

The background of the cover features a complex geometric design. At the top, there is a grid of squares in shades of blue. Below this, a large, light blue sphere is outlined with a white wireframe. Inside this sphere, there are several overlapping circles in various shades of blue and green. The overall aesthetic is modern and scientific.

A COCHRANE HANDBOOK

The Knowledgeable Patient

Communication and
Participation in Health

SOPHIE HILL

COCHRANE BOOK SERIES

 WILEY-BLACKWELL

The Knowledgeable Patient

Communication and
Participation in Health

A Cochrane Handbook

Edited by

Sophie Hill BA (Hons), MA, PhD

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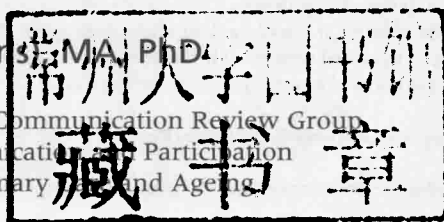
Centre for Health Communication and Participation

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Preface

A Google search of 'knowledgeable patient' brings up all the change and flux of the last century. If I take the words of the google search result at face value, what are my thoughts?¹

'Investigating the role of lay knowledge' (leading me to wonder, does the patient know something that the doctor does not?)

'A beautiful woman goes to the gynaecologist' (patients (and women) are still the butt of jokes)

'Your first knowledgeable patient' (doctors confront people with knowledge – and questions!)

'Compliant ... the patient needs to be educated – by us – to understand why he needs to follow our instructions' (the patient knows nothing and must be obedient)

'Inside the mind of ...' (we have to take knowledgeable patients seriously)

In the twentieth century, patients moved from passivity to participation, and like all major social change, movement was uneven. Being more involved may also mean being more responsible for one's health. This is a public policy dilemma because being sick can lead to vulnerability,

¹ www.google.com.au. I searched with 'knowledgeable patient' on 26 June 2009. The extracts are taken from the first five listings of the search result, with the source material being:

'Investigating ...' Karlsson M (2007) *The knowledgeable patient: investigating the role of lay knowledge in the production of health*. www.ageing.ox.ac.uk/files/workingpaper_208.pdf.

'A beautiful ...' hnbaby (2007) *Medical Geek Forum*. www.medicalgeek.com/medicaljokes/7025-knowledgeable-patient.html.

'Your ...' Blades K (2004) *Pulse*. www.pulsetoday.co.uk/article-content/-/article_display_list/10899114/your-first-knowledgeable-patient.

'Compliant ...' Romano PE (1987) *Archives of Ophthalmology*. <http://archophth.ama-assn.org/cgi/reprint/105/3/315-a.pdf>.

'Inside ...' Dillon B (2008) *Geovoices: Geonetric Blog*. <http://geovoices.wordpress.com/2008/05/06/inside-the-mind-of-the-cancer-patient>.

and speaking up may not be the priority for the sick person. It confronts us with the test of fairness because poorer people have more ill health than those who are well off materially and socially.

In the twenty-first century, the pressures of this change are apparent. 'Ordinary' people have to be extraordinary. Much is expected: keep up to date with screening, know your medicines, recognise the latest risks, manage the family's health, eat sensibly, exercise, plan for end of life, understand your insurance options and communicate your wishes. And possibly contribute to your community by volunteering your time and support.

The 'knowledgeable patient', then, is sometimes a patient, sometimes a family carer, sometimes a member of the public interested in health issues, sometimes a consumer advocate, contributing to the health system or to a healthier society – and sometimes all of these things. In other words, the knowledgeable patient is fundamental to improving health and managing illness.

Being more knowledgeable creates a new dynamic in the health system. The knowledgeable patient may create demand, ask questions and seek information. Expectations on people may be too high, though, and people could get lost in confusion, preyed on by unscrupulous parties promoting the latest cure-all. Simply, the health system may be too busy to answer questions, or not able to comprehend the complex demands it faces.

This book sits at the forefront of these changes. It will be an essential guide for the new era of complex healthcare. Its purpose is to help health professionals to understand the vital relationship they will have with the 'knowledgeable patient' and equip them to contribute to a new form of health system, based on evidence of effective and responsive strategies for improving communication and participation.

The book is for 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. Another important audience are those who want to read patient stories and who want to know the evidence behind strategies to communicate better and involve people in health.

The book contains a wealth of issues for exploration and discussion, with many different health examples – safe medicine use, chronic disease self-management, surgery, the complexity of multimorbidity and rare disease risk. It contributes research to our growing understanding of knowledge transfer, i.e. getting research into health practice and into

people's lives. New issues in health – public involvement in research, emerging health communication technologies and health literacy – are documented. Research examples are not confined to one service domain but span living in the community, health service treatment, governance and policy making.

It is international in scope, giving readers ideas, concepts, taxonomies, evidence and practical tools to understand the central role of communication and participation to a well-functioning health system. It draws on several research paradigms, presenting qualitative research of experiences for integrating with evidence from systematic reviews of controlled trials.

