ELSEVIER

Patient Education and Counseling 60 (2006) 102–114

Patient Education and Counseling

www.elsevier.com/locate/pateducou

Review

Patients' preference for involvement in medical decision making: A narrative review

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Received 14 June 2004; received in revised form 31 January 2005; accepted 17 February 2005

Abstract

Objective: This review aimed to clarify present knowledge about the factors which influence patients' preference for involvement in medical decision making.
Methods: A thorough search of the literature was carried out to identify quantitative and qualitative studies investigating the factors which influence patients' preference for involvement in decision making. All studies were rigorously critically appraised.
Results: Patients' preferences are influenced by: demographic variables (with younger, better educated patients and women being quite consistently found to prefer a more active role in decision making), their experience of illness and medical care, their diagnosis and health status, the type of decision they need to make, the amount of knowledge they have acquired about their condition, their attitude towards involvement, and the interactions and relationships they experience with health professionals. Their preferences are likely to develop over time as they gain experience and may change at different stages of their illness.
Conclusion: While patients' preferences for involvement in decision making are variable and the process of developing them likely to be highly complex, this review has identified a number of influences on patients' preference for involvement in medical decision making, some of which are consistent across studies.
Practice implications: By identifying the factors which might influence patients' preference for involvement, health professionals may be more sensitive to individual patients' preferences and provide better patient-centred care.

Keywords: Shared decision making; Patient participation

Contents

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0738-3991/$ – see front matter
doi:10.1016/j.pec.2005.02.003

1. Introduction

Increasing emphasis is being placed on involving patients in making decisions about their care [1]. This is the result of a number of socio-political factors [2]. As disease patterns have shifted towards a high prevalence of chronic disease there is, for an increasing number of conditions, no overall best treatment. Many patients and health professionals feel patients themselves are in the best position to evaluate the trade-offs between the benefits and risks of alternative treatments [3,4].

Patient expectations about their role in choice and decision making have been influenced by living in a consumer society [3]. Ready access to health information via media such as the Internet has become the norm for many. Social movements, such as the women's movement, have emphasised the importance of autonomy and have actively challenged medical authority [5].

Furthermore, highly publicised scandals and widely reported concerns of under-funding have eroded patient confidence in the NHS and the medical profession leaving patients seeking more information and involvement in their care [3,6]. Involving patients also helps meet demands for accountability as health professionals can be more open about decision making [3,6].

There are a number of roles for doctor and patient in medical decision making. These have been conceptualised as a spectrum with paternalism at one end, at the extreme of which the doctor makes decisions on behalf of the passive patient based on clinical expertise and without considering the patient's preferences. At the other end is informed decision making, in which the doctor fully informs the patient, detailing all treatment options and their implications, transferring technical expertise so that the patient can make a decision alone, based on his or her own preferences (active involvement) [5,7–9]. Shared decision making, in which doctor and patient exchange information, both detailing their treatment preferences, deliberating and then deciding the treatment together, is in the middle of the spectrum [3]. An alternative model is that of an agency relationship in which the patient fully informs the doctor of his or her preferences and then delegates responsibility for decision making to the doctor, who ideally would then make an identical decision to that the patient would make, if the patient had the clinical expertise of the doctor [10].

Whilst research has consistently shown that doctors underestimate the amount of information that patients want [11], it is less clear how much patients actually want to be involved in making decisions about their treatment and what influences their preference for involvement. This literature review focuses on what influences patients' desire to be involved in medical decision making in order to clarify present knowledge and identify further research opportunities.

2. Method

Searches were carried out using Medline, Web of Science, PsychINFO, CINAHL, The Cochrane Library and HMIC (key words consumer participation, patient participation, decision making, patient preferences, shared decision making, patient involvement in decision making) covering the years 1975–2003. The references of identified articles, the indexes of journals from which articles were retrieved, important texts about patient involvement in decision making and key reviews were also searched.

Quantitative studies were included if they were primary research investigating the factors affecting patient preference for involvement in decision making published in English. As this is an exploratory area of research all identified studies were included but were rigorously critically appraised by at least two of the authors to identify methodological limitations and potential biases in order to assess validity and reliability which are referred to throughout this paper and summarised in Section 3.2.6.

Qualitative studies that focused on broader questions were included if influence on decision making was a clear focus of at least one aspect of analysis. Qualitative studies were assessed in terms of the validity criteria for the paradigm employed in the research, where that was clear in the paper. Coherence of the research question or rationale with the methods of data collection and analysis was examined. Analysis was scrutinised for the appropriate application of reliability and verification strategies. This appraisal is summarised in Section 3.3.1.

3. Results

Thirty three articles were identified; 25 quantitative studies, seven qualitative studies and one mixed method study (see Tables 1 and 2).

3.1. Patients' preferences for involvement

Quantitative studies reported wide variation in the proportion of patients who preferred to be involved in making medical decisions (Table 1). Variation in preference for involvement may be due to a number of methodological