title and abstract for exclusion criteria (population and study type). Articles that discussed barriers and facilitators to healthcare engagement for CALD groups or frameworks for greater cultural competency were eligible for inclusion. We also included articles reporting interventions to improve SDM in the context of any chronic disease (excluding cancer). Interventions trialed with only CALD populations or where CALD results could be distinguished and separately analysed were eligible for inclusion.

Results

1668 articles were located with 132 to be included in the final analysis. CALD patients experience worse health outcomes compared to their Western counterparts across a broad range of chronic diseases, including higher prevalence of CKD with a more rapid progression to dialysis. Within CALD patient–healthcare provider interactions, distinct barriers include patient perceived wider power–distance, low health literacy and poor provider cultural competence. Resolution of these barriers is difficult under the language and communication constraints, whereby translators are underutilized. As a result CALD patients are less likely to engage in SDM.

Across chronic disease contexts, few secondary and tertiary interventions exist to support CALD populations to participate in decision-making. Where interventions have been trialed in CALD populations, the majority have not been targeted, tailored or altered according to the core values of diverse cultural groups.

Discussion

In 2015, American Journal of Kidney Disease identified the provision of culturally appropriate information as the second most important CKD research priority, and there is growing recognition of the need to support socially-disadvantaged adults to engage in decision-making about their health. This review demonstrates the need for more culturally-sensitive SDM interventions, targeted and tailored for CALD groups with chronic diseases.

Multi-regional Implementation of Three Prostate Cancer Patient Decision Aids in The Netherlands: Results and Lessons Learned from the JIPPA Study

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Background

Yearly, around 10,000 Dutch men are diagnosed with prostate cancer (Pca). At an early stage, multiple treatments (surgery, radiation therapy, active surveillance) are available with equal positive survival perspectives but with different procedures, risks and side-effects. To select the best suiting treatment, patients have to weigh their preferences and personal values against the treatment characteristics. Preferably, this preference-sensitive decision is a shared decision between a patient and his doctor. Three Dutch Pca treatment decision aids (DAs) were developed to support this process of shared decision making. This study aimed to investigate DA implementation in routine care, as uptake of DAs in routine clinical care is low.

Methods and materials

The three developed DAs varied in format, consisting of a concise booklet-only, an even more concise hybrid (booklet + online) and an elaborate online-only DA (with values clarification exercises). Half of all Dutch hospitals (44/90) participated in this study and implemented one of the three DAs or served as a control group. All localized Pca patients with more than one treatment option were eligible to receive a DA. Patients (n=998) and oncology care providers (n=94) filled out questionnaires on treatment decision-making and DA usage. DA implementation was estimated based on the number of DAs distributed as a proportion of the number of eligible patients per hospital, as obtained from registry data.

Results

Choice awareness, decision involvement, decisional conflict, knowledge, and satisfaction with information was better after a DA compared to the aggregated control group (all with $p<.001$). Main DA effects were replicated with each DA. The average achieved degree of DA implementation was 35%, ranging from 5 to 100% across participating hospitals. The main reason for not giving a DA was the oncology care provider's perception that the patient was unable or unwilling to use a DA. Time constraints were not perceived as a barrier for DA implementation.

The first week following diagnosis was the preferred time to receive the DA for most patients. Patients felt that the urologist was most suited to present the DA. However, when the DA was presented by an (oncology) nurse, patients were equally satisfied, less conflicted and more knowledgeable (both with $p<.01$) compared to patients who received the DA from their urologist. When a booklet DA was received, almost all patients (96%) were satisfied with the format, while for the online DAs, 80% was satisfied and 20% preferred to have received a printed version.

Conclusion

Although all three DAs were effective, implementation varied widely between hospitals for all DAs. The oncology care provider's judgement of the patient was reported most often as a reason for not offering a DA. In contrast to earlier DA studies, time constraints were not perceived as a barrier for implementation. To further improve implementation, (oncology) nurses could have a larger role in DA distribution and more research is needed to understand differences DA uptake between hospitals.

Evaluation of Option Grid[TM] Decision Aids to Support Shared Decision-Making in Breast Cancer Treatment

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Background and aims

Shared decision-making (SDM) is important in oncology, where many preference-sensitive treatment options exist. Many cancer patients want active engagement in treatment decision-making. Despite evidence, SDM is not widely implemented in routine practice. Option Grid decision aids are short decision aids that help patients and physicians to compare treatment options. Before this study, Option Grid decision aids were not available in German. The aims of this study were 1) to translate and adapt two Option Grid decision aids on breast cancer treatment, 2) to evaluate their acceptance and feasibility in German routine care, and 3) to assess needs for further Option Grid decision aids.

Methods

We conducted a two-phased study: 1) Translation of both Option Grid decision aids into German, comparison to German clinical standards, testing of patients' understanding via cognitive interviews, adaptation of the German versions of the Option Grid decision aids. 2) Pilot testing including focus groups and interviews with patients and clinicians to assess acceptability, followed by real world testing in routine breast cancer care using participant observation.

Results

Results show that physicians and patients valued the idea of Option Grid decision aids. However, several cycles of adaptation were necessary in order to reach adequate acceptance. In addition, several physicians questioned the feasibility of using Option Grid decision aids in Germany. They expressed doubt, if Option Grid decision aids can be used in current health care structures, and questioned, if the options in the translated Option Grid decision aids are the most relevant ones in Germany. Many additional topics, where Option Grid decision aids would be helpful, were found. During participant observations, the Option Grid decision aids were used in 12 out of 33 consultations, in which the planning of a surgery was part of the consultation. Option Grid decision aids were mostly only shortly introduced by the physician without engaging in a more thorough discussion of the content of the decision aids, and subsequently given to the patient to take them home.

Conclusion

This study provided German versions of two Option Grid decision aids for breast cancer treatment to be used in Germany for the first time. While the idea of Option Grid decision aids was generally appreciated by patients and physicians, the adaptation process was rather extensive and the use in routine care needs further evaluation. Physicians were found to be ambivalent about the use of tool such as Option Grid decision aids. They did not seem to support the active use of encounter tools during the consultation.

Decision aids for second-line palliative chemotherapy: a randomised multicentre trial

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Background

Few decision aids (DAs) are available to support patients with advanced cancer in treatment decision-making. This randomised study evaluated safety and efficacy of DAs on second-line chemotherapy for advanced breast or colorectal cancer. Methods: 45 patients were randomised to usual care and 83 patients to usual care plus a DA. Using the DA, nurses offered information on adverse events, tumour response and survival. Patients completed questionnaires to assess safety (primary outcome: anxiety) and efficacy in terms of quality of the decision-making process and the resulting choice. Findings: The DAs did not adversely affect patients' well-being, including anxiety. Patients in the DA group tended to be more in favour of chemotherapy (96% vs. 84%; p=0.067), but eventually 88% and 84% of patients started chemotherapy (p=0.746). Patients in the DA group had stronger treatment preferences (3.0 vs. 2.5; p=0.030) and higher subjective knowledge (6.7 vs. 6.3; p=0.022). No differences were seen in objective knowledge, risk perception or patient involvement. Discussion: DAs with outcome information on second-line treatment could be safely offered to patients. Only some improvements in the quality of the decision-making process and the resulting choice were found. Future studies might clarify whether this relative lack of effects is common for palliative treatment decisions.

Development and testing of two decision support tools for older women with breast cancer: Bridging the Age Gap Study

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SDM AND DECISION AIDS

Background

Around a third of breast cancers diagnosed each year in the UK are in women aged 70 years and older. Older people are often considered as less involved in decision-making and desire to be involved less, they may therefore be prime candidates to benefit from decision support. There is variation throughout the UK in treatment given to older women with breast cancer. Surgery is the standard treatment, however primary endocrine therapy (PET) is also used with rates of PET varying across the UK (12 to 40%). Rates of chemotherapy in this age group also vary widely throughout the UK (6 to 60% in high risk women). Currently, there is little evidence-based guidance specifically on the management of these older patients. A large UK cohort study is currently underway to address this lack of evidence and two decision support interventions (DESIs) have been developed alongside this to support shared decision-making.

Methods

Each DESI included a short tool (a list of frequently asked questions and answers), to be used within a consultation, and a booklet with more detailed information and a values clarification exercise for outside the consultation. An initial prototype based on a number of evidence sources and the Coping in Deliberation framework was developed for women with a choice of PET or surgery with endocrine therapy (surgery+ET) to treat their breast cancer. Semi-structured interviews with healthy volunteers (user testing) and patients (field testing) explored the acceptability, usability and utility of the DESI. A framework approach was used to analyse the interviews. A second DESI for women deciding whether or not to have chemotherapy was later developed based on similar methods using transferable information (such as preference for language and diagram use) that had been gained from developing the first DESI.

Results

Feedback from participants (n=22, aged 75-94 years, 64% healthy volunteers, 36% patients) about the PET/surgery+ET DESI suggested it was clear and comprehensive. Women thought the short tool would prompt questions during consultations and the booklet useful to take home and read. They also highlighted the importance of discussions with clinicians. Changes were made in response to clarifications and suggested improvements. For example, a diagram showing a breast cancer was amended because it had been misinterpreted. Feedback from participants (n=14, aged 70-87 years, 57% healthy volunteers, 43% patients) about the chemotherapy DESI was also largely positive, but with some improvements to content suggested.

Conclusion

The DESIs may promote shared decision-making by supporting discussions within consultations as well as providing additional information to support coping and deliberation outside consultations. This may be particularly valuable for older women, especially those who may not have been involved with decisions previously and who may experience difficulty when facing treatment choices. Development of additional DESIs for similar target populations using transferable information may be an efficient way to develop future DESIs. The DESIs are currently being tested as part of a complex intervention in a UK-wide trial in older women with breast cancer to examine the impact on shared decision-making and quality of life.

An online value based decision aid as part of a consistent complex on SDM in the Netherlands

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The Kidney Guide is an innovative online instrument with video clips of 42 kidney patients. They talk about their experiences with Renal Replacement Therapy (RRT). All 9 therapy options are discussed, including dialysis in the hospital or at home, transplantation and conservative treatment. The patients are interviewed on 19 subjects. For instance school/work, energy, having children, food/drink. The Kidney Guide helps to give patients ideas about what a specific RRT means in their life and how they want things to be.

Users can search on treatment and topic, a person and keywords. They can also find the option grid (see below) and a basic explanation of every treatment. Users can save video's and note down their own remarks. They can also print it or send it by e-mail.

The Dutch Kidney Patients Association (NVN) took initiative for this value based decision aid. It complements the option grid that was initiated by the Dutch Nephrology Federation (NfN) and the question prompt sheet 'Three good questions ' (known in the UK as 'Ask three questions). All three decision aids are included in the medical guideline 'Renal replacement therapy, yes or no', that also contains a paragraph on shared decision making (SDM). The developmental lines of guideline, option grid and Kidney Guide were in close contact during the whole process. All together we created a very consistent and practical complex on SDM and RRT in the Netherlands.

The Kidney Guide was based on an international search for decision aids on RRT. This was followed by structured interviews with over 40 CKD patients of all RRT modalities that were put on film. We searched for different patients between 20-85 years, in different regions of The Netherlands and with different accents, man and women. It's a decision aid based on patient experiences. Subjective but because there are different patients with different stories, the user gets a broader perspective. The main perspective of the Kidney guide is to bring the patients perspective into the process of SDM.

To build the Kidney Guide, we started a steering committee with representatives from different professions (nephrologist, nurse, social worker) – these professionals also participated in the working group of the medical guideline - , and with a representative of the Dutch Kidney Foundation and a health insurance company. Besides this we started a patient group with 9 kidney patients in different phases of their CKD and 1 partner of a kidney patient to co-create the Kidney Guide.

We tested the instrument with 9 patients who did a User's Acceptance Test – (UAT). Every test person was observed during their activity and also filled in a questionnaire. We also asked 9 care professionals and their patients to do an online test of the instrument with the same questionnaire as the patients who did the UAT. The outcome of these tests were used to clarify and simplify the instrument in the functionalities and the way some aspects were presented.

In the end also the implementation was done in cooperation with the different professionals.

Using encounter decision aids to share decisions with women presenting with heavy menstrual bleeding

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Background and aims

Heavy menstrual bleeding impacts women's quality of life and can be treated in a variety of ways. Shared decision-making (SDM) requires providing tailored information to the patient about options and eliciting and integrating patient preferences as treatments are selected. Decision aids used in the clinical encounter may facilitate SDM. We evaluated the impact of introducing encounter decision aids (Option Grid™ decision aid) for women presenting with heavy menstrual bleeding on the level of SDM.

Methods

A before-after study was conducted in a general OB-GYN practice in an academic medical center and two community practices in the United States between December 2014 and May 2015. Consultations were compared before (T1) and after (T2) introduction of two encounter decision aids on treatment options for heavy menstrual bleeding with and without accompanying uterine fibroids. Clinicians participating in the study were offered an interactive and hands-on group training on the use of the encounter decision aids before T2. Immediately after appointments discussing treatment options, patients filled out a brief validated measure (CollaboRATE) of SDM. Additionally, three trained observers rated audio recordings of consultations for SDM using the OPTION[5] instrument. Based on sample size calculated we aimed to include at least 25 patients before and 25 patients after introduction of the decision aids.

Results

Altogether, 16 providers participated, 25 patients were enrolled in T1, and 28 patients were enrolled in T2. The groups of patients did not differ on demographic characteristics. The proportion of patients reporting SDM increased significantly from T1 (50%) to T2 (75%; $p < 0.05$). The mean observer-rated level of SDM also increased significantly from T1 to T2 (mean difference = 12.50 on a scale of 0-100, where threshold for clinical relevance is 11.9).

Among individual OPTION[5] items, item 2 (ie. 'The clinician reassures the patient, or re-affirms, that the clinician will support the patient to become informed and to deliberate about the options') increased the least and item 4 (ie. 'The clinician makes an effort to elicit the patient's preferences in response to the options that have been described') increased the most. The overall interrater reliability for all three raters reached an ICC 0.723 (95% CI 0.56-0.83).

Conclusion

Implementation of encounter decision aids for women presenting with heavy menstrual bleeding was associated with a higher level of SDM between women and providers, both from the patient and observer perspective. Given these promising results we encourage clinicians to use these encounter decision aids with their patients. Replicating the study at a larger scale using a randomized design will provide more insight into the feasibility and impact of implementing these tools in routine care.

Title: Decision Aids' Efficacy to Support Women's Fertility Preservation Choices Before Cancer Treatment: An Environmental Scan.

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Background and aims

To evaluate patient information and clinical guidelines developed for women making fertility preservation choices before cancer treatment. As some cancer treatments increase women's chance of infertility, oncology and fertility services provide information preparing women for fertility preservation procedures. Women report current resources are not sufficient to support their fertility preservation decisions during their cancer care.

Methods

An environmental scan of open-access decision support resources carried out using systematic review methods (December 2015). Three data sources were searched: internet (Google): healthcare decision support repositories (Decision Aids Library Inventory; Trips; NHS Evidence; National Guidelines Clearinghouse; Clinical Trials); shared decision making experts (SHARED-L distribution list). Inclusion criteria were, information about: women receiving cancer treatment; consequences cancer treatment on fertility; fertility preservation options; statements supporting women's choices. The International Patient Decision Aid Standards (IPDAS) criteria informed the data extraction sheet developed to elicit information about resources' content. Data were evaluated critically against these components, assessing resources' validity to support actively people's decision making between options.

Results

Of the 116 patient decision aids and 42 clinical guidelines identified, 24 decision aids met the inclusion criteria. Resources varied in amount (2 – 90 pages) and type (pdf – App) of information. Most were rated as difficult to read (Flesch <60); few were endorsed independently (e.g. DALI, Crystal Mark). A third stated the resource's purpose was to support women's decision making; most aimed to inform and prepare women for fertility preservation and/or infertility procedures. Most resources provided questions for women to engage with health professionals rather than prompts and structures supporting deliberative thinking about which options fit best into their life now, and after cancer treatment (e.g. decision maps, parallel presentation options and attributes; risk figures, value clarification prompts). Most descriptions of cancer and infertility missed out information from one of the five schema people need when making sense of illness. Most resources met less than 50% of the IPDAS criteria.

Conclusions

Resources provided information about fertility preservation and infertility treatment options; about 20% adhered to IPDAS guidance and readability standards. Most resources were designed for women with breast cancer after referral to infertility services. A decision aid supporting women's deliberation about fertility preservation, or not, when receiving treatment for any cancer is likely to meet UK and international service needs.

Updated Cochrane Review of Patient Decision Aids: With sub-analysis of PDAs used within and in preparation for the consultation

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Background

Patient decision aids (PtDAs) are evidence-based knowledge tools designed to help patients make informed health decisions congruent with their preferences. The aim of this study was to update the Cochrane systematic review of PtDAs and explored if results vary based on when PtDAs are used (in preparation for consultation versus within consultation).

Methods

We searched MEDLINE, CENTRAL, EMBASE, PsycINFO, and grey literature from 2012 to April 2015. We included published randomised trials comparing PtDAs to usual care and/or non-PtDA interventions. For this update, we excluded studies comparing detailed to simple PtDAs. Two reviewers independently screened citations for inclusion, extracted data, and assessed risk of bias. Primary outcomes based on the International Patient Decision Aid Standards (IPDAS) included attributes of the choice made and attributes of the decision-making process. Secondary outcomes included behavioral, health, and health-system effects. We pooled results using mean differences (MD) and relative risks (RR), applying a random-effects model. Sub-analysis was conducted of trials using the PtDA in preparation for the consultation and those used within the consultation. We used GRADE to indicate strength of the evidence.

Results

A total of 105 studies involving 31,043 participants from 10 countries were included. This update added 18 new studies and removed 28 previously included studies comparing detailed to simple PtDAs. Compared to usual care, patients exposed to PtDAs had: a) greater knowledge (MD 13.27/100; 95% confidence interval (CI) 11.32,15.23; n=52 studies); b) more accurate risk perceptions (RR 2.10; 95% CI 1.66, 2.66; n=17); c) better values-choice congruence (RR 2.06; 95% CI 1.46, 2.91; n=10); d) reduced decisional conflict related to feeling uninformed (MD -9.28/100; 95% CI -12.20, -6.36; n=27) and related to unclear values (MD -8.81; 95% CI -11.99, -5.63; n=23); and e) lower passivity in decision making (RR 0.68; 95% CI 0.55, 0.83; n=16). The median effect of PDAs on length of consultation was 7.5% longer (2.6 minutes) than usual care. There was no impact on satisfaction or reporting of apparent harms. Sub-group analysis for PDAs used within (16 studies) or in preparation for the consultation (89 studies) showed no difference in knowledge (WMD 10.57% versus 13.77%; p=0.31) and accurate risk perceptions (RR 1.79 versus 2.25; P=0.33).

Conclusion

Our findings are consistent with findings of previous updates. Compared to usual care, people exposed to PDA have: a) better knowledge, feel more informed and clearer about their values (high-quality evidence); b) probably have more accurate expectations of benefits and possible harms of options and participate more in decision making (moderate-quality evidence); and c) may achieve decisions that are consistent with their informed values (low-quality evidence). When PDAs are used either within or in preparation for the consultation, there was no difference in knowledge and accurate expectations. There remains limited evidence on the effect of PDAs on adherence to the chosen option, resource use, cost-effectiveness, and use with various cultural or literacy groups.

Pilot testing of an education resource on genomic testing for breast cancer risk

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Introduction

We are undertaking a prospective, mixed-method study of the psychological and behavioural impact of disclosing genomic testing results for common risk variants associated with breast cancer. An education pamphlet for women considering testing for common risk variants to assess their breast cancer risk was developed and pilot tested. Participants of an existing study titled: 'Common Genetic Variants and Familial Cancer' were invited to take part in this study.

Methods

The two-page education pamphlet provides a brief explanation of rare high-risk gene mutations (*BRCA1* and *BRCA2*) and common risk variants in breast cancer. It covers a range of topics relevant to genomic testing for breast cancer risk, including meaning and implications of results, impact on family members and insurance. The pamphlet was written in accordance with health literacy guidelines and at a grade nine literacy standard (14-15 years old). The pamphlet was pilot-tested with 28 female participants of the parent study. Descriptive statistics were calculated for all responses.

Results

All women thought their understanding of the risks and benefits of genetic testing had improved. The majority of participants (68%) reported that the education pamphlet did not make them feel worried, with 71% actually reporting feeling reassured. Participants provided detailed suggestions for amendments including visual presentation, and readability. Feedback provided has since been incorporated and the final pamphlet has been reduced to a grade 8 literacy level (12-14 years old).

Conclusions

The revised pamphlet with the information on genomic testing and breast cancer risk will be used in the prospective psychosocial study.

Online, interactive Option Grid™ decision aids: shifting user preferences

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Background

Randomized trials have shown that decision aids modify user preference, yet little is known about the *active ingredients* embedded in the decision aid that shift user preference. The web-based **Option Grid™** interactive journey enables us to identify which information elements are most valued by users, and whether they are associated with preference shift. Our aim was to determine whether Option Grid interactive decision aids shifted user preference, and which information elements embedded in the tools were associated with that shift.

Methods

We conducted a cross-sectional analysis of data derived from the usage of interactive Option Grid tools to determine whether or not users shifted their preference. All interactive decision aids completed by users who created an account on the Option Grid website between June 1, 2015 and January 31, 2016 were eligible for inclusion. The five most-used Option Grid decision aids were analyzed for this study. The McNemar-Bowker paired test was used to compare preference shift before and after the use of the tool. Five multinomial regression analyses were conducted (one for each of the five Option Grid decision aids) to investigate possible associations between information elements and preference shift.

Results

The amniocentesis, angina, breast cancer, Prostate Specific Antigen (PSA) test, and statins Option Grid decision aids were included for analysis. Among those five, the breast cancer ($p < 0.001$), PSA ($p = 0.011$), and statins ($p < .001$) tools shifted user preference. Users of the breast cancer Option Grid who initially were uncertain or who preferred the 'lumpectomy with radiotherapy' treatment option shifted their preference toward the 'mastectomy' treatment option. Information elements regarding the potential for the cancer to return, the possibility of lymph gland removal, and whether or not the patient will lose their hair all shifted preference toward mastectomy. Users of the PSA tool typically chose more conservative options, shifting their preference toward not having a PSA test or becoming uncertain after completing the interactive Option Grid. Information on the meaning of having a high, or normal, PSA level and its link to cancer shifted user preference. Data on the overall risk of the test and the risks associated with prostate biopsy also influenced preference. All the information elements in the statins Option Grid shifted user preference away from starting a statin or changing their diet toward being physically active. For the angina Option Grid, preferences shifted toward medical management and away from stenting or uncertainty. What the treatment involved, the likelihood that the treatment lowered heart attack risk and how well the treatment worked all influenced the direction of the preference shift for those who went through the angina interactive tool. Amniocentesis Option Grid users did not shift their preference in any direction that was statistically significant.

Conclusion

Option Grid decision aids provide insight into the information elements that seem to influence change in preference. Identifying the *active ingredients* of decision aids can transform the design of these tools to better support decision making.

"Provoking conversations": case studies of organizations where Option Grid™ decision aids have become 'normalized'

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Background

Implementing patient decision aids in clinic workflow has proven to be a challenge for healthcare organizations and physicians. Time pressures, the tool's potential lack of applicability to specific clinical problems and a lack of trust in the information they contain have been cited as significant barriers to routine implementation. Given these implementation challenges, an alternative approach to examine successful implementation would be to search for examples where organizations have independently identified and embedded decision aids in existing workflows. We had become aware of settings where the **Option Grid** decision aids for clinical encounters had been adopted or 'normalized' as part of routine practice. These tools are one-page, evidence-based summaries of treatment or screening options and their attributes in a tabular format. Our aim was to determine the organizational strategies, motivations, and facilitating factors to the routine implementation of these encounter decision aids at two independent settings.

Methods

Case studies conducted by semi-structured interview, using the Normalization Process Theory (NPT) as a framework for thematic analysis. NPT has four theoretical tenets: (i) coherence: the 'sense-making' that helps people working in the organization reach consensus about the intervention and its aim, (ii) collective action: the operational work that allocates tasks to each member of the organization to build and sustain the use of the intervention, (iii) cognitive participation: the relational work that influences 'implementation and legitimation' of the intervention, (iv) reflexive monitoring: the communal appraisal work that aids the assessment and comprehension of the effects of the intervention. 23 interviews with physicians, nurses, hospital staff and stakeholders were conducted at: 1) *CapitalCare* Medical Group in Albany, New York; 2) HealthPartners Clinics in Minneapolis, Minnesota. The positive deviance approach helped us identify the 'deviants' – the settings that have routinely implemented the tool in their clinic workflow, and helped us study the organizations in-depth through semi-structured interviews.

Results

'Coherent' motivations were guided by financial incentives at CapitalCare, and by a 'champion' physician at HealthPartners. Nurses worked 'collectively' at both settings and played an important role at sites where successful implementation occurred. Some physicians did not understand the proposed utility of Option Grid, which led to varying degrees of implementation success across sites. The appraisal work (reflexive monitoring) identified benefits, particularly in terms of information provision. Physicians at both settings, however, were concerned with time pressures and the suitability of the tool for patients with low levels of health literacy.

Conclusion

Although both practice settings illustrated the mechanisms of normalization postulated by the theory, the extent to which some were routinely embedded in clinic workflow varied between sites, and between clinicians. This case study suggests that patient decision aids that are specifically designed for use in clinical encounters can be embedded in clinical settings, provided there is agreement about the need to use them, that the team members are willing to work together to make sure that such tools can be integrated in existing work patterns, and understood as making a positive overall contribution to the work that has to be performed.

Predictors of mismatched preferences about housing decisions between caregivers and their senior loved ones

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Background and aims

Caregivers play an essential role in caring for seniors, including in their housing decisions. However, each may have different preferences about housing choices, which may lead to conflict, regret and unhappiness if not discussed and resolved. We aimed to assess how often mismatched preferences about housing choices arise between caregivers and seniors, and to identify characteristics (related to the senior, caregiver, care, and involvement in decision- making) that predict these mismatches.

Methods

This is a secondary analysis of cross-sectional survey data on Dutch informal caregivers.

Caregivers self-completed questionnaires (2010-2011) about their caregiving and decision-making experiences regarding home care, medical care, and end-of-life plans for their loved one. They were also asked about the housing option they preferred for their loved one (staying, moving, or ambivalent) and what they thought their loved one would prefer. We computed a dichotomous variable "mismatch" indicating whether preferences were matched (0) or mismatched (1). We included data from all caregivers who took care of a senior loved one (60+ years old) and had complete data on the dependent variable (mismatch). Bivariate regression analysis was conducted between this variable and socio-demographic and medical characteristics, and caregiver involvement in care and decision-making. Variables with significance levels of $p<0.10$ were retained for multivariate analysis (using "enter" parsimonal logistic regression analysis).

Results

Caregivers (n=3143) were on average 65 years old, adult children (61%) or spouses

(23%) of the senior. Seniors were on average 84 years old, and living at home (74%). Many seniors suffered from physical (82%) or mental (38%) deterioration. One-third of caregivers reported a mismatch in preferences about the senior's housing. Most often seniors preferred to stay at home while caregivers were ambivalent (49%) or preferred that they move (29%). Mismatch was associated with "more safety concerns about the seniors' current living environment" (OR=2.5), "mental deterioration as a reason for caregiving" (OR=1.3), "caregivers who were not the partner of the senior" (OR=2.9), "higher caregiver burden" (OR=1.4), "the senior's current living situation as independent at home" (OR=0.403), "fewer hours of caregiving per week" (OR=0.9), "less acceptance of home care by the senior" (OR=0.8), "less agreement of the caregiver with the extent to which GPs involve him/her in decision-making" (OR=0.8). These factors together explained 22% of the variance.

Conclusion

One-third of the caregivers reported mismatched preferences about the senior's housing options, most often when seniors were living at home and wanted to stay there. Caregivers were ambivalent about what was best for their loved ones. Although mismatch often seemed to be a result of increasing demands in caregiving situations, the multitude of factors associated with this mismatch and their often value-sensitive nature suggest the importance of all those involved in housing decisions being involved in discussing reasons for preferences.

Implementation of Shared Decision-Making: A Qualitative Study of the Choice for Next Birth after a Caesarean Section

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Background and Aims
Vaginal birth after caesarean (VBAC) is a safe and recommended option, however most eligible women give birth by repeat caesarean. Shared decision-making (SDM) interventions for birth after caesarean (patient decision aids, decision coaches), increase knowledge, realistic risk perceptions, and reduce decisional conflict. Despite these benefits, they are not associated with increased SDM for mode of delivery. This may be due to context-specific barriers to SDM such as lack of access to the option of planned VBAC. Previous studies have identified patient and provider perceptions of "barriers and facilitators" to SDM across various health decisions. Little is known about the relationships between these factors and how they influence implementation of SDM for birth after caesarean. We sought to explore attitudes toward and experiences with decision-making for mode of birth after previous caesarean section and identify factors that influence implementation of SDM.

Method
In-depth, semi-structured interviews were conducted with women, care providers, and decision makers recruited from 3 rural and 2 urban communities in British Columbia. Interviews explored the patient (micro), health services (meso), and policy (macro) factors that influence decision-making for mode of delivery. Interview guides were informed by a) previous systematic reviews of the literature on patient and health care professional barriers and facilitators to implementation of SDM, and b) previous literature on the factors that influence high rates of repeat caesarean in developed nations. Implementation and knowledge translation principles guided study design, and constructionist grounded theory informed iterative data collection and analysis. Findings were interpreted using complex adaptive systems theory (CAS). Throughout data collection and analysis, we engaged in activities to facilitate mutual understanding among stakeholder groups, including policy dialogues and the use of a policy brief.

Results
Analysis of interviews (n=57) revealed that the factors influencing next birth decisions resulted from interactions between the micro, meso, and macro levels of the health care system. Women formed early preferences for mode of delivery (after the primary caesarean) through careful deliberation of the social risks and benefits of mode of delivery. Physicians acted as information providers of clinical risks and benefits, with limited discussion of patient preferences. Decision makers serving large hospitals revealed concerns related to liability and patient safety. These stemmed from perceptions of limited access to surgical resources, which had resulted from budget constraints.

Conclusion
To facilitate the effective implementation of SDM in clinical practice for mode of delivery after a previous caesarean section, it is necessary to address the needs of women, care providers, and decision makers. These needs include initiating decision support immediately after the primary caesarean, assisting women to address the social risks that influence their preferences, managing perceptions of risk related to patient safety and litigation among physicians, and adequate access to the health care resources that support planned VBAC.

Pharmacist-led SDM intervention to reduce inappropriate polypharmacy in older people: development and pilot study

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Background and aims

Medicine reviews have the potential to reduce inappropriate and/or harmful medicines in older people with comorbidity, however there is lack of involvement of older people in this process. We have developed a Conversation Guide to be used by pharmacists. The Guide aims to increase involvement of older people in medicine decisions related to reducing medicines and inappropriate polypharmacy in the context of a Home Medicines Review (HMR). The Guide is designed for a pharmacist to use with their older patients to discuss: general health understanding, decision-making and information preferences, health priorities related to medicines, patient goals and fears, views on important activities and trade-offs. In Australia, the HMR program is a nationally-funded scheme, led by pharmacists in collaboration with a patient's doctor, to optimise medication use for older people. This study describes the development, pilot and refinement of the Conversation Guide which will inform a randomised trial evaluation. This evaluation will assess whether the Guide supports shared decision making for older patients (aged 65+) who are taking 5 or more medicines in the context of HMRs.

Methods

We have pilot tested the Guide as an additional component of HMR for older people who are taking 5 or more medicines. The first stage pilot was an iterative development process, followed by a process of reviewing and redrafting the Guide based on informal feedback from clinicians, older people and pharmacists.

For the second stage pilot, we recruited 10 accredited pharmacists who conduct HMRs, 15 of their patients (aged 65+) and their companions. A researcher observed the HMRs and interviewed patients and pharmacists afterwards to discuss the acceptability and feasibility of the Guide. Transcribed audio-recordings of the interviews were thematically coded and a Framework Analysis method used.

Results

Results showed that pharmacists found the Guide to be an acceptable and useful component to the HMR, especially among patients with limited knowledge about their medicines. Some questions were not relevant for all patients and several found it hard to understand the questions related to quality of life and making trade-offs between potential benefits and harms of medicines. Overall, pharmacists and patients found the Guide to be an important addition to the HMR as a more holistic approach.

Conclusion

Pharmacists and patients reported the Guide fits in with the HMR encounter relatively easily and promoted greater communication about medicines, priorities and goals. This study highlighted some key challenges for communication about polypharmacy and medicine appropriateness. The Guide may be useful to understand a patient's overall outlook about their medicines but discussions about trade-offs were considered challenging and could be improved by drawing on specific medications.

Informed, Patient Centered Decisions Lead to Better Health Outcomes in Orthopedic Care: A Prospective Cohort Study

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Background
Clinical guidelines encourage shared decision making (SDM) for elective surgery in orthopedics. However, few studies have been adequately powered to examine the relationship between SDM and health outcomes. The purpose of this study was to examine whether patients who are well-informed and receive their preferred treatment have better health outcomes.

Methods
We enrolled eligible patients with knee or hip osteoarthritis, lumbar herniated disc (LDH) or lumbar spinal stenosis (LSS) in a prospective study. We surveyed patients one week after an initial visit with a specialist using Decision Quality Instruments (to measure knowledge and preferred treatment) and general and disease specific quality of life (QoL) (EQ-5D, Knee injury and Osteoarthritis Outcome Score (KOOS), Harris Hip Score, Oswestry Disability Index (ODI)). A follow-up survey was sent about six months later that measured treatment received, QoL, Decision Regret and satisfaction. Patients with a passing knowledge score and who received their preferred treatment (either surgery or non surgical) were considered to have made an informed, patient-centered (IPC) decision. Regression analyses accounted for clustering of patients within clinicians and controlled for surgery, age, gender, joint and baseline QoL to test hypotheses that patients who made IPC decisions would have higher QoL, higher satisfaction and less decision regret at follow-up. With 550 surveys the study had more than 80% power to detect a difference of 0.05 on the EQ-5D between those who made IPC decision or not.

Results
The response rate to the initial survey was (652/926, 70.3%) and to the follow up survey was (551/648, 85%). The sample was on average 63.9 (SD 12.1) years old, 52.8% female, 92.4% White, non Hispanic, and 62.6% had a college degree. About half had surgery (49.0%) within the 6 months of the visit. One third (36.0%) met the criteria for IPC decisions, and IPC decisions were associated with significantly better overall and disease-specific quality of life, across all topics. The unadjusted increases were 0.06 for EQ-5D p=0.006, 4.72 points for KOOS symptoms p=0.009, 2.93 points for Harris Hip Score p<0.0001, and -7.59 points on ODI p<0.0001. Participants who made IPC decisions were more likely to be extremely satisfied with their pain (76.68% vs. 41.86%, p=0.0003), more likely to be very or extremely satisfied with treatment (70.68% vs. 34.66%, p=0.0003), and had less regret (5.2% vs. 15.0% p=0.0006).

Conclusions
Patient engagement in elective surgery decisions is important ethically, and evidence from this study suggests that well-informed patients who receive their preferred treatment have higher satisfaction and small improvements in health outcomes.

Meaningful Relationships to Support Shared Decision-Making with Older Adults and Caregivers

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Background and aims

Engaged patients are more likely to understand their health conditions, participate in proposed treatment plans, and report greater satisfaction with their healthcare and quality of life (Davis et al., 2005). However, there is a lack of consensus on how this can be achieved, especially with older patients and their caregivers who are often not well accommodated in existing practice models. In prior work, we synthesized available theories and evidence around engagement of older adults in healthcare decision-making into the "CHOICE" Patient Engagement Framework (Stolee et al., 2015; Elliott et al., 2016). The CHOICE framework emphasizes the development of meaningful relationships that allow mutual understanding of the values and preferences of older patients, caregivers and healthcare providers; this then can provide a basis for shared decision-making around care plans and treatment options. In partnership with patients, caregivers and healthcare providers, the current project aimed to answer the following questions: 1) How do the CHOICE principles correspond with actual experiences of engagement? 2) What factors currently facilitate/hinder the development of meaningful relationships between older patients and their healthcare providers? and 3) What materials and implementation strategies are needed to support meaningful relationships in various healthcare settings?

Methods

Experience and perspectives of patient engagement and relationship building were gained through multiple methods, including in-depth interviews with patients (n=12), family caregivers (n=14), and healthcare providers (n=18) from several healthcare settings. Furthermore, healthcare providers of various professions (n=60) from multiple care settings (including acute care, primary care, rehabilitation, community care, and long-term care) were consulted in a facilitated one-day workshop, with notes taken of small group discussion and individual feedback. Data were analyzed in using emergent coding as well as directed coding guided by the CHOICE framework.

Results

System constraints (e.g. time, pressure to discharge patients quickly, service availability, etc.), lack of education, and family dynamics present challenges to establishing meaningful relationships with patients and families in decision-making. Flexibility in care approaches, knowledgeable care providers, and building trust through open communication and consideration of goals and preferences, facilitate more meaningful relationships and engagement in decision-making. Healthcare providers indicated a need for more education on strategies for building meaningful relationships with patients and families in decision-making; preferred education modalities include hands-on workshops and e-learning modules.

Conclusion

Findings are being used to develop educational resources to foster meaningful relationships between healthcare providers, patients and their families. These are being co- created with patients, family caregivers and healthcare providers, for use in multiple care settings. Ongoing educational workshops are being discussed at a regional level. In the next phases of our work, we aim to link strategies to foster meaningful relationships, which enable mutual understanding of values and preferences, with shared decision-making tools that support consideration of available research evidence.

Is treatment burden documented by clinicians? Preliminary results from a cross sectional study

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Background and aims

Diabetes management requires work that can overwhelm patients. The workload of healthcare and its impact on patient well-being contribute to the burden of treatment. High treatment burden is associated with lower treatment adherence and exhaustion with self-care.[1] While issues of treatment burden arise in most encounters, they are only addressed in fewer than one in three encounters.[2] Also, Tran et al showed that clinicians could not estimate the treatment burden patients experience.[3] We sought to describe the extent of concordance between patient-reported and clinician-documented treatment burden in specialty diabetes care.