It places communication and participation firmly in the future of evidence-based healthcare. It gives us a language to communicate a better future.

Sophie Hill, Editor

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J Grimshaw, in the Rx for Change database project. Table 3.2 is adapted from Lowe D, Ryan R, Santesso N, Hill S. (2010) Development of a taxonomy of interventions to organise the evidence on consumers' medicines use, *Patient Education and Counseling* DOI: 10.1016/j.pec.2010.09.024, with permission of Elsevier, Copyright © 2010, Elsevier Publishing. In Chapter 3, I define interventions for communication and participation as purposeful, planned and formalised strategies associated with a diverse range of intentions or aims. The provenance for this concept is that I first presented it at a Plenary (A.E.I.O.U. of Communication and Participation', Hill S, Pictor M. 4th Australasian Conference on Quality and Safety, Melbourne, 21–23 August 2006). A condensed outline was published in *Communicating with consumers and carers – Part 1 – Pilot of evidence-based selection of communication strategies to improve communication between consumers/carers and health services*, Victorian Quality Council, 2007; and which is reproduced with permission (refer to Chapter 15 below). Chapter 3 extends the concept and combines it with the concept of multi-directionality, which was first published in 2009, Hill S, Directions in health communication, *Bulletin of the World Health Organization*, 87, 648.

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Where derived from the original reports, the material in Chapter 15 is Copyright © State of Victoria, Australia and reproduced with permission of the Victorian Minister for Health. Unauthorised reproduction and other uses comprised in the copyright are prohibited without permission. The knowledge translation research in Chapter 15 was funded by the Victorian Quality Council in 2004, and conducted with a major commitment from the staff at the Royal Women's Hospital. The Project Officer at the CC&CRG was Ms Angela Melder and her contribution to the project's successful conduct is gratefully acknowledged.

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In Chapter 18, Table 18.2 is adapted with permission from Professor Aziz Sheikh, and first published in Catwell L, Sheikh A. (2009) Evaluating eHealth interventions: the need for continuous systemic evaluation. *Public Library of Science Medicine*. 6, e1000126.

The book has several figures that capture concepts and ideas so well, it makes the words redundant! So I would like to acknowledge and thank Helen Dilkes for her original work for Figures 2.1, 2.2, 16.1 and 17.1–17.3. I thank and acknowledge Jessica Kaufman for Figure 7.1 and Dianne Lowe for Figures 9.1 and 9.2.

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Sophie Hill, Editor

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CHAPTER 1

Does communication with consumers and carers need to improve?

Megan Prictor¹ and Sophie Hill²

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The stories we solicited reverberated with recurring and troubling themes: You cannot get a human being on the telephone, and you cannot get an appointment. When you do have an appointment, you wait an excessive time before seeing the doctor, who is in a hurry, does not seem to care, and provides inadequate explanation and education . . . Each event had the potential to weaken the patient's relationship with the clinician and culminate in loss of trust in the health care system [1].

When my (MP) daughter was aged about 3, after a series of colds she was referred to a specialist for advice on mild fluid on the ears. This experience, although she does not remember it, shook my confidence in the health system. Things got off to a poor start when the specialist, who happened to be male and probably in his fifties, did not greet my daughter nor ask my name (preferring to call me 'mum'), and did not introduce himself until prompted. Without a hearing test, after a brief look in her ears, he pronounced that she needed surgery to insert grommets to drain the fluid; that I would be grateful and would thank him once it was done; and that he could squeeze us in 2 days before Christmas. Rather taken aback, I enquired about possible risks or side effects of the procedure and was informed there were none. When I suggested I would rather take a 'wait-and-see' approach, he warned me not to stick my

head in the sand and that adverse consequences would likely follow. After the appointment, I sought a second opinion and did not proceed with surgery.

I am an educated white female in my thirties, working for an organisation that conducts research into what makes for good doctor–patient communication. I had read about the health problem and the procedure beforehand, so had a good idea that what the specialist was telling me was not quite correct. Although there were no practical adverse consequences (i.e. my daughter was not subjected to unnecessary surgery), the experience left me so shaken that afterwards I burst into tears, and years later, it stayed with me. And I wondered about the parents of other patients of this specialist – did some of them also harbour doubts, but accepted his recommendations because he similarly implied that they were bad parents if they failed to heed his advice? Did they accept being treated rudely because, after all, he was the doctor?

What is the broader health policy and social context?

It could be argued that treatment effectiveness – whether a particular medicine or surgery works to improve life of the patient – is more important than whether the patient feels good about their relationship with their doctor, whether they are well informed about their treatment and whether they have been involved in decision-making. This might be particularly claimed in resource-poor or crisis settings, where efforts must focus unambiguously on the preservation of life [2]. In the bigger picture, my experience of poor communication with the specialist is arguably of very little consequence.

