

ESSAY REVIEW

Hill, S. (ed.) (2011). *The Knowledgeable Patient; Communication and Participation in Health: A Cochrane Handbook*. Chichester: Wiley-Blackwell ISBN 978-1-4443-3717-4

Margot Lindsay RGN BA MPhil MCLIP PhD

Correspondence address

Dr. Margot Lindsay, Research Department of Mental Health Sciences, Charles Bell House, 2nd Floor, 67-73 Riding House Street, London, W1W 7EJ. E-mail: rejumev@ucl.ac.uk

Accepted for publication: 23 January 2013

Introduction

As a preliminary to this review it is necessary to introduce the international network which produced the book with Wiley-Blackwell. The Cochrane Collaboration consists of more than 28,000 people from over 100 countries working together to help healthcare providers, policy-makers, patients, their advocates and carers, make well-informed decisions about healthcare, by preparing, updating and promoting the accessibility of Cochrane Reviews. Their work is internationally recognised as the benchmark for high quality information about the effectiveness of healthcare. Cochrane Reviews are unique because they are both produced by and are relevant to everyone interested in the effects of human healthcare. Practitioners can find out if an intervention is effective in a specific clinical context. Patients and other healthcare users can assess the potential risks and benefits of their treatment. It has to be conceded, of course, that the reductive methods of the Collaboration remain the subject of major debate and readers can gain substantial insight into the nature of this debate elsewhere.

This book provides people involved in healthcare with new ideas and practical resources to communicate and participate in services. This is based on evidence-based healthcare and explains what it means and why it is relevant to practice and theory. There is a consistent voice throughout the 18 chapters which includes the editor in much of the discussion. Starting by addressing the question of the need to improve communication with patients and carers, the reasons for intervention are examined followed by the effects or outcomes of interventions and participation. The difficult subject of communicating risk is sensitively addressed with statistics for preventing chronic disease. In considering what patient participation means, the authors examine the significance of surgery. Another potentially sensitive subject is carefully considered in the debate about disclosure of medically acquired risk. There are important chapters on using online health information critically, learning to communicate, getting the most out of research and managing multiple health problems. There is an evidence-based approach to

improving communication with women in a maternity hospital setting. The last 3 chapters explain how to build health-literate societies with tools for building research capacity and knowledge and describing emerging technologies for health communication.

Intended audience

The book is aimed at people who are interested in a 'consumer-perspective' on health issues. Those who are training to be health professionals or coming back to study for postgraduate education are an important audience. It is relevant to a broad group, such as those training for clinical roles in health or medicine, or those undertaking education in public health, health policy, health administration or health information management. Its international approach provides ideas, concepts, taxonomies, evidence and practical tools to enable people to understand the central role of communication and participation in a well-functioning health system. The 4 primary groups who use health research evidence include: policy makers, healthcare professionals, researchers and consumers. For all these groups, reviews that compile evidence across individual trials and studies are valuable sources of information.

The thesis of the book

Systematic reviews synthesise the research that has already been conducted on a given topic and can provide new insight and a more complex picture than each isolated study. There are examples within the book of how Cochrane reviews can provide evidence that is relevant to different audiences and how that evidence can be used by them. Scenarios of the different users of Cochrane reviews are provided. These include a health policy maker who has to prepare a report for the health department, examining the effectiveness of patient contracts in changing health behaviour, a health professional in a cancer hospital who

has to undertake a review and audit of the role of breast cancer nurses in improving outcomes for breast cancer patients, a graduate student who is developing a research proposal for a thesis on peer-supported healthcare initiatives as well as a patient with a painful foot condition who is seeking information to help her make a treatment decision.

Conceptual framework

A knowledgeable patient becomes part of a knowledgeable society and research about experiences, needs and preferences in democratic participation leads to better health outcomes. Research on the effects of interventions for communication and participation also contributes to better health outcomes. This is an essential message within the book illustrated by a conceptual framework advocating evidence-informed communication and participation. This framework is built on the concept associated with consumer empowerment, patient-centred care and evidence-based healthcare. It therefore links science and democracy. The book advocates evidence-informed communication and participation as an individual, shared and civic interest.

What does participation mean?

Interestingly, the book discusses what patient participation means in a modern society. Patients' views of their experiences of undergoing treatment were analysed. This was based on interviews with 30 people who underwent a major surgical procedure, focussing on their views of the entire experience, their actions and decisions. Their communication with doctors and the process of treatment is described and the importance of healthcare staff learning to listen to people's voices and to become immersed in the social world of the patients is emphasised. The in-depth interviews were with people aged 53 to 93. Those people who experienced one or more symptoms had sought medical attention immediately. They were ready to act and initiate action. Others were more uncertain and hesitant to take their first step towards interaction and although they experienced symptoms, they did not immediately recognise these symptoms to be a cause for concern. Although the timeframe for initial participation period varied significantly, most people sought medical treatment after experiencing symptoms. However, some individuals experienced no symptoms at all and their participation began in a different way. These individuals were diagnosed by doctors during examinations, with the news coming as a surprise for subsequent participation. The asymptomatic people were often characterised by an increased willingness to be guided by recommendations and doctors.

