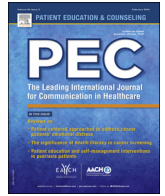




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Discussion

A patient in the clinic; a person in the world. Why shared decision making needs to center on the person rather than the medical encounter

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ABSTRACT

Interest in shared decision making (SDM) has increased and become widely promoted. However, from both practical and measurement perspectives, SDM's origin as an outgrowth of patient autonomy has resulted in narrowly conceptualizing and operationalizing decision making. The narrow focus on individual patient autonomy fails in four main ways: 1) excluding several facets of the roles, actions, and influences of decision partners in decision making; 2) focusing solely on the medical encounter; 3) ignoring the informational environment to which patients have access; and 4) treating each encounter as independent of all others. In addition to creating a research agenda that could answer important outstanding questions about how decisions are made and the consequences thereof, reconceiving SDM as centered on the person rather than the medical encounter has the potential to transform how illness is experienced by patients and families and how clinicians find meaning in their work.

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1. Introduction

Shared decision making (SDM) is promoted nationally and internationally as a part of patient and family-centered care, an ethical imperative, and as a way to tailor evidence-based guidelines to individual patient needs [1–3]. SDM requires that at least two people engage in discussion that includes information exchange and an explication of patient values and preferences in order to come to a decision that meets that patient's needs at that point in time [4–6]. However, conceptualization and research on SDM have been narrow, giving scant attention to factors – both inside and outside the medical visit – that may influence the patient experience of decision making. Through this paper, we will explain how the narrow view of SDM became prominent and argue for the necessity of explicitly envisioning and creating

opportunities to expand the narrow view to effect Person Centered Decision Making (PCDM).

While patient-centered medicine, particularly with respect to SDM, is not new [7–9], we emphasize that a change from patient-centered to person-centered, although seemingly just a matter of words, implies a much broader view on medical work. While 'patient' carries a notion of someone (temporarily or permanently) limited by illness or disease, increasing the risk that the provider primarily sees these limitations and acts accordingly, 'person' widens the scope: this someone has a life, a history, and relationships, from which s/he cannot be separated. We propose that the perspective the change of words introduces will have profound effects on our perception of self-determination and autonomy [10]. Patient-centered medicine includes the patient's "lifeworld" [11] as an important component to care, but consideration of how decisions are made, from the patient's point of view, is less clear. That is, the clinician is encouraged to see the patient as a full person, but SDM research has ignored what is analogous to what has been termed "the invisible work of being a patient" [12]: that is, the invisible work of contributing to and sharing in decision making.

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2. Shortcomings of recent work on SDM

2.1. A focus on individual, rather than relational, autonomy

SDM developed out of the bioethical principle of respect for autonomy, particularly as related to research participation [5]. Therefore, the emphasis has been on individual autonomy at the moment of perceived decision making or decision resolution rather than recognizing the lived context of the patient. This seems odd, as SDM promotes a tailored approach to decision making – but the emphasis on individual rights has resulted in researchers' focus on the individual patient's role in decisions rather than truly incorporating the biopsychosocial perspective. While Engel's biopsychosocial model posits that societal and cultural factors significantly influence the experience of illness [13], the parallel ascension of individual patient rights resulted in a view that simultaneously asked providers to recognize the patient's social situation yet insist on complete self-determination in decision making.

This bifurcated circumstance disregards ways in which the larger societal and social context actually affect decision making. The most glaring omission is that of family members' participation in decisions. Here, we refer to family as any person who consider themselves related biologically, legally, or emotionally [14]. There is a relatively small body of literature on how family members participate in decisions, recently summarized by Laidsaar-Powell and colleagues [15]. However, this work (our own included) still has little to say about how family members come to be engaged in decisions and the ways in which those relationships influence the patient's own decision making, both inside and outside of the medical visit. Importantly, their review does show that patients who are in more need, for example, more ill, are consistently more likely to have family members in the visit with them.

