

The 2nd International

Shared Decision Making Conference

Book of Abstracts



2-4 September 2003
University of Wales Swansea

Shared Decision Making Conference

Organised by:

- [Glyn Elwyn](#) - University of Wales Swansea
- [Adrian Edwards](#) - University of Wales Swansea
- [Angela Coulter](#) - Picker Institute Europe
- [Theo Schofield](#) - Ethox, University of Oxford; board member of EACH
- [David Pink](#) - Long Term Medical Conditions Alliance
- [Aileen Clarke](#) - Society for Social Medicine; London School of Hygiene and Tropical Medicine; NHS Service Delivery and Organisation Programme

To be opened by:

- [Dr Ruth Hall](#) The Chief Medical Officer of NHS Wales

Keynote Speakers:

- [Professor Annette O'Connor](#)
Canada Research Chair in Health Care Consumer Decision Support
Professor, University of Ottawa
- [Professor Albert G. Mulley, Jr. M.D., M.P.P.](#)
Chief, General Medicine Division
Director, Medical Practices Evaluation Center
Massachusetts General Hospital

Scientific Committee:

- [Angela Coulter](#) - Picker Institute Europe
- [Theo Schofield](#) - Ethox, University of Oxford; board member of EACH
- [Aileen Clarke](#) - Society for Social Medicine; London School of Hygiene and Tropical Medicine; NHS Service Delivery and Organisation Programme
- [David Rovner](#) - Michigan State University
- [Glyn Elwyn](#) - University of Wales Swansea
- [Adrian Edwards](#) - University of Wales Swansea
- [Rhodri Evans](#) - University of Wales Swansea

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Foreword



Foreword

Swansea: 'an ugly, lovely town'.

Dylan Thomas

Croeso cynnes i Gymru, ac i Abertawe. A warm welcome to Wales, and to Swansea. We are delighted to host this second 'shared decision making' conference, and on behalf of the organising committee, wish to thank you for your contributions and co-operation. It's a risky exercise to organise an international meeting, but I hope you will enjoy it and benefit from the fantastic set of minds that have made the journey to this green part of the globe to share their work, ideas and developments. If things go haywire, it is us and the organising committee that you should collar; if things go well, thank our administrative staff, Gwennan Thomas and Unhan Lovitt, and our webmaster, Mari Arthur, and the conference office in Swansea. It is their design skills and efficiency that have got us all here.

The conference bodes well. There are over 100 presentations, and a variety of workshops, posters and also opportunities to hold open fora, where you can nominate a subject so that others with a similar interest can vote with their feet. We have also left some free time for the one of the most important activities of all – that of making new contacts, exchanging ideas and developing new collaborations. You will notice some building work going on and we apologise if this causes any problems. A new medical school is being commissioned, which is one of the exciting new developments on the campus.

For those who came to the first meeting in Oxford in 2001, it will be interesting to reflect on the changes to the programme content. There was the distinct impression two years ago that 'shared decision making' was a novel idea, and debate about the feasibility, wisdom, and practicality of involving patients in health care issues, from planning to individual treatment decisions. This debate has not gone away, we still have theoretical areas to clarify: there is a lot of work to do, especially to engage the social sciences and the humanities properly in a more rounded understanding of the day to day complexity and indeterminability of decisions, that we often don't 'decide', that we procrastinate until options close and we are left with narrow pathways. Despite the areas of uncertainty, the field has moved on and it is not any more a question of 'whether' to involve patients, it is a question of 'how' and 'when', or maybe more accurately, 'when' and 'how'. In a few decades, the fact that we did not involve patients in the design of services, and their delivery, at population and individual level, will look peculiar. It's good to be part of a paradigm shift: enjoy your journeys.

Glyn Elwyn, Foundation Chair of Primary Care
Adrian Edwards, Reader in Primary Care
School of Medicine, University of Wales Swansea

On behalf of the Organising Committee

- **Angela Coulter** - Picker Institute Europe
- **Theo Schofield** - Ethox, University of Oxford; board member of EACH
- **David Pink** - Long Term Medical Conditions Alliance
- **Aileen Clarke** - Society for Social Medicine; London School of Hygiene and Tropical Medicine; NHS Service Delivery and Organisation Programme

Keynote Speakers



Dr. Albert G. Mulley, Jr. is Associate Professor of Medicine and Associate Professor of Health Policy at Harvard Medical School, and Chief of the General Medicine Division and Director of the Medical Practices evaluation center at Massachusetts General Hospital. He graduated from Dartmouth College and was awarded doctor of medicine and masters in public policy degrees from Harvard before training in internal Medicine at Massachusetts General Hospital.

Dr. Mulley's research has focused on the use of decision theory and outcomes research to distinguish between warranted and unwarranted variations in clinical practice. This work has led to development of research instruments and approaches, including shared decision-making programs, to support clinicians and patients in their decision-making roles, and to catalyze clinical trials. These approaches have been shown to decrease utilization of high cost medical and surgical interventions while improving measures of decision quality, including stronger associations between patients' personal preferences for health outcomes and the care that they receive.

Dr. Mulley's work aimed at improving the quality of health care decision making has influenced the agendas of many public and private organizations engaged in clinical care as well as medical research and education. He serves as a director of the Foundation for Informed Medical Decision Making and of the Health Commons Institute. He has also served on multiple committees of the Institute of Medicine, of professional societies and as a consultant and visiting professor to government agencies, health care organizations, and academic medical centers in North America, Europe and Asia.

Professor Annette M. O'Connor is Professor at University of Ottawa in the School of Nursing, and Department of Epidemiology & Community Health, she is also the Canada Research Chair in Health Care Consumer Decision Support, and Senior Scientist at Ottawa Health Research Institute Clinical Epidemiology Program

Over the past 20 years, Dr. O'Connor's research program has focused on understanding and improving the decision making of people facing health care choices and improving the support provided by health professionals who counsel them. She has been involved in over 55 projects and produced over 100 publications, a conceptual framework of decision support; 20 decision aids for patients/practitioners; a widely used evaluation measure of decisional conflict; a systematic review of trials of patient decision aids, and several educational programs and courses on shared decision making.

Internationally, Dr. O'Connor has contributed to several scientific societies including the Society for Medical Decision Making, the Cochrane Collaboration, and the Oxford Forum on Shared Decision Making. She has contributed to projects in China and Chile to promote evidence-based decision making.

Dr. O'Connor has received numerous awards including: the 1986 JC Laidlaw Prize for Outstanding Research from the University of Toronto, Faculty of Medicine, the 1988 Award for the best research proposal in Oncology Nursing, and Career Scientist Awards from the Medical Research Council of Canada (1990-95) and the Ontario Ministry of Health (1995-2002). In 2002, she was awarded the first Canada Research Chair in Health Care Consumer Decision Support.

Research Interests:

Development and evaluation of decision aids
Development and testing of decision support/evaluation methods
Educating health practitioners/clinicians and consumers in shared decision making
Decisional conflict models

Programme



Programme

	Tuesday	Wednesday	Thursday
09:00 - 09:30		<i>Plenary</i> : Professor Angela Coulter - Recent Developments (ESSO Theatre)	<i>Plenary</i> : Professor Al Mulley (ESSO Theatre, Faraday Building)
09:30 - 11:00	There will be a board available at the reception desk in the Faraday Building, to post up suggestions for the discussion at the 'Open Agenda' on Thursday. <i>Please be prepared to lead the discussion.</i>	Workshops and Parallel Sessions (Lecture Rooms & ESSO, Faraday Building)	Workshops and Parallel Sessions (Lecture Rooms & ESSO, Faraday Building)
11:00 - 12:30		Coffee, Posters, Networking (Arts Hall)	Coffee, Posters, Networking (Arts Hall) and / or EACH (The European Association for Communication in Health Care) AGM - everyone welcome (ESSO Theatre, Faraday Building)
12:30 - 13:30	Check In: (Lewis-Jones Halls of Residence)	Lunch (Fulton House)	Lunch (Fulton House)
13:30 - 15:00	Registration (Faraday Building) Poster set up, tea & coffee (Arts Hall)	Workshops and Parallel Sessions (Lecture Rooms & ESSO, Faraday Building)	Workshops and Parallel Sessions (Lecture Rooms & ESSO, Faraday Building)
15:00 - 15:30	Tea + coffee (Arts Hall)	Tea + coffee (Arts Hall)	Tea and departure
15:30 - 16:00	Conference Opening: Mrs Ann Lloyd, Director NHS Wales (ESSO Theatre)	Free time	
16:00 - 17:00	<i>Plenary</i> : Professor Annette O'Connor, Ottawa (ESSO Theatre, Faraday Building)	<i>Open Agenda</i> : Participants can gather to discuss areas of mutual interest: pre advertised on preceding day. (Rooms to be allocated)	
17:15 - 19:15	Optional sea-front walk to The Mumbles (Assembly Point: Front of Fulton House)	Free time	
19:15	Drinks Reception (Café West)	Drinks Reception (Café West)	
20:00	Carvery Dinner and Harp music by Meinir Heulyn (Fulton House)	Dinner and Jazz (Fulton House)	

Schedule for Presentations



SCHEDULE FOR PAPER

DATE & TIME	ROOM	ID NO.	AUTHORS	TITLE
03-09-03 0930-1100	Session 1 – ESSO Room <i>Decision Aids</i> CHAIRMAN: Glyn Elwyn	091	Llewellyn-Thomas H, Weinstein J, Mimnaugh D	Patients' Decision Aids For Elective Total Joint Replacement: What Would Orthopaedic Surgeons Prefer?
		020	Pignone M, Felix C, Sutherland L, Fowler B, Googe S, McCoy-Hopper R, Campbell M, Sheridan S, Lewis C, Golin C	Development and usability testing of a computer-based colorectal cancer screening decision aid
		090	Whelan T, Levine M, Gafni A, Willan A, Sanders K, Mirsky D, Chambers S, O'Brien MA, Dubois S, Reid S	Empowering women and their physicians with the evidence: a randomized trial of a Decision Board for breast cancer surgery
		038	Dowding D, Bland R., Swanson V, Thomson P, Mair C, Taylor A, Morrison A, Beechey C, Simpson R	The evaluation of a computerised clinical guidance tree program for Benign Prostatic Hyperplasia and Hypertension
03-09-03 0930-1100	Session 1 – A Room Instruments and Assessment CHAIRMAN: Härter M	007	Stalmeier PFM, Roosmalen MS van, Verhoef LCG, Hoekstra-Weebers JEHM, Oosterwijk JC, Hoogerbrugge N, Moog U, Daal WAJ van	On the Evaluation of Shared Decision Making: The Decisional Evaluation Scales
		031	Otten W, Stiggelbout AM, Molewijk AC, Kievit J	Risk communication in consultations regarding the treatment of asymptomatic abdominal aneurysm
		093	Arora NK, Ayanian JZ, Guadagnoli E	Examining Correlates of Patient Participation in Medical Decision-Making
		077	Giersdorf N, Loh A., Härter M	Development and validation of assessment instruments for shared decision making
03-09-03 0930-1100	Session 1 – B Room <i>User Involvement</i> CHAIRMAN: Bremond A	027	Stevens T, Stewart D, Hearn J, Stead M.	What is the national strategy for developing the involvement of consumers in cancer research?
		001	Hodgkin P	From disability to competitive advantage - building a viable business model around user involvement
		016	Powell J, Clarke A	Learning from experience: how mental health consumers use health information
		111	Camhi B, Bremond A	Patient involvement in healthcare: access of French patients to their medical files
03-09-03 0930-1100	Session 1 – C Room <i>Patient Preferences</i> CHAIRMANr: Murray E	061	Dormandy E, Michie S, Marteau T	Variation in uptake of antenatal Down syndrome screening across ethnic groups: do these reflect differences in women's values or a failure of health care systems to facilitate informed choice equitably?
		119	Weber H, Nübling M, Langewitz W	How patient-centred are patients and which characteristics are predictive? Results from two rounds of questionnaires: 1997 and 2001 in Switzerland
		101	Doering T, Steuernagel B, Glowienka-Wiedenroth F, Hübner M-S, Rohlfing H	Different Perspectives of shared decision making in a consultation
		012	Murray E	Styles of clinical decision-making: patients and doctors preferences and experiences

03-09-03 0930-1100	Session 1- D Room <i>Systematic Reviews</i> CHAIRMAN: Stevenson F	107	Car J, Sheikh A	Scope and effectiveness of telephone consultations: systematic review
		003	Reis S, Hermoni D, Van-Raalte R, Dahan R, Borkan J	Meta-Analysis of Qualitative Studies – From Theory to Practice Patient Priorities and General Practice/Family Medicine Evaluations
		099	Cox K, Stevenson F, Britten N, Dunder Y	A systematic review of interventions involving two-way communication between patients and health care professionals about medicines
03-09-03 0930-1100	Session 1 – E Room Antenatal and Children's Health Care CHAIRMAN: Bensing J	056	Nassar N, Raynes-Greenow CH, Roberts CL, Barratt A	Jumping in feet first – development of a decision support tool for pregnant women with a breech presentation
		113	Davies A.	Parent Held Child Health Records promoting partnerships incare
		013	Olumide G, Bury M, Gabe J	Children's Experiences of Sharing Health Decisions
		095	Tates K, Dulmen S. van, Bensing, J	Parents' perspectives on interdisciplinary attuning of information and role attributions in child oncological care
03-09-03 0930-1100	Session 1 – F Room Decision Making in Health Care for People with Chronic Pain and Arthritis CHAIRMAN: O'Connor A	072	Lyne L, O'Connor AM, Drake E, Duguay P, Grover SA	Development of a decision aid for patients at high risk of cardiovascular disease
		084	Brown JB, Swartzman LC, Herbert C, Smyth L	Chronic Pain Patients' Decision-Making about Using Complementary/Alternative Medicine (CAM)
		074	Herbert C, Swartzman L, Valentine L	How do individuals with fibromyalgia (FM) and rheumatoid arthritis (RA) distinguish between various treatment options? A qualitative study aided by the inclusion of a quantitative (card sort) task
		104	Guimond P, Dubouloz CJ, O'Connor A	Perceptions of Patients with Rheumatoid Arthritis on their Decision Making Process
03-09-03 1330-1500	Session 2 – ESSO Room Decision Making in Women's Health Care CHAIRMAN: Angela Coulter	002	Protheroe J, Chew-Graham C	The role of primary care in the diagnosis and management of menorrhagia: a qualitative study of women referred to a gynaecology outpatient department with menorrhagia.
		051	Vuorma S, McCallum A, Aalto AM, Teperi J	"Why did you and your doctor choose that particular treatment?" - a study of treatment decision in women with menorrhagia
		089	Murtagh M	Forms of freedom? General Practitioner accounts of women's decision making at menopause
		085	Herbert A, McPherson K, Judge A	Hysterectomy: keeping urologist busy?

03-09-03 1330-1500	Session 2 – A Room <i>Exploring SDM</i> CHAIRMAN: Theo Schofield	032	Griffiths F, Green E	Uncertainty in the doctor-patient encounter
		094	Kasper J, Heesen C, Kùgow M, Mùhlhauser I	Shared decision making (SDM) as a mutual negotiation of uncertainties
		017	Sanders T	Patient participation as an expression of uncertainty in treatment decision-making
		081	Makoul G, Schofield T, Ford S	Evidence-based patient choice: theory vs. practice
03-09-03 1330-1500	Session 2 – B Room <i>Decision Aids</i> CHAIRMAN: Martin Härter	082	Kirshner M, O'Connor A, Stacey D, Tait V	Proposed Analytic Framework for Identifying Features of High Performing Decision Aids
		043	Evans R, Edwards A, Brett J, Bradburn M, Elwyn G, Watson E, Wright P, Hewitson P, Bukach C, Austoker J	PSA decision aids: A systematic review
		015	Scheibler F*, Kuch C*; Stoffel MP**; Baldamus CA**, Pfaff H*	Shared Decision Making in Chronic/End Stage Renal Disease: A literature Review
		096	Van Schaik P, Flynn D, van Wersch A, Ahmed T, Chadwick D	The Utility of a Multimedia Education Program for Prostate Cancer Patients
03-09-03 1330-1500	Session 2 – C Room Formats of Presenting Risk Information CHAIRMAN: Adrian Edwards	005	Vahabi M	Breast Cancer Screening: The Effects of Format Presentation on Comprehension and Intentions.
		033	Timmermans D, Molewijk B, Stiggelbout A, Kievit J	Different Formats For Communicating Surgical Risks To Patients And The Effect On Choice Of Treatment
		057	Trevena L, Barratt A, Irwig L	New approaches to preference elicitation, estimation and representation of probabilistic screening information within a home-based decision aid for colorectal cancer screening in general practice
		076	Tudor Jones R, Edwards A, Wright P	Does the format through which information is presented to healthcare users influence their interpretation of the data and if so how? A systematic review
03-09-03 1330-1500	Session 2 – D Room User Involvement in Cancer Care CHAIRMAN: Adrian Visser	059	Carretier J, Fervers B, Leichtnam-Dugarin L, Brusco S, Delavigne V., Philip T	Involving cancer patients in the development of evidence-based patient information : the SOR SAVOIR PATIENT programme
		055	Vrakking AM, van der Heide A, van der Maas PJ, van der Wal G	End-of life decisions in patients under 18 in the Netherlands
		092	Hack T, Pickles T, Bultz B, Ruether D, Degner L	Providing Audiotapes of Primary Adjuvant Treatment Consultations to Men with Prostate "Cancer". Patient Involvement in Decision Making Predicts Quality of Life, Information Recall, and Satisfaction with Oncologist Communication and Intervention
		046	van Oorschot B, Schweitzer S	Involvement in medical decisions – cancer patients, relatives and doctors views

03-09-03 1330-1500	Session 2 – E Room Analysing Talk in Consultations CHAIRMAN: David Pink	106	Robertson Maggie	Co-operating or Controlling? Doctors Pronoun Use in Shared Decision-Making
		105	McGregor S	What surgeons tell their patients with localised prostate cancer
		049	Goss C, Mazzi MA, Del Piccolo L, Zimmermann C	Information giving in general practice. Association with antecedent and subsequent patient talk
		062	Weaver N F, Murtagh MJ, Thomson RG.	Patient understandings of risk: implications for risk communication
03-09-03 1330-1500	Session 2 – F Room Consultation Approached CHAIRMAN: Aileen Clarke	014	Brown C, Wilcock P, Bateson J, Machin S, Wright M	The Discovery Interview Process: a technique for eliciting patients' and carers' experience of healthcare
		025	Kim, Sung Soo	The Effect of Physician Empathy on Patient Outcomes (patient satisfaction and compliance) in Korea
		026	Bahrs O, Heim S, Kalitzkus V, Mattheißen P, Meister P, Müller H	Salutogenesis in General Practice
		036	Jansen SJT, Otten W, Stiggelbout AM	Perceived lack of freedom of treatment choice may be related to a tendency to transfer responsibility
04-09-03 0930-1100	Session 3 - ESSO Room Decision Aids CHAIRMAN: Hilary Llewellyn-Thomas	006	Roosmalen MS van, Stalmeier PFM, Verhoef LCG, Hoekstra-Weebers JEHM, Oosterwijk JC, Hoogerbrugge N, Moog U, Daal WAJ van	Randomized trial of a shared decision making intervention, consisting of trade-offs and individualized treatment information, for BRCA1/2 mutation carriers
		018	Holmes-Rovner M, Rovner D	Iconographic-Numeric Optimization (INO): a principle to guide decision support design
		069	Graham I, Logan J, O'Connor A, Weeks K, Tetroe J.	A Physician Survey of Attitudes Toward and Intention to Use Patient Decision Aids
		028	Stacey D, O'Connor AM, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M, Jones J	Decision Aids for People Facing Health Decisions: Systematic Review 2002 Update
04-09-03 0930-1100	Session 3 – A Room Concepts and Models in Health Decision Making Chair: Bensing J	008	Snead SL	Power and Ethics in Routine Staff/Client Decision Making
		070	Innes A, Griffiths, F, Campion P	Complexity and the Consultation
		021	Légaré F,	Ten years, 3 conceptual frameworks, and 2 methods to explore 1 decision: hormone therapy or not?
		009	Bensing J, Tromp F, van Dulmen S	Historical shifts in GP communication with hypertension patients
04-09-03 0930-1100	Session 3 –B Room Decision Making in Cancer Care Chronic Illness CHAIRMAN: Adrian Visser	114	Van Kleffens T, Van Baarsen B, Van Leeuwen E	Treatment decision making in clinical oncology: patients' deliberations concerning accepting or refusing a recommended treatment
		115	Katz S, Lantz P, Janz N, Fagerlin A	Shared decision-making and receipt of mastectomy for women with early stage breast cancer: doctor knows best?
		109	Tattersall M HN, Butow P	Question prompts for people with cancer
		050	Silcock J, Raynor T, Atkin K	Heart failure: Patients' experience of treatment and attitudes towards self-management

04-09-03 0930-11:00	Session 3 – C Room	066	Hepworth J	Type 2 diabetes self-management: a narrative theory of health behaviour change
	Decision Making in Chronic Disease	052	Roberts CW, Elwyn G, Williams DRR	Primary Prevention of Type 2 Diabetes – a person centred approach involving shared decision making?
		083	Bieber C, Müller KG, Richter A, Blumenstiel K, Wilke S, Eich W	A randomised controlled study on the effects of shared decision making with chronic pain patients (fibromyalgia)
		044	van Steenkiste B, van der Weijden T, Stoffers HEJH, Timmermans D, Grol R.	Improving cardiovascular risk management by patient involvement: A risk communication tool in general practice
04-09-03 0930-11:00	Session 3 – D Room	098	Kim YM, Rinehart W, Johnson S, Church K, Martin A, Rosdiana D, Putjuk F, Lewis G	The evaluation of the WHO / CCP ‘Decision-making Tool’ on family planning counseling in Mexico and Indonesia
	Decision Making in Innovative Areas	103	Heerey M, Kim YM, Amoa M and Kols A	Voluntary Counseling and Testing for HIV/AIDS in Cameroon, West Africa: qualitative analysis of decision making, client - provider interaction and information sharing
		087	Car J, Freeman GK, Griffiths C, Sheikh A, Rhodes T, Ashcroft RE, Lais M	Exploring patient-doctor partnership in white european and south asian adults with asthma: qualitative interview study
		112	Rapport F, Rance, J.	Decision making in Assisted Reproductive Technology medicine
04-09-03 0930-11:00	Session 3 – E Room	024	Bunn H, Jacobsen MJ, Whitelaw C, Ritchie L, McIntosh A, Fox J	Decision-Making In Clinical Depression: A Canadian Perspective
	Decision Making in Mental Health Care	078	Loh, A., Giersdorf, N., Simon, D., Härter M.	Shared decision making in primary care of depression – general practitioners clinical management and patient’s perception of decision making process
		079	Simon D., Loh A., Giersdorf N., Härter M.	The process of communication and decision-making between physician and patient in primary care of depressive disorders
		011	Wills CE	Primary Care Patient Depression Treatment Decision-Making: Needs, Preferences, and Sources of Decisional Conflict
04-09-03 0930-11:00	Session 3 – F Room	019	Wensing M, Wetzels R, Aaen Geest T, Ferreira PL, Grol R, Baker R	General practitioners' views on involving older patients: a European qualitative study
	Doctors' Views of Patient Involvement	063	Lipman T, Murtagh MJ, Thomson R	Using evidence in shared decision making: a qualitative study of general practitioners' decision making about anti-coagulation in atrial fibrillation
		039	Toiviainen H, Vuorenkoski L, Hemminki E	Physicians' grounds for their attitudes towards consumer-patients
		010	Edwards A, Elwyn G, Smith C, Wood F, Prior L, Houston H	Applying shared decision making and risk communication in practice: qualitative study of general practitioners? Experiences in an explanatory trial
CHAIRMAN: van der Weijden T				
CHAIRMAN: Rapport F				
Chair: Wills CE				
CHAIRMAN: Adrian Edwards				

04:09-03 1330:15:00	Session 4 - ESSO Room	041	Robinson PJ, Booth NS	Sharing on-line information in the primary care consultation: how to teach the required communication skills
	EHealth Decision Support CHAIRMAN: Margaret Rovner	047	McPherson A, Ziebland S,	DIPEX (personal experiences of health and illness) narratives: a resource for collaborative research
		067	Rapley T, Heaven B, Kaner E, Murtagh M, May C, Thomson R, Graham, R.	"Well, we'll come back to that question": The impact of a computerised decision-support tool on doctor-patient interaction.
04:09-03 1330:15:00	Session 4 – A Room	037	Weiss M	Outcome measures used in shared approaches: their relevance for concordance
	Instruments and Assessment CHAIRMAN: Glyn Elwyn	023	Brehaut J, O'Connor A, Wood TJ, Hack T, Siminoff L, Gordon E, Feldman-Stewart, D	Patient Regret in Decision-Making
		060	Marteau T, Dormandy E, Michie S	Measuring Informed Choice: validation of a multidimensional classification
		029	Elwyn G, Hutchings H, Edwards A, Cheung I, Wensing M, Grol R	Low level patient involvement in routine general practice consultations: results of OPTION scale (2002) to measure shared decision making
04:09-03 1330:15:00	Session 4 – B Room	058	Roos Ian A G, Duchesne, Gillian M	THE PATIENT EXPERIENCE: Learning, Meaning and Identity
	Developing Users Involvement Chair: Moumjid N	080	Gillard S, Silverman J, Howells R	Teaching Explanation, Planning and Shared Decision Making to Medical Students: Experiences within the Cambridge University School of Clinical Medicine
		053	Hamann J, Kissling W	Shared decision making for inpatients with schizophrenia
		035	Moumjid N, Morelle M, Carrère MO, Bachelot T, Mignotte H, Brémond A	Partnership with patients in healthcare : Elaborating patient information with patients themselves
04:09-03 1330:15:00	Session 4 – G WORKSHOP	005	Thomson R, Murtagh MJ	Tensions in public health policy: evidence, patient and public involvement in decision making, and health inequalities

Posters



POSTERS

ID NO.	AUTHORS	TITLE
004	Reis S, Rabinowitz I, Luzatti R	THE PATIENTS' MONOLOGUE. Length, Rate of completion and correlations to other components of the clinical encounter
022	O'Connor AM, Jacobsen MJ, Drake ER, Brehaut J, Tait V, Khangura S, Wells G, Graham I, Cranney A, Tugwell P	Ottawa Health Decision Centre: Patient Decision Aids and Online Resources
030	Otten W, Stiggelbout AM	Shared decision making and risk communication: development of an elective course for 2nd year medical students
034	Vodermaier A, Bauerfeind I, Caspari C, Kahlert S, Untch M	Decision board development and evaluation for therapeutic options in adjuvant treatment of primary breast cancer
040	Robinson PJ, Booth NS	"I'd prefer to give them a leaflet". GP Trainers' reactions to using shared screens in role-played consultations
042	Christoph H, Kasper J, Busche J, Becker S, Koepke S, Mönch A, Mühlhauser I	Risk communication in multiple sclerosis: information needs, autonomy preferences and effects of an evidence-based information
045	Van Audenhove Ch., Vertommen H	Shared decision making in intake and treatment choice in mental health care
048	Jansen SJT, Stiggelbout AM, Otten W	The impact of perceived freedom of treatment choice on satisfaction with assigned treatment, experienced treatment difficulty, and current quality of life
054	Roelands M, Van Oost P, Stevens V, Depoorter AM, Buysse A	Do clinical practice guidelines improve shared decision-making about assistive device use in home care? A pilot study.
064	Chan E, Vernon SW, Ahn CW, Greisinger A	Knowledge about prostate cancer screening with prostate specific antigen in public and private-clinic African American men
065	Chan E, Vernon SW, Ahn CW, Greisinger A	Accuracy of self-reports of prostate cancer screening with prostate specific antigen at two sites
068	Ropka M, Wenzel J, Phillips E, Becker M, Philbrick J	A Qualitative Systematic Review of Decisions Related to Cancer Genetic Counseling and/or Testing (CGC/T): Research Peaks and Valleys
071	Guttridge K, Bryan S, Gill P, Greenfield S, Marshall T	Communicating with patients about CHD treatment: the development of a preference elicitation tool
073	Belkora J, Edlow B, Aviv C, Sepucha K, Mutchnick S, Esserman L	The Diffusion of Consultation Planning at Community Clinics and Resource Centers in Northern California
075	Mimnaugh D, O'Connor MA, Fowler Jr. FJ, Llewellyn-Thomas HA, Gallagher P, Puera J	Developmental Evaluation of Video-based Decision Aids for Patients: A Systematic Approach Using Focus Groups
086	¹ Car J, ¹ Freeman GK, ¹ Ashcroft RE, ² Sheikh A,	Interventions for improving patients' trust in doctors

088	Belkora J, Sepucha, K	Early work on a Decision Dialogue Process for improving the quality of medical decisions
097	Cox K, White P, Britten N	GPs' ability to detect their patients' desire for involvement in decision-making about medicines
100	Doering T, Steuernagel B, Glowienka-Wiedenroth F, Hübner M-S, Rohlfing H	Competences for the share decision making in family doctors practice
102	de Haes H, Koedoot CG, Oort FJ, de Haan RJ, Bakker PJM, de Graeff A.	Information given to patients who choose between palliative chemotherapy and watchful waiting: how informed is their choice?
108	Suurmond J, Seeleman M.C.	Intercultural Decision Making
110	Reis S, Stashefski-Margalit R, Larson S, Roter D	The Effect of the Electronic Medical Record (EMR) on the Doctor-Patient Interaction in Primary Care Visits
116	Schroeder S, Rothschild S	Advances in shared medical decision making aids: will these lead to greater use among family physicians?
117	Henderson BJ, Maguire B T, Gray, J, Morrison V.	How people make decisions to pursue predictive genetic testing: An analogue study
118	Nübling M, Langewitz W, Weber H	Do patient characteristics predict the amount of deficits reported after a hospital stay?
120	Fischer M*, Voerman B*, Visser A*, Garszen B*, van Andel G**	"Shared decision making in prostate cancer: Preliminary results from the Quality of life study in Dutch prostate cancer patients and their needs for psycho-oncological care."
121	Laura A. Rapp, RN, MSN Andrea J. Powers, RN, BSN Sr. Helen Burke, RN, MSN	Operationalizing Patient Competencies Through the Use of Health Coaching

Schedule for Workshops



Schedule for Workshops

Date & Time	Room	ID No.	Authors	Title
03-09-03 0930-1100	Session 1 <i>Lecture Theatre G</i>	007	Shaddock J	CHIQ guidelines for producing quality health information
03-09-03 0930-1100	Session 1 <i>Lecture Theatre H</i>	003	Murtagh M, Hepworth J, Rapley T	The very idea of shared decision making: views from social science
03-09-03 1330-1500	Session 2 <i>Lecture Theatre H</i>	006	Shaw J, Knight L	Sharing decision making about medicines with lay mentors
04-09-03 0930-11:00	Session 3 <i>Lecture Theatre G</i>	002	Brink S, McFarren A	Use of Multimedia Technology to Encourage Shared Decision Making
04-09-03 0930-11:00	Session 3 <i>Lecture Theatre H</i>	004	Barratt A, Trevena L, McCaffery K, Davey H	Dilemmas in screening decision aids: Formulating minimum quality criteria.
04:09-03 1330:15:00	Session 4 <i>Lecture Theatre G</i>	005	Thomson R, Murtagh MJ	Tensions in public health policy: evidence, patient and public involvement in decision making, and health inequalities

Abstract

- Presentation and Poster
 - Workshop



001

Presentation

FROM DISABILITY TO COMPETITIVE ADVANTAGE - BUILDING A VIABLE BUSINESS MODEL AROUND USER INVOLVEMENT

HODGKIN P
Primary Care Future

Background: The demography of the UK means that professionals need patients more than patients need us. We cannot provide a high quality health service without the help of expert patients and drawing on the time and skills of the well elderly and those on incapacity benefit.

Method: A proposal to start a social enterprise where patients are paid to provide services to primary care for various expert perspectives has been submitted to one PCT with backing from SRB money.