Participation styles

The different styles of patient participation identified in the book are discussed in turn. The most active form of participation is initiation. Those patients who initiate participation with the existence of symptoms, start a discussion in favour of a specific course of treatment and ask questions assertively. The participation style is characterised by a readiness to act. Active agreement implies an individual informed according to need. This means that patients feel comfortable interacting with doctors, but they may also choose to be silent. Medical authority is not experienced as oppressive, nor is it challenged. Instead, patients have a sense of equal worth and ease of relation is reflected in the preferred communication style. Those patients, whose participation is characterised as acceptance by a sense of uncertainty can be described as accepting the need to act, rather than initiating or agreeing with action. This form of participation may entail considerable strain. There may be resistance to the newly acquired information of risk, reluctance to ask questions or raise concerns and dissatisfaction with the communication styles of doctors or information provided. This resistance is not total, however, choice and acceptance of treatment are still made, though it may be a reluctant choice, or the strain of the overall experience may remain after its completion. The strain of the experience may mean that people readily complain about aspects of their treatment, such as the rudeness of students, costs of treatment or the threatening way in which information may have been provided. This may also mean that the information provided is insufficient or cannot be readily understood when it is provided.

A key feature of health participation and decision-making examined in the book is informing people according to need. This includes tailoring to the audience by varying the quantity, timing and format of information to suit the preferences of individuals. Several people involved their family members in the information exchange process. Some were too frightened to read information pamphlets and instead passed them along to family members. People had very different preferences with regard to the amount of information they wanted from their doctors. Some people who wanted a great deal of detailed information found it difficult to obtain, but most were informed to a degree that they found satisfactory.

For people who did not necessarily want to know everything that was going to happen to them, their doctor's intention to inform them was still important. Regarding timing, several people expressed a strong preference to receive information at the end of their experience and after surgery rather than before it. Before the procedure, the information was too frightening to read, but learning about it later helped them make sense of the experience. Some other patients sought as much information as possible before their operation, even performing their own research to add to that which was provided by their physician. Information-seeking behaviour and the type of information needed by any individual can also change over time with the addition of multiple new diagnoses. The accumulation

of illness could mean that a person became too sick and tired to look or process detailed information. Regarding format, not all the patients preferred to receive information from their doctors exclusively. Some wanted to speak to patients who had undergone the same surgery and others looked to medical books on their own to work out what was happening to them.

Shared decision-making

The book describes shared decision-making as a model of the physician-patient relationship in which both parties have an equal role in determining the course of treatment. Shared decision-making is characterised by 4 features: it involves at least the patient and the physician (though additional people may join the process); both parties share information, contribute to the treatment decision and agree upon the final treatment choice. The discussion of the patient's willingness and ability to follow a given course of action is also critical in determining the most appropriate option. People valued the opportunity to ask questions of their doctors and were frustrated when they could not get answers or when they were not given the chance to ask. The people who expressed high levels of satisfaction with their experiences were those who felt that their physicians treated them as equals and that their treatment decision was made with input from both the physician and the patient. Positive health outcomes, including symptom resolution and pain control, have been linked to effective communication and agreement between the physician and the patient. Health professionals should be given the resources and training necessary to improve and develop their communication skills and enable them to encourage a shared decision-making approach as part of patient consultation.

The social meanings of being a patient

The description of a conceptual framework for interpreting treatment experiences within the book features 3 main forms of participation: those who agree to act to fix the problem, those who accept the need to act but are dealing with the problem with strain and those who initiate action. The patient's role has 3 aspects: the participation/action style, the patient's relationship to information and the way in which the patient exercises authority. The patient's relationship with doctors is comprised by the character of the doctor-patient interaction and the patient's perception of and trust in medical authority. Two features of the conceptual framework apply to all patients: personal meaning of the treatment experience and participation transformation.

Helping people managing their own health

Patients need to know where to find reviews, why they are a reliable source of health information and what type of information they can provide. Clinicians should be up to date with the latest research from systematic reviews in order to refer patients in their practice to relevant information. They must also understand the structure of reviews and be able to explain how to reinterpret the information back to individuals. Review results can be confusing and patients may need an explanation of concepts such as risk of bias (in relation to individual studies) and how this relates to the overall findings of that review. A knowledgeable clinician can help sort through information that patients have found independently.

