



## Exploring patient involvement in healthcare decision making across different education and functional health literacy groups<sup>☆</sup>

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### ABSTRACT

Education and health literacy potentially limit a person's ability to be involved in decisions about their health. Few studies, however, have explored understandings and experiences of involvement in decision making among patients varying in education and health literacy. This paper reports on a qualitative interview study of 73 men and women living in Sydney, Australia, with varying education and functional health literacy levels. Participants were recruited from a community sample with lower educational attainment, plus an educated sample of University of Sydney alumni. The transcripts were analysed using the 'Framework' approach, a matrix-based method of thematic analysis. We found that participants with different education conceptualised their involvement in decision making in diverse ways. Participants with higher education appeared to conceive their involvement as sharing the responsibility with the doctor throughout the decision-making process. This entailed verifying the credibility of the information and exploring options beyond those presented in the consultation. They also viewed themselves as helping others in their health decisions and acting as information resources. In contrast, participants with lower education appeared to conceive their involvement in terms of consenting to an option recommended by the doctor, and having responsibility for the ultimate decision, to agree or disagree with the recommendation. They also described how relatives and friends sought information on their behalf and played a key role in their decisions. Both education groups described how aspects of the patient–practitioner relationship (e.g. continuity, negotiation, trust) and the practitioner's interpersonal communication skills influenced their involvement. Health information served a variety of needs for all groups (e.g. supporting psychosocial, practical and decision support needs). These findings have practical implications for how to involve patients with different education and literacy levels in decision making, and highlight the important role of the patient–practitioner relationship in the process of decision making.

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### Introduction

Involving patients in healthcare decision making has become a priority for health practitioners and policy makers, and is now endorsed by leading health organisations (Institute of Medicine, 2001; UK Department of Health, 2009; World Health Organization, 2000). The shift toward greater patient involvement in healthcare

has been driven by a number of socio-political changes. During the 1960s, the women's and civil rights movement actively challenged medical paternalism, as contributing to the disempowerment of patients (Charles, Gafni, & Whelan, 1997). In a similar vein, movements in bioethics and medical law have advocated greater respect for patient autonomy since the 1970s (Beauchamp & Childress, 2001). More recently, increased participation reflects the enormous advance in information technology, with greater public access of health information made possible via the internet (Eaton, 2002). Greater involvement has also been shown to lead to better decision-making outcomes for patients (O'Connor et al., 2003).

The shift towards increased involvement has inevitably led to changes in the roles, expectations and relationships that doctors and patients have during the consultation. In traditional paternalistic approaches, the doctor took a dominant role and made decisions on behalf of the patient, a 'passive' recipient in the

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process (Emanuel & Emanuel, 1992). Newer approaches reflect the notion that patients may adopt a more 'active' role. One of the most commonly cited models of involvement is the shared decision-making approach (Charles, Gafni, & Whelan, 1999), whereby patients and doctors work in partnership, exchanging information, both detailing their preferences and then deciding on options together.

Although the shared model is referred to as an approach which patients and doctors strive for, its tendency to focus narrowly on patients choosing between treatment options, fails to acknowledge the more 'nuanced' aspects of involvement (Entwistle & Watt, 2006, p. 269). Furthermore, previous research looking at involvement has tended to rely on quantitative self-report methods, to identify the role the patient wishes to play (Degner, Sloan, & Venkatesh, 1997). However, asking people to choose from a list of role description statements may not fully capture broader aspects of involvement such as, how a patient feels about their role in the process. This has led some researchers to adopt qualitative approaches, to explore how patients experience involvement (Davey, Lim, Butow, Barratt, & Redman, 2004; Entwistle, Prior, Skea, & Francis, 2008).

Greater involvement in decision making, however, places increased demands on a patient's literacy skills, in order to understand complex health information and articulate their preferences. There is growing concern that *some* patients, particularly those with lower education and literacy may have difficulties participating in the process. Low literacy is prevalent in most developed nations, with up to half of the population possessing below basic (inadequate), or basic (marginal) literacy skills and experiencing difficulties reading basic written information encountered in day-to-day life. Furthermore, lower literacy is most common among populations already disadvantaged, due to their relative social position, lack of educational qualifications and limited employment opportunities (Australian Bureau of Statistics, 2006; Department for Education and Skills, 2003; Kutner, Greenberg, & Baer, 2006).

