

Which surgical decisions should patients participate in and how? Reflections on women's recollections of discussions about variants of hysterectomy

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Abstract

Current guidance about informed consent suggests patients ought to know about the procedures involved in any treatments they agree to undergo, and have a right to be involved in decisions about their care. However, it is not clear how this guidance is and should be applied to decisions between variant surgical procedures such as abdominal or vaginal hysterectomy.

We sent structured questionnaires about information provision and decision-making to 157 women who were scheduled for hysterectomy in north-east Scotland. A purposive sub-sample of 20 women was interviewed in depth post-operatively.

104 women (66%) responded to the questionnaires. 75% reported being told at outpatient clinics what kind of hysterectomy they would have, but fewer than half had been told about the advantages and disadvantages of different kinds. Between 26% and 65% of women thought they had been given too little information about various issues pertaining to different types of hysterectomy.

The interview accounts suggested that gynaecologists offered women little opportunity to influence the selection of a surgical procedure. Women did not express a desire for a greater say in this selection, but appreciated being told, or would have liked to know, why particular procedures were recommended for them. There may be circumstances in which it is important for surgeons to tell patients about options they have ruled out in their particular cases.

Decisions between alternative surgical procedures are often highly contingent on the dispositions and skills of individual surgeons. They raise practical and ethical issues that have been neglected in recent discussions about patient involvement in decision-making. As policy makers continue to emphasise the importance of choice and patients become increasingly aware of the existence of variant procedures, these issues need careful consideration.

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Introduction

Legal and policy standards for informed consent and patient involvement in treatment decision-making have

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been raised in recent years. Several factors have contributed to this, including an expanding range of possible interventions; a growing awareness that many choices between health care interventions are sensitive to individual preferences; the emergence of evidence that doctors cannot reliably predict the preferences of their patients (Coulter, Peto, & Doll, 1994; Protheroe, Fahey, Montgomery, Peters, & Smeeth, 2000), that most people prefer to be informed about and involved in important decisions about their health care (Guadagnoli & Ward, 1998), and that people who are well informed and involved in decisions about their health care may have better health care experiences and outcomes than those who are not (O'Connor et al., 2003; Salkovskis, Wroe, & Rees, 2004; Stewart, 1995).

Informed consent can be conceptualised in various ways (Alderson & Goodey, 1998). In medicine and law, positivist conceptualisations tend to emphasise the importance of the factual provision of particular elements of information by health professionals. However, social constructionist conceptualisations, which emphasise the complexity of consent and encourage a social process of collaborative decision-making are increasingly influential. Discussions about consent increasingly consider both the elements of information that health professionals should provide and the roles that patients should play in the processes of decision-making.

In the United Kingdom, current guidance recommends that patients ought to know about 'options for treatment or management' and 'details of the procedures or therapies involved' in any treatment proposed (Department of Health, 2001; General Medical Council, 1998). Recent legal judgements support an expectation that health professionals should offer any information that might affect 'a reasonable patient's' judgement about any treatments they propose (Department of Health, 2001). Doctors are encouraged to identify and fulfil the particular information needs of individual patients (General Medical Council, 1998).

The National Health Service aspires to offer patients more choice in terms of the type and location of their treatment (Department of Health, 2000, 2003b; NHS Executive, 1996) and to enhance patient involvement in decision-making. The General Medical Council requires doctors to 'respect the right of patients to be fully involved in decisions about their care' (2001).

However, there is a lack of clarity about the scope of choice that should be offered and the forms of patient involvement that should be facilitated. Various models of doctor-patient communication during decision-making have been elucidated over the years (e.g. Charles, Gafni, & Whelan, 1997 and 1999; Emmanuel & Emmanuel, 1992; Szasz & Hollender, 1956). The appropriateness of particular models is recognised to vary across different types of decision and clinical

context, but there is no consensus about how people should be informed about and enabled to influence the diverse decisions made in the course of their care (Entwistle, Sheldon, Sowden, & Watt, 1998).

Decision-making relating to surgery raises a number of issues that have been neglected in recent considerations of informed consent and patient involvement. A decision to have an operation such as hysterectomy or hip replacement entails numerous associated decisions relating, for example, to when and where the operation takes place; who operates; which anaesthetics, surgical procedures, and post-operative analgesics are used; and what kinds of recuperative care are given, where and by whom. These decisions are constrained and influenced by many factors including health care policies, clinical practice guidelines, local systems and resources, the characteristics of the health care providers and patients involved, and events during the health care episode (Pope, 2002). The questions of what patients need to know and whether and how they can and should be given choice and 'involved' in them warrant careful consideration.

In this paper we focus on elective surgery and situations in which there are several variant surgical procedures for a 'basic' type of operation. We present data from a study of women's views of decision-making about hysterectomy and discuss the reflections these prompted about the desirability and feasibility of informing people about and giving them a say in the selection of surgical procedures.

Hysterectomy is a good example of an operation with several variant forms. It may be performed by open or laparoscopic abdominal techniques or by vaginal techniques, which may be laparoscopically assisted. Hysterectomy may be 'total' (removing the entire uterus), 'sub-total' (preserving the neck of the uterus or cervix) or 'radical' (removing the entire uterus and surrounding tissues, including the upper portion of the vagina).

Several studies have attempted to compare the outcomes and costs of different types of hysterectomy (e.g. Cohen & Young, 1998; Garry et al., 2004; Roovers, van der Bom, van der Vaart, & Heintz, 2003; Thakar, Ayers, Clarkson, Stanton, & Manyonda, 2002). However, surgeons have differing opinions about the relative merits of the variant procedures and vary significantly in terms of the proportion of hysterectomies of different types that they perform (Garry et al., 2004).

In our study context, women with gynaecological problems needing specialist assessment are referred to hospital-based gynaecologists by their general practitioners. Their first encounter with a gynaecologist is typically at an outpatient (ambulatory care) clinic. During the course of one or several visits to the clinic, women are examined and given clinical tests. Consultations at the clinic are usually the primary forum for

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