

Whose decision? Negotiating epistemic and deontic rights in medical treatment decisions



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Abstract

Shared decision making has become an ideal in contemporary clinical practice, and guidelines recommend exploring patients' preferences and providing them with options so they can make informed decisions. This paper examines how the ideal of sharedness is maintained and negotiated through epistemic and deontic resources in secondary care consultations where patients are given a choice between invasive and non-invasive treatment options. The analysis suggests that the physician's presentation of treatment options is often tilted in favor of one proposal over the other, yet giving the patient the right to make the final decision. The patients on the other hand regularly resist this responsibility by claiming lack of epistemic authority (e.g. *I know nothing about it*) or by making the decision contingent on the physician taking a stronger deontic stance (e.g. *if you think so*). This may be characterized as an inverted use of deontic authority from both parties: Physicians give patients deontic rights in their pursuit of independent commitment to their preferred option, while patients orient to physicians' epistemic and deontic rights as a way to resist committing to the physicians' propositions. These conflicting orientations to epistemic and deontic authority counteract the ideal of shared decision making.

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1. Introduction

Patient autonomy has gained a prominent position in medical ethics. It is generally recognized and implemented in health policies and contemporary clinical guidelines through the principles of patient-centeredness that encourage patient involvement in care, especially through shared decision making (Barry and Edgman-Levitan, 2012; Kristvik, 2011; “Lov om pasient- og brukerrettigheter [Patients' Rights Act],” 1999; Mead and Bower, 2000). Evidence indicates beneficial outcomes of interventions on patient-centeredness and shared decision making, although central outcome measures such as health status and concordance are limited or provide mixed results (Crawford et al., 2002; Dwamena et al., 2012). More unambiguous are reports from observational studies, indicating that the doctor-centered approach is tenacious and that patients still have a limited degree of participation in decision making (Braddock et al., 1999; Campion et al., 2002).

Studies also indicate that preferences for being informed and participating in decision making vary amongst patients (de Haes, 2006; Degner and Sloan, 1992; Swenson et al., 2004), and Elwyn et al. (2012, p. 1363) note that: “Some patients initially decline decisional responsibility role, and are wary about participating”. de Haes (2006) takes a step further by pointing out that patient-centeredness, understood as “paying attention to psychosocial issues, to stimulate

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autonomy and empowerment, among others by giving information and sharing decisions” might not be appropriate or effective for all patients. Rather, being patient-centered “in the original sense may imply the opposite” (2006, p. 296). de Haes suggests that this may be related to the potential burden of making choices as described in Schwartz (2004), i.e. through anticipated regret, where “one may worry about the outcome and feel responsible if such outcome turns out to be negative” (2006, p. 296). Thus, the assumption within patient-centered approaches that patients want to (and should) be involved and participate actively in decision making has been contested in various ways.

This brief overview indicate a complex and ambiguous picture that calls for closer investigation on an area that has received less attention: how *participants themselves* understand and orient to the task of making and sharing decisions in actual consultations (Seedhouse, 2005; Toerien et al., 2013). More specifically, we will explore how the ideal of sharedness is maintained in secondary care consultations where patients are given a choice between invasive and non-invasive treatment options. Drawing on conversation analytic (CA) principles and findings, we will focus on how participants deploy epistemic and deontic resources in negotiating these decisions.

Conversation analytic studies have nuanced the general picture of patients’ limited participation in decision making. Subtle practices patients deploy for participating in treatment negotiations and even influencing outcomes have been identified (e.g. Teas Gill, 2005), and Stivers’ (2006) influential studies have documented that treatment decisions are oriented to as the responsibility of both physician and patient (or parent), in that acceptance of physicians’ treatment recommendations regularly are treated as relevant upon completion. Most of the CA literature has until recently focused on primary care interactions, and described medical decision making as a three-part structure, where physicians’ treatment recommendations are treated as proposals that must be accepted before moving on to a next activity. When patient resistance is forthcoming, e.g. by withholding acceptance, negotiation regularly follows (Koenig, 2011; Stivers, 2005).

However, recently, in examining interactions from Polish secondary care, Weidner (2012) suggests that invasive treatment recommendations are presented more cautiously than non-invasive recommendations in that physicians’ provision of accounts (i.e. a medical rationale) seem to be treated as appropriate before acceptability can be reached. Studying British neurology interactions, Toerien et al. (2013) has called for studies with a broadened scope that also includes evidence of physicians’ efforts to offer choice; thus examining practices more in line with current policies. In their recent study, Toerien et al. (2013) compare ‘recommending’ and ‘option-listing’ and show that these two practices provide different response slots for patients. While recommendations make acceptance the relevant next action, option-listing provides a more open-ended slot for patients’ announcements of their selection. The authors argue that this has implications for the distribution of medical authority, where “option-listing is a practice whereby doctors relinquish at least a little of their authority” (p. 885).

This study will go further in that vein, in examining consultations from Norwegian secondary care where patients are given a possibility to choose between invasive and non-invasive treatment options. Invasive treatments are diagnostic and treatment-related procedures that involve entry into the body (i.e. biopsy, surgery, and anesthesia). Non-invasive treatments include all other treatments and minor tests, i.e. self-administrated drugs, blood tests, as well as the option of “watchful waiting” (Elwyn et al., 2000). As invasive treatments are always associated with some degree of medical uncertainty and risk, the decisions to be made may be seen as more serious and difficult, especially for patients (Grimen, 2009). This may affect the dynamics of the interactions in that the question of who is responsible for making the decisions is unclear: On the one hand, patients seem to resist making decisions based on their lack of knowledge, while on the other hand physicians resist making the final decisions with reference to the fact that the patient’s preference or experience of illness should be the basis of the decision. This may be seen as a two-way struggle of avoiding sole responsibility, in that both physicians and patients confer the right to decide and thereby also the responsibility for the decision to their interlocutor.

These negotiations seem to operate at the intersection of two questions: First, who should make the decision, which falls within the deontic domain, and second, what knowledge should be the basis of the decision, which falls within the epistemic domain.

1.1. Epistemic and deontic rights

A person’s epistemic domain comprises his or her knowledge and personal experiences (Heritage, 2012; Stivers and Rossano, 2010). Within medicine, patients’ and physicians’ epistemic domains are complementary, or even constitute a knowledge gap (Grimen, 2009): Patients have primary epistemic rights to knowledge about their experience of symptoms, preferences and life-world circumstances, while physicians have primary epistemic rights to knowledge about diagnoses, treatments etc. A person’s rights to knowledge within a certain domain can be described as *epistemic status*, and in conversation, speakers rely on their relative statuses as interactional resources (Heritage, 2012).

Deontic rights on the other hand relate to someone’s right to determine future actions (Stevanovic, 2013). While in traditional medicine this has been seen as the physicians’ responsibility (i.e. the notion of “doctor’s order”), based on their medical expertise and experience (epistemic status), contemporary guidelines for patient-centered approaches recommend a more even distribution of these rights, acknowledging also patients’ deontic rights; For instance, the

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