Interest in the relationship between literacy and health has resulted in the development of the construct of health literacy (Nutbeam, 2008). Health literacy is defined as the 'degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' (Institute of Medicine, 2004). However, some experts argue that health literacy means more than the ability to read information; it extends to the ability to interact with a health professional and exert greater control over everyday situations (Nutbeam, 2000). It can also relate to having an awareness of public health issues, scientific processes and cultural differences (Zarcadoolas, Pleasant, & Greer, 2005).

The way that health literacy is defined has important implications for how it is measured. Current health literacy assessments only measure skills in the functional sense (i.e. reading ability and numeracy), and do not capture the multifaceted nature of this construct (Baker, 2006; Nutbeam, 2008). For example, if health literacy is conceptualised more broadly as social skills, that enable patients to negotiate with health professionals, then existing instruments are not appropriate.

Health literacy research is a rapidly expanding field of inquiry, with many studies (predominately from the US) documenting the association between functional health literacy and health outcomes. Patients with lower functional health literacy have been shown to engage less in preventive health activities (Miller, Brownlee, McCoy, & Pignone, 2007), and have poorer knowledge about their condition(s) and how to manage them (Gazmararian, Williams, Peel, & Baker, 2003). They also appear less confident in expressing their concerns, and participating in the decision-making process (DeWalt, Boone, & Pignone, 2007; McKinstry, 2000).

To date, however, there has been little qualitative work exploring the impact of education and functional health literacy skills on patients' understandings of involvement in decision making. Lupton (1997) found that adults from lower socio-economic groups appeared to more readily accept the doctor's advice due to greater levels of respect, whereas those from higher socio-economic groups appeared more comfortable questioning the doctor. In addition, patients with lower literacy report difficulties asking questions and feel that doctors do not listen, or communicate to them clearly (Baker et al., 1996). Relatedly, consultations that contain more technical language and fast paced monologue may be particularly problematic and dissatisfying for lower literacy groups. However, this work was not conducted with real patients so its implications are limited (Roter, Erby, Larson, & Ellington, 2007).

A number of social and linguistic theories have been put forward to explain doctor-patient interaction. Some social scientists and health researchers (Rapley et al., 2006; Strong, 1979) have drawn on interactionist social theory (Goffman, 1967), proposing that normative, 'ceremonial rules' are often so entrenched within the medical encounter that they are unquestioned, and subsequently serve to reinforce the status quo and power relations between the doctor and patient. In contrast, Pierre Bourdieu (Bourdieu, 1999), a social theorist, posits that in order to understand the actions of individuals and social groups, it is important to consider how broader structures of society including cultures, education and social position, shape social and communication practices. Consistent with Bourdieu's theory, doctors have been shown to act differently when conversing with patients from lower socio-economic groups, exhibiting less positive socio-emotional behaviour such as listening, reassurance, and empathy, and underestimating the amount of information they desire (Willems, De Maesschalck, Deveugele, Derese, & De Maeseeneer, 2005).

Bourdieu states that a person's perceived social position may shape how they view their interactions with others within social structures and institutions of authority (e.g. the healthcare system). There is an important distinction, however, between a person's social position and their literacy. Socio-economic position (as generally measured by education, occupation and income) denotes a person's position within the socio-economic structure. Evidence shows that social disadvantage is associated with poorer health, and structural factors such as housing and unemployment, as well as psychosocial variables (e.g. perceived control over life, stress and depression) mediate this relationship (Wilkinson, 1999). Literacy on the other hand, reflects a person's actual skill, rather than their perceived social position, across a range of abilities including reading, numeracy, oral communication, as well as social skills which enable them to interact with others, and participate in society (Appleby & Hamilton, 2006).

This paper reports on a qualitative study to explore experiences of involvement among patients varying in education (as a marker of socio-economic position) and functional health literacy; and to explore whether shifts towards greater involvement, choice and shared decision making had differentially impacted on patients' understandings of healthcare decision making.

## Methodology

This qualitative study drew on phenomenology as a theoretical orientation and research methodology (Smith, 2007). Phenomenology is concerned with understanding human experience in terms of 'individual consciousness' (Reeves, Albert, Kuper, & Hodges, 2008, p. 632). This means that the empirical focus is on the individual experience, appropriate for our interest in patients' perceptions of involvement in health decision making.

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