Methods

Adult patients with type 2 diabetes (T2DM) visiting an endocrinology clinic at a tertiary medical center were identified by screening clinic calendars and recruited from February 2016 onwards. As part of an ongoing study, patients were surveyed using the Patients Experience with Treatment and Self-Management (PETS) Scale which measures 9 domains of treatment burden. After calibration, three reviewers, blinded to patients' PETS scale responses, evaluated endocrinologist notes for aspects of treatment burden mentioned in the patient record. We reported the concordance between these entries and patient-reported aspects of treatment burden.

Results

The first 100 participants recruited were seen by 22 different physicians; 98 completed the survey. Of these, 75 reported at least one domain of treatment burden. Patients most commonly reported treatment burden in the domains of healthcare services (n=61 patients), medical expenses (n=47), and physical and mental exhaustion with self-care (n=34). None of the physician notes documented any issues with healthcare services, 4 contained expense issues, and 1 documented exhaustion. By far, treatment burden from medications was the most commonly physician-documented aspect of treatment burden (documented in 29 notes, and reported by 27 patients; $\varkappa=0.3$). We could not determine whether aspects left out of the record were also not discussed in the encounters. The chance-adjusted agreement between domains reported by patients and those documented by clinicians was very low ($\varkappa=0.07$).

Conclusion

We found that patients with T2DM are commonly reporting burden from healthcare expenses and services and exhaustion from self-care. Clinicians rarely documented these domains, most commonly documenting burden from medications. While patient-clinician concordance on approaches to care is associated with improved health outcomes, it is less likely in patients with poor health and those with non-health competing demands.[4,5] Thus a patient-centered approach requires consideration of how the workload of healthcare fits into patients' daily lives.[6,7] Shared decision making, in determining which treatment plan best fits the context of the patient, could help address treatment burden and reduce clinician blind spots.

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Organizational- and System-level Factors that Influence the Implementation of Shared Decision-making – a Scoping Review

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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. To date, no studies have synthesized the literature around organizational- and system-level factors that influence the implementation of SDM in routine care. Such a synthesis would be important, allowing exploration of potential interventions addressing these factors. Thus, the aim of this study is to compile a comprehensive overview on organizational-level factors (i.e. characteristics of a healthcare organization) and system-level factors (i.e. characteristics of a healthcare system) that influence the implementation of SDM in routine care.

Methods

We conducted a scoping review using the Arksey & O'Malley framework: 1) identifying the research question, 2) identifying relevant studies, 3) selecting studies, 4) charting the data, and 5) collating, summarizing and reporting results. The search strategy included an electronic search in three databases (Pubmed, Web of Science, CINAHL). We included publications in English and German that reported on a project or study that aimed to promote implementation of SDM or other decision support interventions in routine health care. Titles and abstracts were screened and full texts were assessed for eligibility by the review team. An ongoing secondary search includes books, grey literature, and reference tracking of key publications.

Results

After screening 7,624 records and assessing 275 full texts for eligibility, 29 publications on 24 distinct implementation projects were included and subject to data extraction. Most of the implementation projects (N=16) were conducted in the US. Nineteen projects focused on the implementation of SDM through decision aids or other forms of decision support (e.g. via phone) and 5 had a broader focus on implementing SDM in routine practice. Several organizational-level factors were described to influence the implementation of SDM in the different studies. They comprise organizational leadership, culture, resources, and priorities, as well as teams and networks, and workflows. System-level factors identified to influence the implementation of SDM in routine care included aspects of incentivization, policies, and guidelines. Some of the included papers discussed approaches to changing identified organizational- and system-level factors, including reorganization of workflows, implementation of multidisciplinary teams, a push for culture change, a push for new legislation, as well as financial incentives. Secondary search results will be available at the time of the conference.

Conclusion

A broad range of organizational- and system-level characteristics are found to influence implementation of SDM in routine care. However, more work is needed to undertake a gap analysis in the identified characteristics and to evaluate the impact of potential interventions. Health care organizations that plan to implement SDM should carefully consider the role of organizational-level characteristics that promote or impede implementation. Using implementation and organizational theory could be a useful way of complementing and addressing the identified factors. Health policy could foster SDM implementation by designing legislation that supports the use of a SDM process, as well as by expediting payment reforms that incentivize SDM performance.

"A very good thing to try, absolutely." Interviews about patient activation and engagement with health professionals in two established accountable care organizations

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Background and aims

Activated and engaged patients are more likely to manage their health effectively. Meaningful patient activation and engagement (PAE) is essential for all value based payment models, including accountable care organizations (ACOs). PAE techniques include goal-setting, motivational interviewing, and shared decision making. Studies have shown that clinicians are trained in these strategies, however, little research has been done to gauge their knowledge and execution in clinical practice. We did this study to assess understanding and implementation of PAE practices by clinical teams within ACOs.

Methods

We conducted a multi-site, mixed method study across two large ACOs in Los Angeles and Chicago. Data collection involved visiting eight clinical sites associated with each ACO. We interviewed 102 clinicians and clinical team members over a two-year period. There were two interview cycles separated by one year. After the first cycle, semi-structured interview guides were revised to reflect more attention to emerging themes. Interviews focused on awareness, attitudes, understanding, and implementation of three target patient activation and engagement approaches: goal-setting, motivational interviewing, and shared decision-making. The interview transcripts were analyzed and coded using an inductive thematic approach.

A summary of results

Four dominant themes emerged from the thematic analysis.

Participants

1. were aware of PAE approaches and terminology
2. had positive appraisal for PAE approaches
3. had limited understanding of PAE approaches
4. reported no or only partial implementation of PAE approaches

Most interviewees recognized and endorsed the three approaches. Their understanding of the concepts, however, was limited. The participants perceived goal-setting as a need for patients to meet biomedical targets. They also perceived motivational interviewing and shared decision making as patient education or interpersonal communication with patients. Routine implementation of PAE practices in clinical care was found to be either limited or a non-existent, aspirational goal.

Conclusion

Without clear understanding of activation and engagement approaches, successful execution and sustainable implementation of PAE is not possible. Even within leading ACOs, there was minimal understanding or execution of these critical principles. Despite their lack of understanding, clinical teams confidently report that they use these approaches in routine care. Unchecked misunderstanding will continue to minimize the value and potential these approaches could offer. To fulfill their vision, clinical teams need to better understand the principles of PAE in order to practice the patient-centered care they were intended to deliver.

Policies that Move Shared Decision Making into Value-based Care Programs: Challenges and Opportunities

Background

There are increasing incentives at both a state and federal level for clinicians to engage in shared decision making as better informed consent. Yet, as health systems begin designing strategies to move shared decision into routine clinical care, we must clarify the intentions and specifications of current and future regulations to ensure effective implementation. Accordingly, this workshop will:

(1) Describe U.S. state and federal activity promoting shared decision making into value based care; and

(2) Outline key challenges and opportunities for future implementation.

Methods

Recent U.S. state and federal activities have moved shared decision making into value based care. At the state level, Washington State passed legislation encouraging shared decision making as an alternative to traditional informed consent. Under the Washington State statutory framework physicians who engage in shared decision making with a "certified" patient decision aid (PDA) as part of the informed consent process receive increased legal protection. In 2016, Washington State started the certification process to certify PDAs for maternal and fetal care, and specific orthopedic conditions, and will soon expand to cardiac and end of life decision making. Under a state innovation model grant the state as first mover will require shared decision making in their state-run health plans. Up to 1.8 million citizens may be affected.

Sparked by Washington State, the National Quality Forum has developed national certification standards for PDAs. Furthermore, the Centers for Medicare and Medicaid services announced shared decision making as a pre-condition for payment for an increasing number of procedures, including low dose CT Scans for lung cancer screening and for left atrial appendage closure. Shared decision making is also being included in the new Merit Based Incentive Payment System.

Yet there are significant challenges to implementation. Many clinicians believe they already practice shared decision making, so may view these new regulations as another drain on their time. Clear definitions of shared decision making are needed, along with support for integrating PDAs into the shared decision making and informed consent discussions. Three things are necessary for this to occur:

(1) Ample education and training, along with feedback and reimbursement incentives;

(2) A commitment to ensuring that only high-quality PDAs are in use; and

(3) Research on studies of dissemination and implementation.

Without these three, there is a risk that shared decision making will become a mere check-box item and will not achieve its fullest potential for patients or for our healthcare system.

Conclusions

It is exciting that new policies are driving shared decision making into value-based care. But there is an urgency to ensure that the implementation process supports clinician engagement with clear definitions and standards for shared decision making. The authors will engage the audience in discussion around recent legislation and next-steps to facilitate implementation.

Shared Decision Making in Routine Childhood Vaccination: What do Parents Want?

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Background and Aim

Routine childhood vaccines are medically recommended because the benefits of reduced mortality and morbidity at a public health level far outweigh the potential harms. However, individual parental attitudes to vaccines can range from 'accepting' to 'hesitant' or occasionally 'refusing'. Healthcare professionals (HCPs) can find it challenging to navigate this diversity and have particular difficulty negotiating decision making with parents who are vaccine-declining. Informed by approaches in shared decision making and motivational interviewing, we developed a system of resources for clinicians to support evidence-informed, values-congruent parental decisions about routine childhood vaccines. This study aimed to identify information preferences across a range of parental attitudes and to develop a package of resources for use at vaccination encounters.

Method

We conducted eleven focus groups (63 parents) across four of the categories in the Vaccination Hesitancy Framework (unquestioning acceptors, cautious acceptors, hesitant or undecided, delayed or selective). Participants were shown some or all of five resources intended for parents across a spectrum of hesitancy. These resources were 1) a hesitancy screening and valid consent tool 2) five Question and Answer sheets addressing common concerns 3) a decision aid 4) an option for specialist referral and 5) anticipatory guidance about the symptoms and signs of vaccine preventable diseases (shown only to the most hesitant parents planning to not vaccinate). Discussions were audiotaped, transcribed verbatim, and analysed using grounded theory.

Results

1) Regardless of their attitude to vaccination, almost all parents wanted to be involved in decisions and to be provided with at least a minimum set of information to enable valid consent alongside the opportunity to ask questions. They reported inconsistent experiences of agreeing consent about childhood vaccines. Many parents wanted to receive information before their child's appointment. Our 'hesitancy screening & consent tool' was acceptable and may create efficiencies of information exchange within vaccination consultations. It appeared to be useful for valid consent. 2) Having access to more detailed information about vaccine efficacy and safety implied transparency, which engendered trust. However, the more accepting parents did not want these routinely provided, suggesting they should be reserved for those who have questions or concerns. 3) Based on participant feedback, we heavily modified our previous decision aid to focus more on values clarification, linking positive and negative experiences they might have in choosing to vaccinate or not. The final checklist therefore forms a scaffold for a conversation with the HCP. 4) The option of a specialist referral pathway if their primary provider could not answer their questions was a further enhancement of trust. 5) Hesitant parents reacted to the anticipatory guidance positively and did not perceive it to be a scare tactic.

Conclusion

Communication strategies about routine childhood vaccines can be aligned with parental information preferences. Through this holistic package, providers can potentially identify and address a diversity of attitudes in clinical practice. This system is undergoing further intervention optimisation for subsequent evaluation and potential implementation in Australia.

Patient-Centered Outcomes of Broad vs. Narrow Spectrum Antibiotics for Acute Respiratory Tract Infections in Children

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Background

Outpatient acute respiratory tract infections (ARTIs) account for the vast majority of antibiotic exposure in children and broad-spectrum antibiotic prescribing has been increasing, even when narrow-spectrum antibiotics are recommended. In the absence of head-to-head trials, it remains unclear if treating ARTIs with broad-spectrum antibiotics leads to improved patient-centered outcomes compared to treatment with narrow-spectrum agents, information needed to shape well-informed preferences.

Aims

To compare the effectiveness of narrow- and broad-spectrum antibiotic therapy on patient-centered outcomes for ARTIs.

Methods

A prospective cohort study was conducted in a network of 31 pediatric primary care practices to compare the effectiveness of narrow- and broad-spectrum antibiotics on patient-centered outcomes previously identified via semi-structured interviews of caregivers and patients. Between January 2015 and April 2016, a stratified sample of caregivers of children treated with antibiotics for an ARTI (acute otitis media, Group A streptococcal pharyngitis, acute sinusitis) were contacted by telephone to complete two structured interviews, one at 5-10 days and one at 14-20 days post diagnosis. The primary outcome was health related quality of life measured by the PedsQLTM total score obtained at the first interview. Secondary patient-centered outcomes included missed school/daycare, requiring additional childcare, side effects, and persistence of symptoms 3 days after diagnosis. Propensity-score based full matching was conducted to obtain adjusted PedsQLTM score or risk differences.

Results

Telephone interviews were conducted with 2472 caregivers. Treatment of ARTIs with narrow-spectrum antibiotics versus broad was associated with a higher health related quality of life score (mean 91.6 [SD: 9.3] vs. mean 90.2 [10.5], p = .01). Use of broad-spectrum antibiotics was associated with increased risk of adverse drug effects (percent experiencing adverse effects 35.5% vs. 25.2%, p < .001) but was not associated with improved outcomes on any of the other secondary patient-centered outcomes compared to narrow-spectrum antibiotics (all p > .08).

Conclusion

On patient-centered outcomes, treatment with broad-spectrum antibiotics was inferior to narrow-spectrum antibiotics for children with acute otitis media, streptococcal pharyngitis, and acute sinusitis on a quality of life measure and was also associated with higher rates of adverse drug effects. Given increasing antimicrobial resistance secondary to overuse of broad spectrum antibiotics, these data should inform families' preferences for treatment in an area of consequence for child and public health.

Improving the decision-making process with caregivers of elderly people about housing options: a cluster randomised trial

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Background

When elderly people begin to lose their autonomy and need more care, deciding whether to stay at home or relocate is a difficult decision. This study sought to evaluate the impact of an inter-professional approach to shared decision making (SDM) on the proportion of caregivers who report being active in the decision-making process about staying home or moving.

Methods/Design

We conducted a multicentre cluster randomised trial with inter-professional home-care teams in the Province of Quebec with post-intervention measures. Units of randomisation were community-based primary health care organisations. We enrolled 16 of these and asked each to provide one home-care inter-professional team involved with eligible caregivers in decision-making about planning care for their loved one. Caregivers were eligible if: i) they were taking care of an elderly person aged ≥65 who was receiving care from the participating inter-professional home-care team; ii) had faced a decision about relocating in the period following the implementation of the intervention; iii) were able to read, understand and write French or English; and iv) were able to give informed consent. The intervention arm received training in SDM and use of a decision guide. The control arm received no intervention. The primary outcome was the role assumed in the decision-making process as assessed by caregivers using a modified version of the Control Preferences Scale. Secondary outcomes were: preferred option and decision made, match between role preferred and assumed in decision-making, decisional conflict, decision regret, and burden of care of caregivers. Multilevel modelling was used to take the hierarchical structure of the data into account.

Results

In total, 309 caregivers were recruited and 296 included in the analysis. Median age was 60 years in the intervention arm and 63 years in the control arm. The percentage of caregivers reporting an active/collaborative role in decision making was 68.4% in the control group and 79.6% in the intervention group (absolute difference 11.2%; RR: 1.18; 95% CI 0.97–1.43; p=0.966). When sub-groups were analysed by region, the absolute difference was 16.6% in favour of the intervention group in urban/semi-urban regions (RR: 1.20; 95% CI 1.00 - 1.43; p=0.0459) and 9.6% in favour of the intervention group in rural regions (RR: 1.14; 95% CI 0.87 - 1.50; p=0.3276). The percentage of caregivers reporting a mismatch between their preferred and assumed role in decision making was 74.5% in the control group and 25.5% in the intervention group (absolute difference 49%; RR: 1.19; 95% CI 1.1 – 1.3; p <0.0001). No differences were found between groups regarding decisional conflict, decision regret or burden of care.

Conclusion
The inter-professional SDM approach enhanced caregivers participation in decision-making and led to fewer mismatches between preferred and actual role in decision-making. This approach did not increase caregivers' decision regret or burden of care. Further research should assess how this approach affects the decision-making process of the elderly and caregivers as dyads, and the conflicts between their respective values.

Health professionals' Intention to Use a Decision Aid for Down Syndrome Screening: A Theory-Based Web Survey

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Background

Health care professionals are expected to engage pregnant women in decisions about prenatal screening testing for Down syndrome. Shared decision making and decision aids (DAs) can help them make informed value-based decisions. The objective of this study was to assess the influence of psychosocial factors on HCPs' intention to use a DA for supporting decisions about prenatal screening for Down syndrome.

Methods

We conducted a survey of health professionals in the province of Quebec (Canada) using a Web panel. Eligible health professionals: (i) were family physicians, gynecologist-obstetricians or midwives (residents included), (ii) carried out pregnancy follow-ups or parental visits, and (iii) had not already participated in one of the two preliminary stages of the project (interviews and test-retest). We based the questionnaire on an extended version of the Theory of Planned Behaviour (TPB). We considered all eight of its psychosocial constructs (attitude, anticipated regret, subjective norm, descriptive norm, moral norm, personal identity, personal efficiency, and perceived control) and the three related sets of beliefs. We also collected sociodemographic data. Participants first watched a video showing two consecutive simulated prenatal pregnancy follow-up consultations during which a health professional shows a pregnant woman and her partner a DA they can use to help them decide about Down syndrome prenatal screening. The participants were then asked a series of close-ended questions about factors that would influence their use of the DA. Descriptive, bivariate, and multiple linear regression analyses were performed.

Results

We retained 310 of the 520 health professionals (response rate: 60%) who completed the Web-based questionnaire. Among the 310 health professionals, 251 were female (81%), 171 were family physicians (55%), 105 were obstetrician-gynecologists (34%), and 34 were midwives (11%). The mean age of participants was 39.6 ± 11.5 years old. In order of importance, factors influencing health professionals' intention to use a DA for Down syndrome prenatal screening were: 1) personal identity ($\beta=0.325$, $P<0.0001$), 2) attitude ($\beta=0.297$, $P<0.0001$), 3) moral norms ($\beta=0.288$, $P<0.0001$), 4) descriptive norms ($\beta=0.166$, $P<0.0001$), and 5) anticipated regret ($\beta=0.099$, $P=0.0026$). Specific attitudinal beliefs significantly related to their intention were that using a DA would give them satisfaction ($\beta=0.233$, $P<0.0001$) and would help pregnant women reflect upon the issue ($\beta=0.089$, $P=0.031$).

Conclusions

Implementation interventions targeting the use of a DA for Down syndrome prenatal screening by health professionals should address a number of factors, including introducing the advantages of using the DA (attitude), reminding health professionals of their role in helping pregnant women make this decision (personal identity), making health professionals aware of pregnant women's needs and increasing their perception that using a DA could meet those needs (moral norms), presenting the use of DAs as a common practice (descriptive norm), and mentioning to health care professionals that they might regret not using it (anticipated regret).

Nurse-led DEcision Coaching In people with Multiple Sclerosis – pilot randomised controlled trial and process evaluation

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Background and aims

Multiple sclerosis (MS) is a chronic disease of the central nervous system with a disease onset around the age of 30. While in 2017, 15 immunotreatment options will be available, profound and comprehensive information on benefits and risks through physician encounters is becoming increasingly difficult. In Germany, nurses are usually only involved in immunotreatment decision processes after decisions have been made. The "nurse decision coach model" aims to redistribute health professionals' tasks in supporting immunotreatment decision making processes by people with multiple sclerosis (PwMS) following the principles of shared decision making. The aim of this pilot study was to test the recruitment procedure for the main cluster randomised-controlled trial (RCT) and to gain data on the feasibility of the intervention.

Methods

Programme development followed the MRC framework for developing and evaluating complex interventions. MS-nurses were trained as decision coaches and provided the intervention based on evidence-based patient information materials and a shared decision-making approach. The pilot RCT was conducted in two German MS outpatient clinics in combination with an embedded mixed methods process evaluation. Eligible people with suspected or relapsing-remitting MS facing immunotreatment decisions on first line drugs were randomised to the intervention (n=38) or control group (n=35). PwMS in the intervention group received decision coaching by a nurse and care as usual in the control group. Both groups had access to an evidence-based online information platform. Nurses were not blinded to group assignment, while PwMS and physicians were. The primary outcome was 'informed choice' after six months including the sub-dimensions' risk knowledge (after 14 days), attitude concerning immunotreatment (after physician consultation) and treatment uptake (after six months). Secondary outcomes included decisional conflict and shared decision-making (questionnaires and videos of coaching sessions). Quantitative process data were collected from PwMS, nurses and physicians. Due to the explorative character of the study we refrained from statistical testing. Interviews were performed with all nurses and a convenient sample of nine PwMS.

Results

Groups were comparable at baseline. Data of 49 PwMS (67%) were available for the primary endpoint. In the intervention group 15 of 29 (52%) PwMS achieved an informed choice after six months and 6 of 20 (30%) PwMS in the control group. Analysis of coaching videos showed good involvement of PwMS in shared decision-making. Process evaluation data showed promising results concerning acceptability and feasibility of the intervention, which was well perceived by PwMS, most nurses and physicians.

Conclusions

Our data suggest that nurses can provide evidence-based decision coaching on immunotreatment options in MS. Delegating treatment information provision to trained nurses has the potential to change current physician-focussed practice in Germany.

Shared decision making implemented

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Background and aims;

It is known that involving patients in deciding which treatment should be done, benefits the actual effectiveness of the treatment. For patients, it is not easy to weigh and compare the harms and benefits – and risk thereof - of each treatment option. Therefore, there is a need to guide/support patients in their decision-making.

The principles of shared decision making are well documented, but there is a lack of guidance about how to accomplish the approach in routine clinical practice. Yet, despite attention to principles and competences, there remains a lack of clear guidance about how to accomplish SDM in routine practice (Elwyn, 2012). Clinicians can acquire the skills to implement SDM competences and to use risk communication aids (Elwyn, 2004). Unfortunately, it is unknown what kind of courses or instructions are currently available for clinicians to implement shared decision making.

Our objective is to create awareness for shared decision making, implementing shared decision making and to improve shared decision making in clinical practice

We will create an overview of all available courses and instructions to implement shared decision making, with or without patient decision aids. Furthermore, an overview of clinicians' and patients' requirements to implement shared decision making. These requirements will be compared with the availability of the training and if these do not match, these will be adjusted or if needed a new training will be developed.

Description of methods

The literature will be reviewed to describe

a. the different elements a training needs to consist of.

b. the different developed material, nationally and internationally

c. the requirement of clinicians and patients

Furthermore, the training needs of the clinicians will be assessed regarding shared decision making.

Preliminary results

Clinicians experience difficulties to interrupt their daily practice for shared decision making. Furthermore, they overrate themselves in engaging patients in shared decisions. Training materials do not fit daily practice, clinicians are enthusiastic about the concept of shared decision making and patient decision aids. But they experience a lack of guidance on how to effectuate the approach in routine clinical practice.

Conclusion

Shared decision making is a complex and dynamic process. One of the best ways to learn these skills is to use simulations, either with colleagues or with trained actors. Currently we think there is a need for new courses and instructions for clinicians.

Timely preparing for decisions about dementia: an intervention to help professionals to start conversations about future issues

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Background and aim

Shared decision-making in the context of dementia includes making decisions about issues in the future, so called advance care planning. Research has shown that advance care planning in dementia is difficult. One of the difficulties is that professionals like general practitioners and case managers dementia are hesitant of initiating advance care conversations. They feel unsupported to do so. This study aimed at developing an intervention that supports professionals working with people with dementia and their relatives in engaging in conversations about future issues.

Methods

This study has two parts. In part one of the study we developed a conversation tool, based on (1) relevant literature on advance care planning in dementia, (2) semi-structured interviews with 9 people with dementia, 9 informal caregivers, and 4 general practitioners, and (3) two focus group interviews with case managers dementia. In part two of the study (February 2017 – December 2017) we will evaluate the conversation tool in a pilot study. For this purpose ten general practitioners and twenty case managers will use the tool in their daily practice over the course of six months, after receiving an instructional video. During the pilot two reflection meetings will be organized to support the implementation of the tool in practice. Semi-structured interviews are planned with the participating professionals as well as the people with dementia and their informal caregivers that they support.

Results

Results from part one of the study: According to the participants, six conversations topics need to be discussed with respect to future: (1) daily enjoyment, (2) daily care, (3) medical treatment and policy, (4) coping with the dementia and the (nearing) death, (5) financial and legal issues, and (6) social network & living arrangements. The interviews yielded suggestions for how to discuss these sometimes sensitive issues. The topics and suggestions for questions were incorporated in the conversation tool.

Results from part two of the study: during the presentation the preliminary results regarding the feasibility of the tool in practice will be discussed, as well as lessons learned from the implementation.

Conclusion

Advance care planning in the context of dementia includes issues related to the daily life of people with dementia and their informal caregivers as well as medical and legal issues. During the presentation the feasibility of a conversation tool to initiate conversations with people with dementia and their informal caregivers about these topics will be discussed.

Efficacy of a web-based training module for physicians to facilitate shared decision making – a randomized controlled trial

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Background and aims

Shared decision making (SDM) requires physicians that are able to communicate accordingly. This ability is hardly learned sufficiently during medical education. Hence it has to be learned by physicians later on the job. Existing training approaches differ in their didactics: there are individual or group-based approaches and web-based programs. The latter are easily scalable and therefore have the potential to broadly facilitate SDM. This study aims at evaluating the efficacy of a web-based training module for SDM on colon cancer screening (CCS) decisions regarding improvement of SDM-related evaluation competences.

Methods

Intervention: The didactics used in the *doktormitSDM* training program were transformed into a web-based format. The module comprises 1) medical information on risks, benefit and harms related to CCS, 2) teaching the six steps to SDM, 3) a video-based interactive training course with 7 examples of a physician actor and 4) a certifying test.

Endpoints: SDM competences were operationalized as a) knowledge about SDM and b) the ability to evaluate given communication examples. Endpoints were assessed using an 8-item multiple choice questionnaire (a) and a test-scoring of a consultation recording using MAPPIN'SDM (b). Therefore, participants' judgements were compared to an expert standard and expressed in terms of an inter-rater-agreement.

Sample and study design: All 195 second year medical students at the University of Kiel in 2016 (119 female; mean age 22.8) were included and randomized block-wise to either intervention group (IG) or waiting control group (CG). Both groups started with a short lecture about SDM. The endpoints were assessed before the training (CG) or thereafter (IG).

Results

IG showed a) higher knowledge about SDM (Mann-Whitney-U test; p<.001) and b) higher accuracy in SDM judgements (p<.05). Randomization checks revealed no relevant group differences regarding age, sex, prior medical experience or attitude towards SDM.

Conclusion

The web-based training module enhanced SDM-related evaluation competences of medical students which are regarded as important preconditions for the adaption of active SDM communication competence. Further studies will test effects of the training module on the actual communication between health professionals and patients in clinical practice.

User-centered and theory-based design of e-TUDE, an online professional training program on shared decision making

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Background and aims

Training of healthcare professionals can foster shared decision making (SDM), especially if it incorporates the use of decision aids. Participation in educational meetings can, however, be challenging for busy healthcare professionals, even more so if they work in rural areas. In addition, a single SDM training activity cannot cover the many health options available to people consulting in primary care. We thus aimed to involve healthcare professionals in the design of a generic, online, professional training program on SDM (the e-TUDE program) to complement our decision aid library, the Decision Boxes (http://www.decisionbox.ulaval.ca).

Methods

Guided by the DECISION+ professional training program, we developed a beta version of e-TUDE. After completing e-TUDE, healthcare professionals should be able to explain SDM and its advantages/disadvantages, and to use Decision Boxes to communicate risks, identify the values and preferences of patients, and ultimately implement SDM in practice. We then used a mixed-method evaluation of e-TUDE, in three rounds, to optimize users' intention to adopt SDM. We recruited 15 healthcare professionals who worked in family medicine clinics. In a first round, five were invited to use e-TUDE during a semi-structured think-aloud session. After each section, we asked their perceptions of the content and teaching strategies, and recorded usability issues. The sessions were screen-captured and audio-recorded. Before and after the session, participants completed a questionnaire to assess: (1) their attitude towards SDM (validation ongoing) (2) their intention to adopt SDM (CPD-REACTION questionnaire), and (3) their preferred role in decision-making (role preference scale). We then analyzed their answers and modified e-TUDE to optimize e-TUDE. We then used the same evaluation/modification process in two more rounds, with new participants each time. Two researchers conducted a deductive/inductive thematic qualitative analysis of the factors likely to limit adoption of SDM. They searched for factors from the CPD-REACTION domains (intention, social influence, beliefs about capabilities, moral norms, attitude/beliefs about consequences) and integrated new themes mentioned by participants. We then modified e-TUDE by adding/enhancing behaviour-change techniques targeting these factors.

Preliminary findings

Out of 18 healthcare professionals, we recruited 15 (13 physicians,1 social worker, 1 nurse; 8 women) from two family practice clinics located in two rural regions in the province of Quebec. The think-aloud sessions lasted on average 75 minutes (±SD 30 minutes). The preliminary findings suggest that the think-aloud and iterative approaches are informative to uncover issues such as redundant content, unclear concepts (here in the risk communication section), and inappropriate learning strategies (here voices of the avatars in some of the videos). The approach also served to recognize a few usability issues, such a lag time when starting one of the videos. Participants appreciated the risk communication module the most, and they liked that training validated some of their current practices.

Conclusion

This approach helped develop a training program centred on the users. It ensured meeting the needs and interests of healthcare professionals. In the next steps, an experimental study will allow assessing whether e-TUDE changes healthcare provider's attitude towards SDM and its adoption.

Chronic disease and SDM	Salle de conférence Médiathèque
SDM and decision aids	Room 106, CIER
Measuring SDM	Room 107, CIER
SDM training for healthcare professionals	Room Amphi B, CIER
SDM in Europe	Room Salle du Conseil
Motivational interviewing and CPG	Room Amphi Revol

ISDM 2017

Exploring the experience of decision-making throughout the CKD trajectory among CALD patients: A qualitative interview study

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Background

Patients from culturally and linguistically diverse (CALD) backgrounds experience a higher prevalence of chronic kidney disease (CKD) with a more rapid progression to dialysis. CALD patients are less likely to engage in shared decision making (SDM). However, there are currently few interventions to support CALD CKD patients to be involved in decision-making about their healthcare.

Aims

To explore the experience of decision-making throughout the CKD trajectory among CALD patients with Stage 5 CKD who are currently receiving haemodialysis, with a focus on core value influences on medical decision-making processes.

Methods

Semi-structured interviews were conducted with patients from non–Western backgrounds at in-center and satellite haemodialysis units in Western Sydney, Australia. Purposive sampling was used to target Arabic speakers and English-speakers from the Indian subcontinent and Pacific Islands. Interviews were audio-recorded, transcribed, and analysed using Framework Analysis, a matrix-based approach to thematic analysis.

Results

Twenty-three dialysis patients were invited to participate in a 30-minute interview between January and February, 2017. Interviews were conducted with 17 participants (74% participation). The majority were female (n=10) with an average age of 68 years. 75% had a $\leq$ high school education. Many participants indicated that they wanted to be informed about their health, "*it's my heath, I want to know*", and participate in healthcare decision-making, "*I prefer that I make my own decision*" [NEP03]. However they felt constrained by perceptions of high power distance in the healthcare environment. Participants had difficulty understanding SDM questions when presented in the English language. Given these self-identified barriers, patients often resigned to more passive decision-making styles, "*I have to do what the doctor says*", and reported feeling disconnected with the decision-making process "*we weren't given a choice…we were never explained about it*" [NIHU01].

Family and religion emerged as central to cultural identity of participants and influenced their perceptions of health. Participants' prioritisation of family (e.g. "*it's always about my kids*" [PCDC03]) reflects the tenants of collectivism as promoting kinship and community above the needs of the individual. Participants reinforced community interdependence citing religious institutions as a support network and faith as a source of strength during illness.

Conclusions

Qualitative insights will inform the development of a novel SDM training program for CALD adults living with *CKD.* Interview findings demonstrate the need for targeted and tailored SDM interventions that simultaneously acknowledge and address culturally-specific barriers and promote patient participation to the degree to which patients' desire.

Health literacy and shared decision-making among breast cancer patients: the national VICAN survey

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Background and aims

Inadequate health literacy (HL) level can impair many aspect of communication including shared decision-making. Our aim was to study this association among breast cancer patients.

Methods

VICAN (VIe après le CANcer) is a national survey on French cancer survivors, aged 18–82, diagnosed with primary cancer between January and June 2010. Data were collected from telephone interviews with patients 2 and 5 years after diagnosis. Questionnaires asked for perceived involvement in decision-making and wish for more involvement. The Single Item Literacy Screener (SILS) was used to define inadequate functional HL. Several questions also measured the perceived quality of communication with healthcare team (**Figure**).

Results

639 women with breast cancer responded to both VICAN surveys (2 and 5 years after diagnosis). They were 50.2 ±10.8 years old at diagnosis (range 26 to 82) and 131 (20.5%) were classified as having an inadequate HL level. Women with an inadequate HL level were on average 2.5 years older than those with adequate HL (p=0.013) but had received the same treatments (surgery=99.5%, radiotherapy=89.8%, chemotherapy=60.4%) except for a tendency to receive less often hormone therapies (65.6% vs 74.2%, p=.050). They also reported worse communication with healthcare team (p<.01 except for quantity of information [p=.098], **Figure**).

Figure. Perceived quality of communication with healthcare team depending on HL level.

Women with an inadequate HL level were more likely to report they did not participate in therapeutic choices (56.2% vs 46.1%, p=0.040). Consistently a larger proportion of low-literate women would have wished higher involvement in decision-making (33.9% vs 24.2%, p=0.028). After adjustment for age and treatments, inadequate HL level (adjusted Odds Ratio=0.66, 95% confidence interval [0.45 to 0.99], p=.043) and radiotherapy treatment (adjOR=0.53 [0.30 to 0.95], p=.032) were associated with less participation in decision-making.

Conclusion
Better communication is needed to improve decision-making among low-literate breast cancer patients.

The development and feasibility of a health optimization system for people with bipolar disorder

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Background and aims

People with bipolar disorder often experience ill health for prolonged periods of time, and have considerably reduced life expectancy. Suboptimal treatment is common and includes lack of effect of medicines, overtreatment, and non-adherence to medical interventions and lifestyle measures. Current patient decision aids for chronic disorders rarely focus on continuous follow-up nor use regularly added, self-reported data and generally limit their support to the selection of treatment or diagnostic procedure. The objective of this work was to develop and test the usability of a health optimization system targeting suboptimal treatment, and to compare the service to other genres and strategies.

Methods

Based on the theoretical frameworks of shared decision-making, multi-criteria decision analysis, and single subjects research design, we interviewed potential users, reviewed research and current approaches, and created a first version using a rapid prototyping framework. We then iteratively improved and expanded the service based on formative usability testing with patients, healthcare providers and laypeople from Norway, the UK and Ukraine. Evidence-based and patient-centered information populating the system was developed using systematic methods. The System Usability Scale and a questionnaire were administered in formative and summative tests. A comparison of the system to current requirements for clinical practice guidelines and patient decision aids was performed.

Results

Driven by user feedback, we developed a limited first version into a comprehensive health optimization system. The current version encompasses 21 integrated, core features enabling shared decision-making within 6 health optimization strategies:

1. Find the best, safe treatment
2. Find the best dosage
3. Increase adherence
4. Live more healthily
5. Get support from professionals
6. Improve the decision process

Features supporting each health optimization strategy are only shown if the patient perceives a need for it. Options, outcomes, expected performances and the trade-off for outcomes are personalized based on patient-specific data.

Expected performances and the trade-off of outcomes are also personalized using longitudinal monitoring of data. 22 out of 24 modules in the system are integrated by means of MCDA-based algorithms.

78 potential users identified 82 issues which were all corrected. Mean ± SD (median) system usability score (n=37) of the patient-oriented subsystem was 71 ± 18 (73). Mean ± SD (median) system usability score (n=5) in summative usability testing was 78 ± 18 (75), well above the norm score of 68. Questionnaire feedback was positive. Responses to 18 out of 23 crucial components in the system are not required in international standards for patient decision aids and clinical practice guidelines.

Conclusion

We have developed the first evidence-based patient decision aid and health optimization system enabling patients, clinicians and carers to collaborate on optimizing the patient´s health on a shared platform, integrating longitudinal, self-reported and research data with patient preferences. User tests indicate that the system has acceptable feasibility. The system is currently being integrated in a electronic medical record system. Created as an authoring suite enabling the creation of health optimization systems, systems for 12 other chronic disorders are currently being developed.

Evaluation of a decision-support intervention for patients with advanced chronic kidney disease and their families

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Background and aim

Patients' decision making regarding dialysis modalities is hampered by delayed time windows for decision making, difficulties accepting one's disease when asymptomatic, and strong emotional reactions to being told one needs dialysis. Nurses usually provide support and education but their role as decision coach has not been studied in detail nor has the perspectives of family caregivers. A three-phase study was designed to develop, implement, and evaluate a decision-support intervention. The phase 3 results are presented including nurses', patients', and family caregivers' experiences of the decision-support intervention.

Method

We used a qualitative and participatory research design involving multiple cases, and the constructivist evaluation method of Guba & Lincoln, (1989). Based on a decisional need assessment, other theoretical models in addition to the Ottawa Decision Support Framework were added: Duhamel's systemic family approach (Duhamel, 2015) and Leventhal's model (Leventhal et al. 1984). Nurses were trained as decision coaches to assess and address patients' and families' **unfolding** emotional, cognitive, social, and motivational needs that hampered progress in decision making.