Results: No results so far -0 this is very much work in progress but I would welcome a forum to discuss and gain feedback on the evolving proposal

Conclusion: So far its looks very interesting!

002

Presentation

WOMEN'S VIEWS OF THE ROLE OF PRIMARY CARE IN THE DIAGNOSIS AND MANAGEMENT OF MENORRHAGIA: A QUALITATIVE STUDY OF WOMEN REFERRED TO A GYNAECOLOGY OUTPATIENT DEPARTMENT WITH MENORRHAGIA.

PROTHEROE J, CHEW-GRAHAM C
NPCRDC, University of Manchester

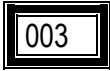
Background: Shared decision-making has been accepted as a goal for effective clinical management of menorrhagia, a common condition in general practice with many equally effective treatments. However for patients to take part in decision-making about treatment, they need to have access to appropriate information. Guidelines for the management of menorrhagia are available to GPs but the management of women in this study appears not to follow current guidelines.

The aim of this research was to examine women's knowledge of and attitudes towards treatment for menorrhagia, to explore where they obtain their information and to determine how accurate (according to current best evidence) their information is.

Method: Fifteen semi-structured interviews were conducted with women referred to a gynaecologist with a diagnosis of heavy menstrual bleeding. The data were subjected to constant comparative analysis and Layder's Adaptive Theory was the conceptual framework that particularly contributed to the interpretation of the data.

Results: Women had limited and often inaccurate knowledge of most treatment options, but were all aware of hysterectomy. The information women had about treatment was obtained from a variety of sources, mostly friends and family, but not from the GP, or from health related Patient Information Leaflets. However the most important and significant themes, to emerge from this data, were the women's feelings of diagnostic uncertainty, the lack of an explanation and need for a 'label' for symptoms, and the women's perception of the failure of the GP, to provide this.

Conclusion: Women referred to secondary care with a diagnosis of menorrhagia do not seem to have had their concerns and expectations regarding their menstrual symptoms addressed. In addition, they do not feel that their GP has communicated a diagnosis to them. Women must be able to feel that they have been diagnosed in order that treatment options can then be properly discussed, and a shared management decision reached. Reasons for the apparent lack of adherence to guidelines are discussed.



Presentation

META-ANALYSIS OF QUALITATIVE STUDIES – FROM THEORY TO PRACTICE PATIENT PRIORITIES AND GENERAL PRACTICE/FAMILY MEDICINE EVALUATIONS

REIS S ^(1,3), HERMONI D ⁽¹⁾, VAN-RAALTE R ⁽¹⁾, DAHAN R ⁽¹⁾, BORKAN J ^(2,3)

- 1) Technion-Israel Institute of Technology
- 2) Tel Aviv University, Tel Aviv, Israel.
- 3) Clalit Health Services in Israel
Brown Medical School/Memorial Hospital
of RI, Providence, RI, USA

Background: Context: An aggregation of qualitative studies remains rare and controversial. We have attempted it within a research of patient priorities and evaluations in Primary Care.

Objectives:

1. To conduct a literature search of qualitative research on patient priorities and evaluations.
2. To adapt a framework for quality assessment of qualitative studies.
3. To attempt an aggregation of the included literature.

Method: Design: A search strategy, inclusion and exclusion criteria and a quality instrument are described. Deliberations about qualitative meta-analysis led to the adoption of a metasynthesis approach. The articles were equally distributed between two teams in random fashion and inter-rater agreement was calculated. Included articles were separated into subcategories and metasynthesis within two of the six applicable subcategories was performed.

Results: Thirty-seven articles met the inclusion criteria. Twenty-three articles were of sufficient quality for metasynthesis. Inter-rater agreement ranged from 0.22 to 0.77 and 0.38 to 0.60 for pair and assessor comparisons respectively. Agreement on a global rating item ranged from 0.36 to 1. No new items were found other than those related to technological changes. Immersion in a subcategory yielded insights and practical implications.

Conclusion:

1. The attempts at implementing the stated goals of quality assessment and metasynthesis seem feasible and useful, though problematic and in need of refinement.
2. We have devised a modestly reliable instrument to assess the quality of qualitative work.
3. We have also attempted to aggregate large amounts of qualitative material by focusing on metasynthesis within subcategories. This exercise was reflexive and yielded new aims and insights.

THE PATIENTS' MONOLOGUE. LENGTH, RATE OF COMPLETION AND CORRELATIONS TO OTHER COMPONENTS OF THE CLINICAL ENCOUNTER

REIS S, RABINOWITZ I, LUZATTI R
Technion, B.rappaport Fac of Medicin

Background: Physicians often interrupt the patient's opening statement (referred to here as the patient's monologue), probably on the assumption that he/she will use more time than the physician is willing to allow. Goals: In this study we examined the length and rate of completion of the patients' monologue in family-practice encounters, which included a new clinical problem. Then we examined the effect of an intervention.

Method: A total of 235 consecutive encounters, between 8 family physicians and their patients were audio-video recorded, on two separate days, in 6 family-clinics in northern Israel. Before the start of the second day the physicians were handed a written note with the following request: "When the patient starts speaking, please do not interrupt him or her until you are satisfied that he or she has finished". The encounters were all viewed and those that included a new clinical problem were examined for length of patient monologue, monologue completion, total encounter time and more.

Results: 214 (91%) encounters were viewed. Of these -112 (52.3%) involved a new clinical problem. The average length of the patients' monologue was 26 before and 28 seconds after intervention (not statistically significant). The rate of monologue completion before the intervention was 32% and after 65%. ($P < 0.001$).

Conclusion: Although the monologue length did not alter significantly after the intervention, a significant increase occurred in the rate of monologue completion. This is compatible with the observation that completed monologues are just marginally longer than interrupted ones.

BREAST CANCER SCREENING: THE EFFECTS OF FORMAT PRESENTATION ON COMPREHENSION AND INTENTIONS

VAHABI, MANDANA
University of Toronto; Toronto District Health Council

Background: For effective communication of risk/benefit information, it is important to ensure that the recipient understands probabilistic information. Comprehension may be influenced by whether the format in which probabilistic information is presented (i.e., numeric versus verbal) matches people's format preferences. An experimental design was used to explore this problem in the context of mammography screening.

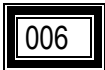
Method: A convenience sample of 180 women aged 25-45 years with no history of breast cancer and mammography received pre-assembled randomized packages, which contained a breast health information pamphlet and four questionnaires, in either verbal or numeric format. The questionnaires assessed women's comprehension and their intention to use screening mammography. Match ($n=95$) and mismatch ($n=85$) subgroups emerged based on whether or not the received format was congruent with women's preferences.

Results: There was no significant difference in overall mean comprehension between match/mismatch subgroups. However, the mean comprehension score was significantly lower in those who received numeric but preferred verbal (mean = 16) than in those who received and preferred verbal format (mean = 44) ($p < 0.001$). Among the women who

received the numeric format, overall comprehension was related to educational level; the mean comprehension score was significantly lower for those with < grade 13 (mean=17) than those with higher education (mean=42): ($p = 0.001$).

There was no significant difference in intention to use screening mammography between match/mismatch subgroups. Those intended to seek screening reported higher overall baseline knowledge of breast cancer / screening (OR = 1.26; CI= 1.13, 1.40), higher perceived risk of encountering breast cancer (OR = 3.35; CI=1.19, 9.46), and perceived usefulness and relevance of information (OR= 7.56; CI= 2.40, 23.89).

Conclusion: This study is unique in targeting younger women and revealing limited breast cancer knowledge in this group. The results indicate that comprehension may be associated with format preference, particularly when information is communicated quantitatively. Further investigation is needed to characterize the relationships among format preferences, various types of numeracy problems, and strategies for communicating information that foster satisfactory levels of comprehension. The study design could guide future exploratory investigations regarding decision formation in other screening programs.



Presentation

RANDOMIZED TRIAL OF A SHARED DECISION MAKING INTERVENTION, CONSISTING OF TRADE-OFFS AND INDIVIDUALIZED TREATMENT INFORMATION, FOR BRCA1/2 MUTATION CARRIERS

VAN ROOSMALEN MS , STALMEIER PFM, VERHOEF LCG, HOEKSTRA-WEEBERS JEHM, OOSTERWIJK JC, HOOGERBRUGGE N, MOOG U, VAN DAAL WAJ
UMC Nijmegen

Background: Objective: To evaluate a shared decision making intervention (SDMI) for BRCA1/2 mutation carriers.

Method: The SDMI consisted of two value assessment sessions, using the time trade-off method, followed by individualized treatment information based on life expectancy and quality adjusted life expectancy. After the baseline assessment (2 weeks after a positive test result), women were randomized to the SDMI group (n=44), receiving the SDMI 2 months after the test result, or to the control group (n=44). The short and long term effects of the SDMI were assessed using questionnaires at 3 and 9 months after the test result, respectively. Data were collected on well-being, treatment choice, and decision related outcomes. Subgroup analyses were done for women affected and unaffected with cancer.

Results: On the short term, the SDMI had no beneficial effects. On the long term, with respect to well-being, the SDMI group had less intrusive thoughts ($p=0.05$), a better general health ($p=0.01$), and tended to be less depressed ($p=0.07$). With respect to decision related outcomes, the SDMI group held stronger preferences ($p=0.02$) and agreed more strongly to having weighed the pros and cons ($p=0.01$) for the breast treatment. No effect was found on treatment choice, neither on the short nor long term. The SDMI showed an overall beneficial effect for unaffected women but detrimental effects on decision related outcomes for affected women.

Conclusion: We conclude that the SDMI improved decision making in unaffected BRCA1/2 mutation carriers. We discuss why the SDMI may be effective. Supporting decision making in a structured and systematic way using trade-offs is beneficial for unaffected women.

007

Presentation

ON THE EVALUATION OF SHARED DECISION MAKING: THE DECISIONAL EVALUATION SCALES

STALMEIER PFM, VAN ROOSMALEN MS, VERHOEF LCG, HOEKSTRA-WEEBERS JEHM, OOSTERWIJK JC,
HOOGERBRUGGE N, MOOG U, VAN DAAL WAJ
UMC Nijmegen

Background: There are several instruments to assess how patients evaluate their medical treatment choice.

Objectives: To investigate which psychological factors play a role in patients evaluating their medical treatment choices. To validate these measures and contrast their performance with commonly used measures.

Method: A pool of 36 items was constructed, covering concepts such as uncertainty and satisfaction with the decision, informed choice, effective decision making, responsibility for the decision, perceived riskiness of the choice, and social support regarding the decision. This pool was presented to patients at high risk for breast and ovarian cancer, awaiting the genetic test result, and facing the choice between prophylactic surgery or screening. Additional measures were assessed for validation purposes. Sensitivity was investigated by testing these measures in trials of two decision aids. Factor analyses were used for data reduction.

Results: Data from 368 women were analysed. Three Rasch scales summarised the psychological factors concerning decisional evaluation: Satisfaction-Uncertainty, Informed Choice, and Pressure. Reliabilities (Cronbach's alfa's of the three scales were 0.79, 0.85, and 0.75, respectively. Construct validity hypotheses were confirmed.

Conclusion: It has been proposed that 'decision satisfaction' and 'uncertainty' are distinct scales; our data suggest that these two concepts form a single scale. The Informed Choice scale was less responsive than simple items asking about 'the amount of information received so far.' The Satisfaction-Uncertainty scale was less responsive than Strength of Preference and 'I weighed up the pros and cons' items. The Pressure scale is a new and promising scale to evaluate decision aids.

008

Presentation

POWER AND ETHICS IN ROUTINE STAFF/CLIENT DECISION MAKING

SNEAD SL
University of Newcastle

Background: The unique and mosaic deficits in cognitive processes with people with acquired brain injury (ABI) compound the difficulties and ethical implications staff face when supporting such individuals. Historical hierarchies from the medical model of rehabilitation also exacerbate the potential for power to be misused in therapeutic relationships. The current research is exploring the relation of these themes to the task of decision making by staff in community outreach settings.

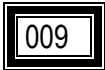
Method: Qualitative interviews were conducted with front line ABI staff to generate grounded theory about how staff perceive and experience decision making with and on behalf of their clients.

Results: The data revealed a tendency by staff to make decisions about which decisions were appropriate for clients to make, and which decisions staff would make. The data suggests that staff tend to only recognize ethical implications in major life decisions, and make these decisions in consultation with key stakeholders. Routine, mundane decisions are hardly recognized as having ethical implications, despite the higher occurrence of such decisions in the staff-client

relationship. Staff who demonstrated greater self awareness also demonstrated greater awareness of ethical implications in their daily work.

Conclusion: The qualitative data lends support to the literature which accentuates the need for staff to be aware of their own personal values, attitudes and emotions in order to be able to guard against impinging on client autonomy and choice. At the time of this writing, the research is preparing to conduct a second phase of data collecting to further explore the issue and its lack of recognition by staff in the field. By the time of the conference, additional results may be available.

Presentation



HISTORICAL SHIFTS IN GP COMMUNICATION WITH HYPERTENSION PATIENTS

BENSING J, TROMP F, VAN DULMEN S
NIVEL

Background: According to the literature there have been major changes in the doctor-patient relationship, both from the patients' and from the doctors' point of view. However, there is little empirical evidence about changes in doctor and patient behaviour in medical consultations. The aim of this study is to identify historical shifts in physician and patient communication behaviour in a homogeneous group of routine follow-up consultations with hypertension patients in general practice from the hypothesis that in recent consultations patients would be more active participants and physicians more task-oriented as compared to twenty years ago.

Method: Secondary analysis of two representative datasets of videotaped GP consultations that were collected in the period 1983-1986 versus 2001-2002, using the same methodology and coding system (RIAS). A selection was made of all hypertension patients (first dataset; n=102), respectively the first hypertension patient of each participating GP (second dataset; n=108).

Results: There were no differences in age and sex of patient groups in both study periods. Contrary to our expectations patients were less active in recent consultations, talking less, asking less questions and showing less concerns. General practitioners provided more medical information, but were less engaged in empathic support and process-oriented behaviour. Together this means that consultations of the 2001/2002 shift had a more task-oriented and less affective atmosphere as compared to twenty years before. GPs affective behaviour was related to the amount of patient contribution, while task-oriented behaviour was not.

Conclusion: The ideology of a more equalitarian relationship in General Practice with patients as active and critical consumers is not reflected in this sample of hypertensive patients in General Practice. The most important shift that could be observed over the years was a shift towards a more businesslike, task-oriented GP communication style, reflecting the recent emphasis on evidence-based medicine and protocollised care. Some concerns may be raised about the effectiveness of modern medicine in facilitating patients to voice their concerns.

010

Presentation

APPLYING SHARED DECISION MAKING AND RISK COMMUNICATION IN PRACTICE: QUALITATIVE STUDY OF GENERAL PRACTITIONERS? EXPERIENCES IN AN EXPLANATORY TRIAL

EDWARDS A, ELWYN G, SMITH C, WOOD F, PRIOR L, HOUSTON H
The Clinical School, University of Wales Swansea

Background: Whilst greater involvement of patients in decisions about their treatment or care is generally supported, there are few data on the responses of professionals to this, particularly from those who have undergone training to acquire and then apply the skills in practice.

Aim: This study aimed to identify the views of professionals who had participated in a large practice-based intervention study of shared decision making and risk communication training, both during the process and on completion.

Method: Setting and participants: 20 general practitioners (GPs) who had been in practice between 1 and 10 years, and participated in a randomised trial which lasted 5 months. The trial interventions comprised training in shared decision making skills and the use of risk communication materials, first separately then combined. The doctors consulted with up to 48 patients each (mean = 40) for the study. Half the consultations were audio-taped for further analysis.

Exit interviews using focus group methodology. Validation of data by reference to questionnaire evaluations during the trial, and feedback of focus group analyses to participants.

Results: The GPs in this sample were highly trained in the interventions but without prior exposure or specific interest in the topic. They indicated generally high levels of acceptability for the training, positive attitudes towards involving patients and described positive effects on their consultations when they did so. However, the frequency with which they applied the new skills and tools was limited: reported performance lagged behind (perceived) competence. These professionals described being selective in the situations in which they felt greater patient involvement was appropriate and feasible, rather than seeking to apply the approach to the majority of their consultations. Time limitations were important in not implementing the approach more widely.

Conclusion: Current policy to promote patient involvement appears likely to continue. Professionals appear receptive to this, and willing to acquire the relevant skills. Possible strategies to achieve wider implementation of patient involvement should address the ways consultations are scheduled in primary care, and ways of raising consumers' expectations or desires for involvement.

011

Presentation

PRIMARY CARE PATIENT DEPRESSION TREATMENT DECISION-MAKING: NEEDS, PREFERENCES, AND SOURCES OF DECISIONAL CONFLICT

WILLS CE
Michigan State University, College of Nursing

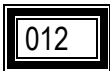
Background: As part of developing a patient-centered decision support intervention (DSI), decision-making needs, preferences, and sources of conflict for depression treatment decision-making were assessed for a diverse sample of depressed primary care patients (N=112) enrolled in a large Midwestern HMO in the U.S

Method: Semi-structured telephone interview, based in part on concepts in the Ottawa Decision Support Framework. Standardized measures included the PRIME-MD, Center for Epidemiological Studies Depression Scale (CESD),

Decisional Conflict Scale (DCS), Satisfaction With Decision (SWD) Scale, and a knowledge scale regarding depression/depression treatment.

Results: Only 16% of respondents preferred medication as a first-choice treatment option. Higher DCS and lower SWD scores were associated with lower knowledge about depression and its treatment ($r = -.34, p < .01$; $r = -.28, p < .05$), and lower DCS scores were associated with higher SWD scores ($r = .57, p < .001$). Compared to those not currently making a decision related to depression treatment ($N=64$; "Non-deciders"), those who were currently making a decision related to treatment ($N=48$; "Deciders") were more depressed ($M=31.8/SD=13.1$ vs $20.3/10.8, p < .001$), rated currently-taken medications as less effective ($M=2.06/SD=.66$ vs $2.5/.62, p < .05$), and had higher decisional conflict ($M=2.7/SD=.96$ vs $2.2/.7, p < .05$). Most Deciders preferred control of treatment decision-making, but non-whites rated their providers as less likely to provide the patient with control ($M=2.5/SD=1.4$ vs $3.4/1.4, p < .01$) and responsibility ($M=2.9/SD=1.7$ vs $3.7/1.3, p < .05$). Deciders endorsed multiple sources of decision-making difficulty, including ambivalence, lack of motivation/readiness to decide, physiological distress, delaying the decision, unclear personal values, pressure/lack of support from others, insufficient information to make a choice, and multiple health system access barriers

Conclusion: A subgroup of depressed primary care patients was identified with specific needs, preferences, and sources of decisional conflict related to depression treatment decision-making. The processes and outcomes of usual depression care may be improved by patient-centered DSIs that are targeted to these needs and preferences. Funding: This research is supported by a U.S. Public Health Service National Institute of Mental Health Mentored Clinical Scientist Career Development (K08) Award (#MH01721).



Presentation

STYLES OF CLINICAL DECISION-MAKING: PATIENTS AND DOCTORS PREFERENCES AND EXPERIENCES

MURRAY E

Department of Primary Care and Population Sciences, University College London

Background: Shared decision-making has been widely advocated, and research has concentrated on achieving this. However, there is scant data on patients' or doctors' preference for, or experience of, different styles of medical decision-making: paternalist, shared, or consumerist.

Aims. To determine: (1) the style of decision-making preferred by patients and doctors; (2) the style of decision-making experienced; and (3) the congruence between the two. We hypothesised that these outcomes would be independently associated with socio-economic status and the doctor-patient relationship.

Method: Nationally representative surveys of the U.S. public (3,209 completed interviews; 72% completion rate) and U.S. physicians (1,050 responses; 53% response rate).

Univariate and multivariate analyses were used to determine the relationships between socio-economic status, pre-existing doctor-patient relationship and outcomes of interest.

Results: 62% of the public preferred shared decision-making, 29% preferred consumerism and 9% preferred paternalism. 71% of respondents experienced their preferred style. Not experiencing the preferred style was independently associated with low socio-economic status and a poor doctor-patient relationship.

75% of doctors preferred shared decision-making, 14% preferred paternalism, and 11% preferred consumerism. 87% of doctors experienced their preferred style. Doctors with high proportions of minority or low-income patients were less likely to experience their preferred style of decision-making.

38% of patients reported not having enough information to make a medical decision most of the time. 31% said doctors hardly ever or never spent enough time with patients. These outcomes were strongly independently associated with low socio-economic status, and a poor doctor-patient relationship.

Conclusion: We found significant inequalities in medical decision-making for people with low socio-economic status, which were modified by having a good doctor-patient relationship. Implications: health inequalities may be diminished by continuity of care, allowing a good doctor-patient relationship to develop; and by targeting information to people of low SES.



Presentation

CHILDREN'S EXPERIENCES OF SHARING HEALTH DECISIONS

OLUMIDE G, BURY M, GABE J

University of Wales Swansea (Olumide) / Royal Holloway, University of London (Bury and Gabe)

Background: The research project Patients as Partners: Children and the NHS was undertaken as part of the DoH Health in Partnership research programme.

Based on research undertaken in a paediatric outpatient clinic of a London teaching hospital, the paper enquires into children's perceptions of themselves as partners and decision makers in matters of their health.

Method: The views (about shared decision making) of health professionals involved with aspects of the treatment of clinic users and a sample of children using the clinic were collected through interviews. In the case of the children, these 40 interviews took place in their homes and were tape recorded for later transcription.

Results: On the one hand the data show an enthusiastic cross professional rhetoric concerning the involvement of children in their health affairs. This contains expressions of distinct and even 'moral' views of participation. On the other hand, the children's interviews show awareness of their limitations and the extent to which they wish or need to share or delegate decision making responsibility to a trusted older person.

Conclusion: The policy of doctor-patient partnership, or shared decision making, constructs health service users as willing and able to engage in decision making and carrying through behaviours suggested as health promoting into everyday life. The accounts of children show a complexity of factors affecting health choices in daily lives. Children's own constructions of health related behaviours take account of their own beliefs, desires and motives as well as the limitations to choice involved in the routines and negotiations of family life.

Moreover, policies of doctor-patient partnership appear to focus heavily on the individual health service user. Children's accounts show how decisions may depend more on collaborative than individual processes. These data suggest need for reflection on some of the more superficial recommendations for patient partnership.

THE DISCOVERY INTERVIEW PROCESS: A TECHNIQUE FOR ELICITING PATIENTS' AND CARERS' EXPERIENCE OF HEALTHCARE

BROWN C, WILCOCK P, BATESON J, MACHIN S, WRIGHT M
NHS Modernisation Agency

Background: Two Programmes within the NHS Modernisation Agency, the Coronary Heart Disease Collaborative and the Critical Care Programme are using information from patient interviews to generate improvements to the healthcare system based on patients' and carers' experiences. This is in accordance with recent government advice relating to patient and public involvement at all levels in the NHS.

Method: An anonymised transcription of a semi structured interview, undertaken with patients and carers separately, is read out to the clinical team responsible for the care of the patient. Based on judgements made by the team, improvement projects take place which enable future patients to have a better experience. Three general methods of improvement are possible, based on the ease with which a change in the healthcare process can be generated - a change that can be implemented immediately, a change requiring small step changes to produce a larger effect, and a change which requires collection of more "data" before it can be carried out.

Results: There are many different examples to date of specific improvements generated as a result of this technique. Additionally, the "common sense analysis" of the data (which may be termed "practical phenomenology") allows clinical teams to identify general sable needs which can be met, both locally and generally. For example clear communication, orientation and meeting patients' expectations.

Conclusion: Improvements to the service by this method are generated by reflective practitioners who identify problems and own the solutions. A narrative technique of presentation of "data" is an effective engine for service improvement.

The motivation induced by the narrative is an effective means of reducing the research - practice gap.

SHARED DECISION MAKING IN CHRONIC/END STAGE RENAL DISEASE: A LITERATURE REVIEW

SCHEIBLER F ⁽¹⁾, KUCH C ⁽¹⁾, STOFFEL MP ⁽²⁾, BALDAMUS CA ⁽²⁾, PFAFF H⁽¹⁾

1) Division of Medical Sociology

2) Division of Nephrology

Department of Medicine, University Hospital Cologne, Germany

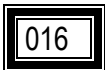
Background: Is shared decision-making (SDM) feasible in consultations with patients who suffer from chronic- or end-stage renal disease (CRD/ESRD)? Do patients with CRD/ESRD wish to be involved in their consultations? To better understand opportunities and limitations of this method in connection with CRD/ ESRD we conducted a structured literature review.

Method: Articles were identified from a MEDLINE search, an internet-search and a review of references from eligible papers.

Results: 50 references were suitable for final review. Fourteen of these articles do not refer to empirical data. Some of these point out important stages of the treatment process of CRD/ESRD where decisions are to be made. Five articles

apply qualitative methods to describe subjective views of patients, eight describe statistically determinants of decision making and four explain determinants of satisfaction with decision making. Five articles evaluate information material and two correlate quality of life with the method of decision making. Beyond that a clinical practice guideline on SDM has been established by the Renal Physicians Association in cooperation with the American Society of Nephrology. We did not find any papers reporting decision making preferences of patients with CRD/ESRD. No established generic instruments have been applied so far in this field. A comparison of these patients' preferences to those of similar patient groups with other severe chronic diseases is not possible yet.

Conclusion: Eligible papers indicate a feasibility of SDM also within the CRD/ ESRD patient group. Further research has to be done to better understand this particular kind of physician-patient-interaction and to prove the feasibility of SDM within this particular clinical context of medically and economically devastating chronic disease.



Presentation

LEARNING FROM EXPERIENCE: HOW MENTAL HEALTH CONSUMERS USE HEALTH INFORMATION

POWELL J, CLARKE A

London School of Hygiene & Tropical Medicine

Background: Little is known about the information needs or information behaviour of mental health consumers. New developments in electronic consumer information are having a profound impact on the ways in which consumers seek and interact with information.

Method: 35 in-depth interviews were carried out with a purposive sample of users of mental health services. Qualitative analysis was undertaken using the framework approach. Two researchers identified common themes, and constant comparison and deviant case analysis were used to strengthen validity.

Results: Mental health users describe a lack of information. They describe carrying out their own research into health problems and services, explaining that available information is often too generic and basic. Specific features of the Internet are attractive to mental health consumers including anonymity and ease of access to expert information. Users are conscious of the challenge that this presents to health professionals. A key theme identified was "Other people's experience". The benefits of hearing other peoples experience can be sub-categorised into (1) universality (one's situation is not unique); (2) instillation of hope (others have been through the same and recovered); and (3) understanding and empathy (others who have been through the same experience are better able to understand one's problems). These findings correlate with Yalom's categorisation of therapeutic factors in groups.

Conclusion: Mental health users report themselves as poorly served with information. They use the Internet to redress this lack, both as a medium of mass communication and for interpersonal learning. Users want to learn about other people's experience and this use of the Internet appears to have some parallels with beneficial features of therapeutic groups. Little research has been done on the use of Internet interactivity for therapeutic purposes - but this and other uses of the Internet for health care information are an important area for further exploration.

PATIENT PARTICIPATION AS AN EXPRESSION OF UNCERTAINTY IN TREATMENT DECISION-MAKING

SANDERS T
University of Manchester

Background: Research in cancer has shown conflicting evidence regarding the extent to which patients participate in treatment decision-making. Active participation by patients may not necessarily be due to the allocation of more time by the clinician to the consultation. When patients are faced with a problem or dilemma, they may seek greater involvement in the decision-making process with the clinician in an attempt to resolve their uncertainty. This paper explores the factors that influence patient involvement in treatment decision-making.

Method: The observations were conducted at two weekly bowel cancer clinics at a regional oncology centre in the south west of England. The study population was selected on the basis of a convenience sample. Patients, who had an initial appointment at the oncology clinic, were approached. In total, 49 observations (involving 49 patients) were conducted of new presentations to the oncology department. Structured observation methods were employed to investigate oncologist-patient interactions during clinics to investigate the process of treatment decision-making. The constant comparative method was adopted where the data were explored for salient themes throughout the duration of the fieldwork.

Results: A significant minority of patients (23 out of 49) were involved to varying degrees in decision-making. Active involvement usually resulted from: 1) conflicting expectations between the doctor and the patient about the most appropriate treatment 2) unexpected information 3) issues related to treatment costs and benefits and 4) the lack of a clear treatment recommendation from the oncologist.

Conclusion: The informed consent procedure requests that full information is provided to patients about their condition and its treatment, although there is no equivalent requirement to offer an interpretation of the information. In order to help patients make optimal decisions regarding treatment, it is recommended that an adequate level of information, and interpretation, be provided to patients about the pros and cons of treatment.

ICONOGRAPHIC-NUMERIC OPTIMIZATION (INO): A PRINCIPLE TO GUIDE DECISION SUPPORT DESIGN

HOLMES-ROVNER M, ROVNER D
Michigan State University

Background: Decision supports rely on scientific information that is accurate, complete, and quantitative, but at the same time, understandable, and efficient for patients and providers. Patient decision support extant approaches include 1) medical/traditional, 2) technology assessment, and 3) patient-centered. All improve knowledge, and may assist in informed choice among screening or treatment alternatives. Our patient-centered model is quantitative, but recontextualizes information to address the social and temporal context of patients in the disease and decision process, employing the principle of iconographic/numeric optimization (INO). We illustrate with a decision aid, and provide feedback from formative evaluation studies

Method: Focus groups (FG), reviewing draft booklet, Making the Choice: What to Do About Early Stage Prostate Cancer. FGs, of 6-12 men w/interviewer, assistant. Audiotape recorded, transcribed, analyzed, to evaluate content comprehension, suggested improvements, and acceptability of graphics, language and statistical data.

Study Population: 50+ yr.-old men in urban Michigan: 4 groups: African American (AA) men (1 post-treatment, 1 public), White men (1 post-treatment, 1 public).

Results: High acceptability among public and post-treatment men, who especially noted importance of side effect rates, mortality rates, simple language, size and length of booklet. Public men felt the material greatly increased their understanding of PCA and treatment. Post-treatment men indicated statistical information would have saved a month of searching, and suggested adding the emotional impact of treatment. Differences by race: AA: higher levels of fear of cancer, importance of information architecture.

Conclusion: While not a test of the INO principle, the resulting decision booklet appears to satisfy earlier established criteria for decision aid content selection, and is engaging to patients. Further evaluation is needed, though design principles, and development process should generalize to other screening and treatment decisions.



Presentation

GENERAL PRACTITIONERS' VIEWS ON INVOLVING OLDER PATIENTS: A EUROPEAN QUALITATIVE STUDY

WENSING M, WETZELS R, AAEN GEEST T, FERREIRA PL, GROL R, BAKER R
Centre for Quality of Care Research, University Medical Centre Nijmegen

Background: Involving patients in general practice is not common practice. The aim of this study was to explore general practitioners views on the concept of patient involvement, and their perceptions of barriers for involving patients.

Method: An international study in 11 countries was performed, based on qualitative interviews with 233 GPs. The interviews were fully transcribed and analysed in an iterative process.

Results: GPs saw patient involvement mainly as a process during consultations. They thought that involving older patients has positive outcomes, but mentioned barriers such as lack of experience, older patients' strong feelings of respect for doctors and possible mental and physical impairments. There was little variation across countries.

Conclusion: Implementation of patient involvement in general practice requires further reflection on the concept as well as interventions to address practitioners' perceptions.



Presentation

DEVELOPMENT AND USABILITY TESTING OF A COMPUTER-BASED COLORECTAL CANCER SCREENING DECISION AID

PIGNONE M, FELIX C, SUTHERLAND L, FOWLER B, GOOGE S, MCCOY-HOPPER R, CAMPBELL M, SHERIDAN S, LEWIS C, GOLIN C
University of North Carolina - Chapel Hill

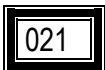
Background: We developed, and tested the usability of, a computer-based decision aid for patients to improve communication between providers and patients and to increase colorectal cancer screening in primary care practices.

