

CHAPTER 1

Does communication with consumers and carers need to improve?

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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

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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

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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

failures – either between clinicians or between clinicians and patients – as being associated with 31% of these events [21]. Communication failures between clinicians and patients contribute to wrong-site surgery, in which surgery is conducted on the wrong part of the body, the wrong surgery is done or the wrong patient is operated on [22]. Not communicating well with patients and their families and not including the patient or family in identifying the right surgical site are key causal factors in this type of error [23]. The World Health Organization's Surgical Safety Checklist for clinicians includes, as a necessary first step, that the patient has confirmed his or her identify, the surgical site and the surgical procedure, and given his or her consent [24].

A classic definition of medical error from the research literature is 'failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim' [25]. People using healthcare, however, have a broader conception of the term. Gallagher, Burroughs and colleagues have identified that patients see medical errors as including communication problems such as being treated rudely, poor responsiveness on the part of the clinician and long waiting times [25, 26]. Researchers portray this conception of medical errors as being plainly wrong, a misunderstanding on the part of patients. Consequently, the authors call for doctors to explain more clearly to patients the 'correct' meaning of the term 'medical error'. This so-called misunderstanding by patients could, instead, stimulate a broad reconceptualisation of the term to encompass the things that patients are concerned about and see as wrong in healthcare, such as access and communication difficulties. If, as Kuzel and others have identified, being treated offhandedly and not being able to see a doctor loom large in people's concerns about the health system, there must be a greater emphasis on addressing communication problems seriously and systematically. As Kuzel notes, 'respectful communication should not be an optional extra in healthcare. Studies of patients' or service users' experiences and perspectives allow us to recognize more readily that hurtful comments are harmful comments and that failures of respect can be both unhelpful and damaging to health' [27].

Litigation

Poor communication is known to be a key contributing factor in litigation against primary care physicians [28]. Moreover, in circumstances in which an adverse event has already occurred, clear communication becomes critical [29]. A recent study about open-disclosure policies in Australian hospitals found that 'how patients were treated, whether their experiences were valued and whether their questions were answered truthfully influenced patients' judgements about the merit of the process' [29]. In a US study of parents who filed malpractice claims for perinatal injuries, those who felt misled or not sufficiently well informed by

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the healthcare provider about their child's problems and their cause were more likely to sue even if the care provided had been technically adequate [30].

How can things be improved?

There is growing recognition of the importance of communication and participation in healthcare. There is a substantial body of research – conducted particularly by researchers in the United Kingdom, Western Europe, USA, Canada and Australia – into better ways to communicate with and involve people in their health management and healthcare delivery and planning. Health literacy interventions, self-management programmes, written information, new communication technologies, empathetic communication styles and the involvement of family caregivers are among the wide-ranging research streams that have been the focus of attention and funding.

Recognition of the significance of effective communication in the healthcare context was highlighted by the 1997 establishment of a review group within the internationally recognised Cochrane Collaboration, focusing on this topic. The Cochrane Consumers and Communication Review Group (www.latrobe.edu.au/chcp/cochrane) facilitates systematic reviews of interventions which affect consumers' interactions with healthcare professionals, services and researchers (see Box 1.1). The interventions may relate, for example, to individual use of healthcare services or to consumer participation in health planning, policy and research (discussed further in Chapter 2). This places communication – and poor communication – in a new context, that of evidence-based healthcare. All of the authors of this book are involved in the Cochrane Consumers and Communication Review Group, as editors, researchers, referees and collaborating colleagues.

The scope of the book

This book is about the importance of knowledgeable patients in all their various roles and regardless of their label – as patients, consumers, carers, lay persons, peers, volunteers or advocates – and how they contribute to the creation of a healthier society. It is about the importance of communication and participation at all levels, from individual through to collective contexts.

One of the aims of the book is to inform and educate health professionals and equip them with the resources to explore these issues further. It places communication and participation firmly into the context of evidence-based healthcare, explaining what this means and why it is relevant to practice and policy.

Box 1.1 Systematic reviews

You are browsing the newspaper and read about the results of a controlled clinical trial. The trial's conclusions are positive – the treatment 'Now Even Better' has been shown to work and is described as the best choice. Six months later, you read that a new trial has concluded that 'Now Even Better' is no more effective than 'Now Better', which has been around for many years and is cheaper. (Side effects are not described in either article.) Which piece of research do you believe? This dilemma faces health professionals and consumers all the time, and is increasingly problematic as more research is conducted.

