



10^e Conférence internationale
sur la décision partagée

10th International Shared Decision
Making Conference

ISDM 2019

Recueil des résumés : Sessions orales
8, 9 et 10 juillet 2019
(en ordre de numéro de résumé)

Book of Abstracts: Oral Sessions
July 8, 9 & 10, 2019
(by Abstract ID)

Merci à nos précieux collaborateurs / Thanks to our precious collaborators:



003 - Patient engagement with online decision-aids in mental health: Lessons learnt from the development and Phase II RCT of a bipolar II decision-aid website.

Alana Fisher^{1,2}, Ilona Juraskova^{1,2}, Rachael Keast^{1,2}, Dan Costa², Josephine Anderson³, Vijaya Manicavasagar³, Louise Sharpe¹

¹The University of Sydney, The School of Psychology, NSW, Australia, ²The University of Sydney, The Centre for Medical and Evidence-based Decision-making (CeMPED), NSW, Australia, ³The Black Dog Institute, NSW, Australia

Introduction: Substantial research supports the efficacy of decision-aids (DAs), however their use in clinical practice is typically low. This research-practice gap may be especially pertinent in the context of online mental health DAs, where there may be additional challenges to DA uptake. Since practical implementation strategies in this setting are still lacking, this presentation will outline key challenges and strategies for patient engagement during the development and Phase II RCT of a DA website (e-DA) to assist patients deciding on options to prevent relapse in bipolar II disorder.

Methods: The DA content/format were developed according to IPDAS, and included expert working party review, and piloting with potential end-users. The subsequent e-DA design included a systematic co-development process involving: prototyping and iterations to the user-interface and key website features, and usability testing with potential end-users. For the Phase II RCT, a consecutive patient sample was randomised (1:1) to receive currently available online information with/without the e-DA (Intervention/Control). At baseline (T0), post-decision (T1), and three-months' follow-up (T2), validated and purpose-designed questionnaires assessed the e-DA's acceptability, feasibility and potential efficacy.

Results: The DA's content/format were considered highly acceptable and safe amongst potential end-users (30 patients, 13 family). Usability testing of the e-DA addressed suggested changes to the website content, format, and usability prior to RCT commencement. During the RCT, a number of challenges arose which affected patient recruitment (clinic restructuring), onboarding to the e-DA (patient information overload), and patient retention (study follow-up mode). Strategies were implemented to address these. Preliminary analyses revealed that, at T0, Intervention patients whose main treatment goal was more aligned with the e-DA's content (relapse prevention) than other goals (treating symptoms), reported better engagement with the e-DA at T1 (beta=0.486, $p=0.025$), over and above sociodemographic variables.

Conclusion: This presentation provides practical strategies for addressing some of the "real-world" challenges, which arise when evaluating an online mental health DA. Additionally, preliminary RCT findings highlight the importance of targeting DA provisions according to patients' self-identified treatment goals. Using a systematic co-development process which involves potential end-users, and identifying strategies to improve e-DA uptake in RCTs are critical first-steps for future implementation.

008 - Perceptions from health professionals and patients that attend to San Pantaleon Health Community Center (SPHCC) regarding participation in the Shared Decision Making (SDM) Process

Gauna Alan¹, Carrara Carolina¹, Terrasa Sergio¹

¹Family Medicine, Hospital Italiano de Buenos Aires, Argentina

Background

SDM has shown to improve health care standards; however it is not always applied in our daily practice. Population that attends to SPHCC have low socioeconomic status, low level of education, and poor health literacy, characteristics that predict less interest in participating in SDM.

Aims

Methods

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

First stage: Observation and Participant observation.

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

Results

First stage (6 months): SDM is carried out exceptionally during scheduled consultations and was not observed in any of the non-scheduled consultations.

Second Stage:

Health professionals (7 interviews) expressed difficulties due to cultural difference and lower educational level: "It raises many questions about how far they can understand what we say"

Patients (4 interviews) expressed that it is the doctor who must make decisions about their health, and they prioritize it as the main source of information. "You give me a medication, I do not argue"

Barriers perceived to carry SDM were:

Difficulties in the implementation due to lack of initiative from health professionals and patients, to the perception that SDM is a complex process that takes more time than is available, and difficulty in applying it to low health literacy patients.

Structural difficulties related to the availability of time for consultations, delays in obtaining appointments, lack of audiovisual material and computers in the offices.

No facilitators to carry out SDM were perceived.

In the few cases in which SDM was carried out, an increase in the satisfaction was expressed.

Conclusion

Shared decision making should not be overlooked just for acting in a context of vulnerability and difficulties, and it should be adapted to local conditions in order to improve health care standards.

009 - The LEAD trial. The effectiveness of a decision aid on decision making among citizens with lower educational attainment who have not participated in FIT-based colorectal cancer screening in Denmark: a randomised controlled trial

Pernille Gabel^{1,2}, Adrian Edwards³, Pia Kirkegaard¹, Mette Bach Larsen¹, Berit Andersen^{1,2}

¹Department of Public Health Programmes, Randers Regional Hospital, Denmark, ²Department of Clinical Medicine, Aarhus University, Denmark, ³Division of Population Medicine, School of Medicine, Cardiff University, UK

Objectives

This trial sought to test the effectiveness of a newly developed self-administered web-based decision aid, targeted at citizens with lower educational attainment, on informed choice about colorectal cancer screening participation.

Methods

The trial was a randomised controlled effectiveness trial, nested into the colorectal cancer screening programme in the Central Denmark Region.

A population-based random sample of 2,702 screening-naïve citizens, 53-74 years old, with lower educational attainment, received a baseline questionnaire. Respondents (62%) were allocated to intervention and control groups.

Both groups received the standard screening reminder, and the intervention group also received the decision aid.

Primary outcome was informed choice as assessed by group levels of knowledge, attitudes and uptake. Secondary outcomes were worries and decisional conflict.

Results

A total of 339 citizens was eligible for analysis. The decision aid did not affect knowledge (mean difference in score change between intervention and control group: 0.00, 95% confidence interval (CI): -0.38;0.38). There were trends towards more positive screening attitudes (mean difference in score change: 0.72, 95% CI: -0.38;1.81) and higher screening uptake (7.6%, 95% CI:-2.2;17.4%). Worries decreased marginally (-0.33, 95% CI: -0.97;0.32) and decisional conflict was slightly reduced (mean difference: -3.5, 95%CI: -7.0;-0.1).

Conclusions

An overall effect of the web-based decision aid on informed choice was not observed in this study, but being a simple web-based intervention, easily administered in a screening programme, it could represent a cost-effective way of enhancing screening uptake, and some elements of informed decision-making, particularly for hard-to-reach groups with usually screening uptake.

010 - The impact of physicians' recommendations on treatment preference and attitudes: An experimental study on shared decision making

Marie Eggeling¹, Martina Bientzle¹, Joachim Kimmerle¹

¹Leibniz-Institut für Wissensmedien, Tuebingen, Germany

Even though most patients are interested in making shared or autonomous medical decisions, implementing shared decision-making is very challenging. Many patients feel that they lack the knowledge to make a decision, underestimate the importance of personal preferences and individual experiences, and expect a recommendation by their physician. This may be problematic, since physicians' recommendations strongly influence decision-making and may even impair initial decisions. In the experimental study presented here we examined the impact of physicians' recommendations on the decision-making process in a situation where participants had been explicitly explained that their decision was preference sensitive as there was no scientific evidence for the superiority of a particular treatment option.

N = 145 participants were placed in a hypothetical scenario where they suffered from a cruciate ligament rupture and were provided basic information about the treatment options (surgery or physiotherapy). In a 3x2 between-group design we investigated the impact of physicians' recommendation (for surgery, for physiotherapy, no recommendation) and reasoning style (scientific, anecdotal). Participants indicated initial preferences, certainty, satisfaction, and attitudes toward both treatments. Then they watched one of six different videos of a consultation with a physician. All videos first showed a physician giving the diagnosis, informing about the treatments and explaining that the decision would depend on the patient's preferences. The second part of the videos differed regarding recommendation and reasoning style. Afterwards, participants again indicated preferences, certainty, satisfaction, and attitudes.

We found that the recommendation had a significant influence on treatment preference and attitudes toward both treatments. Additionally, we found a significant increase in people's certainty and satisfaction regarding treatment preference, independent of whether or not they received a recommendation. There were no differences regarding reasoning style.

Participants were likely to adjust their treatment preferences and attitudes to the physician's recommendation, even though they had been told that they should rely on their personal preferences. These results indicate that physicians should be careful with recommendations when aiming for shared decisions. Certainty and satisfaction with the hypothetical decision increased in all groups, suggesting that a recommendation was not required to strengthen participants' confidence in their decision.

019 - Implementing cardiovascular disease prevention guidelines using a theory-based intervention to translate evidence-based medicine and shared decision making into general practice: A qualitative piloting and quantitative feasibility study.

Carissa Bonner^{1,2,3}, Michael Anthony Fajardo^{1,2}, Jenny Doust^{2,4}, Kirsten McCaffery^{1,2,3}, Lyndal Trevena^{1,2}

¹The University of Sydney, School of Public Health, ²ASK-GP Centre for Research Excellence,

³Sydney Health Literacy Lab, ⁴Bond University

Background and aims: The implementation of cardiovascular disease (CVD) prevention guidelines based on absolute risk assessment is poor around the world, including Australia where 75% of high risk patients are under-treated and 25% of low risk patients are over-treated. Behavioural barriers amongst GPs and patients include capability (e.g. difficulty communicating/understanding risk) and motivation (e.g. attitudes towards guidelines/medication). This paper outlines qualitative piloting and a quantitative feasibility study for a theory-based intervention to address these barriers. It aims to facilitate evidence-based CVD risk assessment and shared decision making between GPs and patients.

Methods: The intervention was informed by The Healthy Heart Study, involving 400 GPs and 600 patients/consumers from 2011-2018 to identify barriers to CVD prevention guidelines. The development process included analysis of behavioural barriers and evidence-based solutions using the Behaviour Change Wheel (BCW) framework. The intervention was co-developed with GPs (n=18), piloted at a national GP conference session/stall (n=113/25), and developed iteratively based on “think aloud” interviews with GPs and patients to improve acceptability (n=19). A feasibility study to evaluate demand and potential efficacy was conducted with 123 GPs, with follow-up after 1 month (n=98).

Results: Qualitative feedback from the GP conference was positive, with an average 8.4/10 star rating. Iterative user testing with GPs and patients improved acceptability (content and usability) over three rounds of development. The feasibility study suggested potential efficacy with improved identification of hypothetical high risk patients (from 29% to 78%) and recommended medication (from 59% to 87%) after viewing the website. Demand was high, with most GPs (89%) indicating they would use the website in the next month, and 72% reported using it again after one month. Open feedback identified a need for integration with medical practice software.

Conclusions: This project used a theory-based framework, iterative user feedback and feasibility testing to develop a novel online version of CVD prevention guidelines that addresses behavioural barriers amongst GPs and patients. The resulting intervention was acceptable for users, with high demand and potential efficacy for improving the identification of high risk patients and guidelines-based medication recommendations. Implementation will be based on user-identified strategies.

021 - A Prospective Cohort Study of Shared Decision Making in Lung Cancer Diagnostics: Impact of Using a Patient Decision Aid

Stine R Søndergaard¹, Poul Henning Madsen², Ole Hilberg^{1,5}, Karina M Jensen¹, Karina Olling⁴, Karina D Steffensen^{3,4,5}

¹Department of Internal Medicine, The Lung Cancer Diagnostic Organization, Lillebaelt Hospital, Vejle, Denmark., ²Department of Internal Medicine, Lillebaelt Hospital, Kolding, Denmark., ³Department of Oncology, Lillebaelt Hospital, Vejle, Denmark., ⁴Center for Shared Decision Making, Lillebaelt Hospital, Vejle, Denmark., ⁵Institute of Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark.

Background and aim Patients referred to fast-track evaluation with suspicion of lung malignancy are, based on CT scans, most often recommended further evaluation to establish diagnosis. However, in a significant number of the patients lung cancer is not very likely but at the same time cannot be ruled out based on the CT scan and referral note. In this group of patients it is not scientifically clear whether to recommend further diagnostic, invasive procedures with potential risks involved, arrange close follow-up with regular CT scans, or deselect further evaluation. Guidelines have encouraged the use of Shared Decision Making (SDM) to engage patients in the decision on the intensity of the diagnostic process, but the practice is not consistent among pulmonologists. With its systematic approach, SDM can help clinicians engage their patients to ensure that decision making is based on patient preferences as well as evidence based clinical information.

The aim of this study was to investigate the impact on patient-reported outcomes of introducing SDM and an in-consultation Patient Decision Aid (PtDA) in the initial process of lung cancer diagnostics.

Methods. We conducted a prospective cohort study, where a control cohort was consulted according to usual clinical practice. After introducing SDM through a PtDA and training of the staff, the SDM cohort was enrolled in the study. All patients completed four questionnaires: the Decisional Conflict Scale (DCS) before and after the consultation, the CollaboRATE scale after the consultation, and the Decision Regret Scale (DRS) six months after the consultation.

Results. Patients exposed to SDM and a PtDA had significantly improved DCS scores after the consultation compared to the control group (a difference of 10.26, $p = 0.0128$) and significantly lower DRS scores (a difference of 8.98, $p = 0.0197$). Of the 82 control patients and 52 SDM patients 29% and 54%, respectively, reported maximum score on the CollaboRATE scale (Pearson's χ^2 8.0946, $p = 0.004$).

Conclusion. The use of SDM and a PtDA had significant positive impact on patient-reported outcomes. This may encourage the increased uptake of SDM in the initial process of lung cancer diagnostics.

022 - Development and user-testing of a within-consultation personalised decision aid for cataract surgery

Kate Lifford¹, Natalie Joseph-Williams¹, Daniella Holland-Hart¹, Pippa Craggs², Christalla Pithara², John Sparrow²

¹Cardiff University, Cardiff, UK, ²University Hospitals Bristol NHS Foundation Trust, Bristol, UK

Background and aims

Cataract surgery is the most common surgery in the UK, but patients and clinicians face significant uncertainties regarding outcomes when approaching decisions about whether or not to proceed with surgery. Benefits and risks are usually presented in vague terms (e.g. 'likely to see better after the operation'), with or without overall averages for complications or visual harm. Surgeons may sometimes offer 'gut feeling' estimates for personalised probabilities of benefits and harms based on clinical experience or assumptions about the patient. In a 'post-Montgomery' environment these approaches lack precision and do not adequately involve patients in the decision-making process. We aimed to develop and user-test a within consultation personalised patient decision aid (PtDA) for cataract surgery, which presents likely patient-reported benefits and risks of harms for individual patients.

Methods

A User Reference Group (URG) comprising patients, clinicians and researchers was established, to ensure a 'co-production' approach to PtDA development. A focus group was conducted with previous cataract patients. A prototype PtDA was developed via an iterative process by the URG using the evidence base available for cataract surgery outcomes, and results from the focus group. Semi-structured telephone interviews were conducted with patients and clinicians to user-test the prototype PtDA. Interviews were recorded, transcribed verbatim and thematically analysed.

Results

Semi-structured interviews were conducted with 20 patients and six clinicians. Seven key themes emerged from the thematic analysis: presentation / format of PtDA; patients' frequently asked questions; previous experiences of shared decision making (SDM); perceptions of the SDM process; preferences for SDM; anticipated behaviour change; PtDA implementation in routine clinical setting / barriers to use. Overall, patients and clinicians were clear about the purpose and were positive about the format, content, and usefulness of the PtDA, especially the personalised element. Recommended format /content changes, practical concerns and barriers were highlighted.

Conclusion

Patients and clinicians perceived that the PtDA likely improve the decision-making process, increase co-production, and is feasible in routine clinical settings. Feedback provided will be considered during PtDA revision and implementation planning, and the decision aid will be subjected to a feasibility randomised controlled trial.

023 - “I'd like to have more of a say, because it's my body” Adolescents' Perceived Barriers to and Facilitators of Shared Decision-Making about Long-Term Healthcare

Amber Jordan¹, Dr Natalie Joseph-Williams¹, Prof Adrian Edwards¹, Dr Fiona Wood¹

¹Cardiff University, Cardiff, UK

Background

Most adolescents living with long-term conditions (LTCs) want to have a say in decisions about their healthcare, but they often feel as though they are left out of discussions and decisions with healthcare practitioners, which can give them the impression that their views are not important. Shared decision-making (SDM) allows adolescents with LTCs to evaluate the risks, benefits and difficulties of various healthcare options, while enabling a shared understanding of preferences and possible issues. However, SDM does not occur consistently in clinical encounters, and adolescents often act as bystanders. Research on the adolescents' perspective of SDM is limited. The aim of this study is to explore adolescents' perceptions and experiences, focusing on identifying the perceived barriers to and facilitators for their involvement in SDM.

Methods

Adolescents (12-18 years) with LTCs were recruited from endocrinology, rheumatology, neurology and nephrology clinics. A purposive sample was attempted to obtain an equal number of participants from each clinic, males/females, and age groups between 12-15 and 16-18 years. Qualitative interviews were conducted using participatory methods, including life-grids and pie charts, and semi-structured follow-up questions. Transcripts were analysed thematically.

Results

Nineteen participants were included in the study. Four overarching themes were identified, each comprising of two sub-themes, which describe the needs of adolescents with LTCs in order for them to be involved in SDM. Adolescents need to feel as though their involvement is *supported* by parents and healthcare professionals, that their contribution to the decision-making process is *important*, and will yield a positive outcome. Adolescents feel it is their *right* to be involved in decisions that affect them, but they often feel as though the adults' contributions to the decisions are more valuable. Adolescents need to feel *capable* of being involved, in terms of being able to understand and process information about the available options, and ask appropriate questions.

Conclusion

This work highlights a number of needs which must be met in order for SDM to occur between healthcare practitioners and adolescents with LTCs. Identifying the needs of adolescents with LTCs is necessary for optimising the SDM process and to support them during healthcare consultations.

024 - Chemotherapy decision making by advanced cancer patients and their oncologists: A secondary analysis of patient-oncologist encounters

Shama S. Alam¹, Garrett T. Wasp², Olivia A. Sacks^{1,3}, Kristin E. Knutzen¹, Matthew A. Liu⁴, Kathryn Pollak⁵, James A. Tulsky⁶, Amber E. Barnato^{1,2,3}

¹The Dartmouth Institute for Health Policy & Clinical Practice, ²Dartmouth-Hitchcock Norris Cotton Cancer Center, ³Geisel School of Medicine at Dartmouth, ⁴University of California San Diego School of Medicine, ⁵Duke University School of Medicine, ⁶Center for Palliative Care, Harvard Medical School

Background: Decisions about continuing or stopping palliative chemotherapy are critical for advanced cancer patients. Little is known about how patients and oncologists make such decisions or whether they meet criteria for shared decision making (SDM). We sought to describe oncologist-patient discussions regarding starting, modifying, or stopping systemic therapy (chemotherapy and immunotherapy) among advanced cancer patients.

Design and methods: We performed a secondary qualitative analysis of audio-recorded outpatient oncology visits from two U.S. academic medical centers between November 2010 and September 2014 for the Communication in Oncologist-Patient Encounters (COPE) randomized controlled trial. The trial tested the effect of a patient-facing intervention on empathic communication. We randomly sampled 8 patient-oncologist dyads, each with 3 longitudinal outpatient encounters, from each of 4 trial arms (N=32 dyads; 96 encounters). A multidisciplinary team conducted close reading and discussion of encounters, identified patterns in talk related to starting, modifying or stopping systemic therapy, then two coders applied the codebook to sampled encounters.

Preliminary Results: Of 15 encounters across 5 dyads analyzed to date (3 male, 2 female patients), we observed 2 discussions about starting, 3 discussions about modifying, and 1 discussion about stopping systemic therapy. Oncologists rarely outlined all treatment options, including the option of stopping chemotherapy, or mentioned that there was no best option. Oncologists seldom invited patients to participate in deliberation about next steps; instead, they offered “think aloud” discussions of treatment alternatives, often invoking complex information from published and ongoing clinical trials. They sometimes offered anticipatory guidance regarding availability of additional treatment options; they infrequently offered anticipatory guidance regarding stopping chemotherapy or transitioning to comfort-focused care. Oncologists seldom elicited goals of treatment; instead they elicited specific symptoms and immediate management without referencing their burdensomeness.

Preliminary conclusions: In this initial small sample of patient-oncologist encounters involving palliative systemic therapy decisions, oncologists tend to present active treatment options and discuss pros and cons, but deliberation/partnership, preference elicitation, and preference incorporation were rare. As a result, patients may not have any awareness that there is a role for them in the decision-making process.

026 - Shared decision making and patient-centered care in the Middle East: A comparative study of physicians' perceptions

Yaara Zisman-Ilani¹, Rana Obeidat², Lauren Fang³, Young Shin Kim⁴, Sarah Hsieh³, Zackary Berger^{5,6}

¹Temple University, Philadelphia, Pennsylvania, USA, ²Zarqa University, Jordan, ³Johns Hopkins University, Baltimore, Maryland, USA, ⁴Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA, ⁵Johns Hopkins School of Medicine, Baltimore, Maryland, USA, ⁶Johns Hopkins Berman Institute of Bioethics, Baltimore, Maryland, USA

Objective: To compare beliefs, attitudes, and reported practices of physicians regarding shared decision making (SDM) and patient-centered care (PCC) in four regions in the Middle East: Israel, Jordan, the West Bank and Gaza Strip; a group of USA physicians was also included as a comparison.

Methods: This pilot, hypothesis-generating study included: (1) free text responses by physicians regarding their beliefs, attitudes, and practices around PCC and SDM in their health care setting, and (2) assessment of SDM in clinical encounters using a validated instrument, the SDM-Q-Doc. Snowball sampling was used. We used an iterative

Results: There were a total of 34 responses (Jordan n=15, US n=12, Israel n=9), but only 28 were fully completed (Jordan n=11, US=10, Israel n=7). Due to the exploratory nature of this work, 33 surveys with greater than 50% completion were included in the analyses (Jordan n=15, US n=11, Israel n=7). We did not receive any responses from physicians in the West Bank and Gaza. SDM-Q-Doc score did not differ. Systematic problems related to health most reported by US physicians were insurance coverage, cost of healthcare, and social determinants; by Jordanian physicians, quality of care and a lack of resources; and by Israeli physicians, staff shortage and a lack of resources. When asked to define PCC, most US physicians responded with prioritizing patient needs and preferences, while both Jordan and Israel physicians stated that PCC includes holistic care and prioritizing patient needs. Barriers

to implementing PCC seen by US physicians were mostly centered around limited time and insurance coverage. In Jordan, staff shortage was seen to lead to unreasonable patient loads. The majority of physicians from all three locations defined SDM as informing the patient and allowing patient participation, decision, or approval. Barriers of implementation in the US focused on limited time, whereas Jordan physicians believed that a lack of education limits SDM practices.

Conclusion: Our novel, exploratory survey of physicians in the Middle East and USA suggests that perceptions of PCC might differ among regions, while concepts of SDM might be shared. Future work should clarify these differences and include Palestinian respondents more effectively.

027 - Enrolment fraud in online shared decision-making research: lessons learned in an Internet-based randomised controlled trial

Gabrielle Stevens¹, Hillary Washburn², Regan Theiler³, Elisabeth Woodhams⁴, Kyla Donnelly¹, Rachel Thompson⁵

¹Dartmouth College, New Hampshire, United States, ²Patient Partner, New Hampshire, United States, ³Mayo Clinic, Minnesota, United States, ⁴Boston Medical Center, Massachusetts, United States, ⁵The University of Sydney, New South Wales, Australia

Background and Aims: Studies that recruit participants, deploy interventions, collect data, and compensate participants via the Internet have been enabled by technological advancements. Such studies represent a low-cost approach to research, may be more inclusive than those adopting conventional recruitment methods, and, where interventions are intended to be deployed electronically, may also be highly ecologically valid. However, they are also vulnerable to enrolment fraud. In this paper, we will describe the enrolment fraud we encountered in a recent study and share lessons learned relevant to others conducting Internet-based research.

Methods: We conducted an Internet-based randomised controlled trial of a patient decision aid on postpartum contraception [ClinicalTrials.gov Identifier: NCT03500952]. Eligible to enrol were people who were pregnant, lived in the United States, and met other criteria. A range of recruitment methods was employed including paid Facebook and YouTube advertisements, Facebook and Twitter posts, and outreach to relevant communities with an online presence. Recruitment materials directed individuals to a website at which they could become informed about the study, consent, be screened for eligibility, and complete an initial survey. Participants were offered \$20 and \$30 Amazon.com gift cards for completing a second and third survey, respectively. The target sample size was 392 participants.

Results and Conclusions: We discontinued recruitment efforts after significant and persisting incidents of enrolment fraud. Altogether, 1290 of the 1331 people who passed eligibility screening and were randomized were determined to be ineligible for the study. We detected the enrolment fraud via large volumes of enrolment in concentrated periods of time, patterns and duplication in the email clients and email addresses of consecutive enrollees, participant IP addresses originating outside of the United States and in regions different from reported state of residence, and other unusual item responses and patterns. Informed by our experiences and our subsequent consultation of the literature and with others, we developed a set of strategies for preventing enrolment fraud in Internet-based research (e.g., provision of compensation by mail only), as well as strategies for detecting, responding to, and minimizing the negative impact of enrolment fraud.

028 - Patients and clinicians' views on information and decision support needs for breast cancer screening: developing a patient decision aid in Argentina

Paula Riganti^{1,2}, Maria Victoria Ruiz Yanzi¹, Juan Victor Ariel Franco^{1,2}, Karin Kopitowski^{1,2}

¹Department of Family and Community Medicine, Hospital Italiano, Buenos Aires, Argentina,

²Department of Research, Instituto Universitario Hospital Italiano, Buenos Aires, Argentina

Introduction

Shared Decision Making (SDM) is a patient-centered approach where clinicians and patients work together to make decisions based on the best available evidence and the patient's values and preferences. This model is particularly relevant when making decisions where there is a close trade-off between benefits and harms, such as screening for breast cancer. Patient decisions aids are useful tools to support SDM, but they have not yet been developed in lower-middle income countries.

Objectives

To elicit patient and clinicians' views on information and decision support needs for breast cancer screening

Methods

We conducted 30 semi-structured individual interviews with physicians and average-risk for breast cancer women in an Academic Hospital in Buenos Aires (Argentina). Participants were selected using convenience sampling and data was analyzed by three independent researchers. This study is part of a larger project aimed to develop a patient decision aid on breast cancer screening.

Results

Patients have incorporated breast cancer screening as part of the health care check-up. Decisional conflict or discomfort experienced during screening seems to be focused on receiving the results of the study rather than deciding to participate in it. The vast majority mentioned mammography as the main option for screening and expressed that receiving more information about the probabilities of its harms and benefits could help in the decision-making process. They considered that information about harms should be carefully provided during consultation rather than a general approach as to avoid misunderstandings that could lead women to refrain from participating in screening. From the physician's perspective, patients tend to overestimate and misinterpret the benefits of screening. They thought that the information disclosed by the media could be misleading and act as a barrier for advising patients.

Conclusion

Patients seem "convinced" about participating in breast cancer screening, but these decisions are not met with accurate information about harms. Physicians indicated that patients might need more information on benefits and harms. These results will guide the development of a decision aid tool to support SDM on breast cancer screening in our setting.

032 - How is person-centred care included in undergraduate medical and nursing curricula in the UK?

Heather L Moore¹, Rose Watson¹, Allison Farnworth¹, Karen Giles², David Tomson^{1,3}, Richard G. Thompson¹

¹Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK, ²Faculty of Health and Wellbeing, University of Sunderland, Sunderland, UK, ³Collingwood Surgery, Collingwood Health Group, North Shields, UK

Background

Person-centred care (PCC) is an essential component of training for healthcare professionals, but little is known about factors influencing education provision. We aimed to understand how PCC is represented in UK national professional curricula standards for undergraduate medical and nursing education and explore how these standards are reflected in programme provision.

Methods

We conducted a scoping review to define PCC, then used identified keywords to scan professional curricula standards; two published by the General Medical Council (GMC; current and most recent), and the Nursing and Midwifery Council's (NMC) previous version. To explore undergraduate curricula, we identified themes using framework analysis of interviews with an informant with high-level responsibility for medical/nursing undergraduate programmes at six English universities. A keyword search captured PCC components within curricula documents provided by five universities.

Results

The GMC and NMC approach PCC differently in their national curricula; overall, the GMC appears to promote a more paternalistic model of care and the NMC a more collaborative model. The GMC includes discrete components in specific sections, whereas the NMC distributes PCC throughout. The discrepancies observed in curricula standards consistently emerged during analysis of interviews and curricula documents.

Greater barriers to inclusion of PCC in programme delivery were perceived within medical education. However, cultural and organisational attributes were commonly identified in both fields, including: variation in the definition of PCC; belief in its importance in healthcare and that it can be taught; high-level leadership support; buy in from professionals key to training delivery; time; and resources. There was a lack of clarity about how PCC should be taught, and what level a nursing/medical graduate should have achieved at the end of their undergraduate training. Interviews revealed a number of PCC teaching and assessment techniques; however, no institution evaluated PCC teaching content or its impact on professional practice.

Conclusion

Development of a PCC skills competence framework would increase consistency and support teaching and assessment in undergraduate curricula. High-level support from senior HEIs leaders, multi-disciplinary approaches to curricula development, teaching, and assessment, and greater inclusion of service users may ensure high quality PCC education for undergraduate medical and nursing students.

035 - Are Patient Decision Aids used in clinical practice after rigorous evaluation? A survey of trial authors

Dawn Stacey^{1,2}, Victoria Suwalska^{1,2}, Laura Boland^{2,3}, Krystina B. Lewis¹, Justin Presseau^{1,2}, Richard Thomson⁴

¹University of Ottawa, Ontario, Canada, ²Ottawa Hospital Research Institute, Ontario, Canada,

³Western University, Ontario, Canada, ⁴Newcastle University, Newcastle upon Tyne, England

Background: Patient decision aids (PtDAs) are effective interventions to support patient involvement in healthcare decisions, but there is little use in practice. Our study aimed to determine subsequent PtDA use in clinical practice following published randomized controlled trials.

Design: A descriptive study using an email-embedded questionnaire survey targeting authors of 133 trials included in Cochrane Reviews of PtDAs (106 authors). We classified PtDA level of use as: a) implementation - defined as integrating within care processes; b) dissemination to target users with planned strategies; and c) diffusion - defined as passive, unplanned spread. We conducted content analysis to identify barriers and enablers guided by the Ottawa Model of Research Use.

Results: Ninety-eight authors responded (92.5%) on 108 trialed PtDAs. Reported levels of use were implementation (n=29; 27%), dissemination to target user(s) (n=9; 8%), diffusion (n=7; 7%); 62 (57%) reported no uptake; and 1 no response (1%). Barriers to use in clinical practice were identified at the level of researchers (e.g. lack of post-trial plan); PtDAs (e.g., outdated, delivery mechanism); clinicians (e.g. disagreed with PtDA use); and practice environment (e.g. infrastructure support; funding). Enablers were online delivery, organisational endorsement (e.g., professional organization, charity, government), and design for, and integration into, the care process.

Limitations: Self-report bias and potential for recall bias.

Conclusions: Only 42% of PtDA trial authors indicated some level of subsequent use following their trial. The most commonly reported barriers were lack of funding, outdated PtDAs, and clinician disagreement with PtDA use. To improve subsequent use, researchers should co-design PtDAs with end users to ensure fit with clinical practice and develop an implementation plan. National systems (e.g., platforms, endorsement, funding) can enable use.

039 - The diversity of diabetes-related self-monitoring and problem-solving practices across health literacy levels: An interview study and implications for shared decision making

Julie Ayre¹, Carissa Bonner^{1,2}, Danielle Muscat¹, Sian Bramwell³, Sharon McClelland³, Rajini Jayaballa^{3,4}, Glen Maberly^{3,5}, Kirsten McCaffery¹

¹Sydney Health Literacy Lab, Sydney School of Public Health, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia, ²Ask, Share, Know: Rapid Evidence for General Practice Decisions Centre for Research Excellence, The University of Sydney, Sydney, Australia, ³Western Sydney Diabetes, Western Sydney Local Health District, Blacktown, Australia, ⁴School of Medicine, Western Sydney University, Blacktown, Australia, ⁵Sydney School of Public Health, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

Background and aims: It has recently been acknowledged that shared decision making is an important aspect of developing goals and actions for managing a patient's chronic condition. For conditions that involve self-management, such as diabetes, this necessarily involves personalised care planning that incorporates behaviour change techniques (BCTs). Despite the strong evidence base for BCTs such as self-monitoring and problem solving, the effectiveness of these techniques may depend on the way that individuals engage with them. As such, this study aimed to explore how people with type 2 diabetes and varying health literacy levels used BCTs to improve their diabetes self-management.

Methods: 24 participants took part in semi-structured interviews and completed a measure of health literacy (Newest Vital Sign: NVS). Interviews were audio-recorded, transcribed and coded using Framework Analysis.

Results: 56% of participants (N=13) had inadequate health literacy, and 43% (N=10) had adequate health literacy. Two themes were identified: 1) Self-monitoring as a complex BCT; 2) The problem-solving 'tool-kit'. Self-monitoring was a common BCT, and practices ranged from simply increasing awareness about a behaviour or outcome, to deliberately monitoring weight or blood glucose to increase motivation, and setting weight or blood glucose thresholds for recovering from relapses. Another common BCT was problem-solving. Participants described how over time they developed a repository of problem-solving strategies to fall back on after a lapse in self-management. In contrast, others described relying solely on willpower to make lifestyle changes.

Conclusions: This study highlights the importance of understanding individual variations in behaviour change practices and their implications for personalised care planning. This is particularly relevant for providing high quality care to people with varying levels of health literacy. To successfully integrate shared decision making into the management of a patient's chronic condition, these findings suggest that it is important to acknowledge that BCTs are implemented in diverse ways and consider how these relate to a patient's changing goals, needs and preferences. This can contribute to improvements in the process of developing and revising personalised care plans for people with diabetes.

041 - Developing and improving a web-based tool for clients in long-term care: a user-centred design

Karin van Leersum¹, Albine Moser^{1,2}, Ben van Steenkiste¹, Judith W³, Trudy van der Weijden¹

¹Maastricht University, ²Zuyd University of Applied Sciences, ³Radboud UMC Nijmegen

Background: The decision-making process for clients in need of long-term care is challenging and clients need to make choices about the care they prefer. A tool to elicit on preferences could be beneficial for these clients and their caregivers. The aim is to investigate the user-requirements of a tool for the decision-making.

Methods: We applied a user-centred design to develop this tool. This was an interactive process of collecting data with end-users and improving the prototypes. The end-users included clients, relatives, or caregivers. Four end-users participated in a development team and 21 end-users were interviewed individually. We collected data during three phases of iteration: look and feel, navigation, and content. We analysed the data using thematic analysis and adjusted the prototype after each phase.

Findings: The lay-out was approved by all participants during the look and feel phase, but there was a need for different/neutral pictures. During the navigation phase, participants experienced easy navigation, but text-blocks had to be shortened. Considering the content, participants missed questions about their well-being. After the third phase, the tool was finalized.

Discussion: The user-centred design was necessary to move from the prototypes to the finalized tool fitting usability-requirements of end-users. The tool 'What matters to me' (www.watikbelangrijkvind.nl) is currently in the feasibility-testing phase.

042 - The feasibility of 'What matters to me' a web-based value elicitation tool for clients aiming for long-term care: a process-evaluation

Karin van Leersum¹, Albine Moser^{1,2}, Ben van Steenkiste¹, Judith W³, Trudy van der Weijden¹

¹Maastricht University, ²Zuyd University of Applied Sciences, ³Radboud UMC Nijmegen

Background: The decision-making process for clients in need of long-term care is complex, often resulting in a mismatch between client's preferences and received care. Clients are expected to play a role in the deliberation about the care they prefer. The tool 'what matters to me' was developed in order to assist value elicitation and make clients aware of their preferences. The tool consists of five categories including living, family and friends, finances, lifestyle, and health. The aim of the study is to investigate the feasibility of this tool in current practice.

Methods: A mixed-method approach was applied using the six-step process-evaluation plan of Saunders et al. (2005)¹: fidelity, dose delivered, dose received/satisfaction, reach, recruitment, and context. The participants included potential users, clients, relatives, or caregivers involved in the decision-making for long-term care. Data was collected from May 2018 to September 2018 consisting of online user activity logs (N=71), questionnaires (N=38), and interviews (N=11). Satisfaction was investigated with the Post-Study System Usability Questionnaire (PSSUQ). Descriptive statistics were used for the quantitative data, and a thematic analysis for the qualitative data.

Findings: Considering the fidelity, 58% of the users complete three or more out of five categories. Dose delivered consisted of information about the tool and the study materials. The satisfaction was high, 95% regarded the tool useful in practice, and the lay-out was rated 6.63 (± 0.88) out of seven in the PSSUQ. Participants gave suggestions for improvements, e.g. a second version of the questions specific for relatives, and a non-digital version of the tool. The reach was 100% for use and 60% for completion of the questionnaires. The recruitment rates were low. The user context varied, users were involved in elderly care, care for people with disabilities, mental health care, or social support.

Discussion: The process-evaluation demonstrates that the tool 'what matters to me' is a feasible tool for the value elicitation. A following study will investigate actual use in practice and the experienced impact on conversations about long-term care.

Reference

¹ Saunders, R.P., Evans, M.H. & Joshi, P. (2005). Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. *Health.Promot.Pract*, 6(2), 134-147.

045 - Can patient satisfaction be explained by the implementation of shared decision-making? A nation-wide study in the Chilean primary care

Paulina Bravo¹, Luis Villarroel²

¹School of Nursing, Pontificia Universidad Católica de Chile, ²School of Medicine, Pontificia Universidad Católica de Chile

Chile is committed to increase patient participation. Thus, patient-centered care has been established as a key component of primary care (PC), acknowledging the importance of actively involving patients through shared decision-making (SDM) to improve satisfaction and clinical outcomes. However, there is no understanding of how much participation is occurring in the consultation or how this is affecting patients' satisfaction. Aim: To develop a model of the relationships among expected patient participation in decision-making, experienced participation in the decision, decisional conflict and satisfaction with PC provider for the Chilean population. Methods: A cross-sectional, observational and individual study was conducted. PC patients across the country were selected after the consultation and were asked to complete a questionnaire that included: Expected participation (API), Decisional Conflict Scale, Experienced participation (CollaboRATE-Chile), and Satisfaction with the provider. Multiple lineal regression and structural equation model were performed. Findings: 2,223 patients participated (24 PC centers). Most were women (78,8%) and the average age was 51 years. Patients reported high levels of expected and experienced participation. Both constructs were significantly associated with patient health perception. One out of five had decisional conflict, and the majority was highly satisfied with the provider. High scores of API were significantly associated with low experienced participation. Those who participated less had more decisional conflict ($p < 0,001$). Almost 60% of patients' satisfaction with healthcare providers can be explained by the SDM constructs, particularly by experienced participation. Conclusion: This study showed for the first time the prevalence of patient participation in decision making in the country and the association with patient satisfaction. This could inform future interventions for patient involvement, by including some patients' characteristics such as health perception. Considering the impact of SDM in patient satisfaction, healthcare providers should also be trained on how to promote an active role of patients in the clinical encounter.

049 - Less is More: A randomized comparative effectiveness trial of decision support strategies for hip and knee osteoarthritis (DECIDE-OA Study)

Karen Sepucha¹, Hany Bedair², Liyang Yu³, Janet Dorrwachter⁴, Maureen Dwyer⁵, Carl Talmo⁶, Ha Vo⁷, Andrew Freiberg⁸

¹Massachusetts General Hospital Harvard Medical School, MA, USA, ²Massachusetts General Hospital Harvard Medical School, MA, USA, ³Massachusetts General Hospital Harvard Medical School, MA, USA, ⁴Massachusetts General Hospital, MA, USA, ⁵Newton Wellesley Hospital, MA, USA, ⁶New England Baptist Hospital, MA, USA, ⁷Massachusetts General Hospital, MA, USA, ⁸Massachusetts General Hospital Harvard Medical School, MA, USA

Background: As guidelines and payers increasingly recommend use of patient decision aids (DAs), evidence about the comparative effectiveness of available DAs is critical for organizations interested in implementing them.

Methods: A factorial randomized trial enrolling patients with hip and knee osteoarthritis at three sites.

Interventions: Patients were randomly assigned to a long, detailed DA (Long DA) or short, interactive DA (Short DA). The Long DA included a DVD and booklet with detailed information about options and patient narratives. The Short DA had five sections including a knowledge quiz and explicit values clarification exercise. Surgeons were randomly assigned to receive a Preference Report (MD-PPR) detailing patients' goals and treatment preferences or usual care (MD-UC).

Main outcomes: The primary outcome is the percentage of patients who were informed and received their preferred treatment (IPC decision). Secondary outcomes included knowledge, shared decision making, surgical rates, and surgeon satisfaction. Surgeons completed short survey after a random sample of 30% of their patient visits.

Results: We received 1220/1636 (75% RR) baseline and 967/1124 (86% RR) post-visit surveys. The sample was 65 years old (SD10), female (57%), White, non-Hispanic (91%), with knee osteoarthritis (67%). The majority made IPC decisions (67.4%) and the rate did not vary significantly across DA or MD groups ($p=0.16$ for DA, $p=0.72$ for MD groups). Knowledge scores were higher for the Short DA (mean difference 9 points, $p<0.001$). More than half of the sample (60.1%) had surgery within six months of the visit, and rates did not differ significantly by DA or MD groups. Overall, surgeons were highly satisfied and reported the majority (86.7%) of visits were normal length or shorter than normal.

Conclusion: DECIDE-OA study is the first randomized comparative effectiveness trial of orthopedic DAs. Contrary to our hypotheses, the Short DA outperformed the Long DA on knowledge and was comparable on other outcomes. The surgeons reported high satisfaction and no increase in visit length with both DAs.

050 - PATIENT PERCEPTIONS ABOUT COLORECTAL CANCER SCREENING AFTER VIEWING A DECISION AID TARGETED TO OLDER ADULTS

C.L. Lewis¹, A.F. Dalton¹, C.B. Morris², R.M. Ferrari³, C.E. Kistler³, C.E. Golin³

¹University of Colorado School of Medicine, Aurora, CO, USA., ²IQVIA, Missouri, USA, ³University of North Carolina at Chapel Hill, North Carolina, USA

Purpose: To compare perceptions about colorectal cancer (CRC) screening between an intervention group and an attention control in a study of a decision aid (DA) designed to promote individualized decision making about CRC screening in older adults.

Methods: We conducted a single-blinded, randomized controlled trial to test the efficacy of a CRC DA designed for older adults. Potentially eligible patients were adults ages 70-84 who were not up to date with CRC screening and who had a scheduled appointment with a provider in a participating primary care practice. Participants completed written questions after interacting with the DA or the control information about driver safety but before seeing their physician that included: knowledge assessment, likelihood of discussing screening preferences for decision making process, life expectancy, likelihood that screening will prolong life, decisional balance between risks and benefits, and provider's screening preference.

Results: 424 participants ages 70-84 were recruited from 14 primary care practices within the Duke Primary Care Research Consortium. The intervention group had a higher knowledge score than the control group (4.1 vs. 2.3 out of 5; $p < .0001$). The intervention group was more likely than the control group to say they were very/somewhat likely to talk with their doctor about CRC screening (60% vs 44%; $p = .001$), versus somewhat/very unlikely. In both groups, >78% of participants preferred to share the decision making process with their doctor in some capacity. Patients who received the DA were less likely than the control to believe screening would prolong their lives "a lot" (12% vs. 23%; $p = .005$). The intervention group was less likely than the control to say the "Benefits greatly outweigh the risks" of screening (30% vs. 46%; $p = .001$). There was no significant difference between the groups' perceptions of their providers' screening preference.

Conclusions: Exposure to the DA appears to increase patients' knowledge and intent to discuss CRC screening with providers compared to the intention control. Patients who received the DA seemed to better understand the nuances of individualized decision making around CRC screening in older adults.

054 - Nurse-led immunotreatment DEcision Coaching In people with Multiple Sclerosis (DECIMS) – process evaluation results on a prematurely terminated cluster randomised controlled trial (ISRCTN37929939)

Rahn AC^{*1}, Köpke S², Barabasch A¹, Mühlhauser I³, Heesen C¹

^{1*}, Institute of Neuroimmunology and Multiple Sclerosis, University Medical Center Hamburg-

Eppendorf, Hamburg, Germany, ²Nursing Research Unit, University of Lübeck, Lübeck, Germany,

³Unit of Health Sciences, University of Hamburg, Hamburg, Germany;

Background and aims

Multiple sclerosis (MS) is an inflammatory, degenerative disease of the central nervous system usually manifesting with relapses in early adulthood. With an availability of currently 15 different treatment options, decision-making in MS is challenging for people with MS (PwMS).

Therefore, we developed the “nurse decision coach” programme aiming to redistribute health professionals’ tasks in supporting treatment decision-making by PwMS following the principles of shared decision-making.

Methods

The programme was evaluated in a cluster randomised-controlled trial (cRCT) and an accompanying process evaluation following the MRC framework for developing and evaluating complex interventions. It was planned to recruit 300 people with suspected or relapsing-remitting MS facing immunotreatment decisions in 12 centres. PwMS in the intervention clusters (IC) received decision coaching by a trained nurse and had access to an evidence-based online information platform. PwMS in the control clusters (CC) had also access to the information platform and received otherwise care as usual.

The primary outcome was ‘informed choice’ after 6 months.

Quantitative process data were collected from PwMS, nurses, and physicians over the trial period. Qualitative interviews with nurses and physicians from the IC were performed afterwards and data was analysed thematically.

Results

12 nurses from 8 centres participated in the coaching training. Due to insufficient recruitment, the cRCT was terminated prematurely with 125 participants (n=42 IC, n=83 CC). For the process evaluation, 7 nurses (6 centres) and 5 physicians (5 centres) were interviewed. Main implementation barriers were lack of structural resources, great effort per coaching, using a camera during coaching, and a lack of cooperation/support in the centres. The training course, the coaching material, motivation of nurses and physicians to take part in the study, overcoming the fear of using the camera, and cooperation/support in the centres were identified as main implementation facilitators.

Conclusion

While the coaching programme was successfully tested in a pilot RCT, realisation within a cRCT was limited. Other implementation strategies have to be applied to evaluate this promising concept.

057 - The effect of using a patient decision aid in a spine surgery clinic - A randomized controlled trial

Stina Brogård Andersen^{1,2,3}, Mikkel Ø. Andersen^{1,3}, Leah Y. Carreon^{1,3,4}, Angela Coulter^{2,3,5}, Karina Dahl Steffensen^{2,3,6}

¹Spine Surgery and Research, Spine Center of Southern Denmark, Lillebaelt Hospital, Middelfart, Denmark, ²Center for Shared Decision Making, Lillebaelt Hospital, Vejle, Denmark, ³Institute of Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark, ⁴Norton Leatherman Spine Center, Louisville, Kentucky, ⁵Nuffield Department of Population Health, University of Oxford, ⁶Department of Clinical Oncology, Lillebaelt Hospital, Vejle, Denmark

Background and aim

Making decisions about having or not having surgery for a lumbar disc herniation (LDH) can be complex. The aim of this study was to determine if the use of a Patient Decision Aid (PtDA) in a spine surgery clinic was superior to standard consultation, in terms of involving and informing patients with lumbar disc herniation in the decision of treatment.

Methods

This study was a randomized controlled trial. Eight surgeons were randomized in a 1:1 ratio to either using or not using a PtDA [BESLUTNINGSHJÆLPER™] for LDH. Decision quality was assessed by patients using the level of knowledge and decision process dimensions from the Decision Quality worksheet –for herniated disc (DQW-HD) and decisional conflict was measured using the Decisional Conflict Scale (DCS). Patients included were >18 years old and assessed as candidates for primary surgery for LDH. Patients with diagnosis of psychiatric disorder or who presented with manifest paresis were excluded.

Differences in scores between the groups were tested using nonparametric Mann-Whitney test for independent samples. Sample size rationale was powered from the knowledge score.

Results

Overall 130 patients were included in the study: 67 in the "PtDA" arm and 63 in the "usual consultation" arm. Patients were equally distributed successfully between the two groups according to gender, age and educational level. Surgeons were also equally distributed successfully between the two groups according to age and years of surgical experience. A difference was found in the sum of the ranks in all three outcomes, showing a trend towards a higher rank sum in the PtDA group. DQW-knowledge score [4750.5 vs. 3764.5, $P=0.0791$], DQW-process score [4574.5 vs. 3940.5, $P=0.3771$], DCS [3641 vs. 3262 $P=0.8182$]. However, none of the differences reached statistical significance.

Conclusion

Using a PtDA for LDH showed no statistical significant differences in either patients' level of knowledge, the quality of the decision making process or in patients' decisional conflict.

058 - Implementing SDM into Clinical Practice: Law and Policy Update

Thaddeus Mason Pope¹

¹Mitchell Hamline School of Law

Implementing SDM into Clinical Practice: Law and Policy Update

Conferences like ISDM (and SMDM and ICCH) offer tremendous opportunities to explore the latest tools and strategies for achieving and improving patient-oriented shared decision making. Medical and social science research appropriately remain the focus of these conferences. But we must also explore ways to increase clinician uptake, because real-world use of SDM and PDAs remains sparse.

PROBLEM

It is not enough to design communication materials and best practices. We must also ensure that they get adopted and assimilated into clinician-patient encounters. Many decision scientists come to ISDM to share their PDAs and research on PDAs. Yet, these scientists admit that few clinicians use their valuable tools in mainstream care. Therefore, we must move these tools from research to practice, from the laboratory to the clinic. We

SOLUTION

This presentation offers a comprehensive and up-to-date status report on legal and policy incentives for SDM implementation. In this highly graphic session, an attorney - bioethicist will describe both current and forthcoming legal incentives for clinicians to use PDAs and engage in SDM. He will also assess how effectively these incentives are working. Because more work has been done on SDM in the USA than in any other country, most (but not all) of these examples will be from new state and federal laws in the USA.

Law cannot solve the implementation challenge by itself. Last year's Bertelsmann Foundation report and similar guidance documents identify multiple, overlapping strategies for implementing SDM. Still, law remains one important piece of the puzzle. This session offers a succinct, yet comprehensive, review of recent law and policy related to SDM and PDAs.

059 - Psychometric Testing of SHARED - a patient reported outcome measure of shared decision making.

Hilary Bekker¹, Anne Stiggelbout², Marleen Kunneman², Ellen Enge², Arwen Pieterse²

¹University of Leeds, Leeds, UK, ²Leiden University Medical Centre, Leiden, Netherlands

OBJECTIVE: To assess the reliability and validity of SHARED as a patient reported outcome measure of shared decision making (SDM). SDM was defined as the process jointly shared by patients and professionals when planning treatment decisions within consultations. SHARED is a ten-item, multi-construct measure assessing the SDM a) process as professionals (items 1-4) and patients (items 5-7) exchange reasoning about treatment options, and b) outcome around choice agreement (items 8-10); items rated on five-point scales (strongly disagree, disagree, not sure, agree, strongly agree).

BACKGROUND: SHARED was developed for use within the NHS Right Care Shared Decision Making quality improvement programmes (2011-2013) which included staff training and patient decision aid implementation. Evaluations from over 800 consultations and 40 clinical services showed SHARED was integrated into usual care and responsive to SDM initiatives, and had satisfactory content validity.