Shared decision-making is an important element of the doctor-patient relationship, particularly as it relates to patient participation and better communication. The patient, rather than the health problem, should be the focus of any consultation and both the patient and the clinician should be in agreement about the problem and the course of action to be taken. Clinicians must be able to adapt to the information needs of different patients and to the same patient in different situations. Some individuals do not want to be informed in detail. Others require information pamphlets and several consultations to feel comfortably informed. Health professionals may need to be trained to encourage question asking rather than seeing it as a threat to consultation length. The book contains very sensible advice on avoiding over-reliance on information technology as IT should strictly be used as a tool, not as an oracle. Practical information about the language of IT searching skills is provided with a model search strategy in Medline presented in a concise, tabulated form.

Learning to communicate

Interaction between healthcare providers and consumers is a key element of healthcare quality and is discussed in detail within the book. We learn that successful communication can positively influence patient outcomes such as treatment adherence, satisfaction with care, health status and pain management. In contrast, poor communication is a major factor in complaints by patients. Communication problems may also give rise to harmful psychological and emotional outcomes for both health professionals and patients, including anxiety, uncertainty, stress and dissatisfaction.

Reflecting the shift of the doctor's role from paternalistic expert to shared decision-making partner and the importance of improving communication with patients is a transition being emphasised by British and American Medical Associations. In addition, the World Health Organization has incorporated communication standards into international guidance for the management of a range of health issues, including chronic diseases and tuberculosis. Training doctors to communicate more

effectively cannot simply 'solve' the communication 'problem'. To improve outcomes, training must be directed to users of health services as well as health professionals. Some research suggests that more involved patients may have better health outcomes, such as reduced anxiety, although this is not yet well established. Some training interventions are directed at both clinicians and consumers, building skills for each group by encouraging them to work collaboratively. Detailed information is provided within the book in tables citing information about reviews of interventions directed to health professionals and separate references for patients to improve communication. Citations include bibliographic data; review objectives; features of the review; outcomes measures as well as review findings.

Reviews which focus on only one or the other side of the communication divide can impede the ability of health professionals to view the changes in communication within the context of a conversation between two people. Patients may also be involved in the training and education of physicians. Promoting the involvement and communication skills of patients and doctors is no longer seen as simply 'good to do', but rather as crucial to the efforts of improving health systems and outcomes. The book describes how existing systematic reviews may help to bring patient-centred communication to the fore in discussions of healthcare quality by indicating that communication interventions can and should, be informed by high quality evidence. Involving patients, clinicians and other stakeholders in discussion regarding which interventions to implement may help to address questions of the applicability of the existing body of evidence to a particular setting. Systematic reviews synthesise the research that has already been conducted on a particular topic and can provide new insight and a more complete picture than an isolated study.

Users of evidence may be confronted by different findings, from systematic reviews – the intervention does not work as expected, the research is still ambivalent and does not work as expected, the research is still ambivalent in its key messages or the intervention may be subject to widespread variation in practice. The book emphasises that public involvement is important, because systematic reviews provide a way of drawing together current best evidence for patients to share decisions about their care with their health professionals, confident that the evidence they have is the best available, where 'best' is seen in terms of methodological rigour.

The research agenda for knowledgeable patients reaches across health areas and settings, the terms used to describe the people involved vary widely, with different conventions depending on the region and discipline. Terms include patient, public, user, consumer, carer, lay person and citizen. This book considers primarily the interests of patients. However, patients are part of a wider public and the concept of involvement is equally applicable to carers, service users who are not ill and the wider public – all of whom may bring or use knowledge for decisions about health services and products.

Information on multi-morbidity

The book describes what information sources exist for managing multiple health problems from the health user's point-of-view. At present, research evidence and information materials derived from it for both doctors and consumers principally focus on one disease and largely ignore the interaction of diseases in patients' lives. This means that there may be little or no information for patients with multi-morbidity to support treatment, self-management or other health actions. There may also be little information that is suitable for doctors to share with their patients when multi-morbidity is present. A further problem arises because it is not possible to simply apply what is known from research and information from single diseases to people with multi-morbidity. Rather, considerable skills become necessary and clinicians and patients enter a situation of considerable complexity.

Health-literate societies

In discussing the building of health-literate societies, the book argues that strategies to empower consumers should be informed by scientific approaches such as evidence-based healthcare and systematic reviews and individual or civic involvement. It concludes that integrating scientific approaches with democratic participation leads to awareness that health treatments should be based where possible on rigorous evidence of benefit. The book also describes approaches to communication with and involving people should also be based where possible on evidence of effectiveness. Literacy can be built not only by directing strategies to individual consumers but also by directing interventions to the community level, health professionals and health organisations.

Conclusion

Besides health professionals and users of health services, this book is an indispensable asset to healthcare librarians who endeavour to save the time of the reader by identifying systematic reviews and careful analysis of research studies on carefully selected themes. This Cochrane handbook will enrich the practice of all the partners in care and it needs to be widely available in clinicians' practice rooms, college libraries and hospital wards. In order to increase the availability of the book to patients it should be included in the self-help section of public libraries.