Systematic reviews of interventions are major types of research. In a systematic review, all the findings of controlled clinical trials of a specific intervention are collated and summarised to find out if on average the intervention works [31]. The aim is to provide a conclusive summary and synthesis so that decision-makers – whether they are health professionals, consumers or policy makers – can make a decision informed by all the relevant research on the topic.

This book provides information about all facets of systematic reviews of interventions for communication and participation. All chapters reference relevant Cochrane systematic reviews (i.e. reviews prepared by people involved in The Cochrane Collaboration and published on *The Cochrane Library*, www.cochrane.org). Chapter 2 gives a summary of evidence-based healthcare and the role of systematic reviews; Chapter 3 describes what interventions are; and Chapter 4 outlines the range of outcomes from communication and participation interventions. In Chapter 8, stories from consumers on how they used Cochrane reviews for personal decisions are presented, and the chapter includes a guide to all sections of a Cochrane review. Chapter 9 aims to quantify the systematic reviews relevant to improving health systems. Chapter 12 shows how to get the most from Cochrane reviews.

The book has four sections:

1: What are the benefits of improving people's participation in their health through effective interaction?

Chapters 1–4 establish the scope of the book and provide the conceptual building blocks and practical knowledge tools.

Chapter 1 has provided the justification for why action to improve communication with consumers and measures to support their involvement are worth pursuing.

Chapter 2 advances an overarching conceptual framework, situates the book in the context of the evidence-based healthcare movement and provides key definitions and terms.

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Chapter 3 defines interventions for communication and participation and includes a case study of interventions for safe medicine use.

Chapter 4 looks at the types of outcomes resulting from interventions that promote knowledgeable and involved consumers and carers. It looks at what outcomes have been measured in the past and proposes a new taxonomy of outcomes of importance to consumers of interventions for improving communication and participation.

2: What do people want from communication and participation in health?

Chapters 5–8 present research findings from qualitative research into people's experiences of health and identify what consumers and carers want in terms of communication and participation.

Chapter 5 explores the different ways in which absolute risk for cardiovascular disease can be discussed by consumers and general practitioners in primary care settings.

Chapter 6 examines consumer participation from the patient's perspective. It draws from in-depth interviews with people who had carotid endarterectomy surgery to identify three major participation patterns.

Chapter 7 outlines the findings of a systematic review of the experiences, views and needs of people at medically acquired risk for Creutzfeldt–Jakob disease (CJD) and variant CJD and presents a framework which identifies how communication might best happen in these situations.

Chapter 8 presents research with consumers about how they used evidence from systematic reviews in planning and managing their health.

3: Where is the evidence: information sources, skills and tools for health professionals and consumers?

Not only are we bombarded with information but increasingly we are confronted by new health research. The field of evidence on improving communication and participation is no different. When should we look, what will we find and how should we use research? These questions are addressed in Chapters 9–12.

Chapter 9 combines two concepts in order to identify the scope and quantity of evidence for improving health and the experience of treatment. The first concept is termed evidence for health systems decision-making and the second is evidence to promote health and improve the experience of illness and treatment.

Chapter 10 takes a critical perspective to the topic of online health literacy and looks at how users can be misled. The implications for a realistic assessment of educational strategies to achieve the 'autonomous' patient are discussed.

Chapter 11 reviews and discusses the current evidence and future research agenda for educational interventions directed to health

professionals and consumers to improve their ability to communicate with one another.

Chapter 12 looks at examples of how Cochrane reviews can provide evidence that is relevant to different audiences and how it is used by them.

4: How to build capacity for a health system focused on communication and participation?

Chapters 13–18 conclude the book by drawing from research into knowledge transfer and health reform processes to provide lessons for future actions.

Chapter 13 considers how research is funded and the opportunities this presents for involving patients and the wider public in deciding what problems deserve research and how that research should be done.

Chapter 14 examines the emerging issue of multimorbidity, i.e. having more than one health problem. It examines what evidence exists to support the use of evidence-based interventions for communication and participation in the area of medicines where people have more than one health condition.

Chapter 15 contributes to the growing literature on evidence-informed health service improvement by examining how research on communication was integrated into a service improvement project at a major women's hospital in Victoria, Australia.

Chapter 16 discusses the concept of health literacy and its relation to evidence-based healthcare and draws on submissions to a major national health reform process to identify how different players and health organisations want health literacy improved.

Chapter 17 describes healthcare intervention trials, research evaluation, knowledge transfer and capacity building, and the international initiatives putting these concepts into practice.

Chapter 18 introduces the reader to an array of health information technologies that may facilitate patient communication, discusses the potential of these technologies to improve healthcare through improved communication and participation, and outlines the challenges of implementing communication technologies.

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