Participants were considered co-researchers in the research process: 2 nurses and 6 patients with advanced chronic kidney disease and their family caregivers. Patients and families received 4 decision-coaching sessions embedded in an educational program to aid them in considering the available options and communicating their preferred choices:

Session 1 **Individual Telephone call** (10-15 min.) After Nephrologist offers options & education manual given	Session 2 **Individual Meeting Nurse's Office** (45 min.) Prior to group class	Session 3 **Group Education classroom** (4 afternoons; 3 hours) Monthly	Session 4 **Individual Meeting Nurse's Office** (45-60 min.) Follow-up within 1 week
Assess and address patients' and family's emotional, social, cognitive, and motivational needs to:			
Increase awareness of disease	Increase receptivity to information	Increase skills to deliberate on options (Professional and expert patient information; Patient decision aid)	Increase skills to communicate one's preference

In order to reach a prospective understanding of the decision support intervention, qualitative interviews were held at different time points: After the second and third decision-coaching session for the nurses and the patients and their families, and after the consultation with the nephrologist for the patients and their families.

Results

Participants revealed that the intervention was acceptable, useful, and applicable for use with this population. Their experiences were generally positive. Patients made informed values-based decisions, and nurses developed their skills in providing needs-based decision support as decision coaches.

Conclusion

This study has laid the groundwork for further empirical evaluation with a larger more diverse population patients, families, and nurses on such outcomes as decision quality and sustainable implementation. In particular, this study has proposed an innovative approach to develop and evaluate a decision support intervention provided by a predialysis nurse's decision coaching for a patient and family making a decision about dialysis modality.

Building Consensus: An interim case summary of a patient support system for juvenile idiopathic arthritis (JIA) in Sweden

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Background/Aims

The active engagement of patients and providers to achieve treatment consensus is challenging and can lead to fragmented clinical care and poor patient outcomes. Communication models enhanced by novel technologies like smartphones or apps hold promise as a consensus-building tool. Yet integration of these new technologies into established practice is slow. For children with Juvenile Idiopathic Arthritis (JIA), a chronic and painful condition requiring significant clinical intervention, the challenge of longitudinal treatment care coordination presents barriers to consensus building. A technology focused on care coordination may mitigate these barriers by providing an effective alternative to intermittent care decisions, better engaging patients and care teams, thus leading to improved outcomes. The purpose of this work is to study the development and early adoption of a novel Patient Support System (PSS) to improve patient and provider engagement and consensus for care among patients diagnosed with JIA.

Methods

We conducted an observational interim case summary to characterize the development and early adoption process of the PSS in the largest JIA clinic in Sweden. Based on case study theory, we developed a protocol and case analysis outline to frame data collection in the following domains: Context of Development, Research Questions, Successes, and Challenges. Swedish research partners facilitated provider and patient interviews during the introduction, onboarding, and early adoption of the PSS in the JIA clinics. Case meeting reports from these interviews were collected from inception through iterative development cycles of the PSS, and qualitatively assessed every month by two members of the research team.

Participants

This case study reports feedback from JIA patients who used the PSS, a physiotherapist, occupational therapist, lead clinician, and members of the PSS development team.

Results

Content analysis of case report notes generated thematic highlights of the development and early adoption of the PSS. Identification of provider and patient "early adopters" who serve as co-designers throughout iterative testing cycles is the main contributor to refinement of the PSS, and successful spread within the clinic. Early implementation efforts demonstrate the value of PSS to promote consensus between patients and clinicians, and to foster patient engagement in the process of co-creating care plans. Challenges of collaborating across teams, determining best practices, and choosing outcomes of interest are superseded by patient, family, and clinician feedback. Ongoing work is needed with patients, families, and clinicians to clarify best-practices, design pros and cons, and fit with current lived experiences.

Conclusions

A co-designed PSS evaluated in routine clinical practice shows potential to overcome challenges of care fragmentation among JIA patients and providers. A PSS that catalyzes current practice through continuous learning and consensus building may reduce practice burden while increasing patient engagement and autonomy in making treatment decisions.

Does multimorbidity influence personal views on the ageing process: a qualitative analysis

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Background

For older persons with multiple chronic conditions (MCC) insight into what they perceive as important in their lives is essential when discussing preferences in the shared decision making process. The aims of this study were to 1) investigate the personal views on the ageing process communicated by older persons and 2) compare the personal views of older persons with and without MCC.

Methods

Using structured interviews, 547 community dwelling older persons aged 70 years and above were asked five questions about what they perceived as important in terms of ageing, worries, their future, healthy ageing and quality of life. Two independent researchers coded the data and performed content analyses. A stratified content analysis was performed to explore whether persons with and without MCC expressed different personal views with regard to the ageing process.

Results

The mean (SD) age was 78.9 (5.9) years, and 60.3% were female. MCC were present in 72% of the study sample. There were no significant differences in demographic characteristics between persons with and without MCC. The clinical characteristics showed that persons with MCC more often had polypharmacy (43% vs 24%; p<0.001), more difficulties with (instrumental) activities of daily living (mean number of impairments 2.4 vs 0.8; p< 0.001) and reported more falls (35% vs 23% p = 0.01) than those without MCC. The qualitative analysis identified the following main themes: ageing was associated with acceptance of ageing, (further) deterioration, and worries about limitations and family. A healthy lifestyle, being busy, maintaining social contacts and a positive attitude were considered prerequisites to healthy ageing. In 24 out of 28 sub-themes no significant differences were found between participants with and without MCC. Persons with MCC more often expressed that ageing for them meant having to cope with deterioration and limitations, they had more worries and feared more limitations compared to those without MCC. Also persons with MCC less often considered a positive attitude to life a prerequisite to healthy ageing.

Conclusions

Acceptance of ageing, (further) deterioration, and worries about limitations and family were important themes on the ageing process communicated by older persons. Overall, we found no major differences between persons with and without MCC. The results of this study may help raise awareness amongst health care professionals that eliciting and understanding an older persons' views on the ageing process is an important first step in making health decisions that support an older persons personal goals and expectations.

Review of decision aids and integration with clinical practice guidelines to improve SDM in cardiovascular disease prevention

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Background & aims

Doctor-patient communication issues are a significant barrier to GP use of cardiovascular disease (CVD) risk assessment tools, which in turn prevents SDM. This project aimed to review and evaluate currently available decision aids and risk calculators for CVD prevention, in order to integrate them with clinical practice guidelines and improve SDM. The resulting intervention consists of a new online format for CVD prevention guidelines that links them with personalised decision aids to help GPs communicate risk and management guidelines to patients. It aims to increase:

1. GP use of absolute CVD risk assessment;
2. Guidelines-based prescribing of CVD preventive medication (to high risk and not low risk patients);
3. Patient knowledge of their CVD risk and recommended management options; and
4. Patient involvement in decision making about management.

Method

Systematic review and evaluation of existing online CVD risk calculators and decision aids (based on IPDAS and PEMAT criteria). Development/piloting of a new version of the Australian CVD risk calculator linked to tailored patient decision aids, based on the review findings and the Behaviour Change Wheel framework for theory-based intervention development.

Results

The review identified 20 decision aids and 50 risk calculators with varying levels of understandability and actionability. High scoring examples based on IPDAS and PEMAT criteria were used to inform the development of a new version of the Australian CVD risk calculator, including:

1. Multiple risk presentation formats (numerical, verbal, graphical);
2. Inclusion of all perceived risk factors regardless of whether they are included in the CVD model algorithm or not (e.g. family history, alcohol);
3. Interactive tool to show how changes to patients' existing lifestyle would reduce the risk result (e.g. start low dose statins vs increase physical activity); and
4. Tailored decision aid based on current risk, future risk, and selected management options.

The development process and results of piloting with GPs and patients will be presented.

Conclusion

This program of research will provide compelling data to support the development of a new format for the Australian CVD prevention guidelines linked to tailored patient decision aids. Providing a more useful and effective communication tool to GPs has the potential to improve SDM about the management of CVD risk.

Scaling up shared decision making to the general public through workshops in public libraries: proof of concept study

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Background and aims

Shared decision making (SDM) is a process whereby decisions are made together by patients and/or families and clinicians. Yet patients are often unaware of the importance of SDM when faced with a decision in the consulting room. Awareness of SDM and its proven benefits thus needs scaling up to the general public. We therefore assessed the feasibility, acceptability and impact of a SDM public awareness campaign in public libraries.

Methods

We developed a partnership with the Quebec City public library network and were awarded a CIHR dissemination grant to fund the study. Our executive committee met every month to co-design a 1.5 hour interactive workshop to be presented in public libraries. First, we chose a clinical topic of maximum reach: deciding to take antibiotics or not for acute respiratory infections. This is a common problem yet the implications of the treatment choice are not well known. Then we designed the workshop content and devised a format whereby a physician presents the information and a scientific communicator/journalist invites questions and participation. We recruited 10 physicians (6 family doctors, 4 emergency physicians) and rehearsed the format with support from the scientific journalist team member. We publicized the event with the public at large. We gave the workshop free of charge and in different areas of the city to maximize participant diversity. Using an evaluation form we collected participants' sociodemographics, opinions and level of satisfaction. We measured self-reported knowledge gain on antibiotics and SDM before and after workshops. Knowledge level was measured on a scale of 1-10. We used t-test and ANOVA to compare means at 5% threshold.

Results

Nine out of 24 public libraries participated in the project. From October 12th to November 30th 2016, all planned 10 workshops were held at different times (morning, afternoon or evening) on different days of the week including week-ends to maximize attendance. All 10 physicians rehearsed the workshop. Out of 106 attendees (range: 4 to 19 attendees per workshop), 89 (84.0%) participants were included in the analysis. A majority of participants were women (77.6%), retired (46.1%) and aged over 45 years. Overall, participants considered that the content of the activity was relevant (94.4%), well adapted (93.2%), and provided clear information (98.9%); 75% reported satisfaction above 8.7/10. They appreciated the close rapport between speakers. There was a significant difference of 2.4 (95% CI: 2.0 - 2.8) between self-reported knowledge levels on antibiotics before and after the workshop. There was also a significant average gain of 4.0 (95% CI: 3.4 - 4.5) in knowledge about SDM. Knowledge gain about SDM seemed significantly higher than about antibiotics: 4.0 versus 2.4 (*P <.001*). Although there was an inverse relationship between knowledge gain about SDM and age, our data did not suggest it was significant (*P =.239*). Knowledge gain did not vary by sex or employment status.

Conclusion

This proof of concept demonstrated the feasibility and acceptability of scaling up SDM to the general public via the public library system.

Developing a General Decision Aid for Future Cancer Care: Getting Feedback from Users in Busy Hospital Environments

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Background and Aims

During the last decade more and more design researchers and practitioners have been collaborating with clinicians, patients and relatives in order to improve healthcare systems. Shared decision making has thereby been one field, attracting increased attention. Hospitals pose a specific challenge for involving all stakeholders in the design development process and therefore require the development of methods that work in busy healthcare environments. Based on this perspective, the abstract presents an ongoing research collaboration (started in 2014) between The Patients Cancer Hospital in Vejle and Design School Kolding in Denmark with the main objective of creating a general decision aid for future cancer care. The aims of the collaborative design development are twofold: to enhance clarity and understanding of the decision aid via communication design and to decrease barriers for successful implementation via extensive involvement of patients, relatives and clinicians in the design process. The present abstract puts forward a participatory method of getting feedback from different stakeholder groups on the illustration design of the decision aid.

Methods

The decision aid was presented on a poster to get feedback on the visual design of the illustrations. Three different visual versions of illustrations have been tested with patients, relatives and clinicians. Stakeholders were asked to vote for the most professional, clear, trustworthy and friendly version of the tool. The voting was facilitated by a sticker dot beyond the version most appreciated. Additionally, voters were asked to explain their choice verbally on the backside of a comment card. 16 posters have been mounted in staff rooms, waiting rooms as well as hospital hallways for a period of 24 days. Clinical staff has received information on the voting experiment and introduced the project to patients and relatives. One designer circulated from poster to poster, giving additional information and collecting stakeholders' immediate feedback. A second poster voting round (building on learnings from the first one) is currently undertaken, final results will be available by the end of March 2017.

Results

In the course of the first poster voting round, 200 clinicians, patients and relatives took part in the poster experiment, 33 cards with comments were handed in and 40 informal interviews were conducted. Clinicians and patients choose the same design proposals - 90% went for the identical design suggestion, commenting on it as being friendly, easy to understand and positive. In one oncology department's staff room an alternative proposal received the majority of votes.

Conclusions

Human-centered design in healthcare requires methods adapted to its demanding and occupied environments. Methods based on a strong visual impact and a simple voting system attract widespread attention of all stakeholders, while keeping time requirements to a minimum. According to contemporary research, successful implementation of SDM remains a key challenge. Methods that support story telling of SDM, as well as extensive stakeholder involvement are thus put forward as a valuable tool for design and implementation.

Innovative methods for the identification of treatment criteria in the development of a patient decision aid

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Background and aim

The International Patient Decision Aids Standards provide recommendations for the development of patient decision aids. This includes the assessment of patients' and clinicians' perspectives about the information needed to make the decision. The information included in patient decision aids is often selected based on some qualitative research, but few recommendations are available. There is a need to gain insight into methods for this selection process. In this study, we aim to describe and test the feasibility of an innovative, thorough and rigorous methodology to select the information provided in the patient decision aid, i.e. combining focus groups using a nominal group technique with a best-worst scaling, and discuss its advantages and disadvantages. This study was performed for the development of a decision support tool based on multi criteria decision analysis (MCDA) for multiple sclerosis (MS). In an MCDA-approach, treatment options are described according to specific criteria, and the importance of these criteria according to the individual patient is combined with the actual performance of the treatment options to provide a rating of options based on their suitability to the patient's preferences.

Methods

The process of selecting the criteria for the decision support tool consisted of three steps, in which qualitative and quantitative methods are combined. First, after an initial scoping review and discussion with professionals, focus groups with MS patients were formed (N=3; total 19 patients). A nominal group technique was used during the focus groups to identify criteria of disease modifying drugs that are important to consider in the treatment decision. Second, a best-worst scaling was conducted among 185 MS patients and 60 neurologists and nurses to prioritize the list of identified criteria. In the best-worst scaling, 17 choice tasks were presented with each a different combination of five criteria selected from the list of identified criteria. The respondents were asked to select the most and least important criterion for the decision from the five criteria. Based on the results and the requirements for criteria according to the MCDA-approach, a selection of criteria was made that will be included in the decision support tool. Last, this selection was reviewed and approved among an advisory group of neurologists, nurses and MS patients.

Results

A total of 27 criteria were identified in the focus groups and ranked according to their importance in the best-worst scaling. The patients' and healthcare professionals' perspective are largely similar. Finally, ten criteria were selected for the inclusion in the decision support tool based on their relative importance. The relevance and comprehensiveness of this selection was confirmed by the advisory group.

Conclusion

We demonstrate the feasibility of using a nominal group technique within focus groups and a best-worst scaling to select the criteria of – or information needed about – treatment options to include in a decision support tool, especially for tools for which a prioritization of criteria is needed. Our approach is rigorous, transparent and could increase the face validity of patient decision aids, but may also have some drawbacks.

Patient Perspectives on National Standards for the Certification of Patient Decision Aids

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Background and Aims

In late 2016, the National Quality Forum in the United States published National Standards for the Certification of Patient Decision Aids. These standards propose seven screening criteria for determining whether a patient decision aid (DA) is eligible for certification and twelve certifying criteria for determining the level to which a DA facilitates decision-making, with some of these certifying criteria optionally met by either the DA itself or a supporting document. While these screening and certifying criteria emerged from the recommendations of a multi-stakeholder expert panel, there was only minimal involvement of patients. We set out to explore patient perspectives on some of the proposed criteria and other potential DA content as part of the process of developing a DA on postpartum contraception.

Methods

We administered an online patient survey using a commercial panel service. Eligible participants were currently pregnant and/or $\leq$ 24 months postpartum, could read and write English, and resided in the United States. As part of the survey, we presented participants with a list of thirteen DA elements and asked whether each should be included in or excluded from the DA. We then presented participants with a list of six pieces of information, five of which were related to certifying criteria that could be met by either the DA or a supporting document, and asked where each should be included. Before responding, participants were advised that "*we want to make sure that the guide is as short as possible but still includes all the information that people need*".

Results

Altogether, 286 eligible participants completed the survey. A majority thought that each of the thirteen DA elements should be included. The least popular element was "*other people's stories about making birth control decisions after having a baby*" (64% recommended inclusion) and the most popular was "*a list of birth control methods that can be used after having a baby*" (93% recommended inclusion). Among the five pieces of information that were related to certifying criteria that could be met by either the DA or a supporting document, the sample slightly favoured three for inclusion in the DA itself (i.e., information about development process and user testing, information about evidence sources, information about update policy and next expected update). The sample slightly favoured the other two for inclusion in a supporting document (i.e., information about competing interests and/or policy, information about readability levels). The remaining piece of information assessed – information on DA authors and their qualifications – was not a proposed screening or certifying criterion but was favoured for inclusion in the DA by 64% of the sample.

Conclusions

The findings of our exploration of patient perspectives on the newly-developed National Standards for the Certification of Patient Decision Aids are relevant to both DA developers and those working in DA certification. Although patients reported fairly extensive information needs, introducing challenges for the development of concise DAs, some of these may acceptably be addressed in ancillary materials.

Periviable GOALS: Formative research to create a decision support tool for periviable decision making

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Background

Parents of periviable neonates (born 22 to 25 weeks gestation) are faced with making 'end-of-life' decisions at the very beginning of life. Because the decision to pursue life-support measures or palliation for these neonates is preference-sensitive and value laden, shared decision making (SDM) can promote more informed, patient-centered care. To facilitate SDM between providers and parents facing the threat of periviable delivery, we set out to develop a decision support tool called Periviable GOALS (Getting Optimal Alignment around Life Support) with personalized outcome estimation and values clarification exercises. Study goals were to utilize a novel, people-centered design approach to: 1) engage patient advisory boards (PABs) comprised of various stakeholders to identify attitudes, values, and goals of care that drive resuscitation decisions; and, 2) use generative data from PABs to co-design a decision support GOALS tool prototype suitable to test in a future planned multisite randomized controlled trial.

Methods

In partnership with the Indiana University (IU) Patient Engagement Core (PEC), we convened 4 PABs comprised of the following stakeholder groups: women and support partners who experienced a periviable delivery within the last 5 years with a child that did (PAB 1) or did not (PAB 2) survive; healthy pregnant women at 20-26 weeks gestation and support partners (PAB 3); and, obstetricians, neonatologists and nurses (PAB 4). Each PAB participated in a two-hour facilitated session in pre-planned activities traditionally used in design research to help stakeholders engage quickly in the topic to generate ideas, and facilitate the sharing of values, goals and attitudes. Sessions were audio recorded and coded. Common themes and insights informed the "should haves, might haves, and cannot haves" that shaped the design of three prototypes (an iPad application, family story videos, and a virtual reality experience) for a final co-design session. A subset of PAB participants engaged in a final session to discuss the pros and cons of each prototype.

Results

Ninety-five individuals (48 mothers/support partners; 47 providers) participated. Parents and providers agreed that the tool should include factual, unbiased outcomes and probabilities. Mothers and support partners felt it should also contain comprehensive explanation of delivery and care options, while not making assumptions or excluding the partner or support person. Providers wanted a tool to ease communication, help elicit values and share patient testimonials. Participants concluded the iPad application provided unbiased information, but did not satisfactorily incorporate personal testimonials. Although family story videos were helpful and relatable, majority of participants felt they should encompass more outcomes. Participants felt the virtual reality experience was emotionally incompatible with the situation of periviable delivery, but may be helpful in preparing families for the NICU experience.

Conclusion

Our results suggest that a periviable decision support tool that combines unbiased information and personalized outcome estimates with family story videos would be meaningful for periviable SDM. Future research efforts include alpha and beta testing the GOALS tool, testing the intervention to evaluate its effect on SDM in periviable counseling and assessing other improvements in decision quality, including decisional conflict and satisfaction.

session	population	method	aim
1	women with hx of periviable delivery	EXPERIENCE MAP	AIM 1: Identify attitudes, values, and goals of care that drive resuscitation decisions for periviable delivery (DESIGN)
2	expecting women	DISTILLATION GAME	
3	providers	CARD SORTING	
4	participants from sessions 1,2,& 3	ENVISIONING	AIM 2: Develop decision support tool trough co-design process

generation of decision tool prototype

| | participants from session 4 | | |
| | expecting women, women w/ hx of periviable delivery, & providers | | α Alpha Testing |

decision tool design

| | expecting women with a potential periviable | FIELD TESTING AT STUDY SITES | β Beta Testing |

refined decision tool design for RCT (AIM 3)

Figure 1. Systematic process Periviable GOALS tool development

Translation, Cross-cultural adaptation and validation of two questionnaires about Shared Decision Making (SDM)

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Introduction and Objectives

Shared decision making (SDM) is a process where health professionals and patients work together to make health decisions. There is a growing interest in the development of SDM measurement tools.

The Health Foundation (HF - UK) developed an instrument to evaluate SDM from two perspectives (user and health provider). Elwyn et al also created a questionnaire named *"CollaboRATE"*

The objectives of this study are to translate to argentinian spanish, to cross-cultural adapt and to validate these tools.

Methods

Study was conducted in Hospital Italiano de Buenos Aires, a university hospital in Buenos Aires, Argentina.

Translation and cross-cultural adaptation: Forward and back translations were performed by bilingual researchers. Following revision and conciliation of the versions, and cognitive interviews were conducted. Later, the interviews were reviewed and a final version was obtained.

Validation:

Patients and Physicians were interviewed after a scheduled outpatient medical appointment with a primary care provider or other physician.

The sample was adequated according to the Kaiser Meyer Olkin (KMO) index. Content validity was performed by experts. Factor Analysis was used to analyse construct validity. Internal consistency was evaluated through the Cronbach's alpha coefficient. The instruments were validated using the hypothesis confirmation method.

Results

After the translation process, 56 observations were conducted (more than 10 observations per item).

For the Sample Adequation: The KMO index values were 0,72 and 0,62 for the HF-UK questionnaires, and 0,74 for the CollaboRATE. The Bartlett test was < 0.0001 for the three instruments and the Diagonal Elements of the AIC Matrix were all > 0,5

Construct Validity

	Analysis Methods		**Ask 3 questions (Patients)**	**Ask 3 questions (Physicians)**	**Collaborate**
Principal Components Analysis(PCA)	Kaiser Criterion	1st. Component	2,4	2,1	2,9
		2nd. Component	0,77	0,83	0,07
	% variance explained by 1st. component (>50 %) Carmines		Yes	Yes	Yes
	Ratio between the difference of 1st. y 2nd. eigenvalue, and 3rd. and 4th. Eigenvalue. Hattie		5,6	9	49
	Factorial loads > 0.55		100%	100%	100%

Reliability:

Cronbach's alpha coefficient was 0.77-0.69 for the HF questionnaires

Conclusion

These are the first tools available in Argentinian Spanish designed to measure the construct of SDM taking place in a clinical encounter.

Validation of the 9-item Shared Decision Making Questionnaire (SDM-Q-9) in breast cancer patients making treatment decision

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Background
Shared Decision Making (SDM) promotes patients' involvement in their own treatment decision-making for better health outcomes. SDM-Q-9 has been developed to measure the level of SDM and it has shown good validity and reliability in German, Spanish and Dutch. However, the validity is not transferable across population divided by patient values, cultural and healthcare system differences.

Aims
To translate and adapt the 9-item Shared Decision Making Questionnaire (SDM-Q-9) and assess the reliability and validity of the English, Malay and Chinese SDM-Q-9.

Methods
The translation of the Malay SDM-Q-9 from the German version was carried out using the forward and back translation method. The Malay translated and the existing English and Chinese SDM-Q-9 versions were assessed for content validity by SDM experts. They rated items 'relevance' to SDM concept using a 4-point scale. SDM-Q-9 was then assessed for face validity by five breast cancer patients for each version. For the main validation study, newly diagnosed breast cancer patients who were making treatment decisions were sampled conveniently at a tertiary hospital and two medical centres in an urban setting in Malaysia between August 2015 and February 2016. They completed the SDM-Q-9 after their consultations with the doctors. Data were analysed using SPSS and AMOS software.

Results
A total of 222 breast cancer patients were recruited where 87 participants answered in English (39.2%), 66 in Malay (29.7%) and 69 in Chinese (31.1%). The mean age of the participants was 54.8 (SD=12.3). All SDM experts agreed the nine items in the instrument were content valid and the breast cancer patients found the questions to be clear with no modification necessary for each version (face validity). Reliability analyses showed high Cronbach's alpha of 0.88, 0.92 and 0.92; and good inter-item correlations r=0.35-0.72, 0.56-0.84 and 0.45-0.77 for English, Malay and Chinese versions respectively. In exploratory factor analyses the KMO values were excellent (0.87, 0.89 and 0.91). Single factors were extracted for all three language versions and each accounted for more than 50% of the variance. In confirmatory factor analysis, Item 1 and 9 in all three versions were highly correlated with other items in the construct, hence were dropped. The final model with 7 items showed acceptable model fit.

Conclusion
The English, Malay and Chinese SDM-Q-9 demonstrated good reliability, face validity and content validity. In all versions, seven items in the SDM-Q-9 demonstrated good validity hence we propose the use of a 7-item questionnaire among the breast cancer patients in Malaysia for assessing their treatment decision making.

The most common outcome measure for decision support interventions: a scoping review on the Decisional Conflict Scale

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Background & aims

The Decisional Conflict Scale (DCS) is a 16-item scale measuring 5 dimensions of decision-making (personal uncertainty, feeling informed, values clarity, feeling supported and effective decision-making). Based on the Ottawa Decision Support Framework, psychometric testing demonstrates validity and moderate/strong reliability. Since its inception in 1995, new formats and translations have been published. We sought to explore overall levels of DCS scores since 1995 and how these vary across different DCS formats, decisions and health contexts.

Methods

We conducted a scoping review.

Search strategy

With help from an information specialist, a citation search was performed in Google analytics, Web of Science and Pubmed, followed by a keyword search in Cochrane Library, Pubmed, Ovid MEDLINE, EMBASE, CINAHL, AMED, PsycINFO PRO-Quest and Web of Science.

Eligibility criteria

Included studies 1) were published between 1995 and March 2015, 2) used an original experimental or observational research design, 3) concerned a health-related decision, 4) provided data on the DCS (any version, but only full scales/subscales).

Selection and extraction

Pairs of authors independently and consecutively screened titles, abstracts, and full texts and then extracted data.

Analysis (ongoing)

We performed narrative data synthesis. Data will be further charted according to key themes, issues and factors associated with the DCS.

Results

Our search identified 8762 citations; after removing duplicates 3984 titles/abstracts and 900 full-texts were screened. 393 papers were included in the review. Since 1995, the number of studies using the DCS increased steadily (from 2 in 1995 to 43 in 2014). Studies were conducted in North America (n=248), Europe (n=75), Australia (n=45), Asia (n=14), and South America (n=3). 311 studies (79%) used the original DCS, of which 71 (18%) made substantial modifications (such as adding or removing items and subscales). Modified DCS versions used included: the low literacy DCS (n=33), the SURE test (n=7), the dyadic Patient Provider Process Assessment Instrument (n=4), the pictorial DCS (n=2) and other (n=6). The DCS has been translated into 11 languages. Most often mentioned applications of the scale were measuring: decisional conflict (n=237), uncertainty (n=66), subscales titles (n=28), difficulty deciding (n=13), satisfaction (n=7), decision confidence (n=5) and decision comfort (n=5). The DCS was used for 220 different decision types and 3 categories of decision- makers: patients (n=353), caregivers (n=36), and multiple stakeholders (n=12). 227 studies compared DCS scores between groups (e.g., between decision support interventions or populations), and 154 conducted multivariate analysis to assess factors associated with DCS. Analysis is underway to determine mean DCS scores in various decision-making contexts and populations, and factors associated with these DCS scores.

Discussion

DCS use, as well as the number of versions and applications, has increased steadily since its development in 1995. It has been used worldwide for multiple decision types, clinical contexts and populations, demonstrating that it has become an important decision-making evaluation measure. Furthermore, there are ongoing efforts to improve and/or adapt the DCS and its application. We will create DCS-score norm tables and user guides for different contexts to improve its relevance for evaluating the effects of decision support interventions.

The German Version of OPTION5 – Translation and Psychometric Testing

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Background and aims

In order to conduct studies on shared decision-making (SDM) and to implement SDM in routine practice, psychometrically sound measures are needed. While a range of observer measures exist, the 12-item OPTION scale (OPTION12) has been used most frequently. However, shortcomings have been found, leading to the development of a revised and shorter 5-item version (OPTION5) with adequate psychometric properties. The aim of this study was to translate the OPTION5 rating scale into German and to test its psychometric properties.

Methods:

The translation was performed in a standardized translation process. The German OPTION5 was then tested using audio recordings of 79 patient-physician-consultations in German outpatient care (secondary data analysis). The ratings were done by two raters independently. To assess inter- and intra-rater reliability intra-class correlation coefficients (ICC) were calculated. To assess convergent validity, a correlation (Spearman) of the sum score of OPTION5 with the sum score of OPTION12 was calculated. A high correlation was hypothesized.

Results

After several rounds of discussions with the original authors, a final German translation was reached. Analysis of inter-rater reliability yielded an intra-class correlation coefficient (ICC) of .82 for the sum score; ICCs ranged between .45 and .77 across the five single items. Analysis of the intra-rater reliability showed an ICC of .83 for the sum score; ICCs ranged between .45 and .86 across the five single items. Mean sum scores were 11.8 (SD=11.9) for OPTION5 and 11.5 (SD=6.1) for OPTION12. The correlation between the sum score of OPTION5 and OPTION12 was high with r=.60 (p<.01).

Conclusion

The results regarding inter- and intra-rater reliability are very promising on the total score level and on single-item level for items 3 to 5. ICCs of items 1 and 2 are less good in terms of inter-and intra-rater reliability respectively. OPTION5 showed good convergent validity. The results are generally comparable to the results of the original English version of OPTION5. Thus, the German version of OPTION5 can be used in research and practice.

The challenges of measuring shared decision making in complex real-life encounters.

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MEASURING SDM

Background and aims

Whilst the identification and testing of new shared decision making (SDM) interventions, as well as their integration into organizational infrastructure has received attention, we know little about how SDM occurs in real-life encounters. General focus on the development and implementation of interventions has meant that less attention has been placed on measuring SDM in more complex clinical situations. We aimed to understand what actually happens in real-life complex SDM consultations. This paper reports on some of the measurement issues we confronted whilst conducting the research.

Methods

A purposive sample of patients who had a choice of treatment from secondary care SDM trained renal and breast teams from the UK Cardiff and Vale University Health board were recruited. A mixed-methods approach was applied. Clinicians and patients were asked to rate their experience of SDM following their consultation using a self-report dyadic version of SureScore. Consultations were also audio-recorded and scored using observer OPTION[5] measure of SDM.

Results

SDM was measured in 25 breast care and 26 renal consultations. All consultations were rated using OPTION[5] and all clinicians and patients completed the SureScore measure. Elements of SDM were observed in all consultations. SureScore data indicated that both patients and clinicians felt that SDM was occurring, however it exhibited ceiling effects. The self-reported measure indicated whether SDM took place at that time; however the data was unable to provide an indication of the quality of the interaction. Highest scoring items for OPTION[5] were "incorporating patient preference into decisions" for the breast team (mean 92.5, S.D. 11.96) and "eliciting patient preferences to options" presented for the renal team (mean 80.76, S.D. 17.40). The observational data indicated which elements of SDM were observed and how well they were achieved during the observed consultation. However, a lower score might be misleading because SDM is often a distributed process, over a number of consultations and with different clinicians (e.g. consultant and specialist nurse). One-time observational measures were unable to capture previous discussions.

Conclusion

The SDM encounter is multi-faceted and distributed. A key question is at which point should SDM be measured? If patients are given a self-reported measure after one clinic appointment, the measure would not be able to capture the extended SDM process that occurs over multiple consultations and with multiple clinicians. Therefore, patients completing self-report measures would need clear guidance on what and who they are scoring when being presented with the measure. Similarly, if SDM is measured using OPTION[5] at one consultation, it is unlikely that an accurate representation of the 'distributed' SDM process would be captured because SDM processes could occur at different times (e.g. presentation of options at a diagnostic consultation and patient preference elicitation at a follow-up consultation). Furthermore, patients have many other interactions that cannot be captured, even if every clinic appointment is observed e.g. phone calls to the clinician, discussions with family members and GP appointments. These findings show that it is particularly difficult to capture the SDM process in complex real-life encounters.

A three-talk model for shared decision making: a revision.

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Background and aims

Shared decision making represents a significant shift in how to practice medicine. It is clear that this transformation is not easy for clinicians who often have attitudes formed by different assumptions, experience and training. Clinician are often cautious, skeptical or even dismissive. To change attitudes, a helpful first step might be to support clinicians consider collaboration as one that can be feasible and quickly learnt. Our aim in this work was to revise a model developed to facilitate learning how to accomplish shared decision making.

Methods

Step 1: Experience gained by using a previously published three-step model was used to propose a revision. Colleagues known to have contributed significantly to shared decision making models and concepts were asked to critique a proposed revision.

Step 2: The model was updated based on their comments, and an online survey developed to collect quantitative and qualitative responses. This online survey was targeted at researchers and clinicians, and advertised widely in early February 2017.

Step 3: A revised model, derived from step 2, will be subjected to review by a sample of clinicians from different specialties in 2017.

Results

Step 1: Sixteen colleagues responded with comments and suggestions: nine were medical practitioners (PH, PK, TvdW, PG, ZSB, AA, MH, AE, LT), and 7 were researchers (AS, DF, IS, LPP, AL, MAD, NJW). In response, the model illustrated was developed. Opinion differed most on the use of the term 'team talk' rather than the previous term 'choice talk'. One respondent commented that *patients* do not see "themselves as being in a team of health professionals", revealing that it was not clear that the purpose of the model is to act as a teaching tool for health professionals. Compared to the model published in 2012,

the inclusion of goal elicitation and risk communication was welcomed. A number of respondents raised concern about over-simplification, arguing that it too difficult to parse a complex dialogue into three types of talk. Some suggested visually representing the relative time allocations, suggesting that option talk would consume most time.

Step 2: To date, the revised model received comments from 145 respondents (41% researchers / 34% health professionals) to the online survey. 61% of respondents found the model was easy to understand and 79% found it helpful for teaching. All terms used in the model received positive ratings by the majority of respondents: the term 'team talk' caused most debate. Sixty-four respondents (44%) found the term 'team talk' to be helpful, and 22 (15%) answered that it was neither helpful nor unhelpful.

Step 3: This phase will be initiated in March 2017.

Conclusion

The response from researchers and clinicians has supported a possible revision of the three-talk model. A few respondents voice dissenting opinions related to terminology. The majority of respondents support the use of a frugal model for teaching shared decision making. The data support our experience of using the model during teaching workshops over the last five years.

Development and pilot testing of a face-to-face SDM coaching intervention for oncologists

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Background and aims

Cancer patients often don't feel to be included in important treatment decisions. To train physicians in shared decision making (SDM) is a promising approach to overcome this problem. Studies have shown that SDM training leads to an improved quality of doctor-patient interaction, a positive long-term effect on treatment adherence, psychological well-being and coping abilities of the patient.

We report on the development and pilot testing of an on-site face-to-face SDM training at the oncologists' workplace which we developed for an RCT comparing an e-learning intervention with an individual on-site training and a waiting group.

Methods

To develop the training the ADDIE model (analysis, design, development, implementation, and evaluation) was applied. The development process was monitored by a team of SDM experts. To pilot test the face-to-face training we assessed participants' appraisal of the training with an online questionnaire. To assess the improvement in SDM performance trained simulation patients visit the physician before and after the intervention videotaping the consultation. The consultation was rated with OPTION12 and MAPPIN'SDM from three perspectives: physician, patient and observer.

Development of the intervention

The content of the training is based on a SDM manual evaluated in previous studies. Learning goals are (1) knowing the different information models, (2) recognizing situations where SDM can be implemented, (3) knowing and being able to apply the SDM steps, (4) communicate outcome and risks of different treatment options in a patient-relevant form and (5) handling difficult situations. To address the need of time-efficiency the training can be completed within two hours, and will be provided on-site in the hospital or the outpatient practice. The training is structured in two parts. First the SDM approach, including information models, definition of SDM, and the applicability of SDM are explained in a dialogue. Second the steps of SDM (team talk, option talk, decision talk) are explained and discussed using the videotape of the first consultation with the simulation patient.

Preliminary results of pilot testing

Up to date 51 physicians were included and randomized: 21% are working in a practice and 75% in a hospital. 35% are assistant physicians, 22% specialists, 27% senior physicians and 5% head physician. Until now 7 physicians received the face-to-face intervention. Preliminary evaluation of the online questionnaire shows that the physicians rated the information as interesting, the learning atmosphere as comfortable, and the video feedback as helpful.

Conclusion

The development and pilot testing of a face-to-face SDM coaching showed promising results. Comprehensive results of the pilot testing including OPTION and MAPPIN'SDM rating will be provided at the conference.

Evaluation of SDM skills training for medical students with Objective Structured Clinical Examinations

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Background and aims

The University Medical Center Hamburg-Eppendorf has established in 2012 a new curriculum of medical training (iMED). As part of this new curriculum, students are trained in *shared decision-making* (SDM) during their second year. The SDM training consists of a lecture (90 min.) and two following workshops (150 min. each), where students practice decision making for different clinical situations with simulated patients in small groups (10 students per group). An observer-rated, objective structured clinical examination (OSCE) has been developed to control for the learning progress. During this OSCE students were asked to actively engage a simulated patient with asthma in a treatment decision and to support this process by using a simple decision board. In order to optimize the validity of this OSCE, we used the OPTION 5 scale as a validated assessment instrument. Aim of this presentation is to share the experiences with the OSCE and the validation process.

Methods

At the end of the summer term 2016, 185 students took part in the OSCE. 4 members of the teaching staff were trained in using the OPTION 5 by rating consultation videos with simulated patients and calibrating rating differences. For validation, 33 students were evaluated by a second rater using an additional evaluation sheet, which was developed before based on learning objectives of the SDM training. For interrater reliability, 16 of these 33 students consultations have been rated using the OPTION 5 by the 2nd rater.