It is now well established, however, that good communication is fundamental to healthcare, both of itself and as a mechanism to ensure safe, effective treatment. This chapter establishes the case for efforts to improve communication between healthcare professionals and patients. It identifies how we can find out about the nature and extent of communication problems, and most importantly, what the consequences of these problems are. By demonstrating that communication-related difficulties affect not only people's feelings but also the quality, efficacy and safety of the medical and surgical treatments they receive, we establish that attempts to overcome the difficulties are more than just feel-good strategies. Rather, they are critical to improving people's health and ensuring that medical mistakes are avoided.

How do we find out about communication problems?

Data on communication difficulties in healthcare settings are available in diverse locations. Discussions of healthcare quality and safety often circle around these issues. Observational data are routinely collected

by hospitals and healthcare quality agencies. For instance in Victoria, Australia, public hospital data on adult inpatients are gathered annually using the Victorian Patient Satisfaction Monitor, a tool which incorporates measures of (1) written and oral provision of information to patients about the hospital, treatment, medications and at discharge; (2) staff attitudes, responsiveness and communication; and (3) complaints management [3]. Stories about the impact of communication problems on patients, their families and clinicians also make it into the mainstream literature. Nancy Berlinger's paper on people's experiences of communication around medical error draws on narratives published in books, journals, general magazines and the internet [4]. Indeed, the focus on medical mistakes and adverse events heralded by the landmark 2000 Institute of Medicine report *To Err Is Human: Building a Safer Health System* arguably lends weight to research and discussion of patient involvement and improved clinician–patient interaction, since there is growing evidence – discussed below – that they are more than merely window dressing.

Healthcare complaints data, which are sometimes publicly reported, are the key to better understanding these issues. Poor communication itself is a major stimulus for complaints to hospitals and monitoring bodies. People may feel that they have been treated discourteously or given insufficient or incorrect information [5]. The US Agency for Healthcare Research and Quality noted that in 2005, for instance, almost one in ten adults reported poor communication when using health services in the previous year [6]. Significantly, poor communication was reported more often by people from racial and ethnic minority groups and those on lower incomes [7]. A study of people who had made complaints to hospitals in the Netherlands had similar findings, whereby 9% of these complaints were solely about communication between doctors and patients [8]. Obviously, diverse coding taxonomies result in different findings; however, there is no reason to expect the picture is any better in Australia. A study of 1308 complaints made at a major South Australian hospital over a 30-month period found that fully 45% ($n = 621$) of complaints were about communication problems, comprising a lack of communication ($n = 240$), offensive attitude ($n = 124$), lack of care ($n = 112$), inadequate information ($n = 98$), conflicting information ($n = 47$) and undignified service ($n = 6$) [9, 10].

Complaints data also reveal that communication failures underpin many other types of health system problems. The Victorian Health Services Commissioner noted in 2008 that 'communication is a feature of all complaints' – whether they fall into the 'communication' category or not [5], whilst in West Australia, many of the complaints categorised as relating to treatment or access also related to the provision of information and effective consultation [11]. In the Dutch study, most complaints (68%) were about the clinical conduct of healthcare professionals 'frequently in

combination with shortcomings in relational conduct or shortcomings in the information provided by the professional' [8].

Communication problems matter to patients

In the example above, poor communication had no impact other than that I felt upset and angry. I did not see it as part of a broader problem. Yet poor communication in the healthcare setting is very common. Personal accounts give some indication that poor communication can have a severe and lasting impact on people's experiences. In a recent paper about rare diseases, the mother of a child with fragile X syndrome described as 'the hell of my life' not the child's illness itself, but rather the clumsy and insensitive diagnosis disclosure by the physician [12].

Kuzel and colleagues, in a 2004 paper, pointed out that the focus on medical errors – such as medication and surgical mistakes in inpatient settings – highlighted by the *To Err Is Human* report is at odds with the types of problems that patients generally describe in encountering the health system. Patients in primary care are more likely to talk about difficulties in the doctor–patient relationship (primarily disrespect or insensitivity) and access difficulties, which overwhelmingly cause them psychological or emotional harms – including anger, frustration and loss of trust – as well as physical harm (particularly pain) and financial cost [1]. This is supported by Commonwealth Fund surveys showing that access difficulties, and breakdowns in care coordination and information flow, were experienced by most US adults [13, 14].

There is clear evidence that people want more information than they are given and that clinicians tend to overestimate the amount of information they have provided [15, 16]. Roter and Makoul have noted that only 58% of people studied said their healthcare provider told them things in a way they could understand [17]. Unsurprisingly, communication difficulties have been shown to affect diagnosis: Stewart noted that '50% of psychosocial and psychiatric problems are missed, that physicians interrupted patients an average of 18 seconds into the patient's description of the presenting problem, that 54% of patient problems and 45% of patient concerns are neither elicited by the physician nor disclosed by the patient' [18].

Adverse events

Communication failures can cause not only dissatisfaction but serious adverse events (an 'injury caused by medical care' [19]). In 2008–2009, the report on such events in Victorian hospitals identified that communication was a contributing factor in 20% of these events, with health information a factor in another 8% of cases [20]. Similarly a US review of adverse events in obstetrics and gynaecology identified communication