Method: We developed the decision aid based on 4 sources: 1) evidence-based systematic reviews; 2) interviews of patients who had undergone screening; 3) constructs from the Trans-theoretical Model; and 4) our previously validated

colorectal cancer videotape decision aid. The decision aid was programmed using Active Server Pages (ASP) and was modified through an iterative process among the investigators. Questionnaires to assess Trans-theoretical Model constructs were embedded before and after the main contents to allow web-based data collection. We then performed two rounds of usability testing on the decision aid by observing and taping representative users as they worked with the decision aid using Think Aloud Protocol.

Results: The decision aid consists of seven 3-5 minute duration modules: 1) one required introductory module, 2) five optional in-depth modules describing the individual screening tests, and 3) a final optional module comparing the different tests. The decision aid's usability was tested in 15 patients over age 50 presenting for usual care in the Internal Medicine practice. The participants were purposely sampled to produce balance in age, gender, and previous computer experience. Qualitative analysis of the initial user sessions identified the following usability problems: 1) difficulties using the mouse, and understanding how the browser works (recognition of hypertext links, how to close windows) in participants with low computer proficiency (50% of participants), and 2) legibility problems with font and color choices in design elements and text. Interface design revisions included changes in the placement, increased size, and color contrast of navigation elements and content, simplification of navigation options and operation of the video segments, and more explicit instructions on use of program features. The second round of testing showed that these changes resulted in greater ease of use and less confusion, especially for users with low-computer proficiency.

Conclusion: We have developed an evidence-based colorectal cancer decision aid for patients that can be used successfully by patients with a wide range of previous computer experience and education. We next plan to test the effect of the decision aid in a before and after trial in our General Internal Medicine practice to determine its effect on communication and screening.



Presentation

TEN YEARS, 3 CONCEPTUAL FRAMEWORKS, AND 2 METHODS TO EXPLORE 1 DECISION: HORMONE THERAPY OR NOT?

LÉGARÉ F

Université Laval and University of Ottawa

Background: At menopause, decision about hormone therapy (HT) is the quintessential representation of clinical equipoise. This presentation summarises 10 years of studies on HT decision-making by the author. The objective is to draw the strengths and limitations of three conceptual frameworks that were used.

Method: The Theory of Planned Behaviour (TPB) was used to conduct 3 surveys on: the intention to adopt HT of 644 women, their uptake of HT after 1 year and the intention to prescribe HT of 1426 physicians. The Explanatory Model of Illness (EMI) was used to conduct interviews with 12 women and 7 physicians and to assess 12 clinical encounters that focused on decision about HT. The Ottawa Decision Support Framework (ODSF) was used to assess the agreement between 184 women's and their 40 physicians' decisional conflict regarding HT and factors related to the difference in score between women's and their physicians' decisional conflict. Data were analysed using quantitative (i.e. linear, logistic and multilevel regression techniques) and qualitative (i.e. content analysis) methods.

Results: The TPB emphasises that while most women are uncertain about using HT only a small proportion of physicians is uncertain. Although the EMI is helpful to elicit women's and physicians' rich explanatory models of menopause and HT, it is not helpful to analyse clinical encounters in which no negotiation occurs. A decision support intervention based on the ODSF improves agreement between women's and their physicians' decisional conflict regarding HT when compared with a pamphlet.

Conclusion: The TPB provides information about the determinants to adopt HT but does not address uncertainty. The EMI provides insight into individual explanatory models but does not address the interaction occurring during clinical encounters. The ODSF addresses uncertainty in individuals and in the context of clinical encounters. Therefore, the ODSF provides clinicians and public health officials with a paradigm that fits clinical equipoise.

022

Poster

OTTAWA HEALTH DECISION CENTRE: PATIENT DECISION AIDS AND ONLINE RESOURCES

O'CONNOR AM, JACOBSEN MJ, DRAKE ER, BREHAUT J, TAIT V, KHANGURA S, WELLS G, GRAHAM I, CRANNEY A, TUGWELL P
Ottawa Health Research Institute

Background: To exhibit a selection of the evidence-based therapeutic patient decision aids developed, evaluated and implemented by our Centre. Decision aids are interventions designed to help people make specific and deliberative choices among options by providing (at the minimum) information on the options and outcomes relevant to the person's health status.

Method: Our approach to decision support involves preparing the patient and practitioner for decision making and structuring follow-up counseling. Our decision aids include general information on health conditions, options, and outcomes and incorporate a personal worksheet. The worksheet assists patients identify the benefits and risks of the options, clarify their values, identify their questions, their preference for participation, as well as their leaning toward the options. The decision aids are delivered via self-paced, self-administered booklets, audio-booklets or online.

Results: Our evaluative studies indicate that our decision aids decrease decisional conflict and increase the likelihood that choices are based on better knowledge, more realistic expectations and personal values. We plan to exhibit our decision aids and demonstrate a new generic on-line decision aid.

Conclusion: A conclusion section on the poster will summarize the most current evidence of the impact of patient decision aids.

023

Presentation

PATIENT REGRET IN DECISION-MAKING

BREHAUT J, O'CONNOR A, WOOD TJ, HACK T, SIMINOFF L, GORDON E, FELDMAN-STEWART, D
Ottawa Health Research Institute

Background: Study of regret in decision-making has primarily occurred in the consumer and marketing literatures. In contrast to many consumer decisions, treatment decisions made by patients are complex, emotion-laden, and can involve serious consequences. The extent to which regret can result from such decisions, and the predictors of this regret, have not been examined. We validated a measure of regret after healthcare treatment decisions, and examined how the construct of regret was associated with various outcomes and decision process measures.

Method: A 5-item decision regret scale was administered to four groups of patients making different health care decisions (hormone replacement therapy, breast cancer adjuvant therapy, breast cancer treatment, prostate cancer treatment), along with health outcome measures and decision process measures.

Results: The scale showed good internal consistency, with Cronbach's alpha ranging from 0.81 to 0.92. Regret scores correlated both with outcome measures and with decision process variables. Stepwise regression showed the four most important predictors of regret were satisfaction with the decision (beta = -0.25, p < .001), change in the decision (beta = -0.28, p < .001), satisfaction with the doctor's visit (beta = -0.25, p < .001), and decisional conflict (beta = -0.17, p < .05).

Conclusion: The scale can serve as an indicator of regret over a health care decision. It is short and easy to administer, appropriate for a wide variety of clinical contexts, and performs well over a variety of treatment decisions. Further study of the construct of regret in the context of health care decisions may prove useful by providing a metric of the quality of preference-sensitive decisions, by understanding how regret can affect subsequent contacts with the health care system, and suggest ways in which patients can be prepared so that regret is minimized in the face of a bad outcome.

024

Presentation

DECISION-MAKING IN CLINICAL DEPRESSION: A CANADIAN PERSPECTIVE

BUNN H, JACOBSEN MJ, WHITELAW C, RITCHIE L, MCINTOSH A, FOX J
University of Ottawa

Background: Recent trends suggest the need for increased involvement of psychiatric patients in health care decision-making. However, little is known about their preferences for participation in decision-making, the types of decisions they are making or how practitioners can provide decision support.

Method: Report results of a survey of a convenience sample of 66 patients recruited from 2 hospitals in Ottawa, Canada, and diagnosed with clinical depression. Survey was based on the Ottawa Decision Support Framework.

Results: The most common decisions were medication related (38%). Participants (59%) reported high levels of decisional conflict due primarily to lack of support and insufficient information. Most participants (94%) expressed interest in being involved in decision-making with 42% wanting to share decision-making with their practitioner. 71% identified psychiatrists and 22% identified nurses as being involved in their decision-making.

For participants making both current (n=25) & recent past (n=41) decisions, lower levels of patient involvement in decision-making correlated with lower satisfaction with practitioners (p<0.000). For current decisions, higher levels of decisional conflict (p<0.045) and lower levels of patient involvement in decision-making (p<0.002) correlated with lower satisfaction with practitioners.

For past decisions, higher levels of decisional conflict correlated with both lower perceptions of effective decision-making (p<0.000) and lower satisfaction with decisions (p<0.000). Lower satisfaction with past decisions correlated with lower levels of satisfaction with current practitioner (p=0.000) and lower perceptions of involvement in patient decision-making with current practitioner (p=0.000).

Conclusion: Findings have relevance for clinicians who are trying to develop better ways to support psychiatric patients to make more informed decisions. The results of the project will be used to design an intervention to assist mental health practitioners to support patient decision making. The intervention will be tailored to modify the key factors contributing to decisional conflict in clinical depression.

025

Presentation

THE EFFECT OF PHYSICIAN EMPATHY ON PATIENT OUTCOMES (PATIENT SATISFACTION AND COMPLIANCE) IN KOREA

KIM, SS
Institute for Health Care Studies at Michigan State University

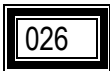
Background: Doctor-patient communication has an important influence on cost, quality of care, and achievement of desired health care outcomes. Particularly, physician empathy has been reported to be one of the most important

determinants of patients' outcomes (Olson, 1995). Like American patients, empathic physicians may be desired by Korean patients as well, but rarely found in medical settings in Korea. Furthermore, the effects of Korean physician empathy on patients' outcomes are little known up to now. Despite general agreement that the presence of empathy is an essential variable in successful physician-patient communication, few studies have addressed the mechanism of how the physician's empathy affects patient outcomes such as satisfaction and compliance. Moreover, much research focuses solely on either cognitive or affective dimensions of empathy instead of employing a more comprehensive, dualistic model that sees empathy as irreducibly an interaction of cognitive and affective elements.

Method: Participants in this study were recruited from a large, multifaceted university hospital in Pusan, Korea in 1999. Five hundred fifty (550) outpatients were participated in this survey. Structural equation analysis using EQS software program (Windows 5.7b version) was utilized to test the empathy model.

Results: The physician's empathic communication skills significantly influenced patient satisfaction and patient compliance via the mediating factors such as partnership and perception of physician expertise. Above all, for Korean patients, emotional aspects of physicians' communicative behaviors played the most important roles in their compliance and satisfaction (e.g., partnership and affective empathy).

Conclusion: The findings of the study could help health providers reduce costs and improve effectiveness of care by preventing patients' frequent changes of doctors due to patients' dissatisfaction. Furthermore, improved measurement of physicians' empathy would allow for potentially effective training interventions through medical school, residency training, or continuing education.



Presentation

SALUTOGENESIS IN GENERAL PRACTICE

BAHRS O, HEIM S, KALITZKUS V, MATTHIEßEN P, MEISTER P, MÜLLER H
Abt. Medizinische Psychologie (Medical Psychology), University of Goettingen

Background: Salutogenesis is a term coined by Aaron Antonovsky (1983) in his aim to understand what keeps people healthy. The concept is now used in the context of patient centred medicine focusing on the health promoting resources of patients rather than on pathogenic factors. Two research teams were established (University of Göttingen and Witten/Herdecke, Germany) for a 3 year long study (2003 - 2005) to analyse doctor-patient-communication in this respect. Key factors in the GPs practice should be identified that hinder or foster the promotion of salutogenic factors especially in patients with long-term conditions (Diabetes Mellitus Typ II, Asthma/COPD).

Method: Two interdisciplinary Peer Review Groups (PRG) were implemented, comprised mainly of GPs, but also of non-medical professionals. In order to integrate the patients perspective patient representatives are also part of the respective groups. In the meetings the PRGs work on identifying unused scopes of action in the doctor-patient-communication to promote a salutogenic orientation in GPs practice. Working with video documentation of consultations in general practice, the focus is set on the process of interaction and the reconstruction of structures generated within the interaction itself. Sequential analysis enables the differentiation of specific communication situations in various settings. The project is indebted to qualitative research methods, using mainly structural hermeneutics and sequential analysis. In addition to the video documentations narrative interviews with doctors and the respective patients are conducted and used for validation (triangulation).

Results: The potential of interdisciplinary PRGs accompanied by research teams both for medical training and research in primary health care will be presented.

Conclusion: The project is still in progress with the aim to diagnose context specific differences in communication styles with respect towards a salutogenetic orientation and, in the next step, to develop the results into a tool for medical training of communication skills.

WHAT IS THE NATIONAL STRATEGY FOR DEVELOPING THE INVOLVEMENT OF CONSUMERS IN CANCER RESEARCH?

STEVENS T, STEWART D, HEARN J, STEAD M
National Cancer Research Network

Background: There is increasing evidence of the benefits of involving consumers in cancer research. However, involvement has often been project driven with a high degree of variation, limited co-ordination and integration.

Method: Organisational change

A Consumer Liaison Group (CLG), part of the National Cancer Research Institute (NCRI) has already been set up and helps to provide consumer involvement to the site specific Clinical Studies Groups. Other new national organisations such as the National Cancer Research Network and the National Translational Cancer Research Network are also committed to the principle of embedding consumer involvement in research at all stages and levels. These new national groups provide a framework for developing a national strategy for the involvement of consumers in cancer research.

Results: The strategic goals

To ensure that consumers have the opportunity to influence all stages of the research process

To strengthen the consumer voice locally, regionally (through the 34 Cancer Networks) and nationally (through NCRI Consumer Liaison Group, the Clinical Studies Groups and Clinical Trials Units)

To link together existing groups and develop capacity within existing organisations to facilitate greater consumer involvement

To raise awareness among health professionals and consumers of the potential benefits of consumer involvement in research

To co-ordinate and integrate guidelines for involving consumers in cancer research, including resourcing, training, mentoring and payment, in accordance with recommendations from Consumers in NHS Research Support Unit

To develop a system for monitoring consumer involvement initiatives in cancer research and identify models of best practice

To evaluate the impact of consumer involvement in cancer research

To develop a public information programme aimed at raising general understanding about cancer research

Conclusion: The new national infrastructure providing a strategic overview of cancer research is a unique opportunity to extend and integrate the scope of consumer involvement.

DECISION AIDS FOR PEOPLE FACING HEALTH DECISIONS: SYSTEMATIC REVIEW 2002 UPDATE

STACEY D, O'CONNOR AM, ENTWISTLE V, LLEWELLYN-THOMAS H, ROVNER D, HOLMES-ROVNER M, TAIT V, TETROE J, Fiset V, BARRY M, JONES J

University of Ottawa CA, University of Aberdeen UK, Dartmouth College US, Michigan State University US

Background: Decision aids (DA) prepare people to participate in decisions characterized by uncertain outcomes or the need to make value tradeoffs between benefits versus harms.

Objectives were to establish an inventory of patient health related DAs and review randomized controlled trials of DAs.

Method: Search strategy included electronic databases and contact with researchers up to September 2002. Screening and data extraction were done by two independent reviewers. Quality was assessed using the CREDIBLE criteria for DAs and using the Jadad Scale for trials.

Results: There were: 221 DAs total; 30 DAs evaluated in 34 trials; a suite of 8 DAs evaluated in 1 trial; and 30 ongoing trials. Using CREDIBLE to assess quality of 131 available DAs: a) most include harms/benefits, display developers' credentials, are free of perceived conflict of interest, and describe the development process; b) many include reference to relevant literature; and c) few have been evaluated or include information on uncertainty regarding the evidence.

Compared to usual care, DAs performed better in terms of: a) knowledge of options (WMD=19 out of 100, 95% CI: 13, 24); b) realistic expectations (RR=1.4, 95%CI: 1.1, 1.9); c) decisional conflict related to feeling informed (WMD = -9.1 of 100, 95%CI: -12, -6); and d) proportion of people active in decision making (RR = 1.4, 95% CI: 1.0, 2.3). Compared to simpler DAs, more detailed DAs showed improvement in: a) knowledge (WMD =4 out of 100, 95% CI: 3, 6); b) realistic expectations (RR 1.5, 95%CI: 1.3, 1.7); and c) agreement between values and choice. DAs had a variable effect on options selected.

Conclusion: The number of decision aids is expanding with variable quality ratings. Trials found that decision aids impact positively on several important outcomes. However, little is known about cost-effectiveness, implementation, or longer-term outcomes.

LOW LEVEL PATIENT INVOLVEMENT IN ROUTINE GENERAL PRACTICE CONSULTATIONS: RESULTS OF OPTION SCALE (2002) TO MEASURE SHARED DECISION MAKING

ELWYN G, HUTCHINGS H, EDWARDS A, CHEUNG I, WENSING M, GROL R

The Swansea Clinical School, University of Wales Swansea

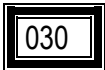
Background: The OPTION scale was developed to measure the extent to which clinicians involve patients in decision making processes within consultations. Following initial use in a randomised cross over trial of shared decision making and risk communication (published 2003), modifications were made to the scale, and translations in German and Dutch are being produced. The agreed modifications were to introduce a criterion based scale of skills observed rather than the previous attitudinal scale (degree of agreement with descriptive statements) and to refine item wording and order. The aim of this study was to undertake a psychometric assessment of the modified scale.

Method: The new scale (OPTION 2002) was finalised, agreed and a new manual developed. The scale used is a 12-item instrument that asks raters to score the extent to which clinicians involve patients in decision making. The same

raters as in the original psychometric assessment were asked to use the modified scale on the same dataset, i.e. 186 consultations recorded in routine practice from 21 general practitioners in Wales (average of 8 consultations per practitioner). Descriptive statistical analysis was performed (response rates and missing data frequency). Mean transformed OPTION score (0=min, 100=max) for each GP (based on average score from assessor 1 and 2) were calculated. Inter-rater intra-class correlation coefficient and Cohen's kappa were calculated. Cronbach's alpha scores were examined and exploratory factor analysis conducted.

Results: General practitioner ages were between 32-58 years, mean age 38.41 years, 8 were female. The mean consultation duration was 8 minutes. All items with the exception of items 8 and 9 showed a predominance of zero scores, indicating low or nil levels of patient involvement as specified by the items. Items 8 and 9 showed the most variation across the scale, although results were still confined to lower scores. On none of the items did the score exceed 2 for any consultation. With the exception of item 8 the five scale Cohen's kappa ranged from 0.45 to 0.98 indicating acceptable inter-rater agreement after correcting for chance. Aggregating to scores to produce a two-point binary scale showed similar kappa values. The inter-rater intra-class correlation coefficient for the total OPTION score was 0.77, with values ranging from 0.11 to 0.98 for the individual questions, which again (with the exception of item 9 showed good levels of agreement). Factor analysis revealed that working on a forced one-factor solution was the most robust way to deal with the instrument characteristics. The single factor solution explained 27.5% of the variability. Removal of questions 1 and 8 did not appear to improve the reliability of the scale.

Conclusion: On clinical and theoretical grounds, the scale development group feel that it is conceptually coherent, and that it is acceptable to recommend the scale in its entirety whilst ensuring that rater training is enhanced in order to improve inter-rater reliability across all items. Dutch and German versions are being produced using rigorous translation protocols.



Poster

SHARED DECISION MAKING AND RISK COMMUNICATION: DEVELOPMENT OF AN ELECTIVE COURSE FOR 2ND YEAR MEDICAL STUDENTS

OTTEN W, STIGGELBOUT AM
Leiden University Medical Center

Background: In recent years, teaching has become case-based or problem-based in most medical schools in the Netherlands. At the Leiden University a wholly new curriculum was introduced in 1999, in which problem-based learning is organized around themes. In elective courses students can deepen their knowledge on topics of their interest. At our department, we developed a 3-week elective course on Shared Decision Making and Risk Communication for 2nd year students. Aim is acquisition of knowledge, not skills training. We will present information on the development and evaluation of the course.

Method: The course consists of two phases. In the first (week 1), a theoretical basis is laid for the second phase (weeks 2 and 3), which is devoted to the writing and presenting of a paper. The first week consists of tutorials following self-study assignments. The first half is devoted to models of physician-patient decision making, the second half to risk communication (including the offering of various tools). Course material consists of a workbook, which presents classic and recent papers on the topic, assignments, illustrations, websites, etc. Scattered over the three weeks illustrations are provided, in which clinicians discuss their experience with the topic with the students, or in which videos are discussed. In our paper, we will present details of the layout and content of the course.

Results: Students filled out an extensive questionnaire, and two student representatives provided qualitative feedback after consulting with their colleagues. After adaptation following the 2002 evaluation the average grade was 8.3 (on a 10-point scale). Many students indicate that this course should be compulsory, since it covers a topic not yet covered in depth and relevant to all clinicians. We are currently exploring this option.

Conclusion: The elective course we developed on Shared Decision Making and Risk Communication is very positively evaluated by the students. In its present format it presents a well-balanced academic introduction into this topic.

RISK COMMUNICATION IN CONSULTATIONS REGARDING THE TREATMENT OF ASYMPTOMATIC ABDOMINAL ANEURYSM

OTTEN W, STIGGELBOUT AM, MOLEWIJK AC, KIEVIT J
Leiden University Medical Center

Background: Providing information about treatment options and related risks is essential for informed consent and decision making. The present study focuses at the treatment of an asymptomatic abdominal aneurysm. We examine whether patients and surgeons differ in their recall of the risks discussed in the consultation. In addition, we assess the effects of the risks discussed on the perceived clarity and threat of the risk information.

Method: Data were collected within the framework of a larger clinical trial on the impact of decision support. The present study focuses on the evaluation of the first consult, before the decision support was provided. Both patients and their surgeons evaluated the consult through a questionnaire. This questionnaire presented ten risks related to two treatment strategies (elective surgery and regular follow-up) and respondents could tick off which risks were discussed in the consultation.

Results: From 111 consultations both patient's and surgeon's questionnaires were filled in (69% response-rate). Surgeons indicated that more risks were discussed than patients (4.0 vs 2.9 out of 10 risks, $p < .001$). When surgeons had surgery in mind as treatment strategy more risks were discussed than when follow-up was the intended strategy (4.3 vs 2.9 risks, $p < .001$). If more risks were discussed patients evaluated this information as more comprehensive. Interestingly, patients indicated that they hardly felt more threatened if more risks were discussed ($r = .19$, $p = .047$), whereas surgeons believed that when they told more risks the patient would feel more threatened ($r = .30$, $p < .001$).

Conclusion: The amount of risks discussed is affected by the intended treatment which implies that informed decision making could be hampered because both treatment options are not treated equivalently. One reason could be that surgeons unjustly think that patients will be frightened by much risk information.

UNCERTAINTY IN THE DOCTOR-PATIENT ENCOUNTER

GRIFFITHS F, GREEN E
University of Warwick and University of Teesside

Background: Since the development of reductionist medicine there has been tension within medicine between the reductionist approach and that of understanding each particular individual in context. However the two are mutually constitutive in practice. The evidence based medicine movement has raised practitioner's awareness of a particular aspect of this tension, epistemological uncertainty. What is the relationship between evidence from reductionist medicine and patient centred clinical practice? This presentation describes how epistemological uncertainty is played out in clinical consultations. The data is drawn from an ESRC/MRC funded study of health technology at women's midlife, which aims to understand the micro-processes of how health technology and society interact.

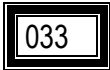
Method: Consultations related to HRT, breast screening or bone densitometry were recorded in general practice and specialist clinics. A total of 113 relevant consultations were recorded of which one third provided data that significantly contributed to the analysis presented here. The other consultations and over 150 interviews with women and health professionals undertaken for the study provide background data.

Results: Women attempt to interpret medical evidence for their own embodied experience, for their current social situation and social risks and in the light of their experiences of illness. In some consultations there was explicit discussion about epistemological uncertainty. The approach taken to epistemological uncertainty in the consultations could be categorised into

- focus on certainty limited in time and place
- focus on a coherent account that left detail and uncertainty out of focus
- use of provisional decisions

These categories will be illustrated with consultation data.

Conclusion: This presentation provides a descriptive account of how epistemological uncertainty is handled in consultations between patients and doctors. This contributes to understanding the dynamic tension between reductionist medicine and its use in individual focused clinical care and how this may impinge on shared decision making.



Presentation

DIFFERENT FORMATS FOR COMMUNICATING SURGICAL RISKS TO PATIENTS AND THE EFFECT ON CHOICE OF TREATMENT

TIMMERMANS D, MOLEWIJK B, STIGGELBOUT A, KIEVIT J

Department of Social Medicine, EMGO-Institute, VU University Medical Center

Background: Effective communication of treatment risks is important to enable patients to make informed decisions. This study aimed to determine the effect of different risk formats on the way in which participants evaluate and interpret risk information and on their choice of hypothetical treatment options.

Method: Participants (N=44) were recruited among patients who had undergone surgery for an abdominal aneurysm. They were asked to evaluate treatment risks presented in one of three formats: numbers, vertical bars or icons. The risks were presented for two hypothetical cases, i.e., choosing surgery or an observation policy when having an asymptomatic abdominal aneurysm. The effects of the risk formats on participants' evaluation of the information and on their treatment decision were measured on several variables.

Results: Risk information presented in vertical bars was evaluated as the most difficult to comprehend, and the perceived threat of this information was evaluated as higher than that of the other risk formats. Risk information presented as icons was evaluated as more helpful for making a decision, but resulted in a lower percentage of participants choosing for surgery (i.e., the optimal choice in terms of life expectancy calculated with an evidence-based model) than when risks were presented in the other formats. Participants who indicated that they preferred to be more involved in the decision-making process also indicated more often that they found the information easy to understand, more helpful for making a decision and less often threatening.

Conclusion: In conclusion, this study showed that different risk formats have different effects on participants' evaluation of the information and on their choice. Doctors should therefore be careful in choosing the format in which they present treatment risks.

DECISION BOARD DEVELOPMENT AND EVALUATION FOR TREATMENT OPTIONS IN PRIMARY BREAST CANCER

VODERMAIER A, BAUERFEIND I, CASPARI C, KAHLERT S, UNTCH M
Department of Obstetrics and Gynecology - Grosshadern, University of Munich

Background: Therapies for breast cancer are stressful, especially chemotherapy. Many patients are unsure about their optimal therapy. A considerable proportion of women want to be more involved in treatment decisions. To investigate several options in breast cancer therapy, decision boards for three therapeutic and one diagnostic option were developed. This methodological development project is part of a larger ongoing study on shared decision making in breast cancer.

Method: The developed decision boards focus on the following options:

1. breast conserving therapy and irradiation vs. radical mastectomy (tumour size < 2 cm)
2. diagnostic decision making between sentinel lymph node biopsy and lymphonodectomy (tumour size < 2 cm)
3. chemotherapy and endocrine therapy vs. pure endocrine therapy (tumour size < 2 cm and hormone receptor positive tumour)
4. preoperative chemotherapy vs. postoperative chemotherapy (tumour size > 2 cm)

The decision boards were evaluated with 35 patients in routine follow up after therapy and 36 senior nurse students. Breast cancer patients were asked about their actual, nurses about their hypothetical decision making concerning breast cancer therapy and their appraisal of the decision boards.

Results: In general breast cancer patients would make the same decisions as they were actually treated. 66% of the patients would decide again for breast conserving therapy and 73% would decide for additional chemotherapy to hormone therapy. Preoperative chemotherapy would be chosen by 44% of the patients. A higher proportion of the nurses would decide for breast conserving therapy and preoperative chemotherapy and healthy women would more often abandon chemotherapy.

Evaluation of the decision boards showed that the comprehensibility of the tools was assessed very favourably. The method was appraised to facilitate participation in decision making and their introduction was highly recommended.

Conclusion: A high proportion of breast cancer patients and nurses would choose breast conserving therapy (again). There was a high interest in preoperative chemotherapy. Some breast cancer patients would abandon chemotherapy if they had the choice, in healthy women without a history of cancer this proportion would be even higher. Evaluation of the tools revealed a high interest and satisfaction with the instruments developed. Therefore decision boards seem to be an effective tool in alleviating therapeutic decisions on the patients side.

PARTNERSHIP WITH PATIENTS IN HEALTHCARE : ELABORATING PATIENT INFORMATION WITH PATIENTS THEMSELVES

MOUMJID N, MORELLE M, CARRÈRE MO, BACHELOT T, MIGNOTTE H, BRÉMOND A
GRESAC, UMR 5823 CNRS, Centre Léon Bérard

Background: Since the beginning of the 1980s, numerous studies have brought evidence that most cancer patients say they want information. However, which information should be given and in what form ? This is the question we address here.

Method: A qualitative study based on focus group discussions conducted in a comprehensive Cancer Centre, Centre Léon Bérard, in France. A multidisciplinary working group (oncologists, health economists and one clinical psychologist) wrote up initial information booklets concerning possible breast cancer treatments (surgery, chemotherapy, radiotherapy and hormone therapy). A focus group comprised of patients with a history of breast cancer and healthy volunteers discussed their reactions to these documents.

Results: The focus group proposed numerous, significant modifications to answer requests for additional information, clarification and better readability in the information booklets.

Conclusion: This qualitative analysis showed a significant input of patients' perspective in the elaboration of patient information. It is also an additional support to the feasibility and appropriateness of the focus group technique. The next stage will be to test whether information booklets produced here conform to the needs of patients currently undergoing treatment.



Presentation

PERCEIVED LACK OF FREEDOM OF TREATMENT CHOICE MAY BE RELATED TO A TENDENCY TO TRANSFER RESPONSIBILITY

JANSEN SJT, OTTEN W, STIGGELBOUT AM

Dept. of Medical Decision Making, Leiden University Medical Center

Background: In recent years an increased emphasis has been placed on involving patients in decision-making about their medical care. The purpose of this study was to assess retrospectively patients' perceptions of freedom of choice regarding treatment with adjuvant chemotherapy and the determinants thereof.

Method: Three hundred and thirty-eight patients, who had been treated for breast cancer within the past five years, filled out a questionnaire that contained questions on perceived freedom of choice ("did you have a choice for (no) adjuvant chemotherapy?"). Potential determinants that were examined were: specialist's recommendation, impact of disease, own ability to decide, trust in (expertise) of specialist, and willingness to participate in treatment decision-making.

Results: Two hundred sixty-four patients (78%) had perceived a lack of choice. These patients agreed more often with three statements that either the doctor or the disease had dictated chemotherapy and agreed less often with a statement that they could decide by themselves about the necessity of chemotherapy (all $p < 0.01$, Mann-Whitney U-test). Furthermore, these patients more often indicated that they would always try to follow their specialist's advice ($p < 0.05$). There were no differences between choice/no choice groups with regard to perceived expertise of and trust in their specialist. With regard to preferred level of participation in treatment decision-making, these patients more often preferred the doctor to make the decision, both in the case of medical care in general ($p < 0.05$) and in the case of adjuvant chemotherapy ($p < 0.01$).

Conclusion: Patients who perceive to have had a lack of choice of treatment may be more inclined to hand over the decision for their medical care to their specialist.

037

Presentation

OUTCOME MEASURES USED IN SHARED APPROACHES: THEIR RELEVANCE FOR CONCORDANCE

WEISS M

University of Bristol

Background: Concordance is the concept used to describe the enhanced respect, relative to the traditional paternalistic model, accorded to the patient's perspective in the health care professional-patient encounter when making decisions about treatment. Although primarily concerned with interactions involving discussions about medicines, concordance is conceptually close to the shared model of treatment decision-making. The importance of this approach has been recently demonstrated with the establishment of the Medicines Partnership Task Force, tasked with implementing the policy on concordance.

Method: The aim of this project is to evaluate a range of outcome measures for their relevance to concordance. These outcomes measures will be evaluated for the extent to which they meet the four core constructs of concordance as defined by the author: (1) eliciting the patient's ideas, concerns and expectations; (2) providing evidence based information for patients; (3) ascertaining patient preferences for information and role involvement and; (4) the development of an action plan to which both parties have contributed.

Results: The measures evaluated have been drawn from a range of paradigms such as patient centredness, shared decision making, empathy and informed shared decision-making. The main findings will be presented in relation to the extent to which the different paradigms and resulting outcome measures map onto the core constructs of concordance. Particular issues to be considered include the role of empathy in shared approaches, equipoise and its relevance for concordance, the implicit and explicit role of paternalism in designing outcome measures and the differing emphases of skill development versus overall conceptual goals. Several outcome measures will be discussed in depth and used as illustration for discussion.