METHODS: Secondary analysis of oncology decision making consultations (Netherlands); 144 female participants making adjuvant treatment choices for breast cancer. SHARED was translated to Dutch using forward-backward translation. Multi-dimensionality (principal component) and internal reliability (Cronbach α) analyses were carried out.

RESULTS: Good internal consistency was observed (Cronbach's α 0.87) for all items (item-deletion Cronbach's α 0.84-0.88). Three components were extracted: Factor 1 (48%) information exchanged about patient values (items 4,5,7 - professional asked my views, I talked about my values, risks and benefits to me); Factor 2 (15%) agreed best choice made (items 9,10 - best choice made for me, professional-patient agreed on choice); Factor 3 (11%) information exchanged about different treatments (items 1,2,3,6,8 - professional talked about other options, professional not talked about medically best option or own views, I talked about what suited me and felt any option could be chosen). For 19% of patients, all 10 items were reported as present in their consultation (mean 38.4, s.d. 8.5); 85% felt the choice was agreed, 37% reported professionals discussed different options, 60% reported professionals asked for their views, and 50% and talked about why one option suited them better than another.

DISCUSSION: SHARED shows promise as a conceptually robust, patient reported outcome measure of SDM for use in quality improvement, audit and research.

060 - Perceived communication quality and shared decision-making in medical encounters from general practitioners' perspective

Mirjam Körner¹, Nicole Röttele¹, Erik Farin-Glattacker², Christian Schlett², Andy Maun³, Andrea C. Schöpf³, Piet van der Keylen⁴, Sebastian Voigt-Radloff⁵

¹Medical Psychology and Medical Sociology, Medical Faculty, Albert-Ludwigs-University, Freiburg, Germany, ²Section of Health Care Research and Rehabilitation Research, Faculty of Medicine and Medical Center - University of Freiburg, Germany, ³Division of General Practice/Family Medicine, Medical Center – University of Freiburg, Faculty of Medicine, University of Freiburg, Germany,

⁴Institute of General Practice, Friedrich-Alexander University Erlangen-Nürnberg, Germany, ⁵Cochrane Germany, Faculty of Medicine and Medical Center - University of Freiburg, Germany

⁴Institute of General Practice, Friedrich-Alexander University Erlangen-Nürnberg, Germany, ⁵Cochrane Germany, Faculty of Medicine and Medical Center - University of Freiburg, Germany

Background

High-quality communication and shared decision making in medical encounters improve many relevant patient outcomes. There is evidence that patients are dissatisfied with clinical consultations and there is a demand for improvement in doctors' communication skills. However, less is known on physicians' perception on their own communication skills, while different studies show different results. Therefore, the aim of this study was to investigate how GPs perceive and assess the quality of the communication and patients' participation in their consultations.

Methods

In 2018, 71 GPs in Bavaria were asked to provide ratings of the perceived communication quality in consultations with back pain patients. Communication quality was assessed using the Shared Decision-Making Questionnaire-Physician version (SDM-Q-Doc), five scales of the German doctor-patient interaction questionnaire for physicians (P.A.INT-Questionnaire), one scale of the German communication behavior questionnaire (KOVA-Questionnaire), and a scale measuring the extend of patients' decision making (Man-Son-Hing Scale). Linear transformed (0-100) sum scores were calculated, with higher values indicating stronger occurrence of the examined construct.

Results

Overall, 66 (93%) GPs participated. 67% (n = 44) were male, mean age was 49.7 years (SD = 9.2). The scale measuring *openness and confidence* (M = 87.7; SD = 11.3) revealed the highest sum score, followed by the scale *empathy* (M = 80.1; SD = 14.2), *esteem and sympathy* (M = 79.2; SD = 13.6), *satisfaction with contact* (M = 75.0; SD = 12.5), *effective communication* (M = 74.4; SD = 10.6), *shared decision-making* (M = 70.0; SD = 14.9) and *extend of patients' decision making* (M = 43.2; SD = 12.8). The lowest sum score revealed the scale *barriers in contact* (M = 25.6; SD = 18.5).

Conclusion

This small group of GPs perceived the quality of communication in their own consultations as good. While a comparison with results from patient ratings and external observations of the same consultations are necessary to obtain a holistic perspective of the communication quality, the results of this study might partly explain why there is low intrinsic demand of GPs for improvement of communication skills.

062 - Factors Affecting Shared Decision-Making in Breast Cancer

Dena Schulman-Green¹, Emily Cherlin², Renee Capasso³, Helen Sayward³, Sarah Mougalian⁴, Shiyi Wang², Cary Gross⁴, Preeti Bajaj⁵, Katherine Eakle⁵, Sharmi Patel⁵, Kerin Adelson^{3,4}

¹Yale School of Nursing, CT, USA, ²Yale School of Public Health, CT, USA, ³Smilow Cancer Hospital, CT, USA, ⁴Yale School of Medicine, CT, USA, ⁵Genentech Corporation, CA, USA

Background and Aims. Shared decision-making is essential to patient-centered care, yet clinical pathway tools have not incorporated patient preferences around treatment burden, efficacy, and toxicity outcomes. Previous studies have indicated symptom burden, fear of recurrence, and quality of life as key influencers of patient decision-making. We sought to identify a broader range of factors that affect treatment decision-making as a means of incorporating patient preferences into MyPATHway, a patient-centered, interactive clinical pathway platform for patients with breast cancer.

Methods. We conducted a qualitative study using an interpretive description approach. Eligible participants were women aged 18 years or older being treated for Stage I-III breast cancer at Smilow Cancer Hospital in New Haven, CT. We interviewed participants about a recent treatment decision and about factors that affected that treatment decision. Interviews were digitally recorded, transcribed, coded, and analyzed for themes.

Results. Participants' (n=22) mean age was 56 (range 28-74 years). Eight (36.4%) had Stage I breast cancer, eight (36.4%) had Stage II, and six (27.2%) had Stage III. Six themes emerged among factors affecting treatment decision-making: 1) Physical (e.g., physical appearance, patient age); 2) Prognosis (e.g., fear of recurrence, survival); 3) Psychosocial (e.g., sense of control, hope); 4) Family (e.g., effects on family, milestone events); 5) Provider/Health Care System (e.g., quality of communication, financial/insurance); and 6) Treatment (e.g., expectations, other patients' stories). Participants expressed the importance of finding balance between their own treatment preferences and provider-recommended standard of care.

Conclusion. Participants identified an array of factors affecting their treatment decision-making with providers. Providers should consider these factors in helping patients to weigh treatment options. Providers should engage patients early in the treatment-planning process to understand what factors are most important to the patient. Clinical pathway tools like MyPATHway could be organized to address the identified themes so that patients will know what to expect in terms of how the treatment will affect them and their families physically, emotionally, and socially, as well as how treatment choices differ from one another and how well a treatment will work for them.

064 - Shared decision-making with children: Engaging children in participatory research

Marjorie Montreuil¹, Aline Bogossian², Eric Racine³

¹Ingram School of Nursing, McGill University, Montréal, Québec, Canada, ²Université de Montréal, Québec, Canada, ³Pragmatic Health Ethics Research Unit, Institut de recherche clinique de Montréal, Québec, Canada

Background and aims: There has been a shift from considering children as the objects of research to active agents who can meaningfully contribute to the research process. The aim of children's involvement is to redress power imbalances, to prevent potential harms, and lead to better, more meaningful research outcomes. However, the participation of younger children raises specific challenges. We systematically reviewed studies that included children in the research process to compare and contrast the different strategies employed in participatory research with children and analyzed the ethical implications of their involvement.

Methods: We conducted a realist review to synthesize the current literature on the topic to (1) identify the different approaches used to engage children in participatory research, (2) consider the ethical implications of these approaches and (3) analyze whether or not the approaches foster children's meaningful engagement and how. This type of review is highly suitable for the study of participatory research processes as it aims to explain what works for what context and for whom, instead of solely describing the approach or trying to identify the universal best way to address an issue.

Results: Most of the research conducted using participatory research with children was published in the last 15 years within Western countries. Except for group discussions and focus groups that were used with all the different age groups, the type of approaches used typically differed based on the age of the participants. It was highlighted in certain studies that children improved certain skills or abilities as a result of their participation, such as active listening, teamwork, assertiveness, communication abilities and decision-making skills. Numerous ethical issues were raised, for example, power differentials, privacy remuneration, advocacy, authenticity, feeling of inclusion, representation, protection and vulnerability. Addressing these ethical issues has direct implications for the quality of children's engagement and study outcomes.

Conclusion: As patient involvement and engagement in research is increasingly popular and sometimes an institutional requirement, researchers should pay attention to how to engage younger children in research and policy development in a way that is inclusive of their perspectives and ethically-sound.

066 - Development of the IcanSDM instrument to assess primary care clinicians' ability to adopt shared decision making

Anik Giguère^{1,2,3,4}, Pierre-Hugues Carmichael¹, Anja Lindig⁵, Laetitia Coudert^{1,3}, Jean-Sébastien Renaud², France Légaré^{2,3,4}, Philippe Voyer^{1,3,6}, Holly O Witteman^{2,3,4}, Edeltraut Kröger^{1,3,4,7}, Charo Rodriguez⁸, Bernard Martineau⁹

¹Quebec Excellence Research Centre in Aging, Quebec, Canada, ²Department of Family Medicine and Emergency Medicine, Laval University, Quebec, Canada, ³Laval University Research Centre on Community-Based Primary Health Care (CERSSPL-UL), Quebec, Canada, ⁴Axe Santé des populations et pratiques optimales en santé du Centre de recherche du CHU de Québec, Quebec, Canada, ⁵University Medical Center Hamburg-Eppendorf, Hamburg, Germany, ⁶Faculty of Nursing, Laval University, Quebec, Canada, ⁷Faculty of Pharmacy, Laval University, Quebec, Canada, ⁸Department of Family Medicine McGill University, Quebec, Canada, ⁹Department of Family Medicine and Emergency Medicine, Sherbrooke University, Quebec, Canada

Purpose: To develop the IcanSDM instrument in French and in German, to assess clinicians' ability to adopt shared decision making (SDM).

Methods: An expert panel created an initial 11-item IcanSDM version from a literature review on clinicians' perceptions of the barriers to implementing SDM. We then recruited a first convenience sample of 16 primary care clinicians (12 physicians, two nurses, two social workers) who worked in family medicine clinics located near Quebec city. They completed IcanSDM before and after a distance-training program on SDM, together with the Belief about Capabilities subscale of the CPD-REACTION. We audio-recorded and transcribed their comments as they completed IcanSDM. We evaluated item-wise consistency using partial correlation coefficients. We visually inspected the distribution of responses to each item before and after training. These analyses led to selecting items to create a second 8-item IcanSDM version. This 8-item version was adapted to German following the TRAPD protocol and understanding assessed through cognitive interviews with eleven German clinicians (three doctors, six nurses, two psycho-oncologists), which led to modifying one item. We then assessed the modified 8-item version with a third sample of 47 clinicians in Quebec: we measured its internal consistency using Cronbach's alpha coefficient, and its responsiveness by comparing pre- and post-training means (Student's t-test). We estimated the correlation between IcanSDM's and the Capabilities subscale (Pearson's r), as the two scales measure similar constructs.

Results: In the initial IcanSDM version, three items lacked clarity or responsiveness, or showed negative partial correlations with the whole instrument. We thus removed these items and adapted the scale to German. Most of the German clinicians who assessed this version misunderstood one item, which we modified both in German and in French. Then, 47 clinicians in Quebec used this modified scale before training, and 17 after. Cronbach's alphas were 0.87 before and 0.67 after. We measure a non-significant 6% increase in IcanSDM's total score after training, compared to before training. We found no significant correlation between IcanSDM and the Capabilities subscale ($P = 0.09$).

Conclusions: IcanSDM seems promising. Further validations are required both in French and in German.

074 - Implementing a PDA in a developing country: Using a multi-voting process and stakeholder meetings to tailor an implementation strategy

Yew Kong Lee¹, Wen Ting Tong¹, Chirk Jenn Ng¹, Ping Yein Lee²

¹Department of Primary Care Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia, ²Department of Family Medicine, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Serdang, Malaysia

Background and aim

Effective implementation of patient decision aids (PDAs) are hampered by multiple barriers. However, development of implementation strategy to overcome selected key barriers is rarely reported. This paper reports a stakeholder multivoting technique and meeting to prioritize barriers and development of implementation strategy to implement an insulin-choice PDA in Malaysia.

Methods

Multivoting technique was adopted to elicit prioritized barriers among doctors, diabetes educators, staff nurses and patients. The participants underwent two rounds of voting of highest priority barriers from a list of 49 barriers identified from an earlier exploratory study. Next, implementation interventions were selected to overcome barriers by the researchers. Subsequently, a stakeholder meeting involving participants from the multivoting process was conducted. The prioritized barriers and implementation interventions selected to overcome the barriers were presented and discussed. The implementation strategy was finalized when consensus was reached.

Results

The multivoting process reduced 49 barriers to 13 key barriers to implementation of the insulin PDA. Twelve implementation interventions were selected to overcome the key barriers. Interventions such as 'include other staff in delivery other than doctor' and 'giving PDA to patient ahead of consultation' were selected to address barriers such as 'Patient cannot read or understand the PDA' and 'time constraints', respectively. However, the following stakeholders' meeting saw the removal of these interventions given the absence of diabetes educators who would play the major role in these two interventions. In addition, the delivery of PDA to patients changed from pre-consultation to at-the-point of consultation. Finalized interventions include mandate change, conduct educational meeting, systematic documentation, audit and provide feedback, making PDA accessible and revise professional roles (expansion of role to include new task).

Conclusion

The multivoting process and stakeholder meeting was effective in identifying the key barriers and potential effective implementation interventions for effective implementation of PDAs, taking into account the contextual factors of the clinic.

075 - Implementing a PDA in a developing country: Theories, methods and outcomes: Physician adoption and sustained use of an insulin-choice PDA following implementation interventions

Ping Yein Lee¹, Wen Ting Tong², Yew Kong Lee², Chirk Jenn Ng²

¹Department of Family Medicine, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Serdang, Malaysia, ²Department of Primary Care Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia

Background and aim

Evidences have shown that patient decision aids (PDA) improve patient's decision quality. However, various studies have reported barriers in physicians' adoption of PDAs. This study aims to describe doctors' adoption and the sustained use of an insulin-choice PDA, and factors influencing their decision to use the PDA following exposure to implementation interventions.

Methods

This mixed-method study was conducted among doctors in a teaching hospital primary care clinic between April-November 2018. Two workshops were conducted (April and Aug) and a total of 48 doctors were trained in using the PDA. The implementation was carried out for 7 months (April to Nov). Doctors' adoption of the PDA was tracked using a tracking form. The rate of PDA adoption was calculated by taking the number of PDAs given to patients divided by total clinic sessions of the trained doctors, per month. Qualitative interviews were conducted to explore factors influencing their PDA adoption.

Results

A total of 42/48 doctors adopted the PDA in their practice. Monthly adoption rates of the PDA ranged from 0.05 to 0.13 PDAs / clinic session over the seven-month implementation period. The main challenges to doctors' adoption of the PDA were: *'patients were not using the PDA'*, *'patients were not keen on insulin treatment as a choice'*, *'doctors forgot to use the PDA'* and *'doctors felt that the PDA was not able to meet individual patient's needs'*. Facilitators to PDA adoption were: *'PDA helps to facilitate discussion of insulin initiation with patients'*, *'PDA helps to provide information to patient that could not be provided during consultation'* and *'audit and feedback report as a motivator and reminder'*. Most doctors stated their willingness to continue the PDA usage because it has shown benefits to their clinical practice and patient care.

Conclusion

Most doctors in this study adopted the use of the PDA. Doctors' desire for patient-centred care and shared decision making facilitate the use of PDA. Audit and feedback reports help overcome the barriers of forgetting to use the PDA. More active, point-of-care reminders (e.g. via EMR) may improve adoption.

083 - Effect of three types of information leaflets on general public perceptions of diagnostic imaging for low back pain: a randomised controlled trial

Sweekriti Sharma^{1,5}, Adrian Traeger^{1,5}, Mary O'Keeffe^{1,5}, Tessa Copp¹, Alexandra Freeman³, Chris Needs⁴, Tammy Hoffmann², Bethan Richar⁴, Chris Maher^{1,5}

¹University of Sydney, Australia, ²Bond University, Queensland, Australia, ³University of Cambridge, UK, ⁴Royal Prince Alfred Hospital, Sydney, Australia, ⁵Institute for Musculoskeletal Health, Sydney, Australia

Background

Shared decision-making can reduce the uptake of some unnecessary tests and procedures. Although awareness of shared decision-making is increasing, overuse of diagnostic tests for common clinical conditions, such as low back pain, remains high. Recent public health campaigns, such as the 'Choosing Wisely' Initiative, attempt to persuade consumers to avoid unnecessary tests, rather than provide neutral information on benefits and harms. It is unclear whether persuasive information materials can influence perceptions of imaging tests more than neutral materials, and whether such public health approaches could have unintended consequences (e.g. decision regret).

Aim To evaluate the effect of different types of information leaflets on public perceptions of imaging for low back pain.

Methods

Design Randomised online experiment.

Setting Community (online) and 1 tertiary hospital.

Participants 360 members of the general public (recruited via Facebook) with or without low back pain, who have been asked to imagine they have experienced a severe episode of low back pain. Recruitment of the general public sample is due for completion in March 2019. We are also purposively sampling patients attending the back-pain outpatient clinic of a large tertiary hospital, who are being interviewed about the leaflets.

Intervention We are randomising participants to read one of the three leaflets on their computer screen, tablet, or smart phone: (i) Control leaflet: guideline information (ii) Neutral leaflet: balanced information on benefits/harms of imaging (iii) Persuasive leaflet: information biased towards harms of imaging. Immediately after reading the leaflet participants complete an online survey.

Outcome measures Intention to undergo imaging for low back pain (primary outcome measure). Secondary outcome measures include beliefs about necessity of imaging, usefulness of leaflet, knowledge, worry, harms, satisfaction with decision, decision regret.

Results

The study is underway and due for completion in April 2019. We will present results in full at the conference.

Conclusion

This study will be the first to compare the impact of information leaflets designed for a public health campaign about unnecessary imaging of low back pain. The data will inform future development of public health resources and shared decision-making interventions.

085 - Exploring patient and family decision roles in a multi-cultural setting part 2

Julia Patrick Engkasan¹, Low Wah Yun¹, Ng Chirk Jen¹

¹University of Malaya, Malaysia

Part 2: Family involvement in bladder management options in people with spinal cord injury

Background and Aims

Neurogenic bladder frequently occurs in men suffering from a spinal cord injury (SCI), and for the majority of patients, it is a lifelong condition. Neurogenic bladder is associated with the inability to sense bladder fullness and initiation of voluntary micturition, thus alternative method to empty the bladder is an important component of neurogenic bladder management. There is a dearth of literature available on how the decision of choosing a bladder drainage method is made. Making this decision requires patients to weigh not only the advantages and disadvantages of each treatment option, but also the effects the treatment will have on their lives. This study aims to explore family influence on the choice of bladder management for male patients with spinal cord injury.

Methods

Semi-structured (one-on-one) interviews of 17 patients with spinal cord injury (SCI); seven were in-patients with a recent injury and ten lived in the community. All had a neurogenic bladder and were on various methods of bladder drainage. Interviews were audio-recorded, transcribed verbatim, and analyzed using thematic analyses. The analysis focused on the reasons why the patients chose or rejected a particular treatment option or changed their bladder management method.

Results

This study did not find that family support had a direct influence on the patients' decision-making process. Participants felt that their families were not knowledgeable about their condition, and some felt uncomfortable discussing bladder drainage methods with their family, because it was perceived as something private. However, participants did consider the burden of care their choices might have on their family and choose methods that were the easiest for their families to manage.

Conclusion

The choice of bladder management in people with SCI is not influenced directly by family members.

087 - Multi-level implementation of time out and shared decision-making in Dutch Oncology Care. Part 1: Effectiveness of a tailored implementation program in breast cancer care.

Haske van Veenendaal^{1,2}, Helene Voogdt-Pruis^{1,3}, Dirk T Ubbink⁴, Carina G J M Hilders², Ella Visserman¹, Esther van Weele¹, Jannie Oskam⁵, Maaïke Schuurman⁵

¹Dutch Federation for cancer Patient Organisations (NFK), ²Erasmus School of Health Policy & Management, ³Encorps, ⁴Department of Surgery, Amsterdam UMC, ⁵Dutch Breast Cancer Patients Association (BVN)

Background and aims

The aim of a series of projects - led by patient organizations - in which a tailored, team-based implementation program is designed and tested, is to evaluate whether it enhances the level of shared decision-making (SDM) in clinical consultations. This program involved mixed methods (i.e. training, feedback, patient involvement, collaborative meetings) to cover important barriers and facilitators for change and has been tested in early breast cancer (Project1, surgery, 6 hospitals), breast cancer (Project2, systemic therapy, 5 hospitals) and lung – and colon cancer (Project3, lung/colon cancer, 4 hospitals).

Patients with early-stage breast cancer deserve SDM as to their treatment options. However, the level of SDM still shows room for improvement. We evaluated the effectiveness of a multi-faceted implementation program for clinicians and patients to improve the level of SDM in clinical consultations for early-stage breast cancer patients.

Description of methods

A tailored multifaceted implementation program was designed so that important barriers and facilitators for change were covered. It included training and feedback for caregivers and involvement of patients (organization). Six Dutch hospital teams participated. The study ran from April 2016 to September 2017. Pre- and post-implementation audio-recordings of the consultations were analyzed using the OPTION-5 instrument. Patients completed the SDM-Q-9 questionnaire. Participants were interviewed about the design of the implementation program (part 2).

Summary of results

Five out of the 6 hospital teams involved fully participated in the program while continuing clinical care. Audiotaped consultations of 80 patients before and 59 patients after implementation showed a significant increase in mean OPTION-5 scores of 38.5 before and 53.3 after implementation. The implementation program accounted for the largest increase in OPTION-5-scores. No significant change before and after implementation were observed in the SDM-Q-9 scores of the 105 participating patients who completed the questionnaire (MD = -3.7; 95% CI= 1.9– -9.3). The study is at the final stage and the results will be available in July 2019.

Conclusion

This SDM-implementation program seems feasible to use in the context of daily care and improved patient involvement in the decision-making process regarding breast cancer treatment in daily practice.

088 - Multi-level implementation of time out and shared decision-making in Dutch Oncology Care. Part 2: Designing and evaluating effective tailored implementation programs for oncology care.

haske van veenendaal^{1,2}, Helene Voogdt-Pruis^{1,3}, Dirk Ubbink⁴, Carina G J M Hilders², Ella Visserman¹, Esther van Weele¹, Jannie Oskam⁵, Maaïke Schuurman⁵

¹Dutch Federation for cancer Patient Organisations (NFK), ²Erasmus School of Health Policy & Management, ³Encorps, ⁴Department of Surgery, Amsterdam UMC, ⁵Dutch Breast Cancer Patients Association (BVN)

Background and aims

The aim of a series of projects - led by patient organizations - in which a tailored, team-based implementation program is designed and tested, is to evaluate whether it enhances the level of shared decision-making (SDM) in clinical consultations. This program involved mixed methods (i.e. training, feedback, patient involvement, collaborative meetings) to cover important barriers and facilitators for change and has been tested in early breast cancer (Project1, surgery, 6 hospitals), breast cancer (Project2, systemic therapy, 5 hospitals) and lung – and colon cancer (Project3, lung/colon cancer, 4 hospitals).

The design of each of the consecutive program is evaluated with participating clinicians.

Description of methods

Six hospital teams participated in Project1 and 5 teams in Project2. Project3 starts in 2019 with 4 hospital teams. The tailored implementation program was designed so that important barriers and facilitators for change were covered. Clinicians in the program all received a standard questionnaire and 2 clinicians from each participating hospital were interviewed about barriers and facilitators for implementation and about the effectiveness of the components of the program.

Summary of results

Two series (2017 & 2019) of interviews were held with 21 clinicians for Project1 & Project2 and all clinicians received the questionnaire. Project3 starts in 2019 so interviews will be conducted later. Overall the participants were positive about the implementation program however barriers like lack of time, unclear communication with the researchers and the lack of examples were identified. Recommendations were i.e. emphasizing personal benefits, fewer and more efficient meetings, providing specific examples and feedback, and better communication between the researchers and the hospitals. Lessons learned from implementation and recommendations for future implementation programs will be presented.

Conclusion

Our implementation approach enhanced SDM in daily practice (part1). After the first program, changes in the design have been made, i.e. to strengthen patient involvement, to improve the educational methods and to support implementation more intensively on the local level. The results of the implementation of the second program will be available in July 2019 so a new design for implementing SDM in clinical practice can be presented.

089 - Multi-level implementation of time out and shared decision-making in Dutch Oncology Care. Part 4: Co-creation for integrating patients perspectives.

Ella Visserman¹, Esther van Weele¹, haske van veenendaal^{1,3}, Jannie Oskam², Maaïke Schuurman², Lidia Barberio⁴, Dorien van Benthem⁵

¹Dutch Federation of Oncology Patient Organizations (NFK), Utrecht, The Netherlands, ²Dutch Breast Cancer Patients Association (BVN), Utrecht, The Netherlands, ³Erasmus School of Health Policy & Management, Rotterdam, the Netherlands, ⁴Longkanker Nederland Patients Association, Utrecht, The Netherlands, ⁵Dutch Bowel Cancer Patients Association, Utrecht, The Netherlands

Background and aims

The aim of a series of projects - led by patient organizations - in which a tailored, team-based implementation program is designed and tested, is to evaluate whether it enhances the level of shared decision-making (SDM) in clinical consultations. This program involved mixed methods (i.e. training, feedback, patient involvement, collaborative meetings) to cover important barriers and facilitators for change and has been tested in early breast cancer (Project1, surgery, 6 hospitals), breast cancer (Project2, systemic therapy, 5 hospitals) and lung – and colon cancer (Project3, lung/colon cancer, 4 hospitals).

As SDM takes two to tango, we consider patient involvement to be an essential part of any implementation effort. In this session we present effective methods for patient involvement in the implementation of SDM and how this was experienced by participating clinicians in the program.

Description of methods

In the design of the implementation program the following methods for patient involvement were applied:

- Representation in the project-team, the collaborative working sessions and local hospital team sessions.
- Website surveys to provide teams with (ex-)cancer patients views on relevant SDM issues.
- Conducting focus groups.
- Recruiting and training of patient advocates to join and support the local hospital teams.

Patient involvement was evaluated via semi-structured interviews with participating clinicians and patient representatives.

Summary of results

In three consecutive projects, methods for patient involvement contained:

- Patient representatives participated in all three project teams and co-designed all program elements including several implementation tools and the feedback to clinicians.
- Patient advocates were recruited, trained (including a user manual) and participated in all 11 breast cancer teams (Project1&2).
- Four website surveys were carried out.

- Five focus groups were organised.

Combining different and effective methods for patient involvement regarding the implementation of SDM, is crucial. Methods and examples of results of this involvement will be presented.

Conclusion

A multi-level involvement of patient(s) (advocates) is crucial to the implementation of SDM. Effective methods were tested and found both feasible as effective as part of an implementation program that led to a significant increase of OPTION-5 outcomes.

090 - Multi-level implementation of time out and shared decision-making in Dutch Oncology Care. Part 3: Educating clinicians in shared decision-making.

Jannie Oskam¹, Maaïke Schuurman¹, Ella Visserman², Esther van Weele², Haske van Veenendaal^{2,3}, Lidia Barberio⁴, Dorien van Benthem⁵

¹Dutch Breast Cancer Patients Association (BVN), Utrecht, The Netherlands, ²Dutch Federation of Oncology Patient Organizations (NFK), Utrecht, The Netherlands, ³Erasmus School of Health Policy & Management, Rotterdam, the Netherlands, ⁴Longkanker Nederland Patients Association, Utrecht, The Netherlands, ⁵Dutch Bowel Cancer Patients Association, Utrecht, The Netherlands

Background and aims

The aim of a series of projects - led by patient organizations - in which a tailored, team-based implementation program is designed and tested, is to evaluate whether it enhances the level of shared decision-making (SDM) in clinical consultations. This program involved mixed methods (i.e. training, feedback, patient involvement, collaborative meetings) to cover important barriers and facilitators for change and has been tested in early breast cancer (Project1, surgery, 6 hospitals), breast cancer (Project2, systemic therapy, 5 hospitals) and lung – and colon cancer (Project3, lung/colon cancer, 4 hospitals).

In this session we present the design of and experiences with diverse educational interventions.

Description of methods

Educating clinicians seems promising to stimulate SDM. As part of our implementation program, we developed:

- Interdisciplinary customized team training
- E-learning SDM containing theory, patient perspective and a consultation as an example
- Standardized feedback report based on the OPTION-5 observations combined with a one-hour feedback session for clinicians

The educational interventions are evaluated via interviews with participating clinicians.

Summary of results

Qualitative interviews were held with 21 clinicians to evaluate the effectiveness and design of the training methods for supporting the application of SDM in consultations (Project1 & Project2). Clinicians felt that training and feedback are essential for applying SDM in practice. The team training has evolved in a 3 hour session including participation of patient advocates and actors for roleplay. The e-learning is based on key literature regarding SDM, and developed in co-design with patients, clinicians and experts on SDM. It takes 45-60 minutes and has been used by 375 Dutch clinicians in 2018. Twenty-one feedback reports and feedback sessions have been organized for breast cancer, and 4 for lung and colon cancer teams (Project3).

Conclusion

Educating clinicians is a key element in supporting the implementation of SDM in daily care. In a series of oncology projects, a combination of e-learning, interdisciplinary training and feedback on consultations was tested and evaluated with participating clinicians as part of an implementation program that led to a significant increase of OPTION5 outcomes. Insights are currently used for the implementation project³.

091 - Exploring patient and family decision roles in a multi-cultural setting Part 1 Family decision making role preference shifts as medical severity increases- A Malaysian cross-sectional online panel study

Khatijah Lim Abdullah¹, Yew Kong Lee¹, Chirk Jenn Ng¹, Ping Yein Lee², John Friend³, Dana L. Alden³

¹University of Malaya, Malaysia, ²University Putra Malaysia, Malaysia, ³Shidler College Business, University of Hawaii

Introduction

In a doctor-patient dyad, patient's decisional role preferences can shift as the severity of conditions increases. This pattern may be different when it comes to a doctor-patient-family triad, especially in societies with strong family ties such as Malaysia. This study aims to measure participant role preferences for family involvement across six scenarios from mild, moderate and severe health situations.

Methods

This was a simple descriptive cross-sectional survey. Malaysian data was collected from a larger 7-country online panel survey conducted on 280-300 participants per country utilising a commercial professional survey provider. Participants were quota sampled according to Malaysian ethnic proportions. Six medical scenarios of increasing severity were developed by medically-qualified researchers and pilot-tested with healthcare professionals and laypersons. These scenarios were runny nose treatment (Mild1), itchy rash medication choice (Mild2), asthma medication choice (Moderate1), insulin initiation (Moderate2), amputation due to diabetes (Severe1), and lung cancer treatment (Severe2). 5-point Likert scoring was used to measure patient preference for autonomous (self and doctor decides; self decides with doctor after consulting family), shared decision making (SDM) (family, doctor and self decides) and family decides (family decides with doctor after consulting patient; family decides with doctor). Data analysis was done descriptively using simple frequencies to identify patterns of decisional preference.

Results

294 participants had an average age of 35.5 years, equal gender distribution, and 75% were married/living with partner. In mild situations, the distribution of preferences was weighted more towards autonomy (64.5% autonomous, 15.7% shared, 19.9% family decides). In moderate situations, the majority still preferred autonomy but with a reduced percentage compared to mild situations (43.9% autonomous, 29.1% shared, 27 % family decides). Finally, in severe situations the majority preferred shared decision making in the triad (33.2 % autonomous, 35.2 % shared, 31.65 % family decides). Individual scenario analysis showed that insulin (Moderate2) closely resembled severe decision preferences despite being labelled as moderate.

Conclusion

Decisional preferences shifted towards SDM involving the family as severity increased. However, interpretations of severity could differ from researcher definitions. These results are preliminary and require further in-depth analysis.

092 - Exploring patient and family decision roles in a multi-cultural setting. Part 3 Family involvement in breast cancer prevention decision-making among women with BRCA mutations

Kar See Yeoh¹, Yew Kong Lee¹, Nur Aishah Mohd Taib¹, Sook Yee Yoon³, Barlow-Stewart Kristine⁴, Cheng Har Yip²

¹University of Malaya, Kuala Lumpur, Malaysia, ²Subang Jaya Medical Centre, Selangor, Malaysia,

³Cancer Research Malaysia, Selangor, Malaysia, ⁴University of Sydney, Sydney Australia

Women carrying a deleterious *BRCA1/2* mutation have a significantly increased lifetime risk of developing breast cancer compared to the general population. To minimize this risk, women face difficult decisions regarding multiple complex medical options and health outcomes, and integrating these options into their life planning. This presents unique medical and psychosocial challenges to women's decision-making without the benefits of any appropriate decision support interventions. To guide intervention development, we conducted a qualitative study among *BRCA* carriers to understand women's perspectives about how they decide on risk-reducing options (screening, chemoprevention or risk-reducing mastectomy, RRM) available to them.

Methods

Using purposive sampling technique, we recruited participants from a multidisciplinary risk management clinic of a large university-teaching hospital in Kuala Lumpur and an outpatient breast surgery clinic of a private hospital in Selangor, Malaysia. We conducted in-depth interviews, using a semi-structured interview guide, with 35 *BRCA1/2* carriers who knew their mutation status. Audio-recording of the interview data were transcribed verbatim. NVivo 10 software facilitated the coding of data. Data were analyzed using thematic content analysis.

Results

Women's familial support and spousal attitudes towards RRM influenced women's choice for breast cancer preventive options. Having enough support and encouragement from the people in their lives was the crucial motivator for women to choose RRM. Familial support and encouragement gave women the courage and strength to make this difficult choice. For married women, spousal positive attitudes towards RRM and explicit encouragement provided the support they need to choose this preventive measure. For single women, though they feared the negative impact of RRM on their body image, they were able to make the decision to remove their breasts with the support and encouragement from families. In contrast, most women who chose screening did not have familial support and encouragement to pursue RRM even though some of them might be oriented towards this option. Family exerted influence on women's choices by explicitly discouraging RRM.

Conclusion

Thus, family involvement can act as barriers or motivators to women's decision-making regarding breast cancer prevention. Future support interventions and clinical discussions should explicitly address women's familial support and spousal attitudes towards RRM.

093 - Exploring patient and family decision roles in a multi-cultural setting. Part 4: Family Matters: Family Involvement in Decision-Making Process for The Ovary and Fallopian Tube Removal or Risk Reducing Bilateral Salpingo-Oophorectomy (RRBSO) Among Malaysian BRCA Gene Mutation Carriers.

Hamizah Sa'at¹, Yew Kong Lee¹, Sook Yee Yoon², Wong Siu Wan², Woo Yin Ling¹, Nur Aishah Taib¹

¹University of Malaya, Kuala Lumpur Malaysia, ²Cancer Research Malaysia, Subang Jaya Malaysia

Part 4

Background: Decision-making for ovarian cancer risk-reduction is challenging among BRCA mutation carriers. RRBSO may reduce 80% risk of ovarian cancer and remain the only risk-reduction option. Immediate menopause and psychosocial conditions can cause decisional conflict for self and significant others, especially in Asian societies where family members play an important role in health decision-making. This study describes family involvement in the decision-making process for RRBSO among Malaysian BRCA mutation carriers.

Method: A total of 31 semi-structured interviews and 11 clinic observations were conducted on Malaysian BRCA mutation carriers with age range of 28-68 years. Thematic analysis was used for data analysis.

Results: Family involvement was vital in the decision-making process for RRBSO among participants. Three major themes emerged: 1) supportive family; 2) conflicted family; and 3) excluded family. Many sought for opinion and support from husband and family members and some described RRBSO as a 'group decision'. Women felt empowered to reach final decision when they received decisional reassurance and emotional support from them. Married carriers always sought approval and support from their husbands. Although some husbands did not take an active role during the decision-making process, most women made their husbands aware of the possible post-surgical menopausal impact. However, some women found it challenging to gain desirable support to make decision. The mismatch preference with husband/family about RRBSO was mainly due to conflicting values about the removal of unaffected ovaries and different perception about cancer risk. While some chose to avoid RRBSO for the sake of family harmony, some women remained indecisive in making the decision. Some women completely excluded family members from the decision-making process when they were unsupportive or showed unpleasant responses although they expressed a strong desire for family support. Others made an independent decision as they felt they were responsible for their own body.

Conclusion: Value congruence with husbands and family members is important for RRBSO decision-making in BRCA carriers. This finding informs the design of decision support tool to include husband and family members as important components in facilitating decision-making process for RRBSO among Malaysian BRCA mutation carriers.

097 - De l'importance des sanctions : pourquoi l'adoption de la prise de décision partagée comme norme légale pourrait ne pas améliorer la participation des patients aux décisions de soins qui les concernent

Audrey Ferron Parayre¹

¹Section de droit civil, Université d'Ottawa, Ontario, Canada

L'adoption de la prise de décision partagée (PDP) comme critère légal modifiant la norme actuelle du consentement éclairé est parfois présentée comme une solution juridique permettant une plus grande participation des patients aux décisions de soins. L'objectif de cette étude est de démontrer que l'adoption de la PDP pourrait ne pas être suffisante pour améliorer la participation des patients à la prise de décision médicale. En effet, l'effectivité du droit suppose qu'afin qu'une norme soit effective, il est nécessaire que les sanctions qui sont rattachées aux transgressions de cette norme soient appliquées avec assiduité.

Nous avons procédé à une analyse juridique critique en matière de responsabilité déontologique et civile afin de déterminer dans quelle mesure les sanctions associées au non-respect de la norme actuelle du consentement éclairé aux soins sont appliquées. En matière déontologique, nous avons effectué une revue systématique des décisions rendues entre 2002 et 2018 par le Conseil de discipline du Collège des médecins du Québec. En ce qui a trait à la responsabilité civile, nous avons réalisé une revue systématique des décisions rendues par la Cour supérieure du Québec entre 2010 et 2018.

Sur le plan déontologique, nous avons recensé 13 décisions portant sur le consentement aux soins. De ces décisions, aucune ne reconnaît la culpabilité d'un médecin du seul fait d'une transgression à son obligation d'information ou d'obtenir le consentement du patient ; les décisions où le médecin est reconnu coupable de fautes déontologiques s'appuient toutes sur des infractions autres que le seul consentement. Notre recherche portant sur la responsabilité civile nous a permis d'identifier 17 décisions. La responsabilité civile du médecin pour une faute commise dans le processus de consentement aux soins est reconnue dans 18% des cas (n=3). Ce faible taux s'explique principalement par la difficulté d'établir le lien de causalité entre la faute du médecin et le préjudice subi par le patient.

Notre analyse juridique critique nous indique que les sanctions associées au non-respect du consentement éclairé sont faiblement appliquées. En l'absence d'une telle application, il est peu probable que la modification de la norme entraîne de réels changements dans les pratiques cliniques.

099 - Patient-oriented research: Lessons Learned for Recruiting and Training Indigenous Patient Partners

Marie-Claude Tremblay¹, Éline Brière³, Maude Bradette-Laplane¹, Joyce Maman Dogba¹, Holly O. Witteman¹, France Légaré¹, Jonathan McGavock², Alex M. McComber^{4,5}, Gary F. Lewis⁶, Danielle Bérubé³, Nicole Moisan³

¹Département de médecine familiale et de médecine d'urgence, Université Laval, Québec, Canada,

²Department of Pediatrics, Faculty of Health Sciences, University of Manitoba, Winnipeg, Canada,

³Nation des Malécites de Viger, ⁴Nation Mohawk de Kahnawake, ⁵Cercle des patients autochtones d'Action Diabète Canada, ⁶Department of Medicine and Department of Physiology, University of Toronto, Toronto, Canada

Context: Patient-oriented research (POR) is an approach that encourages active participation of patients in health research with measurable advantages related to improved quality, validity, and relevance of research and its results. POR is a particularly relevant approach when working with marginalized or underserved groups, such as Indigenous populations in Canada (including First Nations, Métis, Inuit). However, these populations are often underrepresented in POR projects.

Objective: To understand how to better recruit, train and support new Indigenous patient partners so they may play an active role in health research.

Method: This one-year initiative aimed at building a team of active Indigenous patient partners using a participatory approach involving researchers, Indigenous people living with chronic disease and healthcare organizations in the province of Quebec. A core committee guided the development and implementation of the initiative, defined the vision of the initiative, set operational norms, and identified specific engagement strategies. Following the initiative, we conducted an implementation evaluation, building on interviews with committee members and documentation analysis. The aim of the evaluation was to identify barriers and facilitators to the engagement of Indigenous patients in POR. A thematic analysis strategy was used to analyze the data.

Result: The results provide lessons for engaging Indigenous patient at different stages of engagement. Better practices include recruiting patient partners within communities, developing trusting relationships, developing competencies to build capacity, offering participation in several projects or at various levels, and favoring projects with tangible outcomes for the patients' communities. Specific challenges for Indigenous patient partners included understanding their role as active participants in the research process and developing self-confidence in their capacities.

Conclusion: There is a need to train Indigenous patient partners and develop their capacities for POR to ensure healthcare practices, policies and research take their particular needs, stories and culture into account. The results of this project are consistent with existing literature on POR. They additionally highlight specific challenges of involving marginalized populations who have been historically and systemically disempowered.

101 - Measuring patient-reported shared decision-making: assessment of collaboRATE's group-level reliability

Rachel Forcino¹, Marcus Thygeson², James O'Malley^{1,3}, Marjan Faber⁴, Gert Westert⁴, Glyn Elwyn¹

¹The Dartmouth Institute for Health Policy & Clinical Practice, New Hampshire, United States, ²Bind Benefits, Minnesota, United States, ³Department of Biomedical Data Science, Dartmouth College, New Hampshire, United States, ⁴Scientific Center for Quality of Healthcare, Radboud university medical center, Nijmegen, Netherlands

Background and aims

This study compared collaboRATE, a patient-reported measure of shared decision-making (SDM), to widely-used Consumer Assessment of Healthcare Providers and Systems (CAHPS) measures of SDM and communication with regard to score reliability (how well scores differentiate performance across providers) and concurrent validity (correlation with another validated measure of a related construct).

Methods

We conducted secondary analysis of cross-sectional survey data from the 2017 California Patient Assessment Survey (PAS). PAS participants include privately-insured adult (ages 18 and older) patients who received ambulatory healthcare services at one of 153 participating provider organizations between January and October 2016. The PAS survey vendor invited a random sample of eligible patients to complete the survey, offered by email, postal mail, and telephone in English, Spanish, Chinese, Korean, and Vietnamese languages.

To evaluate provider group-level score reliability, we adopted the Adams (2009) approach. For each measure, we used mixed-effects regression analysis to estimate the provider-to-provider variance. Using this provider-to-provider variance estimate and Adams' (2009) formula, we calculated provider group-level score reliability and reported median estimates across all provider groups. To examine concurrent validity, we conducted Pearson correlation analysis.

Results

CollaboRATE provider group-level reliability was moderate with a median value of 0.70 (range: 0.27-0.93), while the median CAHPS shared decision-making group-level reliability was low at 0.37 (range: 0.05-0.79). Group-level reliability of CAHPS communication items had a median value of 0.77 (range: 0.30-0.95). We observed strong concurrent validity between collaboRATE and the CAHPS communication measure ($r=0.83$). Correlations were moderate between the CAHPS shared decision-making composite and collaboRATE ($r=0.52$) and the CAHPS shared decision-making and communication measures ($r=0.61$).

Conclusion

CollaboRATE demonstrates similar reliability to the CAHPS communication measure while far exceeding the reliability of the CAHPS SDM measure. Given its demonstrated ability to reliably differentiate SDM performance at a similar level to the widely-accepted CAHPS communication measure, collaboRATE may be useful for promoting SDM by making provider group performance transparent and enabling provider incentives based on that performance.

103 - Do collaboRATE scores reflect different experience of shared decision making by age, race and language? The question of case mix adjustment

Rachel Forcino¹, Marcus Thygeson², James O'Malley^{1,3}, Gert Westert⁴, Marjan Faber⁴, Glyn Elwyn¹

¹The Dartmouth Institute for Health Policy & Clinical Practice, New Hampshire, United States, ²Bind Benefits, Minnesota, United States, ³Department of Biomedical Data Science, Dartmouth College, New Hampshire, United States, ⁴Scientific Center for Quality of Healthcare, Radboud university medical center, Nijmegen, NL

Background and aims

Shared decision-making (SDM) improves decision-related outcomes among disadvantaged patients and may reduce health disparities. However, the prevalence and quality of SDM can vary by patient characteristics. In this study, we evaluate the association between patient-level characteristics and patient-rated SDM scores (measured by collaboRATE).

Methods

Participants included adults receiving ambulatory services at one of 153 participating California-based medical groups between January-October 2016 and who completed a routine survey by mail, telephone, or web. We conducted multivariable mixed-effects logistic regression analysis to determine which patient characteristics were associated with collaboRATE top-box scores. Patient characteristics (fixed effects) included: age; general health status; mental health status; gender; educational attainment; race; Hispanic or Latino origin; and primary language. Analysis controlled for clustering by medical group (random effect). An alpha level ≤ 0.01 was considered statistically significant.

Results

Among our sample of 30,265 patients, collaboRATE scores increased with age ($p < 0.01$). Poorer general and mental health were associated with poorer collaboRATE scores ($p < 0.001$). Women were 15% more likely than men to give collaboRATE top box scores, i.e. highest-possible scores (OR 1.151; 95% CI 1.093-1.213). Higher educational attainment was associated with lower collaboRATE scores ($p < 0.001$). Additionally, Asian-American respondents were 22% less likely than others to give a top collaboRATE score (OR 0.783; 95% CI 0.677-0.906). Finally, compared to patients who speak English at home, patients who speak Spanish (OR 0.774; 95% CI 0.683-0.876) or some other language (OR 0.806; 95% CI 0.718-0.905) gave lower collaboRATE scores. A random-effect variance of 0.038 suggests moderate variation in SDM across medical groups.

Conclusion

Our findings show the impact of patient characteristics on SDM measurement among a large sample in a routine survey setting. Some measures utilize case-mix adjustment to account for these differences in patient-reported scores. Instead, we suggest that score variation can be directly attributed to these patient factors; we advocate for highlighting disparities in SDM across diverse patient populations to improve awareness and potentially expand SDM resources available to healthcare professionals.

106 - Comparison of Three Measures of Shared Decision-Making: SDM Process, CollaboRATE and SURE scales

Suzanne Brodney¹, Floyd J Fowler Jr², Michael J Barry¹, Yuchiao Chang¹, Karen Sepucha¹

¹Massachusetts General Hospital, Boston, Massachusetts, ²University of Massachusetts, Boston, Massachusetts

Introduction: In order for shared decision making (SDM) to become an important part of health care quality assessment, it is necessary to have valid, practical measures of SDM. The purpose of this study is to compare the psychometric performance of three short patient-reported measures of SDM.

Methods: Secondary analysis of a longitudinal study of patients who met with a specialist to discuss possible surgery for hip or knee osteoarthritis (Hip/Knee), lumbar herniated disc or lumbar spinal stenosis (Backs). About half the patients received a decision aid (DA) prior to the meeting. Patients were surveyed shortly after the visit and again six months later. The three SDM measures were the SDM Process_4 (SDMP) survey, CollaboRATE, and the SURE scale. The follow up survey included measures of decision regret, satisfaction and decision quality. We tested hypotheses to examine validity: (a) patients who reviewed a DA would have higher SDM scores compared to those who did not, (b) patients with higher scores would have less regret and higher satisfaction, and (c) patients with higher scores would be more likely to have made an Informed Patient-Centered (IPC) Decision.

Results: The sample (n=649) was mean age 63.3 years, 51% female, 60% college educated, and included more Hip/Knee patients than Back patients (69% vs 31%). 49% of all patients had surgery. For Hips/Knees, the SDMP and SURE scores were significantly associated with viewing all the DA compared to those who did not ($p<0.001$), but not for CollaboRATE ($p=0.35$). For Backs, none of the scores were significantly associated with viewing all the DA. All three scores were significantly associated with less regret and higher satisfaction ($p<0.001$) for Hips/Knees. For Backs, only SURE and CollaboRATE were significantly associated with less regret, and only SDMP was significantly associated with higher satisfaction. For Hips/Knees and Backs, the SDMP and SURE scales were significantly associated with an Informed Patient-Centered Decision ($p<0.001$), but this relationship was not significant for CollaboRATE (Hips/Knees: $p=0.24$, Backs: $p=0.25$).

Discussion: Each survey takes a different approach to measuring SDM, and each has some evidence of validity. SURE and SDMP better discriminate DA use and higher decision quality.

107 - Practical evidence-based strategies for communicating with family carers in oncology: The TRIO Guidelines

Rebekah Laidsaar-Powell¹, Ilona Juraskova¹, Fran Boyle^{2,3}, Rachael Keast¹, Phyllis Butow¹

¹Centre for Medical Psychology & Evidence-based Decision-making, School of Psychology, University of Sydney, NSW, Australia, ²Centre for Cancer Care and Research, Mater Hospital, NSW, Australia,

³Northern Clinical School, The University of Sydney, NSW, Australia

Background and aims:

Family carer involvement in cancer consultations and decision-making is often beneficial but can be challenging and complex. Effective carer engagement can result in improved patient/survivor care and outcomes, and can also provide an ideal opportunity for carers to have their own informational and emotional needs met. However, if not well managed, some family carers can derail consultations, reduce patient autonomy, and impede effective clinical care. Few strategies or interventions have been developed to enhance positive carer engagement in cancer consultations. In this project we aimed to develop and evaluate evidence-based guidelines (the TRIO Guidelines) for oncology health professionals to manage and enhance carer involvement in cancer consultations and decisions.

Methods:

The TRIO Guidelines were developed through a comprehensive review of the evidence-base and feedback from an advisory group of 10 academic and clinical experts. Draft guidelines underwent two rounds of evaluation via an online Delphi consensus process involving 35 international experts in medical communication, shared decision-making, family carers and clinical care. A multidisciplinary expert advisory group assisted in the subsequent development of professionally produced short films which model the application of the TRIO Guidelines.

Results:

Thirteen key guidelines (and 48 specific strategies) for managing and enhancing carer involvement in consultations were approved through the international consensus process. The guidelines cover topics such as building rapport with carers, managing sensitive patient information, meeting the emotional needs of carers, and managing challenging and complex situations such as dealing with conflicting patient-family treatment preferences, family dominance, dysfunction, and anger. The TRIO Guidelines also include example behaviours and wording for clinicians to use in clinical practice. Eight purpose-developed short films demonstrate the TRIO Guidelines being used in common clinical scenarios.

Conclusion:

The TRIO guidelines and videos have the potential to improve patient's and family caregiver's experiences in cancer consultations and decision-making, as well as improving clinicians' confidence when interacting with family carers.

112 - Educational booklet for the prostate cancer screening: helping men understanding the risks and benefits of this exams.

Renata Maciel dos Santos¹, Monica de Assis¹

¹National Cancer Institute, Rio de Janeiro, Brazil

Educational booklet for the prostate cancer screening: helping men understanding the risks and benefits of this exams.

Prostate cancer screening is a common practice in Brazil even though the Health Ministry has the support of recognized scientific evidence to be against it. Regardless of the benefits, prostate cancer screenings can also cause harm to men in many ways.

It is intended to give men more know-how to better decide whether they want to go under these tests and so, under these risks. For this reason, the National Cancer Institute made the first educational booklet for men, describing the risks and advocating to share the decision before going under these tests. This booklet was made and evaluated the participation of two groups of men and experts in this field.