Results

During the rater training we acknowledged that the OPTION 5 scale had to be adapted in order to enable a fair examination for students: since none of the rated videos would have passed the exam, the five-point rating scale had to be collapsed into a four-point rating scale by deleting the last rating item category "exemplary effort". Nevertheless, 20 points were the maximum in the adapted OPTION 5. Using this adapted scale, n=165 (89,2%) of the 185 students passed the OSCE with a mean of 14.4 (SD = 2.3). Inter-rater reliability of the two independent raters was r=.917 in the 16 double-rated OSCEs. The correlation of the OPTION 5 score with the former evaluation form was r=.637. Raters reported, that the new evaluation sheet including OPTION 5 was easy to use and reflected the quality of the consultation (face validity).

Conclusions

OPTION 5 seems to be a suitable tool for the evaluation of the students' performance during an OSCE. However, the option "exemplary effort" was too difficult for students in their second year to reach. The scale adaption was reasonable to balance the exam. The new version of the evaluation sheet including the OPTION 5 has been extended since the summer term 2017 with a global rating on patient-centered communication skills for the OSCE. The next evaluation will allow to judge the reached SDM skills of students within the iMED curriculum.

Skills Training for Shared Decision Making: A Randomized Pilot Study

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Background

Shared Decision Making (SDM) is an approach that supports conversations and systems of care that value patients and clinicians making decisions together. Strategies to enhance SDM in the medical encounter are not well-studied. The purpose of this pilot study is to examine the effectiveness and feasibility of SDM training formats using simulated patient interactions (SPI) and written evaluations to determine if: physicians improve in communication skills and SDM concepts, increase confidence to conduct SDM with their patients, and if training methods are acceptable.

Methods

The study recruited physicians from Partners HealthCare System (PHS) in Boston, MA. The study randomly assigned participants to watch a webinar (developed by investigators and featuring demonstrations of SDM skills) or review video decision aids (DAs), and to receive individual feedback on their SPI or not. Clinical topics for the SPIs and DAs included treatments for herniated disc and depression, and lung cancer screening. The SPIs were conducted by phone and were transcribed and coded for the presence/absence of 9 key elements of SDM using the Braddock's Informed Decision Making (IDM) framework. After completing the first SPI, physicians received instructions on their assigned intervention to complete within 2 weeks before their second SPI. A final survey was sent by email link to all physicians, whether or not they completed their assigned intervention. Physicians were surveyed about their confidence in SDM skills, satisfaction with the skills training and completion of their assigned training arm. All activities in the training took each physician approximately 2 hours to complete.

Results

23 clinicians completed the baseline questionnaire and were randomized to an arm. The sample included primary care physicians (60%), female (65%) and median of 11-20 years in practice. The majority (18/23) completed the first SPI, 15/18 completed their assigned intervention (8/10 webinar and 7/8 DA), and 16/18 completed the second SPI and exit survey. At baseline, the average Braddock score was 4.1/9 and after the trainings, it was 5.9/9. Physicians in both groups showed overall improvement in their SDM skills (mean difference 2.25 for webinar and 1.85 for DA). Compared to the DA arm, the webinar group showed greater improvement in 3/9 key elements of Braddock's IDM framework: discussion of the patient's role in decision making, discussion of the clinical issue or nature of the decision, and discussion of the alternatives. Physicians in the webinar group reported higher confidence level in the three SDM skills assessed: ability to communicate risks and benefits of a test or treatment, ability to communicate the likelihood and probability or risks and benefits, and ability to elicit goals and preferences about medical decisions, compared to the DA group.

Conclusion

This pilot provided important evidence of effectiveness of the trainings in changing clinician behavior. Clinicians improved their communication skills in SDM concepts and increased their confidence to use SDM. This training approach using simulated patient interactions was found to be a feasible and acceptable method of changing communication skills and warrants a larger study to further examine impact and detect differences in training methods.

Correlation of an Integrated Assessment Task in Shared Decision Making with Barrier Exam Scores amongst Medical Students

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Background and Aims

Teaching and assessment of shared decision making (SDM) amongst large cohorts of medical students creates pedagogical and resource challenges. There has been very little information about the validity of assessment tools in this field and the validity of written. We have introduced a written assignment in SDM as part of an integrated assessment portfolio within the eight-week General Practice term at the University of Sydney. It adapts the approach that SDM is a strategy for the application of evidence in clinical practice. The Integrated Assessment Portfolio (IAP) has five components 1) the SDM activity, 2) a population health task, 3) a student-led clinical tutorial, and 4) GP supervisor reports and 5) a term exam. The marking schema for the SDM written assignment was adapted from the ACEPP tool. All assignments were double-marked having been randomly assigned to academics. This study aimed to assess the correlation of the SDM task and other components of the IAP with the barrier exam scores for medical students.

Method

Correlation of IAP components in the 2015 student cohort (n=290) with their in-term and barrier exams.

Results

The SDM assignment was the IAP component with the highest correlation to performance in both the In-term (%=0.652; p<0.01) and Barrier exams (% = 0.138; p<0.05). The SDM assignment also had the widest standard deviation, reflecting a better discrimination of student ability. The GP supervisor reports were the least well correlated with final exam scores. Internal reliability of the SDM assignment was better than the Final written exam (0.429 vs 0.406).

Discussion and Conclusion

The use of a written assignment in SDM with a well-structured marking rubric can provide a reliable, discriminant and valid assessment of student performance. In addition, it appears that strong performance in the SDM task was well correlated with overall academic performance. Whilst these results are only based on one cohort of students, it does suggest that perhaps the complexity of applying evidence through the components of SDM is well aligned with clinical reasoning and overall performance of graduating medical students. We believe these results deserve further exploration as we seek to train and equip our health workforces in the future.

Using virtual standardized patients to develop shared decision making skills across multiple professions: lessons learned

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Background and aims

Teaching shared decision making to students based in multiple professions such as medicine, nursing and physician assistant programs, is a challenge given a lack of teaching content, experienced faculty, and curriculum flexibility. To address these problems, we designed an educational process that was hosted online, as web-based course materials and a virtual video conferencing platform that was capable of providing students access to standardized patients and an opportunity to be coached on their shared decision making skills. Our goal in the study was to assess the feasibility of using these platforms, students' reactions to their utility, and their impact on skills.

Methods:

We collected observational and qualitative data to iteratively develop new educational modules and evaluate the novel use of an existing web-based videoconferencing platform. This was a two-year, multidisciplinary study that placed recruited students into three cohorts. Each cohort had a two-week period to use and evaluate the online learning program. We trained standardized patient coaches (SPCs) - existing standardized patients who learned to recognize and give feedback on communication skills required for shared decision making. First, students accessed pre-recorded online educational modules consisting audio-visual presentations about shared decision making. Second, they used the virtual simulation platform, *WebPatientEncounter* to schedule and record two clinical encounters with SPCs. The SPCs assessed the student performance using Observer OPTION[5]. Student feedback was collected after each cohort. Video recordings of the encounters were sent to an independent assessor who used Observer OPTION[5] to score the encounters.

A summary of results

We recruited 32 students from medical, nursing and physician assistant programs. All 32 participants completed the educational modules and 21/32 completed two SPC encounters. The content included: historical background, risk communication, the Three-Talk Model, and Observer OPTION[5]. Student feedback guided the content, structure, and overall user experience. The virtual coaching experience received both positive and negative evaluations. Students appreciated the virtual training and were eager to practice skills with coaching, but were frustrated by technical difficulties on *WebPatientEncounter* that limited the quality of the simulated encounters. One study cohort was abandoned, due to the frequency of technical failures. The differences in Observer OPTION[5] scores evaluated by SPCs showed increases for 16/21 students, no change for 3/21, and decreases for 1/21 students. Technical problems limited the sample available for independent assessment to 11/21 possible recordings. Of the 11 available recordings, 7 showed increases in scores and 4 showed decreases in scores.

Conclusion

Health professional education can include effective shared decision making training without having on-site faculty or disrupting established curricula. We pushed the available technology to its limit with real-time, virtual coaching. Although virtual coaching encounters could not be reliably replicated due to technology, it was shown to be feasible. Despite limitations in technology and inter-rater reliability of evaluation, students expressed appreciation for this online approach and enthusiastic demand for training in these skills.

The development of competencies for Shared Decision Making in postgraduate medical education: a Delphi study

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Background and aims

Patients increasingly desire to participate in medical decision making. Although Shared Decision Making (SDM) is considered to be the preferred approach to involve patients in medical decision making, it is currently not routinely used in clinical practice. The development of SDM training programs for health care professionals is therefore increasing. However, existing programs show a high level of diversity in what and how they deliver, a low level of underpinning with educational theory and a general lack of effect on attitudes and behavior. A competency-based program on SDM is expected to be effective and will be consistent with the current transition of medical education towards competency-based models. Nonetheless, there is still a lack of consensus on SDM competencies for medical education. In study we aimed to develop SDM competencies (including knowledge, attitudes and skills) and entrustable professional activities (EPAs) for postgraduate medical education.

Methods

We developed a list of preliminary SDM competencies and EPAs for postgraduate medical education in the Netherlands based on existing literature, 17 individual semi-structured interviews with experts (i.e. patients, health care professionals and experts in the field of SDM, communication and medical education) and a national expert meeting in the period of September 2016 – March 2017. To reach consensus on this preliminary list of SDM competencies in a group of approximately 50 experts, we will conduct a national computerized Modified Delphi study from April – June 2017. The Delphi will consist of two to three rounds. In the first round, the experts will be asked to rate the competencies and EPAs in terms of importance and feasibility on a 9-point Likert scale. Blanc textboxes will be added to allow experts to explain the rating, to adjust formulations, to add competencies and to make general comments. The questions of the second (and possibly the third) round will be formulated based on the outcome of the previous round. Agreement was specified as a consensus rate of more than 80%.

Results

The literature study and expert interviews resulted in a list of 13 competencies and 17 EPAs for SDM in postgraduate medical education.
The results of the Delphi study will be available in June 2017.

Conclusion

This ongoing study is the first step towards a competency-based program on SDM for postgraduate medical education. The results will be used to describe the current competency level of residents, to define opportunities and barriers for change and to develop a competency-based educational program on SDM.

The 'Shared Decision Making bundle' for implementation in routine NHS settings – lessons from the MAGIC programme, UK

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Adoption of shared decision making (SDM) into routine practice has been remarkably slow, despite forty years of research and considerable policy support. We need to move away from traditional research settings to learn from implementation work with clinicians and leaders responsible for routine healthcare; we need to identify what is and is not going to work in real life clinical settings. The MAGIC (Making Good Decisions in Collaboration) programme was commissioned by The Health Foundation in 2010 to design, test, and identify the best ways to embed SDM into routine primary and secondary care settings (UK), using quality improvement methodology. Here we present learning from the first three years of the implementation programme, reporting key challenges to embedding SDM, and potential solutions to these challenges.

The learning from MAGIC derives from a variety of sources including, facilitated shared learning events, clinic and consultation observations, interviews with clinicians and patients, patient and public involvement panels, focus groups, questionnaires, plan do study act data collection tools, monthly project team meetings (including researchers, clinical teams, healthcare organisations and patient representatives), and an independent evaluation report.

Key challenges to embedding SDM identified during MAGIC (and tested responses to them) included: 1) 'We do this already' (the need to enhance understanding of what SDM is and how it differs from current care) ; 2) 'We don't have the right tools to do SDM' (supporting the development of evidence based decision support tools, and also overcoming the perception that SDM relies only on tools – skills trump tools); 3) 'Patients don't want SDM' (challenging attitudes that patients do not want to be involved in decision making, and supporting patients to be better prepared for SDM); 4) 'How can we measure it?' (supporting organisations to measure SDM, for research or improvement); 5) 'We have too many other demands and priorities' (the need for organisational support and buy-in).

We developed and identified various interventions / approaches that were successful in overcoming these challenges: SDM skills workshops; development of brief SDM tools; patient activation and preparation; measurement tools; organisational buy-in and senior level support; alongside a collaborative and facilitated approach. Many other factors also affect implementation attempts, and the potential solutions we describe must be supported by broader policy changes, input from professional and regulatory bodies, and integration of SDM into medical and nursing curricula. Implementing SDM is challenging, but possible. It requires interventions to support organisations, clinicians, and patients: a 'shared decision making bundle'. No one intervention will succeed in isolation. It requires the bundle of interventions working together, holistically, to achieve SDM across the healthcare setting.

Shared decision-making in physical therapy: Physiotherapists' knowledge, attitudes and self-reported use

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Background and aims

Shared decision-making (SDM) has gained in importance in recent years. It has mainly been investigated in the medical and nursing professions, and research on the adoption of SDM among other health care professionals is limited. Physical therapy is an area in which SDM could be used to improve care. So far, very few studies on SDM were conducted in physical therapy. Therefore, the aims of this study were (1) to investigate knowledge, attitudes, and self-reported use of SDM among German physiotherapists, (2) to explore their association with demographic and professional characteristics, and (3) to assess self-reported barriers to the implementation of SDM.

Methods

We conducted an online survey and recruited physiotherapists through the largest national association of physiotherapists in Germany. The survey was developed within a multidisciplinary team, and consisted of validated SDM measures (CPS, SDM-Q-Doc) and self-developed questions (e.g. on self-reported knowledge, on attitudes and self-reported use of SDM depending on the treated patient group, on the relevance of perceived barriers). The survey was pre-tested with five physiotherapists. We used descriptive statistics to analyze knowledge, attitudes, self-reported use of SDM, and self-reported barriers to the implementation of SDM. To explore associations between variables, we calculated two-level logistic regression models.

Results

357 surveys were completed and included in the analyses. 75.6% of all participants were female and the mean age was 45.0 years. 60.5% of all participants stated that they did not know anything about SDM before participating in the survey. After being introduced to SDM within the survey, half of all participants reported to prefer a shared decision-making approach compared to a paternalistic or an informed decision-making approach. While 29% stated to use SDM in routine care, the majority (68%) stated to use a paternalistic approach. System related barriers, such as time constraints were perceived as being most relevant.

Logistic regression analyses revealed that knowledge on SDM was associated with type of professional training (vocational training vs. university degree) and length of professional experience. Attitudes towards SDM were more positive among female physiotherapists, and self-reported use of SDM increased with length of professional experience and fewer working hours per week. We also found that having knowledge on SDM did neither predict attitudes nor use of SDM and vice versa. Attitudes and use of SDM were found to be predicting each other.

Conclusion

This exploratory study investigated physiotherapists' perspective on SDM. While SDM was perceived as an appropriate concept in physical therapy, knowledge on SDM and self-reported implementation are still lacking among German physiotherapists. In general, our findings are in line with previous international studies conducted with other allied health professionals. These results drawing on data of 357 physiotherapists provide useful insight into the status quo. They can be used as a basis for future research, and might help to put SDM on the agenda in physical therapy.

Working in partnership – the NICE Shared Decision Making Collaborative

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Background and aims

The NICE Shared Decision Making Collaborative is network of people with knowledge of, an interest in, and commitment to, shared decision making (SDM). The Collaborative was established by the UK National Institute for Health and Care Excellence (NICE) in 2015 and has met on 3 occasions to share expertise and knowledge around SDM, and to identify the changes that need to happen in practice to implement an SDM culture in practice. Fundamental to the Collaborative's work is the aspiration that people should be able to choose the evidence based treatment and care options that meet their needs and reflect their preference and values.

Methods

The Collaborative was initially convened as a small group with a particular focus on the national use of UK-based patient decision aids (PDAs), supported by input from international SDM leaders. The group included members from academia, policy makers, professional and patient organisations, arm's length bodies and individuals with an interest in SDM. Two further meetings, with an expanded membership and remit were held in the summers of 2015 and 2016.

Results

The discussions held in the first meeting demonstrated that promoting and implementing the use of PDAs on their own would be insufficient to make SDM a routine part of clinical practice. In view of this, at their second meeting the Collaborative developed a consensus statement which laid out 7 domains where change would need to happen, and what those changes needed to be. Those domains were:

- Leadership and culture change
- Local leadership
- Education and training
- SDM tools
- Guidance development and evidence reviews
- Measurements of successful SDM
- Research

The following year, the Collaborative took the 7 domains and developed a joint action plan with specific short-term intentions and long-term ambitions for individual organisations to take forward. Ten organisations agreed to specific pieces of work to support SDM in their areas of expertise and interest. The Collaborative will meet again in the summer of 2017 to discuss progress against the action plan and identify further areas for action.

Conclusion

The SDM Collaborative is a unique endeavor bringing together UK-based and international partners with a commitment to making SDM part of routine clinical practice, and to ensure that patients are equal partners in decisions about their care. The Collaborative has brought together key organisations and individuals in the SDM arena to work together and identify the barriers to SDM and the cultural changes that need to happen in healthcare to make SDM a reality. The Collaborative has also driven forward action to help achieve this change. Led by NICE, the Collaborative demonstrates the need for a collective approach to overcoming challenges to seeing SDM as the norm for how healthcare is delivered, and demonstrates how this has been done in practice.

Establishing a Centre for Shared Decision Making in a Danish Cancer Hospital

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Background and aims

At present, shared decision-making (SDM) is not widely used in clinical practice in Denmark, including in cancer care. Studies suggest that oncologists often do not involve patients in the decision-making process to the extent the patient desires. In addition, little attention has been paid to organisational and system level factors in which these interactions and decisions are embedded, and how to modify these to ensure that SDM becomes part of routine practice. In order to provide a systematic approach to SDM in clinical cancer care, Lillebaelt Hospital in Vejle has created a multidisciplinary Research Center for SDM embedded in the culture and processes of a cancer hospital. The aim of the present work is to describe the strategic framework for its implementation across the organization and how this task is handled.

Methods

In 2014 a Center for SDM was initiated at Lillebælt Hospital along with a multidisci-plinary board of partners and an international advisory board to oversee and support the work. The strategy and work plan focused on the following key elements: a) Human resources including strong leadership support and recruiting key opinion leaders among hospital staff. b) Staff training including a 1-day training course for clinicians in SDM. c) Development and testing of patient decision aids (DA) with a special focus on development of a generic template for new Danish DAs that could be adapted to specific decisions and tested in various demonstration projects. In these demonstration projects (patient DAs, patient-reported outcome measures (PROMs) and communication skills training for staff), an iterative process has been adopted. Experience from the initial demonstration projects is used to initiate new ones, based on what has been shown to effectively adding value for patients and healthcare professionals in clinical settings.

Results

The following learning points have become apparent: a) Human resources: Need for a solid management foundation and support, importance of strategic partnerships b) Staff training: Strengthening communication and listening skills. c) DAs: Building on existing evidence and knowledge and the need for preparation and support of patients to enhance their ability to play an active role in decision-making.

Conclusions

Although Denmark's politics, healthcare professionals and patients are aware of SDM as a key element for patient-centred care, implementing SDM in clinical practice remains a challenge. Our response to this challenge has been to propose a systematic, organisation-wide approach involving collaboration between multi-disciplinary groups of stakeholders. By these means we aim to embed a patient centred culture from top to bottom in clinical cancer care. The development is still at an early stage, but initial results appear promising.

How can shared decision making become routine? A mixed methods study to learn from teams who are doing it well

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Background and aims

Shared decision making (SDM) is increasingly advocated by healthcare policy makers, professional membership organisations, patient organisations, and governing bodies, but it is not adopted routinely in most healthcare settings. We sought to learn more about how to promote SDM by studying it in teams who are skilled and experienced in SDM, where it is adapted and adopted into their clinical pathways. We aimed to examine what SDM looks like in optimum real-life clinical settings, its enablers and barriers, the patient experience, and the implications for models of SDM and implementation.

Methods

We conducted a mixed-methods study in two secondary care teams in the UK that were routinely implementing SDM: Cardiff and Vale University Health Board's Breast Centre and Pre-Dialysis team. Decision-making healthcare consultations were audio-recorded and transcribed verbatim. The Observer OPTION[5] instrument was used to assess SDM during consultations (dual-rated). Consultation transcripts were analysed thematically to explore the process of SDM, and enabling and limiting factors influencing the process.

Results

We recruited and audio recorded consultations for 25 breast cancer patients and 26 pre-dialysis patients. Elements of SDM were observed in all consultations. OPTION[5] scores ranged from 65-95 (out of 100) in the breast team (mean 82.82; SD 8.50), and 48-80 in the pre-dialysis team (mean 65.5; SD 9.35). OPTION[5] data confirmed that SDM is taking place in these settings, but qualitative data analysis indicated a highly complex picture regarding *how* SDM was happening, and *why* it might be happening that way.

SDM was not a standardized 'one size fits all' process; it looked different for different clinical conditions, and the different phases of the SDM process (e.g. choice talk) had lesser or greater emphasis depending on the clinical context. SDM rarely took place during one clinical encounter. We observed an important 'pre-choice' or 'preparation' phase, which precedes the presentation of choice and options. We also identified the need for broader conceptions of 'decision support' that should include implicit and explicit decision support, and emotional and practical support. We also observed a diffuse, dynamic and iterative 'preference elicitation and checking' process, where both patients *and* clinicians evolved from 'prior' to 'informed' preferences. The 'decision talk' phase included in current models was not reflected in the decision-making consultations for this long-term, progressive condition context (pre-dialysis).

Conclusion

Our results have several implications for current models of SDM and the focus of training and implementation programmes to better reflect what 'good SDM' looks like in practice. We recommend consideration of the preparation phase, the broader conception of decision support, and a 'planning talk' phase, which replaces 'decision talk', and indicates a more fluid and ongoing process. A system levels approach is needed to support SDM across several healthcare encounters over time, with different healthcare professionals, whilst also ensuring continuity. Cultural, micro-level, and macro level changes are all important for the successful implementation of SDM.

Ten-year trends in SDM for patients with primary breast cancer in Germany – the need for valid data

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Background and aims

Shared Decision Making (SDM) has been a central topic in health services research and health care politics and practice have emphasized the importance of SDM for more than 20 years. However, evidence on whether patient participation in decision making actually increased over the last years is scarce.

Methods

Since 2006, primary breast cancer patients who underwent surgery between February and July of each year in one of the Breast Centers in the federal state of North Rhine-Westphalia have been surveyed following hospital discharge. The survey contains two subscales of the „Perceived Involvement in Care Scales" (PICS), measuring physician facilitation of patient involvement and patient participation in decision making. Survey data was analyzed by multilevel modelling.

Results

The number of patients surveyed each year increased from n=3,131 in 2006 to n=4,420 in 2015 (response rate: 88.6 to 85.6%). Between 2006 and 2015 patients' reports on physician facilitation of patient involvement increased from 2.9 to 3.4 (range 1 to 5) and patient participation in decision making increased from 2.6 to 2.9 (range 1 to 5). Multilevel analysis revealed that perceived physician facilitation is associated with lower cancer stage, having received a mastectomy, older age, native language other than German, lower education and living with a partner. Participation in decision-making was only associated with lower cancer staging, mastectomy and private health insurance.

Conclusion

Trend analyses show slight improvements in patients' reports on SDM within 10 years. However, improvements can be regarded as rather small, especially since many other dimensions of patient care assessed in the same survey improved on a similar scale. Our long term data in conjunction with the fact that effective interventions for improving SDM are available emphasize the existence of substantial barriers for the implementation of SDM into routine care in Germany.

Implications for Policy or Practice

Health care policy and providers must form conditions conducive for the implementation of SDM, including for example the provision of evidence-based information and decision aids as well as designing a work environment which facilitates patient-physician communication. Moreover, SDM or the informed decision as a result could be established as valid indicators of quality of care, which are monitored over the long-term. To measure SDM in a valid and comparable way seems to be crucial for drawing the attention to implementation necessities.

Paper Title: Matches & mismatches: how older adults experience the nurse–older-adult interaction in a health promotion setting

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Background and Aim

Health Promotion involves interaction between professionals and clients that allows for information exchange, decision making and advice that takes into account the clients' perspective. Thus far, insights in the experiences of older adults of health promotion interaction are lacking. The aim of this study was to describe how community-dwelling older adults, participating in the nurse-led Health Promotion intervention (Community Health Consultation Offices), experienced the nurse–older-adult interaction, while their views and perceptions of healthy living were taken into account.

Methods

We used a qualitative interview design. Nineteen Dutch older adults aged 62 to 92 years participated. The inclusion criteria were: participation in one of the Community Health Consultation Offices, being at risk of frailty (Groningen Frailty Indicator ≥ 4), and/or having a body mass index ≥ 28, and/or currently being smokers. Semi-structured interviews were transcribed verbatim and coded with the Qualitative Data Analysis Miner software program. The Qualitative Analysis Guide of Leuven was used for data analysis.

Results

Two main themes emerged from the data. The first theme consisted of older adults' views of healthy aging and living, including a holistic health-conscious lifestyle and awareness of opportunities and constraints in aging. The second theme consisted of the interaction between the nurse and the participant emphasizing the concept of connecting: achieving a match between the nurse and the participant, offering advice, and decision-making.

Conclusions

Our study illustrates the importance of tailoring nurse-led interventions to the perceptions and views of older adults about their healthy aging. Their holistic view of health and their ability to adapt to the challenges that they face while growing older must be taken into account. The interaction between nurses and older adults is a useful key to successful health-promotion interventions. However, in practice, nurses use communication approaches such as motivational interviewing and shared decision-making only to a limited extent. They could improve their communication competencies in this area by implementing motivational interviewing and shared decision-making strategies to connect and find shared goals and take older adults' views and preferences into account.

The best of both: integrating shared decision-making and motivational interviewing for professionals in community social teams

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Background and aim
Empowering clients to control their own lives has become a policy goal in recent years. In the Netherlands and in countries worldwide citizens are increasingly expected to take responsibility for their own lives. This implies a change in attitude of both citizens who are confronted with life's challenges and the professionals involved with them. Motivational interviewing (MI) and shared decision-mmaking (SDM) are both relevant in situations where change is needed and the appropriate decisions and course of actions depend on clients' preferences (Elwyn et al., 2014). Combining both methods seems promising in reaching decisions about courses of action and carry them through. We developed a stepwise communication method integrating MI and SDM that supports professionals to cooperate with clients. The current exploratory study evaluates its feasibility and its application in community teams.

Methods
The members of five community social work teams were trained in the new stepwise method (n=92) during a face-to-face course consisting of three sessions of three hours. We evaluated the use of the new method through questionnaires with social work team members (response rate 34%) and semi-structured interviews with social workers (n=5) and clients (n=5).

Results
After training the knowledge of MI and SDM was fair to good. The training itself appeared to be feasible to the community team workers. They experience the combined method as a useful tool in practice. The steps of shared decision-making help structuring the difficult consultations with clients and their networks. However, actively involving all network members and handling conflicting preferences during conversations remained difficult. Reaching consensus about decisions is difficult when interests of the participants are far apart.

Conclusion
The combination of shared decision making and motivational interviewing appears to have potential for social professionals who are working with community living clients with complex life's challenges. The newly developed method may support these professionals in working towards empowerment and personal control of their clients. Research is needed to further develop and evaluate the new method.

Harmonizing Clinical Practice Guidelines and Shared Decision Making

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Background and aims

A predominant framework in clinical practice guideline (CPG) development explicitly grades recommendations as Strong or Weak. Weak recommendations are used when there is uncertainty that benefits outweigh harms and burdens, either due to uncertainty in the evidence or uncertainty in the balance of benefits and harms across the spectrum of patient preferences. A predominant framework in shared decision making (SDM) is that patients should be informed of relevant evidence in understandable and individualized ways for direct inclusion in decision-making for preference-sensitive decisions. Conflating the certainty of evidence for net benefit and the sensitivity to patient preferences into a single dichotomy does not preserve the distinctive importance of these concepts. We report a simple model to convey the strength of recommendations for preference-sensitive and preference-insensitive conditions.

A brief description of methods

The Healthcare Guidance for Patients Society (Healthcare GPS) is an organization led by experts covering the spectrum of evidence-based medicine (EBM) and developing, rating, and using guidelines and SDM. We considered the Grading of Recommendations Assessment, Development and Evaluation (GRADE) and International Patient Decision Aids Standards Collaboration (IPDAS) standards and developed (via a consensus-based approach) a model for clear phrasing for recommendations.

A summary of results to support conclusion/s

An EBM-SDM framework for phrasing recommendations in CPGs would communicate a strong recommendation to offer options with an SDM approach for preference-sensitive conditions with a high certainty of net benefit for some patients. This appears more appropriate for phrasing for certain recommendations, such as chemotherapy with well-established benefits and harms for patients with cancer. Such phrasing formats can be tested in CPGs to assess impact on clinician understanding, patient understanding, patient engagement, and SDM implementation.

	High Certainty of Net Benefit (for average patient)	Low Certainty of Net Benefit (for average patient)
Preference-sensitive (Net Harm will result for patients with different preferences)	Strong recommendation to offer with SDM	Weak recommendation to offer with SDM
Preference-insensitive (Net Benefit across range of acceptable preferences)	Strong recommendation to do	Weak recommendation to do

A conclusion

Although often acknowledged as an important variable, many current clinical guidelines do not incorporate patient preferences or individual perspectives into the development or implementation of recommendations. Patient preferences such as their perspectives, beliefs, and expectations need to be balanced with the benefits and harms of any intervention, SDM tools within guidelines (and explicit recognition of which recommendations are best implemented using an SDM approach) can encourage greater patient engagement and involvement. We believe this principle is critically important and offer a solution on how to incorporate SDM within guideline development.

Classification of Consistency Across Guidelines: A model for informing patients about global guidance

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Background

Many decision aids convey the relevant facts and evidence but do not convey recommendations from guidelines. It is unclear if conveying recommendations from a global view across guidelines would be similar or dissimilar than what would be conveyed by a single guideline. Conveying a global view for rapid simple patient understanding could quickly become unwieldy. We developed a simple model to report the consistency or inconsistency across guidelines for specific recommendations.

Methods

The Healthcare Guidance for Patients Society (Healthcare GPS) is a group of experts covering the spectrum of developing, rating, and using guidance and shared decision-making. We considered the National Academy of Medicine (NAM), Guidelines International Network (G-I-N), and Grading of Recommendations Assessment, Development and Evaluation (GRADE) standards and developed (via a consensus-based approach) a classification system for a recommendation that is represented across multiple entities making recommendations for the same concept

Results

First the consistency across the guidelines is determined regarding whether all guidelines are for (or against) the particular recommendation. For recommendations that are consistent in direction across guidelines, consistency is checked regarding the certainty that desirable consequences outweigh undesirable consequences. Further checking for consistently strong recommendations involves confirmation of a qualified rationale requiring three elements: a systematic review, multidisciplinary input with conflict of interest management, and explicit reporting of values and preferences to inform judgments about the balance between benefits and harms of treatment alternatives.

Conclusion

Healthcare GPS ratings can provide a simple recognizable method to communicate the comprehensive view to the certainty of a recommendation across guidelines. Such communication can be tested in patient decision aids and shared decision-making tools to determine if it facilitates patient understanding.

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                    ┌─────────────────┐
                    │ Recommendations │
                    │    in 2 or      │
                    │  more guidelines│
                    └────────┬────────┘
                             │ Inconsistent        ┌──────────────────┐
                             ├──────────────────→  │  DELTA |         │
                    Consistent                     │  Inconsistent    │
                             │                      │  or              │
                             ↓                      │  Insufficient    │
                    ┌─────────────────┐             │  Guidance        │
                    │  Certainty of   │             └──────────────────┘
                    │ recommendation  │
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       All High or Strong         Some Low or Weak
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                 ↓                        ↓
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        │  Supporting  │ Inconsistent │ Recommendations │
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        └──────┬───────┘         └────────┬─────────┘
           Consistent
               │                     For      Against
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      │ Recommendations  │
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         For      Against
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| ALPHA \| Consistent Strong Recommendation For | OMEGA \| Consistent Strong Recommendation Against | BETA \| Consistent Suggestion For | GAMMA \| Consistent Suggestion Against |

Parallel Session 03
Tuesday 4th
10:30—12:00

Communication and informed consent	Room Salle du Conseil
SDM and decision aids	Room 106, CIER
SDM and cardiovascular diseases	Room Amphi Revol
Measuring SDM	Room 107, CIER
SDM and person-centered care	Salle de conférence Médiathèque

ISDM
2017

Communication and decision-making in palliative care; a supplementary qualitative analysis of the JLA PeolcPSP survey

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[3] *DECIPHer Centre, Social Sciences, Cardiff University, Wales*

Background and aims

The landscape of palliative and end-of-life care research, albeit improving, continues to be under-researched. It is likely, therefore, that key stakeholders have a range of unmet needs, not least of all in relation to communication and decision-making. The James Lind Alliance (JLA) Priority Setting Partnership (PeolcPSP), looked to identify the pertinent 'treatment uncertainties' for palliative and end-of-life care, focusing on interventional based research. Following a national public survey in the UK, the JLA PeolcPSP analysed and generated a list of unanswered questions from a range of stakeholders; the 'Top 10' priorities reflects the importance of communication and decision-making, emphasising Advance Care Planning (ACP) (third priority). However, the dataset is likely to include comments concerning communication and decision-making which do not necessarily meet the criteria of the JLA methodology. The aim of this study was to undertake a supplementary analysis of the data generated by the JLA PeolcPSP survey, pertaining to communication and decision-making.

Methods

A supplementary thematic qualitative analysis of the JLA PeolcPSP free-text data was undertaken. The final dataset of 1403 responses was downloaded to NVivo 11. The original coding framework was reviewed and refined until agreement was reached on the final themes and sub-themes, concentrating on communication and decision-making.

Results

Approximately one quarter of the JLA PeolcPSP survey respondents (N=342; 24.4%), submitted comments relating to communication and decision-making. The thematic analysis led to three overarching themes; these data are preliminary and we aniticipate completing this analysis by June 2017. 1) *Availability, accessibility and improving information:* stakeholders often raised the question/comments as to the availability and accessibility of information (or lack of) on support and guidance, as well as improving and finding information. 2) *Effectiveness of communication between stakeholders:* respondents commented on, and questioned, how to improve communication, openness and transparency between stakeholders; improving the communication of diagnosis and prognosis; exploring and establishing the responsibility of stakeholders, particularly when patients are not able to communicate or make their own decisions. 3) *Eliciting preferences and values:* three key areas were cited; treatment decisions (discussing treatment options and making informed choices), ACP (raising awareness, initiating and supporting ACP) and preferred place of care (facilitating patients and carers' wishes, establishing the most appropriate place of care and supporting families in the community).

Conclusion

This supplementary qualitative analysis of the JLA PeolcPSP survey allowed us to identify a range of communication and decision-making concerns and issues. Whilst ACP remains to be an important issue, stakeholders also have wider communication and decision-making concerns which may not necessarily fit into interventional research methodology. Both quantitative and qualitative methodologies will be needed if research is to truly meet the needs of stakeholders in palliative and end-of-life care.

Right For Me: Results of a Cluster Randomised Controlled Trial of Two Interventions for Facilitating Shared Decision-Making about Contraceptive Methods

Rachel Thompson[1], Kyla Z Donnelly[1], Ruth Manski[1], Gabrielle Stevens[1], Daniela Agusti[1], Michelle Banach[2], Maureen B Boardman[1], Pearl Brady[2], Chrissy Colón Bradt[2], Tina Foster[1,3], Deborah J Johnson[3], Zhongze Li[3], Judy Norsigian[4], Melissa Nothnagle[5], Ardis Olson[1], Heather L Shepherd[6], Lisa F Stern[7], Tor D Tosteson[1,3], Lyndal Trevena[6], Krishna K Upadhya[8], Glyn Elwyn[1]

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Background and Aims

In contraceptive care, shared decision-making represents a potential strategy for promoting health while preserving patient autonomy. Despite this, there remains a paucity of evidence on how to facilitate its adoption. Our multi-disciplinary team of scientists, clinicians, patient partners, and other stakeholders are seeking to assess the comparative effectiveness of patient- and provider-targeted interventions for facilitating shared decision-making about contraceptive methods in the health care visit.

Methods

We are conducting a 2x2 factorial cluster randomised controlled trial of two interventions. The first is a brief video and prompt card intended to be viewed by patients immediately before the visit that encourages them to ask providers three specific questions: (1) *What are my options?* (2) *What are the pros and cons of those options?* and (3) *How likely are those pros and cons to happen to me?* (Shepherd et al., 2016). The second is a set of seven one-page decision aids on contraceptive methods intended to be used by providers with patients during the visit, along with a five-minute training video and written guidance. The clusters are 16 primary care and reproductive health care clinics in the United States that deliver contraceptive services. Clinics were assigned to trial arms using stratified permuted-block randomisation with an equal allocation ratio, with strata based on clinics' pre-trial level of shared decision-making about contraceptive methods. Participants were people who had completed a visit at a participating clinic, were assigned female sex at birth, were aged 15 to 49 years, could read and write English or Spanish, and had not participated in the study previously. We collected study data via patient surveys administered immediately, four weeks, and six months after the visit. The primary outcome was shared decision-making about contraceptive methods and was assessed immediately after the visit using the three-item CollaboRATE measure. Secondary outcomes also assessed immediately after the visit were the occurrence of a conversation about contraception, satisfaction with the conversation about contraception, intended contraceptive method(s), intention to use a highly effective contraceptive method, and values concordance of the intended contraceptive method(s).

Results

Data collection on outcomes assessed immediately after the visit was completed in late 2016. Altogether, 1691 eligible participants provided data during a three-month pre-trial phase of data collection. A further 3347 eligible participants provided data during the six-month trial. Of trial participants, 2802 provided data on the primary outcome of shared decision-making about contraceptive methods. Analysis of the effect of trial arm on shared decision-making and other outcomes assessed immediately after the visit is underway.

Conclusion

The findings of this study will shed important light on the comparative effectiveness of patient- and provider-targeted interventions for facilitating shared decision-making about contraceptive methods in the health care visit. [ClinicalTrials.gov Identifier NCT02759939]

Informed Consent and Shared Decision-Making in Arthroplasty Surgery: An Exploratory Cross-Sectional Study

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Background

Shared decision-making is sought to improve patients' health outcomes and contribute enhancing the efficacy of our healthcare system. In the province of Québec, patients' involvement in shared decision-making is mainly regulated through the legal requirement of informed consent. Informed consent is particularly important regarding elective procedures, such as arthroplasty surgeries (total hip replacement-THR and total knee replacement-TKR). Our main objective was to determine the prevalence of patients giving an informed consent to their THR or TKR surgery.