Conclusion: The findings of this study will be used to inform a future randomised controlled trial of an educational intervention for GPs to evaluate the development of skills in concordance. Supporters of concordance have professed it to be a new approach to the taking of medicines. The extent to which it meets this assertion or represents a duplication of existing conceptual frameworks will be discussed.

038

Presentation

THE EVALUATION OF A COMPUTERISED CLINICAL GUIDANCE TREE PROGRAM FOR BENIGN PROSTATIC HYPERPLASIA AND HYPERTENSION

DOWDING D, BLAND R, SWANSON V, THOMSON P, MAIR C, TAYLOR A, MORRISON A, BEECHEY C, SIMPSON R

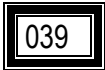
University of York

Background: There is an increasing focus on involving patients in decisions about their treatment. Decision analysis may be a way of doing this, by giving patients up to date research evidence about treatment options, and facilitating them to provide their own values regarding outcomes. We have developed a generic computer program that uses decision analysis as a way of providing information to patients, known as 'guidance trees'. This paper reports the results of a trial of two guidance trees, for Benign Prostatic Hyperplasia (BPH) and Hypertension.

Method: Patients were recruited from 15 GP practices and one acute care trust within one region in Central Scotland. Patients newly diagnosed with either BPH or Hypertension were approached and asked to volunteer to take part. Patients who consented were randomised to either the experimental group (used the guidance tree program) or control group (normal care). Follow up data was collected at 1 month and 6 months post referral. Outcome measures included compliance with chosen treatment, satisfaction with decision and quality of life.

Results: 110 patients were referred to the study, of whom 75 consented to take part. 5 patients have withdrawn, leaving 34 patients in the experimental group and 39 in the control group. Data is currently being analysed. Results presented will include analysis of the effect the program had on patient compliance, satisfaction with the decision process and quality of life. Analysis of how patients used the program, and links to the outcome measures will also be presented.

Conclusion: The paper will discuss the implications of the results of the trial, including issues to do with recruitment in primary care settings.



Presentation

PHYSICIANS' GROUNDS FOR THEIR ATTITUDES TOWARDS CONSUMER-PATIENTS

TOIVAINEN H, LÄMSÄ R, VUORENKOSKI L, HEMMINKI E
National Research and Development Centre for Welfare and Health STAKES

Background: The variety of technologies used in health care continues to grow, the educational level of patients has risen, health and drug information is increasingly available (e.g., the Internet), and today's patients are actively looking for information from different sources.

The aim of the study was to investigate physicians' grounds for their attitudes concerning patients who present clear wishes for care.

Method: The data was gathered as part of the annual physician survey sent to all Finnish physicians (n= 16 698) by the Finnish Medical Association in March 2002. The response rate was 85%. To analyse the issue in question, 1200 forms were randomly selected. Of these, 703 (59%) included grounds for attitudes.

Results: Of physicians involved in patient care (n= 12 255), a considerable proportion had patients who stated immediately on arrival for an appointment that they wanted specific laboratory or other examinations (42%), drugs (30%), and surgical or other procedures (22%). Even more of the physicians reported an increase in such patients (46% for laboratory or other procedures, 42% for drugs, and 33% for surgical or other procedures). Twenty-one percent of the physicians considered such a situation positive for the doctor-patient relationship, while 39% considered it negative and 27% chose the 'cannot say' option. The reasons for the physicians' opinions were many, and the same reason was sometimes used to explain both a positive and a negative attitude. In classifying the reasons, the most useful themes were: 1. decision-making at an appointment (27% of the 703 physicians); 2. content of the patient's request/wish (19%); 3. way of presenting the request/wish (18%); 4. way in which the appointment progressed (17%); and 5. effects on interdependence (17%).

Conclusion: Consumer-patients are a reality in the Finnish health care system. Physicians have varying opinions concerning an active role on the part of patients. Physicians' interpretations of the different phenomena vary.

040

Poster

"I'D PREFER TO GIVE THEM A LEAFLET". GP TRAINERS' REACTIONS TO USING SHARED SCREENS IN ROLE-PLAYED CONSULTATIONS

ROBINSON PJ, BOOTH NS

School of population and health sciences, Newcastle University

Background: Prodigy is an on-line decision support system for GPs. In early field-testing GPs shared background information, intended for the GP, with patients in the consultation. In response to this unexpected use, shared screens, for reading by both GP and patient during the consultation, were developed.

The iiCR (information in the consulting room) project identified communication skills that enable practitioners to use the computer interactively during the consultation while maintaining rapport with the patient. In the second phase of the project a teaching package, which allows rehearsal of these skills, was developed and trialled. Two scenarios in this teaching feature Prodigy shared screens.

Method: Evaluation of the iiCR project included videotaping role-plays and subsequent discussion. The evaluated teaching sessions took place in small groups in three different settings, on ten different occasions, over 18 months. Over 120 GP Trainers participated. Role plays were designed to force computer use in role-played consultations.

Results: None of the participants had previous experience of using shared screens; some were uncomfortable with using them. Some of this discomfort was attributed to the artificiality of role-play. Reservations were expressed about the utility of the material "I know how to explain about glue ear" and many participants felt that providing an information leaflet, for the patient to read after the consultation, was preferable. GP Trainers who participated in these sessions had all expressed some interest in computer use in practice.

Conclusion: This sample's resistance to the use of shared screens is striking. Shared decision making depends on using a conceptual framework that is the exclusive property of neither practitioner nor patient. The shared screen facilitates shared decision making by providing an external framework. The Trainers in our sample are not ready to use it.

041

Presentation

SHARING ON-LINE INFORMATION IN THE PRIMARY CARE CONSULTATION: HOW TO TEACH THE REQUIRED COMMUNICATION SKILLS

ROBINSON PJ, BOOTH NS

School of population and health sciences, Newcastle University

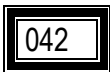
Background: Differences in levels of knowledge and access to information contribute significantly to inequalities of power in the GP consultation and so hinder shared decision-making. Information Technology now offers the potential of providing context-related knowledge and information, for both practitioner and patient, in real time during the consultation.

Change in role for the practitioner is implicit in the use of such technology. Traditionally experts acquire knowledge away from the workplace, in initial training and continuing professional development, and then dispense it during the client contact. Using on-line information sources during the client contact changes the expert's role to explanation and interpretation: the outcome is a co-produced plan of action. Inherent in the use of such technology is the risk of losing rapport with the patient while engaged with the computer as information source.

Method: The first phase of the iiCR (information in the consulting room) project determined and classified the communication skills required to stay in contact with the patient while engaging with on-line information support. The second developed methods and materials that facilitate teaching of these skills to doctors and nurses. Outline scenarios, designed to provoke use of the skill-set, are role-played in small groups facilitated according to the Calgary Cambridge Guide. Evaluation methods used include videotaped discussion of role-plays, early and late evaluation forms.

Results: This presentation describes this teaching and our evaluation of its impact on practitioners. Our focus was communication skills in relation to computer use in the consultation. The issues raised in evaluation related largely to the change in practitioner role.

Conclusion: We believe that a similar methodology could be used in the teaching of communication skills required to facilitate shared decision making in the consultation: irrespective of the role of the computer.



Poster

RISK COMMUNICATION IN MULTIPLE SCLEROSIS: INFORMATION NEEDS, AUTONOMY PREFERENCES AND EFFECTS OF AN EVIDENCE-BASED INFORMATION

CHRISTOPH H, KASPER J, BUSCHE J, BECKER S, KOEPKE S, MÖNCH A, MÜHLHAUSER I
Department of Neurology and Department of Health Sciences, University of Hamburg

Background: In recent years partly effective therapies have been established for multiple sclerosis (MS). Thus MS represents a typical field for shared decision making processes. In this study which is part of a larger investigation on shared decision making in MS we tried to evaluate prerequisite factors for risk communication and decision making in MS: 1. Information status and information interests of patients and 2. autonomy preferences.

Method: Patients for focus groups were recruited. Groups consisted of 5 parts: MS therapy knowledge questionnaire (21 items), presentation of an evidence-based patients information (EBM-info) on a study of interferon-therapy, feedback to the presentation, information ranking (30 items), open discussion. Furthermore we performed a randomized survey among patients with 2 different disease course from the MS outpatient clinic of the university hospital. The survey resembled the focus groups but the EBM-info was presented in print-format. The autonomy preference scale was used for rating of the preferred decision model.

Results: The survey (n=213) confirmed the focus group finding of a low level of MS therapeutic knowledge from a physicians perspective. Only 40% of the questions in the RR subgroup were answered correctly. The EBM-input did increase the ability to calculate absolute risk reductions. Major information interests were diagnostic (especially MRI), prognostic issues and the alleviation of symptoms. Most patients rated autonomy in decision making as the preferred decision model.

Conclusion: Scientific knowledge seems to be poor in MS patients but patients stress their autonomy in therapeutic decisions. This contradiction rises the question of what is the relevant knowledge for a good decision. This study again stresses the need of assessing patients' perceptions on a given disease before developing information tools.

PSA DECISION AIDS: A SYSTEMATIC REVIEW

EVANS R, EDWARDS A, BRETT J, BRADBURN M, ELWYN G, WATSON E, WRIGHT P, HEWITSON P, BUKACH C, AUSTOKER J

The Swansea Clinical School, University of Wales Swansea

Background: The aim of this systematic review was to gather information on PSA decision aids and their evaluations. The objectives were: search for PSA decision aids; search for evaluations of PSA decision aids; assess the quality of the decision aids; assess both the methodological quality and outcomes of the evaluations

Method: The search involved fifteen electronic databases, key journals and individual contacts. Data was extracted with reference to a range of categories for both decision aids and evaluations. A recognised methods score was used to assess the evaluations. Certain outcomes used in the evaluations were subjected to a meta-analysis.

Results: 32596 titles were identified in the electronic search. Six decision aids and ten evaluations were included (six of the evaluations used the same video decision aid). Five of the decision aids were linear documents; one was a video; none were interactive. Information was available on the development of five of the decision aids; three had been formally evaluated.

The methods scores for the evaluations ranged from 12/22 to 21/22. Knowledge of PSA and related issues was used as an outcome measure in seven of the evaluations (five of which used the same video decision aid). The meta-analysis showed significant improvements in knowledge after the decision aid. PSA testing was an outcome measure in nine of the evaluations (six of which used the same video decision aid). The meta-analysis showed a significantly reduced probability in testing after the decision aid (-3.6% $p=0.049$); but there was also significant heterogeneity, probably due to differences in the nature of the decision aids.

Conclusion: PSA decision aids improve knowledge and seem to cause to reductions in PSA testing.

IMPROVING CARDIOVASCULAR RISK MANAGEMENT BY PATIENT INVOLVEMENT: A RISK COMMUNICATION TOOL IN GENERAL PRACTICE

VAN STEENKISTE B, VAN DER WEIJDEN T, STOFFERS HEJH, TIMMERMANS D, GROL R

Centre for Quality of Care Research, Maastricht University, Maastricht

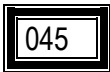
Background: The application of a risk communication tool seems to improve the adherence of the general practitioners (GPs) to the Dutch guideline on cardiovascular risk management. The aim of this paper is to evaluate the process (actual use of the tool), and the effect of the intervention on outcomes at patient level (satisfaction with the consultation, risk perception, anxiousness, self-efficacy).

Method: RCT with 36 GPs. Intervention: GP-training on the use of a tailored risk communication tool (a booklet). In the first consultation the tool was issued by the GP. Patients were invited to make their homework and return within 1-2 weeks to discuss their cardiovascular risk. Each consultation was registered by both the GP (registration form) and the patient (questionnaire).

Results: The 18 intervention GPs managed to hand over the tool to 337 patients of which 192 actually returned. The 18 control GPs registered 296 patient contacts. Both high-risk (61%) and low-risk patients (39%) were included. Nearly

half (43%) of the patients, evenly distributed on high and low-risk, reported anxiousness. Preliminary results on process evaluation: Almost all patients (93%) that returned to their GP read the booklet compared to 74% of the non-returnees. The returnees, characterised by a somewhat lower risk, reported a higher level of understanding of their risk and a higher level of reassurance. Results on the effect of the intervention will be presented at the congress.

Conclusion: The risk communication tool seems a promising strategy to help GPs to adhere to guideline recommendations. Nearly half of the patients did not respond to the GP's invitation to return for a second consultation. The question is whether this subgroup of patients needs further attention.



Poster

SHARED DECISION MAKING IN INTAKE AND TREATMENT CHOICE IN MENTAL HEALTH CARE

VAN AUDENHOVE CH, VERTOMMEN H
Katholieke Universiteit Leuven

Background: Several questions are to be answered during intake processes in mental health care centers: is treatment necessary for this client? and if so, "Is psychotherapy an efficient way of helping?" What form of psychotherapy, which therapist, which setting is most appropriate at this moment? Which method or techniques should be used?

Although at first sight these questions seem very logical, in clinical practice several factors complicate answering them. Our review of the literature confirms the importance of client preferences, client control of the situation of choice and the mutual acceptability of differing views of therapists and clients.

Method: A strategy for shared decision making for treatment choice in mental health care was developed. Four key-elements in this strategy are: the exploration of the client's perspective, informing the client, negotiation as a process of confrontation between the client's and the clinician's perspective, and the client's ultimate choice between alternative treatment proposals. Our hypothesis was that the four ingredients would increase the compatibility between the client's preferences and his or her perception of the psychotherapy process and that this in turn would reduce the number of early dropouts. We also believed that it would have a positive impact on the initial stages of psychotherapy.

Results: To evaluate the effect of these principles in practice, a referral strategy was developed and applied with a mixed group of 60 patients in primary health care. The follow-up data confirmed our hypotheses.

Conclusion: Since the publication of the strategy several mental health care centers in Flanders and the Netherlands introduced this approach for intake. Based on these experiences, the usefulness of a shared-decision making approach to treatment choice in mental health care will be discussed.

INVOLVEMENT IN MEDICAL DECISIONS – CANCER PATIENTS, RELATIVES AND DOCTORS VIEWS

VAN OORSCHOT B, SCHWEITZER S
Friedrich Schiller University, Jena, Germany

Background: In the context of a growing discussion about patient-doctor relationship, medical professionals are expected to adapt their communication and treatment on the individual patient. Studies on attitudes of patients in extreme situations such as terminal cancer patients are rare.

Method: Cancer patients and their relatives were asked to take part in a face-to-face interview using a standardized questionnaire, which was developed based on qualitative interviews. In addition, a representative part of the Thuringian general practitioners were asked to fill in a questionnaire with partly corresponding questions. Initial interviews of 145 patients, 48 relatives and 170 general practitioners could be evaluated.

Results: The majority of patients feel well informed about treatment risks (77%very good/good), course of treatment (73%), fewer about prognosis (44%). Relatives do not feel as good informed as patients (risks 59%, course of treatment 53%, prognosis 41%). Doctors believed their patients were well informed concerning risks in 38%,course of treatment in 39% and prognosis in 16%.

Asked about how they want to be informed about a bad prognosis, patients answered that doctors should tell them in 60%, only when they ask for in 20%, through relatives in 5%, and 10% do not want to know. Relatives feel patients should be told in 20%, only if they ask for in 59%, through relatives in 3% and do not want to know in 10%. Doctors answered patients should be told in 12%, only if they ask for in 25%, through relatives in 1%, with the majority favouring an individual approach (55%).

Conclusion: There is an obvious contrast between how well patients feel informed and the doctors' estimation of patients information level. Some of the above aspects interfere with the current model of shared decision making, since acceptance of open discussion seems to be the basis of SDM.

DIPEX (PERSONAL EXPERIENCES OF HEALTH AND ILLNESS) NARRATIVES: A RESOURCE FOR COLLABORATIVE RESEARCH

MCPHERSON A, ZIEBLAND S
DIPEX, Department of Primary Care, University of Oxford

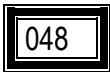
Background: DIPEX (personal experiences of health and illness) is a multimedia website based on collections of video and audio recorded narrative interviews. DIPEX is a registered charity with a research group in the University of Oxford's Department of Primary Health Care. First launched in July 2001, www.dipex.org now includes modules on several cancers (breast, prostate, bowel, cervix, and testes) and many more are in preparation for other cancers (ovarian, lung, melanoma) as well as for other conditions (epilepsy, heart failure, palliative care, sexual health, carers of people with Alzheimer's Disease and parents of children with congenital heart disease).

Method: Interviews with a maximum variation sample of between 40 and 50 participants from all over the UK are collected and analysed for each of the sites. Each website module includes thematic analyses illustrated with around 200 short clips from the interviews. The DIPEX research team has consent from the participants to use the full narratives for broadcasting, teaching and research.

Results: We will present video extracts from the DIPEX interviews to show its use for shared decision making for patients themselves and as a teaching resource. The topics will include:

- Taking and remembering drugs for hypertension
- Choosing watchful waiting or active treatment for prostate cancer
- Whether to have or not have a prosthesis when diagnosed with Testicular cancer
- Treatment choices in epilepsy

Conclusion: The narrative interviews that are the basis of all DIPEX website modules are a rich source of data for researchers who are interested in shared decision making and how patients talk about treatment options. Opportunities to collaborate in collecting DIPEX interviews, conduct secondary analysis using the narratives, or use the resources for teaching, will be discussed.



Poster

THE IMPACT OF PERCEIVED FREEDOM OF TREATMENT CHOICE ON SATISFACTION WITH ASSIGNED TREATMENT, EXPERIENCED TREATMENT DIFFICULTY, AND CURRENT QUALITY OF LIFE

JANSEN SJT, STIGGELBOUT AM, OTTEN W

Dept. of Medical Decision Making, Leiden University Medical Center

Background: Previous research has shown that the involvement of patients in the decision-making process may lower psychological morbidity and consequently improve quality of life. Our purposes were to assess retrospectively (1) whether breast cancer patients perceived freedom of choice regarding treatment with adjuvant chemotherapy and (2) whether perceived freedom of choice was related to satisfaction with the assigned treatment, experienced chemotherapy difficulty (only in patients who had experienced chemotherapy), and current quality of life.

Method: Three hundred and sixty-five patients, treated for breast cancer within the past five years, indicated in a questionnaire whether they perceived to have had a choice for (no) chemotherapy. If not, they could tick off one or more reasons out of ten or provide their own reason(s). Current quality of life was measured on a visual analog scale and by means of the HADS (anxiety and depression).

Results: Two hundred eighty-three patients (78%) had perceived a lack of choice. Both in the group of patients who had experienced adjuvant chemotherapy and in the group who had not, the most frequently indicated reason for having a lack of choice was: "I follow my specialist's recommendation for (no) chemotherapy" (chemotherapy group: 56%, no-chemotherapy group: 52%). There were no differences in satisfaction with assigned treatment, experienced chemotherapy difficulty and current quality of life between patients who had experienced freedom of treatment choice and those who had not.

Conclusion: Our results suggest that patients perceive that they have no choice but to follow their specialist's recommendation. Contrary to the expectations, perception of lack of freedom of treatment choice had no consequences for satisfaction with assigned treatment, experienced treatment difficulty and current quality of life.

INFORMATION GIVING IN GENERAL PRACTICE. ASSOCIATION WITH ANTECEDENT AND SUBSEQUENT PATIENT TALK

GOSS C, MAZZI MA, DEL PICCOLO L, ZIMMERMANN C

Department of Medicine and Public Health, Section of Psychiatry, University of Verona (Italy)

Background: Most patients want to be involved in the decision process regarding their health and physicians should learn to satisfy these needs. Before implementing educational interventions a better understanding of how information is provided in routine clinical practice is necessary.

Method: Aim is to analyse the information giving sequence of general practice consultations. Transcripts of 238 consultations, conducted by six General Practitioners (GPs), were classified with the Verona Medical Interview Classification System (VR-MICS). The VR-MICS provides three information categories: information and instructions on medical problems and information on psychosocial aspects. One lag-sequential analysis was performed to identify patient expressions which precede and follow physicians' information and instructions.

Results: Information giving covered more than a third of the average consultation length. Expressions of listening and agreement were the most likely patient response after information on medical and psychosocial issues (33%) and after instructions (49%). Questions and cues subsequent to information were rare (range between 3% and 13%). Medical information and instructions were preceded most often by patients' replies to previous questions (statements) (36% and 31%), by listening and agreement (21% and 37%) and questions (17% and 14%), less frequently by cues (8% and 4,6%) or opinions (10% and 4,9%). Cues were slightly more likely before psychosocial information (12%).

Conclusion: The few expressions of opinions and questions observed immediately before and after GPs' information and instructions, indicate a scarce degree of patient involvement in the information giving sequence, particularly when compared to the many subsequent expressions of respectful listening and agreement (hmm; yes, doctor; okay). These first results need to be confirmed by extended lag analyses but would already suggest that the facilitation of more active patient contributions should be one essential aspect in an information giving process which furthers shared decisions.

HEART FAILURE: PATIENTS' EXPERIENCE OF TREATMENT AND ATTITUDES TOWARDS SELF-MANAGEMENT

SILCOCK J, RAYNOR T, ATKIN K

University of Leeds

Background: Heart failure is a chronic disease responsible for many hospital admissions. There is evidence for the impact of multi-disciplinary care on heart failure outcomes. Self-management of heart failure may also improve patients' quality of life, but evidence and experience are lacking.

Method: A review of the literature concerning heart failure management was carried out. A general practice surgery in Leeds identified patients with a diagnosis of mild-moderate heart failure and invited them for depth interviews. The interviews focused on experience of heart failure diagnosis, care and treatment. In particular, the impact of heart failure on activities of daily living and the extent to which management was patient-centred were explored. Opinions about aspects of potential self-management were also sought.

Results: 40 invitations have been sent, 15 positive responses received, 12 interviews completed and 10 interviews transcribed for analysis. 7 participants were female, 9 lived alone and ages ranged from 60-90. Some are well-informed about health matters, whereas other only know that they need to take tablets. Healthcare experience is broadly positive, and a good doctor is one who listens and understands.

Many would follow self-management guidelines if they were given, because they trust the doctor to do the right thing, however, no one has expressed a strong desire for more control over care. Attitudes towards self-help groups and meetings to share experiences are broadly negative.

Conclusion: Everyday experience of care and desires for future treatment are far removed from a model of self-management. If self-management is considered desirable, then GPs (who are trusted) would need to promote the concept wholeheartedly. Encouraging patients with similar health problems to meet for discussions could prove difficult, unless the practical purpose of such meetings is clear to them. Further interviews are planned.



Presentation

"WHY DID YOU AND YOUR DOCTOR CHOOSE THAT PARTICULAR TREATMENT?" - A STUDY OF TREATMENT DECISION IN WOMEN WITH MENORRHAGIA

VUORMA S, MCCALLUM A, AALTO AM, TEPERI J
STAKES, National R&D Centre for Welfare and Health

Background: There is a growing consensus that people should be able to influence treatment decisions. For medical decisions with more than one reasonable option, patients' participation in decision making is necessary to optimise agreement between clinical decisions and patient preferences. This study investigated how women expressed decision making in the treatment of menorrhagia.

Method: The participating women (n=569, aged 35–54 years) were attending one of 14 gynaecology outpatient clinics because of menorrhagia. Three months after study recruitment women were mailed a follow-up questionnaire. 508 (89%) women responded and a treatment had been agreed for 462 of them. Of the respondents 395 (85%) described why a particular treatment had been chosen. Responses in an open-ended question asking why she and her doctor had chosen that particular treatment were first coded into sixty detailed categories using grounded theory. Later they were combined into six main groups: woman's own opinion ("my own wish", "I did not want to take any more tablets"), social reasons ("age", "no more children", "birth control"), symptoms ("heavy bleeding", "worsening symptoms"), clinical finding ("anaemia", "enlarged uterus"), doctor's opinion ("doctor recommended", "he/she did not explain very much") and opinion of treatment method ("good, effective method").

Results: Symptoms, clinical findings and opinions about the treatment method were the most common reasons (34%, 32% and 24%, respectively), and woman's own wish and social constructions followed (18% and 14%, respectively). 54 women (12%) expressed the view that the doctor had made treatment decision.

Conclusion: There was limited evidence of shared decision making. However, although biomedical expressions were predominant in women's responses, women's own opinions were more commonly presented than their doctor's recommendation. Despite use of open-ended questions, questionnaire studies provide limited information on decision making. However, while women appeared to have internalised a biomedical model, the findings of the study do not support the predominance of a simple model of doctor led decision-making.

PRIMARY PREVENTION OF TYPE 2 DIABETES – A PERSON CENTRED APPROACH INVOLVING SHARED DECISION MAKING?

ROBERTS CW, ELWYN G, WILLIAMS DRR
Diabetes UK Cymru / The Clinical School, Swansea

Background: Type 2 diabetes is a serious condition. Those affected have a greatly enhanced risk of dying prematurely from heart disease and stroke and are at risk of retinopathy, nephropathy, neuropathy and peripheral vascular disease.

The potential health benefits of preventing (or even delaying) the onset of type 2 diabetes in those who are at increased risk is enormous. Practical measures for realising this potential still need to be identified.

This study aims to address this need. Potential users will be actively and significantly involved in the development of supporting materials so that they are as relevant as possible to the choices that people make about their health.

1. *Method:* Identifying and assessing the tools currently available (or in preparation) which aim to support decision making about lifestyle and treatment options for people at high risk of developing type 2 diabetes
2. Identifying what people (both patients and health professionals) would find useful, accessible and appropriate in a decision making aid for the management of those at high risk.
3. Designing an information leaflet and an aid to decision making.
4. Making detailed recommendations for testing the effectiveness of the decision making aid in clinical practice.

Results: The proposed outcome of this project is a practical preventive approach for the management of people at high risk of developing type 2 diabetes by focusing on the points of view of the people concerned – those at high risk themselves and their health care professionals.

Conclusion:

SHARED DECISION MAKING FOR INPATIENTS WITH SCHIZOPHRENIA

HAMANN J, KISSLING W
Psychiatric Department, Technical University of Munich

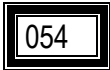
Background: Patients suffering from schizophrenia probably constitute one of the populations most excluded from medical decisions. This might be due to their assumed or existing reduced decisional capacity. However, previous research on the decisional capacity of these patients shows that except for the very acute phases of the illness, patients can show performance equal to that of non-ill controls when adequately informed.

Method: We present results of a randomised controlled trial on the use of a decision aid on antipsychotic drug choice for inpatients with schizophrenia (n=140). In this multi-center study, patients in the interventional group (decision aid + structured discussion between physician and patient on therapeutic options) are compared to patients receiving “usual

care” in regard to their satisfaction with care and perceived involvement. Apart from the outcome variables an accurate documentation of patients’ psychopathology, illness concept and knowledge was performed.

Results: First results show that the ability of the patients to participate in therapeutic decisions depends strongly on the psychopathology and the course of the illness. However, a considerable proportion of even seriously ill patients were able to successfully participate in decision-making. On discharge from hospital, patients in the interventional group were more satisfied with care, had better knowledge of their illness and reported higher perceived involvement than patients in the control group.

Conclusion: It is shown that patients with schizophrenia are in many cases able and willing to participate in important clinical decisions such as antipsychotic drug choice. This finding may be important in reducing existing prejudices about a reduced decisional capacity of schizophrenic patients. Furthermore, the use of a decision aid improves satisfaction and other variables measured on discharge from hospital. Whether the improved inclusion of the patients in therapeutic decisions has a positive influence on compliance and long term outcome will be examined in a follow up study.



Poster

DO CLINICAL PRACTICE GUIDELINES IMPROVE SHARED DECISION-MAKING ABOUT ASSISTIVE DEVICE USE IN HOME CARE? A PILOT STUDY.

ROELANDS M, VAN OOST P, STEVENS V, DEPOORTER AM, BUYSSE A
Ghent University and Free University Brussels

Background: This study examines whether clinical practice guidelines (CPG) regarding the introduction of assistive devices (ADs) in home care improve shared decision-making about AD use and modify its social-cognitive correlates.

Method: Data were collected in an intervention study with quasi-experimental design. Questionnaires were obtained from 141 home nurses and personal support workers and 140 clients with disabilities.

Results: Significant findings revealed that implementation of CPG improved home nurses’ and personal support workers’ self-reported practice: the number of intervention methods that were performed increased, and the intervention methods were performed with increased intensity. Formal caregivers in the action group performed more methods on more clients compared to the control group. CPG increased nurses’ self-efficacy in optimising AD use with clients. However, nurses’ attitudes towards optimising AD use in a shared decision-making process decreased in both action group and control group over time. Clients’ reports about caregivers’ practice showed a minor concurrence with the reports of the caregivers themselves. The complexity of the CPG and a substantial time investment were reported as the main barriers to involving clients in shared decision-making through the experimental CPG.

Conclusion: CPG hold promise for shared decision-making between formal caregivers and community-dwelling persons with disabilities concerning AD use. The findings suggest that these CPG can structure communication between caregiver and client, and can support caregivers in facilitating clients’ self-determination concerning coping with their disabilities.

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Presentation

END-OF LIFE DECISIONS IN PATIENTS UNDER 18 IN THE NETHERLANDS

VRACKING AM, VAN DER HEIDE A, VAN DER MAAS PJ, VAN DER WAL G
Erasmus MC, University Medical Center Rotterdam, department of Public Health

Background: The Objective was to explore the practice of end-of-life decision-making for patients under 18 and to assess the role of patients, parents and caregivers.

Method: Interviews were held with 63 pediatricians in the Netherlands (27 oncologists, 18 intensive care physicians and 18 neurologists). The response was 91%. Questions were asked about the decision making process for the most recent cases of deceased children between 3 months and 18 years old for whom end-of-life decisions were taken.

Results: 2 cases of euthanasia, 17 cases of active life ending without request of the patient, 12 cases of terminal sedation and 44 cases in which possible life-prolonging treatment was forgone were discussed in the interviews. 57 decisions involved patients who were under 12 years of age and 18 decisions involved patients aged 12 years or over. In most cases the decision was not discussed with the patient, mostly because the patient was too young or unconscious. 13 decisions were discussed with the patient and 7 decisions were made at the explicit request of the patient. The decision was in almost all cases discussed with parents. In some cases the decision was made on request of the parents, but the percentage differed between the different end-of-life decisions. Parents agreed with the decision in virtually all cases. The decision was discussed with other pediatricians in 99% of the cases, with nursing staff in more than half of all cases and sometimes with other caregivers.

Conclusion: This study shows that end-of-life decisions in patients under 18 are in most cases subject to shared decision-making. If their age and condition allow it, patients are usually involved in the decision-making. Decisions are virtually never made if parents do not agree.

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Presentation

JUMPING IN FEET FIRST – DEVELOPMENT OF A DECISION SUPPORT TOOL FOR PREGNANT WOMEN WITH A BREECH PRESENTATION

NASSAR N, RAYNES-GREENOW CH, ROBERTS CL, BARRATT A
Centre for Perinatal Health Services Research, University of Sydney, NSW, Australia

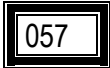
Background: For pregnant women with a breech presentation, external cephalic version (ECV – turning of a baby from feet to head first) and caesarean section are effective management options with risks and benefits. The aim of this study was to assess the need for and develop a decision support tool for pregnant women with a breech presentation; and to assess its acceptability.

Method: We surveyed pregnant women to identify knowledge, attitudes and preferences towards breech presentation and ECV. A breech decision aid (DA) was developed using the Ottawa Decision Support Framework, including systematic review of the evidence to provide probabilistic information about the benefits and risks of options. Acceptability of the DA was assessed using self-administered questionnaires.

Results: Of 174 women surveyed, 90% preferred vaginal delivery, 95% wanted to participate in decisions about pregnancy care and the main concern was for safety of the baby. DA development involved an iterative process of review and revision with a multidisciplinary project group including consumer representatives, taking over 9 months and 8 drafts to develop a version for pilot testing. The DA includes a 30-minute audiotape supplemented by a

workbook and worksheet. It was evaluated among 11 women, revised once more and further evaluated among 20 women in a before-after study. 95% of participants found the DA clear and easy to understand, 80% thought there was enough information for them to make a decision and over 90% found it very helpful and would recommend it to others. Women experienced increased knowledge, low decisional conflict, increased satisfaction and participation in decision-making without increased anxiety.

