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Shared decision-making as an existential journey: Aiming for restored autonomous capacity

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ABSTRACT

Objective: We describe the different ways in which illness represents an existential problem, and its implications for shared decision-making.
Methods: We explore core concepts of shared decision-making in medical encounters (uncertainty, vulnerability, dependency, autonomy, power, trust, responsibility) to interpret and explain existing results and propose a broader understanding of shared-decision making for future studies.
Results: Existential aspects of being are physical, social, psychological, and spiritual. Uncertainty and vulnerability caused by illness expose these aspects and may lead to dependency on the provider, which underscores that autonomy is not just an individual status, but also a varying capacity, relational of nature. In shared decision-making, power and trust are important factors that may increase as well as decrease the patient's dependency, particularly as information overload may increase uncertainty.
Conclusion: The fundamental uncertainty, state of vulnerability, and lack of power of the ill patient, imbue shared decision-making with a deeper existential significance and call for greater attention to the emotional and relational dimensions of care. Hence, we propose that the aim of shared decision-making should be restoration of the patient's autonomous capacity.
Practice implications: In doing shared decision-making, care is needed to encompass existential aspects; informing and exploring preferences is not enough.

1. Introduction

The reason seemed so obvious, and the idea so simple. By informing patients, inviting them to discuss treatment options, and partake in decisions, one would respect autonomy, achieve more tailored decisions that would lead to better outcomes and fewer complaints. Yet it was easier said than done. Despite three decades of advocacy for shared decision-making, in some countries supported by legislation, the approach is not part of mainstream practice [1–3]. There is a disjunction between what is being advocated and everyday practice. This disjunction is not limited to shared decision-making – it is also observed in a generalized lack of person-centeredness in clinical encounters. However, the absolute requirement of active patient engagement in shared decision-making makes the disjunction particularly visible.

Why this clinical inertia? As Stiggelbout et al. puts it: "Shared decision making is a complex intervention, and its implementation in healthcare will need multifaceted strategies coupled with culture change among professionals, their organisations, and patients." [2]. Any initiative that requires a culture change has a long way to go to succeed. Two (espoused) major characteristics of modern medicine are effectiveness and efficiency [4]. It is reasonable that much of the research in the field is about providing evidence for favorable effects of shared decision-making and ways to accomplish shared decision-making without spending too much time. Although effects (patient satisfaction, medication adherence) have been demonstrated in some studies, so far the evidence for better health outcomes remains limited [2].

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While we endorse endeavours to provide evidence that convinces the medical profession to change its practice, this approach also represents a problem. It tends to draw attention away from the particular needs and capacities of the individual patient and the individual physician, exactly what shared decision-making is meant to accomplish. Specifically, we believe the field is not capturing the full range of outcomes that shared decision-making aims to improve. One category of outcomes is existential in nature, which includes not just a spiritual dimension, but also a physical, a social, and a psychological dimension [5]. Important aspects pertaining to medicine here are people's bodily needs and capacities (physical), belonging (social), views about self (psychological), and meaning (spiritual).

It is the existential dimension of shared decision making that we want to examine in this paper. We will focus on fundamental problems of human existence that arise in the experience of illness and health care – uncertainty, vulnerability, autonomy, power, and trust. Our assumption at the outset is that any situation that brings a person to a physician requires both patient and physician to confront these fundamental problems. We will argue for a new way of thinking about shared decision-making: as an existential journey aimed at fostering patient autonomy with the curating help of physicians who are attentive to patients' informational, emotional, and relational needs.

2. Context

2.1. Becoming a patient: uncertainty, vulnerability, and implications for autonomy

The existential journey of becoming ill may typically start with a perception of uncertainty, and proceed with recognition of being vulnerable.

2.1.1. Uncertainty

Minor symptoms, insignificant in their impact or recognized as trivial, may not introduce uncertainty. At some point, however, problems or symptoms, because of their duration or effects on function, will demand cognitive attention, and will give rise to the question: 'What is this?' The previously healthy person experiences uncertainty – a cognitive state usefully summarized as a *subjective perception of ignorance* [6]. Uncertainty about the nature of the problem implies uncertainty about what will follow – is it illness?