The participants were a group of 15 men which gathered information for the development of educational material. The first draft was assessed by eight specialists (five specialists in early cancer detection, one specialist in urology, and two communication specialists) and by a different group of 21 men. The booklet addressed the risks and benefits of prostate cancer screening and invited men to participate in a shared decision with his practioner.

Results: The participants were not aware of the Brazilian Health Ministry 's recommendation against prostate cancer screening. It was possible to identify their doubts and consider them in the booklet. After they learned about the risks, many said that they will not go under the PSA exam. The final booklet, which was published by the Brazilian National Cancer Institute (INCA), was evaluated by participants and specialists, which considered it as a good material to promote shared decision.

Conclusions: The men's participation in the development and assessment of the material confirmed the urgent need to disseminate information regarding the risks and potential damage associated with prostate cancer screening in Brazil. This educational material was considered as complementary strategie to be used as part of the shared decision making.

122 - Development and acceptability testing of a patient decision aid for individuals with localized renal masses considering surgical removal with partial or radical nephrectomy

Kristen McAlpine¹, Rodney H Breau^{1,2}, Dawn Stacey^{2,3}, Christopher Knee^{1,2}, Michael A.S. Jewett⁴, Ilias Cagiannos^{1,2}, Christopher Morash^{1,2}, Luke T. Lavallée^{1,2}

¹Division of Urology, University of Ottawa, Ottawa, ON, Canada, ²Ottawa Hospital Research Institute, University of Ottawa, Ottawa, ON, Canada, ³School of Nursing, University of Ottawa, Ottawa, ON, Canada, ⁴Departments of Surgery (Urology) and Surgical Oncology, Princess Margaret Cancer Centre, University Health Network and the University of Toronto, Toronto, ON, Canada

Introduction:

Patient decision aids are structured clinical tools that facilitate shared decision-making. In urology, the decision between partial and radical nephrectomy for a renal mass is often difficult. We sought to develop and evaluate a decision aid for patients with a localized renal mass considering surgery.

Material and Methods:

A decision aid was systematically created using the International Patient Decision Aids Standards. Review of the literature identified evidence regarding patient-important outcomes of partial and radical nephrectomy. A mixed methods survey was designed to assess acceptability of the decision aid. Kidney cancer survivors, patient advocates, methodological experts and urologists were recruited to evaluate the decision aid. The primary outcome was the acceptability of the decision aid reported by survey responders.

Results:

An evidence-based decision aid was created. Included benefits were overall survival, cancer-free survival, and length of hospital stay. Included harms were post-operative bleeding, urine leak, stage 3 renal failure, renal replacement therapy and flank bulge. The decision aid met the International Patient Decision Aids Standards defining (6 of 6), certification (6 of 6), and quality criteria (21 of 23). Results of acceptability testing were highly favorable. Responders (n=22) reported the decision aid had acceptable language (91%), an appropriate length (82%), and balanced presentation of options (91%). Nine of eleven urologists (82%) reported intended use with future patients.

Conclusions:

A novel, evidence-based decision aid was created for patients with renal masses considering surgery. The decision aid is available at <https://decisionaid.ohri.ca/AZsumm.php?ID=1913>.

123 - Development and acceptability testing of a patient decision aid for urinary diversion with radical cystectomy

Kristen McAlpine¹, Luke T. Lavallée^{1,2}, Dawn Stacey^{2,3}, Preveshen Moodley⁴, Christopher Knee^{1,2}, Ilias Cagiannos^{1,2}, Christopher Morash^{1,2}, Rodney H. Breau^{1,2}

¹Division of Urology, University of Ottawa, Ottawa, ON, Canada, ²Ottawa Hospital Research Institute, University of Ottawa, Ottawa, ON, Canada, ³School of Nursing, University of Ottawa, Ottawa, ON, Canada, ⁴Division of Urology, Health Sciences North, Sudbury, ON, Canada

Abstract

Background:

Urinary diversion at the time of radical cystectomy is one of the most lifestyle-altering procedures performed in urology. This challenging decision occurs at a stressful time when patients are preparing to undergo a major operation for cancer. Patient decision aids (PtDA) are clinical tools that promote shared decision-making by providing information about management options and by helping patients communicate their values and preferences. We sought to develop and evaluate a PtDA for individuals deciding between urinary diversion options prior to cystectomy.

Methods and materials:

The International Patient Decision Aids Standards (IPDAS) were used to guide a systematic development process. A literature review was performed to determine options for urinary diversion and incidence of outcomes. Using the Ottawa Decision Support Framework, a PtDA prototype was created. A 10-question survey based on a previously validated tool, assessed PtDA acceptability amongst patients, allied health professionals, and urologists. The primary outcome was PtDA acceptability amongst survey responders.

Results:

An evidence-based approach was used to develop the PtDA. Ileal conduit and orthotopic neobladder were included as urinary diversion options. Outcomes specific to ileal conduit were stomal stenosis and parastomal hernia. Outcomes specific to orthotopic neobladder were daytime and nighttime urinary incontinence, and urinary retention. Acceptability testing was completed by 8 urologists, 9 patients, and 1 advanced practice nurse. Respondents reported the language was appropriate (94%), length was adequate (94%), and presentation of options were balanced (83%). The PtDA met defining (6 of 6), certification (6 of 6), and 21 of 23 quality criteria as outlined by IPDAS.

Conclusions:

A novel PtDA was created to improve the quality of decisions patients make when deciding between urinary diversion options with cystectomy.

125 - Intraclass correlation coefficients for implementation research on shared decision making in primary care

Ali Ben Charif¹, Jordie Croteau¹, Rhéda Adekpedjou¹, Hervé Tchal¹, Evehouenou Lionel Adisso¹, France Légaré¹

¹Université Laval, Quebec, Canada

Background and aims: Cluster randomized trials are important sources of information on evidence-based practices in primary care. However, there are few sources of intraclass correlation coefficients (ICCs) for designing such trials. We inventoried ICCs for shared decision-making (SDM) measures in primary care.

Methods: We performed a secondary analysis of data involving 14 observational and interventional studies. These studies were led by the Canada Research Chair in Shared Decision Making and Knowledge Translation. Eligible studies were conducted in primary care, included at least two hierarchical levels, included SDM measures for patients or healthcare providers nested under any type of cluster (area, clinic or provider), and were approved by an Ethics Committee. We classified each measure into one of the three constructs of Sepucha and Mulley's conceptual framework: decision antecedents, decision processes, and decision outcomes. We described the characteristics of included studies and measures. We used Bayesian random effect models to estimate mode ICCs and their 95% highest probability density interval (HPDI). We summarized these estimates by calculating median and interquartile range (IQR).

Results: Six out of 14 studies were included: three cluster randomized controlled trials, two cross-sectional surveys and one before-and-after trial. From these, we selected 17 measures related to SDM for which the calculation of ICCs was possible: three binary measures and 14 continuous measures. Overall, we estimated 97 ICCs for the 17 measures across the six studies. ICCs ranged from 0 to 0.5 (median 0.03; IQR 0-0.07). They were slightly higher for process measures (median 0.03, IQR 0-0.07) than for antecedent measures (median 0.02, IQR 0-0.07) or outcome measures (median 0.02, IQR 0-0.06). Respectively in these measurement categories, "decisional conflict" (mode 0.48, 95% HPDI [0.39, 0.57]), "reluctance to disclose uncertainty to patients" (0.5 [0.11, 0.89]) and "quality of the decision" (0.45 [0.14, 0.84]) had the highest ICCs. ICCs for provider-level clustering (median 0.06, IQR 0-0.13) were higher than for other levels.

Conclusions: Overall, we observed high values of ICC estimates for SDM measures in primary care, specifically for decision process measures. Our inventory of ICCs for primary care SDM measures will help researchers better plan SDM implementation studies.

129 - Preferred and Perceived Participation Roles in Advanced Kidney Disease: A Scoping Review

Lily Yeung RN PhD(Student)¹, Asad Merchant MD², Vanita Jassal MD MSc^{2,3}, Lisa Cranley RN PhD¹, Martine Puts RN PhD¹

¹Lawrence Bloomberg Faculty of Nursing, University of Toronto, Ontario, Canada, ²Department of Nephrology, University Health Network, Toronto, Ontario, Canada, ³Institute of Health Policy, Management and Evaluation, University of Toronto, Ontario, Canada

Background: Globally, more than 10% of people have chronic kidney disease (CKD). When CKD progress to advanced stages, patients are asked to determine which treatment (renal replacement therapies or comprehensive conservative renal care) best aligns with their values and preferences. Patients' participation in this decision-making process can be influenced by many factors. However, no literature review has examined factors influencing patients' participation in the nephrology context.

Objective: To synthesize the nephrology literature on factors that influenced the patients' perceived and preferred participation roles, as well as the congruence between perceived and preferred roles.

Methods: A scoping review was conducted guided by Levac and colleagues' refinement of Arksey & O'Malley's framework. The search strategy was developed using two concepts: "Chronic Kidney Disease" and "Decision-Making". Ovid MEDLINE and EBSCO CINAHL databases were searched. This review reports on findings of qualitative studies. Findings related to how patients perceived their participation in decision-making (i.e. perceived roles) and how they preferred to participate (i.e. preferred roles) were extracted from the included studies. Degner and colleagues' control preferences scale (1997) was used to differentiate these roles into active, collaborative, and passive. Perceived and preferred roles were compared to determine congruence. Findings on factors associated with these roles and/or congruence were thematically analyzed.

Results: Twenty-six qualitative studies were included and all described patients' perceived roles. Four themes emerged from findings on factors associated with perceived roles: knowledge, health conditions, relationships with family members, and healthcare provider support. Having adequate knowledge was associated with perceived active and collaborative roles, while having inadequate knowledge was associated with passive roles. Health conditions, relationships with family members, and healthcare provider support varied in how they were associated with patients' perceived roles. These findings suggested that patients varied individually in how factors influenced their participation in decision-making. Three studies described preferred roles, and none explored role congruence.

Conclusions: This review adds to the existing literature by identifying factors that influence patients' perceived roles, and highlighting a lack of qualitative studies examining preferred roles and role congruence. Future research is warranted to better understand what makes the patients' roles congruent or not.

133 - Eliciting patient preferences in shared decision-making: A strategy for engaging patients in the development of a clinical practice guideline on screening for depression among adults

Lynsey Burnett¹, Ainsley Moore^{2,3}, Eddy Lang^{2,4}, Kate Morissette⁵, Kathleen Einarson¹, Shusmita Rashid¹, Alekhya Mascarenhas Johnson¹, Rossella Scoleri¹, Sherry Stein¹, Sharon E. Straus^{1,6}

¹Li Ka Shing Knowledge Institute, St. Michael's Hospital, ²Canadian Task Force on Preventive Health Care, ³Department of Family Medicine, McMaster University, ⁴Department of Emergency Medicine; University of Calgary, ⁵Global Health and Guidelines Division, Public Health Agency of Canada, ⁶Department of Geriatric Medicine, University of Toronto

Background:

Involving patients in the development of clinical practice guidelines can yield recommendations that are more likely to be patient-centered, practical and provide opportunities for shared decision-making (SDM)^{1,2}. The Canadian Task Force on Preventive Health Care elicited patients' values and preferences in the '*screening for depression among adults*' guideline development process; specifically, we asked how important patients believe it is to consider identified outcomes when making depression screening decisions, and what types of information they would want to discuss in SDM conversations about depression screening. Outcomes perceived to be important by patients were included in the evidence review that informed the guideline.

Methods:

We recruited English-speaking Canadians, aged 18+ years, either with or without a personal history of depression, and used a modified RAND Appropriateness Method (RAM)³ for data collection. Participants received a depression backgrounder and list of potential outcomes that could be considered when making depression screening decisions. In a pre-survey, patients rated the importance of each outcome using the Grading Recommendations Assessment, Development and Evaluation (GRADE) 9-point scale (*not important* (1-3), *important* (4-6), or *critical* (7-9)).⁴ Subsequently, participants discussed screening outcomes and preferences in an hour-long focus group or interview via teleconference, with a content expert present. They rated the same outcomes in a post-survey. We used descriptive statistics and thematic analysis to analyze survey and focus group/interview data, respectively.

Results:

We collected data from 16 Canadians, aged 22 to 63 years (7 had a personal history of depression). Median post-survey ratings ranged from 7 (critical) to 8.5 (critical) for benefits, and 6 (important) to 7 (critical) for harms. Participants identified topics they considered important in SDM conversations, including the range of treatment options and their accessibility, how depression may impact friends and family, and potential harms of living with untreated depression.

Conclusion:

Participants rated all identified outcomes of screening for depression as either *important* or *critical*, and may therefore be more responsive to a guideline that is based on evidence pertaining to these outcomes. Results can also inform knowledge translation tools that address information needs of participants and support a discussion on patients' preferences and SDM.

134 - Development of a radiotherapy decision aid for older women with early-stage breast cancer

Shi-Yi Wang^{1,2}, Sarah S. Mougalian^{2,3}, Brigid K. Killelea^{2,4}, Liana Fraenkel⁵, Cary Gross^{2,6}, Suzanne B. Evans^{2,7}

¹Yale University School of Public Health, ²Cancer Outcomes, Public Policy, and Effectiveness Research (COPPER) Center, Yale Cancer Center and Yale University School of Medicine, ³Section of Medical Oncology, Department of Internal Medicine, Yale University School of Medicine, ⁴Department of Surgery, Yale University School of Medicine, ⁵Section of Rheumatology, Department of Internal Medicine, Yale University School of Medicine, ⁶Section of General Internal Medicine, Department of Internal Medicine, Yale University School of Medicine, ⁷Department of Therapeutic Radiology, Yale University School of Medicine

Purpose:

Among older women with early-stage breast cancer who received breast conserving surgery, adjuvant radiotherapy reduces local recurrence but may not improve survival. While guidelines suggest that radiotherapy can be safely omitted, approximately two-thirds of eligible women in the United States still receive it. To help facilitate shared decision-making, we developed an online decision aid (DA) for older patients.

Method:

We established an advisory committee, including breast cancer survivors (n=6), advocates of breast cancer care and aging (n=7), oncology clinicians (n=4), and researchers (n=4). We surveyed 93 patients as part of a needs assessment. Using simulation models, we developed a risk calculator to project personalized all-cause mortality and local recurrence with or without radiotherapy, accounting for an individual's tumor characteristics, comorbidities, and functional status. The risk calculator was presented to 4 eligible patients and 22 volunteers aged 65 or older in a pilot study. We developed a prototype DA through a comprehensive iterative staged process involving literature review, findings from the survey, and input from our advisory committee.

Result:

The DA consisted of five components: 1) information provision, 2) knowledge assessment, 3) a values clarification exercise, 4) a risk calculator, and 5) evaluation of the final decision and certainty of the decision. The tool outlined general information on radiotherapy, options, and benefits/side effects of radiotherapy, with additional hyperlinks to relevant websites of authority organizations. Three questions and a ranking task of four features regarding benefits/side effects of radiotherapy were used to assess knowledge and elicit preferences. The individualized risk estimates were stated in neutral frequencies and graphically displayed using 100-person color-coded pictograms. In the pilot study, 92% of participants strongly agreed or agreed that they would like to use the risk calculator. Approximately 85% of them thought the risk calculator was easy to use. Patient advisory committee members reported that the DA facilitated understanding of radiotherapy benefits and decision-making processes.

Conclusion:

We developed a web-based DA prototype that has the ability to be populated with personalized risk estimates. It is acceptable and easy to use. Future studies are required to demonstrate whether our DA can improve patient-provider communication.

135 - Favoriser l'implication de patients dans la recherche clinique

Nouha Ben Gaied¹

¹Fédération québécoise des Sociétés Alzheimer

Un des défis majeur de la recherche clinique est le recrutement de patients. Ce défi est d'autant plus important lorsqu'il s'agit de la maladie d'Alzheimer et des maladies neurodégénératives, dont l'évolution affecte la mémoire, l'autonomie, le jugement et par le fait même la capacité de la personne à prendre des décisions éclairées. C'est dans ce contexte, que la Fédération québécoise des Sociétés Alzheimer a décidé d'agir et de produire un dépliant informatif qui vise à mieux faire connaître le processus impliqué dans les essais ou les études cliniques et ainsi aider les personnes touchées par ces maladies et leur famille, à faire ce choix et à s'engager dans la recherche. Pour avoir un maximum d'impact, le contenu du dépliant a été préparé avec des chercheurs experts, des professionnels de la santé, mais surtout des personnes atteintes de la maladie d'Alzheimer et des proches aidants. Il était important pour nous de valider d'une part le contenu du dépliant *via* des groupes de discussion, mais surtout d'impliquer des personnes qui ont fait ce choix, pour qu'elles puissent témoigner de leur expérience. Le dépliant a été distribué à plus de 2 000 personnes incluant des cliniques de mémoire, des médecins de famille et des particuliers. L'accueil réservé à cette ressource supplémentaire a été très positif, notamment auprès des particuliers et les intervenants du réseau de la santé, mais des efforts supplémentaires sont néanmoins encore nécessaires auprès des médecins de famille pour favoriser le référencement des patients qui le désirent, vers la recherche clinique.

139 - Cultural adaptation of a Patient Decision-Aid for Insulin Therapy

tan.ngiap.chuan@singhealth.com.^{1,2}, agnes.koong@singhealth.com.sg^{1,2}, leeyk@um.edu.my³, j.furler@umimelb.edu.au⁴, josip.car@ntu.edu.sg⁵, sinead.wang.zhen@singhealth.co^{1,2}, ian.phoon.k.y@singhealth.com.s^{1,2}, paulpandi.muthulakshmi@singhea¹, ngcj@um.edu.my³

¹SingHealth Polyclinics, Singapore., ²SingHealth Duke NUS Family Medicine Academic Clinical Programme, Singapore, ³University Malaya, Malaysia, ⁴University Melbourne, Australia, ⁵Lee Kong Chian School of Medicine, Singapore

Introduction

Patient decision-aids (PDA) support shared decision-making (SDM) between healthcare providers and patients in selecting treatment options via provision of relevant evidence-based information and contextualizing the decision to the latter's values and preferences. Cultural adaptation, a process of adjusting health messages to the target audience, is relevant in adopting PDAs for a different cultural population, so that the information is accurate, relevant and understandable to the target audience. A PDA has been developed to assist Malaysian patients with poorly controlled type 2 diabetes mellitus (T2DM) in SDM with their providers to initiate insulin therapy. Likewise, patients with T2DM in neighboring Singapore are generally reluctant to commence insulin therapy. We postulate that they will benefit from a culturally-adapted PDA to decide on their therapeutic options.

Aim:

The study aimed to explore the views and perceptions of Singaporean primary care providers on a Malaysian PDA and to report the cultural adaptation process used in the design and development of a new PDA to be used in a Singapore primary healthcare institution (SingHealth Polyclinics SHP).

Method

Qualitative research method is deployed to interview healthcare providers from SHP, including primary care physicians and nurses to gather their views and feedbacks on the PDA. The qualitative data was coded under "content" and "design". Together with additional input from the investigators, these feedbacks were deliberated before incorporating into the new PDA. The key cultural adaptation steps included content review, update information and modifications to the PDA content and design.

Results

The investigators conducted in-depth interviews on six physicians and four nurses. The qualitative data were analyzed to identify themes relating to the content, layout, concerns and suggestions, which are incorporated into the new SHP PDA. The latter has different color scheme, design; includes additional treatment option, pictograms, conversion of treatment cost to local currency, and changes to treatment goals based on local clinical practice guidelines.

Conclusion

A PDA on insulin therapy underwent cultural adaptation from its original version before its planned implementation in another population with different multi-ethnic Asian composition and public primary healthcare system. Its relevance and effectiveness will be evaluated in future research.

140 - Evaluation of a patient decision aid with decision coaching for dialysis choice: a post-test study

Jeanette Finderup^{1,2}, Kirsten Lomborg², Jens Kristian Dam Jensen^{1,2}, Dawn Stacey^{3,4}

¹Department of Renal Medicine, Aarhus University Hospital, Aarhus, Denmark, ²Department of Clinical Medicine, Aarhus University, Aarhus, Denmark, ³School of Nursing, University of Ottawa, Canada,

⁴Clinical Epidemiology Program, Ottawa Hospital Research Institute, Ottawa, Canada

Background

Patients with kidney failure experience a complex decision facing the choice of dialysis modality performed either at home or in hospital. A decision, which influences both their physical, psychologic and social life. The purpose of this study was to evaluate an intervention to achieve shared decision-making for dialysis choice (SDM-DC). Specific objectives were to: 1) determine if patients experienced a shared decision-making process; and 2) measure patients' knowledge, readiness for decision-making, and decision quality.

Method

A post-test and mixed methods study design was conducted using both questionnaires and interviews. Eligible participants were patients with kidney failure facing the choice of dialysis modality. The intervention, based on the Three-Talk Model, consists of a patient decision aid and decision coaching sessions provided by the dialysis coordinator. Post-intervention, participants completed the Shared Decision Making questionnaire (SDM Q9) and the Decision Quality Measurement (DQM). Concordance between knowledge, decision and preferences was calculated to measure decision quality.

Results

A total of 349 patients participated in the intervention. Of these 148 patients (42%) completed the questionnaires. Participants mean age was 68 (sd 12), mean eGFR was 12 (sd 4), and 64 % were male. Two-fifth had participated in a kidney school and 69 % had two sessions with the dialysis coordinator. The SDM Q9 mean score was 86 out of 100 (sd 12) indicating evidence of SDM. The DQM indicated a total knowledge score of 82 %, a total readiness score of 86 %, and 83% achieved a high quality decision. There was no statistic difference between participants choosing home-based treatment or hospital-based treatment for the SDM Q9 (87 versus 83; $p \sim 0.627$), the readiness score (87 % versus 84 %; $p \sim 0.908$) and the high quality decision score (83 % versus 83 %; $p \sim 0.935$), but a statistic difference for the knowledge score (84 % versus 75 %; $p \sim 0.006$).

Conclusions

Over 80% of participants exposed to SDM-DC experienced a SDM process and reached a high quality decision. Both participants who chose home- and hospital-based treatment experienced the intervention as SDM and made a high quality choice.

142 - Lessons learned from first Iranian shared decision making workshop

Samira Abbasgholizadeh Rahimi¹, Jordie Croteau², Alireza Sadeghpour^{3,4}, Amir Mohammad Navali^{3,4}, Mahasti Alizadeh³, France Légaré^{5,6}

¹Family Medicine Department, McGill University, ²The Institut national d'excellence en santé et en services sociaux (INESSS), ³Tabriz University of Medical Sciences, Tabriz, Iran, ⁴Orthopedic Surgery Department, Shohada University Hospital, Tabriz, Iran, ⁵Department of Family Medicine and Emergency Medicine, Faculty of Medicine, Université Laval, , ⁶Canada Research Chair in Shared Decision Making and Knowledge Translation

Background: Most of the shared decision making (SDM) education, research and implementation are restricted to a few high-income countries. We assessed the feasibility of an SDM training workshop in Iran—a low and middle-income country new to the SDM concept—with the goal of developing strategies to foster SDM implementation.

Methods: We invited all physicians affiliated with Tabriz University of Medical Sciences, Iran, to attend the training workshop. The workshop focused on the examples of SDM for decisions about prenatal screening and knee replacement surgery. Training activities included provision of a patient decision aid, videos on implementing SDM with and without a decision aid, and the International Patient Decision Aids Standards checklist. Participants completed pre- and post-workshop questionnaires and supplied sociodemographic data. Before the workshop, participants were asked about their familiarity with SDM. During and afterward, using a questionnaire based on the Theory of Planned Behavior, we asked about their level of intention to implement SDM and factors influencing their intention. We also asked about their perceived facilitators/barriers to implementing SDM. We analyzed the collected data using descriptive statistics.

Results: The workshop was given in December 2016. Of the 60 physicians invited, 41 participated (68%). Twenty-three were female (57%), 18 were specialized in family and emergency medicine or community and preventive medicine (43%), nine were surgeons (22%), and 14 (35%) were other specialists. Mean age was 37.51 ± 8.64 years old and mean work experience was 8.09 ± 7.8 years. Pre-workshop, participants ranked familiarity with SDM as 3.1 out of 9. Post-workshop, their level of intention to integrate SDM into their practice was 5.51 ± 1.35 out of 7. Their belief that practicing SDM would be beneficial and useful ($\beta = .67$, 95% CI .27-1.06) had the strongest influence on their intention, and their beliefs about capability ($\beta = .32$, 95% CI -0.08-.72) had the second strongest effect. Training and high patient load were respectively perceived as the main facilitator and barrier to implementation.

Conclusions: Overall, the training workshop was found to be feasible. It seems to motivate Iranian physicians to implement SDM in their clinical practice. Future studies need to explore strategies to remind them of the benefits of practicing SDM, maximize facilitators, and overcome barriers.

143 - Awareness From the Experience of Treatment Withdrawal: Perspectives From Taiwanese Women With Breast Cancer

Mei-Feng Lin¹

¹National Cheng Kung University, Tainan, Taiwan.

Background

The idea that patients should have a self-governing role in treatment decision-making is generally appreciated. However, the practice of seeking patient autonomy within the Chinese medical cultural context has not been explored yet.

Objective: To explore the experiences, reasons, and personal values of those Taiwanese women who withdrew from breast cancer therapy.

Methods: A descriptive, qualitative study design with criterion sampling was used. Women with breast cancer who had withdrawn from scheduled cancer treatment during a 3-year period were recruited. In-depth interviews were analyzed using content analysis.

Results: Seventeen women aged 36–65 participated. Analysis of their perspectives related to withdrawing from cancer treatment revealed two types of motivators. Three significant standpoints underlay the women's reactions to life events: the priority of health, a sense of body autonomy, and a lifestyle transformed. In addition, four themes of contextual awareness associated with their treatment withdrawal were revealed: maintaining the family system, preventing repeated psychological and physical trauma, building defenses to balance harm to the body, and returning to a normal trajectory.

Conclusions: The women's standpoints reflected precedence given to family caretaking over their own cancer treatment. Treatment was withdrawn from due to a desire to diminish adverse effects, physical harm, and vitality decline from a body-mind perspective.

Implications for Practice: Nurses should pay more attention to the reasons and personal values of patients who withdraw from treatment. These findings may help to increase empathetic understanding and acceptance of their standpoints or awareness that led to their cancer treatment withdrawal.

149 - Engaging Parents in the Development of a Hypospadias Decision Aid Prototype

Katherine H Chan¹, Janet Panoch¹, Amr Salama¹, Elhaam Bandali¹, Brandon Cockrum², Courtney Moore², Sarah Wiehe²

¹Indiana University School of Medicine, Department of Urology, Division of Pediatric Urology, ²Indiana University School of Medicine, Department of Pediatrics, Section of Children's Health Services Research

Introduction and Objective: Many parents who choose hypospadias repair for their son experience decisional conflict and regret. The purpose of this study was to engage researchers and parents of boys with hypospadias in the co-design of a decision aid (DA) prototype to help parents make decisions about hypospadias surgery.

Methods: We conducted a co-design workshop with researchers and parents of children with hypospadias, engaging them in a guided discussion of: a) their preferences and priorities regarding decision-making about hypospadias surgery, and b) their recommendations for a DA prototype. They ranked their preferences regarding information sources and decision aid content and their priorities regarding perioperative concerns, surgery goals and the decision-making process. They created DA prototypes in small groups focusing on format, function and content. All activities were audio recorded and professionally transcribed. The transcripts and worksheets were analyzed by six coders using a collaborative coding process, commonly used in human-centered design research, to identify themes and relationships between themes to inform the development of an affinity diagram.

Results: We conducted a co-design workshop and guided discussion in August 2018 with 10 parents (6 mothers, 4 fathers; 8 Caucasian, 2 African-American), ages 28-40, of hypospadias patients. Participants suggested that the DA might be used at home, work, daycare and the doctor's office. The DA tools created by the participants were user-friendly, interactive and available 24/7 (such as a website or smartphone application) and designed for a variety of learning styles. Key functions of the DA included educational content, connecting parents in an online forum and engaging parents in a decision-making activity. Parents also included customizable content about the incidence and spectrum of severity of hypospadias, a review of postoperative care and expert testimonials from parents.

Conclusions: Parents of hypospadias patients desire a DA that is user-friendly, multi-purpose, customizable to their needs and available 24/7. Future directions include focus groups with providers and parents for further refinement of the DA prior to pilot-testing.

152 - Eliciting what matters most to people: The Whiteboard Initiative proof of concept

Kathy kastner¹

¹University of Toronto

Background and aim:

Patient-centered care and shared decision-making are considered gold standard approaches to ensure goals of care are met across life's continuum. We know little of what are the best strategies for eliciting what matters most to people. Thus I aim to explore an innovative low technology strategy for eliciting what matters most to people. This proof of concept initiative was conceptualized, designed, and led by a patient expert in the field of end of life experience, Kathy Kastner. She is active on social media (@kathykastner) and had determined that the strategy to be explored should meet the following criteria: low-technology, interactive, portable, scalable, translatable on social media, and potentially effective in supporting a cognitive behavior change in end of life planning. A convenient sample of delegates attending diverse health care conferences were invited to participate. They were presented with a whiteboard and an erasable marker and asked to 'fill in the blank'. "I want to ____ until I die." They were photographed with their whiteboard using an iPhone and asked if they accepted that their picture be posted in the twitter account of Kathy Kastner. Data collected using the pictures were transcribed in a simple excel spreadsheet. Thematic analyses were performed by Kathy Kastner. Simple descriptive analysis was used to report on characteristics of conferences and participants.

Results

Between September 2017 date and October 2018 date, 6 conferences were attended by Kathy Kastner. Overall out of 100 approached, 99 agreed to participate. In general, a mean of 10 participants per conference were recruited, from (60% female, age 28 – 68; 40% men age 34 - 72) from US, Canada, Mexico, UK, Netherlands, Australia. All agreed to have their picture taken and tweeted. Each smiled without being directed to smile. Participants encouraged others to participate. Overall, the three most common themes written by participants were: feeling purposeful, attending to senses, and being connected.

Conclusion

A tool that is low-tech, portable, interactive, easy-to implement and scale up can help identify what matters most to individuals and possibly reframe end-of-life conversations. Future work could assess if the whiteboard is acceptable by health professionals.

153 - Shared decision-making in cystic fibrosis–related diabetes: development of a decision aid

Owolabi Gaudens ACAKPO¹, Isabelle DURIEU², Nora MOUMJID³

¹Laval University, Quebec, Canada, ²Lyon 1 University, Lyon, France., ³Lyon 1 University, Lyon, France.

Introduction: Diabetes is a common complication in people with cystic fibrosis. Its prevalence is 50% after the age of 30. Treatment of cystic fibrosis usually includes starting insulin whether the patient presents symptoms or not, although some health professionals prefer to wait for the patient to develop symptoms. The decision to start insulin at diagnosis or later needs to involve patients and thus to develop a shared decision-making approach. Currently there are no tools to involve patients in decision-making in this context. We designed a patient decision aid and tested its acceptability, feasibility and psychometric qualities.

Method

We followed the International Patient Decision Aid Standards (IPDAS) to develop the tool. To test its acceptability and the feasibility, we invited from March to June 2018, diabetic patients with cystic fibrosis being cared for at the CRCM (cystic fibrosis centre) from Lyon University hospital (France). We conducted individual semi-structured interviews using notably CollaboRate questionnaire (Elwyn et al. 2013) and the acceptability questionnaire (O'Connor & Cranney 1996)

To test the psychometric properties of the tool, we recruited volunteers in our professional networks using the snowball effect. We used Gulliksen's methods for comprehension, Fleiss' kappa coefficient for validity and test-retest method for reliability.

Results:

Sixteen patients and three doctors evaluated the acceptability and the feasibility of the tool. All patients found that the tool presented the information comprehensibly and impartially and that it improved their knowledge. Eleven volunteers tested its psychometric properties. The majority (7/11) judged it as understandable. Validity scores were significant. The tool was found to be reliable over time (test score 7/10, retest 8/10).

Conclusion: The decision aid was found acceptable, feasible and sensitive ie. understandable, valid and reliable. It is now available for engaging cystic fibrosis patients in the decision process about whether to start insulin treatment sooner or later. Training of health professionals will be necessary for implementation of the tool in the different CRCM.

Key words: *cystic fibrosis, decision aid, shared decision-making*

154 - What patients want to ask their doctors: Data analysis from Question Builder, an online question prompt list tool

Marguerite C Tracy¹, Lyndal Trevena¹, Heather L Shepherd¹, Rowena Ivers¹

¹The University of Sydney, New South Wales, Australia

Background

There is increasing interest in shared decision making (SDM) in Australia. A key strategy of SDM is encouraging patients to ask questions. Question Builder is an internet-based, patient-generated question prompt list (QPL) tool. It has been adapted by Healthdirect for Australia, from the original tool developed by the US Agency for Healthcare Research and Quality.

Aims

(1) Describe the types of questions available within Question Builder. (2) Review use of Question Builder in Australia to establish the types of consultations that patients create a question list for, and the types of questions they select to ask and prioritise for those consultations.

Method

Question Builder's questions were categorised using the modified Roter Interaction Analysis System (RIAS), and, where the questions were related to SDM, the Assessing Communication about Evidence and Patient Preferences (ACEPP) tool was applied.

Just over 12 months of usage data from the online tool Question Builder at www.healthdirect.org.au/question-builder were collected using Google Analytics. Consultation type and questions selected were analysed. Subset data were analysed to establish which questions were more likely to be prioritised by users.

Results

Many questions in Question Builder related to information about treatment and medical conditions, RIAS categories 1 and 2. 16% of the 109 questions were relevant to SDM and were coded using ACEPP.

During the study period Question Builder was accessed 8,915 times with 1,271 lists completed by users. Of the 4,000 lists commenced most were for GP consultations (2444) with specialist consultations being less used (1556).

The proportion of questions chosen from each topic varied. Questions about treatments and costs were chosen more frequently than questions clarifying medical conditions.

35% of the top 20 questions prioritised related to SDM.

Conclusions

This real world QPL usage data show that there is interest in and usage of an online QPL tool.

There is strong demand for QPLs for general practice and specialist consultations.

SDM questions were more likely to be prioritised by users, reflecting patient interest in being involved in decisions about their health. Further research on barriers to completing online QPLs and their acceptability by health professionals is required.

157 - Shared decision making near the end of life: review of gaps and practical challenges of developing an electronic decision aid prototype

Magnolia Cardona^{1,2}, Ebony T Lewis³, Hatem Alkhouri⁴, Nigel Lovell⁵, Gustavo Benfatti-Olivato⁶, Joshua Head⁵, Eyza Koreshe⁷, Isabella Marechal-Ross⁷, Stephen Asha⁸, Robin M Turner⁹

¹Centre for Research in Evidence Based Practice, Bond University, QLD, Australia, ²Gold Coast University Hospital, Southport, QLD, Australia, ³School of Public Health and Community Medicine, University of New South Wales, NSW, Australia, ⁴Emergency Care Institute, Agency for Clinical Innovation, Chatswood, NSW, Australia, ⁵Graduate School of Biomedical Engineering, University of New South Wales, NSW, Australia, ⁶UNSW Medicine, Sydney, NSW, Australia, ⁷School of Public Health, The University of Sydney, NSW, Australia, ⁸Department of Emergency Medicine, St George Hospital, Kogarah, NSW, Australia, ⁹Biostatistics Unit, Dunedin School of Medicine, Otago University, Otago, New Zealand

Background

The preparedness of older patients and their families for poor prognostic news and care planning for near end of life (EOL) depends on personal, clinical and social factors. We investigated decision aids (DAs) for EOL management available in the literature and aimed to address the gaps found in the review to optimize advance care planning in routine practice.

Methods

Systematic review of the English language literature 1995-2015 on 7 databases (PubMed, Medline, EMBASE, EBM Reviews, CINAHL and PsycInfo) to identify available decision aids for end of life and their effectiveness. Subsequent development of a computerized DA prototype for use in hospitals and nursing homes, filling the research gaps to facilitate value-based, informed decision-making. This was executed through an externally-funded researcher-clinician-engineer collaborative, with ongoing involvement of target users and intermittent consumer consultation.

Results

Seventeen DAs for older patients surrogates and/or clinicians met the eligibility criteria for review, with over half designed for self-administration. Most covered understanding of treatment harms/benefits, and treatment preferences not based on quantitative prognosis. Numeric prognostic estimates and patient value statements were generally lacking. Part-funding for a clinician-administered DA prototype development was obtained for three selected terminal conditions. Further literature searches was conducted prior to DA development. The operationalization of the specifications for an 'ideal DA' proposed by clinicians and researchers, met with the realities of what software engineers could achieve in a limited time with insufficient resources. Consumer and clinician feedback during early user testing was valuable in highlighting the time-consuming nature of the newly developed patient values module which reduced its usability in clinical practice, particularly in emergency departments.

Conclusions

Improving the quality of EOL shared decision-making using DAs requires consideration of content relevance and sensitivity. This needs to be balanced with brevity to enable full coverage of the main aspects at first encounter. Optimal shared decision-making still requires several opportunities to consider the suite of choices that need to be made over time, and flexibility for patient/families change of treatment decision. An extended development phase is underway and will attempt to correct the identified drawbacks and encourage uptake by clinicians.

161 - Improving Clinical Trials through Patient-Oriented Research

Monica Parry^{1,4}, Ann Kristin Bjørnnes², Karine Toupin April³, Adhiyat Najam⁴, David Wells⁴, Aditi Sivakumar³, Dawn P. Richards⁵, Tina Ceroni⁵, Marianne Park⁶, Anne K. Ellis⁷, Ian Gilron⁷, Susan Marlin⁵

¹University of Toronto, Ontario, Canada, ²Oslo Metropolitan University, Oslo, Norway, ³University of Ottawa, Ontario, Canada, ⁴Diabetes Action Canada, Canada, ⁵Clinical Trials Ontario, Ontario, Canada, ⁶Network of Women with Disabilities, Canada, ⁷Queen's University, Ontario, Canada

Background. Patient-oriented research (POR) is research designed to engage patients as partners with a focus on patient-identified priorities and outcomes. A 2017 systematic review suggested patient involvement in clinical trials has been limited, with little active engagement in trial design or data analysis/interpretation/dissemination. The overall goal of this project is to build capacity for patient engagement and POR in clinical trials. Specific objectives are to: 1) create capacity and identify opportunities for patient engagement in clinical trials, and 2) enhance new/early investigator skills related to POR.

Methods. We used the Canadian Institutes of Health Research Strategy for Patient-Oriented Research (SPOR) Capacity Development Framework and the SPOR Patient Engagement Framework to guide our project. Specific activities included conducting a scoping review of the literature to identify opportunities for patient engagement/POR in clinical trials, hosting a 1-day consultation workshop, developing tools to build capacity for patient engagement/POR in clinical trial design/conduct, and hosting a 1-day new/early investigator POR training day in conjunction with the 2019 Clinical Trials Ontario (CTO) Conference.

Results. Six electronic databases (CINAHL, MEDLINE, EMBASE, PsychInfo, the Cochrane Library, AMED) were searched from 1996 using keywords and MeSH headings in accordance with the International Association for Public Participation (IAP2) and the search criteria in the bibliographic databases. A total of 79 studies were included in a qualitative synthesis. Standard approaches were also used to search the grey literature. Results were presented at the consultation workshop with 32 attendees; including researchers, patient partners, clinicians, trainees, representative from health charities and patient organizations, research administrators and industry. Based on the plethora of existing POR resources it was unanimously decided by workshop attendees that next steps would include collating relevant POR information into two newly developed decision tools; one aimed at patients and one aimed at researchers. The tools are intended to help each audience weigh their own potential benefits and risks of engaging patients as partners in a clinical trial research team.

Conclusion. Evidence-based decision tools can assist patients to become engaged in clinical trial research. These decision tools will be structured and available (without restriction) on CTO's website.

172 - Shared decision making as a core component of health literacy training for new parents: Development and feasibility testing of the Parenting Plus program

Danielle M Muscat^{1,2}, Julie Ayre¹, Don Nutbeam³, Anne Harris⁴, Lynette Tunchon⁵, Dipti Zachariah⁶, Kirsten McCaffery^{1,2,7}

¹The University of Sydney, Faculty of Medicine and Health, School of Public Health, Sydney Health Literacy Lab, NSW, Australia., ²The University of Sydney, Faculty of Science, School of Psychology, Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), NSW, Australia, ³The University of Sydney, Faculty of Medicine and Health, School of Public Health, NSW, Australia, ⁴Child and Family, HealthOne Hills, Western Sydney Local Health District, NSW, Australia, ⁵Child and Family Health, Integrated and Community Health, Western Sydney Local Health District, NSW, Australia, ⁶Multicultural Health, Integrated and Community Health, Western Sydney Local Health District, NSW, Australia, ⁷The University of Sydney, Faculty of Medicine and Health, School of Public Health, Wiser Healthcare, NSW, Australia.

Introduction: Health literacy is understood as a modifiable health asset that changes as individuals build health knowledge, develop health-related skills and practices, and make informed decisions. Our previous work has shown that tailored training in health literacy can improve skills to communicate with healthcare professionals, extract information, and integrate new knowledge with personal preferences (i.e. shared decision-making) among a diverse range of adults.

Methods: We developed a combined health literacy and shared decision-making training program for new parents ('Parenting Plus'). This included, for example, communicative health literacy skills for question-asking and critical health literacy skills to integrate knowledge with preferences to make an informed decision. The program was embedded within existing parenting groups (4x2-hour sessions) for parents whose child was between 4-26 weeks. We conducted a multi-centre pre-test post-test feasibility study with mixed-methods evaluation; quantitative data were analysed descriptively and qualitative data (focus groups; observations; interviews) were analysed using Framework analysis.

Results: Our program was delivered at six sites in New South Wales, Australia in 2018. We were successful in reaching diverse learners (n=73). High baseline knowledge, skills and confidence limited the potential for change in these outcomes, but shed light on the utility of different measurement instruments. Qualitative analyses indicated that the program, particularly the shared decision-making content, aligned well with the professional objectives of child and family health services, and could positively impact parents' functional health skills and knowledge, and support better communication with healthcare providers.

Conclusions: Our study offers practical insights into the feasibility of embedding a combined health literacy and shared decision-making intervention into established parenting groups with diverse populations. Results have informed a restructure of the program to embed communicative and critical shared decision-making skills within all topics using Sufficient Exemplar Training. Having established feasibility, we are now planning a more structured trial of efficacy.

174 - Fidelity of Use of a Low-Literacy, Multilingual Decision Aid for Rheumatoid Arthritis (RA Choice)

Jennifer L. Barton^{1,4}, Diego Molina Ochoa¹, Laura Trupin², Allison Schue⁴, Edward H. Yelin², Victor M. Montori³

¹Oregon Health & Science University, ²University of California, San Francisco, ³Mayo Clinic, ⁴VA Portland Health Care System

Background: A multilingual, low literacy decision aid for RA (RA Choice) with an adapted medication summary guide improved knowledge and lowered decisional conflict compared with an existing guide. The extent to which RA Choice was used by clinicians is unknown. We aimed to quantify the extent to which clinicians used RA Choice and how fidelity of use correlated with patient outcomes.

Methods: RA patients were consecutively enrolled into 1 of 3 arms: 1) control – patients received existing medication guide prior to clinic; 2) adapted guide before visit; 3) adapted guide before and decision aid during visit. Eligible adults had failed ≥ 1 RA medication and fulfilled one of the following: >65 years, immigrant, non-English speaker, $<$ high school education, limited health literacy, and racial/ethnic minority. Arm 3 visits were audio/videotaped if both patient and clinician consented. Fidelity scoring of taped encounters used an established fidelity checklist designed for similar point-of-care decision aids, scored as the proportion of items present. The acceptable fidelity threshold was set at $\geq 66\%$ based on prior studies. Outcomes collected immediately post-visit included a brief RA knowledge test and the low literacy decisional conflict scale (DCS).

Results: Arm 3 enrolled 60 RA patients, of whom 28 reported a medication change and decision aid use. Of these, 20 visits were audio/videotaped. Patient subjects were 100% female, mean age of 52 ± 12 years, 50% Spanish-, 32% English- and 18% Cantonese/Mandarin-speaking. An interpreter was present for 25% of encounters. The mean fidelity score was 77% (95% CI 69, 85) and 16 encounters (80%) scored $\geq 66\%$. Of patients with an acceptable fidelity score, 94% had adequate knowledge and a mean 13.3 (SD 15) DCS compared with those with lower fidelity, 75% and 5 (SD 10) respectively.

Conclusion: Rheumatology clinicians had high fidelity scores for RA Choice, including use in the presence of interpreters. Broader implementation of the tool is needed to fully assess uptake and efficacy in vulnerable populations. Addressing challenges of effective implementation of SDM tools, including clinician awareness and system change that allows time for meaningful conversations, is necessary to improve patient outcomes.

180 - Evaluating a Web-based module supporting older adults in deciding how to stay independent at home: a qualitative study with end-users

Mirjam M. Garvelink¹, Adriana Freitas¹, Titilayo T. Agbadjé¹, Lysa Bergeron¹, Patrick Archambault^{1,3,4,5}, Louisa Blair¹, Michèle Dugas¹, Noémie Roy^{1,6}, Allyson Jones², Thomas Petitjean⁸, France Légaré^{1,4,7}

¹Centre de recherche sur les soins et les services de première ligne de l'Université Laval, Centre intégré universitaire de santé et services sociaux de la Capitale-Nationale, Québec City, QC, Canada,

²Department of Physical Therapy, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, AB, Canada, ³Centre intégré de santé et de services sociaux de Chaudière-Appalaches, Centre

hospitalier affilié universitaire Hôtel-Dieu de Lévis, Lévis, QC, Canada, ⁴Population Health and Optimal Health Practice Research Unit, Centre hospitalier universitaire de Québec, Université Laval, Québec

City, QC, Canada, ⁵Division of Critical Care Medicine, Department of Anesthesiology and Critical Care Medicine, Université Laval, Québec City, QC, Canada, ⁶School of Architecture, Faculty of Planning,

Architecture, Arts and Design, Université Laval, Québec City, QC, Canada, ⁷Department of Family Medicine and Emergency Medicine, Faculty of Medicine, Université Laval, Québec City, QC, Canada,

⁸Centre for Digital Media, Simon Fraser University, Vancouver, BC, Canada

Background & aim: Most older adults desire to stay independent at home for as long as possible. In Canada, many resources are available to help older adults stay at home once they begin to lose autonomy. Yet often, the decision to move to a nursing home is made without older adults and caregivers being fully aware of the alternatives. We consulted end-users about an existing Web-based module that presents information on these alternatives, aiming to improve its usefulness for keeping older adults at home.

Methods: Through team members' informal networks, we invited older adults (65+) and informal caregivers of older adults that have either recently moved into a nursing home or who are currently struggling to stay independent at home to participate in individual interviews. Before the interviews, respondents were asked to explore the whole module, which consisted of information videos and resource lists on local options for staying independent at home. The interview guide asked about ease of navigation, understandability and usefulness of the information, and video quality. Interviews were audio-recorded, transcribed verbatim, and thematically analyzed by two researchers.

Results: Five older adults and 10 caregivers (n=15) agreed to participate. Overall, participants found the module easy to navigate, and a useful source of information for decision-making about staying independent at home. The most highly-rated aspects of the module were its interactivity; its clear and concise information; and the quantity and quality of videos. Improvements mentioned were a) to rename the website, b) to include information and resources relevant for other provinces or countries, c) to add content for caregivers, e.g. how to get help for themselves, and d) add content on preparing older adults/caregivers to discuss options with health providers.

Conclusions: The module was deemed helpful for the decision-making process, but should enable users to find specific information matched to their profile/needs and local contexts. Results were used to organize an interactive workshop with various end-users to redesign the module.

Keywords : older adults, caregivers, decision making process, staying independent at home

181 - How prognostic are patient treatment preferences and personal values assessed in an online decision for treatment in patients with gallstones?

C.S.S. Latenstein¹, F.M. Thunnissen², B.J. van Wely³, M. Klerkx³, G. Elwyn⁴, M.J. Meinders¹, P.R. de Reuver¹

¹Radboud University Medical Center, Nijmegen, the Netherlands, ²Amsterdam UMC, Location AMC, Amsterdam, the Netherlands, ³Bernhoven, Uden, the Netherlands, ⁴The Dartmouth Institute for Health Policy and Clinical Practice, New Hampshire, USA

Background

Shared decision making, facilitated by decision aids, is indicated for gallbladder removal as watchful waiting is an accepted alternative in selected patients. The aim of this study was to assess the prognostic value of patients' treatment preferences and personal values in an online decision aid for the performed treatment.

Methods

A single centre retrospective study was performed. All patients >18 years with symptomatic gallstones who filled out the decision aid between December 2015 and August 2018, were included. The decision aid was provided after the first consultation with the surgeon, but before the decision consultation. In this decision aid a value clarification exercise is carried out, asking the patient to consider which benefits and risks (considerations: *infrequent/frequent pain attacks, few/many complaints, (not)concerned about surgery*) matter most to them. Secondly, the patient is asked to point out their preferred treatment classified as watchful waiting, no preference or surgery. We performed regression analysis to associate the preferred treatment and personal values of patients with surgical treatment.

Results

In total, 567 patients (median age 52, 30.0% male) were included. The preferred treatment was surgery in 367 patients (64.7%), 79 patients (13.9%) had no preference, and 121 patients (21.3%) preferred watchful waiting. In total, 395 patients (69.7%) underwent surgery, and 172 patients (30.3%) were treated conservatively. The treatment preference of patients corresponded in 88.6% of patients (n=325) and 77.7% of patients (n=94) with performed treatment for respectively surgery and watchful waiting. In univariate analyses frequent pain attacks, many complaints, lower age and preferring surgery were significantly associated with a surgical treatment. In multivariate analysis frequent pain attacks (OR 2.094 95%CI: 1.123-3.904) and preferring surgery (OR 4.366 95%CI: 1.892-10.073) are independently prognostic factors for a surgical treatment.

Conclusion

Gallstone patients' treatment preference assessed in a decision aid corresponds in approximately 80% with performed treatment. Patients' treatment preference is the most important prognostic factor for surgical treatment compared to age, frequency of pain, number of complaints or concerns about surgery.

185 - Patient-Clinician Goal Concordance in Rheumatoid Arthritis: Is it associated with outcomes?

Jennifer L. Barton^{1,2}, Sheila Markwardt¹, Diego Molina Ochoa¹, Allison Schue², Somnath Saha^{1,2}, Edward H. Yelin³

¹Oregon Health & Science University, ²VA Portland Health Care System, ³University of California, San Francisco

Background: Goal concordance between patients with chronic diseases and their clinicians has been linked to improved outcomes. Our objective was to assess the extent to which rheumatoid arthritis (RA) patients' goals for treatment are concordant with their rheumatology clinicians', and whether goal concordance was associated with outcomes of medication adherence or disease activity.

Methods: Patients with RA seen \geq once in the prior 12 months at one of two rheumatology clinics were enrolled in a cross-sectional survey study. Both enrolled RA patients and their rheumatology clinicians completed the RA goals measure (patients and clinicians independently ranked their top 3 goals for the patient's RA treatment out of 8 possibilities) before the clinic visit. Patients then completed a survey on demographics, health literacy, overall health, medication adherence, and a self-report measure of disease activity, the RAPID-3. The primary predictor was goal concordance (yes/no), defined as the patient's #1 goal being listed among any of the top 3 listed by the clinician. An ordered logistic regression was performed to assess the association of goal concordance with medication adherence and disease activity.