Conclusion: Time and resources required to develop a DA should not be underestimated. The pilot study suggests the breech DA will be well accepted and helpful for pregnant women with a breech presentation. Further evaluation in a RCT will assess cognitive, affective and health outcomes.



Presentation

NEW APPROACHES TO PREFERENCE ELICITATION, ESTIMATION AND REPRESENTATION OF PROBABILISTIC SCREENING INFORMATION WITHIN A HOME-BASED DECISION AID FOR COLORECTAL CANCER SCREENING IN GENERAL PRACTICE

TREVENA L, BARRATT A, IRWIG L
The University of Sydney

Background: Screening decisions are undertaken by asymptomatic individuals, usually in primary care settings and sometimes without healthcare providers. This paper uses the example of a decision aid for colorectal cancer screening to illustrate a new approach to a) representing age, sex and family history-specific risk and risk reduction b) estimating and representing cumulative test outcome probabilities and c) eliciting patient values for probabilistic screening information. Preliminary data from a general practice-based randomized trial of efficacy will also be presented.

Method: We developed six age-sex-specific paper-based decision aids with worksheets for use at home by patients of average colorectal cancer risk aged 50-74 years, eligible for faecal occult blood test screening according to Australian guidelines. Cancer registry data was used to estimate 10-year cumulative incidence and mortality for colorectal cancer adjusting for family history and other causes of death. 10-year incidence and mortality reductions were applied as potential benefits of biennial screening. 10-year cumulative probabilities of test outcomes (including screen-detected cancers, interval cancers, missed cancers, large polyps detection and false positives) were estimated on age-sex specific hypothetical cohorts of 1000 using Bayes theorem. Assumptions about the assignment of either positive or negative values to this information by consumers were avoided by using a colour-coded modified Likert scale within the theory-based values clarification exercise. The decision aids are currently being evaluated by randomised trial.

Results: Cumulative incidence, mortality and screening-attributable risk reductions were represented using a new approach combining 1,000 faces and colour-coded bar charts (to be illustrated). Ten-year estimates of cumulative test outcomes were also represented by the same method. The new values-clarification format (described above) will also be presented with preliminary RCT results

Conclusion: Complex tailored probabilistic information about cumulative screening outcomes can be estimated and represented within a home-based decision aid, along with a new approach to clarification of evidence-based screening values

THE PATIENT EXPERIENCE: LEARNING, MEANING AND IDENTITY

ROOS IAN A G, DUCHESNE, GILLIAN M

Centre for Post compulsory Education and Lifelong Learning, Faculty of Education, University of Melbourne, Vic 3010, Australia

Background: The diagnosis of serious illness brings with it a number of issues for the patient. These may include: fear of the illness itself; confronting one's own mortality; practical issues, such as continuing work; quality of life issues; and the question "why me?" In addition, there is the added burden of coping with the emotional responses from friends and loved ones, which, arising from their concern can range from fear to seeking to take charge. Added to this is the need to make choices regarding treatment and obtaining information about the various options regarding these decisions.

Method: Personal reflection, discussion with patients and health professionals and published stories, indicate that key issues in decision making by patients are centred around learning, the meaning resulting from this and the identity that is able to be constructed.

Results: The model of communities of practice provides a useful framework as it deals with the issues learning, meaning and identity. How do patients learn to confront and control these issues? How do patients learn about their affliction and obtain the necessary information and knowledge to make choice regarding their treatment? How do they learn to cope with the issues that arise from surviving their encounter with serious illness? What meaning do they obtain from their learning and how do they construct an identity both as a patient and a survivor?

Conclusion: This paper explores these issues. It suggests that the concept of communities of practice can be applied to the patient experience and provides an understanding that encompasses learning meaning and identity for patients. In this model the patient stands as an information broker between the medical communities of practice in which they become peripheral practitioners, and the various communities of practice that provide them with information from outside the medical community. Additionally, the concept of communities of practice enables medical practitioners to better comprehend the patient journey and assist their patients in that journey, thus enabling shared decision-making and improved social and emotional outcomes.

INVOLVING CANCER PATIENTS IN THE DEVELOPMENT OF EVIDENCE-BASED PATIENT INFORMATION : THE SOR SAVOIR PATIENT PROGRAMME

CARRETIER J, FERVERS B, LEICHTNAM-DUGARIN L, BRUSCO S, DELAVIGNE V, PHILIP T

French National Federation of Comprehensive Cancer Centres

Background: In response to the evolution of the information-seeking behaviour of patients, the French National Federation of Comprehensive Cancer Centres (FNCLCC) initiated the SOR SAVOIR PATIENT project in 1998. This is a programme for the development of evidence-based patient information to respond to the request from the patients for better information about their illness and its management and to facilitate the communication of that information during the physician-patient encounter.

Method: The medical information on which the patient information produced by this programme is based on clinical practice guidelines produced by the FNCLCC and the 20 french regional cancer centres, and the active participation of specialists (public and private sectors), the French Oncology Federation of university hospitals and many learned

societies who form a multidisciplinary working group for each specific guideline. The development process is based on 3 steps : 1/ "translation" into simple language of the relevant specialist guideline which is used as the primary information source by methodologists, a linguist, a health anthropologist and oncology experts ; 2/ the knowledge database produced is adapted to the expressed needs of the patients and their families during focus groups, individual interviews and by questionnaires; 3/ national review of the final document by experts and patients is conducted. A professional working group is consulted throughout the development steps which validates the scientific and medical content of the document. An anthropological approach is also used specially to develop easily understood patient information on specific cancer treatments by ethnographic analysis.

Results: 100 patients have participated in the elaboration of the various SOR SAVOIR PATIENT booklets (drafting, review, improvement of the content and the form of the information). Five patient information guides (understanding non metastatic breast cancer (2000, updated in 2002), neuroblastoma (2000), ovarian cancer and family risk of breast cancer and ovarian cancer (2002) have been published. The publication of seven other booklets is planned for 2003 and 2004 (undersanding cancer of the prostate, lung cancer, osteosarcoma, etc.).

Conclusion: Written information for cancer patients represents a supplement for verbal information in the clinical setting. It's essential that the transmission of the information meets the needs of both the healthcare professionals and the patients. The impact of these booklets on patients' outcomes and physician-patient relationships will have to be assessed. More research is needed, in particular to better understand the cultural context and to identify how to overcome existing barriers.



Presentation

MEASURING INFORMED CHOICE: VALIDATION OF A MULTIDIMENSIONAL CLASSIFICATION

MARTEAU T, DORMANDY E, MICHIE S
King's College London

Background: Research on informed choice has been hampered by the lack of a valid measure.

Aim: to develop a way of classifying choices in the context of screening starting from an operational definition of an informed choice as one that is based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented.

Method: Measure: The Multidimensional Classification of Informed Choice (MCIC) is based on responses to an eight-item knowledge scale, and a four-item measure of attitudes towards undergoing the test. Choices are classified as informed in those with good levels of knowledge (ie above the mid point of the scale), and whose choices are consistent with their attitudes (ie those with a positive attitude towards having the test, undergo it, and those with negative attitudes, not undergoing it).

Participants: 1499 pregnant women offered a Down syndrome screening.

Procedure: Women completed the knowledge and attitude scales before testing. Concurrent validity of the ensuing classification was assessed in a sub-sample that completed the Ottawa Decision Conflict Scale (ODCS) six weeks later.

Results: Internal reliability of the measures of knowledge (alpha coefficient of reliability: 0.62) and attitudes towards undergoing the test (alpha: 0.85) were acceptable. 52% of choices were classified as informed. Uninformed choices reflected low levels of knowledge (evident in 33% of women); and attitude-behaviour inconsistency, (evident in 23%). Those classified as making an informed choice subsequently rated their decisions using the ODCS as being more informed, better supported and of higher quality than did women whose choices were classified as uninformed.

Conclusion: Comment: In addition to being simple to complete, and psychometrically robust, the MCIC specifies how choices are uninformed (lack of knowledge or attitude behaviour inconsistency) thus providing the basis for interventions designed to increase rates of informed choice. Studies are now in progress to evaluate such interventions

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Presentation

VARIATION IN UPTAKE OF ANTENATAL DOWN SYNDROME SCREENING ACROSS ETHNIC GROUPS: DO THESE REFLECT DIFFERENCES IN WOMEN'S VALUES OR A FAILURE OF HEALTH CARE SYSTEMS TO FACILITATE INFORMED CHOICE EQUITABLY?

DORMANDY E, MICHIE S, MARTEAU T
King's College London

Background: The importance of facilitating informed choices for people considering participation in screening programmes is widely acknowledged but little is known about the extent to which this is achieved in practice. In the context of antenatal screening for Down syndrome it has been suggested that observed differences in uptake between ethnic groups may reflect differences in attitudes towards undergoing the test rather than differences in rates of informed choice. This study aims to investigate whether the lower uptake of an antenatal screening test for Down syndrome in women from ethnic minorities reflects differences in rates of informed choice.

Method: Design: A prospective, descriptive study set in two district general hospitals offering antenatal screening for Down syndrome. 104 South-Asian and 1286 white women participated.

Outcome measures: Uptake and Informed choice (a classification based upon women's knowledge about the test and the consistency of their attitudes towards undergoing the test and their decisions about testing).

Results: Screening uptake was lower for South-Asian than for white women (29% vs 52%, 95% CI diff 12, 31). Attitudes towards undergoing the test were similar in both groups (13.9 vs 13.9, $t = 0.3$, $p = 0.77$). South Asian women with positive attitudes towards undergoing screening were less likely to have the test than white women with similar attitudes (45% vs 78%, 95% CI diff 18,44). Knowledge about the screening test was also lower in South-Asian than white women (3.5 vs 5.5, $t = 10.5$, $p < 0.001$). Overall, rates of informed choice were lower for South-Asian women than for white women (20% vs 56%, 95% CI diff 28-44).

Conclusion: The lower screening uptake seen in women from ethnic minorities do not reflect differences in attitudes but rather lower levels of informed choice, suggesting that the health care system is failing to facilitate informed choices for these women.

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Presentation

PATIENT UNDERSTANDINGS OF RISK: IMPLICATIONS FOR RISK COMMUNICATION

WEAVER N F, MURTAGH MJ, THOMSON RG
School of Health Sciences, The Medical School, University of Newcastle upon Tyne

Background: Risk communication and perception are fundamental to high quality care in an era of shared and informed decision making. However, there are concerns about communicating risk effectively in the absence of a clear understanding of what risk means to individuals. Little work has been done on the subjective understanding of information relating to risk in this setting. This interview study therefore explores how people manage and understand information about risk in a real world situation

Method: Objective: To explore the ways in which individuals conceptualise risk in the context of a recent diagnosis of hypertension.

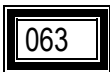
Design: An interview study using discourse analysis.

Setting: General practice.

Participants: Eleven newly diagnosed hypertensive patients.

Results: Participants present a coherent construction of themselves in relation to risk. People adopted one of two broad positions in relation to risk, which we have described as; 'risk concept evasion', and 'risk concept acceptance'. The 'evaders' describe risk as applying to others but not themselves. The 'acceptors' see risk as an unavoidable part of everyday life. Participants deploy these subject positions as a way of dealing with risk and there is evidence of a reflective insight into this self positioning. Some people in both the acceptance and evasion groups demonstrate the use of similar health related behavioural strategies, but with different meaning effects being achieved by the health behaviour. For some 'risk concept evaders' there is evidence of co-existing contradictory constructions, following the new diagnosis of hypertension suggesting a potential mutability in these constructions.

Conclusion: Subject positions adopted in relation to risk function as a strategy for 'getting on with life'. Co-existing contradictory discourses may represent a transitional stage between positions. This clarification of the way people interpret risk information and experience has not been described before.



Presentation

USING EVIDENCE IN SHARED DECISION MAKING: A QUALITATIVE STUDY OF GENERAL PRACTITIONERS' DECISION MAKING ABOUT ANTI-COAGULATION IN ATRIAL FIBRILLATION

LIPMAN T, MURTAGH MJ, THOMSON R

Department of Epidemiology and Public Health, Medical School, University of Newcastle upon Tyne

Background: The aim of this study was to explore how general practitioners (GPs) with an active interest in research or evidence-based medicine (EBM) make decisions about anticoagulation in patients with atrial fibrillation.

Method: Semi-structured interviews with 11 suitable GPs about their experiences in managing patients with atrial fibrillation were recorded on audio-tape, transcribed and analysed using the "Framework" method. A constructivist approach was taken to analysis and interpretation.

Results: All the GPs had made efforts to read and apply research evidence, but they also professed a commitment to sharing decision making with patients. GPs used a variety of sources of evidence, including Clinical Evidence, Cochrane reviews, guidelines and recent publications. Their interpretations of evidence varied, and appeared to be influenced by their experience of critical events and access to reliable monitoring services. Two GPs, who had experienced serious critical events (including the death of a patient), stated that they accepted the suggestion of a recent publication that aspirin was as effective as warfarin in some circumstances.

When making decisions, GPs were only partly influenced by the evidence itself. Secondary care had a strong influence which they found hard to challenge, even when they disagreed with the decision. They were willing to accept patients' decisions to decline treatment because of strongly held personal views, such as an individual who had been a rat catcher and "had seen too many things happen to rats with warfarin". Some expressed unease if high risk patients declined treatment, as though they had failed to make the case properly. GPs with expertise in EBM were both most confident about adequately explaining risks and benefits, and most relaxed if patients declined treatment.

Conclusion: Decision making about anticoagulation is complex, partly determined by a socially constructed view of the evidence, and strongly influenced by the GP's professional role.

KNOWLEDGE ABOUT PROSTATE CANCER SCREENING WITH PROSTATE SPECIFIC ANTIGEN IN PUBLIC AND PRIVATE-CLINIC AFRICAN AMERICAN MEN

CHAN E, VERNON SW, AHN CW, GREISINGER A
University of Texas-Houston Health Sciences Center, Houston, TX, USA

Background: Educational interventions to promote informed decision making for prostate cancer screening with prostate specific antigen (PSA) have been directed at African American (AA) men in general. We determined whether there were differences in knowledge about and experience with PSA screening in AA men attending public vs. private clinics.

Method: We recruited AA men ≥ 50 yr after a general medicine outpatient public (HCC) (n=150) or private clinic visit (KSC) (n=109). Each man completed a survey assessing knowledge and experience with PSA testing. We computed mean global and sub-section knowledge scores (e.g., cancer, screening, treatment), and compared scores for each demographic and experience variable using Student's t-test. We used step-wise linear regression to identify variables associated with knowledge.

Results: Mean global knowledge scores for men for each demographic variable at HCC were lower than for men at KSC. There were more differences in global and sub-section knowledge scores between men who had had experience with PSA compared with men who had not in the HCC group than in the KSC group. In the HCC group, "ever heard of" and "ever had" a PSA were significant predictors of global knowledge; in the KSC group, it was only "ever had" a PSA. In the HCC group, "doctor ever told you to have a PSA," "ever heard of," and "ever had" a PSA were significant predictors of screening knowledge; in the KSC group, it was only "ever had" a PSA.

Conclusion: Knowledge about PSA screening may differ between AA men attending public and private clinics, particularly as a result of their experience with testing. Educational approaches promoting informed decision making about PSA among AA men may need to consider this.

ACCURACY OF SELF-REPORTS OF PROSTATE CANCER SCREENING WITH PROSTATE SPECIFIC ANTIGEN AT TWO SITES

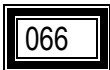
CHAN E, VERNON SW, AHN CW, GREISINGER A
University of Texas-Houston Health Sciences Center, Houston, TX, USA

Background: Because screening for prostate cancer with prostate specific antigen (PSA) is controversial, US professional organizations recommend informed consent. To target educational efforts to improve informed consent for PSA we determined the accuracy of patient self-reports of PSA testing and determined whether demographic, knowledge, or experience variables would predict accuracy.

Method: We recruited men ≥ 50yr. attending the medicine outpatient clinics at Kelsey-Seybold Clinic (KSC) (n=265) and at the University of Texas-Houston (UT-H) (n=137) who had just completed a visit. Each man completed a survey asking whether he had had a PSA test and which assessed his knowledge and experience with PSA testing. A medical record review (n= 402) determined whether a screening PSA was completed. We conducted chi-square tests for accuracy of self-reports of PSA testing across variables and stepwise logistic regression to identify predictors of accurate self-reports of PSA testing and false negative reports.

Results: The prevalence of PSA testing was 90% at KSC and 28% at UT-H. The concordance between self-reports and the medical record at KSC was 65%, and at UT-H, it was 88%. At KSC, the sensitivity, specificity, false positive and false negative rates to the question “Did you have a PSA today?” were 67%, 43%, 57%, and 33%, respectively. At UT-H, the sensitivity, specificity, false positive, false negative rates to the question were 64%, 98%, 2%, and 36%, respectively. At KSC, only “ever had a PSA” and “doctor recommended a PSA test today” predicted accuracy; at UT-H, no variables were significantly associated with accuracy.

Conclusion: The accuracy of patient self-reports of PSA testing, when defined as concordance between self-reports and the medical record, may differ when the prevalence of testing is different. Caution may be required when interpreting the accuracy of self-reports of PSA testing for targeting educational efforts promoting informed consent.



Presentation

TYPE 2 DIABETES SELF-MANAGEMENT: A NARRATIVE THEORY OF HEALTH BEHAVIOUR CHANGE

HEPWORTH J

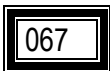
Queen Margaret University College

Background: The purpose of this study was to document accounts of health behaviour change for the self-management of type 2 diabetes and explore the contribution of a narrative approach to understanding the implementation of health care recommendations.

Method: Thirty-two people who have type 2 diabetes participated in a series of qualitative semi-structured interviews that were subsequently examined using narrative analysis based on the work of (Gergen and Gergen, 1986; Robinson, 1990; Rappaport, 1993). The narrative structure, function and change were examined in relation to participants’ goal or goals.

Results: Five narratives of behaviour change for type 2 diabetes self-management were identified: transformative, active self-management, resistance, incapacity and fatalistic.

Conclusion: The implications of a narrative theory of change for the explanation of health behaviour and its translation to clinical settings are explored.



Presentation

“WELL, WE’LL COME BACK TO THAT QUESTION”: THE IMPACT OF A COMPUTERISED DECISION-SUPPORT TOOL ON DOCTOR-PATIENT INTERACTION.

RAPLEY T, HEAVEN B, KANER E, MURTAGH M, MAY C, THOMSON R, GRAHAM R
School of Population and Health Sciences, University of Newcastle upon Tyne

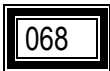
Background: Information and communication technologies are increasingly heralded as enabling both doctors and patients to become ‘real’ partners in clinical decision making. This paper reports on an observational study which examines the behaviour of participants in a randomised controlled trial of a computer-mediated tool intended to facilitate shared decision-making about treatment for people with a vascular disease. The RCT compares a computerised tool specifically designed to help doctors to explain evidence about risk and potential treatment decisions with paper-based guidelines.

Method: Qualitative and quantitative research techniques were used. Consultations were video-taped and transcribed (n=20). The video data was analysed quantitatively (using content analysis) and qualitatively (using conversation analysis). Patients were interviewed within seven days of the consultation and re-interviewed at three months. The semi-structured interviews were audio-taped, transcribed and analysed qualitatively (using discourse analysis). The data was analysed to examine the actual behaviours occurring in the consultations and patients' retrospective accounts of the consultations.

Results: We identified two main courses of action that directed the trajectory of the consultations: the agenda of the computerised tool and the patients' agendas. The interaction was mainly structured by both doctors and patients attending too the 'information needs' of the computerised tools and not the flow of patients' enquiries. In addition, doctors routinely invoked the agenda of the tool to postpone response to patients' questions or to bring the patients' talk to a close. We describe the variety of strategies used by patients to focus doctors' attention on their specific questions and concerns.

Conclusion: When computerised decision-support tools direct the trajectory of the consultation they can place limitations on doctors' and patients' involvement in the decision-making process. However, we found evidence to suggest that when patients' concerns are fore-grounded selective use of the tool can enhance the consultation.

This paper is one of three that forms the empirical background for the workshop "The very idea of shared decision making: views from social science".



Poster

A QUALITATIVE SYSTEMATIC REVIEW OF DECISIONS RELATED TO CANCER GENETIC COUNSELING AND/OR TESTING (CGC/T): RESEARCH PEAKS AND VALLEYS

ROPKA M, WENZEL J, PHILLIPS E, BECKER M, PHILBRICK J
University of Virginia

Background: Individuals and families dealing with hereditary cancer (HC) face many decisions, including whether to obtain CGC/T. Evidence synthesized from studies addressing these decisions provides a basis for developing decision support and guiding future research.

PURPOSE: To identify, appraise, and synthesize evidence from published studies regarding CGC/T decisions.

Method: **SEARCH STRATEGIES:** Searches for cancer genetic counseling (GC) and genetic testing (GT) -- restricted to primary reports, in English, 1990 or later -- were developed in MEDLINE, CINAHL, PSYCHINFO. Reviews and Letters were eliminated (yield=1,887). **STUDY INCLUSION CRITERIA:** Citations were included that met all criteria: (1) cancer-related; (2) adults; (3) examined CGC/T; (4) published 1990 or after; (5) peer-reviewed; (6) involved any of three aspects of decisions: (6a) rate of uptake; (6b) factors related to decision to obtain CGC/T; (6c) impact or consequences of CGC/T (n=111). **DATA ABSTRACTED:** Purpose; aims; decisions; decision making model; theoretical framework; level of evidence; sample, setting; independent, dependent, other variables, and how measured; results. **QUALITY REVIEW:** Two independent reviewers used 14 Standards adapted by investigators to accommodate diverse study designs (not restricted to RCTs).

Results: **DECISION SITUATION(s)** involved (n=130): (1) rate obtained CGC/T, 11.5%, (2) factors influencing CGC/T decision, 50.0%, CGC/T impact, 38.5%.

DECISION FOCUS (n=111) was: GC, 20.7%; both CGC/T, 17.1%; GT, 62.2%.

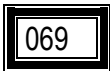
CANCER involved (n=114): breast and/or ovarian, 77.1%; colon, 14.0%; other, 8.9%.

DECISION SUPPORT INTERVENTION(s) TESTED (n=10): booklet/print (3); individual counseling (3); audiotape, computer, slides, videotape (1 each).

LEVELS OF EVIDENCE (n=111): RCT, 11.0%; Controlled Trial without Randomization, 0.0%; Cohort/Case-control, 45.6%; Before-after, Pre-post, Time-series, or Comparisons, 16.5%; Correlational/Descriptive, 54.1%; Qualitative, 13.8%.

Conclusion: PEAKS: Breast and/or ovarian received four-fifths of attention, regardless of CGC/T decision situation or focus. Four-fifths studied GT decisions, despite small percent that actually obtain GT.

VALLEYS: Studies must evolve towards more trial designs, and evaluate decision support interventions.



Presentation

A PHYSICIAN SURVEY OF ATTITUDES TOWARD AND INTENTION TO USE PATIENT DECISION AIDS

GRAHAM I, LOGAN J, O'CONNOR A, WEEKS K, TETROE J
Ottawa Health Research Institute

Background: Patient decision aids are intended to be used in collaboration with a practitioner as an adjunct to counselling. Study objective: to describe physicians' expressed intentions to use, and perceptions of the attributes of decision aids.

Method: A cross-sectional mail survey of random samples of Canadian respirologists and geriatricians. The two decision aids used were (1) a decision aid for patients with severe chronic obstructive pulmonary disease considering mechanical ventilation at the end of their lives, and (2) a decision aid for long-term placement of feeding tubes in the elderly. Physicians were mailed the decision aid kit, a two-page, 49 Likert item questionnaire, and a cheque for \$50.00(CAD).

Results: Of the 348 eligible participants, 53% (n=183) completed questionnaires, another 23% (n=81) returned uncompleted questionnaires. Of the 183 physicians, 50% indicated they were likely to use the decision aid in the future, 80% were comfortable offering it to their patients. Overall, 85% of physicians reported a need for the decision aid. Between 79%- 90% indicated the aid was acceptable, well developed and organized, contained the essential information to make a decision, clearly described the options, provided balanced information, and presented the evidence in an understandable and unbiased way. Between 78-87% of physicians indicated that the aid would: guide patients through the decision making process in a logical way, help patients understand benefits and risks of options, prepare them for decision making, reach a decision and participate in the decision making process. Fewer physicians (<60%), indicated that it would: be easy to use in practice, save time, or improve the quality of patient visits.

Conclusion: This is the first random sample survey to show that physicians consider decision aids some decision aids necessary and overwhelmingly see them as high quality products useful to patients. Despite 80% of physicians being comfortable with patients using specific aids, only half considered using them in their practices. More research is needed on the barriers to physician use of patient decision aids.

COMPLEXITY AND THE CONSULTATION

INNES A, GRIFFITHS F, CAMPION P

University of Hull and University of Warwick (Dr Griffiths)

Over recent years general practice has explored ideas from the emerging science of chaos and complexity. Complexity theory offers an alternative perspective to the Newtonian and largely mechanistic model of the world that has dominated scientific and medical thinking. It is concerned with the study of complex adaptive systems, which can be defined as “a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent’s actions changes the context for other agents”. Non-linearity is a feature of such systems and small changes can have large effects. Complex systems also display “edge of chaos” dynamics when they become unstable and vulnerable to change.

This study seeks to understand whether complexity theory offers a useful framework for clinicians and patients to share an understanding of what happens when they meet in consultations. Preliminary results from the study are presented.

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This study seeks to understand whether complexity theory offers a useful framework for clinicians and patients to share an understanding of what happens when they meet in consultations. Preliminary results from the study are presented.

Method: A qualitative focus group study is being undertaken with general practitioners and lay people. The groups have taken the format of an initial presentation of key concepts of complexity theory followed by discussion facilitated with stimulus materials. The groups are recorded and the transcription analysed using a constant comparative method.

Results: Patients and general practitioners seem to intuitively understand the concepts of complexity, in particular a sense of co-evolution of the relationship between doctors and patients and the problems both face. The nature of uncertainty and the non-linear relationship of cause and effect were appreciated.

Conclusion: The results from preliminary analysis would suggest that complexity theory might offer a useful perspective for doctors and patients in sharing an understanding in consultations, which can form the basis of shared decision-making. It may also provide a useful framework in health professional education.

COMMUNICATING WITH PATIENTS ABOUT CHD TREATMENT: THE DEVELOPMENT OF A PREFERENCE ELICITATION TOOL

GUTRIDGE K, BRYAN S, GILL P, GREENFIELD S, MARSHALL T

Public Health Building, University of Birmingham

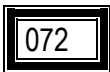
Background: There is substantial evidence of the effectiveness of treatment to prevent heart disease. However, individuals vary in the values they attach to reducing risk of heart disease and taking medication. For shared decision making to occur in the clinical environment it is necessary for a method to be developed that enables patients to

integrate their own values with evidence of effectiveness. To aid this process optimal ways of presenting patients with probabilistic information on effectiveness needs to be determined.

Method: We conducted a narrative review using standard methods of searching; databases Medline, Embase and CINAHL, Psychlit and Econlit; reference list of retrieved papers and personal collection of references. The resulting preference elicitation tool was piloted within a general practice population; aged 35-75 and eligible for screening for primary prevention of CHD.

Results: To elicit preferences a decision tool needs to reflect real life decision making by offering discrete choices and presenting individualised risk and benefit scenarios. Due to variation in inter-interpretation of verbal terms numerical presentation of risk is considered more consistent. Graphical presentation and icon displays have been suggested as useful visual aids. The pilot interviews indicated that patients prefer iconic displays, however, their comprehension was more accurate when they considered bar charts depicting risk. As the use of complementary data displays was advocated in the literature the preference elicitation tool ultimately consisted of bar charts and written information.

Conclusion: Discrete choices reflecting individualised risks and benefits show the most promise in eliciting patient's informed consent and determining their personal optimal decisions. Numerical information, presented on bar charts and in written form, can be used to share information on effectiveness of treatment in a manner that patients can comprehend.



Presentation

DEVELOPMENT OF A DECISION AID FOR PATIENTS AT HIGH RISK OF CARDIOVASCULAR DISEASE

LYNE L, O'CONNOR AM, DRAKE E, DUGUAY P, GROVER SA
Faculty of Pharmacy, University of Montreal

Background: Studies have shown that pharmaceutical care based on patient education, evaluation of cardiovascular disease (CVD) risk, development of a treatment plan, and patient follow-up improve hypertension and dyslipidemia control. A decision aid (DA) may facilitate such a complex intervention. The objective of this project is to develop and pre-test a DA for patients with hypertension or dyslipidemia.

Method: A DA was developed by five researchers and clinicians and was reviewed by a language specialist. A pre-post study design was used with a convenience sample of patients (n = 16) receiving pharmacologic treatment for hypertension and/or dyslipidemia.

Results: The DA consists of a booklet containing general, evidence-based information and a personal worksheet with patient-specific information. The worksheet provides information on patient risk factors, personal estimates of CVD risk and of the benefits of lifestyle changes and medication options. It invites patients to collaborate with a health professional to specify an action plan and follow their own progress over time. In the pre-test study, most patients (86%–93%) rated the presentation of the information as excellent or very good; 80% judged the information about lifestyle changes and medications to be balanced; 93% rated the amount of information “just right”; and 100% found it useful. After using the DA, patients had higher knowledge scores for general risk factors (before-after: 91%-100%; p=0.014), personal risk factors (73%-92%; p=0.016), and treatment options (68%-99%; p<0.001). More patients were able to correctly estimate their CVD risk category (50%-93%; p=0.03) and their absolute 10-year CVD risk (0%-93%; p<0.001), while the overall decisional-conflict score slightly decreased (p=0.007).

Conclusion: In this pre-test study, the DA was acceptable and improved knowledge, risk perception, and decisional conflict. It is therefore now important to assess the feasibility and impact of using the DA in community pharmacies and medical clinics.

THE DIFFUSION OF CONSULTATION PLANNING AT COMMUNITY CLINICS AND RESOURCE CENTERS IN NORTHERN CALIFORNIA

BELKORA J, EDLOW B, AVIV C, SEPUCHA K, MUTCHNICK S, ESSERMAN L
University of California San Francisco and Harvard Medical School

Background: This retrospective study analyzed the implementation of a shared decision-making tool, consultation planning (CP), originally developed and used at the UCSF Breast Care Center. Over a three-year period, in response to expressions of interest, UCSF staff conducted CP training seminars with 36 staff members from 13 community clinics and resource centers in Northern California.

Method: The authors attempted to contact all 36 trainees. Twenty trainees from 10 organizations agreed to formal phone interviews. Eight trainees declined, 6 were unreachable, and 2 deferred to another trainee in the organization. Interviews were tape-recorded, transcribed, and coded using standard qualitative methods. Analysis focused on how patient demographics, physician collaboration, and institutional culture impact the implementation process.

Results: Five out of 10 participating organizations implemented CP. Based on participant self-reporting, these 5 performed a total of 203 CPs over the past 3 years. All 5 organizations that implemented CP were community resource centers. For these organizations, supportive executive management was helpful, but not necessary for implementation; physician support and referral led to higher patient volume; and strategic planning prior to training facilitated implementation. Patient demographics played a minimal role, except with resource centers struggling to provide basic services to underserved populations. Three participating resource centers and 2 participating clinics did not implement CP, citing staffing shortages, time constraints, and funding limitations.

Conclusion: Future trainings should include implementation strategies to meet diverse organizational needs, such as grant-writing, advertising, recruiting volunteers, and establishing a referral network with physicians. Effective implementation in multi-cultural settings requires translation services and outreach. Future studies should investigate how to combine CP with existing patient navigation programs and how to better enlist physician collaboration.