Methods

A cross-sectional study was conducted in patients consenting for THR or TKR in a Quebec City hospital. We recruited patients within a maximum of 7 days following the encounter with an orthopedic surgeon during which they consented to the surgery. To be eligible for this study, patients had to be 18 years or older and be able to consent to research. We used a standardized questionnaire that was administered through phone calls with the participants. Our main outcome, informed consent, was measured using a modified version of the *Multi-dimensional Measure of Informed Choice* (MMIC). In accordance with the MMIC, we used its attitude scale and an objective knowledge scale (the 5-item version of the *Hip/Knee Osteoarthritis Decision Quality Instrument*-HK-DQI). The consents to surgery given by patients were then categorized as Informed or Non-Informed whether patients had positive attitude and satisfying knowledge about their surgery, or either/both negative attitude and poor knowledge, respectively. As secondary outcomes, we explored associations between informed consent and: 1) patients satisfaction (10-item scale) with a Wilcoxon Mann Whitney test, and 2) decisional conflict (*SURE* tool) and 3) patients' involvement in the decision-making (perceived role scale) with an Exact Pearson Chi Square test.

Results

Recruitment took place between September 2015 and June 2016. Sixty patients agreed to participate and completed a full questionnaire. Patients' mean age was 67.7 (95% CI: 65.4-69.9) and 55% (n=33) of them were women. The consent given to surgery was categorized as Informed for 55% of patients (n=33), meaning that 27 patients (45%) did not give an informed consent to their THR or TKR according to the MMIC measure. For the two scales composing the MMIC, attitude was positive for 98.3% of patients (n=59), whereas objective knowledge explained the Non-Informed consent with 45% of patients (n=27) having poor knowledge. Overall satisfaction with the clinical encounter was high (8.1, 95% CI: 7.6-8.5) and was positively associated with informed consent (p-value 0.02). Decisional conflict was detected in 18.3% of patients (n=11) and was not associated with informed consent (p-value 0.2). As for perceived role, 76.7% of patients reported taking the decision considering their surgeon's opinion (n=28) or sharing the decision with their surgeon (n=18). Perceived role was not associated with informed consent (p-value 0.06).

Conclusion

To our knowledge, this study is the first to use a modified MMIC, with short HK-DQI, in order to determine the prevalence of patients giving an informed consent to their TKR/THR surgery. In the light of our findings, interventions aimed at enhancing informed consent and shared decision-making in TKR/THR context should be designed and tested using the modified MMIC.

Do consent forms support informed decisions?

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Background and aims

Informed consent for medical interventions requires evidence-based comprehensive and understandable risk information. In Germany, a physician has to personally communicate and document the information using standardised consent forms. Studies indicate that patients may not receive adequate information and do not understand the information provided in consent forms.

The objectives of the present study were to review the evidence on consent forms and to analyse consent forms as currently used in Germany regarding criteria relevant for evidence-based informed decision-making.

Methods

We performed systematic searches in PubMed, CENTRAL, PSYNDEX, PsycINFO, CINAHL and PEDro until 09/2016 to identify publications which reported content analyses of consent forms. Data synthesis was performed descriptively.

For the content analyses of German consent forms, we used 10 relevant surgical interventions: colonoscopy, mastectomy, percutaneous gastrostomy, cholecystectomy, knee replacement, disc replacement, percutaneous coronary intervention, stent-graft for aortic aneurysm, tonsillectomy, and caesarean section. We asked 8 publishing houses and 142 hospitals / practices in the city Hamburg for corresponding consent forms. For content analyses we used criteria for evidence-based health information regarding content, presentation of data, and transparency. We constructed a 15 items scoring sheet. Two reviewers independently assessed the consent forms. The study protocol is available online (www.gesundheit.uni-hamburg.de).

Results

Database searches identified 9277 references, 294 full-texts were screened, and 13 studies were included. Samples, criteria for evaluation, and results of these content analyses were heterogeneous. 5 content analyses assessed the inclusion of information on benefits, harms, and alternatives; 6 assessed the communication of frequencies and 2 the presentation of frequencies as numerical data. All 13 content analyses revealed shortcomings regarding the provision of complete information necessary for informed decisions.

We included 37 German consent forms into the content analyses. Consent forms provided the names of authors (17/37), the date of issue (21/37), the sources of information (0/37), an objective (28/37), the objective to support a decision (18/28), and the objective to support an informed decision (0/28). The forms could be signed to give consent (37/37) and to refuse consent (29/37). They provided information on the procedure of the intervention (37/37), alternative interventions (26/37), the alternative of no intervention (4/37), benefits (30/37), the probability of benefits (23/30), and the risk of complications (37/37). They provided any numerical presentation of frequencies (10/37).

Conclusion

Our review of the evidence on consent forms indicates substantial shortcomings related to content and presentation of risk information. Consent forms as currently used in Germany are not suitable for informed decision-making. They lack numerical presentation of benefits and harms in comparison with alternative interventions. In addition, they lack transparency and do not allow assessment of the evidence base.

Shared decision making using encounter decision aids during clinical encounters: patients' and providers' views

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Aims

Decision support tools can facilitate shared decision making (SDM), as they help to involve patients and have them actively think about their optimal care choice. Encounter decision aids (eDA) are brief decision support tools that are meant to be used during clinical encounters. They showed to be helpful for clinicians and patients to discuss care-options, structure the conversation and have a more in-depth dialogue about issues that really matter to the patient. However, in practice decision aids are not used that often. The aim of this study is to evaluate the acceptability of eDA's by patients as well as clinicians during patient-provider encounters in the Netherlands.

Method

The study used a prospective mixed-method design combining a survey (first phase) and semi-structured in-depth interviews with a purposive sample of clinicians (second phase). The study was conducted in nine medical centres. Six encounter decision aids were developed for epilepsy, heavy menstrual bleeding, osteoarthritis of the hip, and knee, tonsillitis and fluid in middle ear, based on existing Option Grids. In the first phase clinicians were asked to use an encounter decision aid in at least four patient encounters. After this phase, the providers were asked to fill out a survey including SDM-Q9 and questions about perceived effectiveness, satisfaction, barriers and facilitators. Patients were asked to complete a survey including the patient version of the SDM-Q9. Quantitative analyses (using SPSS) were performed on the questionnaires results. In the second phase, semi-structured in-depth interviews with clinicians were performed using an interview-guide based on the results of the surveys until saturation was reached. These interviews will be transcribed verbatim and analysed through content/thematic analysis.

Results

In the first phase 33 clinicians participated. 36% of clinicians used an eDA four times with their patients. Overall, they included 85 patients. 26 clinicians, and 73 patients completed the survey. Analysis showed that the majority of patients and clinicians thought the eDA was helpful in discussing treatment options, wanted to use it in the future and were willing to recommend it to others. Furthermore, the SDM-Q9 revealed that both clinicians and patients felt that the eDA supported the SDM-process during the clinical encounter. However, both scored two statements lower: 'My doctor made clear that a decision needs to be made.' and 'My doctor wanted to know exactly how I want to be involved in the decision-making.' A significant level of difference ($p < 0.05$) was found between patients and clinicians concerning all results, in which patients showed a higher level of satisfaction. Momentarily, semi-structured interviews are conducted and results are expected this spring.

Conclusion

The results of this study show that clinicians and patients are willing to use the eDA during clinical encounters. The willingness of patients and clinicians to use the tool is a prerequisite. However, this study also provided insight in barriers and facilitators for successful implementation. This is valuable information to be used developing a tailored implementation strategy, including training for clinicians in using eDA's. And consider approaches to improve patient engagement during clinical encounters.

So many and yet so few — the lack of high quality decision aids to compare early abortion methods: A systematic review and environmental scan

Kyla Z. Donnelly[1], Glyn Elwyn[1], Rachel Thompson[1]

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Background and aims

In the United States, over 1 million women have an abortion each year, the majority (64%) of which occur during early pregnancy (i.e., before 9 weeks' gestation). Most women are eligible for both surgical and medication abortion methods, which have comparable success rates but encompass quite different processes. Despite the high incidence of this preference-sensitive decision and evidence that women value making informed decisions about their method, the availability, quality, and impact of patient decision aids on this topic is unknown. The objectives of this study were (1) to conduct a systematic review to identify, appraise, and evaluate the impact of early abortion method decision aids described in the scientific literature, and (2) to conduct an environmental scan of the grey literature to identify and appraise other early abortion method decision aids.

Methods

For the systematic review, we searched MEDLINE, Cochrane Library, CINAHL, EMBASE, PsycINFO, ClinicalTrials.gov, and reference lists for studies published after 2000, when medication abortion became legal in the United States. We included experimental and observational studies evaluating the impact of an early abortion method decision aid versus a comparison group on women's decision-making process or outcomes. The decision aid must have met the definition adopted in the Cochrane review of decision aids (Stacey et al., 2014) and been developed after 2000, for use at any time, and in any format and language. For the environmental scan, we searched Google, Apple and Google Play app stores, and consulted key informants. We included decision aids that met the above inclusion criteria but, additionally, must have been written in English for use in the United States. We assessed decision aid quality using the International Patient Decision Aid Standards (IPDAS) criteria.

Results

The systematic review identified one study, which found more favorable scores on the Decisional Conflict Scale's Informed subscale among women in the decision aid group than in the comparison group. No differences were found in the Uncertainty and Efficacy subscales. This decision aid met few IPDAS criteria: 22% for Content, 55% for Development, and 14% for Effectiveness domains. In contrast, the environmental scan identified 49 decision aids, which appeared to have been created by entities without specialist expertise in decision aid development, including abortion services (n=32) and reproductive health-related organizations (n=7). On average, these tools met 28% of IPDAS criteria for Content, 22% for Development, and 0% for Effectiveness domains.

Conclusions

This study found that only one decision aid on early abortion methods has been evaluated, while many tools that met the Cochrane definition are highly accessible. Although their quality scores are suboptimal, notably, some decision aids identified through the environmental scan were of higher quality than the evaluated decision aid. This study raises important questions about what constitutes a decision aid, the utility of academic definitions of decision aids when applied more broadly, and the validity of IPDAS for appraising tools created by developers without specialist expertise. Lastly, it provides insights germane to the continuing issue of decision aid certification.

Implementing a Shared Decision Making tool in diverse U.S. healthcare systems: it takes champions and integration.

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Background and aims

Shared decision making (SDM) is commonly recommended to improve the value of health care. Yet, little is known on the best way to incorporate SDM tools (decision aids) into a healthcare system. The Statin Choice decision aid (SCDA) is a tool to facilitate a discussion within the clinical encounter on the choice of starting a statin. The decision aid has been made available online and is embeddable within electronic medical record (EMR) systems for use in the clinical workflow. We aimed to implement the SCDA within healthcare systems and evaluate the components of successful implementation and barriers to that success.

Methods

Guided by the AIDED (Assess, Innovate, Develop, Engage, and Devolve) model of scale-up, we used surveys, Google analytics on online usage, and interviews to characterize 3 different healthcare systems in the United States. We then worked with an implementation team at each healthcare system including information technology (IT) personnel to support the implementation of SCDA over a 12-month period. Primary care clinicians were the focus of the evaluation. We evaluated this process using a theory-guided mixed methods approach.

Results

Starting in March 2015, the 3 healthcare systems began the process of implementing the SCDA into their workflows and educating personal on its availability and use. Participating systems were: a system with 86 clinicians with low engagement from implementation team and high IT engagement (system A); a large system with 84 clinicians with high engagement from implementation team and high IT engagement (system B); and a smaller system with 26 clinicians with high engagement by implementation team and low IT involvement (system C). Two of the health systems incorporated the SCDA into their EMR whereas system C provided a desktop browser link. Clinicians use of the decision aid increased over time from 33% occasional-to-routine use of SCDA at baseline to 59% at 6 and 63% at 12 months (P<.001). System C clinicians used the tool, on average, 5.2 times per month, whereas usage was 0.6 in system A and 2.0 uses per month in system B.

Conclusion

The level of leadership engagement did not impact uptake and dissemination of the decision aid, whereas engagement by the implementation team was critical. While EMR integration seems vital in large systems, an engaged clinical team was sufficient to support uptake in a smaller healthcare system.

A validated measure of the user-centeredness of patient decision aid development

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Background

Although international standards stipulate that patients and clinicians should be involved in patient decision aid development, there is little guidance beyond this broad recommendation. Using a framework of user-centered design, we derived a measure of the user-centeredness of current practices for involving patients and other stakeholders in the development of patient decision aids and other patient-oriented tools.

Methods

Our team of patients, caregivers, clinicians, decision aid developers, and researchers conducted a systematic review according to the Cochrane Handbook and PRISMA reporting guidelines. Eligible articles described the development of a patient decision aid or the application of user-centered design to other types of patient-oriented tools. Two independent reviewers screened the references and extracted data from selected articles in a structured data extraction form based on our user-centered design framework, discussing questions at regular team meetings. We merged articles describing different aspects of the same project and contacted authors to validate data. We then analyzed how items related to the user-centeredness of the decision aid development might be combined and used as a scale. To do this, we prioritized items according to their importance within our framework, identified which items formed a positive definite matrix of tetrachoric correlations, and conducted principal component analysis with Varimax rotation, classical item analysis, and confirmatory factor analysis.

Results

From 83,441 potential articles identified in 3 large searches, we retained 579 total articles describing 390 projects of which 348 contained development data. Within this dataset (n=348), out of 19 identified potential items, we retained 11 items in a 3-factor structure explaining 68% of the variance in the data. Factor "pre-prototype involvement" included 2 items: whether patient, family, caregiver or surrogate users were involved in steps to understand users or to develop a prototype. Factor "iterative responsiveness" included 5 items: whether users were asked their opinions, observed using the tool, or involved in steps intended to evaluate the tool, whether the development process had 3 or more iterative cycles, and whether changes between iterative cycles were explicitly reported. Factor "other expert involvement" included 4 items: whether health professionals were asked their opinion, whether health professionals were consulted between initial and final prototypes or before a final prototype was developed, and whether an expert panel was involved. Cronbach's alpha for all 11 items was .72. Classical item difficulty parameters ranged from .28 to .85 and discrimination indices from .29 to .46. Confirmatory factor analysis demonstrated that a second-order model

provided an acceptable to good fit (SRMR=.09, GFI=.96, AGFI=.94, NFI=.93), supporting our hypothesis of a latent construct of user-centeredness that explains the three factors.

Conclusions

Development methods for patient decision aids and other patient-oriented tools are diverse. Nonetheless, using our framework of user-centered design, we were able to derive an internally valid measure of user-centeredness of the development process. Further work will include determining whether the user-centeredness of the development process of patient decision aids is predictive of downstream effects such as increased knowledge and decreased decisional conflict.

Communication in CVD prevention: How can we make the 'absolute risk' concept more meaningful to patients?

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Background

Cardiovascular disease (CVD) prevention guidelines recommend medication for 'high risk' patients, based on their absolute risk of having a heart attack/stroke in the next 5-10 years. However, GPs report difficulties communicating absolute risk to patients, particularly: 1) low risk patients who may progress to high risk unless they make lifestyle changes; and 2) patients treated for isolated risk factors (blood pressure or cholesterol) who think they are high risk, but may actually be low risk when non-modifiable risk factors (age, gender) are taken into account through an absolute risk calculation. This study investigated how patients understand absolute risk communicated in different ways, to identify ways to make this concept more meaningful to patients and enhance SDM.

Methods

GPs recruited 25 patients with at least one CVD/lifestyle risk factor and varying medication history: never offered, refused, taking, or ceased medication. Participants were asked to 'think aloud' while using two online CVD risk calculators that presented absolute risk in different ways (e.g. 5-year vs 10-year risk, numerical vs verbal explanation), supplemented with semi-structured interviews before and after. They were informed that the calculators estimate pre-medication risk. Transcribed audio-recordings were coded using Framework Analysis.

Results

Absolute risk was well understood when explained verbally, but risk category (low, moderate, high) and the effect of lifestyle interventions were more meaningful to participants than the exact percentage risk. Credibility was questioned if the result did not match prior expectations. A 10-year timeframe aligned with perceptions of 'high risk' and intervention effects better than a 5-year timeframe, as the numbers were seen as too low over 5 years. Showing how CVD risk would increase at an older age had more emotional impact than comparisons to target/average risk. Those taking medication did not show great interest in the quantified effect of this on their pre-medication risk.

Conclusion

Absolute risk may be more meaningful to patients when shown over a longer timeframe with a verbal description, risk category, comparison to future risk if nothing changes, and the effect of lifestyle changes relevant to the patient. Low risk patients taking medication for isolated risk factors could be considered over-treated, but they may view medication as beneficial regardless of the number of CVD events avoided. Providing multiple risk formats to patients in general practice would improve SDM about CVD prevention.

Considering implementation during PDA development for implantable cardioverter-defibrillator replacement

A qualitative study

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Background

Every four to seven years, an implantable cardioverter-defibrillators (ICD) pulse generator needs to be surgically replaced. Most are automatically changed without eliciting patients' preferences. A patient decision aid (PDA) focused on the ICD generator replacement was iteratively developed in accordance with international standards by an integrated knowledge translation team (e.g., researchers, patients, family members, health care professionals). As part of the development process, this study aimed to elicit which features of the PDA and its use within current workflow are perceived to facilitate or hinder PDA implementation in clinical practice.

Methods

An interpretive description qualitative study was conducted. Potential PDA end-users were purposively selected. Semi-structured interviews were focused on: 1) current ICD replacement practices; 2) acceptability and usability of the PDA; and 3) implementation of the PDA for ICD replacement. Transcripts were analyzed using thematic analysis. Barriers and facilitators to PDA implementation were categorized according to Légaré and colleagues' (2008) taxonomy.

Results

Sixteen PDA end-users were interviewed including patients, spouses, nurses, electrophysiologists, a palliative care specialist and a psychologist. Preliminary analysis showed that current ICD replacement practices were characterized as *mechanized* whereby ICD replacement occurred routinely, influenced primarily by battery depletion. Subthemes representing current practices included inadvertent paternalism, not knowing the patient, influence of previous discussions, and inadequate documentation from encounters occurring outside the device clinic. The implementation of the PDA was identified as needing to fall within a *standardized* shared decision-making process. Subthemes representing implementation of the PDA included need for individualization, timing (with a distinction between the introduction of the option versus discussion of the option), team approach (including the patient and family), need for policies, procedures and guidelines, patient education, and staff training. To shift current practices to a shared decision-making process, participants identified that an invitation to discuss the option of ICD replacement is required – whether driven by the patient or the clinician. The most common barriers to PDA implementation were lack of applicability due to patient characteristics, lack of expectancy, and factors associated with the environment such as time and resources. The most common facilitator, noted by all participants, was the agreement that shared decision-making for patients facing ICD replacement is needed. The PDA was positively received and iteratively revised four times over the course of the interviews.

Conclusion

All participants believed the PDA to be a valuable intervention that could help facilitate a standardized SDM process for adult patients facing ICD pulse generator replacement. Preparing for implementation during the PDA development phase will allow us to design interventions to overcome perceived barriers and to capitalize on perceived facilitators during actual implementation.

How do patients contribute to healthcare choices in hypertension consultations: A review and synthesis of qualitative studies

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Background

Hypertension (high blood pressure) affects ~31% of people and is the leading preventable cause of premature death worldwide. Management includes lifestyle measures and / or medication. Shared decision making has the potential to support patients in making decisions about treatment. We set out to review and synthesise qualitative studies of patient's contributions to consultations about hypertension. Our aim was to develop conceptual understanding of how patients contribute to consultations about hypertension in order to understand how patient participation in healthcare choices can be better supported.

Methods

Results of comprehensive searches in multiple databases and grey literature were screened and data extracted by two reviewers; disagreements resolved with a third reviewer. Eligible studies were written in English, used qualitative methods of data collection and analysis, and reported on the phenomenon of interest (contribution of patients to healthcare encounters in which healthcare choices are being considered; ways in which patient contribution to consultations is facilitated or hindered by healthcare professionals; nature of patient contributions) from the perspective of patients with hypertension, healthcare professionals, or both .Study quality was assessed using CASP. Following a meta-ethnographic approach, the relationship between studies and themes/concepts within them was explored, before synthesizing study findings.

Results

Of 5402 articles identified, 24 studies were included. 20 reported patient perspectives. Most studies sought to understand how non-compliance with anti-hypertensives can be tackled. Six studies analysed consultation data. 18 studies describe routine healthcare; 6 studies report experiences of interventions in healthcare settings.

Typically, a passive role for patients within consultations for hypertension is described. Clinicians are viewed as experts, and take the active role within consultations.

Most patients have little expectation of involvement in treatment choices. Patients' limited understanding of hypertension, its risks and management are frequently described. Patients anticipate that healthcare professionals (HCPs) do not have time to answer their questions. Physicians discourage contributions non-verbally (e.g. poor eye contact) and verbally (e.g. lack of probing questions, closed questions). Some patients describe guilt about taking clinicians' time with an asymptomatic condition; often their concerns about hypertension are not raised. Trust in clinicians can help to overcome patients' reservations about treatments, and may inhibit patients' questions. Questioning a clinician's plan can be perceived as confrontational and uncomfortable by patients. Patients who are 'non-adherent' describe unhelpful communication with their HCPs characterized by mistrust. In one study, a communication intervention enabled frank conversations in the uncomfortable zone in which clinician and patient views conflict. Decision aids and home blood pressure monitoring both appear to have the potential to empower patients to contribute to consultations.

Conclusions

Analysis and synthesis of the results is ongoing; preliminary findings are reported here and the full analysis will be available at conference. Consultations for hypertension are described as following a biomedical agenda in which compliance with treatment is the implicit aim. Patients usually adopt a passive role within consultations. An in-depth understanding of the patient's understanding of hypertension and its treatments is not achieved, and it is unusual for patients to expect a role in their treatment choices.

Individual effects for Well Informed Shared Decision Making for Atrial FIBrillation thromboembolic prophylaxis: WISDM for A FIB

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Background and aims

Options for prevention of embolic stroke in patients with atrial fibrillation include anticoagulants (apixaban, dabigatran, edoxaban, rivaroxaban, warfarin), antiplatelet agents (aspirin with or without clopidogrel), and left atrial appendage closure. Comparisons of options have limited accuracy for individual decisions due to selective use of evidence for relative risk estimates, not applying relative risk estimates to individual risk, or misalignment of outcomes used for relative risk and individual risk estimates. Accurate individualized estimates must be communicated clearly for clinicians and patients to make informed decisions.

A brief description of methods

We used DynaMed systematic literature surveillance to identify meta-analyses and randomized trials for eight options. For aspirin and warfarin, we extracted relative risk estimates compared to no treatment for ischemic stroke and for major bleeding. For clopidogrel plus aspirin, we extracted relative risk estimates compared to aspirin. For all other options, we extracted relative risk estimates compared to warfarin. We selected CHA2DS2-VASc and HAS-BLED scores as the most accurate predictors for individual risks for embolic stroke and major bleeding, and developed an interactive form to view an individual's estimated annual risk of embolic stroke and major bleeding with selected treatment options. We used Option Grid™ decision aid methods to present the results for patient use for shared decision making support.

A summary of results to support conclusion/s

See www.WISDMforAFIB.com for an online tool providing clinician-facing and patient-facing information. The tool includes best estimates for relative risks of ischemic stroke and major bleeding with each option, expression of absolute risks and number needed to treat or harm for clinicians, and for patients these concepts are express in numbers per 1000 people.

A conclusion

Use of WISDM for A FIB can provide accurate, individualized estimation of benefits (in terms of embolic stroke prevention), harms (in terms of major bleeding and other complications), and burdens (descriptions of use of the treatment) to facilitate shared decision-making.

Development of an OMERACT core set of outcome domains to assess shared decision making interventions in rheumatology

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Background and aims

Shared decision making (SDM) has been shown to improve decisional outcomes and patient-physician communication and holds great potential for improving the management of various rheumatology conditions. However, the lack of consensus on how to measure the effectiveness of SDM process and outcomes in clinical trials creates a barrier to further evaluation of SDM interventions. Members of the SDM Outcome Measures in Rheumatology (OMERACT) working group sought to determine the core set of outcome domains and subdomains for measuring the effectiveness of SDM interventions in rheumatology clinical trials.

Methods

The OMERACT SDM working group followed the OMERACT Filter 2.0 and developed a draft core set of SDM process and outcome domains based on a previous systematic review of SDM and a nominal group process conducted at the OMERACT 2014 meeting. More recently, the working group conducted an international two-round electronic Delphi consensus survey among patients with various rheumatology conditions, caregivers, clinicians and researchers to refine the domains and subdomains of the OMERACT draft core set on a nine-point Likert scale, using the GRADE process and the RAND appropriateness rating system. Subdomains were included in the potential core set if at least 70% of participants found them critically important (rankings of 7 – 9). A workshop was later held at the OMERACT 2016 meeting in which a presentation on SDM, its domains and subdomains derived from the literature and the Delphi survey was given. Two clinical vignettes in the form of skits, one with a high level of SDM behaviours and one with a low level, were performed to help attendees identify SDM outcome domains. Attendees were then divided into breakout groups to discuss the core set. A vote was conducted at a final plenary session.

Results

A total of 170 participants completed Round 1 of the Delphi survey and 116 completed Round 2. Respondents came from 29 countries with 49% being patients/caregivers and 60% having some experience with SDM. 14 of 17 subdomains (within seven domains: identifying the decision, understanding the information, clarifying values, deliberating, making the decision, putting the decision into practice, impact of the decision) exceeded the 70% criterion for both clinicians and patients (endorsement ranged from 83% to 100% of respondents). At the OMERACT 2016 meeting, 8% of the 96 attendees were patients/caregivers. Despite initial votes of support for the core set in breakout groups, workshop attendees did not endorse the set of seven domains and related subdomains (endorsement ranged from 17% to 68% of participants).

Conclusion

Lack of agreement regarding the proposed set of domains and subdomains may be explained by the manner in which the outcomes were presented (emphasis on domains vs. subdomains), variations in participant characteristics (patients vs. clinicians, level of expertise in SDM) and the context of voting (electronic Delphi survey vs. face-to-face meeting). Further efforts are needed to address the methods that would help reach consensus on a core set as well as the limited understanding of SDM and its outcomes among stakeholders in OMERACT and in other organizations.

Evaluating CollaboRATE in a clinical setting: analysis of mode effects on scores, response rates, and costs of data collection

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Background and aims

Shared decision making (SDM) has become a policy priority, yet its implementation is not routinely assessed. To address this gap we tested the delivery of CollaboRATE, a 3-item patient reported experience measure (PREM) of SDM, via multiple survey administration modes. Our aim was to assess CollaboRATE response rates and respondent characteristics across different modes of administration, impact of mode and patient characteristics on SDM performance and cost of administration per response in a real world primary care practice.

Methods

The observational study design featured assessment of SDM performance using CollaboRATE in a primary care clinic over 15 months of data collection. Different modes of administration were introduced sequentially including paper, patient-portal, interactive voice response (IVR) call, text message, and tablet computer. All consecutive patients ≥18 years, or parents/guardians of patients <18 years, visiting participating primary care clinicians were eligible to complete CollaboRATE. The CollaboRATE measure assesses three core SDM tasks: (1) explanation about health issues, (2) elicitation of patient preferences, and (3) integration of patient preferences into decisions. Responses to each item range from 0 (No effort was made) to 9 (Every effort was made). CollaboRATE scores are calculated as the proportion of 25 patients who report a score of nine on each of the three CollaboRATE questions. We calculated mean CollaboRATE top scores, response rates, and costs of data collection by mode, in addition to calculating CollaboRATE top scores at the individual clinician level.

Results

There were 4,421 patients who completed the CollaboRATE survey over 15 months of data collection between April 2014 and October 2015, resulting in an overall CollaboRATE top score of 68% for the clinic. Respondents were slightly older than non-respondents across all modes and represented the overall clinic population with regard to gender. Respondents were slightly more likely than non-respondents to be seen for an annual wellness visit in the patient-portal and SMS modes. Scores appeared to be sensitive to mode effects; the paper mode had the highest average score (81%) and IVR had the lowest (61%). However, relative clinician performance rankings were stable across the different data collection modes – as shown in figure. Tablet computers administered by research staff had the highest response rate (41%), although this approach was costly ($ per completion). The lowest response rate was associated with administration of the survey by clinic staff at exit (12%).

Conclusion

CollaboRATE can be introduced using multiple modes of survey delivery and has produced consistent clinician rankings. This may allow routine assessment and benchmarking of clinician and clinic SDM performance.

Exploring the use of encounter patient decision aids and a short patient experience measure of shared decision making in LuxMed clinics, Poland

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Background

Option Grid[TM] decision aids are brief tools designed to help engage clinicians and patients in evidence-based conversations about healthcare decisions. A patient-reported measure, known as **Collabo**RATE, includes three questions that measure how well clinicians execute share decision making (SDM). The aim of the current project was to evaluate the impact of using Option Grid and CollaboRATE on patient engagement in medical decision making in routine clinical settings in Poland.

Methods

Thirteen clinicians participated in a cross-sectional pre-post interventional study conducted at three LUX MED clinics in Warsaw, Poland. In preparation for the study, Option Grid decision aids covering three conditions with a high patient volume (knee osteoarthritis, considering statins, and heartburn) were translated into Polish and tested using cognitive debrief interviews. All patients over 18 years old visiting one of 13 participating clinicians were invited to take part. In the baseline phase, all patients were asked to complete CollaboRATE on a tablet computer immediately after seeing their clinician. After collecting baseline data, participating clinicians received a one-hour training session on obtaining patient consent, understanding basic principles of SDM, and using Option Grid. In the intervention phase, the decision aids were used with eligible patients during the clinic visit. Patients in the intervention phase (including those who did not use Option Grid) were also asked to complete CollaboRATE. We also compared the baseline and intervention Net Promoter Score (NPS), a patient satisfaction score routinely collected by LUX MED. In the intervention phase, a survey about the clinicians' experiences using Option Grid assessed clinicians' attitudes towards using Option Grid in clinical practice. Top score results were calculated for each patient condition and clinic. CollaboRATE top score percentages and NPS were also calculated for each clinician, and survey results summarized. The Wilcoxon Signed Rank test was used to investigate the pre-post comparisons.

Results

The preliminary analysis indicates that clinician scores, across both phases, vary considerably - from a low of 26% to a high of 92%. CollaboRATE scores varied by clinic and by patient condition. Two of the three participating clinics saw a statistically significant decline in their top score percentages. The impact of introducing the tool seemed to vary across clinicians. Five clinicians achieved higher CollaboRATE scores after being introduced to the tool, while others did not have their scores change, or saw their CollaboRATE scores decline. Data from a post-intervention survey indicated divergent clinician opinion about the acceptability and utility of Option Grid, which may help to interpret the mixed effect of introducing the tool. According to the survey, seven clinicians had a positive view of Option Grid, and five clinicians had a negative view. Two clinicians saw an increase in their NPS score, while eleven clinicians saw their NPS score decrease in the intervention phase.

Conclusion

Option Grid helped some clinicians achieve higher CollaboRATE scores, while others had scores that remained the same or declined. Clinician attitude and the extent to which Option Grid was implemented at each clinic may have influenced CollaboRATE scores given to clinicians by patients.

Illuminating patient push in the 'black box' of shared decision making

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Background and aims

Meaningful measurement of shared decision making (SDM) in practice continues to be problematic, with different informants often providing different accounts of the same clinical encounter. This study aimed to better understand what contributes to these challenges by exploring what actually happens during a clinical encounter. Current measures of SDM focus primarily on clinician behaviours; here, the extent to which patients engage in decision making was of particular interest.

Methods

Mixed-methods (video ethnography; patient and clinician interviews and questionnaires), with deductive and inductive analysis of a diverse sample of 40 video-recorded patient consultations with four primary care and six secondary care clinicians. Secondary care decisions included joint replacement, birth after caesarean section and menorrhagia. An extended version of the OPTION-12 observation tool, and coding of verbal and non-verbal behaviours, provided the framework for identifying key SDM and relational behaviours in both clinician and patient. Dichotomising consultations as 'higher' or 'lower' scoring, based on overall OPTION-12 mean score, enabled sub-group comparisons of participant characteristics, SDM actions, and interpersonal communication behaviours. Video transcripts, researcher field notes and interview data were analysed thematically. Triangulated findings provide a unique, multiple-lens insight into the 'black box' of SDM.

Results

Previously uncaptured elements of SDM were observed, emphasising an inherent patient role: SDM was practiced and initiated by both clinician and patient, and was delivered interactionally. Overall mean OPTION-12 score (sd) = 33/100 (22), range 0-75. Primary care patients prompted clinician behaviours across the OPTION-12 spectrum. In both settings, and predominantly so in secondary care, their prompts initiated discussion of expectations and concerns, and invitation of questions. Patients spontaneously asked unsolicited questions, volunteered concerns, and identified the problem requiring a decision making process. The most frequent verbal behavior in patients was 'giving information', but this went beyond responding to a clinician's question. Patients primarily 'told their story', situating the clinical problem within their personal context. Clinicians were distributed between low/high OPTION-12 sub-groups (mean score (sd)=15(8) & (52(14) resp.), but patients in the low group were older, largely male, and of lower education. Clinicians' verbal behaviours were consistent across sub-groups, and patients in both groups 'gave information' frequently. High sub-group patients more frequently 'registered information', and both patients and clinicians demonstrated higher frequencies of non-verbal behaviours signaling attentiveness (e.g. nodding, continuous eye contact). Inductive analysis of interview and video transcripts, and questionnaire reports of SDM in practice, lend context to these findings. Key features of the decision making process that patients prioritise (being listened to, account of personal circumstances) are highlighted

Conclusions

This in-depth analysis shows that patients play an active and central role in negotiating SDM. Future measures should capture this activity. However, measuring SDM behaviours alone may be insufficient as interactional attributes also appear key to supporting an SDM process. Since patients reflect their sense of involvement in SDM in relational terms, incorporating this perspective would further enhance the development of a truly person-centred measure of SDM in practice.

Evaluation of a Novel Preference Assessment Tool for Patients with Multiple Sclerosis

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Background

We previously developed a Preference Assessment Tool to help assess patient goals, values and preferences for multiple sclerosis (MS) management. All preference items included in the tool were elicited, prioritized, and organized by people with MS. We sought to validate this tool in a national sample of people with MS.

Methods

English-speaking patients with MS between the ages of 21 and 75 who had access to the Internet were recruited for the study. Participants completed the preference tool online, which included separate modules to assess three core preference areas: treatment goals, preferences for attributes of disease modifying therapies (DMT), and factors influencing a change in treatment. The tool generated a summarized overview of participants' goals and preferences. Immediately after viewing the summary, participants were asked to evaluate the tool.

Results

135 people who self-identified as having MS completed the online tool and evaluation. The highest ranked treatment goals were brain health (memory, thinking, and brain), followed by disability concerns (walking, strength, vision).

After viewing the summary of their prioritized goals and preferences, the overwhelming majority of participants reported that the preference summary reflected what matters most to them when it comes to treating their MS. 95% of participants reported that the tool represented their treatment goals "very well' or "extremely well". Nearly all participants stated that completing the tool helped them understand their goals and priorities regarding MS. Nearly all reported that the summary overview appropriately reflected the issues important to them, with the majority (54-63%) reporting that the process was either very helpful or extremely helpful. Most participants (87%) reported that they would like to discuss their treatment goals and priorities with their MS health care provider (HCP), but over a third (37%) reported that they do not routinely share their goals and priorities with their HCP. Most (75%) reported that it would be either very helpful or extremely helpful if their MS HCP were aware of their treatment goals and priorities.

Conclusion

A majority of MS patients participating in this study reported that our MS Preference Assessment Tool accurately summarized what mattered to them regarding their treatment goals, preferences for DMTs, and decisions about changing treatments. Our study findings suggest that this tool could be used to facilitate communication of patient preferences to their HCP.

Shared decision making in stroke services; an implementation study

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Background

During the rehabilitation and the chronic phase of stroke, patients receive multidisciplinary care from several organizations that cooperate in integrated stroke services. To provide care that matches preferences and values of stroke patients and their relatives, it is important that patients are actively involved in decisions about treatment options, healthcare professionals and the setting in which care takes place. However, stroke can limit patients' understanding of the complex information about care options and their probable outcomes and these consequences can impede patient participation in the decision-making process.

Aim

The aim of this project is to improve shared decision making (SDM) about treatment options, choice between healthcare professionals and the care setting for stroke patients in the rehabilitation and chronic phase and their relatives. To that end, SDM will be implemented in four stroke care services in the Netherlands by means of a stroke specific implementation program, consisting of tailored decision aids for stroke patients and relatives, a social map of possible local and regional professionals, training of healthcare professionals and implementation support.

Methods

The implementation program is carried out in four stroke services in The Netherlands. For each stroke service, the current stroke care pathways and the network of healthcare providers from both the rehabilitation center and the primary care practices are mapped. Previously developed decision aids for treatment options are made accessible for patients with aphasia or cognitive problems. The implementation program for SDM is developed by the project team in collaboration with the local teams of professionals, patients and relatives. To evaluate the effectiveness of implementation, the extend of SDM is measured using the Option5 and Shared decision Making Questionnaire-9 (SDMQ-9) at the start and the completion of the program. During and after implementation, barriers and facilitators for implementation are gathered by means of in-depth interviews with professionals, patients and relatives.

Results

Each local team will set objectives for change for key interventions in the stroke care pathway optimizing SDM. Specific goals are defined on patient information and education, use of decision aids and on necessary professional skills. The implementation program addresses the team's objectives, preference-sensitive decisions in the stroke care pathways and previously identified barriers and facilitators. To support SDM about treatment options, the teams use the adapted decision aids. To support SDM about choosing healthcare providers, the teams use social maps of the expert healthcare providers networks. Healthcare providers are trained in required skills for SDM with stroke patients suffering from aphasia or cognitive problems. This study will provide insight in facilitators and barriers of implementation of SDM in stroke services. The design of this study makes it possible to evaluate the feasibility of several interventions aiming for the implementation of SDM in stroke care.