Findings: Data from 197 patient-clinician dyads were analyzed; 15 clinicians were included. Patient subjects were 58% female, 16% Spanish-speaking, and 29% with limited health literacy. "Have less pain" was the #1 ranked patient goal for 64% patients, and "have fewer problems doing daily activities" was ranked #1 by 16%; 80% of dyads displayed goal concordance. In the mixed logistic regression model predicting adherence, only education level ("some college" or more) was associated with better medication adherence ($p < 0.001$). In the model predicting disease activity, depressive symptoms and disease duration were significantly associated with higher disease activity. Goal concordance was not significantly associated with either outcome in multivariate analysis.

Discussion: Among 197 RA patient-clinician dyads, the majority were concordant on the patient's #1 goal, which was overwhelmingly to have less pain. Goal concordance was not associated with medication adherence or disease activity. Future research to examine goal concordance beyond the shared goal of reduced pain may uncover areas of discordance and the need for improved communication and goal elicitation.

186 - Development of a decision aid to support ovarian cancer patient decide on CA125 biomarker monitoring

Anette Kargo^{1,2,3}, Angela Coulter^{2,3,4}, Pernille Tine Jensen^{5,6}, Karina Dahl Steffensen^{1,2,3}

¹Department of Oncology, Vejle Hospital, Vejle, Denmark, ²Institute of Regional Health Research. University of Southern Denmark, Odense, Denmark, ³Center for Shared Decision Making, Vejle, Denmark, ⁴Senior Research Scientist, University of Oxford, Oxford, Great Britain, ⁵Department of Gynaecology and Obstetrics, Odense University Hospital, Odense, Denmark., ⁶Department of Clinical Research. University of Southern Denmark, Odense, Denmark

Introduction

Each year in Denmark 450 women are diagnosed with ovarian cancer (OC). The majorities are diagnosed with advanced disease, and 70-80% will experience relapse with only limited curative potential. Evidence has shown that early initiation of recurrence treatment based alone on rising CA125 alone does not improve survival. Monitoring CA125 is a validated method for detecting relapse, and increasing CA125 can be detected months before symptoms appears and recurrence is visible on imaging. Danish Health Authorities recommend that personal preferences should be taken into account prior to initiating CA125 monitoring through the use of a patient decision aid (ptDA).

Aim:

To develop and validate a ptDA on a preference sensitive decision on CA125 monitoring during follow-up.

Methods

In close collaboration with clinicians, designers, OC patients, and the Danish Cancer Society a draft ptDA was created. The ptDA was discussed with a focus group of 7 former OC patients and the ptDA was modified following their input. Subsequently, the ptDA was alpha tested, using a structured interview guide. The third ptDA development step is beta testing on real time patients including Decision Conflict Scale (DCS) before and after patients have been represented for the ptDA.

Results

Preliminary data from the first 9 patients included in the beta test showed a decline in all DCS subscores and in total DCS score after patients have been presented for the in-consult ptDA. The total DCS score declined from 22.9 before the consultation to 13.0 after the consultation ($p = 0.340$). The uncertainty subscore declined from 18.5 to 5.6 ($p = 0.055$) and the informed subscore declined from 26.9 to 9.3 ($p = 0.103$). Moreover, the clarity and support subscores also decreased; from 28.8 to 17.6 ($p = 0.391$) and from 18.5 to 4.6 ($p = 0.438$) respectively.

Conclusion

None of the DCS scores decreased significantly, probably due to the yet low number of recruited patients. Though, the preliminary data from the beta test showed that the ptDA was helpful and the data indicate that the use of a ptDA leads to a better informed decision and supports the decision making process.

191 - What Makes Difficult Decisions So Difficult?: A View of Physicians Treating Children With Medical Complexity

Francine Buchanan¹, Eyal Cohen^{1,2,3}, Golda Milo-Manson^{1,2,3,4}, Aviv Shachak¹

¹Institute of Health Policy, Management, and Evaluation, University of Toronto, Toronto, Canada,

²Department of Pediatrics, University of Toronto, Toronto, Canada, ³Department of Pediatrics, The Hospital for Sick Children, Toronto, Canada, ⁴Department of Paediatrics, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Canada

Background and aims: Treating Children with medical complexity (CMC) involves making difficult decisions that incorporate people, evidence and tools, within a system of intersecting rules and conventions. Activity Theory (AT) is a cross-disciplinary framework for studying different forms of human practices as developmental processes, with both individual and social levels interlinked at the same time. Application of AT to the study of decision making may provide novel insights into the activity of physicians caring for CMC. The aim of the study was to apply AT to reveal the characteristics of the decision making activity that contribute to the difficulty, highlighting the themes of uncertainty, conflicting beliefs and the numerous goals that intersect to make decision making difficult.

Methods: This study consisted of interviews, based on a Critical Decision Method (CDM) storytelling methodology, with 11 physicians who treat CMC. Taking a framework analysis approach, interview transcripts were analyzed by inductive (open) coding. Codes were compared with a second researcher who coded a subset of 3 of the 11 interviews. The two researchers discussed their analyses, coming to an agreement on the final coding schema. Next, codes were reviewed to identify high-level themes which were incorporated into existing AT categories, while also noting themes that did not fit the AT framework. Analysis reached thematic saturation.

Results: The finding of the study identified three main characteristics of difficult decisions surrounding treatment of CMCs: [1] Difficult decisions are fraught with uncertainty; [2] Conflicting rules, philosophies and beliefs (e.g., consents; shared decision-making) make for incongruity; and [3] Multitude of aims (e.g., form a treatment plan; understand family's needs) increases complexity.

Conclusions: To address these sources of difficulty, the integrated nature of decision making must be acknowledged, noting that potential solutions must consider the elements of the decision making system to be effective. Guidance to support decision-making must not only include supporting medical evidence, but also guidance on managing existing rules, philosophies and beliefs. Finally, understanding the aim of the decision process is key to ensuring that decision-making is shared amongst all involved in the outcome.

195 - Assessing the acceptability and feasibility of a contraceptive choice decision aid material for women from Chinese background in Australia

Hankiz Dolan¹, Deborah Bateson¹, Mu Li¹, Carissa Bonner¹, Michael Tam², Rachel Thompson¹, Lyndal Trevena¹

¹The University of Sydney, NSW, Australia, ²Academic General Practice Unit, Fairfield Hospital, NSW, Australia

Background: Australia is a multicultural country with Chinese being one of the largest, youngest and fastest growing overseas-born groups. There are reports that women from non-English-speaking background and who were not born in Australia are less likely to use modern contraceptive methods than Australian born women due to lack of evidence-based and culturally and linguistically sensitive information. Decision aids are shown to facilitate informed and shared decision-making between patients and healthcare providers. Yet, to date, there is not a Chinese language contraceptive choice decision aid material available in Australia.

Aim: Explore Chinese women and healthcare providers' views on the feasibility, usefulness and appropriateness of a contraceptive choice decision aid material.

Method: We conducted semi-structured in-depth interviews with 22 women from Chinese background and 20 healthcare providers. Chinese women were shown Chinese translated decision aids while healthcare providers were shown the English version. We prompted participants to elaborate on their views and perception on the overall design, information presentation, usefulness and feasibility of the decision aid materials.

Results: This study is ongoing, and results will be updated. Both the Chinese women and healthcare providers perceived the decision aid materials as being informative and comprehensive. Chinese women expressed that having the decision aids in Chinese language help them understand and consider available options. While some healthcare providers are concerned about the length of the decision aids, they stated that overall having the material in Chinese language will help discussing available options with their Chinese patients. While healthcare providers are divided on their preference for the use of verbal descriptors or numerical for presenting probability information, Chinese women mostly preferred numerical presentation, which they perceive as more credible and trustworthy.

Conclusion: Contraceptive choice decision aid materials that are available in both Chinese and English can be useful in helping Chinese women making informed decisions about contraceptive methods.

198 - Whether I need Traditional Chinese Medicine (TCM) as complementary therapies: Decision making in colorectal cancer patients

Wan-ling Chen¹, Shu-huey Chou¹, Ching-yi Feng¹, You-zhen Zhang¹

¹Attending physician of Traditional Chinese Medicine Department of Taichung Veterans General Hospital, Taichung, Taiwan

Colorectal cancer is a major worldwide health problem with an estimated 860 thousands deaths in 2018 according to the World Health Organization. Traditional Chinese Medicine (TCM), one of complementary and alternative medicine (CAM), has been subsidized by the Taiwan's National Health Insurance program since 1996. Patients undergoing cancer therapies during hospital course can receive TCM therapy at the same time for free. Researches had reported that TCM reduce side effects of chemotherapy and increase quality of life. However, these patients don't understand what TCM can do for them. This project aim to provide information about TCM therapy and help colorectal patients decide if they want TCM or not by themselves.

We developed an assessment form which content different kinds of TCM therapies of colorectal cancer patients during surgery, chemotherapy or radiotherapy, including TCM syndromes and corresponding formulas. There are also tables about disease-free survival rate and adverse effects between TCM and non-TCM groups. In addition, these data are made into bilingual videos. After colorectal patients finished watching the video, a four steps questionnaire helped clarify their thoughts and make choices. Finally, patients completed another questionnaire about how this project helped on decision making.

Many positive feedbacks were given from patients participates in this program. They know more about TCM therapy first. Second, they all agree this tool effects on relieving their anxiety and making a rational decision. After all, patients are satisfied with learning more medical knowledge and hope to join similar project in other medical situations.

All patients who confront with a tough therapeutic decision feel helpless and need assistance. This project revealed that patients' unsteady mood eased significantly when they were explained thoroughly about all possible conditions. Patients can reach a decision with doctors once they calm down. This consensus gives patients power and benefits on the following treatment. More shared decision making projects need to development to help various patients in the future.

202 - Promoting shared decision making in colorectal cancer screening in primary care: a cluster randomized trial

Yonas Martin^{1,2}, Julia Schneider¹, Marc-Andrea Janggen¹, Charles Dvorak³, Kali Tal¹, Nikola Biller-Andorna⁴, Jean-Luc Bulliard⁵, Cyril Ducros⁶, Jacques Cornuz⁷, Kevin Selby⁷, Reto Auer^{1,7}

¹Institute of primary health care (BIHAM), University of Bern, Switzerland, ²Department of General Internal Medicine, Inselspital, University of Bern, Switzerland, ³Sentinella Network, Switzerland,

⁴Institute for Biomedical Ethics and History of Medicine, University of Zurich, Switzerland, ⁵Institute of Social and Preventive Medicine, Lausanne, Switzerland, ⁶Foundation for Cancer Screening of the Canton of Vaud (FVDC), Switzerland, ⁷Department of Ambulatory Care and Community Medicine, University of Lausanne, Switzerland

Introduction: Guidelines recommend both colonoscopy and fecal occult blood test (FOBT) for colorectal cancer (CRC) screening, but most primary care physicians (PCPs) in Switzerland exclusively prescribe colonoscopy. When offered both methods, patients choose almost evenly between them, suggesting low FOBT use reflects PCPs' prescription habits, not patient preferences.

Methods: We randomized PCPs in the Sentinella practice-based research network to either a multidimensional intervention promoting shared decision-making (SDM) in CRC screening or to usual care. PCPs in the intervention group received by mail: the study rationale, patient-decision aids to support SDM, a 2-page evidence summary on CRC screening, an immunological FOBT sample kit, and individualized performance feedback based on data they had collected about their CRC screening practices in 2017. PCPs from both groups systematically collected data on 40 consecutive 50-75 y.o. patients, including data on previous CRC testing and patient choices after discussion (screening method, patient refusal). PCPs completed a questionnaire about their intention to prescribe FOBT or colonoscopy. Our primary outcome was the number of PCPs with at least one patient who had had an FOBT at baseline or who planned FOBT after discussion.

Results: Of the 109 PCPs randomized, 79 (64%) collected data. Mean PCP age was 51; 73% were men. PCPs collected data on 3,017 patients (mean age 62; 50% women). The 38 PCPs in the intervention group were more likely to have had at least one patient tested with FOBT at baseline or a patient who planned FOBT after discussion (89%) than PCPs in the control group (61%; $p=0.004$). PCPs in the intervention group were more likely to intend to prescribe FOBT to $\geq 40\%$ of their patients (58%) than PCPs in the control group (28%; $p=0.016$). In the intervention group, 68% of patients (977/1,443) were up-to-date or planned to be tested for CRC; in the control group 65% (1,026/1,574) ($p=0.16$).

Conclusion: A multidimensional mailed intervention promoting SDM in CRC screening increased the number of PCPs prescription and intention to use FOBT, suggesting our intervention increased the likelihood patients would be tested with the method they preferred. ClinicalTrials.gov ID: NCT03552744

204 - MALE INVOLVEMENT IN THE PREVENTION IN THE PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV IN BURKINA FASO

Maman Joyce Dogba¹, Alice Bila², Luc Sermé², Abel Bicaba², Slim H¹

¹Université Laval, ²SERSAP Burkina Faso

Background. Men can play crucial roles at each stage of HIV mother-to-child-transmission (MTCT) prevention. Low male involvement in preventative MTCT in Burkina Faso is partially attributed to increased MTCT rates in the country. Meanwhile, male involvement is barely well understood.

Objective. This explorative qualitative study aims to provide a deeper understanding of male involvement in MTCT prevention in Burkina Faso, in order to collaboratively develop theory and evidence-based interventions with all relevant stakeholders to reduce the transmission.

Methods. We used an intersectional theoretical approach as it positions male involvement at the intersection of social location, systemic forces, individual experiences, and dynamics within couples. We opted for an interpretative qualitative description design. This study was performed at St-Camille's hospital in Ouagadougou, Burkina Faso. Our sample was theoretical with a maximum variation rationale, to contrast for individual experiences and socioeconomic characteristics. Eligible women were identified via chart review and invited to participate with their male partners. We conducted individual semi-structured interviews (12 French; 12 Mooré) with 12 couples using tailored interview grids. We performed a semantic thematic analysis using QDA Miner to identify themes and patterns among subjective perspectives, while accounting for variations between individuals.

Results. First, we found male involvement to be multidimensional: financial, psychological or relational. Second, male reactions at the discovery of their partners HIV-positive status range from rejection to true partnership and can include denial. Third, male involvement varies over time: some male partners initially aggressive became attentive while others initially supportive end up abandoning their partners. These changes often occur at the discovery of the HIV-positive status, during pregnancy or at childbirth. Finally, male involvement was limited by competing priorities, contradictory expectations, organizational opportunities and societal beliefs. Interactions with caregivers impacted male involvement. In fact, men feel unwelcome in the health care services which were not thought nor designed "with" or "for" them. In addition, health care professionals are not trained to jointly care for women and their partners in MTCT prevention services.

Conclusion. Male involvement is a constant negotiation between interconnected individual, organizational and systemic experiences. Increasing male involvement will require implementation of coordinated interventions.

205 - Formation portant sur l'approche centrée sur la personne pour de meilleurs soins maternels et infantiles au Burkina Faso : Partie 1

Thècle Twungubumwe¹, Mylène Tantchou-Dipankui¹, Seydou Barro³, Johanne Ouédraogo¹, Josette Castel¹, Isabelle Savard², Jean Ramdé¹, André.Côté@fsa.ulaval.ca¹, Judith Lapierre¹, Isabelle Auclair¹, Inheldia Cossou-Gbeto¹, Ruth Ndjaboue¹, Maman Joyce Dogba¹

¹Université Laval, ²Teluq, ³Burkina Faso

Introduction. Dans un contexte de santé maternelle et infantile, l'approche de soins centrée sur la personne (ACP) permet de dispenser des soins holistiques aux patientes et à leurs enfants ; en intégrant leurs valeurs et préférences dans les prises de décision thérapeutiques. La deuxième phase du *Programme d'amélioration de la santé des mères et des enfants (PASME)* 2 au Burkina Faso inclut un projet de recherche-action dénommé ACP-PASME 2 qui vise à développer et implanter une formation de type ACP puis à évaluer son impact sur les soins maternels et infantiles.

Objectif : Cette première des trois composantes d'ACP-PASME 2 vise à comprendre le sens donné par les patientes et les professionnels de la santé à l'ACP dans le contexte de soins burkinabè.

Méthodes. Le cadre conceptuel de Barro (2012), validé au Burkina Faso et qui conceptualise l'ACP en cinq dimensions a été utilisé. Nous avons opté pour une recherche qualitative de type ethnographique et effectué des entrevues (n = 35), des observations directes d'interaction soignant-soigné terrain (»275 heures) et des groupes de discussions (n = 2) auprès des patientes et des professionnels de la santé afin de dévoiler le sens donné à l'ACP dans ce contexte de soins. Nous avons effectué une analyse thématique sémantique.

Résultats. Toutes les cinq dimensions ont été évoquées : i) perspective biopsychosociale, ii) partage de pouvoir et de responsabilité entre le professionnel et le patient, iii) professionnel en tant que personne dont les humeurs peuvent interférer avec les soins administrés, et iv) patient en tant que personne, expert, ressource ou partenaire et v) alliance thérapeutique. Mais leur prise en compte dans ce contexte de soins est limitée par la tolérance de la violence envers les patientes, les inégalités systématiques de genre, les faibles niveaux d'éducation des patientes et la sage gestion des accompagnants. De plus, l'absence de formation et de mise à jour des connaissances des professionnels a été identifié comme un obstacle majeur à l'ACP.

Conclusion. Ces particularités de l'ACP au Burkina Faso ont été intégrées dans une formation qui se donne présentement dans les structures de soins.

206 - Formation portant sur l'approche centrée sur la personne pour de meilleurs soins maternels et infantiles au Burkina Faso : Partie 2

Johanne Ouédraogo¹, Seydou Barro², Thècle Twungubuwme¹, Josette Castel¹, Isabelle Savard³, Jean Ramdé¹, Judith L:apierre¹, Isabelle Auclair¹, Marie-Julie Babin¹, Marlyse Mbakop¹, Mory Gbane¹, Inheldia Cossou-Gbeto¹, Ruth Ndjaboue¹, Maman Joyce Dogba¹

¹Université Laval, ²Burkina Faso, ³TELUQ

Introduction. La deuxième phase du *Programme d'amélioration de la santé des mères et des enfants* (PASME-2) visait le développement d'une formation portant sur l'approche centrée sur la personne. Cette présentation décrit le processus de développement et d'implantation de ladite formation nommée formation ACP-PASME 2 et discute des défis dans l'adoption d'une approche participative et interdisciplinaire dans un contexte international. De courtes vidéos didactiques seront présentées.

Méthodes. De juin 2016 à décembre 2018, une équipe interdisciplinaire (sciences de l'éducation, médecine, sciences infirmières, administration de la santé) et internationale a inclus toutes les parties prenantes dans le développement d'ACP-PASME 2. En combinant la méthodologie de la recherche basée sur le design ou « *Design-Based Research* », et le modèle de développement d'un curriculum de Kern, nous avons : i) analysé les besoins et élaboré des objectifs de formation, ii) identifié des stratégies éducatives, iii) déployé la première formation, iv) évalué la formation, v) produit version finale de la formation et vi) déployé la cascade de formation.

Résultats. Il s'agit d'une formation continue, interprofessionnelle, en présentiel, d'une durée de 20 heures et sexo-spécifique puisqu'elle reconnaît les besoins différenciés des hommes et des femmes et les aborde tant dans le contenu que dans l'organisation de la formation.

Plusieurs approches pédagogiques (présentations magistrales, ateliers en petits groupes, discussions en plénières, jeux de rôle, présentations de films d'animation) ont été utilisées dans cette formation decinq thèmes : 1) la dimension biospsychosociale des soins (perspective biopsychosociale, déterminants de la santé et santé durable) ; 2) la patiente en tant que personne (patiente-corps malade versus patiente-personne, accueil et communication, approche genre) ; 3) l'alliance thérapeutique (notion de pouvoir, collaboration et partenariat, prise de décision partagée ; 4) le partage du pouvoir et des responsabilités (transformations sociétales, savoir expérientiel, chartes et codes en vigueur dans le pays) ; 5) le professionnel en tant que personne (interprofessionnalisme, obstacles à l'ACP et pratique réflexive).

Conclusion. Cette formation pourrait être intégrée à la formation initiale des professionnels dans les écoles de formation. De plus, les réflexions se poursuivent pour un accompagnement virtuel des apprenants dans les changements d'habitudes dans leurs pratiques.

207 - The patient role in co-creating shared decision making consultations: a mixed methods study

R G Thomson¹, S Hrisos¹, L Stobbart¹, J Scott², A Vaittinen¹

¹Institute of Health and Society, Newcastle University, Newcastle upon Tyne, United Kingdom,

²Northumbria University, Newcastle upon Tyne, United Kingdom

Background and aims

Most measures and models of shared decision making (SDM) emphasise the clinician role. However, the consultation is a dynamic, co-produced interaction. Little in-depth research has investigated how these interactions occur. We aimed to explore where variation in observed SDM occurred, and the patient role in this variation.

Methods

A mixed-methods study including in-depth analysis of 40 video-recorded consultations with four primary care and six secondary care clinicians. The OPTION-12 observation tool (modified to score both clinician- and patient-initiated behaviours) and coding of verbal and non-verbal behaviours were applied. We compared consultations with more or fewer SDM behaviours and dichotomised consultations as 'higher' or 'lower' quality SDM (i.e. those with a quality score > mean of 33 [n=20 consultations] vs those scoring below this mean [n=20 consultations]), and compared participant characteristics, SDM actions, and interpersonal communication behaviours.

Results

Across the 40 consultations analysed, clinicians exhibited, on average, seven (range 0 – 11) SDM behaviours per consultation; 18/40 consultations displayed eight or more behaviours. Patients were seen to initiate eleven of the twelve OPTION-12 clinician behaviours. Within the 18 consultations, instances of SDM behaviours prompted by patients were proportionately more frequent (70% vs 39% respectively), and proportionally more of these consultations took place in secondary, than in primary care (50% vs 38% respectively). Clinician/patient dyads in the lower quality SDM consultations interacted less directly, and displayed fewer interpersonal cues, than in the higher scoring group. In particular, there were fewer instances of non-verbal communication in both clinicians and patients that indicate attentiveness and listening, e.g. nodding, eye contact, body posture. A difference in patient demographics was also apparent, with patients in the lower scoring group being, on average, older, less educated and more likely to be male.

Conclusions

These findings further emphasise the dynamic role that patients play in shaping SDM within consultations and demonstrate need for further research exploring interactional elements of consultations that may promote or inhibit SDM. Implementation of SDM has largely focused on clinicians and systems, but further debate around the patient role in the implementation effort is required.

208 - Formation portant sur l'approche centrée sur la personne pour de meilleurs soins maternels et infantiles au Burkina Faso : Partie 3

Maman Joyce Dogba¹, Kadjidjatou Bah¹, Seydou Barro², Johanne Ouédraogo¹, Josette Castel¹, Isabelle Savard³, Jean Ramdé¹, Inheldia Cossou-Gbeto¹, Ruth Ndjaboue¹, André Côté¹, Clémentine Vimbamba², Isabelle Auclair¹

¹Université Laval, ²Burkina Faso, ³Teluq

Introduction. La deuxième phase du *Programme d'amélioration de la santé des mères et des enfants* (PASME-2) visait le développement d'une formation portant sur l'approche centrée sur la personne (ACP), pour de meilleurs soins maternels et infantiles. Cette formation se voulait sexospécifique puisqu'elle reconnaît les besoins spécifiques des hommes et des femmes et les aborde dans le contenu et l'organisation de la formation.

Objectifs. Discuter des enjeux de l'intégration de l'approche genre tant dans le contenu que dans le déroulement de la formation.

Méthodes. Recherche-action participative effectuée en équipe interdisciplinaire (sciences de l'éducation, médecine, sciences infirmières, administration de la santé) et internationale, incluant des spécialistes de l'approche genre. Méthodologie de la recherche basée sur le design ou « *Design-Based Research* », et recherche qualitative ethnographique avec immersion dans le milieu. Les activités suivantes ont été réalisées : i) rencontres itératives avec les spécialistes de l'approche genre ; ii) validation de contenu et du langage « genré » lors des discussions avec les collaborateurs terrain, iii) création de personnages adaptés au contexte du Burkina Faso, iv) contextualisation des cas cliniques, v) établissement d'une stratégie de recrutement des participants à la formation.

Résultats. L'utilisation systématique des noms féminins à la place du masculin pluriel a été adoptée puisqu'acceptable dans le contexte Burkinabè (patientes et patients au lieu de patients). Les personnages des films d'animation ont été créés par une compagnie locale pour refléter des femmes et des hommes Burkinabè travaillant dans des zones rurales et parlant avec l'accent de leur pays. Des exemples de violences subtiles faites aux femmes enceintes ont été intégrés dans les activités pédagogiques. Les discussions au sein des groupes de travail ont permis de rappeler les inégalités systématiques de genre dans le contexte de soins maternels et infantiles. Bien qu'explicité comme critère de participation à la formation, une représentation égalitaire des sexes n'a pas été possible, après deux cycles de recrutement.

Discussion : L'intégration de l'approche genre a influencé les activités pédagogiques ainsi que le choix des stratégies éducatives d'ACP-PASME 2. Elle a changé la perspective des formateurs et « coloré » le déroulement de la formation.

209 - Whose Leg Is It Anyway? When engaging with a limb just doesn't get the right response ...

Thomson R¹, Clewlow C², Elliott A², Spencer J^{1,2}, Hrisos S.¹

¹Institute of Health & Society, Newcastle University, Newcastle upon Tyne, UK, ²Operating Theatre, www.operatingtheatre.org.uk

Background

Involving people in their care is a major trend in contemporary healthcare practice. However, patients frequently express concerns about appearing rude or demanding when asking healthcare professionals questions, who in turn can be reluctant to engage with patients who ask questions due to feelings of being criticised or judged professionally. Helping professionals understand how their behaviour is key to enabling patient involvement is crucial to overcoming such relational barriers, but it can be a very sensitive area to broach.

Methods

In collaboration with Operating Theatre, a UK-based film and drama company, we developed a series of offbeat and humorous video sketches that are based on real issues raised in our empirical research exploring the perceptions of patients and clinicians on promoting patient involvement. The 'Whose Leg is it Anyway?' sketches are deliberately surreal and thought-provoking, to encourage reflection and discussion of the attitudes and feelings invoked by the situations depicted in the sketches. Acceptability and educational value of "*Whose Leg Is It Anyway?*" were explored with 50 trainee radiologists attending a UK-based regional training event. Trainees were encouraged to reflect on their own practice and what they could do as individuals to break down relational barriers.

Results

Trainees actively engaged in small group work and full audience reflection. They were positive about the use of humour and dramatisation in enhancing their understanding and enabling sensitive issues to be discussed amongst their peers. As an educational resource, "*Whose Leg Is It Anyway?*" was felt to have generic relevance to other specialities. Trainees proposed the inclusion of additional contexts and uses, particularly communication generally; risk communication; and non-verbal communication.

Conclusion

"*Whose Leg Is It Anyway?*" is a unique and potentially impactful approach to interpreting and disseminating research findings. This presentation will demonstrate its use in encouraging self-reflection and shared learning in healthcare professionals, using the radiologists training event as an exemplar. We will also discuss the potential in other settings, for example with patients and patient groups.

210 - Formation portant sur l'approche centrée sur la personne pour de meilleurs soins maternels et infantiles au Burkina Faso : Partie 4

Inheldia Cossou-Gbeto¹, Gérard Ngueta¹, Johanne Ouédraogo¹, Landry Traore¹, Seydou Barro², Thècle Twungubumwe¹, Josette Castel¹, Isabelle Savard³, Jean Ramdé¹, André Côté¹, Ruth Ndjaboue¹, Maman Joyce Dogba¹

¹Université Laval, ²Burkina Faso, ³Teluq

Contexte. La deuxième phase du *programme d'amélioration de la santé des mères et des enfants* (PASME2) au Burkina Faso a permis de développer une formation portant sur l'approche centrée sur la personne (ACP) et destinée aux professionnels de la santé. D'octobre 2018 à Janvier 2019, un total de 319 professionnels ont bénéficié de cette formation au Burkina Faso.

Objectifs. Évaluer : 1) la fidélité de l'implantation de la formation ACP, 2) les déterminants contextuels ayant influencé son implantation et 3) les effets immédiats.

Méthodes. Recherche évaluative participative combinant à méthodes mixtes. La composante qualitative comporte une analyse documentaire et des entrevues de groupe auprès des acteurs impliqués dans le projet afin d'obtenir leurs opinions sur la mise en œuvre de la formation. La composante quantitative se fera à l'aide de trois questionnaires : 1) de satisfaction, 2) d'apprentissage à (T0) et juste après la formation (T1) et 3) de mesure de l'intention d'appliquer les notions apprises lors de la formation. Cette mesure sera faite à l'aide du questionnaire DPC-Réaction qui permet d'évaluer l'intention de changement de comportement des participants à la fin d'une formation.

Résultats. Composante qualitative : l'approche participative a par sa flexibilité permis des ajustements constants dans la conception, la mise en œuvre de la formation. L'absence de personnages africains préexistants, l'accès limité à l'internet et aux ordinateurs ont nécessité l'adoption de solutions innovantes (sous-traitance avec des compagnies locales, tournage de films par les membres de l'équipe). Composante quantitative : 97,15% des participants sont satisfaits ou très satisfaits de la formation ; 96,16% des participants pensent que cette formation leur a permis d'augmenter leur niveau de connaissances et d'habiletés ; 92,31% comptent mettre en application ces nouvelles compétences acquises dans leur pratique quotidienne. Par ailleurs, la moyenne des participants qui ont l'intention d'appliquer l'ACP est de 6,65 sur une échelle de 7. Les concepts les moins bien maîtrisés par les participants sont la prise de décision partagée et les droits des patientes.

Discussion : Un accompagnement virtuel des apprenants dans les changements d'habitudes dans leurs pratiques est en cours surtout pour les aspects moins maîtrisés de la formation.

211 - Missed Opportunities for Advance Care Planning: A Qualitative Study of Patient-Oncologist Encounters

Olivia A. Sacks¹, Kristin E. Knutzen¹, Shama S. Alam¹, Garret T. Wasp¹, Matthew A. Liu², Kathryn I. Pollack³, James A. Tulsky⁴, Amber E. Barnato¹

¹The Dartmouth Institute for Health Policy and Clinical Practice, Geisel School of Medicine at Dartmouth, Lebanon, NH, ²University of California San Diego School of Medicine, La Jolla, CA, ³Duke University School of Medicine, Durham, NC, ⁴Dana-Farber Cancer Institute, Boston, MA

Background: Advance care planning (ACP)—the identification and documentation of patients' goals and values—has been shown to improve satisfaction and decrease end of life (EOL) treatment intensity in advanced cancer patients. Although ACP facilitates goal-concordant care, these conversations often do not occur until patients are acutely ill or hospitalized. This analysis aims to identify and describe opportunities for ACP that arose naturally in outpatient conversations between oncologists and advanced cancer patients.

Methods: We conducted a secondary analysis of audio-recorded outpatient oncology visits at two U.S. academic medical centers between November 2010 and September 2014 for the Communication in Oncologist-Patient Encounters (COPE) randomized controlled trial. The trial included patients with advanced cancer and tested the effect of patient- and oncologist-facing interventions on empathic communication. We randomly sampled 8 patient-oncologist dyads, each with 3 consecutive visits, from each of 4 trial arms (N=32 dyads; 96 encounters). One theme identified from an inductive coding process was missed opportunities for ACP. A multidisciplinary team defined this theme as failures to explore patient values, goals, and preferences in response to statements regarding cancer progression, death, or the experience of their disease.

Results: Of 30 encounters across 10 dyads, analyzed to date, 50% of patients were female, and most common diagnoses were prostate cancer and melanoma. 100% of conversations included missed opportunities for ACP. Instead of exploring values, goals, and preferences for medical care, oncologists responded by: [1] ignoring (n=3/16, 19%), [2] changing the subject (n=3/16, 19%), [3] declaratively stating the next steps for cancer-directed treatment (n=4/16, 25%), or [4] normalizing (n=6/16, 37%). In some longitudinal dyad conversations, cancer was progressing and quality of life decreasing; still, oncologists and patients did not discuss ACP.

Conclusions: In this small sample of patient-oncologist conversations, we found that oncologists and patients frequently missed opportunities to discuss ACP. We acknowledge that ACP may have occurred during visits prior to the recorded conversations. However, even if they have occurred before, revisiting these discussions helps facilitate shared decision-making. Failure to capitalize on these opportunities may result in patients not receiving care that is consistent with their goals and values.

212 - How embedded is person-centred care in UK post-graduate medical curricula?

Watson RM¹, Thomson RG¹, Moore H¹, Tomson D^{1,2}, Giles K³, Farnworth A⁴

¹Institute of Health and Society, Newcastle University, ²Collingwood Surgery, Collingwood Health Group, North Shields, UK., ³Faculty of Health and Wellbeing, University of Sunderland, Sunderland, UK, ⁴Institute of Cellular Medicine, Newcastle University

Background and Aim

Person-centred care (PCC) is a fundamental standard of the UK Care Quality Commission and Five Year Forward View. Medical practitioners in the UK National Health Service (NHS) are expected to deliver PCC, however little is known about the extent to which postgraduate medical education supports development of the necessary skills. Aim - To explore how PCC is addressed in UK Royal College (RC) post-graduate medical curricula.

Methods

A training needs analysis was conducted using curricula documents from the RCs of Physicians, Psychiatrists, Surgeons, and General Practitioners (GPs), supplemented by a framework analysis of interviews with key informants from each. The framework comprised various facets of PCC (e.g. care planning, coordination, shared decision making, and communication skills) as identified from published literature and national policy documents.

Results

Royal Colleges are primarily influenced to address PCC in their curricula by the policies and guidelines of the UK General Medical Council (GMC), although other influences were identified. Other influences did not always directly reference PCC, such as Human Rights Legislation. Components of PCC were identified in curricula documents provided by all RCs, although variation existed between RCs in terms of language used and the importance placed on the various elements of PCC. PCC was, however, often poorly defined, and guidance delivered in general terms, leaving scope for interpretation during development and implementation of training. This finding was echoed by interviewees who suggested that this posed challenges for those delivering training and assessing competence in PCC skills. There was little evidence of patients or the public influencing the content of national curricula.

Conclusion

There are a number of influences on the inclusion of PCC within medical post-graduate curricula in the UK, the most important being the GMC. The content of curricula varied across colleges, but in all cases was high level, leaving much open to interpretation by those developing and delivering local curricula. Greater clarity about the skills and knowledge expected of a PCC competent practitioner are required if consistency is to be achieved in teaching, assessment and practice. There is opportunity to enhance patient/public involvement in this sphere.

216 - Limited understanding of icon arrays among adults of lower socioeconomic status: The French love bars!

Julien MANCINI¹, Renata W. YEN², Marie-Anne DURAND²

¹Aix-Marseille Univ, APMH, INSERM, IRD, SESSTIM, “Cancer, Biomedicine & Society” group, Hop Timone, BIOSTIC, Marseille, France, ²The Dartmouth Institute for Health Policy & Clinical Practice, Dartmouth College, Lebanon, NH, USA

Introduction/objectives

A recent US survey showed that people of lower socioeconomic status (SES) had rather low graph literacy and difficulties understanding icon arrays compared to bar graphs or tables, with format preferences aligned with comprehension. Our objective was to replicate this survey in France.

Methods

We conducted a cross-sectional online survey using IPSOS i-Say sampling panel among adults with low annual household incomes. We presented three formats (table, bar graph, and icon arrays) showing hypothetical recurrence risks of cancer treatments in a randomized order. Following each format, we asked three comprehension questions (range 0-3), confidence in their answers (range 0-3), and perceived format usefulness (range 0-3). After each participant saw all three formats, we asked which was preferred. We also collected sociodemographic information, health literacy, numeracy (SNS3) and graph literacy (short form adaptation, range 0-4).

Results

All 401 participants were living with at least one person with annual income of <12,000€ (68.1%) or alone with annual income <9,000€ (31.9%). Mean age was 40.0 years (SD=14.1). Most were female (63.6%), had a high school diploma or less (61.8%), and 44.9% had free Universal Health Insurance Coverage. Only a quarter (26.7%) had a graph literacy score ≥ 3 .

Overall comprehension was correlated ($\rho > 0.5$) with significantly higher means for bar graph (1.65) and table (1.63) compared to icon arrays (1.41). There was no difference in confidence but bar graph had higher usefulness rating (1.69 vs 1.62 for icon arrays and 1.59 for tables) and was the preferred format (38.7% vs 36.4% for tables and 24.9% for icon arrays).

Higher graph literacy was the only variable associated with smaller differences in comprehension scores between icon arrays and the two other formats. However, icon arrays still had the lowest comprehension (1.83 vs 1.96 for both tables and bar graphs) among those with high graph literacy.

Conclusion

Among French people of lower SES, bar graph was the most understood and preferred format. Icon arrays format has low scores for all measurements such as in the initial US survey. It reinforces the need to reconsider their use among people of lower SES.

217 - The impact and utility of encounter patient decision aids: systematic review, meta-analysis and narrative synthesis

Peter Scalia¹, Marie-Anne Durand¹, Julia Berkowitz¹, Nithya Puttige Ramesh¹, Marjan J. Faber², Jan A.M. Kremer², Glyn Elwyn¹

¹The Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College, Lebanon, New Hampshire, USA, ²Scientific Institute for Quality of Healthcare, Radboud university medical center, Nijmegen, Netherlands

Background: There is increasing interest in patient decision aids (PDAs) designed to facilitate collaboration in clinical encounters –encounter PDAs. The effects of encounter tools on patient outcomes, however, have never been summarized, and little is known about the implementation of encounter PDAs into routine workflows.

Aim: To determine the effect of encounter PDAs as evaluated in randomized controlled trials (RCTs) and conduct a narrative synthesis of non-randomized studies assessing feasibility, utility and their integration into clinical workflows.

Methods: Medline, PsycINFO, Web of Science, CINAHL, and the Cochrane Library (from inception to November 16, 2017) were systematically searched for RCTs of encounter PDAs to enable the conduct of a meta-analysis. The search strategy included a combination of key words and MeSH terms related to “clinical encounter”, “PDAs”, and “patient-provider communication/shared decision making”. We used a framework approach based on our pre-specified perspectives of feasibility, utility, and integration to qualitatively analyze the integration of encounter PDAs into practice of non-randomized studies.

Results: The search strategy identified 2969 articles, but only 248 articles were selected for full-text review. Ultimately, we included 23 RCTs and 30 non-randomized studies. Encounter PDAs significantly increased knowledge (SMD= 0.42; 95% CI 0.30, 0.55), lowered decisional conflict scores (SMD= -0.33; 95% CI -0.56, -0.09), increased observational-based assessment of shared decision making (SMD= 0.94; 95% CI 0.40, 1.48) and satisfaction with the decision-making process (OR= 1.78; 95% CI 1.19, 2.66) without increasing visit durations (SMD= -0.06; 95% CI -0.29, 0.16). The narrative synthesis showed that encounter tools have high utility for patients and clinicians in terms of facilitating shared decision making. Yet, time pressures, lack of training on how to use them, and disagreement with the content and format of the tools impedes implementation. Implementation is feasible provided clinicians agree to their use, the clinical team agrees on the mechanisms to disseminate the tools to patients, and there is a critical appraisal process to identify and address barriers.

Conclusion: Encounter PDAs have a positive impact on patient-clinician collaboration, despite facing implementation barriers. The potential utility of encounter PDAs requires addressing the systemic barriers that prevent adoption in clinical practice.

220 - Decisional needs of patients and families making health or social decisions: A systematic review of studies using the Ottawa Decision Support Framework

Lauren Hoefel¹, Krystina Lewis¹, Laura Boland², Annette O'Connor¹, Dawn Stacey^{1,2}

¹University of Ottawa, Ontario, Canada, ²Ottawa Hospital Research Institute, Ottawa, Canada

Background

The Ottawa Decision Support Framework (ODSF) guides practitioners' support for patients making difficult health or social decisions. The premise is that decision support improves quality decision-making by addressing decisional needs including: inadequate knowledge, unrealistic expectations, unclear values, inadequate support/resources, decisional conflict, and needs arising from personal/clinical characteristics. Most needs categories were verified by predominately Canadian studies 10 years ago and require updated verification with recent evidence.

Objectives

Our systematic review aims to: (a) synthesize the evidence from ODSF-based studies of patients' and families' decisional needs when facing health or social decisions, (b) verify if ODSF needs categories emerge within a broader context of countries and decisions; and (c) identify any new decisional needs.

Methods

A systematic review is being conducted based on the Cochrane Handbook and PRISMA-P reporting guidelines. Electronic databases searched: Medline, CINAHL, PsycINFO, Cochrane Library, Embase, AMED, Scopus, Web of Science and Social Services Abstracts. Studies were eligible for inclusion if they assessed patients' or families' decisional needs when making health or social decisions for themselves, a child, or a mentally incapable person; or health and social care providers reporting on patient decisional needs. Studies had to use the ODSF to guide their methods. Only primary studies published in peer-reviewed journals were included. Exclusion criteria were systematic reviews and if decisional needs were related to hypothetical scenarios. Search findings were screened independently by two team members to identify eligible studies. Data extraction is being done using a standardized form and studies are quality appraised using the Mixed Method Appraisal Tool.

Results

Of 4532 citations, 45 studies from 7 countries were identified as decisional needs assessments based on the ODSF: 27 qualitative, 11 quantitative, and 7 mixed methods. Two population surveys elicited a range of difficult decisions; 43 smaller clinical studies focused on 27 specific decisions. Further results will be presented.

Conclusion

This is the first synthesis of decisional needs for patients making health or social decisions based on the ODSF. Findings will be used to update the ODSF decisional needs categories, the needs assessment interview guides and surveys and to identify research gaps.

221 - Optimiser les pratiques infirmières aux services d'urgence lors de la fausse couche : Présentation d'une approche participative d'élaboration d'intervention

Tina Emond¹, Laurence Guillaumie¹, Francine de Montigny²

¹Université Laval, ²Université du Québec en Outaouais

Introduction : Une grossesse sur cinq se termine par une fausse couche. Les parents qui y sont confrontés se présentent généralement aux services d'urgence pour être pris en charge et cette visite constitue souvent leur seule occasion pour bénéficier d'un soutien informatif et émotionnel. Les rares études s'étant intéressées à l'expérience des parents lors d'une fausse couche aux services d'urgence rapportent une insatisfaction quant aux soins reçus. Il existe très peu de recherches d'intervention visant à améliorer les pratiques de soins aux services d'urgence pour les parents.

Objectifs : Élaborer une intervention visant à optimiser les pratiques infirmières aux services d'urgence lors d'une fausse couche en misant sur la participation de parents et d'intervenants-clés.

Méthode : Cette recherche s'est déroulée en partenariat avec un service d'urgence d'un hôpital du Nouveau-Brunswick. L'approche participative a été mobilisée pour élaborer un Modèle Logique d'intervention d'approche théorique (Kellogg Foundation, 2004). Les étapes ont consisté en (1) une étude qualitative auprès de parents et d'infirmières (N=26) pour décrire les besoins des parents lors d'une fausse couche aux services d'urgence et (2) en l'élaboration de l'intervention dans le cadre d'ateliers participatifs tenus avec des parents, des professionnels de santé et des gestionnaires des services d'urgence (N=17).

Résultats : Les besoins des parents ont été identifiés et ont mis en évidence la faible considération de l'état émotionnel des parents, les lacunes dans l'information transmise et la méconnaissance de lignes directrices existantes. L'intervention élaborée comprend 3 volets : la formation des professionnels des services d'urgence à l'égard des soins à offrir lors de la fausse couche, la mise à disposition d'outils d'information et d'enseignement ainsi que l'implantation d'un suivi systématique pour les parents.

Conclusion : La participation des parents et des intervenants-clés a permis de décrire avec précision l'expérience des parents, le contexte de soins et de dégager des stratégies pouvant être réalistement implantées et améliorer la qualité des soins. L'approche participative a permis de susciter des prises de conscience dans le milieu de soins et ainsi que l'appropriation de l'intervention développée.

226 - Making Shared Decision Meaningful: Contextual, Conceptual, and Operational Challenges in Measurement

J.S. Blumenthal-Barby¹, Douglas J. Opel², Neal W. Dickert³, Daniel B. Kramer⁴, Brownsyne Tucker Edmonds⁵, Keren Ladin⁶, Monica Peek⁷, Jeff Peppercorn⁸, Jon C. Tilburt⁹

¹Baylor College of Medicine, ²University of Washington School of Medicine, ³Emory University School of Medicine, ⁴Beth Israel Deaconess Medical Center, ⁵Indiana University School of Medicine, ⁶Tufts University, ⁷University of Chicago, ⁸Massachusetts General Hospital Cancer Center, ⁹Mayo Clinic

Background: Shared decision making (SDM) is moving swiftly towards widespread clinical and policy implementation in the U.S. For example, the Centers for Medicare & Medicaid Services (CMS) now mandates proof of SDM with patients as a condition of reimbursement for low-dose computed tomography lung cancer screening, left atrial appendage closure for atrial fibrillation, and implantable cardioverter-defibrillator (ICD) placement. These efforts depend on validated and meaningful ways to measure SDM in practice.

Methods: We evaluated 40 tools to measure SDM for various ways in which they may or may not fit many real-life clinical contexts (contextual considerations), for ways in which they imply debatable assumptions (conceptual considerations), and for ways in which they may produce scores that do not reflect the reality of whether SDM occurred (operational considerations).

Results: On the contextual front, most instruments fail to translate to real-life clinical contexts in two important ways: they assume an individualistic decision making model with little to no mention of family members' roles or considerations, and they are artificially centered on an acute, discrete, decision making event. Second, on the conceptual front, most instruments focus heavily on information disclosure and exchange rather than relational dynamics (e.g., whether the patient truly felt that her voice was heard and the decision was shared), they imply that patients cannot delegate decisions, they promulgate the idea that SDM requires neutrality, and they fail to incorporate social and public health interests. Finally, on the operational front, many existing instruments may be prone to halo and ceiling effects.

Conclusion: SDM holds considerable promise for making a positive impact on modern healthcare. Yet in order to realize that potential, the concerns outlined here must be addressed in order know what we are measuring and to ensure that these measurements correspond to meaningful encounters in the lives of patients, families, and practicing clinicians. As policy initiatives for SDM move forward, we must ensure that the tools that we are using to define and measure SDM are valid and meaningful in the multitude of contexts within which they are applied. Otherwise, we risk measuring, and aiming for, the wrong goal.

227 - Variations in factors associated with home care providers' intention to engage in interprofessional shared decision making: results of two cross-sectional surveys

Rhéda Adekpedjou¹, Julie Haesebaert², Dawn Stacey³, Nathalie Brière¹, Adriana Freitas¹, Louis-Paul Rivest¹, France Légaré¹

¹Université Laval, ²Université de Lyon, ³University of Ottawa

Background: DOLCE is a post-intervention clustered randomized trial (cRT) which assessed the impact of training home care teams in interprofessional shared decision-making (IP-SDM) on caregivers' perception of their participation in health-related housing decisions for the seniors they care for. In a secondary study alongside the cRT, we sought to monitor healthcare providers' level of behavioural intention to engage in an IP-SDM approach and to identify factors associated with this intention.

Methods: We conducted two cross-sectional surveys, one each at cRT entry and exit. All home care providers in the 16 participating sites self-completed an identical questionnaire at entry and exit. Informed by a psychosocial model explaining health providers' clinical behaviour, we assessed their behavioural intention to engage in IP-SDM to support seniors and caregivers of seniors with cognitive impairment (as proxies) to make health-related housing decisions. We also assessed psychosocial variables underlying their behavioural intention and collected sociodemographic data. We used descriptive statistics and linear mixed models to account for clustering.

Results: Between 2014 and 2016, 271 healthcare providers participated at study entry and 171 at exit. At entry, median intention level was 6 (Interquartile range (IQR): 5–6.5) and determinants of higher intention were higher social influence ($\beta=0.27$, $P<0.0001$), higher beliefs about one's capabilities ($\beta=0.43$, $P<0.0001$), higher moral norm ($\beta=0.31$, $P<0.0001$) and higher beliefs about consequences ($\beta=0.21$, $P<0.0001$). At exit, median intention level was lower at 5.5 (IQR: 4.5–6.5). Except for moral norm, the determinants of higher intention were the same. However, determinants of lower intention at exit were working in rehabilitation ($\beta=-0.39$, $P=0.018$) and working as a technician (compared to as a social worker) ($\beta=-0.41$, $P=0.069$).

Conclusion: Factors associated with intention changed from study entry to study exit. These findings can largely be explained by the major restructuring of the health and social care system that took place during the two years of the study, leading to rapid staff turnover and organisational disturbance in home care teams. Future research should give more attention to contextual factors and design implementation interventions to withstand the disruption of system- and organisational-level disturbances.

230 - Making the Patient Central to Healthcare Decision-Making Again: Linking Shared Decision-making skills to Evidence-Based Medicine principles for Family Medicine Clerkship students

Amy Tan¹, Martina Kelly¹

¹Department of Family Medicine, Cumming School of Medicine, University of Calgary

Background:

Shared decision-making (SDM) actively engages patients in their own healthcare decisions, while improving patient health outcomes. The process of shared decision-making oftentimes is not made explicit to students. Thus, their knowledge and skills engaging in shared decision-making with patients is lacking. Concurrently, there is an emphasis for students to apply evidence-based medicine to patient management plans.

Objectives or Questions:

Our curricular innovation project explicitly links evidence-based medicine with shared decision-making whereby evidence is applied to the individual patient in a collaborative manner to determine its outcomes on student learning.

Methods:

All students must answer a specific clinical question based on a patient encounter during their Family Medicine Clerkship rotation, and critically appraise the evidence to answer the question. Then, the student engages in a shared decision-making conversation with the patient, where the evidence is presented, and the patient's individual context, values and goals are explored to make a patient-centred informed decision together. Students' written reflections on this interaction of making shared decisions in a collaborative manner were inductively analyzed for themes.

Results and Findings:

Thematic analysis of the written reflections on the SDM process highlights that medical students are reminded that the patient is central to individualized healthcare decision-making. Students realized that a patient's values and goals must always be applied to make the best decision(s) for the individual patient, and not to merely focus on what the evidence states. Analysis shows this exercise allowed students to authentically derive the definition of "patient-centred care" themselves as key learning.

Conclusions and Significance:

Our results will inform programs on how to provide explicit training opportunities to develop shared decision-making skills experientially, and how to use evidence to inform, rather than dictate a patient's healthcare decisions.

233 - Evaluation of an interprofessional training module in Shared Decision Making (Ready for SDM): a cluster randomized controlled trial

Simone Kienlin^{1,2,3}, Jürgen Kasper¹, Katrin Liethmann⁴, Alexander Grafe⁵, Dawn Stacey^{6,7}, Kari Nytrøen⁸

¹Arctic University of Tromsø, Department of Health and Caring Sciences, Tromsø, Norway, ²University Hospital of North Norway, Division of Internal Medicine, Tromsø, Norway, ³South - Eastern Norway Regional Health Authority, Department of Health Care Coordination and User Involvement, Oslo, Norway, ⁴University of Hamburg, Unit of Health Sciences and Education, Hamburg, Germany, ⁵MSH Medical School Hamburg, University of Applied Sciences and Medical, ⁶University of Ottawa, Ontario, Canada, ⁷Ottawa Hospital Research Institute, Ontario, Canada, ⁸University of Oslo, Faculty of Medicine University

Background and aims

In response to an obvious lack of shared decision making (SDM) health care professional training in Norway, the “Ready for SDM” curriculum (Norw. “Klar for samvalg”) was drafted based on a proven effective German module (doktormitSDM). This curriculum comprises several modules and provides guidance to tailor the SDM training according to particular contexts and different needs of health professionals. The current study aims to evaluate the efficacy of a 2-hour multidisciplinary SDM training module on SDM-related competencies.