HOW DO INDIVIDUALS WITH FIBROMYALGIA (FM) AND RHEUMATOID ARTHRITIS (RA) DISTINGUISH BETWEEN VARIOUS TREATMENT OPTIONS? A QUALITATIVE STUDY AIDED BY THE INCLUSION OF A QUANTITATIVE (CARD SORT) TASK

HERBERT C, SWARTZMAN L, VALENTINE L
Faculty of Medicine & Dentistry, The University of Western Ontario

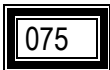
Background: This study builds on an earlier focus group study, in which we had difficulty engaging individuals with RA and FM in a discussion of what they consider important features of treatments, as well as what makes Complementary /Alternative Medicine (CAM) "alternative". In this study, we tried to make this rather abstract endeavor more accessible to participants by structuring our interview around a more concrete (i.e., card sort) task.

Method: Participants were twelve individuals (2 males, 10 females; 8 FM, 4 RA; mean age = 50.6) recruited from conventional medical and CAM practices. Individual interviews were loosely structured around a card sort task, which involved sorting 19 treatments for RA and FM into piles of similar treatments.

Results: Participants tended to initially classify treatments based on whether they were or might be effective (e.g., "Useless", "It may help", "I would use as a third resort") or were to be avoided. Through probes, and subsequent

(higher - order) card sorts, participants went on to articulate more abstract treatment features, which included the distinction between "aggressive (invasive)" vs "gentle", "temporary" vs "permanent (curative)", and "high" vs "low personally controllable" treatments. Notably, none of the participants spontaneously categorized treatments as complementary/alternative (CAM) versus conventional, though were quite willing to do so when asked. Moreover, by asking participants why they placed particular treatments in the "CAM" versus "Conventional" piles, we were able to help them reflect on their (largely heretofore) implicit views about CAM versus conventional treatments at a depth that had not been possible with the focus group participants.

Conclusion: The card sort task, used as an adjunct in our qualitative interviews, helped our participants engage in the rather abstract task of discussing salient features of treatments, and, in so doing, helped them make their implicit views "explicit."



Poster

DEVELOPMENTAL EVALUATION OF VIDEO-BASED DECISION AIDS FOR PATIENTS: A SYSTEMATIC APPROACH USING FOCUS GROUPS

MIMNAUGH D, O'CONNOR MA, FOWLER JR. FJ, LLEWELLYN-THOMAS HA, GALLAGHER P, PUERA J
Dartmouth Medical School

Background: High-quality patients' decision aids (DAs) present evidence-based information in an understandable and balanced manner.

The Foundation for Informed Medical Decision Making (FIMDM) -- the world's largest developer of video-based DAs -- collaborates with Boston's Center for Survey Research (CSR) and Dartmouth's Health Decision Research (HDR) program to ensure that early DA prototypes are thoroughly assessed by potential users.

The purpose of this paper is to outline the principles guiding early developmental evaluation.

Method: For each prototype, the CSR and HDR independently recruit 15 members of the target population. Consenting participants meet in 2-hour focus groups of 6-8, and view the prototype video together. Then each person completes a questionnaire using Likert scales to obtain ratings of the amount, clarity, and balance of the video's information, and its perceived helpfulness with values clarification and decision confidence. Next, the group provides suggestions for revision based on individuals' ratings.

Finally, the group evaluates the draft booklet accompanying the video. Group discussions are audio-taped. Descriptive statistics are computed for the quantitative responses, and the qualitative data are content analyzed using categories reflecting the questionnaire's conceptual structure.

Results: In the past year, 20 focus groups have assessed 10 prototypes. The evaluative principles outlined above consistently reveal clear patterns about how to revise the prototypes to ensure they are understandable and balanced.

Conclusion: When creating new DAs, all developmental steps should be systematically recorded and reported. One essential step is to seek reactions of potential patient-users. An explicit procedure that could be replicated by other investigators should be used to obtain those reactions. We advocate that the strategy outlined here could serve as a procedural standard for the early developmental assessment of video-based decision aids.

DOES THE FORMAT THROUGH WHICH INFORMATION IS PRESENTED TO HEALTHCARE USERS INFLUENCE THEIR INTERPRETATION OF THE DATA AND IF SO HOW? A SYSTEMATIC REVIEW

TUDOR JONES R, EDWARDS A, WRIGHT P
University of Wales College of Medicine

Background: New models of healthcare delivery are being developed as societal expectations shift and we move towards a healthcare professional-patient partnership, for example shared decision making. In order for a healthcare user to make an informed decision we must share the information required. The way in which we choose to deliver that information may influence the decision making process. This may be either intentional or unintentional through framing effects. Our systematic review of the literature will establish whether and how the format through which we deliver information affects patient understanding.

Method: A systematic review of the literature based on established guidelines. A comprehensive search of electronic databases was supplemented by reference list screening, hand searches of key journals and contact with leading authors in the field. The method will include systematic data extraction and synthesis including meta-analysis where feasible and a qualitative meta-synthesis.

Results: Provisional results will be available by September.

Conclusion: We aim to establish a clear understanding of accuracy of patient perception of data delivered through a variety of formats. Satisfaction, stability of decision-making and concordance may also be influenced by format of information delivery and influence on health outcomes. Increased understanding in this field will enhance communication between patients and healthcare professionals. Our review will also contribute to the expanding field of decision aid development. Individuals come to a consultation with a background of experience and values that contribute to their decision-making. The relative balance of power that these beliefs hold in relation to the scientific facts will be variable and must also be considered when deciding the most appropriate course of action for an individual.

DEVELOPMENT AND VALIDATION OF ASSESSMENT INSTRUMENTS FOR SHARED DECISION MAKING

GIERSDORF N, LOH A, HÄRTER M
Health Services Research, Universitätsklinik Freiburg, Abt. Psychiatrie und psychotherapie mit Poliklinik

Background: Aims of the study are the development and validation of assessment measures to evaluate process and outcomes of shared decision making.

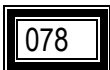
Method: Since October 2001 the German Ministry for Health and Social Security is funding 10 projects aiming to introduce shared decision making in clinical practice (e.g. in patients with depression, multiple sclerosis, cancer). These 10 projects have agreed on a core-set of questionnaires to measure process and outcome of shared decision making. The core-set consists of the „Autonomy Preference Index“ (API), the „Combined Outcome Measure For Risk Communication And Treatment Decision Making Effectiveness“ (COMRADE), the „Patients' Perceived Involvement in Care Scale“ (PICS) and the „Control Preferences Scale“. Data analysis of the core-set data – now including 800 patients - is conducted by the method centre in Freiburg. Reliability and validity of the instruments are assessed by item and factor analysis. The results are integrated in a new instrument which will be validated for application in health care.

Results: There is a general lack of variables assessing the doctor-patient-relationship. We conducted an item and factor analysis (N=561) for the API subscale „Preference for Decision Making“ (C's alpha = .70). The analysis suggests the elimination of item 4 and 6. The same applies to item 5 of the subscale „Preference for Information Seeking (C's alpha = .73).

With respect to PICS the good results of prior studies could be replicated (C's alpha = .82, N = 435). Further, we validated the factor structure of the original study.

Our factor analysis of the COMRADE data revealed that working with a two-factor solution might not be appropriate for our sample. Correlation between the two factors as well as factor loadings amounting to 1.00 indicate redundancy within the scales and items (N=354). In addition to that, a ceiling effect can be observed throughout the items.

Conclusion: Our results demonstrate the potential for improvement of the current instruments used in shared decision making. They might also need for validation studies with larger sample sizes and different disorders. The quality of the subscales (API and COMRADE) should be improved in particular. Moreover, variables assessing the doctor-patient-relationship should be added.



Presentation

SHARED DECISION MAKING IN PRIMARY CARE OF DEPRESSION – GENERAL PRACTITIONERS CLINICAL MANAGEMENT AND PATIENT'S PERCEPTION OF DECISION MAKING PROCESS

LOH A, GIERSDORF N, SIMON D, HÄRTER M

Health Services Research, Universitätsklinik Freiburg Abt. Psychiatrie und Psychotherapie mit Poliklinik

Background: The main aim of the study is the quality improvement of diagnosis and therapy in primary care by promoting an active patient participation in an evidence based and guideline oriented care of depression.

Method: In the framework of a randomised controlled trial of effects of a “Shared Decision Making – Training” with general practitioners, baseline characteristics of primary care of depression in southwest Germany were assessed. 33 general practitioners were included to document their diagnostic and therapeutic strategies with depressive patients. 220 depressive patients were asked for autonomy preference (API), perceived involvement in care (PICS), risk communication and decision making effectiveness (COMRADE), health locus of control (MHLC), self efficacy, satisfaction with decision, quality of life (SF-12) and health status (PHQ). To measure the effects of medical care data were collected twice within 6 weeks (t₁-t₂).

Results: The evaluation of the clinical status of depression (PHQ) shows, that 31% of the patients were mild, 27% moderate and 14% severely depressive. 28% of the study patients have subsyndromal depression corresponding to the PHQ. There is a lack of accordance between physicians and patients in the perception of diagnostic features: 63 percent of patients, who described themselves as depressive, were recognised as depressive by their practitioner. The accordance between physician and patient was even lower (56 %), when patients do not see themselves as depressive. The information needs (API) of patients were consistently high in all grades of severity of depression (up to 91,9%), the participation preference (API) shows moderate levels (up to 52,3%). Even severe depressive patients want information about the disease (93,8%) and want to participate in the decision (50,9%). With an increase of severity, patients lightly tend to leave the medical decision more in the hand of the physicians (PICS).

Conclusion: Patients with depressive disorders constitute a highly relevant group for outpatient care. An important condition for promoting Shared Decision Making is a shared and corresponding assessment of diagnosis, which seems to appear as a main deficit in the primary care management of depression. Patients needs for information and participation in decision making are substantially high, so that it is worth while to implement Shared Decision Making in daily routine. A specific training with general practitioners and participating depressive patients is in process. The general practitioners and the patients are randomised to intervention and control group and post data collection including a 6-month-follow-up will be implemented.

THE PROCESS OF COMMUNICATION AND DECISION-MAKING BETWEEN PHYSICIAN AND PATIENT IN PRIMARY CARE OF DEPRESSIVE DISORDERS

SIMON D, LOH A, GIERSDORF N, HÄRTER M

Health Services Research, Universitätsklinik Freiburg Abt. Psychiatrie und Psychotherapie mit Poliklinik

Background: The aim of this study is to identify relevant problems and barriers in the decision-making process between general practitioners and depressive patients.

Method: This study is embedded in a project which implements the shared decision making concept in primary care of depressive disorders. To find out about problems and barriers in the decision making process, semi-structured interviews were conducted with 40 depressive patients. These interviews were carried out with the following topics: origin, time and amount of information, kinds of decisions and associated meanings of their options, physician's way of preparing the patient for decision making.

Results: The preference for information depends upon the condition of the illness. In a severe stage of depression it is rather low but for the further course of the illness patients report a lack of information. In many cases physicians weren't able to give more information than the diagnosis. Decision-related problems arise mainly when patients have to accept that they suffer from a mental illness. Decision making for in-patient treatment can take up to several months if patients don't suffer from a severe form of depression. Every temporary improvement in symptoms makes them hesitate about the necessity of such a treatment. Relatives and friends play an important role in convincing patients that they need treatment.

Conclusion: The results show that patients need more information about their illness and treatment options in the course of depression. They also wish for more support from their physician when they are faced with unpleasant treatment side effects, a possible relapse or with the issue of being stigmatised as mentally ill. Furthermore physicians should explore patients attitudes and concerns to a greater extent.

TEACHING EXPLANATION, PLANNING AND SHARED DECISION MAKING TO MEDICAL STUDENTS: EXPERIENCES WITHIN THE CAMBRIDGE UNIVERSITY SCHOOL OF CLINICAL MEDICINE

GILLARD S, SILVERMAN J, HOWELLS R

School of Clinical Medicine, Cambridge University

Background: The second half of the consultation is where explanations are given, plans and shared decisions are made. If done well doctors can potentially optimise medical management, maximise health service efficiency, patient satisfaction and personal job satisfaction. This area is neglected in the teaching of communication skills to medical students, since teaching usually focuses on interviewing and relationship-building skills. Previous research has shown that information-gathering skills training does not fully equip students for effective information-giving and shared decision making.

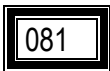
For the last three years, explanation and planning has been part of the second year clinical medical student curriculum, with assessment consisting of OSCE stations. Teaching of shared decision making (incorporating presentation of risk) is commencing for third year clinical students this year.

Method: Teaching in second and third clinical years comprises of an interactive lecture. There follows facilitated small group seminars, using trained simulated patients to provide a safe and informal environment for students to practice

and refine the skills taught. Students return feedback to the course organisers on completion of the last seminar, which provides information on the content and process of teaching undertaken using a visual analogue scale. Scores and free text comments are collated. The students then undertake a 10 minute station with a simulated patient, within a larger OSCE. An explanation and planning assessment tool has been developed, which is presently being evaluated for its reliability and validity.

Results: The feedback from medical students will be presented, as well as plans for the evaluation of the OSCE rating tool.

Conclusion: Skills in explanation, planning and shared decision making are fundamental to the practice of a newly qualified doctor. We wish to present the structure and content of the current teaching, how we conduct assessment and quality assurance and how we propose to objectively evaluate our assessment process in the near future.



Presentation

EVIDENCE-BASED PATIENT CHOICE: THEORY VS. PRACTICE

MAKOUL G, SCHOFIELD T, FORD S

Northwestern University Feinberg School of Medicine / Ethox

Background: Evidence-Based Patient Choice (EBPC) has been defined as “the use of evidence-based information as a way of enhancing people’s choices when those people are patients.” This study focused on: (1) the extent to which evidence and other types of information entered into discussions about tests, new medications, and lifestyle changes; (2) the degree of shared decision making associated with these discussions.

Method: The study sample included 198 videotaped visits to 20 general internists in Chicago, IL and Burlington, VT. All videotapes were independently coded by two research assistants trained to use the EBPC coding instrument; any disagreements were resolved through subsequent discussion. The analysis focuses on the 167 visits in which a new agenda item was coded as a physical, psychological, or emotional problem. Patient age ranged from 41-88 years (mean = 64.0, sd = 11.8); 58.1% were female. Physicians were between 30-48 years of age (mean = 37.7, sd = 5.3), with an average of 7.8 years in practice; 20% were female.

Results: Overall, very little evidence of any kind was shared with patients regarding tests, new medications, or lifestyle. The most frequently invoked forms of evidence were clinical experience (10.4%) and abstract references to “lots of people” (10.4%), both in discussions about new medications. Physicians very rarely referred to studies. In terms of other relevant information, the most frequent categories were the process/plan/procedure (60% tests, 65% new meds, 93% lifestyle) and benefits (55% tests, 85% new meds, 65% lifestyle); physician preferences, patient preferences, risks/side effects, and financial cost were discussed in fewer encounters. Discussion of topics related to adherence was relatively infrequent, whether checking patients’ understanding (max = 22% for new meds), self-efficacy (max = 25% for lifestyle), outcome expectations (max = 7% for lifestyle), or follow-up plan (max = 33% for new meds). Shared decision making profiles varied: Patient involvement was lowest in discussions about tests, and highest in discussions about lifestyle changes.

Conclusion: While Evidence-Based Patient Choice is appealing in theory, it does not appear to be achieved in everyday practice. In terms of methodology, we found that coders could reliably use a new scale for measuring the degree of shared decision-making, and were able to discern differences in decision-making patterns associated with tests, new medications, and lifestyle changes.

PROPOSED ANALYTIC FRAMEWORK FOR IDENTIFYING FEATURES OF HIGH PERFORMING DECISION AIDS

KIRSHNER M, O'CONNOR A, STACEY D, TAIT V
Kaiser Permanente Center for Health Research

Background: The Cochrane Systematic Review of Patient Decision Aids (Cochrane Review) provides a wealth of descriptive information about individual patient decision aids plus individual and meta-analyses of measured outcomes. A deeper examination of the data may sort out and further clarify those features of the decision aids that could account for beneficial outcomes and will better inform future design, development, and implementation of effective decision aids used by patients and clinicians.

The primary objective of the research is to examine empirical evidence to identify those features that are most important as contributors to significant outcomes. The secondary objective is to identify features that are important yet require further empirical evidence to validate their impact. The goal of the research is to add, from a quantitative perspective, to the definition of a 'quality' decision aid.

Method: An analytic framework is created based on: a) key elements of decision aids (e.g. intensity of information on condition options and outcomes, probabilities, values clarification, examples of others, coaching in steps of decision making); b) the processes of applying decision aids in clinical practice (e.g. use in trajectory of clinical care, timing with counselling), and c) the quality of development and evaluation of decision aids using the CREDIBLE criteria and Jadad's scale. This will allow for a standardized approach in evaluating features contained in a decision aid and used in its application. The framework employs univariate analysis and multivariate correlation to describe those variables that are associated with positive outcomes.

Results: The research asks and answers the question; what are the commonalities among high performing decision aids? At the time of the conference, we will have preliminary data to illustrate the usefulness of the analytic framework.

Conclusion: The limits of current empirical data on patient decision aids do not allow for an in-depth evaluation using a complex evaluation framework and therefore limits conclusions of generalizability. However, as more evidence and decision aids become available, a more complete model will be applied and the value of the analytical framework is anticipated to be of greater value.

A RANDOMISED CONTROLLED STUDY ON THE EFFECTS OF SHARED DECISION MAKING WITH CHRONIC PAIN PATIENTS (FIBROMYALGIA)

BIEBER C, MÜLLER KG, RICHTER A, BLUMENSTIEL K, WILKE S, EICH W
Department of Internal Medicine II, University of Heidelberg

Background: In the treatment of chronic pain conditions doctor-patient communication often turns out to be one of the stumbling blocks impeding an effective treatment. The fibromyalgia syndrome (FMS) is an exemplary condition of chronic widespread pain that is difficult to control and often leads to frustration and resignation on side of the patient and the doctor alike. We conducted a prospective randomised controlled study with a one-year follow-up to evaluate the effects of shared decision making on patient satisfaction in patients with chronic pain (fibromyalgia). The study is supported by a grant of the German Federal Health Ministry.

Method: Intervention group I (shared decision group) is treated by physicians trained in shared decision making and has access to a computer-based information tool on fibromyalgia, intervention group II only receives the information tool, the control group gets the standard treatment. Intervention groups are recruited in an university outpatient clinic, the control group in two rheumatologists' practices. Inclusion criteria are ACR-criteria for fibromyalgia, age between 18 and 70 and knowledge of German language. 124 participants are included. Mean age is 50.5 years (SD 9.4), 92.7% are female. Participants are followed up at 3 and 12 months.

The main objective is to improve patient satisfaction measured by the Heidelberg patient satisfaction scale and by a qualitative interview. Secondary outcome measurements are assessed by the decisional conflict scale, the satisfaction with decision scale and the difficult doctor patient relationship questionnaire.

Results: Patient satisfaction is significantly higher in intervention group I compared to both intervention group II and control group ($p = .0005$, $p < .0001$). The perceived difficulty of the doctor-patient-relationship is significantly lower in intervention group I ($p = .02$)

Conclusion: In fibromyalgia shared decision making increases both patient and physician satisfaction with treatment. A specific communication training qualifies physicians to perform shared decision making. Long term effects will be evaluated at the 12-months follow-up.



Presentation

CHRONIC PAIN PATIENTS' DECISION-MAKING ABOUT USING COMPLEMENTARY/ALTERNATIVE MEDICINE (CAM)

BROWN JB, SWARTZMAN LC, HERBERT C, SMYTH L
The University of Western Ontario

Background: Given the popularity of CAM approaches, it is important to determine the basis for their appeal to health care consumers, as well as the basis for the distinction people make between CAM and conventional medicine and their decision-making process regarding use.

Method: The qualitative method of focus groups was used to collect the data. An iterative analysis process was used to examine the verbatim transcripts of the five focus groups. A total of 32 individuals participated in the focus groups and of those 22 had FM, 5 RA and 5 both RA and FM.

Results: The analysis of the data revealed two key themes: (1) Participants' decision-making with regard to using CAM needed to be understood within the context of their unique illness experience - their personal "story" and (2) multiple factors influenced their decision-making process to use or not use CAM. Participants' decision to use CAM treatments was driven by desperation - the intense desire for symptom relief. Moreover, participants' process of treatment decision-making was grounded in their own illness experience rather than on the basis of (nomothetic) research evidence. The perception that "everybody's different" was evident in all the groups and explained why a "trial and error" approach to treatment choices was often necessary. When participants were specifically asked about the distinctions between CAM and conventional approaches, the only consistent view was that conventional approaches are used and/or recommended by physicians, whereas CAM are not. Finally, affordability was cited as the major barrier to accessing CAM as well as conventional medicines.

Conclusion: Among this set of health care consumers - individuals faced with debilitating symptoms - the most salient feature of CAM treatments was their efficacy. Distinctions based on more abstract/theoretical treatment characteristics (e.g. CAM versus conventional) were largely absent.

HYSTERECTOMY: KEEPING UROLOGIST BUSY?

HERBERT A, MCPHERSON K, JUDGE A
MRC HSRC

Background: This study sought to examine whether biologically plausible dysfunctions - the disruption of innervation and anatomical relationships - caused by hysterectomy result in urological problems. We compared the prevalence of self-reported urinary incontinence, overactive bladder and nocturia five years after hysterectomy, with and without bilateral oophorectomy, compared to a control group of women who underwent less invasive surgery for menorrhagia (transcervical endometrial ablation (TCRE)).

Method: A prospective cohort study on 25,000 women who underwent surgery for menorrhagia for benign causes in England, North Ireland and Wales (national audit of all endometrial ablations/resections (TCRE) and hysterectomies from 1993 to 1995). The women were followed by postal questionnaires at one-, three- and five-year post operatively. We now present the self reported "occasional or frequent unexpected loss of urine", "pass of urine every hour or more frequently", "getting up at least once a night to pass urine" in 9,395 eligible 5-year follow up respondents.

Results: After multivariate adjustments for age, BMI, parity and HRT use, the type of surgery significantly increased the likelihood of "dysfunctional" bladder. In comparison with the TCRE group (baseline category, RR=1), the groups undergoing hysterectomy, with (h1) and without (h2) bilateral oophorectomy, had:

The increased urinary incontinence RRh1=1.21, 95% CI (1.10-1.33) and RRh2=1.23, 95% CI (1.08-1.39)

More overactive bladder RRh1=1.37, 95% CI (1.20-1.56)

Higher incidence of nocturia RRh1=1.14, 95% CI (1.01-1.30)

Conclusion: In contrast to previous small trials, the results of our large, patient-centred observational study suggest that having a hysterectomy adversely affects one's bladder functions. This possibility needs to be considered when the decision to perform hysterectomy is made. The paper does not include objective measures of severity nor subjective reports about the bother-impact factor of reported behaviours. It is possible that a dysfunctional bladder is an acceptable inconvenience to bear in return for the resolved menorrhagia. Nonetheless, patient centred health care demands that future patients are duly informed about the ensuing long-term risks of hysterectomy as reported by women.

INTERVENTIONS FOR IMPROVING PATIENTS' TRUST IN DOCTORS

CAR J ⁽¹⁾, FREEMAN GK ⁽¹⁾, ASHCROFT RE ⁽¹⁾, SHEIKH A ⁽²⁾

1) Imperial College London

2) University of Edinburgh

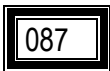
Background: Trust is seen as a global attribute of treatment relationships, one that encompasses subsidiary features such as satisfaction, communication, competency, and privacy, each of which is important in its own right. Trust has become one of the most prominent health care issues in the last decade. This presentation concerns the methodological issues that arose in setting up a Cochrane review focusing on values and attitudes.

Method: We interacted with the Cochrane Consumers and Communication Group and stipulated the following study designs as eligible for inclusion in the review: randomised controlled trials, rigorous controlled clinical trials, controlled before-and-after and interrupted time series studies. In addition, we stipulated that interventions should either be

directed at doctors or patients and intended to promote patients' trust in their doctors. We defined patient 'trust' as, 'the belief that doctors are working in the patient's best interests'.

Results: The main areas of discussion and debate with the Cochrane Group were: 1. The title of the review. Our title has been seen as implying "a rather one-way manipulative view of the doctor-patient relationship". 2. 'Balance' of views on trust. 3. Operationalization of the definition. 4. Qualitative research. Peer-reviewers of the protocol suggested that we should include also qualitative studies in our review.

Conclusion: The review protocol has been confirmed by the Cochrane Consumers and Communication Group. Data searches, quality assessment and extraction are currently in progress. We will assess outcomes for patients as described in the original reports, extracting data about the health care that patients received, their health outcomes and their assessments of their trust in the doctor. Devising a Cochrane review in this area is a challenging task.



Presentation

EXPLORING PATIENT-DOCTOR PARTNERSHIP IN WHITE EUROPEAN AND SOUTH ASIAN ADULTS WITH ASTHMA: QUALITATIVE INTERVIEW STUDY

CAR J ⁽¹⁾, FREEMAN GK ⁽¹⁾, GRIFFITHS C ⁽²⁾, SHEIKH A ⁽³⁾, RHODES T ⁽¹⁾, ASHCROFT RE ⁽¹⁾, LAIS M ⁽¹⁾

1) Imperial College London

2) Queen Mary, University of London

3) University of Edinburgh

Background: South Asian people with asthma have a higher risk of asthma related hospital admission compared with white Europeans. There is no clear evidence of differences in severity or prevalence of asthma, prescribed drugs, asthma education or in the severity of the acute episodes amongst admitted patients in the two ethnic groups. Excess risk is only likely to be in part due to socio-economic status. Difficulty in developing an effective patient-doctor relationship has been suggested as one of the many possible explanatory factors underlying these differences in hospitalisation rates. We examine concepts of the patient-doctor relationship held by white and south Asian people with asthma and identify difficulties and 'enhancers' in the development of patient-doctor relationships.

Method: Subjects are recruited from the Chest Clinic, Ealing Hospital, London, UK and GPs are recruited from the catchment area. Data from in-depth interviews with patients and doctors are being analysed using grounded theory method. We plan to purposively sample approximately 20 South Asian and 20 White adults with asthma and 15 GPs.

Results: Recruitment, interviews and analysis are currently in progress. We plan to present and critically discuss the interim results at the conference.

Conclusion: Preliminary findings show that most patients irrespective of their cultural background desire to receive more information about their asthma from their GP. However white European patients seem to have significantly more proactive attitude towards doctors in actually acquiring this information, by asking questions.

EARLY WORK ON A DECISION DIALOGUE PROCESS FOR IMPROVING THE QUALITY OF MEDICAL DECISIONS

BELKORA J, SEPUCHA K

University of California, San Francisco and Harvard Medical School

Background: Critical Theory suggests that stakeholders should solve their problems by engaging in a process of critical reflection. Each of the parties must articulate their views before critiquing them with other stakeholders and finally redesigning a shared understanding of what actions to take and why. Patients and physicians are stakeholders in medical decisions, so critical reflection may play an important role in improving the quality of decisions.

Method: Relying on models from various disciplines (including decision analysis, psychology, education, and philosophy), we have adapted the concept of critical reflection to the context of medical decision making with the Decision Dialogue Process (DDP). The DDP involves sequencing provider-patient interactions according to the principles of articulate-critique-redesign. The DDP also prescribes the specific content dimensions to be articulated, critiqued, and redesigned so that the patient and provider arrive at a high quality decision. These dimensions of decision quality are: frame, values, alternatives, information, logic, and commitment.

Results: We will present a case study illustrating the DDP with a woman making a decision about treatment for breast cancer. Early indications are that the DDP can be used effectively to integrate visit preparation, consultation, and decision aids, reducing confusion, conflict, and anxiety.

Conclusion: Kurt Lewin's maxim states that there is nothing so practical as a good theory. The DDP represents our attempt to generate better decision-making practices through the theory of critical reflection. Before committing to more formal investigations of the DDP and its impact on critical reflection, decision, and health outcomes, we would like to solicit the feedback of researchers in the field of shared decision-making. This poster presentation will provide an opportunity for us to engage in some critical reflection with our peers while we are still formulating hypotheses.

FORMS OF FREEDOM? GENERAL PRACTITIONER ACCOUNTS OF WOMEN'S DECISION MAKING AT MENOPAUSE. *

MURTAGH M

University of Newcastle

Background: Menopause is commonly understood in biomedical literature as a key time to consider preventive treatment (hormone therapy) for long term health risks. As this preventive intervention may itself be injurious to health the issue of decision-making in health care becomes important. Critical analysis, informed by contemporary social theory, of the understandings of decision making in primary medical care is instructive in untangling the implications of the ways in which women's 'choice'; and 'decision making' are discussed.

Method: Critical poststructural analysis of the findings of a discourse analytic interview study of general practitioners.

Results: Women's 'choice', 'informed decision-making' and 'empowerment' were key discursive themes through which primary medical care for women at menopause was presented by nine general practitioners(1). The ways in which these concepts were deployed by general practitioners in this study produced and constrained the options available to women. General practitioners positioned women as 'informed decision makers' responsible for their 'choices' about

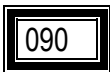
health care and health outcomes at menopause and beyond; However, decision making about menopause was limited to a choice dichotomy (to take or not to take hormone therapy) and was required to be a choice; an 'ethic of autonomy';(2). This restriction of both the concept of choice and the options contained within that choice cannot produce an empowering or emancipatory practice of decision making.

Drawing on concepts of power, ethics and freedom in the work of Michel Foucault and Nicolas Rose I discuss the relationship between autonomy, choice and decision making and assumptions of choice in decision making as emancipatory; a form of freedom.

Conclusion: Questions are raised about the forms of freedom produced by decision making practices.

* This paper is one of three that forms the empirical background for the workshop "The very idea of shared decision making: views from social science".

1. Murtagh, MJ and Hepworth, J. 'Menopause as a long term risk to health: implications of general practitioner accounts of prevention for women's choice and decision making'. *Sociology of Health and Illness*. 25(2) 2003 185-207
2. Murtagh, MJ and Hepworth, J. 'Feminist ethics and menopause: autonomy and decision making in primary medical care'. *Social Science and Medicine*. 56 2003 1643-1652



Presentation

EMPOWERING WOMEN AND THEIR PHYSICIANS WITH THE EVIDENCE: A RANDOMIZED TRIAL OF A DECISION BOARD FOR BREAST CANCER SURGERY

WHELAN T ⁽¹⁾, LEVINE M ⁽¹⁾, GAFNI A ⁽¹⁾, WILLAN A ⁽¹⁾, SANDERS K ⁽¹⁾, MIRSKY D ⁽²⁾, CHAMBERS S⁽¹⁾, O'BRIEN MA ⁽¹⁾, DUBOIS S ⁽¹⁾, REID S ⁽¹⁾

- 1) Cancer Care Ontario Hamilton Regional Cancer Centre, and McMaster University
- 2) Queensway-Carleton Hospital, Ottawa, Ontario, Canada

Background: The long-term results of randomized trials have demonstrated equivalent survival rates for breast-conserving therapy (BCT, lumpectomy plus radiation) and mastectomy. Consequently, the choice of treatment should be based on a patient's values and issues related to her quality of life. We developed an instrument, the Decision Board (DB), to help physicians inform their patients about the different surgical treatment options. The DB consists of a visual aid and written material administered by the clinician during the physician-patient consultation. The purpose of this study was to evaluate the impact of the DB on the clinical encounter.

Method: A process of cluster randomization was used whereby surgeons were randomized to use the DB in the surgical consultation or not; patients received the DB or not based on the surgeon seen. Eligible consenting patients were evaluated following the consultation regarding their knowledge about the surgical treatment of breast cancer, satisfaction with decision-making, treatment choice, anxiety and depression.

Results: Twenty surgeons participated in the study. Of the 208 eligible patients seen by study surgeons, 201 agreed to be evaluated. Of these, 94 were allocated to the DB and 107 to usual practice. Patients in the DB group compared to the control group were more knowledgeable about the treatment options ($P < .001$) and satisfied with decision-making ($P = .05$). Patients who used the DB were more likely to report that they were offered a choice about treatment (87% vs. 69%, $P = .06$) and to choose BCT (96% vs. 76%, $P = .03$). No differences were detected in anxiety or depression.