Many of the uncertainties experienced by patients are primarily scientific in nature and pertain to the diagnosis, prognosis, cause, or treatment of disease [7,8]. Uncertainties pertaining to any one of these issues, can be further categorized as originating from three main sources: probability, ambiguity, and complexity. Probability, or "risk," refers to the fundamental indeterminacy or randomness of future events, and has also been termed "first-order" uncertainty. Ambiguity, a decision theory term introduced by Ellsberg [9], refers to the lack of reliability, credibility, or adequacy of information about probability and is also known as "second-order" uncertainty. Ambiguity arises when risk information is unavailable, inadequate, or imprecise. Complexity refers to inherent features of risk information that make it difficult to understand; examples include the presence of multiple attributes, causes, or consequences of a phenomenon.

People's ability to deal with uncertainty related to illness likely depends on their prior exposure to uncertainty originating from these various sources, and their experiences with managing and coping with it. Positive experiences may enhance self-efficacy, support autonomy, and prevent helplessness. On the other hand, negative experiences may reduce their capacity to manage uncertainty and their sense of self-determination. The medical domain of life is often unfamiliar and complex, which magnifies the uncertainty people experience – further compromising their autonomy [10] and ability to make decisions in threatening situations [11].

2.1.2. Vulnerability

Uncertainty (about one's illness) may create an awareness of *vulnerability* – meaning the ontological condition of our humanity: what applies to all of us and follows from our embodied, finite, and socially contingent existence [12]. This awareness may lead to various emotional reactions; feelings of self-estrangement, not being in full control over body and mind, as well as unaccustomed feelings like fright and dependency [13]. These feelings, in turn, can be dealt with in different ways, including neglect, denial or acceptance, at least for a while. However, when the sick person, whether prompted by others or not, decides to seek a physician, the deeper existential concerns become instantiated in a concrete, social way as a dependency, desired or otherwise, upon other people in general and on the power of medicine in particular.

2.1.3. Autonomy

Shared decision-making is founded on the principle of respect for autonomy: patients' moral right to self-determination [14]. The trajectory from being unconditionally healthy to dependency on others challenges how we think about autonomy. A widely accepted description states that, in order to act autonomously, one must act with intention, understanding, and absence of controlling influences [15]. But when are we free from controlling influences? The philosopher Catriona Mackenzie argues that this understanding of autonomy implies thinking of persons as liberal subjects, self-sufficient, and independent, while "relational theorists claim that these autonomy competencies emerge developmentally and are sustained and exercised in the context of significant social relationships and, hence, that such relationships are necessary background enabling conditions of autonomy." [16]. In other words, autonomy is relational and achieved through interactions with others, and it needs development and exercise. This implies a (varying) *autonomous capacity* to lead a self-determining but not fully independent life, in contrast to the liberal subject *status* of being recognized as an autonomous agent by others. In Fig. 1 we illustrate how autonomy as a capacity may change in a transition from being healthy to the point of seeking help (solid arrow).

Thinking of a patient as having the autonomy of 'a liberal subject' may lead to an underestimation of this patient's vulnerability and reduced ability to make decisions. Thinking of a patient as 'vulnerable', powerless and with loss of agency, may lead to paternalism and underestimation of the patient's willingness to be part of decision-making [16]. The physician cannot assume that the patient has uncompromised autonomy, but needs to explore each situation. Mackenzie argues that an adequate ethics of vulnerability must give central place to the obligation *not just to respect but also to foster autonomy* [16].

2.2. The power of medicine and the need to trust

If we accept that autonomy is relational, we need to pay attention to two other important aspects of human life, those of power and its asymmetry, and trust.

2.2.1. Power

It is medicine's power – the capacity to intervene positively – that brings the patient to the physician as a means of managing the patient's uncertainty and vulnerability. Medicine's power is personified in the physician. This may lead some patients to display deference or subservience, in line with the health care