Methods

Design: Cluster randomized controlled trial

Intervention: The module provides three components: A) a didactic lecture introducing SDM with regard to background, idea, indication and proven effects; B) a didactic lecture, teaching “six steps to SDM”; C) a video-based interactive training, based on domain specific video examples.

Sample and study design: Eight District Psychiatric Centers, conveniently recruited from the South-Eastern Norway Regional Health Authority and the Western Norway Regional Health Authority, were included and randomly allocated to either the training intervention (IG) or a wait-list control group (CG).

Outcomes: Demographics, professional background and attitudes towards SDM were assessed using self-completion questionnaire; SDM competencies operationalized as accuracy of judgements on the MAPPIN-SDM observer scale of a given test video showing a medical consultation, and knowledge about SDM (5 multiple-choice items), both assessed after the training (waiting). Accuracy of judgements referring to a reference standard was expressed using weighted t coefficients and tested using an unpaired t-test. Knowledge was determined using a five multiple-choice items score, and pre-post statistical significance was tested using Mann Whitney U test.

Results

134 of 153 health care providers participating in the trainings provided written consent and were included in the study. After the training, the IG demonstrated higher accuracy when judging SDM behavior compared to the control group (weighted t: CG: 0.21 (SD=0.28); IG 0.31 (SD: 0.20); p= .033) and higher knowledge about SDM, (CG: mean 2.4 (SD1.29), IG: mean 2.9 (SD =1.40); p=0.013).

Conclusion

The 2-hour inter-professional group training can improve health care provider’s SDM-competencies. However, observation competence as a proxy for communication ability requires further validation.

237 - Implementation of a program based on adapted physical activity and recommendations for second cancers prevention for adolescents and young adults with cancer: PREVAPAJA study

Axel Lion¹, Perrine Marec-Bérard², Olivia Febvey-Combes¹, Serge Marvalin¹, Lidia Delrieu¹, Béatrice Fervers^{1,5}, Nora Moumjid^{1,3}, Helen Boyle⁴, Julien CARRETIER^{1,3}

¹Center Léon Bérard, Cancer Environment Department, Lyon, France., ²Center Léon Bérard, AYAs Department- Treatment of AYA's Pain Unit, Lyon, France., ³University Claude Bernard Lyon 1, EA 7425 HESPER- Health Services and Performance Research, Lyon, France, ⁴Institute of Hematology and Oncology Pediatrics, AYAs Department- Treatment of AYA's Pain Unit, Lyon, France, ⁵Oncology Research Center, Lyon, France

Background/Objectives:

About 700 adolescents and young adults (AYAs; 15 to 25 years) are diagnosed annually with cancer in the French Auvergne-Rhône-Alpes region. While their long term survival is about 80%, they are six times more likely to develop a second primary cancer (SPC) compared to their peers. This risk is multifactorial and depends on the type of first cancer, treatment received and prevalence of risk factors (smoking, overweight, sedentary lifestyle, environmental exposures...). PREVAPAJA aims to implement a clinical program based on physical activity (PA) and cancer prevention recommendations for AYAs with cancer at Centre Léon Bérard-AYAs Department.

Design/Methods:

AYAs attended PA sessions during the active treatment period (4-6 months) and participated to individual information meetings on SPC risk prevention. Physical activity (IPAQ, 6MWT), sedentary, anthropometrics (BMI), quality of life (QLQ-C30) and fatigue (VAS) were assessed at baseline (T1) and at the end of treatment (T2). They participated to a final meeting by phone 1 year after T1 (T3) to assess their level of physical activity (IPAQ) and intention of changes in health behaviors.

Results:

63 AYAs (39 boys, 24 girls; median age=18 years) participated in the study. PA level increased between 360 MET-min/week at T1, 1059 MET-min/week at T2 and 1116 MET-min/week at T3. Sedentary time decreased from 56 h/week at T1, 40 h/week at T2 to 30h/week at T3. Fatigue assessed decreased between T1 and T2 ($p<0.01$) and overall quality of life improved statistically significantly between T1 and T2 ($p<0.001$). Information meetings showed important differences in consideration for cancer risk factors.

Conclusions:

This study showed the feasibility of implementing a clinical program based on PA intervention and cancer prevention recommendations for AYAs with cancer. It responded to AYAs' needs for support and discussions regarding physical activity recommendations and ways to prevent SPC. Beneficial outcomes of this program should encourage to systematically proposing PA intervention in combination with information exchanges with AYAs with cancer to strengthen the shared decision-making process.

240 - Codéveloppement d'une formation interprofessionnelle de prise de décision partagée en contexte palliatif: défis et perspectives

Gabrielle Fortin^{1,2}, Serge Dumont^{1,2}

¹Université Laval, ²RQSPAL

Introduction. En 2018, nous avons implanté une formation interprofessionnelle de prise de décision partagée avec le patient et ses proches portant sur l'optimisation des décisions entourant l'orientation des soins en fin de vie. Lors de l'élaboration de la formation, nous avons réuni un comité expert (CE) afin d'élaborer des activités pédagogiques. Celui était composé de onze personnes interpellées par les discussions sur les orientations des soins en fin de vie (deux médecins, deux infirmiers, deux intervenants en soins spirituels, un travailleur social, un psychologue, un gestionnaire détenant une expertise en collaboration interprofessionnelle et deux patient-proches partenaires). **Objectifs.** Présenter l'apport, les défis et les perspectives liées à cette expérience de cocréation impliquant des patient-proches partenaires. **Méthodologie.** Cette étude s'appuie sur les principes de la recherche collaborative et sur le Référentiel de compétences des patients (Direction collaboration et partenariat patient, 2015) qui nous a aidé à recruter, former et soutenir les patient-proches partenaires. **Résultats.** Le CE s'est rencontré à deux reprises, la majorité des échanges s'étant réalisée par courriel et par téléphone. Grâce à ce travail de cocréation, les activités pédagogiques ont été intégrées à un programme de formation visant à optimiser les pratiques au regard : de l'accompagnement du patient dans l'identification de son projet de vie; de l'évaluation des différents enjeux de communication portant sur l'orientation des soins en fin de vie et; du rôle des différents professionnels interpellés dans de telles situations. Les témoignages des patient-proches partenaires ont permis de bonifier le contenu des activités et d'ajouter des exemples illustrant leur vécu. Le principal défi relève de la difficulté à recruter des patient-proches partenaires détenant une expérience en soins palliatifs. Les modalités prévues par le comité scientifique pour leur offrir du soutien ont permis d'augmenter leur sentiment d'aisance à communiquer leur point de vue lors des rencontres. **Conclusion.** Une démarche structurée menée avec des personnes détenant des expertises complémentaires est essentielle pour développer du matériel pédagogique susceptible d'optimiser les pratiques lors de situations décisionnelles complexes en fin de vie. L'apport des patient-proches partenaires s'avère aussi nécessaire au développement de contenu représentatif des besoins des patients et de leur famille.

241 - Mastectomy versus breast conservation therapy: an examination of how individual, clinicopathological, and physician factors influence decision making

Jeffrey Gu¹, Megan Delisle², Rachel Engler-Stringer¹, Gary Groot¹

¹University of Saskatchewan, ²University of Manitoba

Background: The choice of mastectomy versus breast conservation therapy (BCT) in early stage breast cancer (ESBC) is a complicated decision-making process. Canada's interprovincial mastectomy rates vary from 25% to 68% with Saskatchewan reporting the nation's second highest mastectomy rate at 63%. The aim of our research was to better understand the factors that influence decision-making for women with ESBC.

Methods: We created a survey based upon a previously developed framework that organizes the influencing factors into three constructs: clinicopathological, physician, and individual belief factors. All Saskatchewan women diagnosed and treated with ESBC in 2014-2015 inclusive were invited to participate in our survey.

Results: 276 participants completed our survey; 150 underwent mastectomy (54.3%) and 126 underwent BCT (45.7%). Treatment choice was influenced by disease stage and multiple individual belief factors. Women with stage two disease were significantly more likely to undergo mastectomy compared with stage one disease (OR, 7.48). Patients rating 'worry about cancer recurrence' (OR, 3.4) and 'total treatment time' (OR, 1.8) as more influential to their choice were also more likely to undergo mastectomy. Conversely, women rating 'wanting to keep own breast tissue' (OR, 0.17), 'tumor size' (OR, 0.66) and 'surgeon's opinion' (OR, 0.69) as influential to their choice were more likely to undergo BCT.

Participants were also asked to reflect on their involvement in the treatment decision-making process. Women who made their treatment decision completely on their own were more likely to undergo mastectomy. Conversely, when the decision was shared (OR, 0.22; 95% CI, 0.09 – 0.52) or mostly the physician's choice (OR, 0.17; 95% CI, 0.06 – 0.49), participants were significantly more likely to undergo BCT.

Conclusions: Our study demonstrates treatment decision-making for Saskatchewan women with ESBC were primarily influenced by disease stage and individual belief factors. These findings would suggest that women are making their treatment choices predominantly based on individual values and preferences. Furthermore, when physician input is a factor, the direction of treatment influence is towards BCT. The use of mastectomy and BCT rates as an indicator of quality of care may be misleading. Instead, a shift in attention towards patient-centred care is more appropriate.

245 - Informed shared decision making - Nurse-led decision coaching for women with ductal carcinoma in situ in breast care centers: a cluster randomized controlled trial

Birte Berger-Höger¹, Katrin Liethmann³, Ingrid Mühlhauser², Burkhard Haastert⁴, Anke Steckelberg¹

¹Martin-Luther-University Halle-Wittenberg, Germany, ²University of Hamburg, Germany, ³University Medical Center Schleswig-Holstein, Campus Kiel, Germany, ⁴mediStatistica Neuenrade, Germany

Background

Women with breast cancer want to participate in treatment decision-making. Guidelines support the claim for informed shared decision making. We aimed to investigate whether a complex intervention comprising an evidence-based decision aid, nurse-led decision coaching and a structured physician encounter enhances the extent of informed shared decision-making behavior in women with 'ductal carcinoma in situ' and professionals. Further, we aimed to identify implementation barriers and facilitators.

Method

We conducted a cluster randomized controlled trial with an accompanying process evaluation. Sixteen certified German breast care centers were randomized either to intervention or standard care. 192 women with ductal carcinoma in situ facing a primary treatment decision should have been recruited. The decision coaching and physician consultations were videotaped to assess the primary outcome 'extent of patient involvement in shared decision-making' using the MAPPIN-O_{dyad} observer instrument (scores 0 to 4). Secondary endpoints included the sub-measures of the MAPPIN-inventory and 'informed choice'. The accompanying process evaluation comprised the 1) analysis of all video recordings with focus on intervention fidelity and 2) field notes of researchers and feedback from professionals and patients assessed by questionnaires and interviews with focus on implementation barriers and facilitators at different time points.

Results

Protracted recruitment led to termination of the study after 14 centers had included 64 patients (intervention group 36, control group 28). Patient participation in informed shared decision-making was significantly higher in the intervention group (mean (SD) score 2.29 (0.56) vs. 0.42 (0.51) in the control group; difference 1.88 (95% CI 1.26–2.50, $p < 0.0001$). 47.7% women in the intervention group made informed choices, but none in the control group, difference 47.7% (95% CI 12.6–82.7%, $p = 0.016$). Nurses adopted their new roles as intended. Physicians' attitudes, false incentives and structural barriers could be identified as implementation barriers of informed shared decision-making.

Conclusions

Informed shared decision-making is not yet implemented in German breast care centers. Nurse-led decision coaching grounded on evidence-based patient information enhances informed shared decision-making. However, implementation barriers prevented the successful implementation.

Registration No. ISRCTN46305518

252 - The development of a peer-support strategy that prepares Inuit for shared decision making with healthcare providers in cancer care systems: an integrated knowledge translation study

Janet Jull^{1,6}, Alex Hizaka², Lorne McLeod³, Danielle Dorschner⁴, Gabriel Jodouin⁴, Oolee Shoo⁴, Nina Manning⁴, Hannah Oolayou⁴, Michelle Rand⁵, Mara Habash⁵, Ian Graham⁶

¹Queen's University, Kingston, Ontario, Canada, ²Tungasuvvingat Inuit, Ottawa, Ontario, Canada,

³Larga Baffin, Ottawa, Ontario, Canada, ⁴Ottawa Health Services Network Inc., Ottawa, Ontario,

Canada, ⁵Indigenous Cancer Control Unit, Cancer Care Ontario, Toronto, Canada, ⁶Ottawa Hospital Research Institute, Ottawa, Ontario, Canada

Background:

Inuit are resilient and have a strong, unique culture that guides them in their everyday life, and are self-reliant in activities of self-governance and decision making. Inuit also face increased cancer risks: cancer is identified as the leading cause of the difference in life expectancy between Inuit Nunangat, the traditional territory of Inuit in Canada, and the rest of Canada. Shared decision making (SDM) improves peoples' participation and outcomes in health care. There is a need to enhance the participation of Inuit with their healthcare providers in their cancer care decisions. An integrated knowledge translation (KT) approach engages healthcare system users in research processes to co-create research evidence that is more client-centred and likely to be applied in practice.

Objective: To describe the development of a peer-support strategy that prepares Inuit for SDM with healthcare providers in cancer care systems.

Methods:

Cancer care organization and academic research partners conducted an integrated KT study, led by a Steering Committee of Inuit community members and providers and used consensus-building methods to develop: a) a strategy that prepares Inuit for shared decision making with healthcare providers in cancer care systems ("strategy"), b) training in the strategy. Peer-healthcare providers who are community support workers ("CSWs") were trained with the strategy and paired with volunteer community members. CSW-community member pairs were observed to use the strategy and interviewed about their experience, and with thematic analysis of transcripts.

Results:

Development of a peer-support strategy to prepare Inuit for SDM with healthcare providers: a) training for CSWs to provide non-directive support to prepare to make decisions about cancer care with healthcare providers, and b) a 6-question booklet to guide discussion and prepare for SDM with a healthcare provider. Five urban-based Inuit CSWs were trained in the strategy and matched with 8 community members clients in the cancer care system. Interviews relate six themes that affirm the need, appropriateness and acceptance of the strategy structured by the booklet.

Conclusions:

A peer-support strategy may be used to prepare Inuit for SDM with healthcare providers in cancer care systems. Further work is underway to test the strategy.

254 - Validation of the SURE-test for screening decisional conflict among parents making decisions for their child

Laura Boland^{1,4}, France Légaré², Ian D Graham^{3,4}, Daniel I McIsaac^{3,4}, Simon Décary², Monica Taljaard⁴, Dawn Stacey^{3,4}

¹University of Western Ontario, ²CHU de Québec Research Centre-Université Laval site Hôpital St-François d'Assise, ³University of Ottawa, ⁴The Ottawa Hospital Research Institute

Background: The 4-item SURE-test screens for decisional conflict in clinical settings. Although valid in adults, validity data for parents in pediatric clinical practice is lacking. We aimed to validate the SURE-test for use with parents in pediatric practice.

Methods: We conducted a secondary analysis of randomized trial data that evaluated a shared decision-making intervention for parents deciding about antibiotic use for their child. We compared parents' scores on the SURE-test and Decisional Conflict Scale (DCS; gold standard for assessing decisional conflict). A Spearman correlation coefficient was used to describe the association between the scores and linear regression to determine the variance in the DCS explained by the SURE-test. Using clinically significant cut-offs, we dichotomized each measure to calculate sensitivity, specificity, and positive and negative likelihood ratios for the SURE-test. The Kuder-Richardson 20 was used to measure internal consistency between dichotomized measures. We evaluated the presence of effect modification by sex using an interaction term in our linear regression model, followed by sex-specific calculation of validation statistics.

Results: We analysed data from 201 parents (67% female). The average parent age was 36 years (*SD* 6); average child age was 5 years (*SD* 4). Mean total scores were 14.2/100 (*SD* 14.3) for the DCS and 3.8/4 (*SD* 0.7) for the SURE test, which were significantly correlated ($\rho = -0.36$, $P < 0.0001$). The SURE-test explained 34% of the variance in DCS scores. SURE-test sensitivity and specificity for identifying decisional conflict was 82% and 93% respectively; the positive likelihood ratio was 11.9 and negative likelihood ratio 0.2. Internal consistency was moderate at 0.56 ($P < 0.0001$). The SURE-test and DCS total score correlation was higher for females than males (-0.37 vs. -0.21; $P = 0.008$ for the interaction).

Conclusions: The SURE-test demonstrated moderate correlation and reliability with the DCS for parents making a pediatric health decision. As a decisional conflict screening test, SURE-test performance is strong and valid in screening for the presence of decisional conflict, but moderate for ruling it out. The SURE-test performed differently for males and females, suggesting sex-based differences exist in screening for decisional conflict. Our analyses were limited by a low prevalence of decisional conflict.

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

Friedemann Geiger^{1,2,3}, Claudia Hacke^{1,2}, Carmen Wiencke^{1,2}, Katja Reissner^{1,2}, Anja Schuldt^{1,2}, Judith Potthoff^{1,2}, Christine Kuch^{1,2}

¹University Medical Center Schleswig-Holstein, Project SHARE TO CARE, Kiel, Germany, ²University Medical Center Schleswig-Holstein, Department of Pediatrics, Kiel, Germany, ³University of Kiel, Institute of Medical Psychology and Medical Sociology, Kiel, Germany

Background and aims

Shared decision making (SDM) requires specific training for physicians. Few training programs with proven efficacy are available. Even fewer can be delivered online, although large-scale implementation of SDM is hardly possible without easily scalable web-based approaches.

This study aims at evaluating the efficacy of the web-based SHARE TO CARE training module for physicians in terms of improvement of SDM-related competencies.

Methods

Sample and study design: All 167 first year medical students at the University of Kiel in 2019 (108 female; mean age 27.7±3.8 yrs) were included and cluster-randomized to either intervention group (IG) or waiting control group (CG).

Intervention: The online training module was developed as part of the large-scale SDM implementation program SHARE TO CARE, which also includes a face-to-face training for physicians, intervention modules for patients and nurses, and decision aids. It adheres to the SHARE TO CARE model of SDM, which conceptualizes SDM in 6 steps. Following an introduction video, these steps are demonstrated via scripted video examples of doctor-patient-consultations. Each demonstration includes 1) a suboptimal performance, 2) a multiple-choice question about the skill to be improved, 3) a discussion between the physician and a communication coach, and 4) an optimized performance. The training module concludes with a certifying SDM test.

Endpoints: SDM-related competences were operationalized as a) knowledge about SDM and b) the ability to judge given communication examples with regard to their SDM level. 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 rating using weighted t (inter-rater-agreement).

Results

After the training, IG showed a) higher knowledge about SDM (85 vs. 73%; $p<0.001$) and b) higher accuracy in SDM judgements (weighted $t=0.61$ vs. 0.55; $p<0.01$). Randomization checks revealed no relevant group differences regarding age, sex, prior medical experience or attitude towards SDM.

Conclusion

The web-based training module enhanced medical students' SDM-related competences which are regarded as important preconditions for the realization of SDM. The module is currently used to train every physician at Kiel University Hospital (N=850). A Norwegian version is in preparation.

257 - Core information for consent in surgical oncology: an application of core outcome methodology to define what information is important to patients and clinicians

1. Barry G Main¹, 2. Angus McNair¹, Kerry N L Avery¹, Rhiannon Macefield¹, Richard Huxtable¹, Jane M Blazeby¹

¹Centre for Surgical Research, University of Bristol, Bristol, United Kingdom

Background and Aims

The provision of high-quality, patient-centred information is a requirement for informed consent in modern healthcare services worldwide, but standards are lacking. Over-disclosure may overwhelm patients with too much information that may not be important. Patient-led communication, where discussions are guided by the individual, is helpful but patients may lack sufficient baseline knowledge to ask important questions.

A potential solution is a core information set (CIS). This is a scientifically-agreed, minimum amount of information to be discussed with patients to catalyse further discussion of importance to the individual. The aim of this project was to define a core information set for each of three areas in surgical oncology

Methods

Methods established for the development of core outcome sets were applied. Each CIS (oesophageal, head & neck, and colorectal cancer surgery) involved i) reviews of scientific literature, and patient information leaflets provided by hospitals, ii) in-depth interviews with patients and surgeons, iii) operationalisation of Delphi questionnaires, and iv) consensus meetings for professionals and patients. Each CIS consisted of domains rated most important for discussion by patients and healthcare professionals

Results

A total of 332 patients and 268 healthcare professionals participated. The final oesophageal CIS consisted of 8 information domains, the head & neck CIS 13 domains (plus 2 procedure-specific domains), and the colorectal CIS 11 domains. In general, patients favoured information about non-technical aspects of surgery, particularly functional recovery. Surgeons tended to rate operative details and peri-operative complications as most important for discussion.

Conclusion

It is feasible to apply COS methods to the development of CIS. There were areas of overlap between the 3 CIS, suggesting that the development of generic CIS for surgical oncology is possible. Further work is ongoing that will develop methods for implementing and evaluating CIS in routine practice.

260 - A mixed methods pilot study to test the birth choices decision aid for Taiwanese women who have had previous caesarean birth

Shu-Wen Chen¹, Yang-Cheng Chia², Meeiling Gau³, Allison Short⁴

¹PhD, Assistant Professor, National Taipei University of Nursing and Health Science, Taiwan, ²M.D. Deputy Chief, Saint Paul's Hospital, Taiwan, ³PhD, Professor, National Taipei University of Nursing and Health Science Taiwan, , ⁴PhD, Professor, University of Alabama at Birmingham|, USA

Background and Aims

Taiwan has extremely high national cesarean rates (36.26%) and low vaginal birth after cesarean (VBAC) rates (0.43%) in 2016. Literature indicates that women do not receive sufficient information about birth options after cesarean and shared decision-making (SDM) is not an expectation. This study is the first in Taiwan to test whether a birth choices decision aid utilized within obstetric clinic services can increase women's knowledge and engagement in decision-making about birth after cesarean.

Methods

A mixed methods approach was used in a two-phase pilot study within a regional hospital in northern Taiwan. Phase I consisted of a randomized controlled trial involving women with one previous cesarean receiving pregnancy care. A total of 60 women were recruited (14-16 weeks' gestation) during their first routine prenatal visit. A total of 45 were randomly assigned to either the intervention group (birth choice decision aid booklet, n = 22) or control group (usual care, n= 23). Phase II consisted of interviews with postnatal women, one month after birth to explore their decision making experiences. Quantitative measures included the level of knowledge, decisional conflict, decision-making participation, and satisfaction with decisions and outcomes. Qualitative interviews explored the mode of birth decision making experiences.

Results

Preliminary analysis indicates that early preferences regarding mode of birth influenced women's knowledge seeking behaviors as well as expectations or intention for engaging in SDM during pregnancy. There was also a potential disconnect between informed preferences expressed by women prior to the birth at 36 weeks and actual birth outcomes for those who preferred and/ or attempted VBAC.

This study is ongoing and results will be updated.

Conclusion

Changing the traditional doctor-patient relationship to promote SDM in pregnancy remains challenging. Further work is needed in Taiwan to examine ways to enhance women's power and expectation for active engagement in SDM about their birth after cesarean. A future systems analysis is needed to identify how best to equip organizations and practitioners in Taiwan to empower women to translate informed preferences into practice.

261 - A Randomized Controlled Trial of an Individualized Decision aid for Diverse Women with Lupus Nephritis (IDEA-WON)

Jasvinder A. Singh^{1,2}, Liana Fraenkel³, Candace Green¹, Graciela S. Alarcón¹, Jennifer L. Barton⁴, Kenneth G. Saag¹, Leslie M. Hanrahan⁵, Sandra C. Raymond⁵, Robert P. Kimberly¹, Amye L. Leong⁶, Elyse Reyes⁷, Richard L. Street^{9,10}, Maria E. Suarez-Almazor¹⁰, Guy S. Eakin¹¹, Laura Marrow¹¹, Charity J. Morgan¹, Brennda Caro¹², Jeffrey A. Sloan¹³, Bochra Jandali⁸, Salvador R. Garcia⁸, Jennifer Grossman¹⁶, Kevin L. Winthrop⁴, Laura Trupin¹⁵, Maria Dall'Era¹⁵, Alexa Meara¹⁴, Tara Rizvi⁸, W. Winn Chatham¹, Jinoos Yazdany¹⁵

¹University of Alabama at Birmingham; ²Birmingham VA Medical Center, Birmingham, AL, ³Yale University, New Haven, CT, ⁴Oregon Health Science University, Portland, Oregon, ⁵Lupus Foundation of America, Washington, DC, ⁶Healthy Motivation Inc., Los Angeles, CA, ⁷Elyse Reyes consulting, Los Angeles, CA, ⁸Baylor College of Medicine, Houston, TX, ⁹Texas A&M University, College Station, TX, ¹⁰University of Texas MD Anderson Cancer Center, ¹¹Arthritis Foundation, Atlanta, GA, ¹²Georgia State University, Atlanta, GA, ¹³Mayo Clinic School of Medicine, Rochester, MN, ¹⁴Ohio State University, Columbus, Ohio, ¹⁵University of California at San Francisco (UCSF), San Francisco, CA, ¹⁶University of California, Los Angeles (UCLA), Los Angeles, LA

Objectives:

Our objective was to assess the effectiveness of an individualized, culturally-tailored, computerized decision-aid for immunosuppressive medications for lupus nephritis.

Methods:

In a multicenter, randomized controlled trial, diverse adult women with lupus nephritis, largely racial/ethnic minorities with low socio-economic status, were randomized to decision-aid vs. American College of Rheumatology lupus pamphlet (1:1 ratio). Co-primary outcomes were change in decisional conflict and informed choice regarding immunosuppressive medications.

Results:

Of 301 randomized women, 47% were African-American, 26% were Hispanic, and 15% White. Mean age (standard deviation [SD]) was 37 (12) years, 57% had annual income of <\$40,000, and 36% had a high-school education or less. Compared to the pamphlet (n=147), participants randomized to the decision-aid (n=151) had: (1) a clinically meaningful and statistically significant larger decrease in decisional conflict, 21.8 (standard error [SE], 2.5) vs. 12.7 (SE, 2.0, p=0.005), and (2) a clinically meaningful difference in informed choice, statistically non-significant in the main analysis, 41% vs. 31% (p=0.08), but significant in sensitivity analysis (net values for immunosuppressives positive [in favor] vs. negative [against]), 50% vs 35% (p = 0.006). Respectively, unresolved decisional conflict post-intervention was significantly lower, 22% vs. 44% (p<0.001). Significantly more patients in decision-aid vs. pamphlet group rated information to be excellent for understanding lupus nephritis (49% vs. 33%), risk factors (43% vs. 27%), medication options (50% vs. 33%, p≤0.003 for all), and the ease of use of materials higher (51% vs. 38%, p=0.006).

Conclusion:

An individualized decision-aid was effective in reducing decisional conflict for immunosuppressive medications in diverse women with lupus nephritis

265 - Co-designing an intervention to involve patients in organisational decision making

Jess Drinkwater^{1,2}, David Meads¹, Maureen Twiddy³, Anne MacFarlane⁴, Ruth Chadwick², Ailsa Donnelly², Phil Gleeson², Amir Hannan², Nick Hayward², Michael Kelly², Robina Mir², Graham Prestwich², Martin Rathfelder², Robbie Foy¹

¹University of Leeds, Leeds, UK, ²Patient Participation In Improving General practice (PPIG) co-research group, University of Leeds, Leeds, UK, ³University of Hull, Hull, UK, ⁴University of Limerick, Limerick, Ireland

Background and aim

Patient and public involvement in decisions about health care design and delivery is enshrined in the English National Health Service constitution and recognised as important internationally. Every English general practice is contractually required to involve patient groups in service improvement. Evidence suggests much of this involvement is enacted through feedback mechanisms to capture patient experience. However, increasingly organisations are overwhelmed with feedback which can be emotive and rarely leads to service change. An alternative approach is to base shared organisational decisions on patients' values.

This project aims to co-design a locally adaptable intervention to incorporate patient values into shared decisions about organisational change in English general practice.

Methods

Using a participatory research approach, a co-research group involving ten patients, six general practitioners, and one PhD researcher was established. So far, the group has had 18 meetings (approximately 45 hours of discussion) over three years. Through an iterative process we have: conducted a systematic review; used and reflected on participatory facilitation techniques; conducted six focus groups with general practice patient groups (31 patients and 19 staff); and piloted a survey (30 participants) including 15 think aloud interviews.

Meetings, focus groups, and interviews were audio-recorded and transcribed prior to thematic analysis with co-research group involvement.

Results

The process resulted in the development of an adaptable discrete choice experiment (DCE) template; 24 attributes of general practice; and a facilitated process to support patient groups and staff working together to select the attributes to use.

Emerging results suggest the intervention highlights the need for trade-offs when making decisions about service improvement with limited resources. The 24 attributes encourage patients and staff to discuss common topics, whilst also discussing wider issues such as equity. Local adaptability provides ownership over the content. The survey format aims to address the representational deficit of existing patient groups. Discussing values encourages patients to think about others' values, as well as their own.

Conclusion

A co-designed intervention to incorporate patient and staff values into shared organisational decision making appears to address deficits of current involvement mechanisms based solely on patient experience. We are now testing intervention feasibility.

267 - Sinusitis: An Evaluation of Online Audio-Visual Patient Education Material

Kolin Rubel¹, Mohamedkazim Alwani¹, Obi Nwosu¹, Elhaam Bandali², Taha Shipchandler¹, Jonathan Ting¹

¹Indiana University School of Medicine, Indiana, United States of America, ²Richard M. Fairbanks School of Public Health, Indiana, United States of America

Background: Acute and chronic rhinosinusitis are debilitating diseases that affect 5-16% of the population. YouTube is the second most commonly used search engine and is often utilized by patients to garner health information regarding various disease processes and their respective management options. An evaluation of these information resources for quality and reliability is warranted, especially in an era where patients are increasingly turning to audio-visual media to educate themselves regarding their ailments.

Methods: The YouTube video database was searched using the term “Sinusitis” from its inception through to November 2018. The first 50 videos populated under the relevance-based ranking option were collected and parsed by time and language. Of the 50 videos, 10 were eliminated either for length (<1:00 minute or > 20:00 minutes), language (any language other than English), and/or for later being removed by YouTube for copyright. The videos were then assessed using the Patient Education Materials Assessment Tool – Audio/Visual (PEMAT-A/V) by two independent reviewers for understandability and actionability.

Results: A total of 40 videos were examined using the PEMAT-A/V tool. The average understandability score was 57.7% while the average actionability score was 46.3%. Eleven videos (28%) had actionability scores of 0%. Videos most commonly discussed disease management options (38%). The second largest category was case presentations regarding surgical techniques (30%). There were only 6 videos focused primarily on education of the definition and common traits of sinusitis (15%).

Conclusions: Our results show a paucity of high quality online educational media for patients searching for information about sinusitis, with a majority of videos being neither understandable nor actionable. As patients increasingly turn to Internet video databases like YouTube for medical information, it is critical that institutions create new audio-visual material that is accurate and easily accessible to patients.

268 - Defining Neonatal Family Meetings: Results of a Qualitative Analysis of Parent, Nurse, and Neonatologist Interviews

Animesh Sabnis¹, Amanda McArthur², Eunice Hagen³, Derjung M. Tarn¹

¹David Geffen School of Medicine, University of California Los Angeles, Los Angeles, California, United States, ²University of California, Los Angeles, California, United States, ³Keck School of Medicine, University of Southern California, Los Angeles, California, United States

Background & Objective: In the neonatal intensive care unit (NICU), guidelines recommend face-to-face meetings between clinicians and parents to support shared decision making for critically-ill newborns and to provide emotional support for parents. In a prior study, we found poor documentation of family meetings and a lack of consensus about the definition of neonatal family meetings among parents and professionals. This study identifies stakeholder beliefs and preferences about holding neonatal family meetings and explores attitudes about their implementation.

Methods: Qualitative analysis of semi-structured interviews with 25 professionals (7 neonatologists, 16 nurses, 2 social workers) and 13 parents recruited from an academic NICU.

Results: First, parents and professionals identified challenges to and solutions for effective communication during family meetings. Participants identified parental psychosocial burdens and limited medical knowledge as barriers to effective communication. Proposed solutions included allowing more time for parents to speak and explicitly offering emotional support. Participants identified weaknesses in clinicians' communication skills and suggested behaviors to model, such as avoiding jargon, speaking honestly and directly, and checking for understanding. Second, parents and professionals displayed great variation in their preferences for conducting family meetings. Participants stated that infant and family circumstances should determine the logistics of family meetings. For example, the gravity of clinical news may determine whether a meeting should occur at the bedside or in a private room, and the predicted hospitalization duration may determine whether a meeting is necessary or superfluous. Although some parents and professionals doubted the value of meetings for all families, most preferred meetings to occur "regularly," "sooner rather than later," and when events took an unexpected turn.

Conclusion: Parents and professionals hold diverse and contradictory views about the conduct of NICU family meetings. Using participant perspectives, we developed a multi-faceted family meeting guide that elicits parents' preferences about the substance and logistics of their meeting, reminds clinicians to avoid common communication failures, and prompts clinicians to assess elements of shared decision making. Implementation of a neonatal family meeting guide may improve parent outcomes such as comprehension, satisfaction, shared decision making, and psychological distress.

275 - Hearing patients' voices: Including patient perspectives for meaningful interactions

Elly Park¹, Allyson Jones¹, Mary Forhan¹

¹University of Alberta, Edmonton, Canada

Background: It is estimated that more than 1 in 6 Canadian adults are living with osteoarthritis (OA). A significant risk factor for developing OA is obesity. There is little consistency in the way patients with OA and obesity are being supported. Weight bias towards patients with obesity by healthcare professionals is a significant concern, and many practitioners do not have the proper training to address obesity.

Absent from OA research are the voices of patients living with obesity, who are receiving healthcare services. Without hearing their perspectives, it is unclear how programs/treatments are received by patients and whether they feel included and informed in the decision-making process.

Digital storytelling is an arts-based approach in research, used in this project for patients to share their stories of healthcare experiences. The needs and priorities of patients with obesity and OA in a treatment program can contribute to a more meaningful interaction between healthcare professionals and patients about their care pathways.

Aims: To highlight patient perspectives to support the shared decision-making process through digital stories.

Methods: Narrative research methods, drawing on the experiential knowledge of participants was used. Participants created digital stories that focused on specific healthcare experiences meaningful to them. Thematic analysis using NVivo 12 software from a total of 120 meetings with 20 participants was completed.

Results: Preliminary results show an overarching theme of patients' desire for active involvement in the care they are receiving for OA. Participants reported they felt they were treated differently because they have obesity. Patients were told to lose weight but were not provided with resources or more information regarding their condition. Clearer communication and information about realistic options are noted as two patient needs that have not been met.

Conclusion: The results of this study show a need to develop a process where patients with OA and obesity are providing experiential knowledge to practitioners as part of shared decision-making to ensure patients' needs and priorities are considered in OA treatment programs.

277 - Patient-reported measures to assess shared decision-making in routine care: applicability and limitations

Claudia Hacke^{1,2}, Heike Klein^{1,2}, Kai Wehkamp^{1,2,3}, Pola Hahlweg⁴, Isabelle Scholl⁴, Friedemann Geiger^{1,2}, Marion Danner^{1,2}, Faeloep Scheibler^{1,2}

¹University Medical Center Schleswig-Holstein, Project SHARE TO CARE, Kiel, Germany, ²University Medical Center Schleswig-Holstein, Department of Pediatrics, Kiel, Germany, ³University Medical Center Schleswig-Holstein, Department of Internal Medicine I, Kiel, Germany, ⁴University Medical Center Hamburg-Eppendorf, Department of Medical Psychology, Hamburg, Germany

Background and aims

Shared decision-making (SDM) has become a central component of health policy but its implementation in routine clinical care is still limited. Practical and user-friendly patient-reported measures are needed to make progress. Several instruments exist to routinely assess SDM performance. The aim of the present study was to compare different instruments particularly considering patients' rating of SDM and the performance of the enrolled departments.

Methods

The study was conducted at the University Medical Center in Kiel, Germany, as a baseline for the large-scale SDM implementation program SHARE TO CARE. SDM performance was assessed by use of a patient questionnaire combining four instruments: ASK3 Questionnaire (self-developed; 4 items; 3-point scale), Preparation for Decision Making Scale (PrepDM: 10 items; 5-point scale), collaboRATE™ (3 items; 5-point scale), and Perceived Involvement in Care Scale (PICS: 3 subscales, 14 items; 4-point scale). Statistical analyses included correlations between these instruments (continuous data) and a ranking of departments based on each instrument used.

Results

The final sample consisted of 1066 returned questionnaires (66.6%), 991 of which were analysable (participants: 45.2% female, 53.1% between 61-80 yrs). SDM performance was rated comparable to previous German PICS data of patients from departments of internal medicine and surgery ("Kölner Patientenbefragung"). Item-non-response rates and ranges were acceptable for all instruments and none of the scales showed bottom or ceiling effects. Significant associations could be detected with sex (collaboRATE, PICS_Doctor Facilitation Subscale) age (ASK3, PICS_Patient Decision-Making Subscale) and educational level (ASK3, collaboRATE, PICS). Overall, instruments showed low to moderate inter-correlations ($\geq r=0.31$, $p<0.001$), with collaboRATE and PICS ($r=0.63$, $p<0.001$) showing the strongest relation. A consistent order of departments across all instruments could not be observed.

Conclusion

In our study we only employed patient-reported generic instruments not focussing explicitly on a specific consultation. Depending on the instrument used, departments were ranked in a considerably different order. To measure the success of SDM implementation in routine care or to benchmark between hospital units, one has to be aware that the differing concepts and foci of the instruments might alter the results. These concepts should be transparently stated, so that users can choose knowingly.

284 - Developing the **consideRATE** talk guide: a conversation tool to help seriously ill patients, families and their clinicians co-produce care

Catherine H. Saunders¹, Marie-Anne Durand¹, Peter Scalia¹, Kathryn Kirkland^{1,2}, Meredith MacMartin^{1,2}, Ashleigh Jaggars¹, Tanya Butt², Amber Barnato¹, David Wilson Milne², Joan Collison², Gene Nelson¹, Glyn Elwyn¹

¹The Dartmouth Institute for Health Policy & Clinical Practice, Lebanon, NH, USA, ²Dartmouth Hitchcock-Medical Center, Lebanon, NH, USA

Purpose: Good conversations can improve the experience of serious illness for patients and families, reduce treatment intensity and improve emotional outcomes. Although tools exist to facilitate serious illness discussions, none are designed to be guided by patients and clinicians together – coproduction. We aimed to develop the **consideRATE talk guide** to help patients and families have good, co-produced conversations with their care teams.

Methods: This user-centered design study began with element development (phase 1) including a literature review to identify conversation topics most important to people with serious illness and their caregivers, as well as best practices during serious illness conversations. We iteratively developed the **consideRATE talk guide** based on cognitive interviews (phase 2) with patients, families and clinicians until we reached thematic saturation. We piloted (phase 3) the **talk guide** with patients and families and surveyed them about their experiences. Participants included seriously ill individuals with various conditions, their families and their clinicians at Dartmouth-Hitchcock Medical Center in NH, U.S.

Results:

Participants: Eight patients, 8 family members and 7 clinicians participated in cognitive interviews. Two patients, 4 family members and 2 clinicians piloted the **guide**; piloting is ongoing. Demographics were consistent with the regional population.

Findings: During element development (phase 1), we crafted a **talk guide** with 4 elements: agenda setting, planning and notes. During interviews (phase 2), the think-aloud technique revealed participants did not fully understand the concepts, so we expanded the instructions, simplified the language, and added visual cues. Patients and clinicians appreciated the new design, noting it was “beautiful; simple” and “a powerful tool” that is “radically different.” In pilot testing (phase 3), patients reported the guide prompted them to consider and assert their visit priorities. Clinicians felt that the guide did not disrupt workflow and was “natural [...] and a useful adjunct to [...] usual practice.” Clinicians suggested usability improvements, like wall-mounted guides.

Conclusions: Patients, families and their clinicians appreciate the opportunity to co-produce a serious illness conversation with the **consideRATE talk guide**. Clinicians find using the guide fits into their routine workflow, suggesting it may be scalable across health systems.

285 - Developing the **consideRATE** questions: a measure of seriously ill people's experiences

Catherine H. Saunders¹, Marie-Anne Durand¹, Peter Scalia¹, Kathryn Kirkland^{1,2}, Meredith MacMartin^{1,2}, Amber Barnato¹, David Wilson Milne², Joan Collison², Gene Nelson¹, Ashleigh Jaggars¹, Tanya Butt², Glyn Elwyn¹

¹The Dartmouth Institute for Health Policy & Clinical Practice, Lebanon, NH, USA, ²Dartmouth-Hitchcock Medical Center, Lebanon, NH, USA

Purpose: Serious illness – and associated distress – is increasing as the Western population ages. Yet, there are no brief measures that capture patient experience during serious illness care. We aimed to develop a brief patient-reported experience measure, called the **consideRATE questions**, which can share serious illness experience data with care teams to improve care.

Methods: This 4-step, user-centered design study began with item development (phase 1) including a literature review to identify care elements most important to people with serious illness and their caregivers. We iteratively developed items based on cognitive interviews (phase 2) with patients, families and clinicians, and continued until thematic saturation. We also piloted (phase 3) the measure with patients and families and surveyed them about their experiences. Participants included seriously ill individuals with varied diseases, their families and their clinicians across palliative medicine, hematology/oncology and surgery patients in clinics, hospital wards and intensive care units at Dartmouth-Hitchcock Medical Center in NH, U.S.

Results:

Participants: Cognitive interviews (phase 2) included 8 patients, 8 family members and 7 clinicians. We pilot tested (phase 3), with 15 patients and 15 family members. Participants from both high and low income and education levels participated; all participants reported they were White and spoke English.

Findings: Item formulation (phase 1) resulted in 8 questions about care team attention to patients' physical problems, feelings, surroundings; respect for their goals and preferences; and communication about their plans, affairs, and prognosis on a scale from 1 (very bad) to 4 (very good). Using think-aloud techniques during interviews (phase 2), we identified understandability issues, so we simplified words and added visual cues. In final measure piloting (phase 3), participants reported the questions were not distressing (30 participants); disruptive (29 participants) or confusing (30, 25 participants). Combined mean **consideRATE** scores were 3.6, with 1 being very bad and 4 being very good (SD=0.40; min=2.7, max=4.0).

Conclusions: We made substantial changes to the measure to accommodate the cognitive burden of serious illness. This resulted in an easily understandable and feasible tool. **consideRATE** provides the first way to assess serious illness care through the lens of patients' experiences.

288 - Intégration des notions de sexe et de genre dans les interventions d'implantation de la prise de décision partagée : analyse secondaire d'une revue systématique Cochrane

Lionel Adisso^{1,2,3}, Hervé Tchala Vignon Zomahoun^{1,2,3,4}, Amédé Gogovor^{1,2,3,4}, Sylvie-Marianne Rhugenda^{1,2,3}, Sabrina Guay-Bélanger^{1,2,3}, Rhéda Adekpedjou^{1,2,3}, France Légaré^{1,2,3}

¹Chaire de recherche du Canada sur la décision partagée et l'application des connaissances, Université Laval, Québec, Canada, ²Centre de recherche sur les soins et les services de première ligne de l'Université Laval (CERSSPL-UL), Université Laval, Québec, Canada, ³Département de médecine familiale et de médecine d'urgence, Université Laval, Québec, Canada, ⁴Unité de soutien SRAP/Québec, Québec, Canada

Contexte et objectif : Notre objectif était d'évaluer le niveau d'intégration du sexe et/ou du genre dans les interventions visant l'adoption de la prise de décision partagée (PDP), par les professionnels de la santé (PDS).

Méthodes : Nous avons identifié dans les études l'utilisation des termes «sexe», «genre» et des terminologies associées. Nous avons ensuite utilisé un guide des IRSC pour déterminer les études où il conviendrait d'intégrer le sexe ou le genre. Enfin, nous avons utilisé un outil des IRSC pour évaluer le niveau d'intégration du sexe et du genre dans chaque étude. Nous avons évalué le niveau global d'intégration (3 – 12) en utilisant une échelle de Likert.

Résultats : Des 87 études, 67 (77.0%) ont mentionné le sexe, le genre ou les terminologies associées uniquement dans les caractéristiques sociodémographiques. Les notions de sexe étaient applicables dans 54 études (62,1%), le genre dans 58 études (66,7%), le sexe et le genre dans 45 études (51,7%). De ces dernières, le score global moyen était 4,43. Pour les 42 autres études, ce score était de 4,51. Il n'y avait pas de différence statistiquement significative entre ces deux valeurs de score global moyen ($P=0,313$).

Conclusion : Dans les études d'intervention visant l'adoption de la PDP par les PDS, et ciblant les patients et les PDS, le niveau d'intégration du sexe et/ou du genre est faible. Cette prise en compte aurait permis une plus grande applicabilité et donc amélioré leur efficacité.

293 - Shared decision making in collaborative mental health care: How often does it happen and who is involved?

Matthew Menear^{1,2,4}, Michele Dugas², Michel Gervais³, France Légaré^{1,2}

¹Université Laval, ²CERSSPL-UL, ³CIUSSS-CN, ⁴Institut national d'excellence en santé et en services sociaux

Background and aims: Collaborative mental health care (CMHC) is an evidence-based model of care for treating mental disorders in primary care. People with mental disorders and their families should be active partners in collaborative care teams, yet there remains much uncertainty on how to achieve this goal. We aimed to examine the extent to which shared decision-making (SDM) is featured within CMHC programs and describe when SDM occurs and who is involved in the decision-making process.

Methods: We performed a systematic review, building on a previous Cochrane review of CMHC programs for depression and anxiety disorders in primary care (Archer et al. 2012). This latter review identified 79 unique CMHC programs, with searches ending in 2011. To identify more recent programs, we replicated the Cochrane review's searches in the Cochrane CCDAN and CINAHL database using keywords such as depression, anxiety, and collaborative care. We used several search strategies to find 'sibling' articles that could contain additional descriptions of the programs. A team of five review authors performed article screening, and then two review authors extracted data from eligible articles using a structured extraction form and codebook. We extracted study and program details and data on SDM processes and participants.

Results: In addition to the 79 collaborative care programs identified by the 2012 Cochrane review, our review update allowed us to identify 68 new programs for depression or anxiety disorders (total = 147 programs, described in 352 articles). Among all programs, only 35 programs (24%) described SDM processes between health professionals and people with depression or anxiety disorders. Primary care physicians and nurses were involved in SDM in over 50% of programs, while psychiatrists were involved in 26% of programs. In more than one third of programs, SDM only occurred during an initial consultation. No studies reported using decision aids to support decision-making.

Conclusions: While CMHC programs are widely considered evidence-based interventions, they currently do not frequently feature evidence-based approaches – like SDM – that can help people with mental disorders become active partners in their care. This review will provide guidance on how SDM can be better featured within CMHC.

295 - The effect of different communication strategies about stopping cancer screening on intention to screen and cancer anxiety: A randomised online study in older adults

Jenna Smith¹, Rachael Dodd¹, Jolyn Hersch¹, Erin Cvejic¹, Kirsten McCaffery¹, Jesse Jansen¹

¹Sydney School of Public Health, University of Sydney, Sydney, NSW, Australia

Background and aims

General practitioners (GPs) may recommend older adults stop cancer screening as they may be more likely to experience harm than benefit. Recent qualitative work has identified older adults' preferences for different communication strategies about stopping screening. This study experimentally tested the effect of these strategies on screening intention and cancer anxiety.

Methods

271 participants (135 male and 136 female) aged 65 to 90 years were recruited from an online panel and completed a survey including a hypothetical conversation with their GP about stopping cancer screening (breast for women, prostate for men). Participants were randomised to receive one of four statements about stopping screening at T1: (1) control ("*this screening test would harm you more than benefit you*"); (2) health status ("*your other health issues should take priority*" + control); (3) negatively framed life expectancy (FLE) ("*you may not live long enough to benefit from this test*" + control) or (4) positively FLE ("*this test would not help you live longer*" + control). At T2 participants received a second scenario where the GP further explained the recommendation to stop screening by addressing *how* this contradicts previous positive screening messages and *why* recommendations have changed. Primary outcomes, screening intention and cancer anxiety (scale of 1 to 10), were measured at both time-points.

Results

No main effects were significant for screening intention or cancer anxiety (all $p > .05$). However, post-hoc contrasts of the greatest differences revealed screening intention was significantly higher in the health status compared to negatively FLE condition (7.05 vs 5.98, $p=.049$) and cancer anxiety was significantly higher in the positively FLE compared to negatively FLE condition (5.82 vs 4.83, $p=.025$). Explaining the changed recommendation significantly reduced both screening intention (mean difference=0.80, $p=.044$) and cancer anxiety (mean difference=0.26, $p=.034$).

Conclusion

Older adults may have lower screening intention and experience less cancer anxiety when GPs communicate they may not live long enough to benefit from screening and explicitly explain how and why this information contradicts previous messages about cancer screening. Further research should examine the effect of these communication strategies on informed choice to promote shared decision-making.

298 - Adolescent-parent preferences and decision-making for dental care for developmentally absent teeth (hypodontia)

Sophy Barber¹, David Meads², Sue Pavitt², Joachim Marti³, Balvinder Khambay⁴, Hilary Bekker²

¹Leeds Teaching Hospitals NHS Trust, Leeds, West Yorkshire, UK., ²University of Leeds, West Yorkshire, UK, ³Université de Lausanne, Switzerland, ⁴University of Birmingham, UK

Aims

Hypodontia is the failure of one or more teeth to develop causing the tooth/teeth to be permanently missing. This often has a significant impact on oral health-related quality of life. Treatment for hypodontia requires young people and parents to choose between complex treatments where often there is no single 'best' treatment. To support shared decision-making and selection of the most appropriate treatment, this study examined current decision-making practice and adolescent-parent preferences for attributes of hypodontia care.

Materials and methods

Stage One: Examination of decision-making: 1) Systematic literature review (n=56); 2) Analysis of patient information resources (n=30); 3) Naturalistic observation and analysis of clinical consultations (n=5); 4) Interviews with adolescents and parents (n=16); 5) Content analysis of public posts on social media (n=247).

Stage Two: Design and testing of a Discrete Choice Experiment (DCE) Survey: 1) Application of design theory and best practice guidelines; 2) Stakeholder consultation; 3) Piloting (n=20) using cognitive interviewing alongside statistical analysis of preference data; 4) Finalisation of DCE Survey.

Stage Three: Elicitation of adolescent-parent preferences for hypodontia care: 1) UK-wide online DCE Survey to measure population-level preferences (n=204); 2) Face-to-face DCE Survey to observe selection of individual and joint preferences by adolescent-parent dyads (n=30).

Results

Issues were identified in the decision-making process: poor adolescent and parent knowledge about hypodontia and treatment, inadequate professional awareness of shared decision-making, low patient engagement and few tools for incorporating patient preferences into decisions. This resulted in little shared decision-making and adolescent and parent confusion about treatment options.

Important components of dental care for decision-making related to service delivery and treatment outcome. Improved appearance, risks associated with treatment and time factors were particularly important for decision-making. A difference in preferences and approaches to decision-making between adolescents and parents was identified. Detailed analysis of the DCE is underway and will be presented, including an examination of the validity and reliability of this method for adolescent and joint adolescent-parent preference elicitation.

Conclusion

Addressing the issues identified in shared decision-making is essential to driving improvements in care. Preference elicitation methods suggested important differences between adolescents' and parents' approach to decision-making.