Conclusion: The use of the DB by surgeons improved patient knowledge and satisfaction and permitted women to make different treatment choices consistent with their preferences. Wider use of such instruments are likely to have important implications for quality of care with respect to physician-patient communication and shared decision-making.

PATIENTS' DECISION AIDS FOR ELECTIVE TOTAL JOINT REPLACEMENT: WHAT WOULD ORTHOPAEDIC SURGEONS PREFER?

LLEWELLYN-THOMAS H, WEINSTEIN J, MIMNAUGH D
Dartmouth Medical School

Background: Decision aids (DAs) could help patients in shared decision making (SDM) about elective total joint replacement (TJR). However, unless we determine surgeons' attitudes towards such DAs before they are developed, we could create costly DAs that can't be readily disseminated in actual surgical practice.

Method: All eligible members of the American Academy of Hip & Knee Surgeons received a description of a proposed new patients' TJR DA. A questionnaire assessed attitudes about a) SDM in general, b) the importance of fostering information comprehension, preference clarification, and communication skills, c) whether a DA would help to achieve those outcomes, d) preferred DA medium, e) preferred ways of using a DA in practice, and f) the factors that would hinder / promote its clinical implementation.

Results: 293 responded (44% of 664). 85% rated SDM as a good/excellent idea. The majority provided high importance and high helpfulness ratings for a TJR DA that could teach patients about surgical/non-surgical procedures (78%), benefits (80%), and risks (84%), reveal their preferences (61%), and develop a care plan (64%). Opinions varied about using a DA to present TJR costs and practice guidelines. 79% think variations in TJR rates is inappropriate information. Booklets/audiotapes (54%) and videotapes (43%) were preferred media. 53% would prefer patients take a TJR DA home to consider before making a decision. The most frequently reported promoting / hindering factors were increased patient comprehension (68%) and interference with office work (55%).

Conclusion: This first national survey of specialists' opinions implies that surgeons support SDM, but aren't enthusiastic about using a DA to communicate TJR variations in practice, costs, and guidelines. The majority agree on preferred media, practice models, and the importance of a DA's contribution to information comprehension, values clarification, and care planning. Of these 3 outcomes, increased comprehension would strongly encourage surgeons to use DAs in practice.

PROVIDING AUDIOTAPES OF PRIMARY ADJUVANT TREATMENT CONSULTATIONS TO MEN WITH PROSTATE "CANCER". PATIENT INVOLVEMENT IN DECISION MAKING PREDICTS QUALITY OF LIFE, INFORMATION RECALL, AND SATISFACTION WITH ONCOLOGIST COMMUNICATION AND INTERVENTION

HACK T, PICKLES T, BULTZ B, RUETHER D, DEGNER L
University of Manitoba

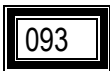
Background: The purpose of this multi-site, randomized controlled trial was to examine the efficacy of providing men with prostate cancer with an audiotape of their primary adjuvant treatment consultation.

Method: A total of 425 men and 15 oncologists from cancer centres in three Canadian cities participated. The men were block randomized to 1 of 4 consultation groups: 1. Standard Care Control Group - Consultation not audiotaped; 2. Audiotaped - Patient not given audiotape; 3. Audiotaped - Patient given audiotape; and 4. Audiotaped - Patient offered choice of receiving the audiotape. Patients received the audiotape immediately after completing the post-consultation measures. Patients completed the Decisional Role Preferences Scale (Degner) before and after the consultation, a measure of communication satisfaction post-consultation, and measures of information recall, mood disturbance

(Profile of Mood State), and breast-specific quality of life (FACT-B) at 3 months post-consultation. A feedback questionnaire was mailed to all participating oncologists.

Results: Showed that patients who received the consultation audiotape had significantly better recall of having discussed treatment and disease information than patients who did not receive the audiotape. The regression analysis showed that, among those who received the audiotape, patients who assumed an active role in decision making during the consultation had significantly higher prostate cancer-specific quality of life at 3-months post-consultation than passive patients. Patients rated the audiotape intervention positively, with an average score of 83.0 out of 100. Fifty-six percent of oncologists stated that either most or all patients should be provided with an audio-taped copy of their adjuvant consultations.

Conclusion: Men with prostate cancer can benefit from receiving consultation audiotapes, and these benefits are more pronounced for patients who assume active roles in treatment decision making.



Presentation

EXAMINING CORRELATES OF PATIENT PARTICIPATION IN MEDICAL DECISION-MAKING

ARORA NK, AYANIAN JZ, GUADAGNOLI E
National Cancer Institute, USA

Background: We applied constructs of the transtheoretical model (TTM) of behavior change to identify determinants of patient participation in decision-making.

Method: 621/1024 (61%) primary care patients in Boston provided complete survey data for analyses. A random half of the sample was used to examine the factor structure of a decisional balance scale and with the other half we confirmed the factor structure and examined the association of patients' stage of readiness to participate in decision-making with decisional balance (pros minus cons), self-efficacy to participate, and trust in their physician.

Results: Patients were classified into four stages of readiness: pre-contemplation (don't participate and don't intend to- 17.2%), contemplation (don't participate but contemplating participating- 6.9%), preparation (participate to some degree- 36.1%), and action (participate fully-39.8%). Consistent with the TTM, factor analysis of the decisional balance items indicated two factors representing the pros and cons of participation (pros-7 items, Cronbach's alpha=0.70; cons-5 items, Cronbach's alpha=0.72). ANCOVA models indicated that subjects at different stages of readiness varied significantly in their pros for ($p<0.001$) and cons against ($p<0.001$) participation. Scores on the pros for participation increased and cons against participation decreased significantly from pre-contemplation to action. A significant association between stage of readiness and self-efficacy was obtained ($p=0.004$), such that self-efficacy scores were the highest for those in the action stage. We also found a significant non-linear association between stage of readiness and trust in physician ($p=0.007$), such that those in the pre-contemplation stage had significantly higher trust scores than those in the other three stages.

Conclusion: Readiness to participate in decision-making is significantly associated with patients' positive and negative beliefs about participation, their self-efficacy, and to some extent, their trust in physicians. Rather than taking a "one-size-fits-all" approach to facilitating participation in decision-making, results suggest that to facilitate participation, interventions should be tailored to patients' stage of readiness to participate.

SHARED DECISION MAKING (SDM) AS A MUTUAL NEGOTIATION OF UNCERTAINTIES

KASPER J, HEESEN C, KÜGOW M, MÜHLHAUSER I

Unit of Health Sciences and Education, University of Hamburg, Martin-Luther-King-Platz 6, D-20146 Hamburg, Germany and the University Hospital Hamburg Eppendorf, Martinistrasse 52, D-20246, Germany

Background: The increasing engagement in shared decision intervention research demands suitable methods to describe the way and extent the patient is affected by this special interaction style.

Since the absence of objective indications is rather the predestined than an exceptional situation in SDM, effects of the intervention can not be found in the area of decision results by definition.

We understand the process of mutual exchange in SDM as an implicit negotiation of uncertainties associated with the subject of decision. The clarifying effect of negotiation should also change patients' representation of "uncertainty in illness". Objective of the study is to create and validate a questionnaire to measure uncertainty in its different meanings.

Method: Source of relevant aspects and verbalisations belonging to uncertainty experiences is a sample of patients with multiple sclerosis in decision contexts. An iterative procedure of in-depth interviews, transcription and analysis will be performed until information saturation. The generated item pool will be tested in a second sequence of construction with another MS- sample to investigate test quality criteria.

Results: We expect a pool of reliable items with an underlying structure of independent factors, interpretable as prepostulated meanings of uncertainty. We have already identified factors relevant for MS-patients: stochastic uncertainty, uncertainty about therapeutic outcome or natural course of illness, interpersonal uncertainty, uncertainty about future coping abilities, aetiological uncertainty, uncertainty concerning complex information processing, uncertainty about diagnosis and uncertainty about perceived changes in the image of one's body.

Conclusion: If we are able to model the mutual process of decision making into a characteristic change pattern of uncertainties this will give advice to construction of shared decision interventions; furthermore to evaluate differences between f.e. a paternalistic and a shared decision approach. Other questions will focus on the matter of generalisability of the questionnaire.

Keywords: communication, decision making, physician patient relation, uncertainty in illness.

PARENTS' PERSPECTIVES ON INTERDISCIPLINARY ATTUNING OF INFORMATION AND ROLE ATTRIBUTIONS IN CHILD ONCOLOGICAL CARE

TATES K, VAN DULMEN S, BENSING J

Dutch Cancer Society / Nivel

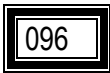
Background: The study is set against the background of patient-centred communication in paediatric oncology. The aim was to identify the experiences and preferences of parents with a child with cancer regarding the processes of information exchange, support and decision-making. Special attention was given to the interdisciplinary attuning of information and to role attributions.

Method: Eleven families with a child diagnosed with cancer, comprising 16 parents (five couples, five mothers and one father), participated in a semi-structured interview. A topic list was composed on the basis of the literature and participatory observations. The interviews, which lasted between 75 and 180 minutes, were audio-taped, transcribed and analysed using the principles and procedures of Grounded Theory, and consisted of a mixture of retrospective and current data.

Results: The analysis led to the identification of a number of themes, including parent involvement, continuity and consistency of information, coordination of care, and emotional support. Most parents had expected a more partnership-based way of interaction with health professionals and wished them to be more attentive to parental preferences regarding role delineation. Those parents who were satisfied with the quality of care provided attributed this to the fact that they had been taken seriously and had worked as a team in collaboration with the health professionals. The perceived marginalisation of the parents' role appeared to be as important as the actual process of information exchange and support itself. In addition, parents mentioned the receipt of inconsistent information from nurses and physicians due to a perceived breakdown of communication between staff members. A lot of parents reported discrepancies between expected and perceived roles of health professionals, especially concerning the perceived lack of emotional support by physicians.

Conclusion: The results are in favour of a more open dialogue between health professionals and parents about parents' as well as professional roles.

Future research should explore the enabling and constraining factors of role attributions in relation to communication.



Presentation

THE UTILITY OF A MULTIMEDIA EDUCATION PROGRAM FOR PROSTATE CANCER PATIENTS

VAN SCHAİK P, FLYNN D, VAN WERSCH A, AHMED T, CHADWICK D
University of Teesside

Background: Patient education has been proven to be an effective strategy for alleviating psychosocial problems in both men and women with cancer. Information provides a sense of control, reduces distress, facilitates adaptive coping, and increases participation in shared decision-making (SDM) with physicians. Despite these benefits, psychosocial problems experienced by men with cancer have received sparse attention compared to women in the literature. Therefore, a multimedia program (MMP) was developed to educate men with prostate cancer about their disease.

Method: A within-subjects design was used to investigate the changes in levels of cancer-related knowledge and uncertainty, psychosocial functioning, treatment decision-making role and information needs immediately after browsing the MMP. The participants were 67 men recently diagnosed with prostate cancer. Psychosocial functioning was assessed with 20 items describing common emotional states and coping strategies employed by cancer patients. Treatment decision-making role was assessed with the Control Preference Scale.

Results: A principle component analysis of the 20 psychosocial items yielded three components: distress, positive approach and non-acceptance. After browsing the MMP significant increases in knowledge and reductions in uncertainty and distress were reported. Married men and those attending the study session with their spouse displayed a significant shift towards a more active role in treatment decisions. The majority of information needs were fulfilled by the MMP; however, information related to the likelihood of a cure, treatment side-effects, coping strategies and aetiology were not completely satisfied by the MMP.

Conclusion: The utility of the MMP as an education tool was supported. However, in order to recommend wide-spread use, the ability of the MMP to influence outcome measures such as participation in SDM should be compared with existing patient education tools in randomised controlled trials. Furthermore, 'usability' (ease of use and acceptability of the MMP) should be examined using combinations of performance measures and assessments of user satisfaction.

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Poster

GPS' ABILITY TO DETECT THEIR PATIENTS' DESIRE FOR INVOLVEMENT IN DECISION-MAKING ABOUT MEDICINES

COX K, WHITE P, BRITTEN N

Guy's, King's and St. Thomas' School of Medicine

Background: Despite the focus on shared decision-making between health care professionals and patients, a large minority of patients do not want to make shared decisions with professionals. Research on GP consultations has found that many patients do not achieve their preferred decision-making role. The aim of this study is to investigate whether GPs can accurately assess their patients' preferred involvement in decisions about medicines, the factors affecting doctors' accuracy, and the impact of doctors' accuracy on patients' satisfaction with the decision-making process and their intentions to adhere to the treatment decisions that are made.

Method: This is a questionnaire study of the agreement between patients' preferences for involvement in decision-making about medicines and GPs' perceptions of these preferences. Six London practices (at least 16 GPs) are taking part. Thirty patients consulting with each GP are recruited. Participating patients complete a pre- and post-consultation questionnaire and GPs complete a post-consultation questionnaire after each patient. Data collection for the study will be complete by July 2003.

Results: Agreement (Cohen's kappa) between patients' preference for involvement in decision-making and GPs' perceptions of this preference will be assessed. Logistic regression analyses and ANOVA will be used to examine the factors affecting this agreement and the extent to which the level of agreement predicts patients' and GPs' satisfaction and patients' intentions to adhere to the treatment decision.

Conclusion: This study will show whether patients are involved in their treatment decisions as much as they wish and the impact that this has on adherence and satisfaction with the consultation. The factors associated with GPs misjudging patients' preferences for involvement will be important in developing strategies to improve how GPs and patients communicate.

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Presentation

THE EVALUATION OF THE WHO / CCP 'DECISION-MAKING TOOL'; ON FAMILY PLANNING COUNSELING IN MEXICO AND INDONESIA

KIM YM, RINEHART W, JOHNSON S, CHURCH K, MARTIN A, ROSDIANA D, PUTJUK F, LEWIS G

Johns Hopkins University

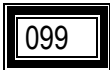
Background: The World Health Organization and Johns Hopkins University Center for Communication Programs have been developing The Decision Making Tool for Family Planning Clients and Providers (DMT), a job-aid in flipchart format designed to improve family planning (FP) counseling. A study was conducted in Mexico and Indonesia, as a part of the tool development process, to assess whether and how the DMT enhanced decision making, client-provider interaction, and the provision of technical FP information. The acceptability and usability of the DMT were also tested.

Method: Study participants were 105 clients of 17 physicians and nurses in 9 MOH hospitals in Mexico City, and 80 clients of 10 nurse-midwives in 10 clinics in West Java, Indonesia. For the intervention, the providers were trained and instructed to use the DMT for one month. This study compared video taped counseling sessions, before and after the intervention. Findings from the follow-up interviews with providers and clients and qualitative analysis from the

video taped sessions are being presented here. Analysis using RIAS (Roter Interaction Analysis System) and OPTION tool is underway.

Results: The providers were using the DMT relatively well after a month of practice, though there was still room for improvement. The quality of client's decision-making was improved through use of the DMT (more options presented and transfer of decision-making to the clients). However, narrowing down method choices was not performed efficiently. The provider-client interactions were also enhanced; in particular providers were more responsive to their clients, and the clients asked more questions. One of the most notable benefits of the DMT was the more organized and complete information-giving on technical aspects of FP. The DMT was well accepted by both providers and clients.

Conclusion: The DMT can enhance the quality of FP consultations, through impacts on decision-making, client-provider interaction, technical information-giving.



Presentation

A SYSTEMATIC REVIEW OF INTERVENTIONS INVOLVING TWO-WAY COMMUNICATION BETWEEN PATIENTS AND HEALTH CARE PROFESSIONALS ABOUT MEDICINES

COX K, STEVENSON F, BRITTEN N, DUNDAR Y
Guy's, King's and St. Thomas' School of Medicine

Background: The aim of this systematic review was to identify and summarise the research on two-way communication between practitioners and patients about medicines. This presentation describes the studies that were identified that examined the impact of interventions that comprised a substantial element of two-way communication about medicines. The review included any study which assessed an intervention involving communication about medicines, regardless of the study design, the setting or the types of health professionals or patients involved.

Method: Six electronic databases (Medline, EMBASE, CINAHL, PsycINFO, Social Science Citation Index and Science Citation Index) were searched using the following categories of search terms: health care professionals, patients/consumers, medicine-taking/prescribing, and communication. Articles were also identified from other sources including handsearches of journals, article reference lists, and the Concordance website. Qualitative and quantitative research written in any language was considered eligible and studies were not excluded on the basis of the designs or methods used. Only studies published between 1991 and 2000 were included. Abstracts of identified articles were assessed by at least two reviewers and the full articles of relevant studies were then reviewed by one reviewer. Data on the design, analysis and relevant findings were extracted. EPPI-Centre criteria were used to assess study quality.

Results: 11801 abstracts were reviewed, and 467 full articles were subsequently retrieved. Of these papers, 10 evaluated 9 different relevant interventions. There were considerable differences in the nature of the interventions identified, the outcome measures used to assess them and the methodological quality of the studies.

Conclusion: The findings indicate that involving patients in discussions about their medicines can help them to have greater understanding of their condition and treatment, reduce their medication-related problems, and lead to improvements in their health. Extended pharmacist-led services and nurses working together with patients to develop a suitable treatment regimen appear to be particularly successful.

COMPETENCES FOR THE SHARE DECISION MAKING IN FAMILY DOCTORS PRACTICE

DOERING T, STEUERNAGEL B, GLOWIENKA-WIEDENROTH F, HÜBNER M-S, ROHLFING H
Medical University Hannover

Background: Due to increasing public interest for better embedding of the patient in medical decisions and rising of medical uncertainty we were asking practitioners regarding the competences of practitioners and patients for the shared decision making (SDM).

Method: 156 practitioners were asked about the necessary medical and patients competences, which are necessary for practitioner-patient-communication and about how goals of treatment were fixed. The practitioners could answer the questionnaires in free context. The questionnaires were evaluated with Delphi.

Results: 49 questionnaires were evaluated. By the question "What kind of expectations do you have towards the patients? 34,7% of the practitioners answered with honesty, openness and sincerity. 30,6% said, that it is important to give an account of requests and complaints. 26,5% demand co-operation and 20,4% compliance respectively the observance of instructions.

By the question "How do you fix the goals of treatment? 42,9% said "together with the patient" ;18,4% "due to the diagnosis" ;14,3% "due to advice and informations regarding options of therapy and 12,2% answered that they will fix the goals of treatment in the communication with the parents.

By the question " What kind of expectations should a practitioner have to be a good part of patient-practitioner communication 34,7% answered with openness and honesty, 18,4% to listen well and 10,2% to have empathy.

Conclusion: From the point of the practitioners the criteria of SDM will be predominantly fulfilled. The 20,4% who wished observance of instructions show that there is still an paternalistic approach going on. If almost one fifth of general practitioner is paternalistic orientated but 42,9% find treatment goals together with the patient than a bridge from the expectation shore to the treatment goals shore must be build to look for better share decision making.

DIFFERENT PERSPECTIVES OF SHARED DECISION MAKING IN A CONSULTATION

DOERING T, STEUERNAGEL B, GLOWIENKA-WIEDENROTH F, HÜBNER M-S, ROHLFING H
Medical University Hannover

Background: Can shared decision making in a general practice consultation be realized and how can this be done was the question of the described trial.

Method: The panel doctors in Lower Saxony were asked about their research interest. Of the interested practitioners 60 intervention practitioners and 60 control practitioners were randomised for the trial. For inclusion patients had to be between 3 and 10 years old and suffer from upper respiratory infection and contact the physician the first time because of this illness. After developing a special competence training for shared decision making the practitioners of the intervention group were instructed. Patients and practitioners were asked about their impression of the consultation using the Man-Son-Hing-scale, which allows a parallel questioning of patients and practitioners about information giving, problem understanding and shared decision making with 7 items.

Results: 60 consultations with mothers/fathers and their sick children were evaluated. The question "Who made decisions about the treatment of your child during the consultation?" answered 2/3 of the patients and practitioners with " both the patient and the doctor". One third of the answers said "mostly the doctor" but in almost 48% the assessments of the same consultation of practitioner and patient did not correspond. Assessing the item "The practitioner involved

the patient sufficiently in decisions about the treatment of the child" 8% of the patients and practitioners agreed, about 20% were undecided. 56% of the answers of patient and physician corresponded, 44% of the answers varied.

Conclusion: The first results showed existing criteria of shared decision making in the first consultation after the competence training of the doctors. However practitioners and patients assessments of the consultation did not correspondent.

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Poster

INFORMATION GIVEN TO PATIENTS WHO CHOOSE BETWEEN PALLIATIVE CHEMOTHERAPY AND WATCHFUL WAITING: HOW INFORMED IS THEIR CHOICE?

DE HAES H, KOEDOOT CG, OORT FJ, DE HAAN RJ, BAKKER PJM, DE GRAEFF A
Academic Medical Centre, Amsterdam, the Netherlands

Background: The study aims at establishing 1) what and how much information is given by medical oncologists when proposing palliative chemotherapy, and 2) whether the information given is influenced by patient or physician characteristics.

Method: In a prospective study, 95 patients with incurable cancer were interviewed before they consulted a medical oncologist. Their first consultation with the oncologist was then audio taped and their eventual decision scored. A coding scheme was developed to determine what and how much information was given during the consultation.

Results: Medical oncologists mentioned or explained in half or less of the consultations the disease course (53%), symptoms (35%) and prognosis (39%). Most patients were told about the absence of the possibility of cure (84%). The alternative treatment option, watchful waiting, was mentioned to only half of the patients: either in one sentence (23%) or more extensively (27%). Multilevel analysis revealed that older and married patients as well as those treated in academic hospitals were likely to receive more information.

Conclusion: Most of the information given by medical oncologists when palliative treatment is proposed relates to 'active' treatment rather than watchful waiting, or, supportive care. To support physicians and patients in the decision making process, the use of decision aids is advocated.

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Presentation

VOLUNTARY COUNSELING AND TESTING FOR HIV/AIDS IN CAMEROON, WEST AFRICA: QUALITATIVE ANALYSIS OF DECISION MAKING, CLIENT - PROVIDER INTERACTION AND INFORMATION SHARING

HEEREY M, KIM YM, AMOA M AND KOLS A
John Hopkins University, Center for Communication Programmas

Background: HIV/AIDS is a major threat to the health and socioeconomic well-being of people globally. In Sub-Saharan Africa, the region most affected, Voluntary Counseling and Testing (VCT) is increasingly being positioned as the centerpiece of national prevention and care strategies. While financial investment to scale-up VCT services is significant, there has been relatively little investigation of the nature of decision-making in this complex health context (e.g. limited treatment, misunderstanding of antiretrovirals, fear around status disclosure, etc.). This study examined

the quality of VCT service provision in Cameroon. Specific elements explored were pre-test counseling before a decision to test, presentation of test results and use of a decision making tool for reducing future risk.

Method: Participants included 90 clients, attended by 30 physicians/nurses in 9 clinics. A total of 90 VCT sessions were audiotaped and transcribed. Qualitative analysis is presented here and analysis using RIAS (Roter Interaction Analysis System) is underway.

Results: In pre-test counseling, providers frequently recommended that clients test, without facilitating a decision making process that explores the advantages and disadvantages of knowing one's status. Interactions were provider-driven with limited client participation. Much effort was spent assessing clients' knowledge about HIV transmission, while little responded to emotional needs or care and support strategies. Male clients expressed their concerns more than female clients. Information was frequently presented in mini-lecture with limited exploration of the nature of clients' sexual relationships and partners' role in decision making processes.

Conclusion: Decision making in the context of VCT is critical. The quality of VCT consultations in Cameroon could be improved by assessing and responding to clients' needs in a holistic manner that facilitates shared decision making processes in the course of VCT and afterwards. Study findings are being used in VCT program design and implementation in Cameroon and elsewhere.



PERCEPTIONS OF PATIENTS WITH RHEUMATOID ARTHRITIS ON THEIR DECISION MAKING PROCESS

GUIMOND P, DUBOULOZ CJ, O'CONNOR A
Faculty of Health Sciences, University of Ottawa

Background: Newly diagnosed RA patients are faced with choices about alternative ways of functioning in their daily living. In order to make the best possible choice, RA patients need professional assistance to help identify and reflect on the potential risk of undesirable outcomes, loss, regret or challenges that could be associated with the various options presented to them. In their current practice, rehabilitation health professionals rely on their knowledge and practical experience to guide clients through the decision making process. As RA clients are involved in decisions related to alternative ways of functioning in daily living, it is important to know how they make difficult choices in order to improve the support rehabilitation health professionals can provide.

Method: The objective of this study was to explore Rheumatoid Arthritis (RA) patients' decision making process regarding rehabilitation help seeking decisions in daily living. The criteria for inclusion were: adult patients, 21 to 65 years of age, either gender, diagnosed with RA, treated at home by an occupational therapist or physiotherapist with the treatment objective of developing new functioning in daily life, and willing to share present experiences and feelings on their difficulty in making help seeking decisions. The Ottawa Decision Support framework was used to analyze four RA patients' decision making processes, as described in one hour semi-directive in-depth interviews.

Results: Preliminary results show that RA rehabilitation patients do experience decisional conflict. However, the decision making process of these patients affected by a chronic illness differs considerably from the decision making process identified with patients experiencing acute illnesses.

Conclusion: Having established the existence of decisional conflict in a small sample, the next step is to conduct a population needs assessment and an adaptation of the Ottawa Decision Support framework for the rehabilitation population.

WHAT SURGEONS TELL THEIR PATIENTS WITH LOCALISED PROSTATE CANCER

MCGREGOR S

Department of General Practice & Primary Care, University of Glasgow

Background: Depending upon the discipline and beliefs of the presenting physician management of localised prostate cancer appears to be radical prostatectomy, radiotherapy or watchful waiting. The differences in survival rates among those three treatment modalities is minor and if patients are to be partners in the decision making process the information they are given and the language used is central to their ability to understand those choices.

Method: To record Consultant Urologists' perceptions of their communicative practices used when they disclose a diagnosis of localised prostate cancer twenty-eight urologists in the central belt of Scotland were interviewed on tape using a semi-structured interview schedule. An inductive analysis of the transcripts allowed identification and classification of recurring themes that enabled a critical and consistent interpretation of the data.

Results: With the intention of protecting patients from what they regarded as a fearful diagnosis most surgeons avoided the immediate use of the word *cancer*. Only when patients asked direct questions were they given unequivocal answers. Elderly men for whom watchful waiting was to be the method of management for their disease were often never told they had cancer.

Conclusion: The information given to patients varied considerably, and was in most cases dependent on the beliefs of their Consultant. Those who did not agree with a specific treatment protocol seldom gave unbiased information. In many cases patients were only told about particular treatments when they asked direct questions. You cannot ask a question however if you do not know what to ask. Because of the diversity of opinions as to the effect of both the disease and the available treatments patients are often given conflicting information. In an attempt to protect them it would seem that some are never told they have cancer while others are told that their cancer is different from all other cancers. If death caused by prostate cancer is not acknowledged or successes celebrated there will always be a fear and mystic surrounding this disease.

CO-OPERATING OR CONTROLLING? DOCTORS PRONOUN USE IN SHARED DECISION-MAKING

ROBERTSON M

Tayside Centre for General Practice
University of Dundee

Background: In spite of a large body of literature on the subject of shared decision-making it is not yet clear how shared decisions are accomplished or to what extent this approach represents a partnership. This paper is part of a doctoral study investigating the nature of SDM with a focus on how participants engage in shared decision-making from a discourse analytic perspective. The paper describes in detail analysed extract[s] from the option negotiation and treatment decision phase of the encounter.

Method: Medical consultations [n110] between GP's and patients were recorded on minidisk and the COMRADE questionnaire [Edwards et al 2000] and semi-structured interviews were used to assess the patient's level of satisfaction with his/her involvement in the clinical decision-making and ascertain from the patient's perspective that the treatment decisions were shared. Ultimately, 30 'best practice' consultations were selected for discourse analysis.

This form of discourse analysis has been used to illuminate the conversational practices and describe the discursive strategies that serve to accomplish shared decision-making consultations.

Results: In the dataset patients were not given any explicit choice about different treatments available for their condition. Discourse analysis identified that the participant's use of 'we' is variable and ambiguous and can be seen to accomplish a number of different actions. What analysis has shown is that any benefit of using 'we' and 'us' to facilitate sharing is undermined if patients are not given the opportunity to respond directly to the treatment 'propositions' or 'invitations' offered by doctors. The use of 'I' by doctors can also be seen to vary in its functionality, for example, 'I' has been found to display doctor empathy and is conducive to partnership. Other times 'I' has been seen to undermine or resist challenges from patients.

Conclusion: Personal pronoun use is seen as a rhetorical strategy or force that disguises coercion and power imbalance. It is expected that the findings from this study will be used to inform consultation skills training programmes.



SCOPE AND EFFECTIVENESS OF TELEPHONE CONSULTATIONS: SYSTEMATIC REVIEW

CAR J ⁽¹⁾, SHEIKH A ⁽²⁾

1) Imperial College London

2) University of Edinburgh

Background: Despite the widespread use of telephones in daily life and the range of possible benefits that telephones offer in medical encounters their role in medical practice remains, for many clinicians, highly controversial. We summarised the evidence evaluating 1. the scope for consultations facilitated by telephone and 2. how the quality and safety of telephone consultations can be ensured.

Method: We used established systematic search methods to identify original research studies and systematic reviews evaluating the role of telephone communication as a means of delivering health care, searching Medline and The Cochrane Library.

Results: Searches yielded a total of 1396 titles of which 103 were considered to be relevant and incorporating original data. A qualitative narrative overview was used to summarise data. Telephones are used for accessing a broad spectrum of healthcare ranging from delivery of routine and emergency care, obtaining repeat prescriptions and results of laboratory investigations, and facilitating health promotional interventions. Interventions range from simple information transfer, to in many cases, complex management decisions. Examples of effective delivery of health care over the telephone are: management of urinary tract infection in women, care monitoring and follow up for depression, management of diabetes, follow-up after trans-urethral prostatectomy. Staff training, protocols for the management of the most common scenarios, dedicated time to receive telephone contacts, documentation of all consultations and a low threshold for organising a face-to-face consultation may help to ensure quality and safety of telephone consultations.

Conclusion: This review has highlighted that telephone-based care is offering an alternative approach to delivering various facets of patient care. Patients are in telephone consultations in an active role performing self-assessment and self-care. Patients in particular value this model for its convenience and improved accessibility. Training devoted to the topic of communication need to be adapted to prepare clinicians for the opportunities and challenges telephone offers.

INTERCULTURAL DECISION MAKING

SUURMOND J, SEELEMAN M C

Amsterdam Medical Centre/University of Amsterdam

Background: Communication between doctors and migrant patients is often said to be problematical. Mentioned are for instance impediments like language problems, the difficulty of diagnosis, the existence of different cultural values and frameworks, compliance and misunderstandings regarding therapy, advices and medication. Because of these impediments reaching a shared decision is generally thought as a difficult process.

Method: We use interactional sociolinguistics and discourse analysis to analyse interviews held with doctors and patients.

Results: In this presentation we want to focus on the way doctors reach a shared decision in their conversations with migrant patients. We will present several excerpts of interviews to illustrate the dynamics that play a role in a successful shared decision making strategy, taking into regard the aforementioned characteristics.

Conclusion: In unsuccessful shared decision making, patient and doctor are engaged in two monologues rather than one dialogue. This pattern starts early in the communication. Once it is started it is hard to change. Causes can be found in (1) non-shared language, e.g. medical terms remain unclear for the patient, (2) non-shared ideas about health care.

Striking is that **unsuccessful** shared decision making often seemed to arise exactly because of these two points (non-shared language, non-shared ideas about health care) rather than conflicting ideas about the disease or about the treatment.

Characteristic of **successful** shared decision making was that there was more or less an explicit agreement between doctor and patient from the start of their encounters. Doctors did a lot of preparing "communicative work" before they would come to a shared decision. For example, patients were given the floor to elaborate on their story though it was the doctor who was in control of turn-taking, also agreement was checked explicitly and concretised by the doctor. When there were non-shared ideas about health care, doctor and patient were focused on the future, on what had to happen, rather than negotiating problem definitions. Besides, occurring conflicts were not avoided, neither by patient nor by doctor.