Conclusion

A comprehensive SDM program for stroke care will be developed and implemented in collaboration with professionals of four local stroke services. Lessons learned will be used to further improve SDM in stroke care in the Netherlands.

Supporting patient-centered care; making knowledge tools more accessible to patients, and professionals

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Background and aims

In dealing with the informational overload in healthcare, we started developing knowledge tools like guidelines, protocols, care pathways and decision aids to help providers and patients decide on their care and options therein. However, in developing these tools we might have gone into overdrive with different types. For example, a scoping review carried out in the Netherlands yielded 51 tool types; excluding tools developed at a local level, and tools outside curative care. Furthermore, descriptions of these tools were often incomplete or missing. Leaving providers mostly confused when to use which tool, and making it hard for developers to decide which tool needs to be developed for whom and for which purpose/aim. A group of international experts – recognizing the Dutch situation - set to the task to develop a framework of patient direct knowledge tools (a part of the tool set) to improve patient engagement and help knowledge tool developers decide which tool to develop.

Methods

Two-day invitational pressure cooker meeting with experts in knowledge tool-development, implementation and decision-making: T. Agoritsas; G. Elwyn; S. Flottorp; A. Gagliardi; S. Hill; L. Kremer; F. Légaré; R. Ryan; N. Santesso; D. Stacey; A. Stiggelbout; S. Treweek; P. Vandvik. Before the invitational took place, articles, and an overview of tools with definitions were provided to the participants to ensure a shared knowledge base.

Results

A framework stating purposes of (see table) and describing the core ingredients of 7 knowledge tool types directed at patients.

PURPOSE	PATIENT DIRECT KNOWLEDGE TOOLS							
	EDUCATION MATERIAL	PATIENT GUIDELINES	INDEPENDENT DECISION AID	ENCOUNTER PATIENT AID	DECISION TREE	CONTENT QUESTION PROMPT LIST	CARE MAP / clinical pathway	DECISION BOX
Information provision (& educate)	+	+	+	+	+	+	+	+
Provide recommendation		+			+		+	?
Support decision making			+	+	+		?	+
Engage into SDM				+		+	?	+

Conclusions

By stating which purpose(s) the tools serve, their use by professionals and patients could be improved, which could have an effect on patient engagement in the healthcare process. By stating the purpose and core ingredients, tool developers can choose the right tool for the right job, and include the necessary ingredients. The framework contributes to clarity on:

- Which tool to develop - next to a guideline - to involve patients in decision-making.
- Core ingredients of knowledge tools aimed at patients.
- Which effect outcomes of the tools are supported by evidence.

Different/unclear definitions of knowledge tools complicated discussions. There doesn't appear to be a clear line between transferring knowledge just to inform the patient, or with the intention to engage/support in decision-making. Questions that were raised: should the framework be descriptive or prescriptive? How to distinguish between core ingredients and presentation formats of the tools? And should we consider knowledge tools based on SRs and/or evidence summaries instead of guidelines? Especially considering that preferably these tools are based on guidelines; while guideline provide recommendations and decision aids are to discuss options. Are they contrary to one another?

The framework is not finished, it needs to be further discussed, probed, tested and tweaked. During the workshop the framework and questions that were raised (and went unanswered) during the invitational will be presented and discussed, after which the participants are asked to discuss in (subgroups) and advice on how to improve and advance the framework.

A three goal model for patients with multimorbidity

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Background
Health care policymakers are increasingly supporting the provision of goal-oriented care. There remains however a need to develop more insight about the concept and how to implement this approach in clinical practice.

Objective
This study aims to develop conceptual descriptions of goal-oriented care by examining the perspectives of general practitioners and clinical geriatricians, and how the concept relates to communication and shared decision-making with elderly patients who have multiple long term conditions.

Method
Qualitative interviews were conducted with general practitioners and clinical geriatricians and analyzed using thematic analysis.

Results
We describe three key themes: 1. Clinicians drew distinctions between different types of goals, namely disease-specific or symptom-specific goals, functional goals, and fundamental goals 2. The consideration of fundamental goals, and 3. The relevance of explicit goals for decision-making. Based on analysis, we describe the concept of 'fundamental goals' as goals specifying a patient's priorities in life, such as their values and core relationships, thus, topics that serve as reference points for decision-making.

Conclusion
Based on the perspectives of clinicians we expanded the concept of goal-oriented care by identifying a three-level goal hierarchy acting as a guide in clinical care of patients with multiple long term conditions. The developed three goal model may provide an important guide for collaborative goal-setting in clinical practice and it's use could support shared decision-making. Future research is needed to refine and validate this model and to provide recommendations for medical training and practice.

Note: A paper presenting the data in detail is submitted to Health Expectations.

Objectives of drug prescription in primary care: how much sharing between patients and doctors?

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Background and aims:
According to a goal-oriented medical care approach, one key element to any prescription process is to define the objectives of the prescription. Discussing these objectives between the physician and the patient in order to reach an agreement on them can support a shared decision making.
The aim of this study was to measure the level of agreement between the objectives of the physician and those of the patient in the drug prescription process in primary care.

Methods:
We conducted a multicentre, cross-sectional study in the Rhône-Alpes region. Investigators were 11 interns in general practice training, under the direct supervision of 23 GP-trainers. Data were collected during one full consultation day, specific to each GP-trainer in December 2015. For each consultation included, the investigating interns listed on a paper questionnaire all the health problems managed and the drugs prescribed for each of them. At the end of the consultation, the intern asked separately to the GP and the patient to indicate the main objective of each drug prescription, among a classification of eight pre-defined objectives. This classification included the following objectives: mortality risk decrease, morbidity risk decrease, disease cure or remission, symptoms improvement, quality of life improvement, functional status improvement, other objective, no objective. The interns secondarily recorded the data collected into a centralized database via a Web server. We calculated the Cohen's kappa coefficient of agreement on the main objective of drug prescriptions between GPs and patients.

Results:
The sample included 355 consults and 1129 prescribed drugs with their related objectives. The main objectives reported by the patients were symptoms improvement (32.6 %), quality of life improvement (22.1 %) and disease cure or remission (16.6 %). The main objectives reported by the GPs were symptoms improvement (45.8 %), morbidity risk decrease (22.7%) and disease cure or remission (10.7 %). Among drug prescriptions, 488 (44.2%) were referred to the same objective by the doctor and the patient and the kappa coefficient was equal to 0.26 (0.23-0.30), which means a poor level of agreement. The main disagreement was about the quality of life improvement (22.1 % for patients vs 10.4 % for GPs).

Conclusion:
The poor level of agreement between the objectives of the doctors and those of the patients regarding drug prescription suggests that shared decision-making is not fully effective yet in primary medical care, even when provided by university trainers. The classification used to describe the main objectives of prescription proved to be simple and operational.

Parallel Session 04
Tuesday 4th
14:00—15:30

Methodological issues	Room Amphi B, CIER
SDM and decision aids	Room 106, CIER
Measuring SDM	Room 107, CIER
SDM and person-centered care	Salle de conférence Médiathèque
SDM and breast cancer screening	Room Salle du Conseil

ISDM 2017

Tolerance of uncertainty: conceptual analysis, integrative model, and implications for healthcare

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Background and aims

Uncertainty tolerance (UT) is an important, well-studied phenomenon in health care and many other important domains of life, yet its conceptualization and measurement have varied substantially and its essential nature remains unclear.

Methods

A narrative review and conceptual analysis of 18 existing measures of Uncertainty and Ambiguity Tolerance was conducted, focusing on how measure developers have defined both the "uncertainty" and "tolerance" components of UT—both explicitly through their writings and implicitly through the items constituting their measures.

Results

The analysis showed that definitions of uncertainty and tolerance vary substantially and are often poorly and inconsistently specified, and a logically coherent, unified theoretical understanding of UT is lacking. To address these gaps, we propose a new integrative definition and multidimensional conceptual model that construes UT as *the set of negative and positive psychological responses—cognitive, emotional, and behavioral—provoked by the conscious awareness of ignorance about particular aspects of the world.* This tentative and flexible model, intended as a point of departure for future research, adds needed breadth, specificity, and precision to efforts to conceptualize and measure UT.

Conclusion

We discuss how the model can facilitate further empirical and theoretical research to better measure and understand the nature, determinants, and outcomes of UT in health care and other domains of life.

A Realist Synthesis of the Shared Decision Making Literature

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Rationale

Shared Decision Making (SDM) is a method of medical decision making that involves a balanced relationship between patients, physicians, and other key players. SDM is purported to improve patient and system outcomes but there are gaps in the current literature between theory and implementation

Methods

We conducted a realist synthesis of the SDM literature to identify "in which situations, how, why, and for whom does SDM between patients and health care providers contribute to improved decision making?" A six step iterative process was used that included: preliminary theory development, establishment of a search strategy, selection and appraisal of literature, data extraction, analysis and synthesis of extracted results from literature, and formation of a revised program theory with the input of patient, physician, nurse navigators, and policy maker from a stakeholder session.

Results

A complex mix of interrelated mechanisms in three domains (health care provider, patient and system support) was identified that interacts with the context of the degree of difficulty of a given decision to result in an intermediate outcome of ability to engage in the SDM process which in turn represents the primary mechanism responsible for a patient having a successful patient informed health decision outcome.

Conclusion

Our realist synthesis resulted a program theory for SDM through the identification of mechanisms which shape the characteristics of when, how, and why SDM will, and will not, work that will be tested empirically in a variety of contexts, the first of which will be the Saskatchewan Indigenous context.

Interventions for improving shared decision making among healthcare professionals (a Cochrane review update)

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Background

Shared decision making (SDM) respects patient rights, has the potential to reduce overuse of options not associated with benefits for all, and may optimise use of diagnosis tests and treatments. However, SDM is not yet part of routine clinical practice. We sought to determine the effectiveness of interventions for improving SDM among healthcare professionals (HCPs).

Methods

This is our third update of a systematic review. We searched for primary studies in *The Cochrane Library*, MEDLINE, EMBASE, CINAHL, the Cochrane Effective Practice and Organisation of Care (EPOC) Specialized Register and PsycINFO from August 2012 to December 2014. We scanned the Clinical Trials.gov registry and conference proceedings. We included randomised and non-randomised trials, controlled before-and-after and interrupted time-series studies. Participants were HCPs and patients. We included studies that evaluated any intervention designed to improve SDM among HCPs. Interventions were categorised as follows: 1) interventions targeting patients, 2) interventions targeting HCPs, and 3) interventions targeting both. Within each category, we examined the outcome of the intervention compared to usual care and/or to another intervention (head to head), resulting in six comparison groups. Our primary outcome was improved SDM among HCPs as assessed using observer-based outcome measures (OBOM) or patient-reported outcome measures (PROM). We performed a meta-analysis where there were enough studies and quantitative data to make the calculations. We calculated the standardized mean difference (SMD) for continuous outcomes and risk difference for categorical outcomes. We applied GRADE to assess the strength of the evidence.

Results

64 studies were included (25 new studies since our last update), including 63 randomised and one non-randomised controlled trial. In OBOM studies, interventions that targeted patients alone had a positive effect compared to usual care (SMD of 0.93; 95% CI: 0.50 to 1.36), as did those targeting HCPs alone (SMD of 1.08; 95% CI: 0.15 to 2.01). OBOM results also suggest that interventions targeting both patients and HCPs perform better than usual care (SMD of 1.41; 95% CI: -0.17 to 2.99). In PROM studies, only interventions targeting patients performed better than usual care (SMD of 0.32; 95% CI: 0.09 to 0.54). Other comparisons provided no evidence of the interventions having a significant effect. OBOM studies comparing interventions targeting patients with other interventions targeting patients suggest that some of these perform better than others (SMD of 1.13; 95% CI: 0.82 to 1.43), e.g. decision aids work better than booklets and pamphlets.

Overall, the quality of the evidence for the primary outcome of interest as assessed with GRADE ranged from very low to moderate.

Conclusion

Interventions that actively target patients, healthcare professionals, or both, show stronger results than usual care. Also, interventions targeting patients and healthcare professionals together show more promise than those targeting only one or the other. Overall, pooled estimates of PROM study results were not consistent with OBOM study results. This could be explained by patients' misunderstanding of what constitutes SDM. Further research is needed to develop better patient-reported measures that involve patients in their development.

Shared Decision Making for Diagnostic Testing, A Systematic Review and Meta-analysis

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Background and aims

While multiple studies have evaluated shared decision making (SDM) interventions that assist patients in selecting among available treatment options, very few assist patients with diagnostic decisions. We conducted a systematic review and meta-analysis of SDM decision support interventions (DSIs) designed to assist patients in selecting among diagnostic options, including the option of foregoing testing.

Methods

An expert librarian, in collaboration with experts in SDM and systematic review methodology, designed and conducted a search of Ovid Medline, Ovid Embase, CENTRAL, and CINAHL databases to identify studies of DSIs intended for use in patients facing decisions about diagnostic testing. Two reviewers assessed studies for inclusion independently and in duplicate; conflicts were resolved through discussion or consultation with a 3rd reviewer. Studies eligible for inclusion were 1) original research studies; 2) published in the peer reviewed literature; 3) prospective and assessed a defined, reproducible SDM intervention; 4) reported objective measures of SDM; 5) compared the intervention to a control group; and 6) tested the intervention in participants who were truly facing the decision of whether to undergo a diagnostic or screening test (not a theoretical scenario). Reviewers extracted data on study characteristics, methodological quality, decision quality, and clinical outcomes.

Results

Seventy-three studies met eligibility criteria. Twenty-seven studies addressed prostate cancer, 16 breast cancer, 12 colon or colorectal cancer, 8 prenatal screening, 3 ovarian cancer, and 11 other clinical conditions. The most commonly reported outcomes were patient knowledge, decisional conflict and diagnostic test uptake. The pooled estimate of effect of the 35 studies that evaluated patient knowledge was +0.26% (0.22,0.29). The pooled estimate of the 16 studies evaluating decisional conflict was -0.39 (-0.33,-0.44). The 17 studies evaluating test uptake showed a variable direction of effect with a pooled estimate showing no effect on test uptake [-0.01 (-0.10,0.09)].

Conclusion

The majority of studies testing DSIs to facilitate SDM in diagnostic decisions have addressed cancer diagnosis(prostate, breast, and colon being the most common). The DSIs increased patient knowledge, decreased decisional conflict, and had no net effect on test uptake.

Knowledge

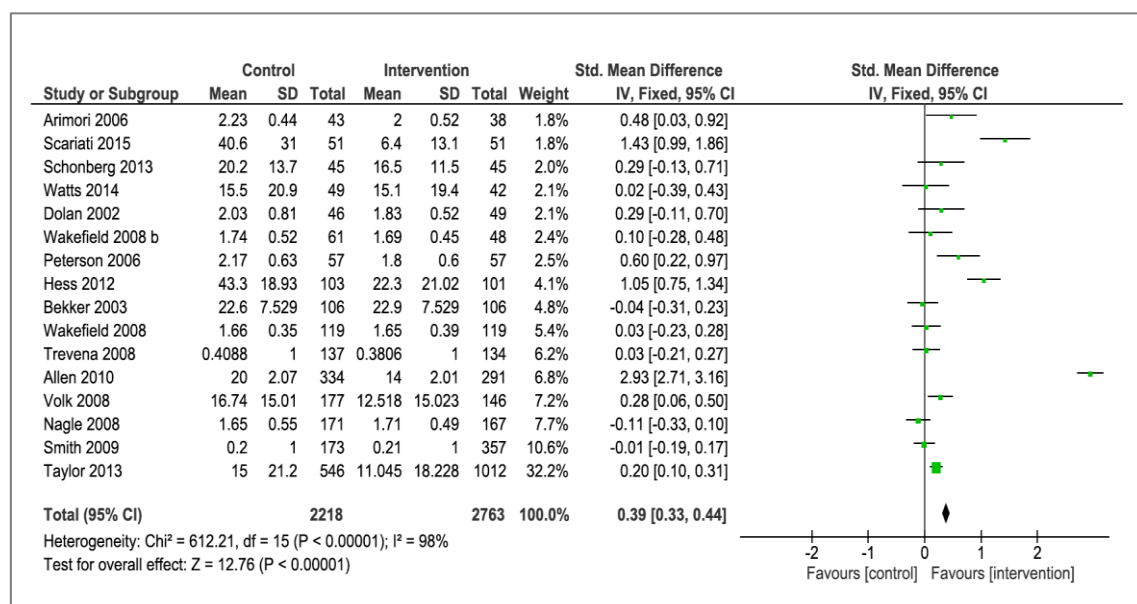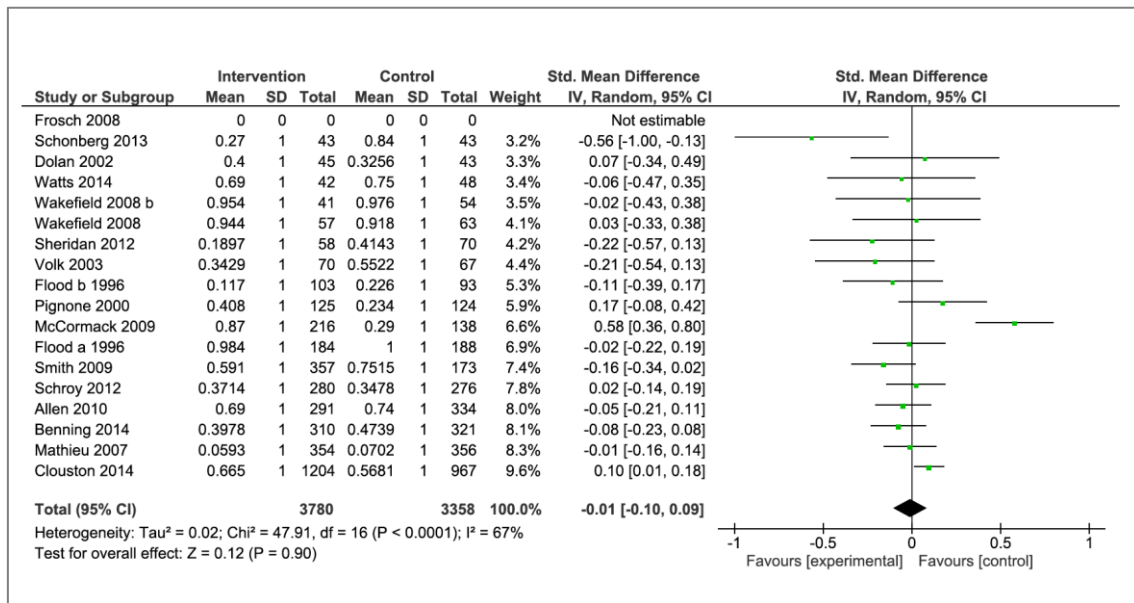| Study or Subgroup	Intervention Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Mancini 2006	102.9	12.32	230	95.3	11.01	11	0.3%	0.62 [0.01, 1.23]
Volk 2014	0.748	0.202	52	0.255	0.207	52	0.5%	2.39 [1.89, 2.90]
Bekker 2004	13.8	2.76	29	13.5	2.93	39	0.5%	0.10 [-0.38, 0.58]
Schonberg 2013	7.3	1.4	45	6.3	1.3	45	0.6%	0.73 [0.31, 1.16]
Watts 2014	8.2	1.6	42	8.1	1.2	47	0.7%	0.07 [-0.35, 0.49]
Stalmeier 1999	7.575	1.116	51	6.165	1.7211	51	0.7%	0.96 [0.55, 1.38]
Wakefield 2008 b	6.5	1.49	48	6.13	1.27	61	0.8%	0.27 [-0.11, 0.65]
Peterson 2006	0.7574	1	57	0.6637	1	57	0.9%	0.09 [-0.27, 0.46]
Green 2004	0.91	1	56	0.8	1	61	0.9%	0.11 [-0.25, 0.47]
Wakefield 2008	7.14	0.88	57	6.68	1.21	63	0.9%	0.43 [0.07, 0.79]
Sheridan 2012	0.47	1	58	0.13	1	70	1.0%	0.34 [-0.01, 0.69]
Volk 2003	0.384	1	70	0.3	1	67	1.0%	0.08 [-0.25, 0.42]
Flood b 1996	0.782	1	103	0.2666	1	93	1.4%	0.51 [0.23, 0.80]
Hess 2012	3.6	1.27	101	3	1.28	103	1.5%	0.47 [0.19, 0.75]
Bekker 2003	14.8	4.15	106	14.3	4.41	106	1.6%	0.12 [-0.15, 0.39]
Weinrich 2008	8.91	2.63	120	8.37	2.517	110	1.7%	0.21 [-0.05, 0.47]
Trevena 2008	0.209	1	134	0.058	1	137	2.1%	0.15 [-0.09, 0.39]
Mathieu 2007	0.94	1	113	0.83	1	189	2.2%	0.11 [-0.12, 0.34]
Frosch 2008	7.71	1.85	152	7.24	1.97	151	2.3%	0.25 [0.02, 0.47]
VanDenBergh 2009	0.514	1	889	0.3814	1	97	2.7%	0.13 [-0.08, 0.34]
Stephens 2008	20.95	2.88	200	18.125	3.14	200	2.7%	0.94 [0.73, 1.14]
Skjoth 2015	0.976	1	123	0.938	1	350	2.8%	0.04 [-0.17, 0.24]
Flood a 1996	0.6563	1	184	0.3073	1	188	2.8%	0.35 [0.14, 0.55]
Sheridan 2004	0.9333	1	188	0.5767	1	188	2.8%	0.36 [0.15, 0.56]
Bjorklund 2012	6.9	1.5	178	6.4	1.8	199	2.8%	0.30 [0.10, 0.50]
Schroy 2011	10.7	1.8	223	8.6	2.7	231	3.1%	0.91 [0.72, 1.10]
Smith 2009	0.5602	1	357	0.19	1	173	3.5%	0.37 [0.19, 0.55]
Partin b	0.717	1	295	0.685	1	290	4.5%	0.03 [-0.13, 0.19]
Partin 2004	0.729	1	308	0.685	1	290	4.5%	0.04 [-0.12, 0.20]
Allen 2010	66	35.48	291	60	29.24	331	4.7%	0.19 [0.03, 0.34]
Haakenson 2006	0.6586	1	420	0.4971	1	248	4.7%	0.16 [0.00, 0.32]
Mathieu 2010	0.766	1	351	0.569	1	357	5.4%	0.20 [0.05, 0.34]
Rimer 2002	0.245	1	339	0.14	1	378	5.4%	0.10 [-0.04, 0.25]
Taylor 2013	12.65	3.34	1006	11	3	544	10.4%	0.51 [0.41, 0.62]
Barry 2015	0.7094	1	1015	0.7049	1	1030	15.6%	0.00 [-0.08, 0.09]
Total (95% CI)			**7991**			**6607**	**100.0%**	**0.26 [0.22, 0.29]**

Heterogeneity: Chi² = 269.37, df = 34 (P < 0.00001); I² = 87%
Test for overall effect: Z = 14.79 (P < 0.00001)

Decisional Conflict

Study or Subgroup	Control Mean	SD	Total	Intervention Mean	SD	Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Arimori 2006	2.23	0.44	43	2	0.52	38	1.8%	0.48 [0.03, 0.92]
Scariati 2015	40.6	31	51	6.4	13.1	51	1.8%	1.43 [0.99, 1.86]
Schonberg 2013	20.2	13.7	45	16.5	11.5	45	2.0%	0.29 [-0.13, 0.71]
Watts 2014	15.5	20.9	49	15.1	19.4	42	2.1%	0.02 [-0.39, 0.43]
Dolan 2002	2.03	0.81	46	1.83	0.52	49	2.1%	0.29 [-0.11, 0.70]
Wakefield 2008 b	1.74	0.52	61	1.69	0.45	48	2.4%	0.10 [-0.28, 0.48]
Peterson 2006	2.17	0.63	57	1.8	0.6	57	2.5%	0.60 [0.22, 0.97]
Hess 2012	43.3	18.93	103	22.3	21.02	101	4.1%	1.05 [0.75, 1.34]
Bekker 2003	22.6	7.529	106	22.9	7.529	106	4.8%	-0.04 [-0.31, 0.23]
Wakefield 2008	1.66	0.35	119	1.65	0.39	119	5.4%	0.03 [-0.23, 0.28]
Trevena 2008	0.4088	1	137	0.3806	1	134	6.2%	0.03 [-0.21, 0.27]
Allen 2010	20	2.07	334	14	2.01	291	6.8%	2.93 [2.71, 3.16]
Volk 2008	16.74	15.01	177	12.518	15.023	146	7.2%	0.28 [0.06, 0.50]
Nagle 2008	1.65	0.55	171	1.71	0.49	167	7.7%	-0.11 [-0.33, 0.10]
Smith 2009	0.2	1	173	0.21	1	357	10.6%	-0.01 [-0.19, 0.17]
Taylor 2013	15	21.2	546	11.045	18.228	1012	32.2%	0.20 [0.10, 0.31]
Total (95% CI)			**2218**			**2763**	**100.0%**	**0.39 [0.33, 0.44]**

Heterogeneity: Chi² = 612.21, df = 15 (P < 0.00001); I² = 98%
Test for overall effect: Z = 12.76 (P < 0.00001)

Test Uptake

Study or Subgroup	Intervention Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Frosch 2008	0	0	0	0	0	0		Not estimable
Schonberg 2013	0.27	1	43	0.84	1	43	3.2%	-0.56 [-1.00, -0.13]
Dolan 2002	0.4	1	45	0.3256	1	43	3.3%	0.07 [-0.34, 0.49]
Watts 2014	0.69	1	42	0.75	1	48	3.4%	-0.06 [-0.47, 0.35]
Wakefield 2008 b	0.954	1	41	0.976	1	54	3.5%	-0.02 [-0.43, 0.38]
Wakefield 2008	0.944	1	57	0.918	1	63	4.1%	0.03 [-0.33, 0.38]
Sheridan 2012	0.1897	1	58	0.4143	1	70	4.2%	-0.22 [-0.57, 0.13]
Volk 2003	0.3429	1	70	0.5522	1	67	4.4%	-0.21 [-0.54, 0.13]
Flood b 1996	0.117	1	103	0.226	1	93	5.3%	-0.11 [-0.39, 0.17]
Pignone 2000	0.408	1	125	0.234	1	124	5.9%	0.17 [-0.08, 0.42]
McCormack 2009	0.87	1	216	0.29	1	138	6.6%	0.58 [0.36, 0.80]
Flood a 1996	0.984	1	184	1	1	188	6.9%	-0.02 [-0.22, 0.19]
Smith 2009	0.591	1	357	0.7515	1	173	7.4%	-0.16 [-0.34, 0.02]
Schroy 2012	0.3714	1	280	0.3478	1	276	7.8%	0.02 [-0.14, 0.19]
Allen 2010	0.69	1	291	0.74	1	334	8.0%	-0.05 [-0.21, 0.11]
Benning 2014	0.3978	1	310	0.4739	1	321	8.1%	-0.08 [-0.23, 0.08]
Mathieu 2007	0.0593	1	354	0.0702	1	356	8.3%	-0.01 [-0.16, 0.14]
Clouston 2014	0.665	1	1204	0.5681	1	967	9.6%	0.10 [0.01, 0.18]
Total (95% CI)			3780			3358	100.0%	-0.01 [-0.10, 0.09]

Heterogeneity: Tau² = 0.02; Chi² = 47.91, df = 16 (P < 0.0001); I² = 67%
Test for overall effect: Z = 0.12 (P = 0.90)

Std. Mean Difference IV, Random, 95% CI

-1   -0.5   0   0.5   1
Favours [experimental]   Favours [control]

Trustworthy Patient Decision Aids: A Qualitative Analysis Addressing the Risk of Competing Interests

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Background and Aim

Identifying and managing financial and intellectual competing interests are increasingly recognised as a vital step when producing clinical practice guidelines for professionals. When similar information is developed for patients, such as in the form of a decision aid, it becomes even more important to minimise competing interests. Our aim in this study was to examine the competing interest policies and procedures of organisations who develop and maintain patient decision aids.

Methods

A standard email outlining the study purpose and a request for documents related to competing interest policies and disclosure forms was sent to organizations identified as potential developers of patient decision aids. Descriptive statistics and thematic analysis were used to identify the competing interest procedures used by patient decision aid developers.

Results

Most, but not all, patient decision aid organisations recognize the need to consider the issue of competing interests. Nevertheless, processes vary widely and, for the most part, seem insufficiently robust to minimise the risk that the information contained in these knowledge tools may be biased. At the time of analysis, we identified 12 organisations who had five or more tools in their inventory, indicating that relatively few number of organisations work in this field. Only half of these organisations had a documented competing interest policy, demonstrating a lack of attention to an area that is causing increasing concern for those summarising evidence for patient and professional consumption. The organisations who had developed policies varied widely in the restrictions imposed on those who declared competing interests, and none required competing interest disclosure to be published on patient decision aids. Some considered declarations to be sufficient, others imposed differing levels of exclusion from content development. No policies definitively prohibited the involvement of individuals with competing interests.

Conclusions

Patient decision aid developers do not have a consistent approach to managing competing interests. Some have developed policies and procedures, while others appear to pay no attention to the issue. As is the case for clinical practice guidelines, increasing attention will need to be given to how the competing interests of contributors of evidence-based publications may influence materials, especially if they are designed for patient use.

A study on best practices to adapt the health literacy demands of decision aids to seniors with dementia and their caregivers

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Background and aims

In the context of dementia care, shared decision-making can be challenging due to cognitive and sensory impairments, the presence/absence of a caregiver, literacy and numeracy issues, and a propensity to rely on clinicians for decision-making. Decision aids (DAs) can improve decisional comfort by increasing knowledge about the benefits/harms of options and helping clarify what is important to patients. However, little is known about the factors influencing the literacy demands of DAs for persons with dementia and how best to involve these patients in the development of DAs. We thus aimed to study best practices to limit the health literacy demands of DAs and support older persons with dementia in expressing their preferences to their clinicians.

Method

We evaluated the health literacy demands of three IPDAS-compliant DAs called Decision Boxes. The DAs covered behavioral symptom management, driving cessation, and advanced directives. Using an iterative user-centred qualitative approach, we asked users to evaluate the DAs in three rounds, based on the Health Literacy Skills framework. We asked clinicians to recruit a target sample of 27 community-based older persons (65+) diagnosed with dementia of any severity and their caregivers, at geriatric ambulatory clinics in Quebec, Canada. In the first round, nine patients and their caregivers assessed the three DAs in semi-structured interviews (3 patients/caregivers per DA). Based on the findings, we adapted the DAs to: (1) limit their health literacy demands, (2) complete any missing information, and (3) ensure that participants understood that they should express their preferences to their clinicians regarding the subject of the DA. We used the same evaluation/modification process again in two more rounds, with new participants each time.The interviews were audio-recorded and transcribed verbatim. Two researchers analyzed the discussions using deductive/inductive thematic qualitative data analyses, first by searching for factors set out in the Health Literacy Skills framework, then by integrating new themes mentioned by participants.

Summary of preliminary findings

Of the eight patients recruited between January and March 2017, five were aged 75-84 years, and three were over 85 years; five were women. Of the nine caregivers recruited, four were aged 45-64 years, four 65-84 years, and one was more than 85 years; seven were men. Findings of the first round confirmed participants' comprehension of the DAs' main message, i.e., to express their preferences to their clinician. The participants pointed to a need for plain language, especially in the advanced directives DA that used legal jargon. Some missing information was highlighted, notably the need to add an option in the advanced directive DA. Caregivers' involvement facilitated patients' concentration, attention and understanding of the information. Social support and clinician knowledge emerged as factors influencing participants' adoption of shared decision-making behaviors.

Conclusion

Older adults with dementia can be involved in the development of DAs and in shared decision-making, however several factors need to be considered. This work will allow proposing best practices for designing DAs that take into account the health literacy level of vulnerable older people and their caregivers.

A Systematic Review of End-Of-Life Decision Aids and Their Ability to Address the Decision-Making Needs of Key Stakeholders

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Background and Aims

Many time-sensitive, critical decisions are made at the end-of-life by patients, caregivers and healthcare professionals. Therefore, the decision-making needs of these stakeholders involved with shared decision making (SDM) are complex. Decision aids (DAs) aim to meet these decision-making needs, to ensure all stakeholders are fully informed and supported throughout the decision-making process. Currently, stakeholders' needs to make critical decisions, compared to available DAs in end-of-life care, are unknown. This systematic review aims first (Search One) to identify the full range of decision-making needs of stakeholders, and secondly (Search Two) to explore to what extent DAs meet these needs.

Methods

This systematic review followed the PRISMA framework. Literature for both searches was identified through systematic searches of the electronic databases Medline, PsychINFO and CINAHL, supplemented with hand-searching of DA databases and reference lists of key papers. Literature, searched in January 2017 and published between 1990–2017, was eligible for inclusion in Search One, if it reported decision-making needs or preferences of key stakeholders within end-of-life care. In Search Two, published or unpublished literature (and hand-searched DAs) were eligible if they evaluated or described an end-of-life DA. Data on study design, study and population characteristics and the needs of decision-making are currently being extracted through content analysis and descriptive synthesis for Search One. For Search Two, similar data-extraction domains are being obtained for DAs, with additional information extraction on DA description, aims, outcome assessment and theoretical basis. All identified DAs will be assessed per IPDAS criteria and rated for global effectiveness. The study is being conducted from October 2016 to May 2017.

Results

Some 1,841 abstracts were screened, and 90 included full-text articles double-coded, reviewed and appraised. Approximately 60 articles for Search One and 30 for Search Two are included, with hand-searches. A large proportion of eligible Search One articles are descriptive, observational studies. Initial themes indicate stakeholder needs diverge throughout the end-of-life period, varying with participant age, ethnicity and disease-typology. Patient decision-making need themes include: 'knowing the patient', 'prepared participation', 'tailored information delivery' and 'decision education'. Family/carer decision-makers require enhanced involvement in decisions, and recognition of themselves and the patient as 'one individual decisional unit'. Education on approaching decision-making is a further reported need amongst families and patients. Doctor and nurse needs are varied and provide insight into decision-making from the professional perspective. Currently, DAs address some traditionally reported needs, but this review highlights modern end-of-life care presents new stakeholder challenges to SDM. Preliminary mapping of needs onto DAs suggest clear areas to improve DAs. Full analysis will identify where DAs are insufficient and need further development.

Conclusion and Implications

Full results and implications for research and practice will be discussed at the conference. Preliminary analysis indicates needs are broad, varied and more extensive than previously perceived. This unique synthesis and DA mapping provides useful insight for DA developers. Further research to develop and evaluate interventions to support patients and family/carers with decisions about their treatment or care towards the end-of-life appears warranted.

Measuring Patient Experiences of Integration in Health Care Delivery: The Psychometric Properties of IntegRATE

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Background and Aims

A well-integrated health care delivery system is likely to support and promote the adoption of shared decision-making. We recently developed IntegRATE, a four-item measure that assesses patient experiences of integration in health care delivery in four domains: effective information transfer across team members, concordant information provision by team members, respect and collaboration among team members, and patient understanding of the different roles of the various team members. The aim of this study was to assess the discriminative validity, concurrent validity, divergent validity, intra-rater reliability, and responsiveness of IntegRATE under controlled conditions.

Methods

We composed three versions of a fictional letter sent by a couple to a hospital describing a recent maternity care experience. The letters were produced in text and audio formats, were matched on structure and word length, and varied only in the degree of integration featured in the care experience. Using these letters, we conducted a 3 x 2 mixed fractional factorial study. The between-subjects factor was letter (L_1 (good integration), L_2 (mixed integration), L_3 (poor integration)) and the within-subjects factor was time (T_1, T_2). Participants were adults who had utilised health care services in the past year and were recruited using a commercial panel service in the United States. Participants were randomly allocated to read (or listen to) L_1, L_2 or L_3 and were asked to complete IntegRATE, the Role Clarity and Coordination within Clinic subscale of the Patient Perceived Continuity of Care from Multiple Clinicians, and a single item measuring perceptions of the hospital's openness to patient feedback, imagining they were an author of the letter. One to three weeks' later, all participants who were originally allocated to L_1 or L_3 were invited to take a second survey. Those that consented were randomly allocated to read (or listen to) either L_1 or L_3 and were again asked to complete all three measures.

Results

Six hundred people participated at T_1 and 190 people participated at T_2. IntegRATE scores were significantly higher for L_1 than L_2 (MD=2.62, p<.001) and significantly higher for L_2 than L_3 (MD=1.92, p<.001). There was a strong, positive correlation between IntegRATE scores and scores on the Role Clarity and Coordination within Clinic subscale (r=.75, p<.001). There was a weak, positive correlation between IntegRATE scores and perceived openness to patient feedback (r_{pb}=.26, p<.001). There was substantial agreement between IntegRATE scores at T_1 and T_2 when participants were allocated to the same letter (ICC(2,1)=.78, p<.001). IntegRATE scores were significantly higher at T_1 than T_2 among people who were allocated to L_1 and then L_3 (MD=5.16, p<.001) and were significantly higher at T_2 than T_1 among people who were allocated to L_3 and then L_1 (MD=-5.15, p<.001). Where sample sizes allowed, analyses were also conducted separately by participant gender and health literacy and yielded largely consistent results.

Conclusion

IntegRATE was found to demonstrate discriminative, concurrent, and divergent validity, as well as intra-rater reliability and responsiveness, under controlled conditions. We recommend that the psychometric properties of IntegRATE now be examined in real-world clinical settings.

First validation of the French version of CollaboRATE: a patient reported measure of shared decision-making process

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Background and aims

CollaboRATE, a three-item measure of shared decision making (SDM) process was recently developed to fulfill the need for a brief, generic, reliable and valid patient-reported measure highlighted in reviews of SDM measures. Our aim was to assess the first psychometric properties of its French version.

Methods

A cross-sectional survey was performed using a single self-administered online questionnaire proposed to all members of *Seintinelles* (www.seintinelles.com), a French national association of people wishing to help cancer research. Participants completed the French version of CollaboRATE asking about the last time they visited a doctor, without any details asked about this visit. Total score range from 0 (no effort made) to 27 (every effort was made to: explain health issue, elicit and integrate patient preferences). Participants also reported their sociodemographics, medical history, functional, communicative and critical health literacy level (FCCHL, possible range: 14 to 70) and cancer information seeking behaviors.