301 - Multidisciplinary cancer clinics as a way to foster shared decision-making? – A qualitative case study

Isabelle Scholl^{1,2}, Sarah Kobrin³, Glyn Elwyn²

¹University Medical Center Hamburg-Eppendorf, Hamburg, Germany, ²Dartmouth College, Lebanon, NH, USA, ³National Cancer Institute, Rockville, MD, USA

Background and Aims:

Multidisciplinary cancer care is mainly delivered through a serial care model (SCM): First, patient information is reviewed in a tumor board and a treatment recommendation is developed by all major specialties without the patient present. Then the patient is sequentially referred to specific specialists. The SCM has shown to neglect patient perspectives and preferences. A different model has superseded the SCM in some cancer centers. In these multidisciplinary clinics (MDCs) the patient meets with all major specialties and support services in a single clinic visit, and the tumor board takes place within this visit. Little is known how treatment decisions are made in MDCs and whether this form of care might offer a way of better implementing SDM. In this study, we explored decision-making processes in MDCs.

Methods:

We conducted a qualitative case study in two cancer centers in the US that have routinely implemented MDCs. In a week-long visit to each site, we conducted participant observation of MDCs and semi-structured interviews with patients, health care providers (HCPs) and cancer center leadership personnel to allow triangulation of data. Observation was recorded in field notes and interviews were audio-recorded, then transcribed. All data was analysed using conventional context analysis.

Results:

The dataset consisted of field notes from observation of 6 MDCs (on five different cancer entities), interviews with N=12 HCPs, N=7 patients and N=4 leadership personnel. Preliminary data analysis shows that this form of multidisciplinary care is quite resource intense and its coordination needs good communication between HCPs. It is generally seen as beneficial for the patients by all stakeholders. It can foster SDM by having several opportunities to inform about options, leaving more room for patients to ask questions and to integrate patients' preferences better than the more common SCM. However, there was variance between different MDCs and different HCPs in terms of use of SDM.

Conclusions:

This case study shows that MDCs have more potential to foster SDM than the SCM, if they take steps to engage patient views. More research beyond this qualitative exploratory design is needed to compare care models regarding SDM implementation.

304 - Translation and psychometric evaluation of **collaboRATETM** in Germany – a 3-item patient-reported measure of shared decision-making

Pola Hahlweg¹, Stefan Zeh¹, Niklas Tillenburger¹, Isabelle Scholl¹, Jödis Zill¹, Jörg Dirmaier¹, Paul Barr², Glyn Elwyn², Martin Härter¹

¹Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany, ²The Dartmouth Institute for Health Policy & Clinical Practice, Dartmouth College, Lebanon, NH, USA

Background and aims: The **collaboRATE**TM measure assesses shared decision-making from patients' perspective with 3 items. Because of its shortness, it is especially feasible in routine care. It was developed in English and has been translated into several languages. The English version showed discriminative validity, concurrent validity, interrater reliability, and sensitivity to change. So far, no German version of the measure existed. This study aimed to translate **collaboRATE** into German, test its comprehensibility, and evaluate its psychometric properties.

Methods: Translation followed the TRAPD protocol. Comprehensibility was tested in cognitive interviews with lay people (N=18). Psychometric properties were evaluated in a secondary analysis of a sample of 507 cancer patients. They assessed **collaboRATE** regarding their care experience in general at the respective hospital. We expected correlations of at least .7 with the 9-item Shared Decision-Making Questionnaire (SDM-Q-9, regarding one specific medical encounter at the hospital) (concurrent validity), less than .5 with patients' satisfaction with care (divergent validity), and less than .1 with patients' distress (divergent validity). We analyzed Pearson product moment or Spearman rank correlation coefficients with **collaboRATE** sum scores (ranging from 0 to 100) and point-biserial correlation coefficients or chi-squared tests with **collaboRATE** top-scores (i.e., highest value in all three items).

Results: During the translation process, the necessity to adapt sentence structures in order to enhance comprehensibility became apparent. Participants in cognitive interviews preferred the adapted items (compared to those translated as closely to the English items as possible) and indicated good comprehensibility. Within the sample for psychometric testing, the mean **collaboRATE** sum score was 82.5 (SD= 19.2), 147 participants (29.0%) indicated the top-score. Regarding concurrent validity, correlations with SDM-Q-9 sum scores were lower than expected (**collaboRATE** sum scores: $r=.43$, $p<.001$; top-scores: $pbr=.30$, $p<.001$). Regarding divergent validity, correlations with satisfaction with care were as expected (**collaboRATE** sum scores: $r_s=.36$, $p<.001$; top-scores: $\chi^2=82.7$, $p<.001$, Cramer's $V=.41$) and with distress were minimally higher than expected (**collaboRATE** sum scores: $r=-.16$, $p<.001$; top-scores: $pbr=-.12$, $p=.008$).

Conclusion: A well-comprehensible German version of **collaboRATE** is now available. However, concurrent validity could not be established. Further research is needed regarding the psychometric properties of the German **collaboRATE** measure.

305 - Translation, adaption, and psychometric testing of two instruments to measure health care professionals' perspective on shared decision-making implementation

Anja Lindig¹, Pola Hahlweg¹, Eva Christalle¹, Isabelle Scholl¹

¹Department of Medical Psychology, University Medical Center Hamburg-Eppendorf (UKE), Hamburg, Germany

Background and aims:

Many cancer patients want active engagement in treatment decision-making. In order to evaluate barriers and facilitators for shared decision-making (SDM) implementation, psychometric measures are needed. The Organizational Readiness for Implementing Change (ORIC) instrument assesses change commitment and change efficacy of health care professionals (HCPs) and is also usable to evaluate other changes in organizations. The IcanSDM instrument is a new measure for attitude towards SDM. Both were not available in German.

The aims of the study were 1) to translate the English versions of ORIC and IcanSDM to German, 2) to assess understandability and adapt if necessary, and 3) to psychometrically test the two measures.

Methods:

The two measures were translated into German following recommendations from the team translation protocol TRAPD (Translation, Review, Adjudication, Pretesting and Documentation). Understandability of the translations was tested via cognitive interviews with HCPs (n=11). Those were qualitatively analyzed by three research team members. Psychometric values (factor analysis, reliability, validity, and acceptance) will be assessed using data from a cluster-randomized SDM implementation program (baseline assessment in March/April 2018, t1 in November/January 2018).

Preliminary Results:

Translation of the ORIC and IcanSDM was successful. Only one item in each measure needed several cycles of adaptation to reach good understandability and acceptance. Data of 179 HCPs were collected at baseline, and so far, data of 127 HCPs were collected at t1. Preliminary results with a subsample showed that ORIC and IcanSDM are well-accepted instruments. Preliminary psychometric analysis of the ORIC was promising (Cronbach's $\alpha > .86$, item difficulties between .54 and .64 on a scale from 0 to 4, corrected item-total-correlation between .64 and .77). Factor analysis suggests a one-dimensional structure. Reliability of the IcanSDM could not be confirmed by preliminary analysis (Cronbach's $\alpha > .41$, item difficulties between .21 and .71 on a scale from 0 to 10, corrected item-total-correlation between .20 and .46). Exploratory factor analysis suggests a three-dimensional structure. Final analysis will be presented at the conference.

Discussion:

Preliminary results suggested that the translated and adapted ORIC and IcanSDM could be helpful instruments to evaluate SDM implementation from HCPs' perspective in German-speaking countries.

308 - Reflecting on Shared Decision Making: A Reflection-Quantification Study

Marleen Kunneman^{1,2}, Christina M. LaVecchia¹, Naykky Singh Ospina³, Abd Moain Abu Dabrh⁴, Emma M. Behnken¹, Patrick Wilson⁵, Megan E. Branda¹, Ian G. Hargraves¹, Kathleen J. Yost⁵, Richard M. Frankel⁶, Victor M. Montori^{1,5}

¹Knowledge and Evaluation Research (KER) Unit, Mayo Clinic, Rochester MN, USA, ²Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, the Netherlands, ³Division of Endocrinology, Department of Medicine, University of Florida, Gainesville, Florida, USA, ⁴Department of Family Medicine, Mayo Clinic, Jacksonville, Florida, USA, ⁵Division of Health Care Policy and Research, Department of Health Sciences Research, Mayo Clinic College of Medicine, Rochester, Minnesota, USA, ⁶Indiana University School of Medicine, Indianapolis, Indiana and Education Institute, Cleveland Clinic, Cleveland, Ohio, USA

Background: Reflecting before rating may help patients more carefully consider the quality of shared decision making (SDM) and mitigate ceiling and halo effects that often limit the performance of self-reported SDM measures.

Methods: We asked patients to reflect on their care before completing the 3-item CollaboRATE SDM measure after an outpatient appointment. Study 1 focused on rephrasing CollaboRATE items to promote participant reflection before each item. Study 2 focused on reflecting before using the whole scale with 5 open-ended questions about what went well and what could be improved upon, signs that the clinician understood the patient's situation, how the situation will be addressed, and why this treatment plan makes sense. A linear analog self-assessment scale assessed the extent to which the plan of care made sense to the patient.

Results: In Study 1, 107 participants completed surveys (84% response rate), 43 (40%) rated a clinical decision, and 27 of those (63%) did so after responding to reflection questions. Adding reflection lowered CollaboRATE scores (signifying "less" SDM) and reduced the proportion of patients giving maximum (ceiling) scores, but these effects were not statistically significant. In Study 2, 103 of 212 responders (49%) fully completed the version containing reflection questions. Reflection did not significantly change the distribution of CollaboRATE scores or of top scores. Participants rated very highly how much sense their plan of care made (mean 9.7 out of 10, SD 0.79), but this rating was weakly correlated with total CollaboRATE scores ($\rho=.4$, $p=.0001$).

Conclusion: Reflection-before-quantification interventions may not improve the performance of patient-reported measures of SDM with substantial ceiling and halo effects.

313 - Decision making about maintenance therapy for ovarian cancer: qualitative exploration of factors important to patients/caregivers and clinicians

Lisa M. Lowenstein¹, Charlotte C. Sun¹, Viola B. Leal¹, Laura Crocker¹, Katerina Savelieva¹, Shannon N. Westin¹, Robert L. Coleman¹, Robert J. Volk¹, Larissa A. Meyer¹

¹The University of Texas MD Anderson Cancer Center, Houston, United States

Background: Most ovarian cancer patients will recur. While maintenance therapies to extend the disease-free interval have been recently FDA-approved, they involve tradeoffs. Decision-making factors important to the subjects were explored.

Methods: Subjects were recruited using purposive sampling. Semi-structured interviews explored preferences and decision-making around maintenance therapy. Interviews were audio-recorded and transcribed verbatim. Framework analyses guided the content analysis using ATLAS.ti, V8. Interviews were independently coded by multiple investigators and consensus obtained.

Results: The sample included 39 patients, median age 60, (range 37-77); 20 caregivers, 30% (n=6) female, 75% (n=15) spouse, median age 57.3 (range 39.5-78.6); and 15 clinicians, 60% (n=9) female.

For many patients/caregivers, the clinician's recommendation was vital in weighing quality and quantity of life. *"When things are put back in her plate, of course she's very uncertain [...] to make a choice that impacts her quality of life. Because it begins to have her churning over making a decision that she's really not qualified to make."* At the same time there was a willingness to suffer side effects to extend survival: *"if you told me I had to stand on my head and whistle Dixie, I would have stood on my head and whistled Dixie if I knew it was going to make me, make me better, help me."*

Clinicians reported making recommendations based on clinical trial data and disease/patient characteristics. However, clinicians' personal views in certain clinical scenarios affected how they framed the decision. *"I just never felt like it was worth the money or the risk for the amount of survival advantage and, obviously I present it in a very biased way but most of our patients agree with me."* Clinicians recognized that *"what the patient wants to hear, [...], not is it recommended in general but do you personally recommend this for me personally. Taking into account the things that make me unique."*

Conclusion: Given the changing landscape of maintenance therapy for ovarian cancer, shared decision-making may help patients/caregivers ask informed questions and express their values and preferences while helping clinicians look beyond clinical characteristics and heuristics to engage in patient-centered care.

314 - Implementing methods for shared decision-making and self-management support at Aarhus University Hospital, Denmark. Part 3: Healthcare professional and manager's perspectives on the implementation

Kirsten Lomborg¹, Helle Max Martin², Charlotte Gjørup Pedersen¹, Marianne Johansson Jørgensen¹

¹Department of Clinical Medicine, Aarhus University, Denmark, ²Danish Knowledge Center for User Involvement in Health Care, DK

Background and aims: The increased attention on patient involvement has prompted a need for developing generic and standardized open-source methods, guidelines, tools and aids on how to systematically implement patient involvement initiatives in various clinical settings. For this purpose, a large-scale program at Aarhus University Hospital was initiated in 2014 with the objective to develop tools and implementation strategies for applying shared decision making and self-management support across diverse medical specialties. This study aimed to evaluate the program with a specific focus on the healthcare professional and management's perspective on the process.

Methods: Thematic analysis of data from semi-structured focus group interviews with healthcare professionals from 21 multidisciplinary clinical teams (9 interviews) and 18 department managers (6 interviews) were used to evaluate the development and implementation process. First, we identified meaning units separately in data from focus group interviews with department managers and multidisciplinary teams, respectively. Then we compared the meaning units from the two separate sub-analyses. Since no differences were identified, the meaning units were merged and subsequently categorized and synthesized into five main themes.

Results: The development and implementation process was significantly influenced by the patients' perspective, the organization of multidisciplinary teams, skill building, management, and information sharing within and across the teams. Two phenomena appeared to be particularly important. Firstly, the first-hand experience of the patient perspective – whether good or bad – strongly motivated the healthcare professionals to qualify their methods and tools and aids for shared decision-making and self-management support. Secondly, the bottom-up approach promoted team spirit and job satisfaction.

Conclusions: The findings of this study led to four recommendations for systematic implementation of patient involvement initiatives based on shared decision-making and self-management support: 1) The patient perspective should be integrated into all parts of the development and implementation process, 2) The clinical teams should be responsible for the development of the new initiatives, 3) A competence development course and continuous support during the process should be given to the clinical teams, and 4) Managers at all levels should clearly demonstrate their support.

317 - Clinical practice guidelines: Do they foster choice awareness in preferences-sensitive decisions?

FR Gärtner¹, JEA Portielje², M Langendam³, D Hairwassers⁴, T Agoritsas^{5,6}, BCM Gijsen⁷, GJ Liefers⁸, AH Pieterse¹, AM Stiggelbout¹

¹Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, The Netherlands, ²Department of Clinical Oncology, Leiden University Medical Center, Leiden, The Netherlands, ³Department of Clinical Epidemiology, Biostatistics and Bioinformatics, Amsterdam University Medical Centers, Amsterdam, The Netherlands, ⁴Breast Cancer Association The Netherlands, The Netherlands, ⁵Division General Internal Medicine, University Hospitals of Geneva, Geneva, Switzerland, ⁶Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Canada, ⁷The Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, The Netherlands, ⁸Department of Surgery, Leiden University Medical Center, Leiden, The Netherlands

Background and Aims: For a better implementation of shared decision making, clinicians need to be aware of options and acknowledge the relevance of patient preferences in preference-sensitive decisions. Clinical practice guidelines (CPGs) are assumed to strongly impact clinicians' choice awareness. In the present study we explore to what extent CPGs acknowledge the concept of preference-sensitivity in the way recommendations are motivated and phrased.

Methods: *First*, we analysed the content of six modules of Dutch oncology CPGs, concerning primary treatment with curative intent. For all treatment recommendations of the six CPG modules, two researchers extracted: strength of the recommendation in terms of GRADE (weak/strong) and its consistency with the CPG text; completeness of presentation of benefits and harms; incorporation of patient preferences; statements on the preferences underlying the CPG panel's weighing of benefits and harms in deriving the recommendation; and advice on patient involvement in decision making. *Second*, we verified these results in 14 semi-structured interviews with the CPG panel members.

Results: We identified 32 recommendations: 18 weak, 14 strong. Three of 14 strong recommendations should have been weak based on further information presented in the module. The benefits-harm presentation was sufficiently complete and clear to inform the recommendation in 1/6 modules only. Absolute, numerical probabilities were often not presented and often generic terms for outcomes were used (e.g. "morbidity"). None of the modules included information on patient preferences. CPG panel members' preferences were not made explicit, but appeared to have impacted 15/32 recommendations. Advice to involve patients and their preferences in decision-making was given for 20 recommendations (14 weak). Interviewees confirmed these findings. Examples of explanations for lack of information was the assumption that clinicians know the information, lack of time, and that CPGs need to be short. Explanations for trade-offs made were cultural-historical preferences and compliance with daily care.

Conclusions: Weak recommendations might be underrepresented in oncology guidelines as a result of the incomplete and unclear benefit-harm presentation, lack of patient preferences information, and influence of panel members' own preferences. The analysed CPGs do not stimulate choice awareness and a neutral presentation of options, thus hindering shared decision making.

318 - Informed shared decision making for patients with type 2 diabetes in primary care: results of a cluster randomized controlled trial

Susanne Buhse¹, Nadine Kuniss², Katrin Liethmann^{1,3}, Ulrich A Müller², Thomas Lehmann², Ingrid Mühlhauser¹

¹University of Hamburg, Germany, ²University Hospital Jena, Germany, ³University Medical Center Schleswig Holstein, Germany

Background and aims

Although diabetes associations have been recommending shared decision making (SDM) in diabetes care for years, it has not yet been implemented. In order to facilitate SDM and informed decisions, we developed an evidence-based decision aid for patients with type 2 diabetes and a corresponding group teaching session provided by medical assistants (MA) with special training in diabetes education. Evaluation of our informed shared decision making programme (ISDM-P) in an RCT at one tertiary care center showed positive results. The present study aimed at translating the ISDM-P to the primary care setting in Germany.

Methods

We conducted a multicenter cluster RCT with general practices. Therefore, the ISDM-P was supplemented by a structured patient-physician consultation and a patient-held documentation sheet with patient-defined treatment goals to be shared with the general practitioner (GP). Control group received standard care. Patients without diagnosis of ischemic heart disease or stroke were included. Practices were randomized after patient recruitment and acquisition of baseline data. Primary endpoint was patients' adherence to antihypertensive or statin therapy by comparing prescriptions and patient-reported uptake after 6 months. Secondary endpoints included informed choice (risk knowledge of at least 8/11 correctly answered questions plus achievement of personal treatment goals) and prioritized treatment goals of GPs and patients.

Results

Eleven practices with 151 patients received the ISDM-P and 11 practices with 128 patients standard care; 12 of 279 patients were lost to follow-up. Baseline characteristics were comparable. Adherence rates were similar for both groups with 80% for antihypertensive drugs and 91% for statin intake. More ISDM-P patients made informed choices regarding statin intake, 34% vs 3%, OR 16.6 (95% CI 4.4 to 63.0), blood pressure control, 39% vs 3%, OR 22.2 (95% CI 5.3 to 93.3) and glycated hemoglobin, 43% vs 3%, OR 26.0 (95% CI 6.5 to 104.8). Agreement on prioritized treatment goals between patients and doctors was higher in the ISDM-P group (88.5% vs 57%).

Conclusion

The ISDM-P was successfully implemented in the primary care setting. Patients made informed decisions and the patient-held documentation sheet ensured that they shared personal treatment goals with their GPs.

Trial registration: ISRCTN77300204

319 - Patient readiness for shared decision making: A scoping review

SM Keij¹, M Kunneman^{1,2}, S Moaddine¹, AM Stiggelbout¹, AH Pieterse¹

¹Medical Decision Making, Dept. of Biomedical Data Sciences, Leiden University Medical Center, The Netherlands, ²Knowledge and Evaluation Research Unit, Mayo Clinic, Rochester MN, USA

Background and Aims:

Patients may not be well-equipped, or *ready*, to become involved in shared decision making (SDM). This study aimed to identify patient-related elements reflecting *patient readiness for SDM* by means of a scoping review, a rigorous method for synthesizing evidence that is heterogeneous in nature. The review addresses the following question: What patient-related elements have been reported to be associated with effective patient engagement in SDM about treatment?

Methods:

We searched PubMed, Embase, Web Of Science, Cochrane, and PsychInfo from inception to June 20, 2017, and hand-searched references of included articles. Two independent raters screened Titles/Abstracts and full-text articles and discussed discrepancies to reach consensus. We included articles if they: were published in a peer-reviewed journal, and reported on patient-related elements and on treatment decision-making. *Quantitative* studies were included if the association between a patient-related element and a measure of SDM had been assessed. *Qualitative* articles were included if the main focus was on what makes patients ready for SDM. We extracted data on: study characteristics, study population, univariate and multivariate results on associations (quantitative studies), and participants' opinions on patient readiness (qualitative studies).

Results:

The search delivered 2636 hits. After title/abstract screening, 458 hits remained for full-text screening; N=34 quantitative and N=32 qualitative full-text articles were included. Data extraction demonstrated a broad list of patient-related elements of which the association had been assessed quantitatively or had been reported to facilitate or hinder patient engagement in SDM. However, the association with SDM had only repeatedly been assessed quantitatively for few elements (e.g., age, gender, diagnosis), and did not reveal obvious associations with SDM. Further, some elements were reported to both facilitate and hinder patient involvement (e.g., trust in physician, uncertainty of the evidence).

Conclusion:

The scoping review provides insight into the current knowledge on patient elements that may be associated with the occurrence of SDM. This is the starting point for collecting more evidence on what patient-related elements actually affect patients' readiness to engage in SDM processes, and are associated with the occurrence of SDM.

322 - Measuring shared decision making: Choice of response scale matters

H. Bomhof-Roordink¹, F.R. Gärtner¹, A.M. Stiggelbout¹, A.H. Pieterse¹

¹Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, The Netherlands

Aim:

To determine which response scale shows greatest variation, fewest ceiling effects, and seems most feasible, for a patient questionnaire developed to assess patient and oncologist shared decision making behaviours in oncology.

Methods:

We drafted four different response scales: 1) a five-point '*agree*' scale ranging from 'Totally disagree' to 'Totally agree'; 2) a five-point '*done*' scale ranging from 'Not done at all' to 'Done completely'; 3) a five-point '*positively unbalanced done*' scale ranging from 'Not done at all' to 'Done completely', with 'neutral' as second response option; and 4) a 100-point '*VAS done*' scale, with ends labelled as 'Not done at all' and 'Done completely'. We approached members of an online cancer patient panel by email and asked them to complete the 16-item draft questionnaire; panel members were randomized to one of the scales. We calculated the sum score (range, 16-80) and mean for each randomized group. We considered the coefficient of variation (CV) and the range of total scores as indicators of variation, and inspected the score distributions to detect ceiling effects. Based on these results, we selected response scales to determine comprehensibility in cognitive interviews.

Results:

Forty-one to 54 panel members responded in each randomization group (total N=191). The groups did not significantly differ regarding age, gender, education, diagnosis, or treatment. In order of magnitude, means were: 61.5 (SD 16.5, CV 0.27, range 27-80), '*done*' scale; 59.9 (SD 16.4, CV 0.27, range 23-80), '*agree*' scale; 58.5 (SD 17.5, CV 0.30, range 21-80), '*positively unbalanced done*' scale; and 52.5 (SD 16.5, CV 0.31, range 22.0-75.7), '*VAS done*' scale. The latter mean was significantly lower compared to the '*done*' and '*agree*' scales. The '*agree*' and '*done*' scales showed the highest ceiling effects, and these were abandoned. Cognitive interviews showed that the '*VAS done*' scale was sometimes interpreted as a dichotomous scale. The '*positively unbalanced done*' scale turned out to be most feasible.

Conclusions:

This study provides clear evidence that the choice of response scale can substantially influence the findings. Questionnaire developers should consider which response scale seems most appropriate, particularly when ceiling effects can be expected.

323 - Implementing methods for shared decision-making and self-management support at Aarhus University Hospital, Denmark. Part 4: Development and test of a decision aid for shared decision-making for anterior cruciate ligament injured patient

Hanne Mainz¹, Lone Frandsen¹, Kirsten Lomborg², Peter Fauno¹, Martin Lind¹

¹Department of Orthopedics. Aarhus University Hospital, Denmark, ²Department of Clinical Medicine, Aarhus University, Denmark

Background and aims

For patients with anterior cruciate ligament (ACL) injury the choice between surgical and non-surgical treatment can be difficult with recent scientific evidence for good clinical outcome for both treatment options. This emphasizes the need for a validated decision aid to support shared decision-making for patients and surgeons in their choice of a treatment, based on the patient's individual needs and preferences.

The aims of this study were to develop and test a decision aid to support patients and surgeons in shared decision-making between surgical or non-surgical treatment after ACL injury.

Methods

Based on interviews and questionnaires, information themes important for the decision regarding surgical or non-surgical treatment were identified and prioritized. For each theme evidence-based knowledge was searched for both treatment methods. To evaluate shared decision-making, 80 patients completed the SDM-Q9 questionnaire before and after implementing the decision aid in clinical practice. Experiences using the decision aid were evaluated qualitatively.

Results

A decision aid was created to highlight pros and cons of surgical and non-surgical ACL injury treatment including eight themes: Knee stability, Possible activities of daily living, Sport ability, Work ability, Clinical results, Risks Rehabilitation, and Sick leave. SDM-Q9 revealed high scores both before and after implementing of the decision aid and no differences were identified. However, the patients experienced that they were involved in the treatment decision process and that they were better informed for taking the treatment decision that was right for their situation. The surgeons experienced that the option grid helped them giving systematic information about both treatment options and consequences after ACL injury based on the individual patient's needs.

Conclusions

Decision aid for shared decision-making was created with patient identified information needed for treatment decision after ACL injury. Implementation of this decision aid did not result in increased SDM-Q9 scores, but both patients and surgeons experienced the decision aid to be supportive in the decision-making in the choice of treatment options.

325 - Eliciting citizen's preferences for home care and local health centres versus hospital care in cancer using a decision aid integrating a contingent valuation survey

Jennifer Margier¹, Nora Moumjid^{1,2}, Amiram Gafni³

¹University Lyon 1 HESPER 5A 7425, Lyon, France, ²Léon Bérard Comprehensive Cancer Centre, Lyon, France, ³Department of Clinical Epidemiology & Biostatistics, Centre for Health Economics and Policy Analysis (CHEPA), McMaster University, Hamilton, Canada

oalIntroduction

In France, cancer treatments are mainly provided in hospitals, but hospitals are expensive, crowded and mainly located around big cities. French public health decision makers thus wish to develop home care and local health centres (ie. GPs, nurses and physiotherapists working together in the same medical office).

Objectives : To study the adequacy between French healthcare policies and citizens' preferences for homecare, local health centres and hospital in cancer care. To test the acceptability and validity of the contingent valuation (CV) method as a mean to obtain values in the general population to guide public policy decision-making.

Methods: A computerized decision aid composed of: 1. Information on the 3 options 2. A survey to measure preferences and reasons of preferences for three different scenarios from curative to heavy (palliative) care at hospital/home/in local health centres. 3. A sociodemographic characteristics and an experience of care questionnaire. 4. A CV survey to assess citizens' Willingness To Pay (WTP) to benefit from their preferred option.

Results:

The survey has been conducted among a representative sample of the Rhône-Alps Region (n=800). For the curative scenario, home care was the preferred option for 46.1% of respondents, followed by hospital (35.1%) and then by local health centres (18.7%). More the management of care was heavy, more the proportion of respondents who prefer hospital increased: for palliative scenario, hospital was the first choice (49%), followed by home 29.5 % and local health centres 21.4%. Safety, wishing to separate home and place of care, thinking that home is not adapted to care, were strongly significant to explain preferences whatever the scenario.

The mean WTP tendency increased when the scenario was heavier: for citizen who preferred home care the $WTP_{S1home}=15.7\text{€}/\text{per household/month}$, $WTP_{S2home}=17.0\text{€}$, $WTP_{S3home}=19.1\text{€}$, for PS $WTP_{S1PS}=13.9\text{€}$, $WTP_{S2PS}=16.1\text{€}$, $WTP_{S3PS}=17.6\text{€}$.

Acceptability and validity of the CV method were confirmed by the few rates of protesters and outliers, and by the correlation between strength of preferences, income and WTP.

Discussion : If the goal is to develop healthcare policies that respond to citizens' preferences it is important to realize that what citizens prefer do not always match with healthcare decisions.

327 - How do online sites of academic and community medical centers portray the harms and benefits of lung cancer screening and what steps do they recommend for patients?

Stephen Clark¹, Daniel Reuland¹, Chineme Enyioha², Daniel Jonas¹

¹University of North Carolina, Division of General Internal Medicine and Clinical Epidemiology,

²University of North Carolina, Dept. of Family Medicine

Background: The USPSTF recommends lung cancer screening to adults aged 55 to 80 years who are current or former heavy smokers. However, because screening can cause substantial harms, these organizations also recommend shared decision-making with patients. Many US medical centers have screening programs and publish online information about screening. Because websites could influence patient perceptions of screening, some experts have expressed concern about persuasive or overly optimistic portrayals of screening in patient-facing websites. We evaluated how medical centers present information about screening benefits and harms as well as recommended next steps for patients.

Methods: We searched for screening information on websites of academic medical centers associated with all (n=152) US allopathic medical schools. With matching by state, we also identified a random sample of screening programs at community medical centers from all (n=1779) American College of Radiology lung cancer screening designated centers. Two investigators reviewed each website for the reporting of benefits, harms, and recommended next steps. We used descriptive statistics and bivariate analysis.

Results: We identified 81 academic centers and 81 community centers (total n=162) with screening program information. Benefits were more frequently reported than harms (98.1% vs. 48.2%, $p<0.01$). False positives (44.4%) were the most frequently reported harm. Academic centers were more likely than community centers to report any harm (56.8% vs. 39.5%, $p=0.03$) along with radiation (43.2% vs. 24.7%, $p=0.01$) and overdiagnosis (13.6% vs. 0.0%, $p<0.01$). Thirty-two (19.8%) webpages explicitly recommended patients weigh the benefits and harms of screening; academic centers were more likely than community centers to include this recommendation (34.5% vs. 18.5%, $p=0.021$). Most (n=157, 96.9%) institutions listed follow up steps for screening, but few (n=29, 17.9%) indicated patients should discuss benefits and harms with their primary provider.

Conclusions: Among academic and community medical centers' online information for lung cancer screening, a balanced message of both benefits and harms was lacking, and harms were commonly ignored. Most centers do not guide patients toward a shared decision-making discussion of harms and benefits with a patient's primary provider. Continued study of public-facing information about screening is needed to ensure value-concordant patient decision making for lung cancer screening.

329 - Creating choice awareness and delivering information neutrally to promote shared decision making: An online video-vignette study

AH Pieterse¹, K Brandes¹, J de Graaf¹, A Knops², N Labrie³, CF Allaart⁴, JEA Portielje⁵, WJW Bos⁶, AM Stiggelbout¹

¹Medical Decision Making, Dept. of Biomedical Data Sciences, Leiden University Medical Center, The Netherlands, ²Patient Federation Netherlands, The Netherlands, ³Athena Institute, Faculty of Beta Sciences, Free University of Amsterdam, The Netherlands, ⁴Dept. of Rheumatology, Leiden University Medical Center, The Netherlands, ⁵Dept. of Clinical Oncology, Leiden University Medical Center, The Netherlands, ⁶Dept. of internal Medicine, Leiden University Medical Center, The Netherlands

Background and Aims:

Achieving shared decision making (SDM) is posited to require 1) making clear that patients' opinion is important (*choice awareness*) and 2) presenting treatment information in neutral ways (*neutral information provision*). Evidence for the effectiveness of these communication strategies is lacking. We tested the effects of these strategies on perceived choice awareness and neutrality of information provision (primary outcomes), and recall and trust in the physician (secondary outcomes) in an online video-vignettes experiment across three different disease types (rheumatoid arthritis, kidney disease, cancer). We hypothesized that the combination of *choice awareness* communication and *absence of steering* has the greatest effect on all outcome measures.

Methods:

We developed disease-specific video-vignettes showcasing a physician presenting two treatment options to a patient, and tested the hypothesis in a 2 (presence/absence of choice awareness communication) x 2 (presence/absence of steering) between-subjects design. We recruited participants (120 patients per disease type and 360 healthy subjects) via online panels. Participants were asked to view the video and imagine that they were the patient, and to report the extent to which they perceived 1) choice awareness (1 item, 1-7 point scale) and 2) the physician to have a treatment preference (one item, 1-11 point scale anchored at the two treatment options). We further assessed recall of the treatments' benefits and harms (four free recall questions) and trust in the physician (one item, 5-point scale). ANOVA analyses were used to assess the differences between conditions.

Results:

Recruitment is ongoing, and has just been completed for the general population (GPOP, N=453) and cancer patients (CA, N=95). Initial results show that choice awareness is higher when choice awareness communication was *present* (GPOP: M_{present}=5.14 vs. M_{absent}=4.77, $P=.006$; CA: M_{present}=4.48 vs. M_{absent}=3.43, $P=.008$) and information provision is perceived to be more neutral when steering communication is *absent* (GPOP: M_{absent}=3.65 vs. M_{present}=4.89, $P<.001$; CA: M_{absent}=2.87 vs. M_{present}=4.90, $P<.001$). Multivariate results, results on the other patient groups, and results regarding recall and trust will also be reported.

Conclusion:

The results provide preliminary evidence for appropriate communication strategies that may inform SDM training for medical students and clinicians.

336 - Collaborative model of clinicians, managers and patients engagement in Community-based Primary Care Practices: A feasibility pilot study

Julie Haesebaert^{1,2}, Isabelle Samson³, H  l  ne Lee-Gosselin⁴, Sabrina Guay-B  langer^{1,2}, Jean-Fran  ois Proteau⁵, Luc Vigneault⁵, Annie Poirier⁵, Priscille-Nice Sanon⁵, Genevi  ve Roch^{1,6,7}, Marie-Eve Poitras⁸, France L  gar  ^{1,2,3}

¹Centre de recherche sur les soins et services de première ligne de l'Université Laval, CIUSSS de la Capitale-Nationale, Québec, Québec, Canada, ²Chaire de recherche du Canada en Décision Partagée et application des connaissances, Université Laval, Québec, Québec, Canada, ³Département of Médecine familiale et de médecine d'urgences, Faculté de Médecine, Université Laval, Québec, Québec, Canada, ⁴Département de gestion, Faculté des Sciences de l'administration, Université Laval, Québec, Québec, Canada, ⁵Patient expert, ⁶Centre de recherche du centre Hospitalier Universitaire de Québec – Université Laval, Hôpital Saint-François d'Assise, Québec City, Québec, Canada, ⁷Faculté des sciences infirmières, Université Laval, Québec, Québec, Canada, ⁸Département de médecine de famille et de médecine d'urgence, Faculté de médecine et des sciences de la santé, Université de Sherbrooke, Campus Saquenay, Chicoutimi, Québec, Canada

Introduction: Despite health policy promoting patient-centered care, best practices to engage patients in community-based primary healthcare (CBPHC) are not well defined. We sought to design and assess the feasibility of a collaborative model of councils involving all stakeholders in CBPHC focused on quality improvement (QI) and patient-oriented research projects.

Methods: We conducted a participatory action research in two CBPHC in Quebec City (Canada) to design a model of council composed of patients/caregivers, clinicians and managers. Eligibility criteria for patients/caregivers were to be registered at the CBPHC, motivated, and available to attend the meetings. Six councils' meetings were planned over the study period, facilitated by two patient-experts supporting participants. The councils were invited to identify QI and research needs, prioritized them and plan actions accordingly. Feasibility was assessed through non-participant observation, audio recording of the meetings, self-administered questionnaires and a focus group during the last meeting on participants' perception and predisposition to engage in the councils. We explored gender issues in participation. Thematic analysis and descriptive statistics were used.

Results: Between December 2017 and June 2018, the two councils met 6 times as initially planned. Each council included 11 patients, a manager and a nurse. Sociodemographics were: 64% women, mean age \pm SD 54 \pm 15 years. A mean of 8 patients attended each meeting while the manager and the clinician attended all 6 meetings. One patient in each council left the study. Each council identified over ≥ 35 topics and prioritized: 1) information on CBPHC to new patients, 2) information on prevention programs, 3) quality of appointments services and 4) improving patient sense of belonging to CBPHC. Each council planned actions addressing those topics and 67% of councils' members perceived an impact of the council on the CBPHC. Median satisfaction level was 8 on a 0-10 scale. Motivations to participate were to support clinicians to improve quality of care and services and to improve patient experience. Main limitation was time constraints. Attendance of the clinic manager and facilitation by patient-expert were identified as major strengths.

Conclusions: A collaborative model of councils involving all stakeholders in CBPHC focused on QI and research projects is feasible.

337 - Barriers and Potential Solutions Regarding the Implementation of Patient Decision Aids

Anshu Ankolekar¹, Adriana Berlanga³, Esther Bloemen², Ben Vanneste¹, Cheryl Roumen¹, Andre Dekker¹, Rianne Fijten¹

¹Department of Radiation Oncology (MAASTRO), GROW School for Oncology and Developmental Biology, Maastricht University Medical Centre+, Maastricht, The Netherlands, ²Fontys University of Applied Sciences, Eindhoven, The Netherlands, ³Maastricht University, Maastricht, The Netherlands

Background/aims

Through meta-analyses, patient decision aids (PDAs) have been shown to improve patient's knowledge and enable values clarification to facilitate shared decision-making (SDM). An increasing number of PDAs is being developed and becoming available to the public. However, even with evidence-based benefits, the use of PDAs in routine clinical practice is lagging. The aim of this study was to explore the barriers in the implementation of a web-based PDA in clinical practice and to identify possible solutions to support this process.

Methods

Semi-structured interviews were conducted with urologists (n=8), radiation oncologists (n=4), oncology nurses (n=4), and representatives from patient organizations (n=2). Questions focused on the current decision-making process experienced by these stakeholders, attitudes towards PDAs and ideas for implementation.

Results

Three main barriers were identified by the medical professionals as:

Subsequently, we asked clinicians to propose strategies to overcome these barriers. For instance, clinician involvement in the development process would increase ownership to the content of a PDA. Additionally, personalizing the PDA for both clinicians (adding hospital-specific figures and videos) and patients (based on their risk level and personal characteristics such as education level) was considered beneficial in motivating users. Furthermore, SDM training was deemed essential since PDAs are only a part of the decision-making process.

Conclusion

Our findings are in line with existing literature and highlight the importance of a multi-faceted implementation strategy to support PDA use. Further actions include:

338 - Making Family Engagement and Family Peer Support a Reality in First Episode Psychosis Programs in Quebec

Mary Anne Levasseur¹, Andrea Legros², Cynthia Delfosse³, Amal Abdel-Baki⁴, Manuela Ferrari⁵, Srividya N. Iyer⁶

¹Douglas Mental Health University Institute/PEPP-Montréal, Quebec, Canada, ²PEPP Montréal, Québec, Canada, ³Association Québécoise Premier Episode Psychotique, Centre National d'Excellence en Santé Mentale, Quebec, Canada, ⁴Centre hospitalier de l'Université de Montréal et Association Québécoise Premier Episode Psychotique, Montréal, Québec, Canada, ⁵Douglas Mental Health University Institute, Quebec Canada, ⁶McGill University and Douglas Mental Health University Institute, Quebec, Canada

Background and aim: Psychosis emerges in adolescence/young adulthood, disrupting personal and social development and inflicting suffering on those affected and their family members (FM). Early intervention services (EIS) for psychosis have the potential to reduce illness burden by identifying needs early; making services more accessible and evidence-based; and by orienting care toward recovery. Family-related interventions are strongly linked to positive outcomes in psychosis. Yet, their implementation remains inadequate and inconsistent across EIS. To bridge this gap, service users (SU), FM (as identified by SU), clinicians, researchers and policy-makers came together to design and implement a consensus development conference to generate consensus on how to build capacities to engage FM in SEI services in Quebec. This presentation describes activities, processes, and outcomes of the project.

Methods: The two-day consensus development conference, held in Montreal, including EIS for psychosis in Quebec, SU, FM, service providers, and policy-makers, met to identify: barriers and facilitators regarding family engagement in EIS services, and learning needs of FM, SU, and service providers to promote family engagement in EIS services. Three webinars were created and shared with conference participants to build knowledge and capacity. During the conference a multi-stakeholder panel discussed the importance of involving FM in treatment; experts presented on key topics including family psycho-education; privacy and confidentiality; participants participated in two workshops to identify problems, propose solutions and generate recommendations. A pre/post-conference questionnaire assessed participants' knowledge; attitudes toward FM involved in treatment; and participants' perceived ability to implement changes in their practices. Outcomes of workshop activities were analyzed using thematic analysis.

Results and conclusions: 87 people attended the conference (8 SU; 14 FM; 32 SEI providers; 18 researchers/policy makers); 58 completed the questionnaire (39 providers; 19 SU and FM; 66.6% response rate). The pre/post-conference analysis (paired sample t-test) showed the conference's success in improving knowledge concerning FM engagement in EIS (p.000); attitudes related to involving FM in EIS (p.000); empowering stakeholders to promote changes in clinical programs (p.001). Workshop activities generated recommendations to be disseminated to EIS in Quebec/Canada, and a multi-stakeholder community of practice to work on advancing recovery as part of FEP programs.

348 - Co-construction of Knowledge by Community Members and Researchers in the Planning and Priority-Setting of Heart and Stroke Research in Canada

Krystina B. Lewis^{1,2}, Nedra Peter³, Anita Kothari³, Christine Faubert⁴, Ian D. Graham^{1,5}

¹University of Ottawa, Ottawa, Canada, ²University of Ottawa Heart Institute, Ottawa, Canada,

³University of Western Ontario, London, Ontario, Canada, ⁴Heart and Stroke Foundation of Canada,

⁵Ottawa Hospital Research Institute, Ottawa, Canada

Background

The perspectives of people with lived experience of disease are infrequently integrated into health policy or clinical practice. The Heart and Stroke Foundation of Canada (HSFC) is transforming their approach to strategic planning by using an integrated knowledge translation approach to narrow this knowledge-to-action gap. Six Mission Critical Area (MCA) councils, composed of researchers and community members including people with lived experience, were formed to identify key issues with the greatest potential for impact for patient support and engagement, research, policy, and systems change. Each council is co-led by a community member and researcher. Together, council members are tasked with providing integrated advisory input to the HSFC on emerging issues, trends, and focus areas within the MCAs.

Objectives

The aim of this research is to understand the process of leading and participating on the councils, exchanging and co-constructing knowledge, and identifying the emerging outcomes from this mechanism of engagement.

Methods

One year into the MCA councils' 2-year mandate, we conducted semi-structured interviews with council co-chairs and focus groups with council members to elicit their understanding of the role of MCA councils, activities, processes and outcomes. Data was analyzed using a framework approach.

Results

Seven co-chairs were interviewed and five councils participated in focus groups. Preliminary qualitative analysis from co-chairs interviews showed that councils were engaged in advocacy and activism when proposing and negotiating priorities within and across councils. HSFC staff leadership, meaningful knowledge exchange between council members, and cross-cutting themes across councils were reported as positive features. Staying connected between meetings, ensuring meaningful engagement of community members, and concerns about the diversity of members were suggested as opportunities for growth. Emerging outcomes fell along a continuum, with benefit at the level of MCA councils, HSFC and Canada's population as a whole.

Conclusion

This is the first evaluation of a Canadian research funding organization engaging both community members and leading researchers in the priority-setting of research funding and associated activities. Findings will be used to identify how best to share and mobilize the knowledge within a council composed of researchers and laypersons tasked with providing advice to a funding organization.

349 - Development of a Single-item Medical Maximizer-Minimizer Screening Question

Brian J. Zikmund-Fisher², Laura D. Scherer¹

¹University of Colorado, Denver, ²University of Michigan

Background: The validated 10-question Medical Maximizer-Minimizer Scale (MMS) reliably discriminates between people who generally prefer more medical interventions versus those who prefer a “watch and wait” approach to healthcare. The MMS predicts an array of outcomes, such as the number of medications that people report taking and preferences to receive cancer screening. However, due to its length, the MMS is impractical for clinical use and some research applications. Therefore, we sought to identify a single question alternative.

Methods: We first developed a new question that asked respondents to self-identify as maximizers or minimizers after reading a short descriptive paragraph. We then conducted a new online survey of 834 U.S. adults that included all original MMS questions, the new question, and medical preference scenarios used in our past research. We conducted correlation analyses between the MMS, individual questions (both original and new), and scenario preferences.

Results: Our newly-developed question failed to correlate highly with the MMS, so we examined questions from the 10-item MMS for use as single-item indicators. One question stood out: “If I have a medical problem, my preference is to go straight to a doctor and ask his or her opinion”. In prior studies, this item (which we now designate the MM1) had the highest factor loading and predicted the greatest number of outcomes. In the new study the MM1 was the most strongly correlated with both MMS scores and preference outcomes. Examining the new data and a prior data set, sensitivity for detecting maximizers ($MMS > 4$ and $MM1 > 4$) was 75% and 86% respectively, and specificity ($MMS < 4$ and $MM1 < 4$) was 84% and 85% respectively. Of participants classified as maximizers only 4% were actually strong minimizers ($MMS \leq 3$); of participants classified as minimizers only 1% were actually strong maximizers ($MMS \geq 5$).

Conclusions: The MM1 single question reliably discriminates among people with medical maximizing versus minimizing tendencies. Its predictive validity approaches that of the full MMS in predicting both preferences for receiving high-value care and willingness to forgo low value care. Use of the MM1 should enable broader assessment of maximizing-minimizing tendencies in both clinical and research contexts.

350 - Diverse perspectives on disability, pain and suffering, and coping among women experiencing the threat of a periviable delivery

Brownsyne Tucker Edmonds¹, Shelley M. Hoffman¹, Tatiana Laitano¹, Erin Jeffries¹, Karen Kavanaugh^{2,3}

¹Department of Obstetrics & Gynecology, Indiana University School of Medicine, Indiana, USA,

²Children's Hospital of Wisconsin, Wisconsin, USA, ³University of Illinois at Chicago, College of Nursing, Illinois, USA

BACKGROUND: Racial/ethnic differences in periviable resuscitation decision-making may reflect underlying cultural differences in patients' values and preferences, as well as attitudes on death and disability. To explore these differences in greater depth, we sought to qualitatively assess whether perceptions of disability, pain/suffering, and coping in periviable delivery differed by maternal race and ethnicity.

METHODS: We recruited 30 women hospitalized for threatened periviable delivery (22-24 weeks gestation). Semi-structured interviews were conducted prior to delivery, after neonatologists counseled women regarding their options to resuscitate or palliate their neonate. Participants were asked to describe their perceptions of disability, pain/suffering, and coping. Interviews were coded and analyzed using NVivo12.

RESULTS: Results were stratified by white (15 Caucasian) and non-white women (11 Black/African-American, 2 Hispanic/Latina, 1 Asian, 1 multiracial). Women commonly expressed love, acceptance, and willingness to adapt/adjust to care for a child's special needs. Short-term pain was described as a 'necessary evil' or 'means to an end'. White women voiced concern for the child's quality of life and described long-term suffering as "torture" and "misery"; whereas nonwhite women were focused almost exclusively on immediate survival, with few comments of life beyond the NICU. Overall, there was more optimism and resilience voiced among the nonwhite women versus realism and reluctance among the white women. Nonwhites spoke of their child's 'strength' and 'fight,' while white women spoke more readily about withdrawing care if treatments were going to "harm more than help." With regard to coping, nonwhite women seemed to utilize denial, avoidance, and faith more readily. Both recognized the importance of social support. Strikingly, the majority of nonwhite women reported that doctors had not addressed the baby's comfort or pain/suffering; while most white women were able to relay details of such discussions to the research assistant.

CONCLUSION: Although the majority agreed that their child would be loved and accepted, there were distinct racial differences in maternal coping (resiliency vs. reluctance), tolerance for pain/suffering (fight vs. torture), and focus on immediate survival vs. future quality of life. Understanding the impact of race/ethnicity and culture on resuscitation decision-making may help tailor interventions for diverse families facing periviable birth.

354 - Chez moi, mes choix: une étude descriptive.

Caroline Cayer^{1,3}, Nicole Dubuc^{1,2}, Caroline Bois¹

¹Université de Sherbrooke, ²CdRV - CIUSSS de l'Estrie - CHUS, Université de Sherbrooke, ³CIUSSS de l'Estrie-CHUS

Au Québec, près d'une personne sur 10, âgée de 65 ans et plus, bénéficie de soins et services du programme de soutien à domicile. Lors d'une demande, un intervenant rencontre ces personnes afin d'obtenir un portrait de leurs besoins puis un plan d'intervention ou de services est établi. Les premières étapes de ce processus sont déterminantes, car plusieurs décisions y sont reliées. Afin de favoriser la participation des aînés dans ces décisions les nouveaux Outils de Cheminement Clinique Informatisés (OCCI) implantés au Québec ont été développés de façon à permettre aux personnes âgées d'exprimer leurs préférences.

Les objectifs de cette étude menée en 2018, étaient de décrire le processus décisionnel menant à l'établissement d'un plan d'intervention ou de services à l'aide des OCCI et d'identifier les obstacles et facteurs facilitant la participation des aînés aux décisions.

Nous avons réalisé une étude exploratoire descriptive-interprétative avec données mixtes. Treize groupes composés d'un intervenant, d'un aîné et, à l'occasion, d'un proche ont été observés lors de visites à domicile. L'utilisation des fonctionnalités des OCCI favorisant la participation des aînés a été observée. Les décisions prises ont été identifiées et cotées selon leur niveau de partage à l'aide de l'outil OPTION 5. La perception du niveau de partage des décisions entre les participants des différents groupes a été comparée. Un groupe de discussion focalisée impliquant dix intervenants ayant participé à la première phase a permis d'identifier les barrières et facilitateurs.

Les résultats ont permis de constater que les fonctionnalités des OCCI sont sous-utilisées, qu'en moyenne 3.2 décisions sont discutées avec l'aîné et son proche, que le score moyen du niveau de partage de ces décisions est faible mais que les perceptions du niveau de partage sont, elles, élevées et semblables entre les participants des groupes. Les barrières et facilitateurs relèvent de trois grandes catégories: l'organisation/système, les aînés/proches et les intervenants.

Cette étude nous a permis d'obtenir un portrait des pratiques visant l'implication des personnes âgées dans les décisions dans ce contexte et de fournir des recommandations pratiques pour optimiser les OCCI et leur utilisation ainsi que pour la formation des futurs utilisateurs.