We suggest that doctor-migrant patient interaction is not a priori a problematic encounter. Rather, it seems to challenge the participants communicative skills, probably more than would do an encounter between participants who share a cultural background.

QUESTION PROMPTS FOR PEOPLE WITH CANCER

TATTERSALL M HN, BUTOW P

Department of Medicine, University of Sydney, NSW 2006, Australia

Background: Patients who are involved in treatment decisions can have better physical and psychological outcomes than those with less involvement (Jefford & Tattersall 2002). Lack of information can cause distress for patients and their families (Fallowfield et al 1995). Provision and use of a question prompt list by cancer patients during an initial consultation has been found in several studies to promote patient question asking (Butow et al 1994, Brown et al 1999). We recently explored the effect of doctor endorsement on the impact of the question prompt list (Brown et al

2001). When (and only when) oncologists specifically endorsed and addressed the prompt list, patients' anxiety levels were significantly reduced after the consultation, consultation duration was decreased and patient recall was significantly improved. As a group, these studies suggest that question prompt lists which are addressed by the physician, are a powerful and cost-effective way to ensure that patients' information needs are met, and their ability to participate in decision-making is enhanced.

Method: In a recently completed randomised trial of pre-consultation preparation packages for patients scheduled to see an oncologist for the first time 24–48 hrs later, we included a question prompt list and a booklet 'How Treatment Decisions are made' presenting the different levels of research evidence.

Results: Patients receiving the intervention: a) asked significantly more questions ($z=-2.8$, $p=0.005$: 11 vs 7 questions); b) tended to interrupt the doctor more ($z=-0.17$, $p=0.08$: 1.01 vs 0.71 interruptions) and challenged information significantly more often ($z=-2.4$, $p=0.05$): twice vs once). Patients receiving the package were less likely to achieve their preferred decision making style (22%) than those receiving the control booklet (35%, $\chi^2=3.56$, $p=0.06$).

Conclusion: A pre consultation preparation package can influence patients' consultation behaviour. However, this intervention was unsuccessful in increasing the percentage of patients whose preferred involvement style in decision making was achieved. There were very few patient questions about evidence underpinning treatment recommendations, and only occasional reference to treatment guidelines (manuscript in preparation). This suggests that such simple informational devices may not be enough to communicate such concepts to patients.



Poster

THE EFFECT OF THE ELECTRONIC MEDICAL RECORD (EMR) ON THE DOCTOR-PATIENT INTERACTION IN PRIMARY CARE VISITS

REIS S, STASHEFSKI-MARGALIT R, LARSON S, ROTER D

Technion, B.Rapapport fac of Medicine, Haifa, Israel and John Hopkin's Blumberg school of Public Health, Baltimore, USA

Background: Purpose: Use of the electronic medical record (EMR) range internationally from a high of over 90% in Israel's Primary Care system to less than 5% in the US. Few studies have directly observed physician use of EMR and its impact on the interpersonal processes of care. Objectives: 1. To explore the extent of EMR use during medical visits, in Israel, a country with widespread use 2. to explore the relationship between EMR use and physician-patient communication.

Method: Methodology: An observational study, of 3 Primary Care physicians and 30 patients. Medical encounters were videotaped and analyzed using the RIAS to identify communication patterns and content-specific categories of EMR use.

Results: Physicians averaged 2.5 minutes (22.7% of total visit time) directly gazing at the screen. Patient's positive talk (laughter, approvals, compliments, and agreements) was negatively associated with the extent of physicians' computer use. Greater computer use was associated more closed-ended biomedical and therapeutic questions. A patient-centered summary score was inversely related to computer use. Computer use was also inversely associated with a variety of positive affect ratings of the physician including Interest, Engagement, Sympathy, Warmth, and Respectfulness. Computer use was positively associated with ratings of physicians' Anger, Hurried affect, and Dominance.

Conclusion: Physicians' use of the EMR appears less than optimal; it is associated with lower levels of patient-centered communication and negative affect ratings. These findings suggest the need for additional training for

interpersonally and educationally effective EMR use, even in settings in which there is virtually complete adoption of EMR technology.

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Presentation

PATIENT INVOLVEMENT IN HEALTHCARE: ACCESS OF FRENCH PATIENTS TO THEIR MEDICAL FILES

CAMHI B, BREMOND A
Centre Léon Bérard

Background: The French law (March 4th, 2002) pertaining to patient rights and the quality of the healthcare system 1) reaffirms existing patient rights, 2) gives a central place to the patient in the physician-patient relationship, and 3) allows the patient direct access to his medical record, which was a major point of debate. Physicians and politicians have underlined the practical implications and difficulties related to this new right, notably the possible risk for some patients who may not be aware of some information and/or willing to read and/or accept it. Two months after the promulgation of the law, our objective was to assess its impact on both patients and physicians of a French Regional Cancer Centre (Centre Léon Bérard) and to analyse their reactions.

Method: After careful reading of the law and parliamentary debates, we developed a first questionnaire that we pilot-tested on 50 cancer patients and 3 oncologists. Based on their answers and reactions, items were slightly modified, then the study was conducted on 700 cancer patients, 42 oncologists and 21 nurses.

Results: Many patients (24,7%) had never heard of patient rights, but all desired to be informed and have easier access to their medical record. Physicians and nurses sometimes gave different answers but, strikingly, physicians' point of view very often differed from patients' one.

Conclusion: Patients' behaviour is interesting: they want to have direct access to all the information concerning their health status, but they also wish to benefit from the explanations of an intermediary physician and to receive psychological help.

If pre-existing texts had been implemented in routine practice, the new law might have appeared pointless. But the fact is that French associations of patients pushed it in order to make patients involved in their own care.

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Presentation

DECISION MAKING IN ASSISTED REPRODUCTIVE TECHNOLOGY MEDICINE

RAPPORT F, RANCE J
University of Wales Swansea

Background: People facing problems of fertility, entering the Assisted Reproductive Technology (ART) arena often find themselves in complex decision making situations as a result of the cyclical and sometimes protracted nature of undergoing repetitive treatment cycles. The confusing variety of treatments available, technical jargon, clinics, statistical probabilities and worrying financial decisions present a particularly appropriate area for exploring the decision making processes that inform patient choice. The aim of this study was to explore how hermeneutic phenomenology could uncover the decision making process for people facing problems of fertility.

Method: This paper presents a study of 11 women from one fertility clinic in Wales who considered becoming egg share donors. The study followed a hermeneutic phenomenological methodology and by so doing offered women the opportunity to express their motivations and experiences of donation through long, phenomenological open-ended interviews. The phenomenological interview is known to emphasise the interviewees voice, help develop conversational relationships and encourage the examination of processes such as decision making by encouraging the building of trust between the interviewer and interviewee.

Results: The phenomenological interviewing technique highlighted a complex process of decision making taking place for donors involved in choosing between treatments in the egg sharing scheme. It also successfully uncovered hidden meanings embedded in participants words illustrating that despite empathic concern with recipient need, the need of potential egg share donors was paramount and, as women strove to achieve motherhood, led to co-dependent relationships developing between donor and recipient.

Conclusion: Hermeneutic phenomenological interviewing techniques can help reveal decision making pathways through the rich, in-depth data that they facilitate.



PARENT HELD CHILD HEALTH RECORDS PROMOTING PARTNERSHIPS INCARE

DAVIES A

School of Health Science, University of Wales Swansea

Background: The use of Parent Held Child Health Records (PHCHR) has become increasingly popular over the last decade. They are seen as a means of opening up the consultation process and facilitating communication during contact with health professionals. The records are perceived to empower parents by enabling access to information about their child which was previously 'hidden' in the official notes and documents held by GPs and Health Visitors (HVs). Parents now wish to take an active role when consulting their GP/HV as they are the experts on their child's health whilst the professional is an expert to be consulted. Indeed government policy suggests that parents become more equal in the health care encounter and should become empowered to actively seek information and challenge accepted practice in the healthcare encounter. PHCHR can be a means of achieving such a goal.

Method: A survey (cross sectional study) was carried out in Pembrokeshire to assess the attitudes of parents and health professionals to PHCHR. One hundred children (from 0-3years) were randomly selected from two GP practices. The parents and health professionals were required to use the PHCHR each time they came into contact with one another. At the end of three months a structured questionnaire was sent to the parents and the health professionals were interviewed using a semistructured interview. Quantitative data was analysed using chisquared analysis and the Fisher exact test. Qualitative data was analysed using content analysis.

Results: The parents felt that the PHCHR empowered them to become more assertive, as they handed over the record to use even if it was not asked for. Parents felt able to raise their concerns more easily and felt the relationship with the GP and HV was more egalitarian and promoted partnership with the health professional. The GPs and HVs were generally positive about the PHCHR feeling that it promoted a more equal relationship and facilitated the consultation process. CMOs especially felt that the PHCHR fostered partnerships in care which was vital in promoting child health and ensuring continuity of care. Only one GP was opposed to their introduction.

Conclusion: PHCHR was valued highly by the parents who felt the record empowered them to seek information and voice issues of concern within a system which was potentially disabling and in which power was traditionally held by the health professional. Health professionals felt the record made the relationship more egalitarian and facilitated parental knowledge and responsibility for their child's health. Traditional secrecy over practice and record keeping was dispelled and ensured that parents were true partners in care by enabling access to all the information they required and the thought processes of the health professionals.

TREATMENT DECISION MAKING IN CLINICAL ONCOLOGY: PATIENTS' DELIBERATIONS CONCERNING ACCEPTING OR REFUSING A RECOMMENDED TREATMENT

VAN KLEFFENS T, VAN BAARSEN B, VAN LEEUWEN E
VU University Medical Center, Amsterdam, The Netherlands

Background: Many studies have focussed on treatment decision making in clinical oncology. However, not much insight has been gained into the deliberations of cancer patients who decide not to accept a recommended oncological treatment. Although the majority of cancer patients accepts primary treatment recommendations, the change of the doctor-patient relationship towards a more active partnership in the decision-making process may sometimes result in a refusal of a recommended oncological treatment. What lead some patients to reject a recommended oncological treatment that is supposed to be the best medical option? The present study focuses on the deliberations patients have in their decision to accept or to refuse a recommended oncological treatment.

Method: Qualitative study design. In-depth interviews with patients who refused (n=30) and with patients who accepted (n=22) a recommended oncological treatment.

Results: In this presentation we will elaborate on the relationship between patients' attitudes regarding end-of-life issues and their decision to refuse or accept a recommended oncological treatment. Furthermore, we discuss the use of medical information about disease and treatment options in the decision making process, and the role of patients' experiences with disease and treatment. Finally, we discuss how offering treatment alternatives influences patients' ideas of experiencing a choice and how interference of physicians in the decision-making process of patients influences patients' ideas of being free to make a decision.

Conclusion: The results of the empirical-ethics study indicate that, in contrast to what is generally believed, decisions of patients to refuse an oncological treatment do not heavily rely on the medical information about disease and treatment options, but are rather inspired by patients' own experiences or those of close others. The medical information and the role of the physician do, however, influence patients' experiences of being free and/or of having a choice. We will discuss how patients' attitudes regarding end-of-life issues relate to their decision to accept or refuse a recommended oncological treatment and whether patients who accept a recommended treatment have attitudes regarding end-of-life issues, including euthanasia, that differ from patients who refuse a treatment.

SHARED DECISION-MAKING AND RECEIPT OF MASTECTOMY FOR WOMEN WITH EARLY STAGE BREAST CANCER: DOCTOR KNOWS BEST?

KATZ S, LANTZ P, JANZ N, FAGERLIN A
University of Michigan

Background: Despite clinical consensus that breast conserving surgery with radiation is preferable to mastectomy for most women with early-stage breast cancer, persistent high rates of mastectomy have motivated lingering concerns about over-treatment. We are performing a population-based survey of women diagnosed with breast cancer during 2002 in the metropolitan areas of Detroit and Los Angeles to examine the decision-making context and determinants of treatments.

Method: We have selected all women with DCIS and an approximate 20% random sample of women with invasive disease over a 12 month period (expected final sample N=1400, response rate 72%) and mailing surveys shortly after diagnosis (followed by a telephone interview for non-responders). We report on 725 completed responses to date, evenly divided between women with DCIS and invasive disease.

Results: One quarter of patients with DCIS and one third of those with invasive disease received a mastectomy. 43.7% of patients reported that they made the surgery decision, 36.8% said that the decision was made together with their surgeon, and 19.5% said that the decision was made by their surgeon. Women with early stage disease (DCIS or stage 1 disease) who reported that they made the decision were more likely to have received a mastectomy than those who reported that the decision was shared or made by the surgeon (27.2%, 20.2% and 7.0%, respectively $p < .01$). Patient concerns about disease recurrence and survival strongly favored a preference for a mastectomy but knowledge about these clinical risk issues was low. For example, only half of women correctly endorsed that survival was the same between mastectomy and lumpectomy with radiation.

Conclusion: These preliminary findings suggest that greater patient decision autonomy may favor receipt of mastectomy and that surgeons play an important modifying role as they generally favor breast conserving surgery. Low patient knowledge about clinical risk trade-offs between procedures suggests clinicians face special challenges in communicating with patients about these issues.



Poster

ADVANCES IN SHARED MEDICAL DECISION MAKING AIDS: WILL THESE LEAD TO GREATER USE AMONG FAMILY PHYSICIANS?

SCHROEDER S, ROTHSCHILD S

Department of Family Medicine, Rush Medical College

Background: Background and Objectives: This exploratory feasibility study with 39 Family Physicians (FP's) (18 faculty and 21 residents) was prompted by advances in shared medical decision aids (DA's) (e.g. Cochrane evaluation scores for 35 DA's) and by growing regulatory pressure for more comprehensive shared medical decision-making (SMD). This study asks the question: Are these advances sufficient to promote greater use of the DA's by FPs?

Method: FPs at two urban residency programs were introduced to DAs through informal discussions/interviews with FPs followed by more formal educational sessions ranging from 40 minutes to 2.5 hours. FP responses to the DAs were obtained through interviews, brainstorming sessions and surveys.

Results: At the start of the study, FPs did not know about the existence of DAs. Once FPs received educational information about DAs they responded favorably to the DAs. Of the 29 (74%) of FPs responding to a final survey, all said they would use DA's if they were free, on the web in a single address and if extra demands on their time could be reduced. Between 38%-45% of FPs were willing to use selective DAs even under more challenging usage conditions. Most residents required at least 2.5 hours of education/practice time to become comfortable with using the DAs.

Conclusion: For wide usage of DAs in the US, remaining obstacles need to be addressed through medical education and structural changes (e.g. making more DAs free and on the web) and providing financial or administrative supports to protect physician time.

HOW PEOPLE MAKE DECISIONS TO PURSUE PREDICTIVE GENETIC TESTING: AN ANALOGUE STUDY.

HENDERSON BJ, MAGUIRE BT, GRAY J, MORRISON V
Institute of Medical and Social Care Research, University of Wales, Bangor

Background: Predictive genetic testing will be possible for more common diseases in the future. Little is known, however, about the decision process people go through when considering genetic testing. This study looked at people's decisions to seek professional advice on genetic testing for a hypothetical adult onset disease.

Method: Twenty individuals were presented with a decision scenario and verbal protocols were collected whilst participants worked through information relevant to the decision. Information was presented to participants via a computer and each participant's path through the information was recorded.

Results: Analysis of the data demonstrated that whilst most participants evaluated the consequences of the various decision options, this strategy was embedded within a variety of decision making styles. These were identified as: conflicted change, unconflicted change, worst case scenario, dominant moral stance, naturalistic style, and vigilance respectively.

Conclusion: Implications for clinical practice and the development of decision aids are discussed.

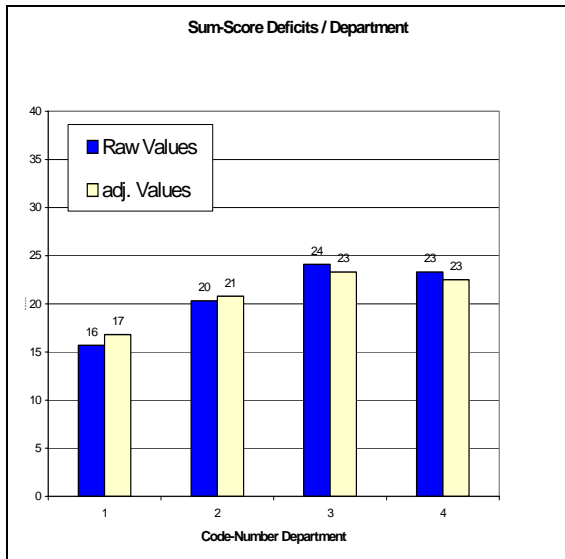
DO PATIENT CHARACTERISTICS PREDICT THE AMOUNT OF DEFICITS REPORTED AFTER A HOSPITAL STAY?

NÜBLING M, LANGEWITZ W, WEBER H
Div. Psychosomatic Medicine/Dept. Internal Medicine, University Hospital Basel, Switzerland

Background: It has become increasingly common practice to ask patients to report on their experiences during a hospital stay to find weak points inside a hospital. When units are compared to identify those who would profit most from an intervention the comparability of different clinics and wards has to be assured. Of course, patients on obstetric wards are younger than those on internal wards, but does that matter?

Method: We investigated in a cohort of 874 patients in whom complete data sets were available (a subset from 1240 patients who had responded to the questionnaire; response rate: 59%) which sociodemographic or health related variables had an impact upon the sum score of deficits.

Results: Patients who judged the success of their treatment below average, patients who had no private insurance, patients who lived alone, those who perceived their current health status as less favourable, and those who rated German as their mother tongue reported more deficits. Taking into account these factors to correct the raw number of deficits in the respective departments (Internal Medicine/Surgery/ Gynaecology & Obstetrics/Neurology & Special Clinics) did not change the general picture significantly (see figure1).



Conclusion: Sociodemographic variables account for less than 10 percent of variance in patients' reports of perceived deficits during a hospital stay

HOW PATIENT-CENTRED ARE PATIENTS AND WHICH CHARACTERISTICS ARE PREDICTIVE? RESULTS FROM TWO ROUNDS OF QUESTIONNAIRES: 1997 AND 2001 IN SWITZERLAND

WEBER H, NÜBLING M, LANGEWITZ W

Div. Psychosomatic Medicine/Dept. Internal Medicine, University Hospital Basel, Switzerland

Background: Even though the evidence is rather thin patient-centred communication is a goal many educators and many medical societies are propagating. Investigations into patients' preferences concerning a more paternalistic or a more participatory style have yielded mixed results (Little, 2001; McKinstry; 2000) in ambulatory settings.

Method: Using three specific questions embedded in a standardised questionnaire (Langewitz, 2002; Nübling, 2003) we investigated to what extent patients are willing to be involved in decision making. We compared two cohorts examined in 1997 (N=338; duration of recruitment: 4 weeks) and 2001 (N=1040; duration of recruitment: 8 weeks) from the University Hospital of Basel. The two cohorts did not differ in sociodemographic variables or in health characteristics. The questions could be answered on four point Likert scales: completely agree/agree/ do not fully agree/totally disagree.

Results: The questions and the percentage of affirmative responses in 1997 and 2001 are:

- One should stick to the physician's advice, even if one is not fully convinced of his ideas: 64.7% agreement in 1997, 79.1% agreement in 2001
- It should completely be left to physicians to decide on a patient's treatment: 62.3% agreement in 1997; 65.6 % agreement in 2001
- **Even when the news are bad the patient must be informed: 99.2 % agreement in 1997; 96.0% agreement in 2001.**

Whereas no single variable predicts patients' preferences of being informed, ANOVA's show that the following sociodemographic characteristics decrease the willingness to hand over responsibility to the physician: higher education, younger age, being female, and speaking German fluently. The current health status has no impact upon the first two questions!

Conclusion: The data show that patients very well differentiate between the need for information and the wish to actually participate in decisions. They seem much less interested in a participatory physician style than most specialists including ourselves had anticipated.

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Poster

“SHARED DECISION MAKING IN PROSTATE CANCER: PRELIMINARY RESULTS FROM THE QUALITY OF LIFE STUDY IN DUTCH PROSTATE CANCER PATIENTS AND THEIR NEEDS FOR PSYCHO-ONCOLOGICAL CARE.”

FISCHER M ⁽¹⁾, VOERMAN B ⁽¹⁾, VISSER A ⁽¹⁾, GARSSSEN B ⁽¹⁾, VAN ANDEL G ⁽²⁾

1) Helen Dowling Institute for psycho-oncology, Utrecht

2) Onze Lieve Vrouwe Gasthuis, Amsterdam

Background: The possible side effects of treatment and the ongoing debate about the relative benefit of one treatment over another, seem to be enough justification for health care providers to discuss treatment options with their patients. In our Quality of life study in prostate cancer patients in the Netherlands, we studied the process of decision making from the patients' point of view and determined the association with other aspects of satisfaction with the medical care provided.

Method: As part of the survey mentioned above, approximately 175 patients had to answer the questions: 1) whether the doctor had discussed different treatment options with them 2) who had decided upon treatment; the doctor, the patient or patient and doctor together; 3) their satisfaction with this type of decision making and 4) their overall satisfaction with the medical treatment that had been decided upon.

Results: Most patients (74%) report that their doctors had discussed several treatment options with them. And 75 % of the patients indicate they had had a chance to decide upon treatment, alone or together with their doctor. Furthermore, 85 % is quite or very satisfied with how the decision making process had taken place. And 87 % is moderately or very satisfied with the medical treatment that they had received.

Significant correlations exist between satisfaction with the decision making process and satisfaction with the medical treatment, and the amount of social support the patients received from their doctors.

The data collection is still ongoing. Final analyses will include correlations between experiences with the decision making process and sociodemographical (age, SES), psychosocial (coping style, QoL) and disease related (prognosis, treatment side effects) factors.

Conclusion: Most patients would like to have an influence on the decision about their treatment. In this study most patients were given this opportunity. The association between satisfaction with the decision making process and the satisfaction with their medical treatment is of practical use to health care providers.

OPERATIONALIZING PATIENT COMPETENCIES THROUGH THE USE OF HEALTH COACHING

RAPP LA, POWERS AJ, BURKE H
Health Dialog

Background: The ability to communicate health problems, feelings, beliefs, and expectations to a provider, and the skills to access and evaluate needed health care information are among the major competencies identified by Towle and Godolphin (1999) as fundamental skills that enable individuals to manage chronic conditions effectively.

Method: Providing evidence-based information, helping patients formulate key questions as they prepare for a provider visit, exploring patients' personal values and preferences with them, and helping patients to establish realistic expectations are among the strategies Health Coaches (HC) use to help individuals develop the basic competencies they need to become effective healthcare consumers.

Results: In a recent study 71% of individuals queried rated their ability to communicate with their care providers as "much better" or "better", as a result of speaking with a HC. In another geographic area- 77% of patients surveyed reported that their quality of care improved after being coached. In the same area, 80% of patients reported that they spoke to their providers about the questions and concerns that they had discussed with a HC.

Conclusion: Health Dialog, Inc. Health Coaches, who are licensed professionals, collaborate to improve patient competencies through transference of the knowledge and skills necessary for the task of self-managing chronic disease conditions.

**USE OF MULTIMEDIA TECHNOLOGY TO ENCOURAGE SHARED DECISION MAKING**

BRINK S, MCFARREN A
HealthMark Multimedia, LLC

Aim: To introduce participants to a process and model used to develop patient-oriented decision tools.

Content: Cancer patients face a bewildering set of treatment and life decisions. They must learn a new vocabulary and make choices that will impact their physical, social and emotional health. Combining education with decision tools and models can assist patients in making decisions together with their doctors and family members. Multimedia is a format

that can provide information and decision aids in a way that supports the complex nature of decision making as well as accommodates different learning styles and various education and health literacy levels.

HealthMark Multimedia, LLC, is developing a series of multimedia CD-ROM-based decision aids for cancer patients. These products incorporate a model of patient decision involvement that includes information gathering, values and preferences clarification and recognition of daily life needs. The model is implemented by applying Social Learning Theory.

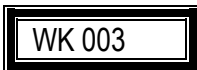
This workshop will illustrate HealthMark Multimedia's model for multimedia decision aid development by examining two of the company's products: Prostate Cancer: Your Decision Notebook® and Breast Cancer: Your Decision Notebook®. The development process, several interactive decision tools and preliminary data from a field trial will be presented.

Method: Participants will:

- Identify methods for measuring the decision process
- Map multimedia components to Social Learning Theory
- Examine combining a shared decision process with self-care management
- Discuss decision presentation when supportive care is an option
- Examine how field trial data can inform decision aid development

Method: Participants will:

- Identify methods for measuring the decision process
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- Examine how field trial data can inform decision aid development



Workshop

THE VERY IDEA OF SHARED DECISION MAKING: VIEWS FROM SOCIAL SCIENCE

Murtagh M ⁽¹⁾, Hepworth J ⁽²⁾, Rapley T ⁽¹⁾

1) University of Newcastle

2) Queen Margaret University College

Aim: To examine the 'idea of shared decision making focusing on assumptions about the concepts 'choice' and 'decision making';

Content: Much of the research literature on shared decision making relies on *a priori* assumptions about concepts of 'choice'; and 'decision making'. Informed by the writings of French philosopher Michel Foucault on power relations, subjectivity and ethics we examine: the effects of employing ideas of 'choice', 'empowerment'; and 'autonomy'; the functions of multiple narratives of self management; and, the ideals of 'shared decision making' and how these ideals are actually practised. Foucault writes "The exercise of power consists in guiding the possibility of conduct and putting order into practice" (Foucault, 1982, p221).

Three papers presented separately at this conference form the empirical background for this workshop.

Murtagh, MJ. Forms of freedom? General Practitioner accounts of women's decision making at menopause.

Hepworth, J. Type II Diabetes self management: a narrative theory of health behaviour change. Rapley, T. et. al. "Well, we'll come back to that question": The impact of a computerised decision-support tool on doctor-patient interaction.

The theoretical perspectives of these papers are discussed in this workshop: poststructuralism and feminist ethics - Madeleine Murtagh; conversation analysis and ethnomethodology - Tim Rapley; and, social construction and narrative - Julie Hepworth.

Method: 1. Setting the scene: Brief overview of three papers (see above) reporting original research.

2. A scripted conversation between the three presenters discussing two or three key papers in the SDM literature informed by their theoretical perspectives.
3. An interactive discussion with the audience, in part using small group techniques.

WK 004

Workshop

DILEMMAS IN SCREENING DECISION AIDS: FORMULATING MINIMUM QUALITY CRITERIA.

BARRATT A, TREVENA L, MCCAFFERY K, DAVEY H
University of Sydney

Aim: To demonstrate conceptual difficulties and dilemmas specific to decision aids for screening and to formulate a draft list of quality criteria for screening decision aids

Content: Informed consent for screening requires weighing up potential benefits, chances of false negative and false positive results, side-effects of follow-up tests and treatments, anxiety, social and economic consequences¹. Benefits and harms may be finely balanced and the decision may be heavily dependent on individual risk profiles, personal values and preferences. Outcomes may be viewed as harms by some and benefits by others, and screening is embedded within a system which seeks to maximise participation. Screening decision aids may facilitate this process but their development poses special challenges. Staff at the Screening and Diagnostic Test Evaluation Program (STEP) and its associated

Sydney Health Decision Group are developing innovative screening decision aids including: a decision aid for colorectal cancer screening (FOBT), and a decision aid for women considering HPV testing following detection of mild cervical atypia. Using these as examples we will explore some of the dilemmas faced in the development of screening decision aids.

From discussion we aim to generate a draft list of quality criteria, which would be regarded as minimal for evidence based, balanced decision aids about screening. This may be further developed and refined collaboratively to form a consensus on quality criteria for decision aids in screening

1. General Medical Council. Seeking patients' consent: the ethical considerations, 1998.

Method: We will use demonstrations of screening decision aids as triggers for debate on key issues (see Content). We will then facilitate the group to generate a draft list of quality criteria. If attendance exceeds 20+, participants will work in small groups to develop criteria relevant to the key issues.

WK 005

Workshop

TENSIONS IN PUBLIC HEALTH POLICY: EVIDENCE, PATIENT AND PUBLIC INVOLVEMENT IN DECISION MAKING, AND HEALTH INEQUALITIES

THOMSON R, MURTAGH MJ
University of Newcastle

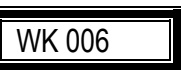
Aim: To examine and discuss the apparent contradictions between central policy which promotes evidence-based health care, legislation and policy which promotes public and patient engagement in decision making and, policy aiming to reduce health inequalities.

Content. A major focus in changing international health care policy is the rise of evidence-based medicine and the increasing emphasis on public and patient engagement. At the same time, many health systems, including the UK NHS, have increased their emphasis on improving the health of populations and on reducing inequalities, encompassing wider perspectives on health and on the influences upon health. We argue there are considerable tensions between these major components of health policy. In particular, we focus on the apparent contradictions between central policy which promotes evidence-based health care, exemplified in the UK by NICE guidelines and National Service Frameworks, legislation and policy which promotes public and patient engagement in decision making and, policy aiming to reduce health inequalities.

There are two major sources of tension. First, there is a tension between the evidence-based approach, which tends to focus on traditional morbidity and mortality outcomes, and the potential effects of engaging patients in decisions through shared or informed decision making, which may not pursue or achieve similar goals: Patients, given the choice, may not opt for 'healthy' alternatives. Secondly, there is a potential disjunction between public and patient engagement in decision making and the aim of reducing inequalities: Those groups already experiencing the greatest deprivation and marginalisation from mainstream society through poverty and discrimination are also those most likely not to engage in public and patient involvement thereby potentially exacerbating inequalities.

Method. We explore tensions in public health policy (described above) with examples informed by the developing literature and based within a theoretical perspective employing concepts power relations, subjectivity and ethics based on the writings of Michel Foucault.

We present an overview of our arguments and raise key questions for debate in facilitated small group discussions.



Workshop

SHARING DECISION MAKING ABOUT MEDICINES WITH LAY MENTORS

SHAW J, KNIGHT L

Medicines Partnership, Terrence Higgins Trust (respectively)

Aim. To share Medicines Partnership's experience of implementing concordance in medicines taking – i.e. involving patients as full partners in decisions about medicines.

To share a specific example of one of Medicines Partnership's projects: the THT lay mentoring project

To share participants' experience and expectations of using lay people in assisting patients to make decisions.

Content. Key elements of concordance in the prescribing and taking of medicines

Research evidence that concordance is effective in improving patient compliance and satisfaction

Differences between concordance and compliance

The role of Medicines Partnership in promoting concordance and supporting practical concordance projects

The lay mentoring programme (Living Well with HIV project) being offered for patients with HIV in the Brighton area considering starting or changing anti-retroviral therapy, run by the Terrence Higgins Trust (including patient case studies)

Opportunities for and pitfalls of the use of lay support more generally in helping patients to make decisions about medicines.

Method. Presentation by Joanne Shaw, Director of Medicines Partnership (25 minutes)

Presentation by Lisa Knight, THT Project co-ordinator (25 minutes)

Discussion in small groups (or plenary, depending on overall group size) on opportunities and pitfalls of providing support to patients through lay people (30 minutes)

Feeding back of conclusions and overall synthesis by Joanne Shaw. (10 minutes)

CHIQ GUIDELINES FOR PRODUCING QUALITY HEALTH INFORMATION*JANE SHADDOCK*

Centre for Health Information Quality (CHIQ)

Aim: To present, explain and discuss guidelines for producing quality health information addressing issues of accuracy, clarity and relevance

Content: CHIQ has developed guidelines to help health professionals to produce their own materials and to assess the quality of existing materials.

Method: A Powerpoint presentation followed by practical group work.

Works best with no more than 50 people. Attendees are divided into small groups to examine and discuss some leaflets applying the CHIQ Guidelines. Their comments are fed back to the entire group. Discussion and debate is encouraged.

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