Reliability was estimated. To assess criterion validity our *a priori* hypotheses were an increase of SDM process among participants who were younger, with higher health literacy level, less prone to report usual difficulties in asking their physicians questions.

Results

In June 2016; 2444 participants answered the questionnaire. They were mostly women (96.5%), often had a cancer history (46.1%) and had a high level of health literacy (mean FCCHL score=55.6±7.1).

ColllaboRATE was well accepted, even among participants with no cancer and/or chronic disease history (missing values for each item ≤ 3%). Reliability was high (Cronbach's α=0.92). "Ceiling effect" was detected (26.3% of highest score possible) consistently with the top score method of scoring CollaboRATE.

As hypothesized, CollaboRATE top score was positively associated with health literacy level (except critical dimension) and lack of difficulties in asking their physicians questions. At contrary, age was positively associated with top score but this unexpected association disappeared after adjustment for difficulties in question asking (**Table**).

Moreover, among cancer patients, those who report seeking cancer information because their health care team does not provide enough (15.8%) less often reported a CollaboRATE top score (8.5% vs 31.8%, $p<.001$).

Table. Multiple logistic regression analysis of CollaboRATE top scores (n=2267).

	adjOR	95% confidence interval	p
Age*, per 1y increase*	1.00	(0.99 to 1.01)	.755
FCCHL*, per 1pt increase*	1.03	(1.02 to 1.05)	<.001
Difficulties in question asking			
At least sometimes	1	(reference)	
Rarely	2.3	(1.8 to 3.1.)	<.001
Never	6.6	(5.1 to 8.6)	<.001
Cancer history	1.1	(0.9 to 1.4)	.408

Conclusion

The French version of CollaboRATE provides a brief reliable and valid measure to explore the process of SDM. Further assessment among French patients is ongoing.

Measuring shared decision making: A content review of observer-based coding schemes

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Background
The interest in implementing shared decision making (SDM) in daily care is growing, as is the need to evaluate the occurrence of SDM. However, variability in measurement instruments used and in how these are composed may hinder the evaluation of the occurrence of SDM and of the effects of SDM interventions. The aim of this review was to assess what communication elements observer-based SDM coding schemes intend to measure, and how these elements relate to SDM stages.

Methods
A secondary analysis was conducted on observer-based SDM coding schemes identified in a recent systematic review of SDM-process measures published up to June 2016.

For this secondary analysis, we excluded schemes if they were translations, if a revised version of was available or if schemes contained the same items but used different scoring systems. Although some differences exist in how SDM stages are grouped, most SDM models identify 1) creating choice awareness, 2) discussing relevant options, 3) discussing patient's preferences, and 4) making the final decision. We deductively (based on these four stages) and inductively (based on items of the schemes) developed a form to extract information about the communication elements included in the schemes. Two coders extracted the content of all items of the included schemes and disagreements were resolved in consensus.

Results
Twenty observer-based SDM coding schemes were identified in the systematic review, of which we excluded eight for this secondary analysis. The 12 schemes contained a total of 194 items (Md=10, range 3-70). Seventy items (36%) assessed elements that could not be classified into one of the four SDM stages, such as discussing medical background, setting the agenda, and inviting patient questions. Of two schemes (17%) the majority of the items could not be classified into the four SDM stages. Five schemes (42%) contained at least one item in all four stages. Items classified into one of the SDM stages assessed creating choice awareness (N=15, 8%), discussing relevant options (N=57, 29%), discussing patient's preferences (N=16, 8%) and making the final decision (N=36, 19%). Relatively many items assessed providing information on pros and cons of available options (N=15, 8%) and checking patient's understanding (N=16, 8%). There were few items assessing discussing patient's treatment preference (N=3, 2%), providing personalized information (N=3, 2%), providing balanced information (N=4, 2%) and providing risk information (N=0).

Conclusion
Large variation exists in the content of observer-based SDM coding schemes. There is a discrepancy between elements that SDM models commonly distinguish and the elements that are assessed in coding schemes that intend to measure SDM. The schemes seem focus on providing patients with information, leading to high scores when information on relevant options is shared, even when this is done in an unbalanced, incomplete or unclear way. Caution is needed in interpreting scores of SDM instruments and effects of SDM interventions on these scores, as they may not assess all elements most relevant to SDM.

The measurement quality of existing SDM-process instruments: need for more evidence and time for improvement

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Background and aims

The quality of study results on shared decision making (SDM) highly depends on the availability of psychometrically sound instruments that measure the process of SDM–the actual realization of SDM in doctor patient interactions. To help researchers choose the qualitatively best instrument, we performed a systematic review to provide an overview of SDM-process instruments and an assessment of their measurement quality, taking into account the methodological quality of each instrument's evaluation studies.

Methods

We systematically searched three databases and two researchers independently evaluated all retrieved records for eligibility using pre-defined inclusion criteria (peer-reviewed articles that describe the development or evaluation of an SDM-process instrument). We performed two quality appraisals; 1) the quality of the methods applied in the included articles, using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN), and 2) the quality of the measurement property per instrument, based on the results of the included articles. We synthesized these two types of quality, into a best level of evidence for each instrument, separately for nine measurement properties; i.e., Internal consistency, Reliability (test-retest, intra-rater, and inter-rater), Measurement error, Content validity, Structural validity, Hypotheses testing, Cross-cultural validity, Criterion validity, and Responsiveness. The levels of evidence were: 'unknown' due to poor methods, 'conflicting', 'limited', 'moderate', and 'strong', in either positive or negative direction.

Results

Forty-six out of 5107 identified articles were included, describing 35 SDM-process instruments; 12 patient questionnaires, 3 provider questionnaires, 18 coding-schemes and two dyadic instruments. In total, six instruments have evidence for positive results for at least one type of reliability and one type of validity.

Overall, six measurement properties were evaluated for <15% of the instruments, taken into account the applicability of the measurement properties: Test-retest reliability (11%), Measurement error (0%), Content validity (13%), Cross-cultural validity (9%), Criterion validity (3%), and Responsiveness (3%).

For two measurement properties, the best level of evidence indicated positive results for the majority of instruments that were evaluated on these aspects: Content validity (60%) and Structural validity (62%). In contrast, evidence for negative results was found in (nearly) half of the instruments for Inter-rater reliability (47%) and Construct validity (55%). Differences between instrument types were found for Internal consistency and Structural validity; results for questionnaires were overall more positive and for coding-schemes more unknown.

Conclusion

A variety of SDM-process instruments exist, but there is a lack of evidence about their quality, partly because not all measurement properties are evaluated and partly because evaluation studies are of poor quality. The choice for the most appropriate instrument should therefore be based on the instrument's content and measurement perspective. For further development and evaluation of SDM-process instruments, we recommend researchers to provide a clear definition of the construct being assessed and to assess Content validity. Furthermore, future research should focus on the issue of reliability testing for questionnaires and on the improvement of intra-rater reliability and construct validity. Also, with the current emphasis on value based healthcare, the applicability of SDM-process instruments within clinical practice needs to be investigated.

How Do Multidisciplinary Teams Make Decisions about Treatment in Advanced Lung Cancer; Findings from the PACT Study

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Background - Aims

Lung cancer patients are known to receive systemic anti-cancer therapy (SACT) inappropriately when they are close to end of life, despite evidence that early palliative intervention can lead to less aggressive care and longer survival. There is evidence of a widespread misunderstanding of the extent of disease, prognosis and aims of treatment by patients, despite guidelines' recommendations that treatment decisions should be made by fully informed patients.

Aim

To identify the information and decision support needs of patients with advanced lung cancer, which will facilitate discussion of the risks/benefits of treatment options.

Methods

Non-participant observation of multi-disciplinary team (MDT) meetings (n=12) was used to determine patients' allocation to treatment pathways and to explore communication of treatment options and decision-making within the members of the teams. Nonverbal communication, interactional behaviours and proxemics were recorded by two researchers and audio-recording was used to minimise bias, securing the actual verbatim of participants interactions. Patient-specific observations were made, focusing on the presentation of the patient, any information provided and considered, the key contributors to discussion, the process of decision-making and the nature of negotiations. Thematic analysis and Mediated Discourse Analysis were used to explore the interactions between MDT attendees, the communication patterns and decision-making processes of the MDT members.

Results

The MDT observations revealed two distinctive processes during the meeting discussions: information sharing and decision-making. Dynamics within the team dictated the level of participation in both processes, with different members being more active at each process. Information was not always actively offered, hence important views and knowledge might not have been shared, unless asked. The chest physicians, radiologists and pathologists contributing most consistently to the information sharing discussions, whereas the chest physician and the oncologist dominated the decision-making process.

The MDT observations revealed patterns of how patients were allocated to treatment pathways. Disease histories and test results were the main factors that facilitated treatment decision-making, whereas performance status was the key moderator for the suggested treatment option. The coding of key turning points suggests that most of the discussions were based on the cancer diagnosis, extend of disease and complications.

Patient presentation during MDT meetings highlighted the limited representation of the functional and social patient in everyday life. Although there was awareness of the need to communicate with patients, patient preferences were often not known. Hence, patient-related factors were often not included at the decision-making discussions.

Conclusions

The lung MDT functioned as a forum where complex and challenging cases were resolved through the shared expertise. Patient attributes represented in the MDT meetings, and the relative importance given to each representation by the team members shaped the decision-making of treatment options. The focus of patient representation on the disease information and less on the patient context has consequences for the way in which proposed treatment will impact on the patient in everyday life. This context is important particularly in advanced lung cancer where options are limited and is vital in order to achieve patient- centred care.

When Talking About Decision Making Comes Too Early: Is Shared Decision Making Possible in Breaking Bad News Encounters?

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Background and aims

One of the most critical encounters in healthcare are breaking bad news (BBN) encounters, where the news about the diagnosis is disclosed. Within these encounters, the patient has to absorb and accept his new health situation and cope with it emotionally. When delivering bad news treatment plan may be discussed and even made. The present study explored the focus of different BBN encounters to identify whether and when treatment decisions are mentioned and what additional elements were part of these medical encounters.

Brief methods

Qualitative, Immersion/Crystallization analysis of 166 narratives of 83 senior year medical students focused on their observations of BBN encounters in the clinics. The analysis was conducted through an iterative consensus-building process to classify the dynamics of the interactions; the manner in which the news was delivered and whether treatment was discussed.

A summary of results

The narratives were diverse in the types of bad news and the physician's behavior. We identified three focuses of the encounter: information provision, dealing with emotions, and focusing on the treatment plan. The interactions differed regarding the balance among these focuses. We found that almost half of the BBN encounters were mostly focused on the treatment plan. This was mostly done without providing critical information about the diagnosis, with limited dealing with the emotional toll related to the news and with limited discussion of different treatment options.

Conclusion

Almost half of the physicians in our study tended to "run" straight to sharing their decision, rather than to providing information, dealing with emotions and later discussing decision options and reaching an agreement. Within this type of encounters, a sense of urgency is emphasized, leaving little space for deliberation. This behavior cannot indeed allow the process needed for shared decision making (SDM). Furthermore, the gap in knowledge is not only related to treatment options but also refers to knowledge about the disease itself and its implications.

This presentation will provide an opportunity to reflect and discuss the role of treatment plans and decisions in BBN encounters and the knowledge and emotional basis needed to allow a good SDM process that will be patient centered.

Tailoring Risk Communication: Do Patient Preferences Help or Hurt?

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TAILORING RISK COMMUNICATION TO IMPROVE COMPREHENSION: DO PATIENT PREFERENCES HELP OR HURT?

Background and aims

Precision medicine literature, however, is yet to acknowledge "precision communication." That is, in the same manner that "one-size-fits-all" treatment which does not acknowledge patient preferences is no longer suitable, "one-size-fits-all" risk communication

might not fit all patients. How then can patient preferences be taken into account? And what would be the effect on comprehension? This is the first examination, to our knowledge, combining shared decision making and precision medicine with precision communication. We examined how (and whether) we should tailor risk information to women at risk of breast cancer, and whether this tailoring should be preference-based.

Methods

One thousand seven women were contacted via an email distributed by local branches of the Cancer Genetics Network (CGN) to complete an online survey. Four hundred seventy-seven women (47% response rate) consented to participate in the study and completed the survey. Of these, breast cancer risk format preferences and risk comprehension data were collected from 361 participants. 1 The analytic sample consisted of 334 participants with

complete data.

A summary of results to support conclusions

Women's initial preferences for risk formats were not associated with risk comprehension scores. That is, taking advantage of the fact that we've measured comprehension, we could gauge to what degree each format yielded comprehension. Women with lower risk comprehension scores were more likely to update their risk format preferences after they evaluated risks in different formats. Perhaps most alarmingly, and definitely most related to SDM, less numerate women were more likely to prefer graphical rather than numeric risk formats. Importantly, we found that women preferring graphical risk formats had lower risk comprehension in these formats compared to numeric formats. Thus, catering to their preferences may result in poorer performance on their behalf. In contrast, women preferring numeric formats were of higher numeracy, and performed equally well across formats.

Conclusions

Our findings suggest that tailoring risk communication to patient preferences may not improve understanding of medical risks, particularly for less numerate women, and point to the potential perils of tailoring risk communication formats to patient preferences. These empirical findings need to be considered against ethical preferences toward SDM. Further, while comprehension is an objective benchmark of 'performance' around risk information, other measures, such as a willingness to engage with the information, might also be considered, as they may show some benefit from incorporating patient preferences.

What works to help people make values-congruent decisions? Eleven strategies tested across a series of six experiments

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Background
The purpose of shared decision making is to help people make evidence-informed, values-congruent health decisions. We aimed to identify strategies that help people make values-congruent decisions.

Methods
We tested eleven different strategies across six between-subjects online randomized experiments in demographically diverse US populations (n1=1346, n2=456, n3=838, n4=1178, n5=841, n6=2033). In each experiment, we first asked participants: if they had to choose, would they rather die or have a colostomy? Participants were then asked to imagine having been diagnosed with colon cancer and facing a choice between two surgeries differing only in that one had a 4% chance of colostomy while the other had a 4% additional chance of death. In each experiment, we randomized participants to receive no intervention or one or two of eleven strategies: (1) visual prompt highlighting the key difference between the two surgeries, (2) reflective prompt, (3) prompt to make an intuitive decision, (4) prompt to make a deliberative decision, (5) emotional self-assessment, (6) narratives about adaptation and prompts to deliberate about their own capacity to adapt, (7) web sliders representing a prototypical values clarification method of rating attributes, (8) static visual feature explicitly informing participants of the best fit for them, (9) web sliders that made the tradeoffs in the decision explicit, (10) dynamic visual feature explicitly informing participants of the best fit for them, (11) providing participants with feedback if their decision didn't align with their values. We then asked participants which of the two surgeries they would prefer. In four of the six experiments, we also assessed decisional conflict as a secondary outcome, using Decisional Conflict Scale items applicable to a hypothetical scenario (Cronbach alpha=0.92). We conducted multivariable logistic (congruence) or linear (decisional conflict) regressions with covariates: age, race/ethnicity, self-reported health status, subjective numeracy. We compared strategies 1-8 to no intervention, strategies 9 and 10 to strategy 7, and estimated additional congruence attributable to strategy 11.

Results
None of strategies 1-7 increased congruence (1:OR 0.83 95%CI[0.62,1.11], 2:OR 1.09 95%CI[0.81,1.47], 3:OR 0.98 95%CI[0.70,1.37], 4:OR 1.04 95%CI[0.73,1.49], 5:OR 0.92 95%CI[0.66,1.28], 6:OR 1.28 95%CI[0.90,1.81], 7:OR 0.93 95%CI[0.66,1.31]). Strategies 8-10 encouraged congruence (8:OR 1.63 95%CI[1.02,2.61], 9:OR 1.40 95%CI[1.08,1.82], 10:OR 1.32 95%CI[1.02,1.71]). The proportion of congruence attributable to Strategy 11 was 0.31 (95%CI[0.21,0.44]). Within the strategies in which we evaluated decisional conflict, four strategies did not reduce decisional conflict (3:p=.06, 5:p=.47, 9:p=.09, 10:p=.67); however, three strategies that each explicitly encouraged some form of deliberation did (4:p=.004, 6:p=.003, 7:p<.001). No strategy that reduced decisional conflict increased values congruence, and no strategy that increased values congruence reduced decisional conflict.

Conclusions
To encourage values-congruent decisions, people benefit from explicit representations of tradeoffs, how what matters to them aligns with their options prior to a decision, and how what matters to them aligns with their decision after expressing a preference. Reduced decisional conflict may signify people feeling they are making a deliberative decision rather than their decision being values-congruent. Shared decision making should incorporate methods shown to encourage values-congruent decisions and researchers should consider how we evaluate decision quality.

What do we expect? A systematic review of clinicians' expectations about the benefits and harms of health interventions: implications for shared decision making

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Background:

As part of shared decision making, patients and clinicians are encouraged to discuss evidence about the benefits and harms of the intervention that is being contemplated. However this requires clinicians to know the best current evidence. Clinicians' expectations of the benefits and harms of interventions can markedly influence decision-making and the care that patients receive, yet studies which have measured the extent to which clinicians have accurate expectations of benefits and harms have not been systematically reviewed.

Aim:

To systematically review all studies which have quantitatively assessed clinicians' expectations of the benefits and/or harms of any treatment, test, or screening test.

Methods:

This systematic review used: a comprehensive search strategy in four databases (MEDLINE, Embase, CINAHL, PsycINFO) from inception to March 2015, with no language or study type restriction; cited reference searches of included studies; and contact with experts and study authors. Two researchers independently evaluated methodological quality and extracted participants' estimates of benefit and harms and authors' contemporaneous estimates.

Results:

Of the 8166 records screened, 48 articles (a total of 13,011 clinicians) were eligible. Twenty studies focused on treatment, 20 on medical imaging, and 8 on screening. Of the 48 studies, 67% (n=30) assessed only harm expectations, 20% (n=9) only benefit expectations, and 13% (n=6) assessed both benefit and harm expectations. Among the studies comparing benefit expectations with a correct answer (total of 28 outcomes), a majority of participants provided correct estimation for only 3 (11%) outcomes. Of the studies comparing expectations of harm with a correct answer (total of 69 outcomes), a majority of participants correctly estimated harm for 9 (13%) outcomes. Where over- or under-estimation data were provided, the majority of participants overestimated benefit for 7 (32%) and underestimated benefit for 2 (9%) of the 22 outcomes; and underestimated harm for 20 (34%) and overestimated harm for 3 (5%) of the 58 outcomes.

Conclusions:

Clinicians rarely had accurate expectations of benefits or harms, with inaccuracies in both directions. However, clinicians more often underestimated (rather than overestimated) harms and overestimated (rather than underestimated) benefits. Implications of inaccurate expectations include that effective interventions may be underused and low value interventions overused. If clinicians do not know or do not discuss accurate benefits and harms in consultations with patients, then informed and shared decision making is compromised.

The effect of a mobile health patient decision aid (mPATH-CRC) on colorectal cancer screening decision-making

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Background

Routine colorectal cancer (CRC) screening saves lives, yet over 40% of Americans are unscreened. Known barriers to CRC screening include limited patient knowledge and limited clinician time to discuss screening options. Decision aids may address these barriers by helping patients make informed screening choices consistent with their preferences.

Aims

We examined the impact of an iPad-based CRC screening patient decision aid on: 1) patients' ability to make a screening decision, 2) patient-provider CRC screening discussions, 3) screening tests ordered, and 4) patient decisional satisfaction.

Methods

The mPATH-CRC app includes a 9-minute video reviewing the rationale for screening and the two most widely-used screening tests (fecal blood testing and colonoscopy). The app then assesses basic knowledge of CRC screening, ability to make a screening decision, and screening intention. Patients who desire can "self-order" a screening test via the app. We tested the app in a randomized-controlled trial of 450 primary care patients aged 50 – 74 who were due for CRC screening. We randomized patients to either mPATH-CRC or an mPATH-Control app (diet and exercise content instead of CRC screening with no option for self-ordering). All patients participated at their primary care provider's office immediately before a routine medical appointment. The day after the visit, participants completed a telephone survey assessing CRC screening discussions with a provider, screening decisions, and satisfaction with that decision based on the Satisfaction with Decision Scale.

Results

450 patients were randomized (n=223 to mPATH-CRC and 227 to mPATH-Control). Compared to control patients, mPATH-CRC patients had greater knowledge of CRC screening (mean score 4.4 vs. 3.3 out of 5 items, p<0.0001) and were more likely to state a specific test preference (97% vs. 71%, p<0.0001). mPATH-CRC patients were more likely to discuss CRC screening with their provider (76% vs. 48%, p<0.001) and were more likely to initiate such discussions (37% vs. 22%, p=0.01). Overall, mPATH-CRC increased the proportion of patients who had a FOBT ordered (36% vs. 11%, p <.0001) or had a colonoscopy ordered (36% vs. 21%, p <.001). When screening was ordered, mPATH-CRC patients were more likely to have a test ordered that was concordant with their stated preferred test (86% vs. 54%, p<0.0001). Satisfaction with decisions made was very high in both groups (4.55 vs. 4.47 out of 5, p=0.21).

Conclusion

An iPad CRC screening decision aid increases patients' ability to make a screening decision, activates patients to discuss screening, and yields screening tests ordered that match patients' preferences. Implementing mPATH-CRC in clinics could improve patient-centered care.

Randomized Trial of a Patient-Centered Decision Aid for Promoting Informed Decisions about Lung Cancer Screening: Characteristics of Participating Smokers

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Background and Aims

Among smokers, lung cancer is an ever-present fear. Screening high-risk smokers for lung cancer reduces lung cancer-specific mortality but is associated with potential harms including radiation exposure, false positives, complications for invasive diagnostic procedures, and overdiagnosis. Eligibility for lung cancer screening includes a cigarette smoking history in equal to or greater than 30 pack-years (one pack year is equivalent to smoking a pack of cigarettes each day for one year). We describe the demographic characteristics, smoking history, and baseline knowledge, of patients participating in a comparative effectiveness trial of a patient decision aid about lung cancer screening.

Methods

Patients from state-based tobacco cessation quitline services in the U.S. were recruited for the trial. Eligibility was assessed following criteria used by the Centers for Medicare & Medicaid Services (e.g., age 55 to 77 years, pack year smoking history of 30 or greater). Patients completed selected questions for the LCS-12, a brief measure of lung cancer screening knowledge developed by the research team.

Results

To date, 516 high-risk smokers from 13 states and four quitline service providers have been enrolled and randomized. The majority of patients were female (62%), 43% were high school graduates or less, and the mean age was 61.6 years (SD= 5.4 years). Smoking history information used to determine, in part, eligibility for screening, is given in the Table. Nearly half (47.3%) of patients also indicated they have a first cigarette within 5 minutes of awakening each day.

Smoking history	Mean	SD	Range
Number of years smoked	43.6	7.7	15 to 66
Number of cigarettes smoked per day	25.3	9.8	10 to 100
Pack-year smoking history	54.8	23.4	30 to 200

At baseline, knowledge of lung cancer screening was poor. Only 32.6% recognized radiation exposure as a harm of screening, 88.4% felt all smokers should be screened (regardless of risk factors), and 8.5% knew most patients with an abnormal screening result will not be diagnosed with lung cancer.

Conclusions

The participants in the comparative effectiveness study of lung cancer screening decision-making were heavy smokers, many having started smoking as teenagers, with pack-year smoking histories well in excess of the eligibility threshold. Knowledge of lung cancer screening is low, suggesting a great opportunity for decision support interventions to prepare patients for informed screening decisions.

Women's preferences for and trade-offs between benefits and harms in breast cancer screening. A discrete choice experiment in France

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Background
Over the past decade, the benefits and harms balance of breast cancer (BC) screening has been widely debated. Both public health authorities and clinicians recognize the necessity to take into account women's preferences to improve their recommendations about BC screening, but women's preferences and trade-offs remain unknown.

Research design
A discrete choice experiment (DCE) was designed to investigate women's trade-offs between the benefits and harms of BC screening. Seven attributes depicting BC screening programmes were selected based on a literature review, focus groups and semi-structured interviews. The inclusion criteria were to be a woman aged between 40 and 74 years, with no history of BC. The participants were recruited by a survey institute and completed the survey online.

Methods
Preferences were modelled at the sample level using error components models and preference heterogeneity was investigated using generalized multinomial logit models from which individual trade-offs were derived. Screening acceptance rates under various benefits/harms ratio were simulated based on the distribution of individual preferences.

Results
Eight hundred and twelve women representative of the French 40-74 years old population completed the DCE questionnaire. The women were willing to accept on average 14.1 overdiagnosis cases (median = 9.6) and 47.8 women with a false-positive result (median = 27.2) to avoid one BC-related death. After accounting for preference heterogeneity, less than 50% of women would be willing to accept 10 overdiagnosis cases for one BC-related death avoided. Screening acceptance rates were higher among women with higher socio-economic level and lower among women with poor health.

Conclusion
Our study demonstrate that women are sensitive to both the benefits and harms of BC screening and display heterogeneous preferences. The results strengthen the need to provide a balanced information on both benefits and harms through an informed decision-making process that would be more respectful of women's preferences.

How Information About Overdetection Changes Breast Screening Decisions: Mediation Analysis Within a Randomised Controlled Trial

Jolyn Hersch[1], Kevin McGeechan[1], Alexandra Barratt[1], Jesse Jansen[1], Les Irwig[1], Gemma Jacklyn[1], Nehmat Houssami[1], Haryana Dhillon[1], Kirsten McCaffery[1]

[1] *The University of Sydney, NSW, Australia*

Background and aims

Breast cancer screening is a persistently controversial issue. New understanding of the harms of screening, especially the complex problem of overdetection (or overdiagnosis), has prompted the need for a shared decision making approach aiming to help women appreciate the potential for harm as well as benefit. As reported previously (at ISDM Conference 2015), we investigated the effects of including information about overdetection in a decision aid for women considering breast screening. We now present a mediation analysis aimed at exploring the pathways through which women who received the intervention processed information about overdetection and integrated it into their decision making.

Methods

In a randomised controlled trial in Australia, we compared the effects of two versions of a decision aid giving women information about breast cancer deaths averted and false positives from screening, either with (intervention) or without (control) information on overdetection. The participants were women aged 48-50 years with no personal history of breast cancer. We then conducted a serial multiple mediation analysis (n=811) examining a series of potential mediators of the relationship between exposure to information about overdetection and subsequent breast screening intentions. The potential mediators included overdetection knowledge, breast cancer worry, breast screening attitudes, and anticipated regret.

Results

Comparing the study groups shortly post-intervention showed that informing women about overdetection reduced their intentions to undergo breast cancer screening. The mediation analysis revealed that the effect of the intervention (providing information about overdetection) on screening intentions was mediated through multiple cognitive and affective pathways. In particular, the intervention led to substantial improvements in women's understanding of overdetection, and influenced – both directly and indirectly via its effect on knowledge – their attitudes towards having screening. The mechanisms involving knowledge and attitudes were particularly important in determining women's intentions about screening participation.

Conclusion

Even in the emotive context of breast cancer screening, this study demonstrates that new information influenced women's decision making by changing their understanding of the possible consequences of screening and their attitudes towards undergoing it. Our novel findings from this mediation analysis underline the importance of providing good-quality information about the benefits and harms of mammography to help women make an informed choice when they are invited to screening. Using effective communication tools and resources, with the capacity to successfully impart new and relevant knowledge, will best support women to make well-informed decisions about whether to participate in breast screening.

2-Year Follow-Up in a Breast Screening Decision Aid RCT: Retention of Overdetection Knowledge and Other Decision Making Effects

Jolyn Hersch[1], Jesse Jansen[1], Alexandra Barratt[1], Nehmat Houssami[1], Haryana Dhillon[1], Kevin McGeechan[1], Gemma Jacklyn[1], Les Irwig[1], Kirsten McCaffery[1]

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Background and aims

Supporting women in making well-informed decisions about breast cancer screening requires effective communication about screening outcomes including overdetection or overdiagnosis (diagnosis and treatment of breast cancers that would never become clinically evident). We investigated the effects of providing information about overdetection in a decision aid for women aged around 50 years considering breast screening. Immediate post-intervention results (reported previously at the International Shared Decision Making Conference in 2015) showed that the intervention increased knowledge and informed choice, made screening attitudes less positive, and reduced intentions to screen. We now present outcomes collected at 2-year follow-up.

Methods

A random cohort of women aged 48-50 was recruited by telephone in 2014 for a community-based randomised controlled trial in Australia. Eligible women had not undergone mammography in the past 2 years and had no personal or strong family history of breast cancer. 879 women were randomised to receive either the intervention decision aid (evidence-based information on overdetection, breast cancer mortality reduction, and false positives) or a control decision aid (identical but without overdetection information). We assessed long-term follow-up outcomes by telephone at 2 years post-intervention (2016). Outcomes include knowledge, attitudes, mammography uptake, future screening intentions, and anticipated regret.

Results

712 women (81% of those randomised) completed 2-year follow-up. Compared with controls, more women in the intervention group retained adequate conceptual knowledge (34% vs. 20%, p<0.01). Both study groups were similar in the proportions of women who expressed positive attitudes towards screening (81% vs. 82%, p=0.66), underwent mammography during the 2-year follow-up period (50% vs. 51%, p=.75), and reported intending to screen within the next 2-3 years (82% vs. 85%, p=.25). Anticipated regret differed between groups: Compared with controls, women in the intervention group agreed less strongly that they might later regret it if they did *not* undergo screening (p=0.02).

Conclusion

A brief decision aid intervention had a long-lasting (2-year) effect on improving women's conceptual knowledge about potential consequences of breast cancer screening, including overdetection. Few previous decision aid trials have demonstrated an impact persisting over such a long time frame. The intervention also changed women's expectations about how they might feel if they decided to screen or not to screen (anticipated regret). Although screening intentions were lower in the intervention group than among controls when measured immediately post-intervention, after 2 years we have not observed an effect of the intervention on self-reported mammography uptake, nor on future breast screening intentions.

Parallel Session 05
Wednesday 5th
9:00—11:00

Chronic disease and SDM	Room 107, CIER
SDM and decision aids	Room Amphi Revol
Involving patients in SDM in practice	Salle de conférence Médiathèque
SDM in mental health	Room Salle du Conseil

ISDM
2017

Discussions about evidence and preferences in real-life general practice consultations with older patients

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Background and aims

In an ideal situation, shared decision making involves a clinician and patient making a health decision together after discussing the options and their potential benefits and harms, and considering the patient's values, preferences and context. Shared decision making for older adults is complex, especially for those who have complex multi-morbidities. Scientific evidence for treatments and tests in the older population is often limited, and older people vary widely in their health and function, their treatment and health outcome preferences and preferences for involvement in decision making. General practitioners (GP) are at the frontline of providing care for older people. They have the difficult task to identify older patient preferences and goals and integrate these with the limited evidence that is available. This study aimed to investigate in how GPs communicate about evidence, patient preferences and context in real-life consultations with older patients (aged 65+ years old).

Methods

Twenty video-taped consultations between older patients (aged 65-90 years) and their GPs were transcribed and analyzed using Framework Analysis with emerging and pre-determined themes. The videos were collected as part of a cluster randomized controlled trial evaluating the impact of an intervention to improve the management of Cardio Vascular Disease risk. Pre-determined themes included information about treatment options and patient involvement; based on the validated ACEPP tool for assessing communication about evidence and patient preferences (Shepherd et al., 2013) and the OPTION scale for measuring the extent that clinicians involve patients in decision making.

Results

Analysis of the consultations provided many examples of GPs discussing the reason for a treatment or test. However, potential benefits and in particular potential harms were seldom discussed. Patient involvement in the consultation varied, some patients seemed to accept treatment decisions without receiving much information or asking further questions, others initiated discussion of options. The conversation in many of the consultations suggested that patients had a long and trusting relationship with their GP. Explicit discussions of preferences were rare and often only occurred after a decision had been made. Medicine discussions (e.g. side effects, practical information) were a recurring theme. In a few consultations reducing the number/dose of medicines was discussed.

Conclusion

In these consultations between GPs and older patients, conversations about preferences and potential benefits and harms of options were rare. The existence of a long and trusting relationship may have reduced the perceived need for explicit discussions around these topics.

An Interprofessional Shared Decision-making and Goal-setting Aid for Complex Patients with Diabetes

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Background
Care of patients with diabetes often occurs in the context of other chronic illness. Competing disease priorities and competing patient-physician priorities present challenges in the provision of care for the complex patient. Guideline implementation interventions to date do not acknowledge these intricacies of clinical practice. As a result, patients and providers are left overwhelmed and paralyzed by the sheer volume of recommendations and tasks. An individualized approach to the patient with diabetes and multiple comorbid conditions using shared decision-making (SDM) and priority-setting has been advocated as a patient-centred approach that may facilitate prioritization of treatment options. Furthermore, incorporating interprofessional integration into practice may overcome barriers to implementation. These strategies have not been taken up extensively in clinical practice.

Objectives
To explore the feasibility of an interprofessional SDM and goal-setting toolkit for patient with diabetes and other chronic diseases for use in clinical care

Methods
Individual semi-structured interviews with healthcare providers and patients were used to explore their experiences with shared decision-making and priority-setting, including facilitators and barriers, and the relevance of a decision aid and toolkit for priority-setting in clinical care. Family physicians, nurses, dietitians, pharmacists, and patients with diabetes and two other comorbidities were recruited through 6 family health teams in the academic and community settings. Audiotapes were transcribed to create a verbatim transcript, which were coded independently by 2 team members for emergent categories and themes within and across interviews.

Results
Preliminary results from 10 interviews (6 physicians, 2 nurses, 1 dietitian, 1 pharmacist) are presented here. We identified 6 themes: 1) *Approach to decision-making* was closely tied into one's professional identity, spanning the spectrum from provision of information to making of the decision, though this was tailored to the specific clinical situation. 2) *Barriers to priority-setting* included tension between the patient's "be" goals and "do" goals, between health professional's and the patient's agenda, competing health and life concerns and lack of time. 3) *Facilitators to priority-setting* included understanding patient barriers, putting the patient's goal in context of the health professional's goal, involving the team and use of flowsheets and case studies. *4) Barriers to SDM* mirrored those for priority-setting. *5) Facilitators to SDM* included patient education, a holistic patient approach, electronic medical record-based flowsheets, and intra-team communication. 6) The use of SDM tools generated mixed feelings: while some thought that they would result in greater efficiencies in time and a positive impact on the relationship, others thought that lack of time, tool complexity and lack of interaction with the patient would be barriers to their use.

Conclusion
Interprofessional SDM regarding priority-setting with the use of a decision aid toolkit may help prioritize care of individuals with multiple comorbid conditions. Our preliminary findings confirm previous knowledge regarding competing issues in the care of the complex patient, but also identify new information regarding facilitators of priority-setting and SDM, namely use of flowsheets in the electronic medical record. Adhering to principles of user-centered design, we will develop and refine a toolkit, by addressing identified barriers and leveraging identified facilitators.

Relationship between Decisional Conflict, Diabetes Distress, Quality of Life and Chronic Illness Care in Patients with Diabetes

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Background

The majority of patients with diabetes have other comorbid chronic conditions. In addition to complex daily self-management requirements, these individuals are faced with competing health concerns which may be prioritized differently by themselves and their healthcare team. Together, these can result in decisional conflict, which may cause distress and negatively impact quality of life. However, the relationship between the constructs of decisional conflict, diabetes distress, quality of life, and patient assessment of chronic illness care is unclear.

Objectives

To evaluate the relationships between decisional conflict, diabetes distress, quality of life and patient assessment of chronic illness care, using the Diabetes Distress Scale (DDS), Short Form Survey (SF12), Patient Assessment of Chronic Illness Care (PACIC) and Decisional Conflict Scale (DCS), respectively, in a diabetes-specific population with 2 or more comorbidities.

Methods

One hundred and ninety nine adults with either Type 1 or 2 diabetes as well as 2 other comorbidities were recruited from 10 primary care group practices in a large Canadian metropolitan area. Participants completed questionnaires for the above constructs, using validated scales (DDS, SF12, PACIC, DCS) as baseline measures for a large randomized controlled trial evaluating a shared decision-making aid. In this cross-sectional study, multiple linear regression models were used to evaluate the associations while adjusting for confounding variables of age, education and income.

Results

The majority of our participants were >65 years of age (63%), with more than college education (63%) and an annual income level less than \$60,000 (54%). DCS was significantly associated with DDS (β=0.0148; CI: 0.00507 to 0.0246; P= 0.0031). However, no significant association was found between the uncertainty sub-score of DCS and the emotional burden sub-score of DDS (β= 0.00358; CI: -0.00699 to 0.0142; P=0.5042). Next, DCS was significantly associated with PACIC (β= -6; CI: -8.25 to -3.75; P <0.0001); this association remained significant when compared specifically with the patient activation sub-score of PACIC (β= -4.08; CI: -5.8 to -2.35; P <0.0001). Finally, DDS was significantly associated with SF12 (β= -3.54; CI: -5.3 to -1.78; P=0.0001); this relationship remained significant when comparing the emotional burden sub-score of DDS with the mental component sub-score of SF12 (β= -2.9; CI: -4.23 to -1.57; P <0.0001).

Conclusion

Patients with diabetes are often faced with multiple comorbidities and stress related to disease management and decision-making. Our findings demonstrate that decisional conflict is positively correlated with diabetes distress and diabetes distress is negatively correlated with quality of life, suggesting the need to reduce decisional conflict to potentially improve quality of life in diabetes patients. Furthermore, the negative correlation of decisional conflict with patient assessment of chronic illness care and patient activation in particular, further reinforces the importance of implementing interventions to improve patient engagement in decision-making.

First things first: starting collaborative deliberation in dementia care networks with recognizing decision needs

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Background and aims
Shared decision-making models in general are less suitable in the context of decision-making for dementia, where decisions are made in care networks consisting of people with dementia, their informal caregivers and their professionals. The aim of this study was to describe the process elements of decision-making for dementia, in order to enrich a model to facilitate shared decision-making for professionals working with people with dementia and their informal caregivers.