356 - Optimiser les services d'éducation prénatale de groupe et en ligne : pour des décisions informées dans les continuums périnataux

Geneviève Roch^{1,2,3}, Geneviève Lapointe^{1,2,4}, Holly Witteman^{1,2,3}, Élisabeth Parent¹, Julie Poissant⁵, Geneviève Painchaud Guérard², Caroline Vaillancourt², Marie-Pierre Gagnon^{1,2,3}

¹Université Laval, Québec, Canada, ²Centre de recherche du CHU de Québec-Université Laval, Québec, Canada, ³Centre de recherche sur les soins et les services de première ligne de l'Université Laval (CERSSPL-UL), Québec, Canada, ⁴CISSS de Chaudière-Appalaches, Québec, Canada,

⁵Université du Québec à Montréal (UQAM), Québec, Canada

Introduction: Les services d'éducation prénatale contribuent à soutenir les futurs parents dans leurs décisions de santé. En réponse aux enjeux d'accessibilité et à l'évolution des besoins, certains établissements intégrés de santé et de services sociaux (EISSS) québécois recommandent l'intégration d'éducation prénatale en ligne (EPL) à leurs services, tout en poursuivant l'offre d'éducation prénatale de groupe (EPG) en présentiel. Certaines études démontrent que l'EPG contribue notamment au développement de connaissances permettant des décisions informées en matière d'accouchement ou d'allaitement. Cependant, l'hétérogénéité des services d'ÉPG menace ces retombées attendues en pratique. De plus, rares sont les études portant sur l'utilisabilité de l'ÉPL que les établissements intègrent à leurs services périnataux. **Objectifs :** Caractériser les services d'EPG dispensés et l'utilisabilité de l'EPL recommandés par les EISSS pour dégager des pistes d'optimisation avec des décideurs, des cliniciens et des représentants de parents. **Méthodes :** Approches de recherche collaboratives incluant : 1) caractérisation des services d'ÉPG et d'ÉPL réalisée via une méthode *environnemental scan* avec sources documentaires (N= 106) et entretiens auprès d'infirmières formatrices (N = 26); 2) tests d'utilisabilité utilisant la méthode de pensée à voix haute auprès de femmes enceintes et de leur partenaire (N = 11) pour documenter l'interface d'ÉPL. **Résultats :** Les principaux enjeux d'harmonisation des services d'EPG se rapportent à l'organisation (p. ex. coûts, accès), au format (p. ex. nombre de séances) et au contenu (p. ex. nombre de thématiques abordées, temps alloué). Les tests-utilisateurs sur l'interface d'EPL ont permis d'identifier différents problèmes d'utilisabilité, d'ergonomie et de design nuisant à l'accès, à la compréhension de l'information et à la crédibilité du contenu. Via des stratégies d'application intégrée, les constats préliminaires ont pu être discutés au profit d'une amélioration des services axés sur l'équité et les besoins des futurs parents. **Conclusion :** L'harmonisation des services d'EPG et la convivialité de l'EPL sont essentiels à une offre de régionale intégrée permettant aux usagers d'accéder aux informations requises aux décisions à prendre tout au long du continuum périnatal. En misant sur une approche collaborative, les services éducatifs peuvent progressivement être optimisés afin de soutenir des choix informés en matière de santé périnatale.

358 - Shared Decision Making Randomized Trials: Choosing Patient, Clinician or Site Level

Megan Branda^{1,2}, Juan P. Brito Campana², Marleen Kunneman², Victor M Montori²

¹University of Colorado-Denver, ²Mayo Clinic, Minnesota, USA

Background and aims: Randomized trials with shared decision making (SDM) intervention should account for potential clustering effect at the clinician and/or site level. To gain insight into the (quality) of the analyses and interpretations of available SDM trials, we assessed (1) how these trials accounted for clustering, and (2) how they reported relevant intra-cluster correlation coefficients (ICC).

Methods: We accepted the list of eligible trials from the latest version of the Cochrane review regardless of level of randomization. We then extracted information about efforts to adjust for clustering analytically, and their reporting of ICCs.

Results: 81 clinical trials were evaluable for assessment, of which 31 were cluster-randomized trials (CRT) and 50 patient-level randomized trials (PRT). Of the 31 CRT, 26 accounted analytically for clustering. Only 5 of these reported ICCs exactly or referred to them in the text of which most reported low ICCs values with researchers deciding to ignore negligible clustering effects, i.e., converting the planned analyses to a fixed-effects model. Of the 50 PRT, 11 used a mixed-effect model to account for clustering at practice, site or clinician level. Of these, 4 included ICC values in text and 1 provided values at the outcome level in a table. The remaining 39 patient-level randomized trials did not assess nor mention impact of clustering.

Conclusion: Clustering is likely to be common in SDM trials, particularly among those in which the intervention is delivered by clinicians or clinics or the outcomes are mediated by their actions (e.g., decisional outcomes). Yet, clustering is commonly ignored in the design or analysis of trials evaluating the efficacy of SDM interventions. The effect of this limitation does not change the effect size but may overestimate the precision of reported findings (receive too much weight in a meta-analysis). Lack of reporting of ICCs limits the ability of researchers to use these data to plan adequately sized trials of SDM interventions.

360 - Shared decision-making in child and adolescent mental health: a scoping review and quality assessment of available parent-involved interventions

Shaun Liverpool^{1,3}, Brent Pereira², Daniel Hayes^{1,3}, Miranda Wolpert^{1,3}, Julian Ebrooke-Childs^{1,3}

¹Anna Freud National Centre for Children and Families, London, UK, ²The Chicago School of Professional Psychology, IL, USA, ³University College London, London, UK

Background: Parents play a critical role in child and adolescent mental health care and treatment. With the increasing implementation of shared decision-making (SDM) across health settings, there is a growing need to understand the decision support interventions used to promote SDM in child and adolescent mental health services. The overall aim of this review is to identify and examine the existing decision support interventions available for parents of children with mental health problems.

Methods: A broad search was conducted using the key concepts “shared decision-making”, “parents” and “child and adolescent mental health”. Five electronic databases were searched: PsycInfo, Embase, Medline, Web of Science and the Cochrane Library. In addition, we searched the Ottawa’s Inventory of Decision Aids, Children’s Hospital of Eastern Ontario website, Google, Google Play and known children’s mental health services’ websites.

Results: The search identified 23 interventions available for use by parents. Interventions were used with various disorders and adopted various modalities including online and paper versions. The majority of the interventions “present options” and “discuss pros and cons”. Factors influencing usage varied across modality and purpose. This review highlighted positive reports on usefulness and acceptability of parent-involved interventions.

Conclusions: Our findings suggest that SDM interventions should be web-based/online and require minimal training for both service providers and service user to increase usage. This review serves to bring awareness of existing parent-involved interventions and can inform guidelines for the development, implementation and usage of new interventions.

362 - Tremblay MC, McGavock J, Witteman HO.

Ndjaboue R¹, Chipenda Dansokho S¹, Dogba MJ^{1,2}, Bianca B¹, Price R², Delgado P², McComber AM², Drescher O^{1,2}, Tremblay MC¹, McGavock J³, Witteman HO.^{1,2}

¹Université Laval, ²Diabetes Action Canada, ³University of Manitoba

Background and aim: To draw on the perspectives of people living with diabetes to identify areas for improvement in health care.

Methods: Using a qualitative descriptive approach, we conducted video interviews with 21 men and women living with diabetes (hereafter called expert patients) from diverse backgrounds, including Indigenous people and immigrants to Canada. Expert patients were recruited through Diabetes Action Canada, a national Patient-Oriented Research network. Three researchers independently analysed videos using framework analysis, resolving differences through discussion until consensus was achieved. We created learning video modules using patients' narratives and two residents in family medicine independently observed the occurrence of competencies in the Canadian Medical Education Directions for Specialists-Family Medicine (CanMEDS-FM) competency-based medical education framework.

Results: Expert patients suggested that improving health professionals' communication skills, including shared decision making, is crucial to improve healthcare. Patients encouraged health professionals to engage patients in more respectful, honest, empathic and open dialogue, to address specific concerns of patients and families, to integrate patients' values and preferences in care, to provide culturally safe and non-marginalized care, to share high-quality diabetes-specific evidence (e.g. risks of complications) with patients in ways that will foster shared decision making, and to discuss all aspects of patient's life related to diabetes management, including emotions, daily challenges and previous experiences. Indigenous patients pointed in particular to the need for health professionals to better understand Indigenous worldviews and to discuss the impact of settler colonialism on Indigenous peoples' health; for example, the history of food deprivation at residential schools. The high occurrence of CanMEDS-FM competencies in our learning video modules supports our findings and suggests that these tools may be interesting and relevant to medical education.

Conclusion: Expert patients suggest that improving communication skills of health professionals can improve diabetes care. Because expert patients' views align with CanMEDS-FM competencies used in many medical schools, our learning modules has the potential to complement academic training in diabetes care. Our next steps with this research will be to evaluate the effects of video learning modules on current and future health professionals' knowledge, emotions, empathy, and behavioural intentions.

364 - Shared Decision-Making in Public Health: Communicating Risks and Benefits When Decisions Can Affect Other People's Health

Hina Hakim¹, Christine T. Chambers², Eve Dubé³, S. Michelle Driedger⁴, Teresa Gavaruzzi⁵, Anik M. C. Giguere¹, Noah M. Ivers⁶, Éric Kavanagh¹, Shannon MacDonald⁷, Rita Orji², Elizabeth Parent¹, Jean-Sébastien Paquette¹, Jacynthe Roberge¹, Beate Sander⁶, Aaron Scherer⁸, Martin Tremblay-Breault¹, Bryna Warshawsky⁹, Kumanan Wilson¹⁰, Daniel Reinharz¹, Holly O. Witteman¹

¹Laval University, Quebec City, Canada, ²Dalhousie University, Halifax, Canada, ³Institut national de santé publique du Québec, Quebec City, Canada, ⁴University of Manitoba, Winnipeg, Canada, ⁵University of Padova, Italy, ⁶University of Toronto, Ontario, Canada, ⁷University of Alberta, Edmonton, Canada, ⁸University of Iowa, Iowa City, United States, ⁹Public Health Ontario, Ontario, Canada, ¹⁰University of Ottawa, Ontario, Canada

Background and aim: Medical decisions often require consideration of risks and benefits at the individual level. Considerable evidence exists regarding how to optimally communicate such individual-level risks and benefits. Less evidence exists about how to communicate interrelated individual- and population-level risks and benefits (e.g., herd immunity in infectious disease). We aimed to address this by designing a dynamic visualization about herd immunity and optimizing cognitive and emotional responses to the visualization.

Methods: Our multidisciplinary team developed a dynamic visualization (a short animated video) about herd immunity based on epidemiological evidence. The visualization shows how different parameters (e.g., vaccine coverage, intra-community contact) influence herd immunity. We predefined communication goals, created visualizations accordingly, and tested iterative versions of our visualization in a university-based human-computer interaction laboratory and community-based settings (a cafeteria, two shopping malls, a public library) across three iterative cycles. Data included psychophysiological measures (eye tracking, galvanic skin response, electroencephalogram) to assess people's interaction with the visualization, and qualitative data (e.g., think-aloud) to assess their interpretations of the visualization content.

Results and analysis: Participants (n1=8, n2=11, n3=83) were 59% women, 37% men (4% not reported), with mean age 41 years (SD 16). Participants' education levels demonstrated acceptable distribution across all levels in the context of population statistics. Many responses aligned with our communication goals. For example, when the visualization showed an infection moving from person to person, this drew participants' attention. Participants demonstrated higher emotional arousal, indicating potential stress or fear, when the visualization showed an infection infecting a baby or older person. However, details such as images and descriptions of different viruses proved confusing and were therefore removed from later versions. Overall, after viewing the visualization, participants' verbal reports suggested they understood how, when sufficient community members are vaccinated, herd immunity safeguards vulnerable community members.

Conclusions: Our prototypes of a dynamic visualization showed promise as methods for conveying interrelated individual- and population-level risks and benefits. We are currently refining the final version of our visualization in preparation for an online randomized controlled trial of its effects on risk perception, knowledge, and vaccination intentions.

366 - Fostering collaboration with patients, users and lay caregivers at INESSS: Lessons learned

Olivier Demers-Payette¹, Marie-Pascale Pomey^{1,2,3}, Isabelle Ganache¹, Mireille Goetghebeur¹, Denis Roy¹

¹Institut national d'excellence en santé et en services sociaux, ²École de santé publique - Université de Montréal, ³Centre de recherche du CHUM

Background: Collaboration with patients, users and lay caregivers in health technology assessment (HTA) projects is increasingly valued to ensure impact of guidelines developed to support healthcare decision-making. However, the 'whom', 'what', 'when' and 'how' of this participation is not well understood. In this context, we share the experience of the National Institute of Excellence in Health and Social Services (INESSS) with novel modalities to engage with patients, users and lay caregivers in its HTA processes and challenges encountered.

Methods: Multiple case study of INESSS's projects during the last five years (2014-2019).

Results: The comparison of more than fifteen projects give rich insights to define the specific contribution of each actor involved (the 'whom' and 'what'), to identify HTA projects that will most benefit from collaboration (the 'when') and to determine the best modalities to engage (the 'how') with them. Lessons learned from this analysis help INESSS to distinguish patients from users, lay caregivers, patient representatives or citizens in terms of expected roles and contributions, participation objectives and privileged types and places of involvement. It also offers benchmarks for targeting projects that will most benefit from their participation. Last, it gives a better understanding of the strengths and limits of novel involvement modalities implemented in HTA projects at INESSS, including the patient partnership jointly developed with a pioneering academic centre.

Conclusion: This multiple case study provides in-practice insights of collaboration with patients, users and lay caregivers in HTA. This understanding is important to generate real learning opportunities for everyone. In the context of rising costs and uncertainty around health technologies and interventions, creating value from stakeholders' engagement is crucial for the accuracy of recommendations and to have an impact on healthcare.

369 - The Participatory Research to Action Framework: Guiding design, embedding processes, and lessons learned in shared decision making - Part 2: Using the PR2A to guide design

Paul Holyoke¹, Courtney Shaw¹, Margaret Saari¹, Heather McNeil¹, Bilal Khan¹, Karthika Yogaratnam¹

¹SE Health Research Centre, Markham, Ontario, Canada

Background: People who are homeless in Canada frequently live with one or more life limiting conditions, and yet they are often underserved by traditional palliative care services. A group of researchers identified this gap in services, and utilized the PR2A framework to collaboratively co-design a palliative care curriculum for social care workers who routinely interact with homeless clients. This presentation will highlight how the PR2A framework enabled shared decision making with key stakeholder and influenced the design process.

Methods: For this project, the PR2A framework was used in conjunction with the knowledge as action framework. Researchers engaged in an iterative design process with social care workers who support homeless clients from across Canada to create a palliative approach to care curriculum. The use of the PR2A framework created opportunities for these stakeholders to feedback on both content and presentation of the curriculum.

Results: The use of the PR2A framework in this design process means the final version of the curriculum is highly responsive to the needs and desires for training of the target population. Multiple stakeholder sites across Canada- including those who were not involved in the design process- have volunteered to participate in the trial evaluation measuring the impact of the training. Early results suggest the PR2A approach has facilitated the design of a curriculum which has broad appeal for the target audience and has high levels of face validity.

Conclusion: The PR2A framework creates opportunities for genuine partnership and collaboration with stakeholders. The methodology highlights the importance of shared decision making in the design process leading to final products which are acceptable and transition readily to practice.

370 - The Participatory Research to Action Framework: Guiding design, embedding processes, and lessons learned in shared decision making - Part 3: Using PR2A to embed shared decision making processes

Paul Holyoke¹, Courtney Shaw¹, Margaret Saari¹, Heather McNeil¹, Bilal Khan¹, Karthika Yogaratnam¹

¹SE Health Research Centre, Markham, Ontario, Canada

Background: The healthcare system is facing unprecedented challenges in ensuring older adults receive the right care, in the right place, at the right time. Gaps in health and social services have led to patients experiencing prolonged hospitalizations and delayed discharges which has negative patient and system outcomes. To facilitate successful hospital to community transitions SE Health and hospital partners established community-based reactivation programs. We share our learnings of how the PR2A Framework guided the design of three reactivation programs.

Methods: Guided by the PR2A Framework we used a mixed methods design and realist evaluation to understand the population, processes and outcomes of three reactivation programs implemented by SE Health in the Greater Toronto Area. Systems mapping using a human factors framework was undertaken to describe the processes and activities of 'reactivation' and explore the potential causal relationships between social and technical aspects of the program. These systems maps were complimented by interview and focus group data from clients and providers to explore their experiences of the program.

Results: The data from these research activities was feedback in a co-design process where frontline staff were invited to create a care planning process that was both evidence based, and person centered. The use of the PR2A framework in this design process enabled shared decision making between all members of the care triad to be embedded into routine care practices at the reactivation sites.

Conclusions: The PR2A framework, when used in conjunction with human factors informed systems mapping and qualitative methodology, can be used to co-design care planning and care activities which codify and normalize shared decision making in routine operations in community based reactivation programs.

380 - A Systems Approach to Shared Decision Making: Embedding SDM into Practice in Safety Net Clinics

Marla L. Clayman¹, Danielle Lazar², Glyn Elwyn³, Marie-Anne Durand³

¹American Institutes for Research, Illinois, USA, ²ACCESS Community Health Network, Illinois, USA,

³Dartmouth College, New Hampshire, USA

Background and aims

Widespread implementation of shared decision making has continued to elude most healthcare systems, particularly safety-net clinics. ACCESS is a network that serves roughly 180,000 unique patients a year from a mostly poor and ethnic-minority population.

ACCESS is in the process of implementing SDM as standard practice across its health network, with a goal of internal sustainability.

Methods

A comprehensive plan to implement SDM was developed and includes: leadership commitment; initial assessment; engaging outside expertise; development of internal clinical committee; SDM training of various types; feedback; and evaluation.

Results

Several steps have been implemented. Senior leadership and other key stakeholders were introduced to SDM and its fit as an extension of the organization's work as a patient-centered medical home. Plans to implement more widely were reviewed and endorsed by leaders including the Chief Medical Officer and CEO.

In 2017, an introduction to SDM was presented at an "All providers" meeting for physicians and nurse practitioners, with roughly 150 people in attendance. Shortly thereafter, 15 regional medical directors and nurse-practitioner mentors received additional training on using decision aids. Similar training on SDM was held with other groups including health center managers and care coordinators.

A workgroup of 6 providers was convened to provide ongoing input and expertise. Based on feedback from the pilot groups, leadership endorsed 1:1 training with providers. Providers were offered times to have trainings using the 3-Talk model of SDM. Three SDM experts provided training in 15 clinics so providers could minimize time away from clinic, and the trainers could see real-world environments for implementation.

For sustainability, in 2018, 10 providers chose to become "embedded experts." These providers received additional SDM training and guidance on training others to implement SDM. All providers are expected to undergo annual refresher trainings on SDM, and each embedded expert is expected to conduct one training each quarter.

Conclusions

Implementing and sustaining SDM requires a long term strategy that requires multiple phases of testing and training, as well as investment from leadership and plans for the institution to take ownership of the concept and material.

382 - Implementation of two SDM trainings for oncologists: A process evaluation

Sarah Dwinger¹, Kathrin Gschwendtner², Lukas Lange¹, Christiane Bieber², Corinna Bergelt¹, Martin Härter¹

¹University Medical Center Hamburg-Eppendorf, ²University Hospital Heidelberg

Background

Due to high participation barriers it is hard to convince physicians to take part in SDM trainings. We implemented two dissemination strategies of an SDM training (face-to-face vs. web-based) to overcome these barriers. Based on the consolidated framework for implementing research (CFIR) we aim to reflect on the different aspects within this study.

Methods

We follow the CFIR to describe the implementation process for two dissemination strategies for a SDM training for physicians on the different levels: interventions characteristics, outer setting, inner setting, characteristics of individuals and process. Aim is to assess the feasibility of such trainings in different settings (inpatient, outpatient) and with different sub-populations (e.g. position in hierarchy, years of work experience). We evaluate satisfaction and usefulness by questioning the participants, the use of the trainings by measuring response and application rate of the approached physicians, barriers and facilitators were measured by notes, documentary data and interview data.

Results

Satisfaction: Of the 39 participants of the face-to-face training 77% were “satisfied”, 21% “rather satisfied” and 98% would recommend it to colleagues. Of the 29 participants of the web-based tutorial 45% were “satisfied”, 48% were “rather satisfied” and 86% would recommend it. *Usefulness:* 87% of the face-to-face and 86% of the web-based training participants “will use what they learned for their work”. *Infiltration:* 3.582 physicians were approached by different acquisition strategies. 6.1% (N=218) declared to participate, of which N=91 dropped out in the further course of the study. 64% already withdraw their expression of interest before starting the study. Gender, position in hierarchy, work experience and specialization were not associated with withdrawal rates, but the rates differed between the two study centres. There were some important *facilitators*, like dedication of the head of the department and existing interest in communication, and *barriers*, like work load, sickness rates and pregnancy.

Discussion

The trainings are well accepted and seem to be useful for the work of the participants. Nevertheless, it is difficult to convince physicians to participate and to prevent them from dropping out. Strategies, like a clinical champion initiative or a certification for the clinic could prevent that phenomenon.

383 - The Shared Decision Making Scorecard – an Application-Oriented Business Management Tool for Comprehensive SDM Implementation at a German University Hospital

Kai Wehkamp^{1,2,3}, Heike Klein^{1,3}, Christine Kuch^{1,3}, Claudia Hacke^{1,3}, Lea Kruse^{1,3}, Salim Greven^{1,3}, Gesine Hoppenstedt^{1,3}, Fülöp Scheibler^{1,3}, Ulrich Rueffer⁴, Friedemann Geiger^{1,3}

¹University Medical Center Schleswig-Holstein, Project SHARE TO CARE, Kiel, Germany, ²University Medical Center Schleswig-Holstein, Department of Internal Medicine I, Kiel, Germany, ³University Medical Center Schleswig-Holstein, Department of Pediatrics I, Kiel, Germany, ⁴TakePart Media & Science, Cologne, Germany

Background:

In 2017, the SHARE TO CARE project started at the University Hospital of Kiel as Germany's largest SDM project. The project aims at the comprehensive implementation of SDM in every clinical department, an approach so far unprecedented in Germany. One of the challenges emerging throughout the project was to maintain SDM routine amongst the complexity and multitude of other important processes within a university hospital. We postulated that for the monitoring of SDM, it might be beneficial to use established business administration tools. Examples of these tools are the Balanced Scorecard (BSC) and Key Performance Indicators (KPI), both commonly used to monitor the success of operational or process-related organizational activities. The goal of this study was to identify aspects of organizational SDM activities that are eligible to be merged into a performance management tool.

Methods:

As a first step, previously defined project evaluation parameters were checked for reasonable use in a continuous measurement process following the concept of BSC and KPI. Additionally, the different interventions of the project were checked for deduction of further potential performance parameters. The identified parameters were discussed for practical operationalization, reference values, informative value, method and supposed effort for data collection. Based on these results, eligible items were selected and merged into a practical performance report.

Results:

Three main categories with each about four items like staff's training level, use of decision aids and others were composed as an SDM performance management tool, referred to as the SDM Scorecard. Reference values and routine of data collection were defined. The report went live to distribution on a biweekly base with evaluation and feedback measures for a close continuous improvement process.

Conclusion:

Hospitals are complex organizations and can be approached by using corporate development and business administration tools. In this context, the SDM-Scorecard may serve as a practical instrument to promote and maintain sustainable use of SDM in hospitals and therefore support SDM implementation. The SDM Scorecard could be connected to future external SDM quality indicators. Further studies should examine continuous development and practical impact and effectiveness of these measures.

384 - Effects of telephone-based health coaching on patient-reported outcomes and health behavior change: a randomized controlled trial

Sarah Dwinger¹, Farhad Rezvani¹, Levente Kriston¹, Jörg Dirmaier¹, Martin Härter¹

¹University Medical Center Hamburg-Eppendorf

Objective: Self-management is a major approach in the treatment of chronic conditions. Telephone based health coaching (TBHC) seems to be a promising approach to foster self-management. Aim of this study was to evaluate the effectiveness of a specific TBHC for people living with chronic conditions in Germany on patient-reported outcomes (PRO) and health behavior. The TBHC, carried out by trained nurses in two study centers, was based on motivational interviewing, goal setting, and shared decision-making.

Methods: Patients insured at a statutory health insurance were randomized to an intervention group (TBHC) and a control group (usual care), using a stratified random allocation before giving informed consent (Zelen's single-consent design). All PROs, like health behaviors, health psychological measures and mental health, were assessed yearly for three years. We used mixed effects models utilizing all available data in a modified intention-to-treat sample for the main analysis. Participants and study centers were included as random effects. All models were adjusted for sociodemographic variables (age, education).

Results: Of the 10,815 invited patients, 4,283 returned their questionnaires at baseline. The mean age was 66.3 years (SD=9.3) and 55.5% were female. TBHC was significantly superior to the usual care regarding 6 of 19 outcomes: physical activity in hours per week ($p = .030$), physical activity measured in metabolic rate per week ($p = .048$), BMI ($p = .009$), measuring blood pressure ($p < .001$), **patient activation** ($p < .001$), and **health literacy** ($p < .001$). Regarding the **stages of change** ($p = .005$) the IG also showed statistically different results than CG, but the conclusion remains inconclusive. Standardized effect sizes were small. TBHC did not show any effect on the other variables of the trial: mental QoL, health status, alcohol, smoking, adherence, measuring blood sugar, foot monitoring, anxiety, depression and distress.

Conclusion: TBHC interventions might have small effects on some patient reported and behavioral outcomes.

Practice Implications: Future research should focus on analyzing which intervention components are effective and who exactly profits most from TBHC interventions to improve this promising intervention.

385 - Shared decision-making when numerous options exist: development of a patient decision aid that simplifies choices.

Nick Bansback^{1,2}, Judy A. Chiu², Robert Carruthers¹, Rebecca Metcalfe^{1,2}, Emmanuelle Lapointe¹, Alice Schabas¹, Marilyn Lenzen³, Larry D. Lynd^{1,2,4}, Anthony Traboulsee¹

¹University of British Columbia, British Columbia, Canada, ²Centre for Health Evaluation & Outcome Sciences, British Columbia, Canada, ³Patient Partner, British Columbia, Canada, ⁴Collaboration for Outcomes Research and Evaluation, British Columbia, Canada

Background: Seven different first-line disease modifying therapies (DMTs) are available for patients with relapsing multiple sclerosis (RMS). Learning about the differences between DMTs and which best matches individual values can be cognitively challenging and confusing. This confusion can lead to decision uncertainty about whether to initiate and adhere to treatment. We sought to develop an interactive patient decision aid (PtDA) which simplified the decision-making process and promote informed value based choices.

Methods: The web-based prototype PtDA was developed following the IPDAS guidelines for development and began with extensive mixed methods research in collaboration with our patient partner. Two unique features were developed to simplify decisions. First, sequential decision-making such that at the first decision point, the beta-interferon drugs were presented as a single option. If selected, a second decision described the three options within this class of drugs. Second, the values clarification exercise was used to order DMTs such that those that best matched values were seen first. We first conducted usability testing using focus groups and an online survey. We then tested the preliminary effectiveness in 50 participants recruited from the University of British Columbia's MS Clinic to participate in an online survey or a focus group.

Results: Participants (n=49) experienced significantly lower decisional conflict and increased knowledge of MS and MS treatments after using the PtDA (pre and post mean (SD): 1.64 (1.31) and 2.70 (1.23)). Participants' knowledge of MS and MS treatments also significantly increased; (pre and post mean responses correct (SD): 3.14 (1.04) and 5.39 (1.41)). Of the 15 participants that have completed the 6-month follow-up so far, 11 (73%) are adherent to the medication choice they made with their neurologist – higher than typical rates.

Conclusions: This mixed methods study has led to the development of a PtDA that can support patients with RMS as they make treatment decisions. Future studies will assess effectiveness compared to simpler, paper based decision aids, the feasibility of implementation beyond our one clinic, and the impact of the PtDA on both the timely treatment initiation and longer-term adherence.

387 - Long-term effect of patient decision aids on use of joint replacement and health care costs

Logan Trenaman¹, Dawn Stacey², Stirling Bryan¹, Katherine Payne³, Gillian Hawker⁴, Nick Bansback¹

¹University of British Columbia, Vancouver Canada, ²University of Ottawa, Ottawa Canada, ³The University of Manchester, Manchester UK, ⁴The University of Toronto, Toronto Canada

Background and aim

There are concerns that a third of joint replacements are performed inappropriately in patients with mild symptoms. Shared decision-making supported by patient decision aids may improve the quality of care and contain costs, as informed patients tend to favor conservative treatment. Two randomized trials (RCTs) found lower utilization of joint replacement in those exposed to decision aids over the short-term, however, it is unclear whether this persists. This aim of this analysis was to evaluate the effect of decision aids, compared to usual care, on 1) utilization of total hip and knee replacement, and 2) osteoarthritis-related costs.

Methods

Participants in a Canadian, prospective multicenter, parallel group, single blind, two-arm RCT were linked to administrative databases which covered hospitalizations, physician billings, inpatient and outpatient rehabilitation, and drugs for individuals age 65 and older. Osteoarthritis-related resource use was identified using relevant ICD-10 codes. The proportion undergoing surgery at two and seven-years were compared using chi-squared tests. Costs were adjusted to 2016 Canadian dollars, and discounted at 1.5%. Mean per-patient costs were compared using two sample t-tests.

Results

Linked data were available for 324 individuals, with an average follow-up of approximately seven years. At two-years follow-up 119 of 161 (73.9%) patients in the intervention and 129 of 163 (79.1%) patients in the usual care arm had undergone surgery ($X^2=1.23$, $p=0.27$). At seven-years, 17 additional patients in both the intervention (136 of 161, 84.4%) and usual care arm (146 of 163, 89.6%) had undergone surgery ($X^2=1.86$, $p=0.17$). Mean per-patient costs were lower in the decision aid arm (\$21,965 vs. \$23,681), but this was not statistically significant ($p=0.39$).

Conclusions

The findings suggest the trend of a lower utilization of joint replacements as health care costs in patients exposed to decision aids may be maintained over the longer-term. While suggestive, neither outcome was statistically significant, and the trial was not adequately powered to detect a difference in use of joint replacement. Further, this analysis did not consider patient outcomes. At two-years follow-up health outcomes were comparable between the two groups but this could have changed over time.

390 - Effects of Shared Decision-Making for Anxious and Depressed Youth: Preliminary Results of a Randomized Trial

David Langer^{1,2}, Lindsay Holly², Martha Thompson², Celia Wills³, Bruce Chorpita⁴

¹Suffolk University, ²Boston University, ³Ohio State University, ⁴University of California, Los Angeles

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

Methods: Forty youth (ages 7 – 15) presenting with an anxiety and/or depressive disorder were randomly assigned to receive either psychosocial treatment planned using SDM ($n = 20$) or psychosocial treatment planned primarily by the clinician ($n = 20$). In the SDM condition, clinicians guided caregivers and youth through a collaborative treatment planning process that incorporates research findings into a discussion that addresses three questions: 1) what will be the target problem(s) for treatment, 2) who will participate in treatment, and 3) what skills will be the focus of treatment. The assessment battery includes measures of decision self-efficacy, treatment motivation, treatment preferences, treatment outcomes expectations, decisional conflict, and decision satisfaction, in addition to measures of symptoms, impairment, and diagnoses.

Results: A sampling of results to be presented includes: Caregivers in the SDM condition reported significantly lower decisional conflict ($p = .005$) and significantly higher decision satisfaction ($p = .021$) relative to the clinician-guided condition. Youth results followed the same pattern, though the results were only marginally significant, possibly reflecting the limited sample size. Learning more information about treatment options (e.g., the likelihood that a treatment may not be effective) did not result in different treatment outcome expectations, or in youth-reported readiness for treatment. Youth receiving SDM treatment planning reported significantly greater therapeutic alliance after the SDM session ($p = .012$), whereas parents reported worse therapeutic alliance ($p = .023$).

Conclusions: Utilizing an SDM model for youth psychotherapy was both feasible and beneficial. Caregivers and youth reported generally high satisfaction with their decisions, low decisional conflict, and generally high alliance (though parents in the clinician-guided condition reported higher alliance). These results will be discussed in the broader context of SDM research, highlighting next steps for research on SDM in youth mental health.

[Oral Presentation Preferred]

396 - Family medicine residents' experienced barriers and facilitators in learning and applying shared decision making: a qualitative study

Anouk Baghus¹, Esther Giroldi¹, Angelique Timmerman¹, trudy van der weijden¹

¹Department of Family Medicine, Care and Public Health Research Institute (CAPHRI), Maastricht University, Maastricht, the Netherlands

Background and aims: Although Shared Decision Making (SDM) is considered the preferred approach to involve patients in medical decisions, it is not routinely used in clinical practice. A competency-based training in SDM for postgraduate medical education, addressing both learners' attitudes and skills, is expected to be effective approach in increasing transfer to clinical practice. To inform the development of a tailored training based on residents learning needs, we explored which barriers and facilitators medical residents experience in learning and applying SDM in clinical encounters.

Methods: This qualitative study was conducted in the setting of Family Medicine specialty training in the Netherlands. Sixteen family medicine residents from four training institutes participated in stimulated recall interviews, of which seven residents were in their first year of training and nine were in their third and final year. Residents' reflections on their own SDM behaviors were enriched by using one or two of their recently videotaped consultations as a stimulus for the interviews. Transcripts were thematically analysed during an iterative cycle of data collection and analysis.

Results: The main barriers experienced by residents include: 1) lack of knowledge about and experience with SDM and the underlying phases and required behavioral actions, 2) medical uncertainty, 3) limited attention for education in SDM, in the clinical workplace and training institute and 4) time constraints. Residents mentioned the following facilitators: 1) longitudinal training in SDM, 2) integration of SDM with training in medical knowledge, 3) confrontation with their own SDM behaviors during clinical encounters 4) concrete example narratives for applying SDM.

Conclusions: Residents' reflections underpin the relevance of a longitudinal SDM program in post-graduate training, integrated in Evidence Based Medicine curricula. To enhance transfer to clinical practice, training necessitates a strong focus on workplace learning, closely involving the residents' clinical supervisors who as a coach and role model are a key actor in residents' learning process. Supervisors can stimulate residents to reflect on their SDM attitudes and behaviors and they can support residents in developing and experimenting with alternative SDM behaviors.

397 - Preliminary Acceptability Testing of a Decision Support Intervention for Youth with Juvenile Idiopathic Arthritis and their Parents

Karine Toupin April^{1,2}, Jennifer Stinson^{3,4}, Adam M. Huber^{5,6}, Deema Couchman^{1,2}, Hannah Sachs¹, Aditi Sivakumar¹, Marco Ragusa^{1,2}, Tania El Hindi¹, Isabelle Gaboury⁷, Ciaran M. Duffy^{1,2,10}, Esi M. Morgan⁸, Lucie Brosseau², Linda C. Li⁹, William Brinkman⁸, Marg Bisch¹⁰, Janice Cohen¹⁰, Elizabeth Stringer^{5,6}, France Légaré¹¹, Laurie Proulx¹², Sabrina Cavallo¹³, Paul R. Fortin¹¹, Peter Tugwell^{2,14}

¹Children's Hospital of Eastern Ontario Research Institute, ²University of Ottawa, ³Hospital for Sick Children, ⁴University of Toronto, ⁵IWK Health Centre, ⁶Dalhousie University, ⁷Université de Sherbrooke, ⁸Cincinnati Children's Hospital, ⁹University of British Columbia, ¹⁰Children's Hospital of Eastern Ontario, ¹¹Université Laval, ¹²Canadian Arthritis Patient Alliance, ¹³Université de Montréal, ¹⁴Ottawa Hospital Research Institute

Background and aims: Youth with juvenile idiopathic arthritis (JIA) face various treatment decisions that can be overwhelming. Our team is developing a decision support intervention, in the form of an electronic patient decision aid combined with decision coaching, to help adolescents with JIA and parents make informed decisions about pain management options. The objective was to assess the preliminary acceptability of the paper version of the decision aid and to determine how to improve its content and format from the perspectives of youth and parents.

Methods: A total of 12 youth with JIA and 11 parents (5 families of youth 8-12 years and 7 families of youth 13-18 years of age) were recruited from hospitals in Canada and the United States to participate in face-to-face or online semi-structured individual interviews in which they reviewed the paper decision aid and assessed its perceived usefulness, content, format, and future use. Interviews were audiotaped, transcribed verbatim and analyzed using simple descriptive content analysis.

Results: All participants agreed that the decision aid would be a useful tool for making decisions about pain management. All participants thought the decision aid had the appropriate amount of information on pain management options except for one parent and two youth who thought there were too many treatment options or that it might be overwhelming for younger youth. Most participants liked the sections on psychological and self-management options, although seven parents requested more information on complementary medicine and nutrition. Participants appreciated the incorporation of scientific evidence and smileys to demonstrate the benefits of options. Most participants preferred an electronic version that would show a few options consistent with their preferences. They wished to use it alone or with their family members, along with a discussion with their healthcare providers.

Conclusion: Findings revealed that the decision aid was acceptable to families but that an electronic version showing a limited number of personalized options was preferred. This feedback was used to improve the decision aid, by simplifying the wording and adding treatment options. Work is underway to develop an electronic version with an algorithm to present options tailored to each user.

398 - Applying Knowledge Action Cycle to implement a patient decision aid in the context of Down syndrome prenatal screening

Titilayo Tatiana Agbadjé¹, Matthew Menear¹, Hubert Robitaille¹, Michèle Dugas¹, Samira Rahimi², Marie-Pierre Gagnon³, François Rousseau⁴, Brenda J. Wilson⁵, France Légaré^{1,6}

¹Canada Research Chair in Shared Decision Making and Knowledge Translation, and Population Health and Practice-Changing Research Group, Université Laval Primary Care Research Centre (CERSSPL-UL), Quebec, Canada, ²Department of Family Medicine, Faculty of Medicine, McGill University, ³Faculty of Nursing, Université Laval, Quebec, Canada, ⁴Department of Molecular Biology, Medical Biochemistry and Pathology, Faculty of Medicine, Université Laval, and MSSS/FRQS/CHUQ Research Chair in Health Technology Assessment and Evidence Based Laboratory Medicine, Quebec, Canada, ⁵School of Epidemiology and Public Health, University of Ottawa, Ontario, Canada, ⁶Department of Family Medicine and Emergency Medicine, Faculty of Medicine, Université Laval, Quebec, Canada

Background: For pregnant women and their partners, the decision to undergo prenatal screening for Down syndrome (DS) can be difficult. We recently developed a decision aid (DA) to support shared decision making (SDM) for DS prenatal screening. However, implementation of both SDM and DAs in clinical practice is recognized as challenging. We thus aimed to develop an implementation plan that outlines the knowledge translation (KT) strategies needed to promote the effective uptake of the DA in different prenatal care contexts.

Methods: The conceptual foundation for our implementation plan was the Knowledge-to-Action (KTA) Framework. To build the plan, we performed a synthesis of our previous research on DS prenatal screening in Quebec and used participatory action research (PAR) to better understand prenatal care contexts, potential barriers, and KT strategies needed to overcome barriers through individual consultation. The synthesis included 10 articles stemming from the PEGASUS project. Two authors independently reviewed the articles and extracted data guided by the KTA Framework and performed content analysis of data issued from consultation with stakeholders. Next, team members met to establish a consensus on the most relevant elements to include in the implementation plan.

Results: In total, we consulted 18 stakeholders (5 pregnant women, 9 prenatal care providers, and 4 research experts in DS prenatal care) for the PAR study phase. We identified three main prenatal care pathways: 1) care from a family physician, 2) care from an obstetrician-gynecologist, and 3) care from a midwife. We identified core elements of the implementation plan, as well as implementation strategies that are tailored to each of the three prenatal care pathways. This research is in progress and will be completed by the conference dates.

Conclusion: The literature identifies many barriers to implementing SDM and DAs in routine clinical practice. In this study, we used data from a knowledge synthesis and consultations with key stakeholders involved in DS prenatal screening to develop an implementation plan that takes into consideration the different contexts in which prenatal screening occurs in Quebec.

400 - Innover pour améliorer l'accès et la qualité des soins pour les personnes en situation de marginalisation : modalités et retombées de la participation citoyenne au projet de recherche

Shelley-Rose Hyppolite¹, Sophie Lauzier², Maxime Robert³, Nicolas Shink³, Nathalie Bouchard³, Geneviève Olivier d'Avignon³

¹Centre intégré universitaire de santé et de services sociaux de la Capitale Nationale, Québec, Canada, ²Faculté de pharmacie, Université Laval, Québec, Canada, ³Clinique SPOT, Québec, Canada

Introduction

Les personnes les plus affectées par les inégalités sociales de santé sont reconnues comme étant les moins bien desservies par le système de santé. Il est recommandé d'améliorer l'accessibilité des services de santé, notamment par la dispensation de services de proximité. Les expérimentations en ce sens demeurent toutefois limitées. Nous avons réalisé une étude visant à identifier les pratiques innovantes ayant pour but d'améliorer l'accès et la qualité des soins pour les personnes en situation de marginalisation mises en œuvre dans trois cliniques au Québec. Cette étude a été guidée par une approche participative impliquant des citoyens ayant utilisé les soins et services offerts à la Clinique SPOT, l'une des cliniques à l'étude.

Objectifs

Cette présentation vise à décrire les modalités de la participation citoyenne dans cette étude et ses retombées.

Méthodes

Un devis qualitatif descriptif a été utilisé pour réaliser l'étude. Afin de documenter les innovations mises en œuvre à SPOT, nous avons réalisé des entrevues semi-dirigées avec des personnes utilisatrices de cette clinique et des observations dans les points de services. En plus des activités réalisées à SPOT, cinq journées d'échanges regroupant les personnes impliquées dans les trois cliniques à l'étude ont été organisées afin d'identifier les pratiques innovantes.

Résultats

L'approche participative s'est d'abord traduite par la formation d'un comité consultatif incluant des chercheuses, des membres du personnel de la Clinique SPOT et des citoyens ayant utilisé les soins et services de la clinique. Quatre citoyens se sont impliqués dans le comité et ont participé à neuf rencontres afin de valider les objectifs du projet, définir la méthodologie, valider les résultats et participer à leur diffusion. Les citoyens ont également codirigé les entrevues semi-dirigées et participé aux journées d'échange avec les cliniques participantes. Les conditions ayant facilité la participation citoyenne, les défis rencontrés et les retombées de cette participation seront présentés selon la perspective des chercheuses, des citoyens impliqués et de la Clinique SPOT.

Conclusion

La participation citoyenne a permis d'éclairer le processus de recherche par différents savoirs et de susciter une réflexion professionnelle et/ou personnelle chez les personnes engagées dans cette démarche.

403 - Shared Decision Making training inside a Virtual Community of Practice for Primary Care professionals: design, usefulness and satisfaction

Valeria Pacheco-Huergo^{1,2,8}, Marta Ballester^{1,2,3}, Lilisbeth Perestelo-Perez^{3,4,5}, Carlos Bermejo-Caja^{3,6}, Debora Koatz^{1,2,3}, Vanesa Ramos-García^{4,5}, Ana Isabel González González^{3,6,7}, Carola Orrego^{1,2,3}

¹Avedis Donabedian Research Institute (FAD), Spain, ²Universitat Autònoma de Barcelona, (Barcelona), Spain, ³Red de investigación en servicios de salud en enfermedades crónicas (REDISSEC), ⁴Evaluation Unit of the Canary Islands Health Service (SESCS). Tenerife. Spain, ⁵Canary Foundation for Health Research. Tenerife. Canary Islands. Spain, ⁶Gerencia Asistencial de Atención Primaria del Servicio Madrileño de Salud. Spain, ⁷Institute of General Practice. Goethe University. Frankfurt. Germany, ⁸Catalan Health Institute (ICS) - Primary Health Care Center Turó-Vilapicina.Barcelona.Spain

BACKGROUND

In the context of a trial for improving attitudes of Primary Care Health professionals (PCHP) towards patient empowerment, a Virtual Community of Practice (VCoP) was developed. Shared Decision Making (SDM) was identified as key component. Different training strategies were designed to cover it.

OBJECTIVE

To evaluate the usefulness of a VCoP for SDM training, and professionals' satisfaction.

METHODS

An observational study through an online survey was carried out to evaluate the intervention arm (163 PCHP) of a controlled, pragmatic, randomized clinical trial with 319 PCHP (family practitioners and nurses).

The intervention group participated in a VCoP for 12 months, while the control group followed usual training.

The VCoP allowed the exchange of information and resources between members. A facilitator proposed contents and dynamized the interaction.

SDM training was dispensed along 3 months in weekly basis and included 4 challenges, 2 training pills and a webinar with an expert.

The continuous computing of the platform allowed to evaluate acceptance and interactions.

At the end, an online questionnaire (Likert scale of 10 points), based on Ranmuthugala's and Mendizabal's, was completed to assess professionals' experience.

RESULTS

131 of 163 participants answered the questionnaire (response rate 80%)

They considered that the experience had contributed with new knowledge, was relevant to practice and had improved their attitude towards empowerment (mean 7.4, SD2.1; 7.6 ± 1.9 and 7.2 ± 2).

SDM and risk communication contents were considered useful (7.7 ± 2 and 7.4 ± 1.9) and the use of Patient Decision Aids, applicable in their context.

They most valued sharing and joint resources (7.6 ± 1.9), solving clinical scenarios (7.5 ± 1.8), also training pills (7.3 ± 1.8) and expert webinar (7.1 ± 2.1).

They found this type of learning methodology agile and interesting because they were able to learn from another professionals' experience. They positively valued that they could decide time and place of access. They were globally satisfied (7.1 ± 2.1) and would recommend the experience to other colleagues (7.3 ± 2.1).

CONCLUSIONS

The use of a VCoP developed for PCHP has proven to be a useful tool for SDM training. It constitutes an innovative and flexible instrument that allows its members to share experiences, resources, and learn together in a satisfactory way.

410 - Implementing methods for shared decision-making and self-management support at Aarhus University Hospital, Denmark. Part 1: Leading the large-scale program

Lisbeth Kallestrup¹, Kirsten Lomborg²

¹Aarhus University Hospital, Denmark, ²Department of Clinical Medicine, Aarhus University

Background and aim

In 2014 a patient involvement program (PI) was launched at Aarhus University Hospital, Denmark. The program included methods for the development and implementation of shared decision making (SDM) and self-management support in more than 20 clinical departments. This study aimed to assess the sustainability of the interventions developed and to explore the leadership approaches that enabled the implementation.

Methods

Each department was asked 5 years after initiating the program, whether the developed aids and guidelines were still in use. Qualitative and quantitative data from agendas and minutes from the Hospital Executive Board and the Hospital Quality Board were explored to identify leadership approaches.

Results/Findings

Four years after initiating the program, 9 out of 11 decision aids developed for SDM were in use and 12 out of 12 aids developed for self-management support were in use. At the conference the results of sustainability five years after the program introduction will be presented.

The leadership approaches used during the intervention were:

Conclusion

Different leadership approaches are needed to ensure sustainability of a large-scale PI program including change in clinical practice and clinical pathways.

AUH's bottom-up leadership approach encouraged and enabled frontline teams and patient to co-produce better healthcare services in terms of shared decision-making and self-management support. The top-down leadership approach motivated and framed the PI program, insisted on the use of innovative methods and required staff to involve patients to formulate key issues and problems. This has affected the results and sustainability of the large-scale program.

415 - Helping people to choose wisely: A pilot study to evaluate methods for shared decision making in populations with different levels of literacy

Edward Hoi-fan Chang¹, Danielle Marie Muscat¹, Rachel Thompson¹, Marguerite Tracy², Erin Cvejic¹, Joshua Zadro³, Jessica Kathleen Smith¹, Robyn Lindner⁴, Kirsten McCaffery¹

¹University of Sydney, Faculty of Medicine and Health, School of Public Health, Sydney Health Literacy Lab, New South Wales, Australia, ²University of Sydney, Faculty of Medicine and Health, School of Public Health, New South Wales, Australia, ³University of Sydney, Faculty of Medicine and Health, School of Public Health, Institute for Musculoskeletal Health, New South Wales, Australia, ⁴NPS Medicinewise, New South Wales, Australia

BACKGROUND:

To facilitate shared decision-making (SDM), Joseph-Williams et al. (2013) suggest that interventions should be delivered in two stages: 'preparation' followed by 'enablement'. The impact of this staged approach for groups with different levels of health literacy is unknown.

AIM:

To pilot test the relative effectiveness of preparation and enablement interventions, across different health literacy levels, on consumers' a) self-efficacy to ask questions and be involved in healthcare decisions and b) intention to engage in SDM.

METHOD:

Design, setting and participants: Randomised controlled trial in Australian adults aged >18 years, recruited via an online market research company.

Intervention: We developed a video to serve as the preparation intervention and selected the Choosing Wisely Australia® question prompt list (QPL) as the enablement intervention.

Randomisation: Participants were presented with a hypothetical 'back pain' scenario and randomised (by a central computer system) to one of three intervention groups (preparation alone; enablement alone; both interventions), stratified by health literacy.

Primary outcomes: Mean difference (from baseline to follow-up) in self-efficacy to ask questions and be involved in healthcare decisions (adapted from Bandura's self-efficacy theory) and intention to engage in SDM.

RESULTS:

164 of the 189 recruited participants completed the pilot study (87%); 55 randomised to the preparation intervention alone, 58 to the enablement intervention alone; and 51 to both interventions. Participants randomised to the preparation video alone had a significantly greater increase in self-efficacy to be involved in healthcare decisions compared to the QPL alone (3.93 vs -0.80; $p=0.044$). A significant intervention-by-health literacy interaction was observed for intention to engage in SDM ($p=0.025$); for those with adequate HL, the combined intervention yielded the greatest change in intention to engage in SDM, followed by video alone, whereas the QPL resulted in no meaningful change. In contrast, for

individuals with lower HL, the QPL alone demonstrated the greatest change in intention followed by combined intervention, with the video alone resulting in little to no change.

CONCLUSION:

SDM preparation and enablement interventions may have a differential impact across health literacy levels. Data from this pilot study will inform the design of a larger trial to evaluate intervention effectiveness.

416 - Shared Decision-Making Predicts Patient Confidence in Self-Care for Adults with Inflammatory Bowel Disease

Aricca Van Citters¹, Megan Holthoff¹, Corey Siegel², Gil Melmed³, Alice Kennedy¹, Paul Barr¹, Brant Oliver^{1,2}, Emily Morgan⁴, Alandra Weaver⁵, Eugene Nelson¹, Glyn Elwyn¹

¹The Dartmouth Institute for Health Policy & Clinical Practice, New Hampshire, USA, ²Dartmouth Hitchcock Medical Center, New Hampshire, USA, ³Cedars Sinai Medical Center, California, USA,

⁴UNC Gillings School of Global Public Health, North Carolina, USA, ⁵Crohn's & Colitis Foundation, New York, USA

Background and Aims:

Shared decision making (SDM) is a process wherein patients are supported to participate in healthcare decisions. We aim to understand the relationship between SDM and patient confidence, health outcomes, and value in a learning health system focused on coproducing healthcare services.

Methods:

Clinician champions at 21 practices in the IBD Qorus Collaborative asked consecutive adult inflammatory bowel disease (IBD) patients to complete the collaboRATE measure of SDM between April and June 2018. Patients at each site completed a separate 15-item pre-visit survey addressing confidence, well-being, disease activity, and healthcare resource utilization. We used chi-square and t-tests to identify differences in outcomes between patients at sites demonstrating top and bottom quartile performance on collaboRATE (n=5 sites/quartile; Top-box collaboRATE score reported by 94% of patients in top quartile and 70% in bottom quartile). We used linear, logistic, and ordinal regressions to determine whether being seen in a top quartile SDM site independently predicted outcomes and resource utilization, after controlling for disease activity.

Results:

Compared to patients in bottom quartile sites (n=335), patients in top quartile sites (n=316) had greater confidence in their ability to control health problems related to IBD, higher well-being, fewer hospitalizations or CT scans, less prednisone use, and less frequent contact with IBD clinicians. There was no association between being seen in a top quartile site and use of emergency department care or narcotics. After controlling for disease activity, being seen at a top quartile SDM site positively predicted confidence in controlling IBD health problems ($p<.01$) and negatively predicted receipt of CT scans ($p<.05$).

Conclusion:

Disease activity is a known predictor of health outcomes and healthcare resource utilization. After accounting for disease activity, being seen in a clinic characterized by high SDM remains a significant contributor to higher patient confidence in self-care and reduced use of potentially harmful CT scans. This analysis is limited by site-level categorization of SDM; future research should explore relationships between patient-level SDM and outcomes. In a learning system focused on coproducing healthcare services, IBD clinicians with high SDM can be role models to peers in supporting behaviors of SDM and coproduction.