A more nuanced view of ethical participation can be seen in descriptions of relational autonomy, that is, the importance and influence of one's relationships on one's self-determination [16,17]. Whereas individual patients weigh benefits and risks, they do so with their familial and societal roles in mind [18]. Considering, or even prioritizing, the needs of the family can allow the patient to maintain his or her relational identity as well as autonomy. This should not be an afterthought; the thoughts, feelings, and actions of family members are not insignificant. In fact, roughly two-thirds of lay persons who have looked for health information online have done so as "surrogate seekers" [19]. Other researchers have pointed out that the field's focus on patient autonomy includes outright suspicion of family by clinicians [18]. While possible, family coercion has been described far less frequently than family involvement as a whole [20]. Ho suggests opening communication with families and patients rather than "paternalistically imposing the individualistic approach to decision making [18]."

2.2. A single medical encounter as the center of decision making

The second contribution to a narrow view of SDM has been a constricted focus on a single medical encounter. The literature on decision making routinely ignores the work patients and families do both prior to and following a medical visit and has little to say about decisions that evolve over time. That is, SDM literature has not truly focused on the entire process of decision making. A great deal of research on SDM is situated either in or immediately proximal to the medical visit. While it has been pointed out that the entirety of the clinical encounter needs to be considered [21], and many decision tools are intended for patient use outside the medical visit [22], few studies have examined the longitudinal nature of some decisions. Those studies that have deal with nature of chronic disease (e.g., pediatric chronic disease [23]) or decisions

that require ongoing adherence (e.g., endocrine therapy for breast cancer [24]). This is a promising route of future work in SDM, as people routinely revisit decisions.

Recent work has divided medical decision discussions into phases, such as "option," "preference" and "decision" talk [25] or as steps of "information sharing," "decision process," and "decision finalization." [26] These models fall short in their characterizations of decisions as discrete events. While it is repeatedly stated that there is no single point at which a shared decision is made, the "decisional moment" implies that a decision is immutable and final. This moment is understood as the culmination of a process of mutual understanding (or at least acceptance), which is the ending point for SDM. An additional problem is comingled with the "decisional moment": only what happens during the medical visit is described. Observational instruments that measure SDM (e.g., OPTION [27], DEEP-SDM [28]) all suffer from this problem, while concepts such as "decisional resolve" [24] are still new: currently no post-decision instruments of concepts such as decisional regret ask if changes to plans have been made between the time of the "decision" and later measured timepoints.

2.3. A patient in the clinic; a person in the world

The medical-encounter-centric view of SDM has additional shortcomings. Notably, this view omits the informational environment in which a patient makes decisions. Take mammographic screening for a woman in her 40s in the United States, for example. In the last several years, both the American Cancer Society and the United States Preventive Services Task Force have revised their breast cancer screening guidelines [29,30]. Several organizations, including the American College of Radiology and Society of Breast Imaging have vehemently argued against the newer guidelines [31]. The backlash from the public and some clinicians has been substantial. When different clinical groups or different individual clinicians can genuinely disagree on topics in their professional capacities, then how can models of SDM fail to integrate an individual patient's exposure to the wide range of information at her fingertips?

Although doctors are still the most highly trusted sources of health information [32], patients are subject to health information (sometimes sought and sometimes by happenstance) from myriad sources. A health services researcher and colleague [33] described a situation in which he consulted reputable websites, patient chat rooms, and YouTube videos when deciding to accept an implantable cardioverter defibrillator. Of particular importance is that patients and families will have information sources to consult after the physician encounter, without necessarily having the opportunity to continue the dialogue with the provider.

2.4. A medical visit is but one chapter in the narrative of illness

Finally, the medical visit conceptualization of SDM encourages researchers to examine individual visits independently, as opposed to being a part of the entire story of a person's illness or experience. The elderly man with diabetes and heart disease who routinely sees a cardiologist, endocrinologist, and primary care clinician juggles all of these relationships and their attendant data points, tradeoffs, and decisions. It has often been pointed out that narrative is essential to both the human [34] and patient [35] experience. A narrative, person-centered model of SDM considers decision making in situ, as it occurs.

From both practical and measurement perspectives, the narrow focus on the individual patient's autonomy therefore fails in four main ways: 1) excluding several facets of the roles, actions, and influences of family members in decision making; 2) focusing solely on the medical encounter; 3) ignoring the informational

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