Methods
We performed a qualitative study based on secondary analysis of 117 semi-structured interviews from 23 care networks consisting of people with dementia, their informal caregivers and professionals. Data were qualitatively analyzed with the model of collaborative deliberation (Elwyn et al, 2014) as a framework.

Results:
We made an enhancement to the existing collaborative deliberation model, to include: (1) constructive network engagement, (2) recognizing the need for a decision, (3) defining what to decide on, (4) developing alternatives, (5) constructing preferences through deliberation and trying out alternatives, (6) multiple preference integration, and (7) evaluating decision-making. Recognizing the need for a decision is a necessary element in dementia care networks because of the acute or gradual emergence of problems stemming from progressive decline of the person with dementia and other changes in the care network. The changes result in an emerging realization that the situation as it is can no longer be maintained. Participants may differ, however, in their level of recognition of problematic situations.

Conclusion
In describing the process elements of decision making in dementia, this empirical study proposes a modification of the model of collaborative deliberation for the context of dementia care. The adaptation highlights the special attention needed to recognize and define what to decide on, try out alternatives, and handle conflicting interests and preferences. Professionals should be attentive to mark the start of the decision-making process and work with participants towards a shared view on the pressing matters at hand.

WikiRecs and BMJ RapidRecs: rapid and trustworthy recommendations that provide ingredients and tools for Shared Decision Making

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Background

It often takes years before practice-changing evidence published in randomized trials reaches patients in routine clinical practice. Contributing factors include the prolonged time it takes for major guideline organizations to update their recommendations, and the lack of translation of evidence summaries into tools for shared decision making. In response, we have created WikiRECS (Wiki is rapid in Indonese, Recommendation and Evidence summaries Composed as Synopses), including the preeminent BMJ RapidRecs project.

Aims

Faced with potentially practice-changing evidence, we aim to, within 90 days, create and disseminate trustworthy recommendations, evidence summaries, and consultation decision aids addressing important topics in: 1) a novel and user-friendly single page synopsis format, and 2) digitally structured multi-layered presentation formats on the MagicApp (www.magicapp.org).

Methods

We screen new evidence daily through a tailored system, developed in partnership with McMasterPLUS, that identifies the most relevant and newsworthy research. After a topic is chosen, in close collaboration with the journal editors, we recruit a full guideline panel with no relevant financial and minimal intellectual interests. A handful of panel members are involved in the systematic review team(s). The panel, including patients, content experts, methodologists, and frontline clinicians identifies patients-important outcomes and finalizes the PICO question. The parallel team performs systematic reviews addressing relative effects, baseline risk, and values and preferences as necessary within 45 days. The panel then considers the evidence and makes recommendations. GRADE guidance provides the framework for each step in the process, in line with the IOM standards. The recommendation, including a brief summary of background and evidence, and accompanied by the full systematic reviews, is published in one or more journal(s). Infographics provide the gist of the evidence, and links to detailed evidence summaries that published online in the MagicApp (www.bmj.com/content/354/bmj.i5191).

Results

In the first 6 months, we have completed 3 BMJ Rapid Recommendations (2 thus far being published), 2 other WikiRecs, and have several more planned or in preparation. All supporting evidence is accompanied by interactive infographics and GRADE summary of findings, which are translated into interactive decision aids designed to support shared decision making between patients and clinicians. The decision aids also include practical issues that are identified through the evidence review and the patients involved in the guideline panel. Delays associated with the peer review and publication process represent an important residual obstacle.

Conclusion

Multidisciplinary teams that involve patients, expert and publishers can produce rapid and trustworthy recommendations, presented in understandable formats that are easily accessible by patients, clinicians, and other stakeholders in a very short timeframe. This approach demonstrates the potential synergies between evidence synthesis, appraisal, dissemination, and the production of tools for shared decision making, within the wider evidence ecosystem.

Revolutionizing Informed Consent: Empowering Patients with Certified Decision Aids

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Background & aims

To understand the impetus, process, and implications of current and growing patient decision aid (PDA) certification by state and federal government entities in the USA.

Methods

A systematic search was conducted across medical and legal databases for: (1) empirical research on PDA effectiveness, (2) federal policy on PDA certification, and (3) implementation of PDA certification in Washington State.

Results

Policymakers are building a new "bridge" to narrow the persistent gap between the theory and practice of informed consent. That bridge is being built with PDAs. These evidence-based educational tools include decision grids, videos, and interactive websites. Already, over 130 randomized controlled studies show that PDAs help patients gain significant knowledge and understanding of their choices. The evidence on PDA effectiveness is substantial. But their use remains mostly limited to investigational trials. Taking the lead on the challenge of moving PDAs from research to practice, Washington State has begun "certifying" PDAs. The federal government is also exploring PDA certification.

Conclusions

Certification incentivizes PDA use by assuring clinicians, patients, and payers that the information is accurate, up-to-date, complete, and understandable. Washington State serves as a model for other states and for the federal government to follow.

Practice implications

Clinicians should modify their informed consent processes by supplementing traditional discourse with certified PDAs to obtain liability protection and reimbursement incentives.

Developing and pilot testing a shared decision-making intervention for dialysis choice

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Background
Evidence is inconclusive on how to guide the patient in decision-making concerning haemodialysis and peritoneal dialysis. International guidelines recommend involvement of the patient in the decision to choose the dialysis modality most suitable for the individual patient. Nevertheless studies show a lack regarding involving the patient in decision-making.

Objectives
To develop and pilot test an intervention for shared decision-making targeting the choice of dialysis modality.

Method
Patients, nurses and doctors have developed the intervention in collaboration based on the design for complex interventions. This study reflects the first two phases. Phase 1: Based on the identification of relevant evidence and theory, and data analysis of 13 patient interviews we developed a manual for shared decision-making, including a variety of decision aids. Phase 2: The pilot test included both the intervention and the feasibility of the validated shared decision-making questionnaire (SDM Q9) applied to evaluate the intervention.

Results
A total of 137 patients tested the intervention. After the intervention, 80 % of the patients chose dialysis at home reflecting an increase by 25 % in home dialysis. The SDM Q9 showed that the majority of the patients experienced the intervention as shared decision-making. A small number of patients experienced to have made the decision concerning dialysis modality on their own.

Conclusion and application for practice
An intervention based on shared decision-making supported by decision aids seemed to increase the number of patient in home dialysis. The SDM Q9 was a feasible evaluation tool. Further research is needed to gain insight into the patients' experiences of involvement and the implications for their choice of dialysis modality.

Patients' views on factors influencing implementation of patient decision aid in an academic primary care clinic

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Background and aims

Most studies on barriers and facilitators to implementation of PDAs often do not consider patients' perspectives, which is crucial as SDM is a collaborative activity. This study aimed to explore factors influencing the implementation of an insulin patient decision aid (iPDA) in an academic primary care clinic in Malaysia from the patients' perspectives.

Methodology

A qualitative approach was utilized for this study. A total of 16 patients were interviewed in nine IDIs and three FGDs. The interviews were conducted with the aid of a semi-structured interview guide. They were audio-recorded, transcribed verbatim and analyzed using thematic approach. Data collection was carried out from February to June 2016.

Results

Six themes emerged and they were doctors' communication approach, doctors' attitude, doctors' time constraints, conducive environment, opportunity to prepare and discuss with doctors, and paying for PDA as a barrier or facilitator. The first three themes underscored the importance of the influences of doctors when implementing the iPDA. Patients felt that doctors needed to stress on the benefits of using the iPDA in order to motivate patients to use it and they felt more receptive if a doctor recommends it. In addition, doctors should take time in explaining the content of the iPDA in a clear, direct, non-threatening manner using layman's terms. Negative doctor attitudes such as being unfriendly and not being patient-centered could deter patients from using the iPDA. In contrast, doctors are more likely to use the iPDA if they are dedicated, friendly, sympathetic and those who genuinely cared for patients Due to time constraints and high patient load, the participants felt that doctors in the clinic would use the iPDA only partially or not at all. Next, the participants highlighted conditions conducive to implement the iPDA such as using it at home as it was comfortable and private, and patients could read during their free time. This is in contrast to the busy and noisy clinic setting where patients might feel anxious. The participants also raised the importance of having the time to prepare and discuss with doctors about the iPDA. Receiving the iPDA while waiting before the consultation would allow them to ask doctors any queries they have as well. Lastly, many participants felt that patients would not be willing to pay for the iPDA unless they needed it or if the doctors asked them to buy. Some opined that patients should be charged to access the iPDA so that they would value the iPDA and use it.

Conclusion

This study revealed that patients wanted healthcare professionals to play an important role when implementing the PDA. Delivering the PDA in a patient-centred manner and preparing the patient in advance may be key to a successful implementation of a PDA.

Malaysian Healthcare Professionals' Views on Implementing an Insulin Initiation Patient Decision Aid in an Academic-based Primary Care Setting

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Background and Aims

Shared decision making and patient decision aids are novel concepts in Malaysia, a developing, middle-income country with a dual-sector public-private health system. Patient decision aids have been developed for the local setting but little is known about how to implement these aids in routine practice. This study aimed to identify Malaysian healthcare professionals' (HCPs) views on implementation strategies of a decision aid for insulin initiation in patients with type 2 diabetes in an academic-based primary care setting.

Methods

A qualitative approach was utilized. Nine in-depth interviews and three focus group discussions (n=16) were conducted with policy makers (n=6), doctors (n=13), diabetes nurse educator (n=4) and staff nurses (n=2). The policy makers interviewed were individuals who were responsible for or involved in making decisions on whether a particular health intervention should be implemented in the hospital while the doctors, diabetes nurse educator and staff nurses were those involved in advising patients about insulin initiation. The interviews were conducted with the aid of a semi-structured interview guide and later audio-recorded, transcribed verbatim and analyzed using thematic approach. Data collection was carried out from December 2015 to March 2016.

Results

HCPs identified various implementation strategies which could be classified under five broad themes: Leadership, timeliness of delivery, training and empowerment, defining roles and targeted dissemination.

Under leadership, policy makers are to set implementation protocols and implementation should involve identifying early adopters or champions among the HCPs to promote the PDA. For timeliness of delivery, it was important to determine when to distribute the PDA to patients (before, during, after consultations) and to remind HCPs to use the PDA via electronic medical record notifications. Under training and empowerment, HCPs should be trained how to use the PDA so that they can deliver the PDA confidently and in a flexible manner. In addition, family members should be utilised to help explain the PDA to patients. Participants also raised the issue of defining doctor vis-à-vis nurse roles in PDA use; they proposed to roll out the PDA to senior doctors before junior doctors used it. Lastly, dissemination of the PDA should target appropriate patients and use strategies to increase awareness and receptivity of the PDAs (e.g. promotional posters and TV material, PDA samples at wait areas, place at high-visibility locations in consultation rooms).

Conclusion

When implementing PDAs, HCPs emphasised that a multi-faceted approach was necessary. These strategies should target relevant stakeholders (patients, policy makers, nurses and doctors) and integrate into existing care pathway (such as HCP roles, timing of delivery) while maintaining flexibility in using the PDA.

Dissemination and Implementation of Evidence-Based Medicine in Primary Care Through The Use of Encounter Decision Aids: The ShareEBM Pragmatic Trial

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Background

Decision aids (DAs) have been proven effective to facilitate patient-centered discussion about evidence-based health information in practice while enabling shared decision making. However, a chasm remains between the promise and the use of DAs in practice.

Aims

The overall goal of this study was to promote the use of encounter DAs in primary care as a means of advancing evidence-based patient-centered care.

Methods

We conducted a mixed-methods study centered around a practice-based, multi-centered pragmatic randomized trial comparing active implementation (AI) to passive dissemination (PD) of 4 encounter DAs for medication management across primary care practices serving patients with chronic conditions. To achieve implementation, we developed ShareEBM, a web-based toolkit comprised of activities/tactics (i.e. leadership-tailored presentations, process mapping) to increase the likelihood that DAs will be routinized in practices. Practices were centrally randomized to AI or PD arm following stratification by setting and size. In the AI arm, researchers worked closely with practices to actively integrate and promote the use of the DAs, tailoring activities/tactics from ShareEBM to the needs of each practice. In the PD arm, practices alone were responsible for the integration and use of encounter DAs, using ShareEBM as needed. The embedded qualitative evaluation included clinician phone interviews (n=10) and site observations (n=5) for AI practices, and exit focus groups for all practices (n=11). Evaluation was guided by the RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) Framework, with DA use as the primary outcome. We adhered to the intention-to-treat principle.

Results

Eleven practices (AI=5) and 62 clinicians (AI=29) participated in the trial. Over 12 months, clinicians in the AI arm used a total of 621 DAs (Mean [SD]: 21 [25] per clinician, range: 0-93) compared to 680 in the PD arm (Mean [SD]: 20 [40] per clinician, range: 0-156, p=.4). Six (21%) clinicians in AI and 14 (41%) in the PD arm (p=.1) did not use any DAs. Clinicians provided feedback along four major themes: general views of using DAs, perceived impact DAs had on patients, strategies used, and how DAs are integrated into practice flow. Clinicians appreciated the design, trustworthiness, and efficiency of DAs. They were concerned about investing time in using them given their uncertain benefits, competing priorities, and incentives. Some clinicians did not use DAs appropriately (i.e. used them as persuasion tools). Many reported difficulties to fit explicit decision making during encounters with patients into existing processes (i.e. timing of blood work, use of EMR) and frustrations caused by ineffective electronic environments that impaired access or use of DAs. There was an overall sentiment that some clinicians were more likely to be "innate adopters" of DAs.

Conclusion

Neither AI nor PD of ShareEBM activities and tactics improved the rate, frequency, consistency, nor quality of DAs use in practice. Likelihood of long term use appears connected to the ability to integrate DAs into the clinical and electronic workflows of the practice, receive ongoing feedback about the quality of DA use during encounters, and overcome clinician's reluctance toward DAs in the face of competing demands.

Cancer patient readiness for shared decision making: A qualitative study

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Background and aims
Both clinicians and cancer patients report that shared decision making (SDM) can be demanding for patients and that patients are not always able to contribute to SDM. However, little is known about what patients need in order to feel enabled and well-equipped to participate in an SDM process. The aim of this study was to identify elements most relevant to cancer patients' readiness for SDM, and to detect areas for which patients could use support.

Methods
In semi-structured interviews we explored elements that may be related to readiness, and gathered suggestions for ways to enhance readiness. Data were analyzed using thematic analysis. We aim to include participants until data saturation has been reached. So far, we have interviewed $n=2$ oncologists, $n=2$ oncology nurses, $n=2$ general practitioners, and $n=3$ researchers in the field of medical decision making or doctor-patient communication. More interviews will take place in the upcoming months. We are awaiting ethical approval to interview patients and decision partners.

Preliminary results
We identified six major categories of elements that may be relevant to cancer patient readiness. **1) Patient health literacy**. Participants had mixed views on health literacy. Some indicated that patients with low health literacy may be less ready for SDM, whereas others indicated that this should not make a difference. Clinicians can compensate for low health literacy by asking additional questions about what is important in patients' life, and by only providing simple and relevant information. **2) Patient communication skills**. Participants indicated that patients have to verbalize their thoughts and emotions. Some participants reported that patients need to be confident enough to express themselves. However, others believed that this is not necessary as clinicians can compensate for a lack of confidence by asking patients additional questions. **3) Patient attitude.** Having an open attitude towards SDM can benefit readiness. This can be enhanced by explaining why SDM can be beneficial. **4) Patients' emotions**. High emotional distress could hinder readiness. Addressing emotions and involving others in the SDM process could increase readiness in distressed patients. **5) Time**. Having sufficient time was indicated to be an important factor throughout the SDM process. However, too much time may be unfavorable for patients with high emotional distress. Depending on patients' needs, it can be beneficial to have more time before, during, or in-between consultations. **6) Patient-clinician relationship**. Participants indicated that empathy, trust, and openness can benefit readiness.

Conclusion
These preliminary results suggest a wide range of elements that are related to cancer patient readiness for SDM. This can guide further research into the application and development of support to enhance cancer patient readiness for SDM.

Decision making about polypharmacy: the attitudes and experiences of healthy and frail older adults and their companions

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Background and aims

Multiple medication use (polypharmacy) is common amongst older adults even though they are less likely to obtain the same benefit from medicines as younger adults and the associated harms of inappropriate polypharmacy are well known. Reducing inappropriate polypharmacy by not starting medicines, tapering or stopping – "deprescribing" – can be safe and beneficial. Deprescribing can be challenging and requires considered communication and a collaborative approach between the clinician and patient. It is important to involve older adults in these discussions but the extent to which a person wants to be involved is likely to be highly individual and may depend on levels of frailty. Furthermore, there is not much evidence or guidance on how to support older patients in this process.

We explored decision making about polypharmacy with healthy and frail older adults, through discussions about their experiences and attitudes towards making decisions about medicines and their thoughts on deprescribing.

Methods

Semi-structured interviews were conducted with 30 healthy and frail older adults (aged 75+) and 15 of their companions; all with varying socio-economic backgrounds and levels of education in NSW, Australia. Older adults were recruited by their general practitioners and from a rehabilitation ward in hospital. Interviews were conducted in the participant's home. Transcribed audio-recordings were thematically coded and a Framework Analysis method was used to ensure rigour.

Results

Three key themes emerged: 1) attitudes towards medicines 2) preferences for involvement in decision making in general 3) openness to deprescribing. Participants varied considerably in relation to these key themes and other factors which led to the identification of three participant types. Type 1 held very positive attitudes towards medicines, preferred to leave most decisions to their doctor and were resistant to deprescribing. Type 2 voiced ambivalent attitudes towards their medicines, preferred a more proactive role in decision making and were open to deprescribing if their medicines were causing problems or were not beneficial. Type 3 were mostly frail, perceived they lacked knowledge about their medicines, and preferred to defer decisions about their medicines to others (doctor or companion). There were additional challenges amongst the frail older adults, who were generally less involved in medication decisions, and their perceived lack of knowledge about their medications was identified as a barrier to shared decision making.

Overall, limited understanding of the benefits and particularly the harms of medicines led to participants being less involved in decision making and less open to deprescribing. Perceived importance of medicines and not recognising potential side effects also contributed to a participant's preference for continuing medications and deferring medicine-related decisions to others. Overall, companions expressed similar views.

Conclusion

Actively involving older adults in decisions about their medicines is important but can be challenging for clinicians and older adults. We found three types of participants which suggest that interventions to support shared decision making about deprescribing may need to be tailored accordingly. The subtypes we identified may need different approaches to meet the needs of the individual and to support patient involvement in deprescribing decisions.

Developing health literacy through SDM training: exploring skill development among lower literacy participants

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Background and aims

Shared decision-making (SDM) skills reflect communicative and critical-level health literacy capacity. However, SDM has not been incorporated into health literacy training programs to date, and little work has been done to support adults with lower literacy to be engaged in healthcare decision-making. We developed a novel SDM training program, focused on knowledge and question-asking, for consumers with lower literacy. Trained adult educators delivered the 6-hour integrated SDM program as part of an adult basic education health literacy course.

Methods

Semi-structured interviews were conducted with learners (n=25) who participated in the SDM program to explore their experience of learning SDM within adult education health literacy programs. Purposive sampling using a maximum variation strategy was used to select a range of learners from English-speaking and non-English-speaking backgrounds from regional and metropolitan areas. Interviews were audio-recorded, transcribed verbatim and analysed using Framework Analysis, a matrix-based approach to thematic analysis.

Results

Learners were often unaware that question-asking is permitted during healthcare encounters. The SDM program facilitated awareness among participants that they had a right to ask questions and participate in decision-making: *"But now we understand that we have an option where we can talk to the doctor"* (2AL05). Some students conceptualised participation in healthcare decision-making as a responsibility, necessarily enacted to ensure they receive the correct treatment, *"I know you have to make decision with the doctor…I have to ask. I have to know. I can't stay like, 'yes, ok, ok'"* (1GR09).Participants reported having increased self-efficacy and confidence to enact their right and responsibility to participate in health decision-making after completing the program: *"But I do feel a lot more comfortable....Because before…you used to feel as if, oh, you'd feel stupid thinking you're saying something silly." (*2AL05).

Most participants described developing skills for participation in healthcare consultations. These skills broadly aligned with Nutbeam's three levels of health literacy, progressively facilitating greater autonomy and control over health decisions. Whilst some participants' reports emphasised the development of functional-level skills (e.g. skills to describe symptoms and ask clarification questions), the majority reported having developed some communicative-level health literacy skills (e.g. skills to extract information about options, benefits and harms via question-asking), *"…But now, with doing that course…if I get something I, I question him* [doctor] *about it and say, you know, there's a right thing for it, is there any downsides? You know?"* (1MA08). A minority of participants moved beyond communicative skill development to exhibit critical health literacy. These participants were not only able to elicit information from healthcare professionals, but also described integrating new knowledge with preferences to make an informed, shared decision.

Conclusion

Our SDM training program served as a way to prepare consumers with lower literacy for participation in healthcare decision-making, increasing awareness of their right and responsibility to engage in decisions about their health, and facilitating the development of skills and self-efficacy to do so. With a tailored SDM program, many adults with low general literacy were able to develop high-order health literacy skills for question-asking and SDM.

Choice awareness as pre-requisite for shared decision making: An analysis of video recordings of clinical encounters

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Backgroun

Three key steps of shared decision making (SDM) are creating choice awareness, discussing relevant options, and eliciting patients' preferences. To date, both SDM research and implementation have focused on the second and third steps. This study aims to assess 1) the extent to which choice awareness is created in clinical care, 2) what impact creating choice awareness has on the subsequent steps of SDM, and 3) whether conversation aids encourage creating choice awareness.

Methods

A secondary analysis was conducted of data collected in 10 randomized trials on communication with and without a conversation tool during clinical encounters, which covered 7 topics (primary prevention of coronary disease, low-risk acute chest pain, stable angina, diabetes, depression, osteoporosis, Graves disease). Encounters were taped and coded with the OPTION12-scale to quantify the extent to which clinicians involved patients in decision making. Reviewers reproducibly rated each video (kappa>.7) while unaware of our hypothesis. For this study, we randomly selected 100 encounters stratified by topic and study arm (control vs. conversation tool). In each video, two reviewers coded in consensus whether and how choice awareness was created. We also coded what happened prior to creating choice awareness to assess whether choice awareness was created before subsequent SDM steps. We followed a generous approach of coding. The association between choice awareness and OPTION12-scores was modeled using a hierarchical generalized linear model with a log link, adjusting for arm, with trial as random effect.

Results

53 of 100 encounters exhibited some form of creating choice awareness. This was done by listing relevant options combined with (N=15/53, 28%), or without a recommendation (N=38/53, 72%). Just before creating choice awareness, clinicians reviewed the patient's situation (N=37/53, 70%), or introduced the conversation tool (N=9/53, 17%). In the 47 encounters in which choice awareness was not created, there were either no other options offered to consider (N=34/47, 72%), or other options were available and implied, but a recommendation was provided without explicit mention of relevant alternatives (N=13/47, 28%). OPTION12-scores were higher in encounters in which choice awareness was created, mean difference 20.1, 95%CI (11.2, 28.9). OPTION12-scores were only modestly better with the conversation tool after adjusting for choice awareness, mean difference 5.8, 95% CI (-1.3, 12.8).

Conclusion

Using a generous definition of choice awareness, clinicians created choice awareness to some extent in over a half of the encounters. Our results suggest that if choice awareness is created, this mostly happens prior to other SDM steps and is linked to a better execution of subsequent steps in SDM, with and without the use of an effective SDM conversation aid. By that, choice awareness seems a prerequisite for SDM and a key preliminary step in the formulation of patient centered conversations.

How Healthcare Provider Communication about Risk and Decision Making Role affects Decisions about Birth after Caesarean

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Background and aims

Despite clinical and policy consensus that all eligible candidates for vaginal birth after a caesarean should be presented with that option, there is controversy and mixed opinion among maternity care providers about the best approach to birth after caesarean and clinical superiority of one option over another has not been established. Shared decision making requires complex risk information for each option to be provided in a format that best facilitates understanding and promotes engagement in decision-making. There is qualitative evidence that sub-optimal risk communication by healthcare providers prohibits women with a history of caesarean section from making informed decisions about subsequent births, but this has not been confirmed in empirical research. Several features of healthcare provider communication may undermine effective shared decision-making, including selective communication of partial risk and benefit information to reflect/create a persuasive bias, providing information about likelihood of outcomes in relative format, and discouraging patient involvement in decision making. We experimentally investigated how health care provider communication of risk information and women's role in decision-making influenced women's mode of birth decisions after a previous caesarean.

Methods

Women who had previously given birth but were not currently pregnant (N = 669) were randomised to one of eight conditions in a 2 (selectivity of risk information) x 2 (format of risk information) x 2 (role in decision making) experimental design. After exposure to a hypothetical decision scenario that varied information communicated by an obstetrician to a pregnant woman with a previous caesarean across the three factors, women were asked to indicate a decisional outcome (repeat caesarean or vaginal birth after caesarean) and their overall perceived risk of each option.

Results

Together, the three independent variables (information selectivity, risk format, and role in decision making) significantly predicted hypothetical childbirth decision [X^2 (3, N = 669) = 29.61, p < .001, Cox and Snell R^2 = .04, Nagelkerke R^2 = .06]. Selective information (incomplete/biased toward repeat caesarean) resulted in 1.57 (95% CI 1.06-2.05) times the odds of choosing caesarean than non-selective information (complete/unbiased). Relative risk information (ratio of incidence being compared e.g. 2.5 times higher) resulted in 2.36 (95% CI 1.62-3.16) times the odds of choosing caesarean than absolute risk information (incidence rate e.g. 0.01 per 100). Variations in communicated decision-making involvement did not significantly influence childbirth preferences. The effect of information selectivity on decisional outcome was completely mediated by perceived risk of the options, and the effect of risk format on decisional outcome was partially mediated by perceived risk.

Conclusions

Findings highlight modifiable aspects of healthcare provider communication that may influence women's decision-making about childbirth after a caesarean birth, and that these effects operate by elevating or attenuating women's perceived risk of the available options. In light of other evidence that communication related to decision making for childbirth after a caesarean tends to be biased in the direction manipulated in our study, our findings suggest that current communication features for shared decision making in practice may be partially responsible for over-use of repeat caesarean.

Results of a Pilot Study of a Tailored Symptom Assessment Tool to Enhance Patient-Centered Care in Rheumatoid Arthritis

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Background/Purpose

Discordance in the assessment of rheumatoid arthritis (RA) disease activity has been reported in 30% of patient-clinician dyads, with discordance higher for those with depressed mood. Our objective was to pilot-test a tablet-based, patient-reported symptom tool to improve communication around preference-sensitive symptoms among diverse RA patients.

Methods

We conducted a pilot study to test the acceptability, feasibility and efficacy of CHOICE RA, a tablet-based, preference-sensitive symptom reporting tool. 58 symptoms derived from the literature and patient and rheumatologist focus groups populate the tool across 4 categories: 1) Physical symptoms, 2) Function; 3) Feelings and relationships, 4) Joint pain and swelling. Patients select and prioritize symptoms based on their perceived need for care. Eligibility was: age ≥18, Spanish or English speaking, and diagnosis of RA. Participants from two university-affiliated rheumatology clinics were enrolled into one of two study arms. All patients completed CHOICE RA before their appointment, and later a post-visit survey. In Arm 2, clinicians received a summary of patients' choices but not in Arm 1. The primary outcome was congruence between mean total patient-reported symptoms and those discussed in the visit. Congruence for high priority symptoms stratified by language was investigated. Acceptability and satisfaction were measured in clinicians and patients. We compared means using t-tests and proportion of high priority symptoms discussed using Fischer's exact tests.

Results

A total of forty-five patients were enrolled (Arm 1: 24, Arm 2: 21), 91% were female; mean age 53±13, 56% Spanish-speaking, and 42% had limited health literacy. There were no statistically significant differences in congruence scores by study arm. However, in subgroup analyses, a significantly greater number of high-priority mood symptoms were discussed in arm 2 (55%) compared to Arm 1 (0%) among Spanish-speakers (p=0.04). Majority (≥ 90%) found the tool acceptable based on ease of use and usefulness. Nearly all patients (98%) reported the tool facilitated communication with their doctor.

Conclusion

CHOICE RA was highly acceptable to Spanish and English-speaking RA patients and clinicians, and helped patients communicate high priority symptoms to their clinician. While it did not increase congruity in total symptoms listed vs. discussed overall, it increased discussion of mood symptoms highly prevalent in this vulnerable group with communication barriers. Results from this promising pilot study should lead to a larger, multi-site trial to evaluate its impact on a broader population.

A cluster randomized controlled trial of a psychoeducational intervention for people with a family history of depression for use in general practice

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Objective
To evaluate the effectiveness of an interactive psychoeducational website (intervention) compared to a general leaflet about depression (control) in facilitating decisions about preventative behaviours in people at increased familial risk for depression.

Design
Cluster randomised controlled trial.

Setting
Primary Health Care.

Population
GP attendees with at least one first-degree relative with major depressive disorder (MDD) or bipolar disorder (BD).

Methods
20 general practices were randomised to provide eligible patients access to either the intervention (n=10) or control condition (n=10). Participants completed outcome measures at baseline and 2-week follow-up.

Outcome Measures
The primary outcome was intention to undergo or actually undergoing psychological therapy as a risk reduction strategy for development of depression. Secondary outcomes were: knowledge of risk factors and risk reduction strategies, perceived risk of developing MDD or BD, depression symptoms, and perceived stigma.

Results
211 patients completed both questionnaires and were included in the analyses. Compared to the control group, the intervention group participants were more likely to intend to use or use therapy (OR=3.45, 95% CI: 1.28–11.20, p=.016), had a significantly greater increase in knowledge (mean difference 0.47, 95% CI: 0.09–0.88, p=.022) and were more likely to accurately estimate their lifetime risk of developing BD (mean difference 11.2, 95% CI: -16.19–-5.48, p <.001). There were no significant differences in the other outcomes measured.

Conclusion

This psychoeducational website can play an important role in improving the outcomes of individuals at familial risk for depression. Testing of the intervention in other health practitioner settings (e.g. psychologists, psychiatrists, genetic counsellors) appears warranted.

How Do Children and Parents Want Their Therapists to be Involved in Making Decisions for Psychotherapy?: A Qualitative Study

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Background and Aims: Treatment planning is a complex process, especially when including parents and children in decision-making, when decisions involve abstract concepts like mental health, and when treatment options may not be readily understandable (e.g., empirically-supported psychosocial techniques like cognitive restructuring and behavioral exposure). Study aims were to assess parent and child perspectives on treatment planning for youth psychotherapy; this submission focuses on perspectives regarding the therapist's role.

Methods: Parents (n = 16) and children (n = 11, 8–14 years old) seeking treatment for childhood depression and/or anxiety were invited to participate in semi-structured qualitative interviews about treatment planning, with a focus on the role of therapists. Interviews were transcribed and coded for analysis guided by a Grounded Theory framework (Glaser & Strauss, 1967). Analyses in the present study focus on providing a "thick" description of participant perspectives (Geertz, 1994), relating variability in perspectives to demographic characteristics and clinical presentations, and comparing and contrasting parent and child perspectives.

Results: Parents and children described a variety of potential treatment planning roles for therapists, including (from most to least commonly noted): collaborating, providing information, sharing opinions, learning and understanding, generally engaging, unilaterally making decisions, deferring to others, and providing emotional support. Parents uniformly viewed therapists as important supporters of decision making, with therapists contributing either objective information about treatment options, their professional opinions, or both. No parent endorsed wanting the therapist to take an exclusively unilateral (or deferential) role in decision making. Some parents focused on the therapist as a "tie breaker" when parents and children disagree. Children agreed with parents that therapists should be collaborative, also noting the potential for therapists to resolve parent–child disagreements. Some children noted that they would want the therapist to have more influence when the therapist has a longstanding relationship with the child.

Conclusions: Parent and child perspectives on therapist roles in the treatment planning process are variable, yet generally converge on basic principles of the therapist being involved in the treatment planning process, and supporting collaborative decision-making by providing support and, when needed, resolving disagreements. This foundational qualitative descriptive research on preferred therapist roles in treatment decision-making will inform the design of shared decision-making interventions to enhance treatment of parents and children who are receiving pediatric mental health care.

Using the Theoretical Domains Framework (TDF) to understand factors that affect clinicians shared decision making in child and youth mental health

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Background

The Theoretical Domains Framework (TDF) is a comprehensive framework for designing behavior change interventions, which focuses on 14 key constructs across 3 overarching domains: Capability, Opportunity, and Motivation. The aim of this study is to apply the TDF to interviews with clinicians to understand factors that influence SDM, and from this develop an intervention aimed at clinicians.

Method

16 clinicians and trainees across 3 child and youth mental health services in England were interviewed about their capability, opportunity and motivation in relation to SDM in child and youth mental health. Interview questions drew upon the Theoretical Domains Framework (TDF). Mean interview time was 38.20 minutes. Data was analysed using thematic analysis.

Results

Capability

Clinicians stated that they felt confident and capable using SDM in their practice, as these were skills they had gained during clinical training. However, they felt that regular training and/or supervision was needed to keep these skills up-to-date. A lack of knowledge about treatment options outside their therapeutic modality was reported, as well as not knowing which resources were available outside the clinical setting. Prompts and questionnaires were frequently used by clinicians to facilitate and feedback on SDM. Clinicians reported a lack of guidance around SDM and what it included. Lastly clinicians were conflicted as to whether inform patients about other treatments outside of the clinic.

Opportunity

Clinicians reported a lack of choice regarding interventions to offer patients as well as a lack of time to do SDM. Buildings and clinic rooms were not seen as being suited to SDM due to layout and other factors. Social influences affected decisions made in appointments. These came from multiple sources including other clinicians, parents, young people, and outside influences such as school and social services.

Motivation

Clinicians reported that SDM was part of their role, and were motivated to do it as it empowered young people, and improved therapeutic relationships. Clinicians reported that in certain circumstances they felt SDM could make patients psychologically worse. In situations related to risk, motivation to engage in SDM was outweighed by a professional duty to protect the patient and act in their best interests. Clinicians reported feeling emotionally overwhelmed due to work pressures which affected SDM.

Conclusion

A range of factors affecting SDM from the clinicians perspective has been established. To improve SDM within child and youth mental health settings, one may wish to target multiple factors within a clinicians capability, opportunity and motivation.

Evaluation of i-THRIVE decision aids for improving shared decision making in child and youth health

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Background

THRIVE is a conceptual framework in child and youth mental health and was developed by a collaboration of authors from the Anna Freud National Centre for Children and Families (AFNCCF) and the Tavistock and Portman NHS Foundation Trust. It conceptualises need into five categories: Thriving, Getting Advice and Signposting, Getting Help, Getting More Help and Getting Risk Support. Central to THRIVE is the premise of SDM with young people. The aim of this study was to develop encounter decision aids for THRIVE to use in assessment clinics and examine if they influenced clinical outcomes.

Methods

Intervention

Working in collaboration with Dartmouth University, five encounter decision aids designed as comparison tables were developed. Encounter decision aids were derived from the Option Grid™ concept and were developed for three presenting problems: depression, self-harm, and ADHD. Encounter decision aids were then implemented in two London assessment clinics in February 2017 using PDSA (Plan Do Study Act) cycles to make further improvements, and examine if encounter decision aids contributed to changes in patient outcomes.

Data collection

Data was collected on SDM, patient satisfaction, modality of care, clinical symptomology, type and delivery of treatment, and THRIVE grouping allocated. Young people, parents, and clinicians were interviewed about encounter decision aid usability and acceptability.

Results and conclusion

Baseline data was collected from 55 service users (33 parents and 22 young people). CollaboRATE showed SDM to be higher in parents than young people on both the mean score (8.1 vs 7.6) and the 'Top Score' which represented 'gold standard' SDM (40% vs 16%). Changes to encounter decision aids included some language and format alterations. We will present results on how the introduction and refinement of encounter decision aids into assessment clinics influenced outcomes, as well as presenting qualitative feedback on usability and acceptability from stakeholders.

Participation preferences of patients with alcohol use disorders in detoxification treatment

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Background and aims

Preferences of patients regarding their involvement in medical decisions have been investigated in various health conditions as well as in public surveys. These preferences include whether the patients want to share the decision with a health care provider (shared decision making, SDM), let the health care provider decide (passive) or want to decide on their own (informed). While the majority of patients across studies prefer to share the decision, there are variations according to age, gender, education and also the health condition of the patients. However, there is little knowledge regarding participation preferences of patients with alcohol use disorders (AUD). Aim of this study was to investigate participation preferences of patients with AUD and to identify factors influencing these preferences.

Methods

Data was collected as part of the project Allocation of patients with alcohol use disorders to appropriate levels of care according to a decision algorithm based on a standardized intake assessment (Trial registration DRKS00005035) in four German psychiatric clinics offering inpatient alcohol detoxification treatment. Patients were excluded when they primary diagnoses other than AUD, insufficient German language skills, or needed crisis intervention. At treatment entry, patients signed an informed consent and completed a patient questionnaire including the Control Preference Scale (CPS). In addition, the Measurements in the Addictions for Triage and Evaluation (MATE) was conducted assessing severity of addiction, treatment readiness, and psychiatric comorbidity. For a comparison across health conditions, samples from former studies of our research group were used (cancer[1], affective disorders[2], anxiety[3]). Chi-square tests and a multinomial regression were performed.

Results

A total of N=242 patients completed the CPS and were included in the study. Mean age was 45.16 years (SD=10.3). The majority of patients (n= 231; 95.5%) were German and male (n=157, 64.9%). Only 10.3% of the study sample preferred a passive decision making (n=25), 39.7% preferred SDM and 50% (n=121) preferred an informed decision making style. Compared to patients with anxiety, affective disorders, or cancer, a higher percentage of patients with AUD preferred informed decision making (p<.001). Despite treatment readiness, there were no associations with clinical or sociodemographic variables and the patients' participation preferences: A higher treatment readiness was associated with a preference for SDM compared to informed decision making (OR=.611, p=.038).

Conclusion

This study revealed first information regarding the participation preferences of patients with AUD but was conducted in a specialized treatment. Further studies should include different health care settings for patients with AUD.

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