418 - Implementing methods for shared decision-making and self-management support at Aarhus University Hospital, Denmark. Part 2: Leadership with staff involvement as a means for efficient implementation

Lisbeth Kallestrup¹, Kirsten Lomborg²

¹Aarhus University Hospital, Denmark, ²Department of Clinical Medicine, Aarhus University, DK

Background and aim

In 2014 a large-scale patient involvement program (PI) was launched at Aarhus University Hospital, Denmark. Increasing the culture of patient involvement is an adaptive challenge, complex and multi-dimensional. The leadership approach was designed by involving different staff from the organization during the implementation of the PI program.

Methods

This case study includes data from agendas and field notes from eight workshops at AUH with changing themes and participation by in total more than 150 employees with different positions at AUH. The workshops were designed to inspire and adjust various aspects of the program management and leadership approach. The workshop themes were:

Results

The adaptive challenge about the right leadership approach was guided by recommendations from iterative workshops with changing themes and participants with different positions in the hospital.

The workshops resulted in recommendations, but also moderated resistance to change by allowing discussions about aim, leadership and implementation and by paying attention to sub-groups. The recommendations were:

Conclusion

Involving staff in defining effective leadership to implement the large-scale program of PI lead to a broader combination of approaches to facilitate implementation and overcome barriers.

419 - The potential value of shared decision making in clinical trial consideration and participation

TJ Sharpe¹, Diana Pankevich², Wilson Mok³, Mary Murray⁴, Sylvie Roulier⁵, Catharine Clay⁶, Nisith Kumar², Simi Balsara⁷, Marla Clayman⁸

¹Patient Advisor, Florida, US, ²Pfizer, Inc, New York, US, ³Merck & Co., NJ, US, ⁴Bristol-Myers Squibb, NJ, US, ⁵Sanofi, France, ⁶K8 Healthcare Consulting, Maine, US, ⁷Roche Products, Ltd., UK, ⁸American Institutes for Research, Illinois, US

Background: The decision about clinical trial participation is well-suited to shared decision making interventions due to the inherent clinical equipoise and need to include patient preferences and values. However, there has been little work on clinical trial participation and shared decision making (SDM).

Methods: TransCelerate BioPharma Inc., a non-profit organization dedicated to improving clinical trial practices, embarked on an effort to assess the potential value of SDM in improving communication of the information needed by patients that enables satisfying clinical trial consideration and participation decisions. The TransCelerate team followed an iterative process involving literature reviews, interviews with subject matter experts, and assessments of existing decision aids and SDM training resources followed by feedback sessions with research sites, decision aid developers, and training vendors.

Results: Reviews of the existing literature on SDM and the patient journey in the clinical trial setting revealed unmet needs. Notably, there was a lack of decision support tools to assist patients and healthcare providers in eliciting patient preferences and values with respect to all available options, including clinical trials. We propose a set of considerations for SDM tool development that incorporates the patient's preferences and priorities along with multiple clinical trial and various standard of care options. We also recognize the need for a rigorous study to test whether SDM communication techniques and training can actually enhance the experience for patients considering clinical trial participation and propose one such pilot study design.

Conclusions: SDM has the potential to reduce the communication imbalance between healthcare providers and patients. Extending the benefits of SDM in conversations about clinical trials could improve patient decision satisfaction and patient experiences, and also have a positive impact on drug development. We believe there is a need for creating a multifaceted SDM training and tool package to address both the interpersonal and informational gaps in decision making regarding clinical trial participation. Testing such a package could run in parallel to existing clinical care processes of patients who are at a decision point about next steps and for whom a clinical trial is available and appropriate.

426 - Results of collaboRATE at U.S. Accredited Cystic Fibrosis Foundation Clinics

Karen Homa¹, Kathy Sabadosa², Rachel Forcino², Glyn Elwyn²

¹Cystic Fibrosis Foundation, ²The Dartmouth Institute for Health Policy and Clinical Practice

Background: collaboRATE, a 3-item patient reported measure of shared decision-making (SDM) was deployed for the first time in chronic care. Cystic Fibrosis (CF) is a complex genetic, multi-organ disease. People with CF are seen four or more times a year by a multi-disciplinary clinical team. Care plans are co-developed during these visits. Since 2015, the CF Foundation has supported the Patient and Family Experience of Care survey (PFEC) to provide clinics with insights from patients and families. In August 2018, PFEC was revised to include collaboRATE within a 30-question survey. We report collaboRATE results by patient populations and clinics. **Methods:** People with CF are invited to complete PFEC after a clinic visit via the Web or by phone at most 2 times a year. There are two versions: pediatric and adult (18+ years). Chi-square tests assessed differences between versions for item-level and overall top-box scores. Funnel plot assessed clinic variation. **Results:** In the first 4 months the revised PFEC was deployed, 1422 surveys were completed at 147 clinics (52% of the 283 CFF-accredited clinics). The average number of surveys per clinic was 9 (range from 1-50). 51% of the surveys were pediatric and 51% of respondents were male. Across all respondents, the overall score for collaboRATE was 69%. Top box scores by collaboRATE item were: 78% for help understanding health issue (item 1), 78% for listening to things that matter most (item 2), 75% for being included in choosing what to do next (item 3). There was a significant difference between the pediatric and adult respondents overall collaboRATE score, (72% pediatric v. 66% adult, $p = 0.02$) and a significant difference in item 3 top box score (78% pediatric v. 72% adult, $p = 0.02$). Among the 48 clinics with 10 or more respondents, the overall collaboRATE score also varied by clinic, 22% to 91% with one clinic significantly lower. Item scores varied: 57%-100% (item 1), 44%-100% (item 2), and 45%-100% (item 3). **Conclusion:** The variation among population groups and clinics in overall and individual item collaboRATE scores indicates an opportunity for improving SDM in CF care planning.

427 - Impact of a Decision Aid for type 2 Diabetes: a cluster randomized trial

Megan Branda², Jonathan Inselman², Victor M Montori², Nilay D Shah²

¹University of Colorado, ²Mayo Clinic, Minnesota, USA

Background and Aims: For patient with type 2 diabetes, Diabetes Medication Choice cards were developed to assist patients and clinicians discuss medication options for the management of diabetes. We conducted a cluster randomized trial to assess the impact of the decision aid on shared decision making and patient outcomes.

Methods: The cluster randomized trial where primary care practices were randomized to Diabetes Choice decision aid (DA) or usual care (UC). Patient surveys were collected post encounter and at 2, 6, and 12 months. Medical record review was conducted to obtain HbA1c value and prescription refills at 12 months post enrollment. Patient outcomes included HbA1c change, medication adherence, and knowledge. Shared decision making was assessed using decisional conflict and patient engagement (OPTION). Cluster adjusted t-test and chi-square tests were conducted to compare arms along with mixed effect models.

Results: Between February 2011 and June 2013, 350 patients were recruited from 20 practices in the Midwestern United States. No difference was seen between arms for HbA1c at 12 months. Medication adherence assessment showed 94% percent of days covered for DA and 89% for UC ($p=0.2$). Knowledge increased significantly in the DA arm where patients knew on average 52% of the items compared to UC at 45% ($p=0.02$). Among the three subscales of DCS, no difference was seen. The OPTION score was significantly higher in the DA arm on average 7.3 points higher (2.9, 11.9 95% CI) than UC.

Conclusion: The Diabetes Medication Choice decision aid did not have a significant impact on clinical outcomes over usual care. Similar to previous decision aid trials, knowledge and patient engagement was significantly higher in the decision aid arm.

430 - The Quality of Lung Cancer Screening Decisions by Patients at Two Academic Medical/Cancer Centers

Robert J. Volk¹, Lisa M. Lowenstein¹, Shawn P.E. Nishi², Tito R. Mendoza³, Laura C. Crocker¹, Cody S. Cruz¹

¹Department of Health Services Research, The University of Texas MD Anderson Cancer Center, Houston, TX, USA, ²Department of Internal Medicine, UTMB Health Division of Pulmonary Critical Care and Sleep, Galveston, TX, USA, ³Department of Symptom Research, The University of Texas MD Anderson Cancer Center, Houston, TX, USA.

Background: Clinical guidelines in the U.S. emphasize eligible current and former smokers have an opportunity to make informed decisions about lung cancer screening (LCS). The Centers for Medicare & Medicaid Services further requires a patient counseling and shared decision making visit prior to patients being referred for LCS.

Aims: We explored patients' understanding of key facts related to LCS and the quality of the LCS decision-making process among recently screened current and former smokers.

Methods: Recently screened patients from three screening programs affiliated with a medical center and cancer center were surveyed. Patients completed a LCS knowledge measure developed by the research team, the Shared Decision Making (SDM) Process Survey, and the SURE measure.

Results: 265 (39%) of the patients completed the survey. The mean age of patients was 65 years, 47% were female, 87% identified as white, 81% had at least some college education, and 38% had a family history of lung cancer. Of the respondents, 33% failed to recognize *not* smoking at the most important way to lower lung cancer risk, 50% knew that LCS should be completed annually, and 12% understood that *most* patients with an abnormal screening result will not have lung cancer. Responses to the SDM Process Survey showed that 68% of patients had a conversation with a health care provider about the benefits of screening, while 62% indicated harms were not discussed at all. Nearly 86% of patients indicated a health care provider talked with them about stopping smoking or continuing to not smoke. About 33% had scores on the SURE measure of less than 4, suggesting some experienced decisional conflict related to the screening decision. Receipt of written or video materials about LCS benefits and harms was reported by 32% of patients.

Conclusion: In this study of patients recently screened for lung cancer, understanding of key facts related to LCS was highly variable. Health care providers emphasized benefits more often than harms, and most addressed smoking cessation or abstinence. Long-term screening adherence should be tracked given mixed understanding of the importance of annual screening and a potential for decisional conflict among some patients.

431 - The Use of Decision Aids to Facilitate Shared Decision Making in Atrial Fibrillation: A Review of Available Tools

Sarah McCarthy PhD MPH^{1,2}, Victor Daniel Torres Roldan MD², Oscar Ponce Ponte MD², Tereza Belluzzo², Lisdamys Morera MD², Christina LaVecchia PhD², Freddy Toloza Bonilla MD², Anjali D Thota², Paige W Organick², Elissa M Ozanne PhD³, Angie Fagerlin PhD³, Peter Noseworthy MD⁴, Victor M Montori MD^{2,5}, Juan P. Brito MD MSc^{2,5}, Francisco Barrera⁶, Soumyia Jaladi², Carolina Liu⁷

¹Department of Psychiatry and Psychology, Mayo Clinic, Rochester, Minnesota, USA, ²KER Unit, Mayo Clinic, Rochester, Minnesota, USA, ³Department of Population Health Sciences, University of Utah, USA, ⁴Department of Cardiovascular Medicine, Mayo Clinic, Rochester, Minnesota, USA, ⁵Department of Endocrinology, Mayo Clinic, Rochester, Minnesota, USA, ⁶Plataforma INVEST Medicina UANL – KER Unit Mayo Clinic (KER Unit Mexico), Universidad Autonoma de Nuevo Leon, Monterrey, Mexico, ⁷School of Medicine “Alberto Hurtado”, Universidad Peruana Cayetano Heredia, Lima, Peru

Background/Aims: Atrial fibrillation (AF) is a heart arrhythmia associated with a 5 fold increase in the risk of stroke. The benefit of anticoagulation therapy to reduce the risk of AF-related stroke is unequivocal, yet many at-risk patients do not receive these therapies. Use of a shared decision making (SDM) process has been recommended to individualize anticoagulation treatment for patients with AF. Our aims were to identify available SDM tools about anticoagulation treatment in AF and empanel experts to identify which tool or tool features they judge most helpful.

Methods: We conducted a systematic review by searching databases from each database's inception up to August 9th, 2018. In addition, we conducted an environmental scan by searching relevant keywords in Facebook, Twitter, and a decision aid databases. We then prepared summaries of these tools, including availability, method of delivery (before or in-consultation), satisfaction of IPDAS criteria, and evidence of efficacy. Finally, we conveyed an expert panel that included patient representatives, cardiologists, and SDM experts.

Results: 1,098 records were identified through online databases and screened, with 85 studies included for full review. Of these, 12 tools fit our criteria, 6 to be used before encounter, 3 during the encounter, and 3 before or during the encounter. None of the tools explicitly stated if the tool supported decision making for new patients or a patient currently on anticoagulation. One tool was developed using a user centered design approach, and three tools underwent testing. This information will be conveyed to an expert panel group.

Discussion: This information will be conveyed to an expert panel group. Expert panel input will be presented at the time of meeting, if abstract is accepted. The expert panel will identify key features of decision aids felt to promote SDM in patients with AF considering anticoagulation treatment. Existing tools will be enhanced with expert identified features in preparation for a large multicenter randomized trial comparing in-consultation SDM tools with patient decision aids for patients with AF considering anticoagulation to prevent strokes.

436 - Clinician-patient-family decision-making in adolescents and young adult cancer: a qualitative synthesis

Danielle Gessler^{1,2,3}, Ilona Juraskova^{1,2,3}, Ursula Sansom-Daly^{4,5,6}, Heather L Shepherd^{1,2,3}, Pandora Patterson^{7,8}, Danielle Muscat⁹

¹School of Psychology, The University of Sydney, Australia, ²Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), The University of Sydney, ³Psycho-Oncology Cooperative Research Group (PoCoG), School of Psychology, The University of Sydney, Australia,

⁴Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital, Randwick, Australia,

⁵Discipline of Paediatrics, School of Women's and Children's Health, UNSW Sydney, Sydney, Australia,

⁶Sydney Youth Cancer Service, Prince of Wales/Sydney Children's Hospital, Randwick, Australia,

⁷Cancer Nursing Research Unit, The University of Sydney, Australia, ⁸CanTeen Australia, NSW, Australia,

⁹Sydney Health Literacy Lab, School of Public Health, Faculty of Medicine and Health, The University of Sydney, Australia

Background and aims

Adolescents and young adults (AYAs) with cancer represent a minority group in the healthcare system. The process of shared decision-making may be particularly difficult for AYAs to engage in, possibly due to lower levels of health literacy. Family members of AYAs may support shared decision making about AYAs' healthcare through distributed health literacy skills and practices. However, the nature of this process among family members is unclear. We conducted a systematic review of qualitative studies that explored the process of decision-making and characterised how AYA healthcare information is shared, from the perspective of the AYA or their family members.

Methods

Electronic searches using EMBASE, MEDLINE, PsycINFO and CINAHL were conducted in May 2018. Duplicates were removed and articles screened for exclusion criteria. Peer-reviewed studies discussing the decision-making process in AYAs and/or their families were eligible for inclusion, as were studies addressing information sharing, decision-making preferences, and health literacy within this group. Data was extracted and appraised by two independent raters, and findings analysed thematically using Framework analysis.

Results

A total of 7273 studies (after removing 1801 duplicates) were screened using title and abstract. Of those, 706 full text studies were screened, resulting in a final list of 14 qualitative studies to be assessed for quality. Included studies reported the experiences of AYAs and their families in Australia, Denmark, Finland, Iran, Spain, UK and USA. Data aligned with the Supported Health Literacy Pathway model (Edwards et al., 2015) in that AYAs draw on their family members' knowledge, skills and practices to generate informed options and make shared decisions. Barriers to AYA involvement were identified, such as being excluded from decisions by parents, clinicians discussing information/options with parents before the AYA, and clinicians using blocking behaviours during medical encounters.

Conclusion

To our knowledge, this is the first systematic review of family processes of information sharing and decision-making in the AYA population. Elucidating the nature of family involvement in AYAs decision-making process is warranted, as many parents/families may facilitate communication and serve as mediators to improve or compensate for AYAs health literacy skills.

437 - Considering shared decision-making in the design of clinical studies: methodological insights on approaching people with scleroderma in British Columbia

Magda Aguiar¹, Sarah Munro^{1,2,6}, Tiasha Burch^{3,4}, Jennifer Beckett³, Julia Kaal¹, Tracey-Lea Laba^{1,5}, Nick Bansback^{1,6}, Mark Harrison^{1,6}

¹University of British Columbia, ²Dartmouth Institute for Health Policy and Clinical Practice, ³Patient Partner, ⁴Scleroderma Association of British Columbia, ⁵The George Institute for Global Health, ⁶Centre for Health Evaluation and Outcome Sciences

Background: Many clinical trials study interventions that require patients to make preference sensitive decisions about using them, even if the proposed study outcomes are successfully met. Stem cell transplants in scleroderma are an example: trials are being designed to study the potential for life extension, but the procedure carries risks of mortality and toxicity, and for some, the need to travel to a hospital offering treatment. In a study with patients and clinicians as research partners, we sought to develop a rigorous and systematic methodology to optimize the design of clinical studies by incorporating patient priorities.

Methods: Scleroderma is a rare, complex condition and care and patients' preferences may vary according to where people live. We undertook focus groups with patients with Scleroderma of any stage, living anywhere within British Columbia, Canada. We used a nominal group technique (NGT) (with an option to participate remotely) to understand what factors matter to people with scleroderma when considering a new treatment. Participants were asked to list the items they find important when considering stem cell transplant treatment. All ideas were noted down, discussed and ranked according to their importance. Group discussion about ranking results and trade-offs followed.

Results: Eight people with scleroderma participated in the focus group. Five participated via web dial-in to facilitate inclusion of people from non-urban locations. Higher ranked factors were survival, chemotherapy-related toxicity, and support from multidisciplinary teams including dietary and mental health support. The NGT method with remote participation was key for the success of the focus group. Its round robin style contribution allowed everyone to have an opportunity to participate, and eased the dynamics between those attending in person, and those joining via video call.

Discussion: Our study is a valuable contribution to overcoming obstacles in reaching patients as we were able to recruit people in remote locations with various degrees of mobility. Our patient partners were crucial to the choice of method and its success, as from the early stage of the research they highlighted the importance of geographic and disease stage variations in scleroderma, and supported us throughout recruitment and application of the methods.

438 - A Case Study of U.S. Clinics that Routinely Offer Patients Recordings of Clinic Visits

Paul J Barr¹, Michelle D. Dannenberg¹, Craig Ganoe², Elizabeth Carpenter Song¹, William Haslett², Amar Das², Roger Arend³, Sheri Piper⁴, Glyn Elwyn¹

¹The Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College, NH, USA, ²The Department of Biomedical Data Sciences, Geisel School of Medicine, Dartmouth College, NH, USA,

³Patient Partner, NH, USA, ⁴Patient Partner, MI, USA

Background: Providing patients with recordings of their clinic visits enhances patient and family engagement. We conducted a case study of clinics that share visit recordings with patients to understand the barriers and facilitators to this practice and to inform the development of the Open Recording Automated Logging System (ORALS), that will use machine-learning to identify and highlight information important to patients from clinic visits.

Methods: We adopted a multiple case design, visiting three clinics - a primary care clinic (Ludington, MI) and a cancer center (Galveston, TX) that share audio recordings, and a neurological institute (Phoenix, AZ) that shares video recordings, between March 2016 - January 2017. Embedded in each case (clinic) were clinicians, patients, and their families, clinic management and administrators. Interviewees were 18-years-or-older and able to communicate in English. Major themes were identified through framework analysis, with three coders independently reviewing transcripts from each site.

Results: We conducted 67 interviews (33 patients, 9 caregivers, 15 clinicians, and 10 clinic staff), with 38 females. Patients had a median age of 66 years (range 36 – 80 years). Experience of recording ranged from first time to four years; some clinicians reported recording longer than the service was formally offered by the clinic. The ability to recall, understand and share visit information were the major motivating factors for recording across all stakeholder groups. The ability to better engage caregivers and be better prepared for future visits were reported as additional benefits. The clinics were highly supportive, with few concerns raised; most stakeholders reported recording could increase the quality of the visit. Patients reviewed recordings at home, while a minority of clinicians reported reviewing recordings, typically during clinical practice e.g. during surgery. Elements of the visit important to stakeholders include: problem/chief complaint, diagnosis, medications, treatment plan, and referral information.

Conclusion: This is the first study of clinics that routinely offer patients recordings of visits. The practice of recording was widely accepted and deemed helpful for all stakeholders, with minimum concerns experienced. We will identify best practices and implementation challenges. Findings will be used to determine the scope and functionality of ORALS.

441 - Perspectives of shared decision-making with patient partners in the design and development of a scleroderma patient-centered research project in British Columbia

Tiasha Burch^{1,2}, Tracey-Lea Laba³, Jennifer Beckett¹, Magda Aguiar⁴, Sarah Munro^{4,5,6}, K. Julia Kaal⁴, Nick Bansback^{4,6}, Mark Harrison^{4,6}

¹Patient Partner, ²Scleroderma Association of British Columbia, ³The George Institute for Global Health, ⁴University of British Columbia, ⁵The Dartmouth Institute for Health Policy and Clinical Practice, ⁶Centre for Health Evaluation and Outcome Sciences

Background

Patient input requirements in clinical trials is often minimal. Treatments or interventions identified may present optimal medical potential without considering bio-psycho-social wellbeing and outcomes most important to patients. Engaging patients as partners to identify patient priorities leads to improvement in their experiences, health outcomes, and health care system effectiveness. We sought to develop methodology that optimizes clinical study design incorporating patient perspectives in every phase of the process, using stem cell transplant for treating scleroderma as an example. This abstract provides patient partner and team insights from a patient-centered research project.

Methods

Patient partner inclusion was maintained through every stage of the research project. Critical reflection on my role was qualitatively documented separate from the project with the goal of informing future patient-orientated research. Comparison of the “patient partner” definition to translation of the role in practice was considered along with how my input was valued and integrated in team decision-making. Feedback was shared where it allowed adaptive improvement to the process. The team perspective was also considered.

Results

The research team had six academics and two patient partners. Patient partners provided background on scleroderma and insight on how the patient community may be affected by the study design to develop cooperative ideas for addressing inclusion criteria. The experience and knowledge of patient partners were valued and considered equal to the academics, unlike previous interactions with researchers interested in scleroderma. As a novel approach to research design, suggested improvements are due to the hindsight nature of developing a new process, such as knowledge sharing of the disease and research process at the very beginning.

Discussion

The greatest obstacles to patient-oriented research are communication and power. Through an open-minded approach of considering and respecting patient partners as equals and people living with scleroderma instead of subjects, the team used patient involvement and the additional knowledge of patient partners to add value and improve project design. All partners should be prepared to listen and explain, approach each other without preconceived notions of knowledge, and realize the benefits of patient involvement outweigh the effort of having to restructure your communication style.

445 - Advance Care Planning in Primary Care: Part 4 Developing Patient-Reported Measures of Goal Concordant Care

Annette Totten¹, David Dorr¹, LeAnn Michaels¹

¹Oregon Health & Science University, Portland OR

Background and aims: Patient-reported concordance of goals with decisions and healthcare for people affected by serious illness is an important primary outcome. However, no validated measure exists of goal concordant care. As part of a trial of ACP, we sought to design items for our trial and develop an approach to for future measure development and refinement.

Methods: We reviewed the literature for measures used to assess goal attainment, shared decision-making, concordance between patients and providers, as well as patient engagement and satisfaction . We invited stakeholders, including patients, providers, and researchers, to discuss what goal concordant care means. We focused on identifying words and phrases that captured the idea of goal concordant care. Based on the literature and discussions, we developed draft items, and reviewed these in two focus groups with patient/family advisors and with research teams from other advance care planning and palliative care projects.

Results: Our draft instrument consists of 3 parts representing different approaches. The first includes six items that rate the care the patient received in terms of goal concordance. Two of these are global items, one asking asks whether their current care supports what is important to them and a second if any care received was unwanted. This is followed by four items about related concepts such as level of confidence that your healthcare provider knows what is important to you. The second part is derived from the Life Preference Scale developed by Ariadne Labs. Our variation asks patients to rate goals often identified as important to patients with serious illnesses and the extent to which their healthcare supports their three most important goals. The third part includes process measures based on the content of serious illness conversations and asks patients if each step or activity happened.

Conclusion: It is possible to develop a patient-reported measure of goal concordant care that has face validity based on measures of related or similar constructs and the input of a range of stakeholders. Validation and ongoing refinement of the measure will need to be conducted in parallel with the trial.

446 - Advance Care Planning in Primary Care: Part 3 Theory-based Design of an Interprofessional Team Version of the Serious Illness Conversation

Danielle Caron¹, Shigeko (Seiko) Izumi², Sabrina Guay-Bélanger¹, France Légaré^{1,3}

¹Centre de recherche sur les soins et les services de première ligne de l'Université Laval (CERSSPL-UL), Université Laval, Québec, Canada, ²Oregon Health & Science University, Portland OR,

³Department of Family Medicine and Emergency Medicine, Université Laval, Quebec, QC, Canada

Background and aims: Implementing advance care planning (ACP) in primary care practice has been challenging. However, an approach incorporating interprofessional (IP) team members to facilitate ACP conversations even though teams may lack formal ACP training may have the potential to address many challenges. Thus we sought to adapt and pilot-test a program to train IP teams to implement ACP in primary care settings.

Methods: We developed an ACP conversation training program for primary care teams by adapting the Serious Illness Care Program by Ariadne Labs and incorporating the Interprofessional Approach to Shared Decision Making Model. The training program consists of a 1.5 hour online module and a 1.5 hour in-person interactive session. The training includes didactic presentation, reflections, video vignette, and role play. Using participatory research methods, the training materials were firstly reviewed by eight health professionals (nurses, physicians, social workers) and three patient and family advisors for acceptability and feasibility. Then training materials were pilot tested with six interdisciplinary members of a primary care team. Reviewers' comments and post training interviews were analyzed using qualitative descriptive analysis methods.

Results: Reviewers' comments included: both concerns about and support for non-physician team members discussing prognosis; questions about how to share the responsibility/time for conversations; and need for communication within teams and with patient/families. Post pilot training interviews also revealed barriers to ACP, and lack of clarity about how to share and communicate the conversations across team members. To address one barrier, the use of the term "prognosis", was replaced by a non-medical phrase "concern about the future" more appropriate to the different team members. Initial assessment indicated the need to adapt ACP approaches for interprofessional team members. Moreover, training materials revision, particularly of the online platform pilot testing, also allowed us to identify usability issues. We modified the training, addressing major issues and created scenarios showing various team-based approaches for ACP.

Conclusion: This pilot test allowed us to adapt an ACP program to train interprofessional primary care teams. Next, we are testing the effectiveness of the modified IP ACP conversation training in primary care practices in the US and Canada.

448 - Advance Care Planning in Primary Care: Part 1 Aspirations and Design of a US-Canada Trial in Primary Care

Annette M. Totten¹, LeAnn Michaels², LJ Fagnan², David Dorr¹, Danielle Caron³, Sabrina Guay-Bélanger³, France Légaré^{3,4}

¹Department of Medical Informatics & Clinical Epidemiology, Oregon Health & Science University, Portland, OR, United States, ²Oregon Rural Practice-based Research Network, Oregon Health & Science University, Portland, OR, United States, ³Centre de recherche sur les soins et les services de première ligne de l'Université Laval, Quebec City, QC, Canada, ⁴Department of Family Medicine and Emergency Medicine, Université Laval, Quebec City, QC, Canada

Introduction and Objective: Large implementation trials in community based primary health care (CBPHC) are needed to improve adoption of best practices and new care models. Advance care planning (ACP) for patients with serious illnesses has the potential to improve patient outcomes but it is uncertain how to best implement ACP. We designed a large USA-Canada trial of ACP to inform implementation in CBPHC and future research on shared decision making (SDM) with patients facing serious illness in CBPHC.

Methods: Grounded in a long term relationship across multiple CBPHC practice based research networks (PBRN) funded by the Agency for Healthcare Research and Quality, a consortium of seven PBRNs in the US and Canada known as Meta-LARC is conducting a cluster randomized trial (cRT) of two models of ACP in CBPHC. This cRT is funded by the Patient Centered Outcome Research Institute (PCORI). This is a comparative effectiveness trial comparing the impact of clinician-focused ACP to team-based ACP. Using participatory research methods integrated with knowledge translation (iKT), Meta-LARC facilitated identification of primary care concerns and topics through collaboration among researchers, PBRN directors, clinicians and patient/family advisors. Over 2 months, the research team used the PBRNs to quickly assess interest, develop options, assess feasibility, refine ideas and obtain buy-in. As part of this iterative process, we identified an existing ACP program (the Serious Illness Care Program by Ariadne Labs) that includes a structured approach to ACP conversations using patient-tested language as the intervention to study. We then adapted the SICP to the needs of our cRT.

Results: The cRT began in November 2017 and is ongoing. This panel will discuss our conceptual drivers and key design elements (Part 1); our systemic approach to engaging patients and stakeholders (Part 2); our adaptation of ACP communication training for teams (Part 3); and development of patient-reported measures of goal concordant care (Part 4).

Conclusion: PBRN networks provide an important infrastructure that can facilitate design of a large, complex study of ACP with the potential to establish a foundation for future large scale implementation trials in shared decision making in CBPHC.

449 - Shared decision-making grants: NIH Perspectives and Context

Susan T. Shero¹, Jennifer Curry¹

¹National Heart, Lung, and Blood Institute, National Institutes of Health, Maryland, USA

Background and aims

The call for shared decision making (SDM) in clinical and community settings from professional societies and policymaking organizations has grown louder in recent years. We sought to describe the state of the USA-based NIH and NHLBI funding for SDM projects over a 10-year period and highlight research gaps related to SDM.

Methods

From March through December 2017, NHLBI investigators collaborated with UberResearch to develop a search strategy and search databases for NIH-funded grants on SDM from 2007 to 2017. Funded projects were identified through title and abstract review of the returned projects, followed by full text and review of project aims when warranted. We extracted manually the characteristics (e.g. the type of grant, funding Institute, and for NHLBI, disease-specific areas addressed) of funded projects. We identified areas related to SDM research by conducting a thematic analysis. We used frequency count and descriptive statistics for quantitative data.

Summary of results to support conclusions

A portfolio analysis of NIH-funded SDM projects 2007-2017 reveals that most of the 106 funded projects have a narrow focus, for example, developing or testing the feasibility of a decision aid for a specific disease, condition, or treatment. Of NHLBI-funded SDM grants, over one-third are R01s (research project grants) with the remaining projects being primarily career development grants. For NIH overall, R01s comprised only about 14% of the funded SDM grants, with the remainder utilizing career development and other award mechanisms related to patient centered outcomes or health literacy. We found few multi-level, comprehensive projects examining how to implement SDM into clinical practice in a sustainable and scalable way.

Conclusion

Our results suggest that there is a pool of both established investigators, and early stage investigators who have results from SDM studies, and may be ready to apply for RO1s and other types of awards. More SDM-related studies that are comprehensive in nature—those that use multidisciplinary teams to implement multi-level interventions at the patient, provider, and systems levels, and consider contextual factors—are needed to advance this field.

452 - Finding the Value: Identifying the Key Elements of Clinic Visits for Patients, Physicians, and Caregivers

Michelle D. Dannenberg¹, Kanak Verma², Kyra Bonasia³, Ariel T. Wampler³, Subasish Bhowmik³, Hansa Sharma⁴, Paul J. Barr¹

¹The Dartmouth Institute for Health Policy & Clinical Practice, Dartmouth College, New Hampshire, USA, ²Children's Hospital of Philadelphia, Pennsylvania, USA, ³Geisel School of Medicine at Dartmouth College, New Hampshire, USA, ⁴Dartmouth College, New Hampshire, USA

Background and aims: A vast amount of information is communicated during clinic visits. A better understanding of what information from clinic visits is of most value to patients, physicians, and caregivers would inform strategies to promote effective communication. However, little is known about information priorities across these key stakeholders. Our aim was to triangulate the perspectives of patients, physicians, and caregivers to understand which aspects of a clinic visit matter most.

Methods: We recruited physicians, patients, and caregivers from a single primary care clinic and four specialty clinics (orthopedics, cardiology, radiation oncology, and gynecologic oncology) at a large academic medical center in the U.S. between November 2016 and June 2018. Clinic visits were audio-recorded and transcribed verbatim. Patients and their caregivers independently listened to the visit recording and labeled sections of audio as important to them, indicating their rationale for doing so. Physicians reviewed transcripts of the same visits and identified what information is most important for their patients. We conducted a grounded analysis to identify visit information deemed most important across stakeholder groups.

Results: Six physicians took part in the study, with sixteen patient visits recorded, four of which included caregivers. Patients had a mean age of 67 years, 59% female, and were predominantly White/non-Hispanic (94%). Caregivers had a mean age of 60 years, were all White/non-Hispanic, and predominantly female (75%). Preliminary findings reveal that discussion of medications, review of lab and imaging results, and patient concerns are the aspects of a visit that matter most across all stakeholder groups. Physicians highlighted 'treatment plan' more often than patients and caregivers, whereas patients focused more on 'symptoms' they reported. Qualitative data analysis is ongoing and will be completed by March 2019.

Conclusion: This is the first study to triangulate the perspectives of patients, physicians, and caregivers to understand which information in the clinic visit matters most. These findings will help guide the development of future interventions to improve communication among these stakeholders, including the development of the Open Recording Automated Logging System (ORALS) by researchers at Dartmouth College.

453 - Advance Care Planning in Primary Care: Part 2 Engaging Patient and Family Advisors in a Large, Complex Trial

Angela Combe¹, Annette M. Totten¹, Mary Minniti², Deborah Dokken²

¹Oregon Health & Science University, Portland, OR, United States, ²Institute for Patient- and Family-Centered Care, Bethesda, MD, United States

Introduction and Objective: Patient and family engagement is essential to successful community-based pragmatic research. However engagement is also very challenging in complex trial. To increase the likelihood of successful engagement, we expanded our trial protocol and developed a detailed Engagement Plan (EP).

Methods: During project initiation, the coordinating center established a working committee to develop the EP PCORI. An initial cohort of 11 Patient and Family Advisors (PFA) was established both to contribute to the EP and to guide the project long term. Seven of the PFAs are associated with participating PBRNs and four are unaffiliated or at-large PFAs (2 US; 2 Canadian). We surveyed PFAs about their goals and objectives related to contributing to research and solicited feedback from PBRNs and engagement experts about how PFAs and other stakeholders might best contribute to our research project. Based on this initial feedback we held meetings dedicated to discussing the goals of engagement, mechanisms for facilitating involvement, and methods for tracking impact. Next we distributed targeted planning and writing assignments, and shared drafts among the project team and stakeholders.

Results: The final EP is based on a quality improvement approach in which monitoring, measuring, and improving engagement provide the framework for engagement activities. Monitoring and measuring engagement include baseline assessment of needs, quarterly surveys of stakeholders and annual check-ins with patient/family advisors. We developed tools to track stakeholder inputs and their resulting impact on the project. PFAs-identified goals that serve as engagement QI targets and inform strategies to clarify expectations, and support diverse forms of participation. The EP specifies that is should be reviewed and updated as needed over the course of the project.

Conclusion: Patient and family engagement is needed to support the successful conduct of our research and increase the likelihood ACP will be sustainable in primary care after the research study ends. Approaching engagement as a component of trial design and execution facilitated development of best practices and science around engagement that have become operationalized as our EP. Additionally, the EP provides a framework to document and share our engagement experience.

456 - Co-construction of recommendations for the replacement of implantable cardiac defibrillator: Lessons learned for engaging patients in HTA

Marie-Pascale Pomey^{1,2,3}, Sylvain Bédard², Michèle de Guise³, isabelle ganache³, Laurie Lambert³, Lucy Boothroyd³, Caroline Colette³, laurie lambert³, lucy boothroyd³

¹CRCHUM, ²Centre d'excellence sur le partenariat avec les patients et le public, ³INESSS

Background: In the province of Québec, Canada, the health technology assessment (HTA) Institute (Institut National d'Excellence en Santé et Services Sociaux (INESSS) launched a project inviting patients to participate, along with health care professionals, in the co-construction of recommendations regarding implantable cardiac defibrillator (ICD) replacement and to think about a shared-decision making tool. The objective of this study was to describe the process of co-construction of recommendations for ICD replacement and to propose some venues to build best-practices on patient involvement in HTA.

Methods: A qualitative case study was realized to understand the co-construction process, the nature of the recommendations and the discussion about the SDM tool. Throughout the whole process, several documents were collected and participant observations were conducted. Eighteen individual interviews were conducted (6 with expert patients, 2 with expert health care professionals, and 9 with HTA agency scientists), from January to March 2018.

Results: On the basis of a preliminary review of the literature on patient experience with ICDs, it was decided that the recommendations could be co-produced by expert patients and clinicians, as well as scientists working at the HTA agency. Two committees were composed, one of the patients and the other of clinicians who reacted to the scientific literature specifically selected for that purpose by scientists working at the INESSS. A joint co-construction committee then discussed the recommendations together. In total, among the 11 recommendations, 7 were directly linked to facilitate a partnership between ICD patients and healthcare professionals and the committee decided to propose a tool to help out the team to discuss with the patient the different options of treatment and their consequences on their lives to open a shared decision-making process between patients and physicians.

Conclusion: This study has led INESSS to structure its approach to patient engagement. In addition, factors to contribute to the PI engagement were identified as; a structured selection process, training for all participants, and a PI dedicated team including patients' advisors.

457 - How Much Does Study Population Matter When User-Testing Patient Communication Materials? An Eye-Tracking Study.

Holly Witteman¹, Selma Chipenda Dansokho¹, Martin Tremblay-Breault¹, Elizabeth Parent¹, Gratiianne Vaisson¹

¹Université Laval

Background and aim: Health communication materials should be widely understandable. It is not known whether achieving such universality requires user testing materials among fully representative populations. We aimed to evaluate whether participants with different levels of motivation and education view and understand a cancer screening infographic similarly.

Methods: We recruited participants in two groups: a university group via institutional listservs and a community group via in-person recruitment in areas with lower socioeconomic status. University participants indicated interest and came to our university-based laboratory. We recruited community participants by inviting people at two shopping malls and a public library, conducting the study onsite in a room with portable laboratory apparatus. In both groups, participants provided written consent, completed a sociodemographic questionnaire, and received CAD\$20. Participants viewed an infographic about a cancer screening decision and described its content. Using a webcam, audio recorder, electroencephalogram, eye-tracking and electrodermal response apparatus, we collected participants' verbal comments, physiological and emotional responses. Two independent, blinded analysts coded anonymized transcripts to determine accuracy of participants' understanding. Here, we present a comparison of attention (measured via eye fixations) and understanding across the two groups. We conducted mediation analyses of participant group (predictor), education level (covariate), total fixation time within infographic elements (mediator) and accurate understanding (outcome).

Results: The university group (n=49) was 70% women, 30% men with median age 34 (interquartile range, IQR 16). The community group (n=34) was 49% women, 51% men with median age 56 (IQR 19). Compared to the community group, the university group was more diverse in nationality (university: 31% born outside Canada; community: 6%), languages spoken (university: 4 languages; community: 2), race/ethnicity (university: 60% White; community: 75%), had higher annual incomes (Chi-squared(5)=16.1, $p<.01$) and educational levels (Chi-squared(6)=29.1, $p<.01$). Fixation time was slightly independently predictive of accurate understanding, with greater time associated with lower accuracy (OR=.969, 95%CI .938-.998, $p=.04$). There were no other effects nor mediation effects.

Conclusions: Despite non-representative populations, university-based samples may be acceptable for eye-tracking studies, at least in our location and for materials similar to those tested. Participants' increased attention may indicate confusion. Further analyses will explore other data collected.

458 - Graph literacy matters: Examining the association between graph literacy, health literacy, and numeracy in adults of lower socioeconomic status and education

Marie-Anne Durand¹, Renata W. Yen¹, Julia Song¹, A. James O'Malley¹, Glyn Elwyn¹, Julien Mancini²

¹The Dartmouth Institute for Health Policy & Clinical Practice, Dartmouth College, Lebanon, NH, USA,

²Aix-Marseille Univ, APHM, INSERM, IRD, SESSTIM, "Cancer, Biomedicine & Society" group, Hop Timone, BIOSTIC, Marseille, France

Introduction

Graphic display formats are often used to enhance health information and promote people-centered health. Yet limited attention has been paid to graph literacy in people of lower socioeconomic status (SES) and education. We aimed to: 1) examine the relationship between graph literacy, numeracy, and health literacy in people of lower SES and 2) determine the impact of graph literacy on comprehension of health information presented in different visual formats.

Methods

We conducted a cross-sectional online survey among people in the US on Medicaid, and of presumed lower SES and lower education. The 30-item survey assessed subjective health literacy, subjective numeracy (SNS), graph literacy, comprehension, and preference of three visual display formats (table, bar chart, and icon array).

Results

The mean graph literacy score among 436 participants was low, at 1.47 (SD 1.05, range: 0 to 4), which was considerably lower than mean scores reported for the general US population (2.21, SD 1.12). Participants with adequate health literacy had higher subjective numeracy scores ($p < .001$). There was a positive relationship between graph literacy and SNS ($p = .037$). Graph literacy and SNS significantly predicted the total comprehension score ($p < .001$ and $p = .037$ respectively). Mean comprehension score was highest for the table (1.91), closely followed by bar graph (1.85) and icon array (1.80). Participants preferred the table format (39.2%) and bar graph (38.1%), versus only 22.7% preferring icon arrays.

Discussion

Graph literacy in people of lower SES in the US was lower than previous estimates in the US. Tables were better understood, with icon arrays yielding the lowest score. Preferences were aligned with comprehension. Since graph literacy was the strongest predictor of graph comprehension (correlated with numeracy), it may be necessary to reconsider the use of graphic display formats (particularly icon arrays) among people of lower SES. Differences in comprehension scores across formats were small, warranting further research.

459 - A patient-oriented development process for identifying decision-making needs: Value proposition and decision mapping techniques

Sarah Munro¹, Sarah Kaufman², Nick Bansback¹

¹University of British Columbia, British Columbia, Canada, ²Fraser Health Authority, British Columbia, Canada

Background and Aims

Shared decision-making (SDM) interventions, such as patient decision aids, should be developed using a systematic, transparent process. In the literature on development of SDM interventions, one core activity is to identify the decision-making needs of patients and health care professionals (HCPs) at the outset. However, there are few reported methods for engaging patients in that process. We aimed to a) identify decision-making needs to inform the scope and design of an SDM intervention in the context of choice of mode of birth after a previous caesarean, b) describe two mapping techniques for engaging patients and HCPs in SDM intervention development.

Methods

We used two user-centred design techniques. 1) Decision mapping is a method of identifying and illustrating the different choices a patient faces in their care pathway. 2) Value proposition mapping is a strategy for designing interventions that deliver benefit and value to the user, and improve the quality of their work (e.g. decision-making). Our advisory group engaged 28 stakeholders through face-to-face meetings in British Columbia, Canada (2017-18). Stakeholders represented government, health authorities, patients, HCPs (obstetricians, midwives, family physicians, nurses), and researchers. We conducted iterative cycles of moderated discussion, mapping, and revision. Each version of the map was dated for an audit trail. The maps were discussed and revised until no new insights arose.

Results

Decision mapping resulted in a visual timeline of the patient's decision points from the time of first caesarean to next delivery. The ideal opportunity for implementing an SDM intervention was at the first decision point, after the primary caesarean. Value proposition mapping identified the context of patient, HCP, and decision maker decisional needs at each stage of the timeline: the key audience, their decision-making tasks, potential benefits/harms of the tasks, and strategies to increase benefit and reduce harm. Mapping results suggested that initiating SDM after the first caesarean would increase benefit and reduce harm by giving patients accurate information personalized to their concerns, prior to discharge from care.

Conclusion

Mapping techniques are a potential strategy for identifying decisional needs and engaging patients as equal partners in the development of SDM interventions.

461 - Using shared decision-making to improve patient-centred infant feeding choices: An environmental scan and scoping review

Sarah Munro¹, Julie Sou¹, Nick Bansback¹

¹University of British Columbia

Background and Aims

Although on balance, human milk confers more health benefits for parents and their infants in comparison to formula, breast/chest feeding may not be the optimal choice for a given family at a given time. Families may experience pressure from health care providers to exclusively breastfeed but simultaneously not receive adequate support when breastfeeding difficulties arise. Shared decision-making (SDM) may improve patient-centred care for infant feeding choices. We aimed to: (i) Identify interventions for supporting SDM for infant feeding; and (ii) Identify which interventions for SDM for infant feeding are most effective.

Methods

We conducted an environmental scan and scoping review, informed by realist review principles. For the environmental scan, we used Google Advanced Search using key word strings related to infant feeding and SDM interventions. To be included, an intervention had to be in English, on infant feeding (e.g. birth to two years, involving breastmilk/formula) and include explicit description of the decision, health problem, and options, benefits, and harms, as well as values clarification. Data were extracted for: title, author/institution, date of publication, source, format, comparator, approximate length, and method of delivery. For the scoping review, academic databases were searched (MEDLINE/PubMed, Cochrane Library, EMBASE, Google Scholar). Titles and abstracts of extracted articles were screened with duplicate entries removed.

Results

Our environmental scan identified 392 tools and resources. Of these, 92 were eligible for full review. The majority were informational handbooks and guidelines (n=35) or websites (n=24). Two resources met the criteria for SDM interventions: (1) an infant feeding patient decision aid (Healthwise, 2017); and (2) a health care professional toolkit (Baby Friendly Initiative Ontario, 2017). Our scoping review yielded no studies on the effect of SDM interventions for infant feeding.

Conclusions

We identified two resources that met the criteria for SDM interventions, however their effect has not been studied. We identified no peer-reviewed literature assessing the effect of SDM interventions on infant feeding decisions. There is a critical need to create and assess SDM interventions that support families to achieve their infant feeding goals, and support healthcare providers in facilitating patient-centred conversations that are neutral and evidence-based.

464 - Adaptation of a decision aid about antibiotic therapy for upper respiratory tract infections to the context of Quebec emergency departments

Jean-Simon Létourneau¹, Simon Berthelot¹, Ariane Plaisance¹, Maude Dionne², Gabrielle Cyr¹, Myriam Brunet-Gauthier¹, Félix-Antoine Fortier¹, Éric Kavanagh¹, Holly Witteman¹, Jeannot Dumaresq³, Michel Labrecque¹, Michel Cauchon¹, France Légaré¹, Annie LeBlanc¹, Marie-Eve Trottier², Patrick Archambault^{1,2}

¹Université Laval, Québec, Canada, ²Centre de recherche du CISSS Chaudière-Appalaches, Québec, Canada, ³CISSS Chaudière-Appalaches, Québec, Canada

Background: Antibiotics are overused for upper respiratory tract infections (URTIs) in Canadian emergency departments (EDs). Decision+2 is a training program and decision aid (DA) that support shared decision making about URTI antibiotic use in the family medicine context. We sought to adapt the DA to the ED context.

Methods: We employed user-centered design (UCD) to adapt Decision+2 to the ED context. In 12/2015, we invited all clinicians at two EDs in Québec, Canada to attend a Decision+2 presentation and provide feedback about adapting the Decision+2 DA to the ED context. We then recruited dyads of patients and ED physicians to conduct 3 cycles of prototyping in real life setting to identify usability problems with our first ED-adapted DA prototype. We audiotaped encounters, made observations about DA usability and conducted semi-structured patient and clinician interviews to collect their thoughts about our DA. After each cycle, we produced a synthesis of the different comments, discussed them with a multidisciplinary team and produced a new prototype after each round.

Results: Out of 56 potential ED physicians, 23 provided feedback about the original DA: 1) simplify knowledge content, 2) eliminate diagnostic criteria section, and 3) include an over-the-counter self-management medications section. We conducted three prototyping cycles with 19 distinct patient-physician dyads. Eleven ED physicians from the 23 above participated in prototyping. Minor modifications were made to the DA: 1) knowledge content was further simplified; 2) patient questions for their physicians were added; and 3) graphic design was simplified. Two major modifications identified during UCD conflicted with International Patient Decision Aids Standards (IPDAS): 1) ED physicians felt that a values clarification section was not needed because it would not help decrease antibiotic overuse, and 2) “nudging” against antibiotic use was desired to reduce antibiotic overuse.

Conclusion: UCD including patients and ED physicians helped us adapt a DA for the ED context. However, UCD also identified modifications that conflicted with IPDAS criteria. Further work is needed to identify the impact of not meeting IPDAS criteria on the usability of our adapted DA and its effectiveness on reducing antibiotic overuse.

466 - Impact of an online training module on the involvement by intensivists of elderly patients in shared decision making for goals of care discussions in a intensive care unit (ICU)

Ariane Plaisance¹, Julien Turgeon¹, Annie Leblanc¹, Tommy Jean¹, Stéphane Turcotte², France Légaré¹, Holly Witteman¹, Jennifer Kryworuchko³, Diane Tapp¹, Patrick Plante⁶, Louise Sauvé⁶, Mark H. Ebell⁷, Carrie Anna McGinn⁸, Alexis F. Turgeon^{1,5}, Tom van de Belt¹⁰, Christian Chabot⁴, Frédéric Noiseux⁵, Todd Gorman^{1,5}, Hubert Marcoux¹, Anne-Marie Boire-Lavigne¹¹, Felix-Antoine Fortier¹, Marie-Frédéric Tremblay⁹, Marie-Eve Trottier², Sarah Alameddine¹², Patrick Archambault^{1,2}

¹Université Laval, Québec, Canada, ²CISSS Chaudière-Appalaches, Québec, Canada, ³University of British Columbia, British Columbia, Canada, ⁴Québec, Canada, ⁵CHU de Québec-Université Laval, Québec, Canada, ⁶Université TÉLUQ, Québec, Canada, ⁷University of Georgia, Georgia, USA, ⁸CIUSSS de la Capitale-Nationale, Québec, Canada, ⁹Université de Montréal, Québec, Canada, ¹⁰Radboudumc RShape Innovation Network Radboud university medical center, Nijmegen, The Netherlands, ¹¹Université de Sherbrooke, Québec, Canada, ¹²Nova Southeastern University, Palm Beach Gardens, Florida, USA

Purpose: Determine the impact of a context-adapted decision aid (DA) and online training module about shared decision making (SDM) on intensivists' involvement of elderly patients in goals of care discussions.

Methods: Between May 2017 and January 2018, we conducted a three-phase before-after study in a closed ICU in the province of Québec, Canada. We video- and/or audiotaped patient-intensivist encounters discussing goals of care during three phases: without access to the DA (Phase 1), with access to the DA without online training (Phase 2), with access to the DA and online training (Phase 3). We included patients aged 65 and older, mentally competent, and for which a goal of care discussion was planned. We excluded patients who were intubated, facing urgent decisions or who did not speak French. Two graduate students administered the third observer OPTION scale to determine the level of patient involvement in decision making in each video/audiotaped encounters. We used descriptive statistics and a Kruskal-Wallis test to compare OPTION scale scores between phases.

Results: Among 46 eligible patients, we recruited 21 patients (7 per phase) and five intensivists. Six patients declined to participate, 3 discussions were missed and 16 planned discussions never occurred. We videotaped 20 clinical encounters and one was audiotaped. Patients were mostly male (n=15 (71%)); median age (interquartile range (IQR)) was 77 years (68-82); without complete high school education (12 (57%)). Intensivists were mostly male (4 (80%); all fellowship-trained; and median age (IQR) was 35 (33-43). All intensivists completed the online training after phase 2. None of the intensivists used our DA in phase 2 or 3. We did not find any differences in OPTION scale scores with overall median (IQR) scores low in each phase (25 (21-29) (Phase 1) vs. 21 (15-25) (Phase 2) vs. 19 (17-29) (Phase 3) (p=0.2699)).

Conclusion: Our online training module did not result in greater involvement of patients in SDM during goals of care discussions. Further investigation is needed to understand why clinicians did not use our context-adapted DA and how SDM can be disseminated in ICU context to improve elderly patients involvement in goals of care decisions.