Twelve myths about shared decision making

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ABSTRACT

Objective: As shared decision makes increasing headway in healthcare policy, it is under more scrutiny. We sought to identify and dispel the most prevalent myths about shared decision making.

Methods: In 20 years in the shared decision making field one of the author has repeatedly heard mention of the same barriers to scaling up shared decision making across the healthcare spectrum. We conducted a selective literature review relating to shared decision making to further investigate these commonly perceived barriers and to seek evidence supporting their existence or not.

Results: Beliefs about barriers to scaling up shared decision making represent a wide range of historical, cultural, financial and scientific concerns. We found little evidence to support twelve of the most common beliefs about barriers to scaling up shared decision making, and indeed found evidence to the contrary.

Conclusion: Our selective review of the literature suggests that twelve of the most commonly perceived barriers to scaling up shared decision making across the healthcare spectrum should be termed myths as they can be dispelled by evidence.

Practice implications: Our review confirms that the current debate about shared decision making must not deter policy makers and clinicians from pursuing its scaling up across the healthcare continuum.

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1. Introduction

Shared decision making, a process whereby health professionals and patients work together to make healthcare choices, is fundamental to informed consent and patient-centered care [1,2]. In recent years, the number of shared decision making publications in scientific journals has surged. In 2000, 95 publications were indexed with these key words, 203 publications in 2006, and 581 in 2013, or an increase of 611% over a ten-year period, with this journal (Patient Education and Counseling) having published the most [3]. Thus, it is no surprise that shared decision making has been making headway in healthcare policy. In 2011, Høtter and colleagues inventoried policy-related activities in 13 countries designed to foster shared decision making across the healthcare continuum [4]. In the United States, for example, policy driven initiatives such as the patient-centered medical home and the Affordable Care Act have reinforced the importance of implementing shared decision making across the health care continuum [5]. In the United Kingdom, health authorities have engaged clinical champions and patient representatives in national initiatives for shared decision making and embarked on a process of widely disseminating patient decision aids [6]. In Germany, patient information and shared decision making are embedded in social health insurance programs, since it is the insurers’ responsibility to maintain their healthy members in good health as well as treat their members’ illnesses [7]. In the Netherlands, the government has emphasized patient experience in its health care programs on a collective level [8].

Notwithstanding these developments, arguments against the scaling up of shared decision making across the healthcare continuum abound. Given its high profile, shared decision making has gained supporters as well as critics. In this paper, we discuss some of the most commonly encountered myths about shared decision making and review the evidence most relevant to these myths.

In preparation for a keynote presentation at the 2013 International Conference in Communication in Health, we selected some of the perceived barriers to scaling up shared decision making found in common arguments, popular beliefs, or anecdotes. We further investigated these perceived barriers by conducting a selective review of the literature that included

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several systematic reviews on shared decision making related topics in which the first author (FL) was either involved or with which she was familiar [9–17]. Together, these reviews covered over 400 original studies published between 1982 [9] and 2013 [17]. If we found insufficient supporting evidence for the arguments, popular beliefs and anecdotes, we labeled them myths. We thus labeled twelve of the commonly perceived barriers as myths.

2. Twelve myths

2.1. Myth #1: Shared decision making is a fad – it will pass

Shared decision making has been around for a long time. Involving patients was described as one of the dimensions of being a “modern doctor” as early as 1959 in a study by Menzel and colleagues [18]. These authors studied an equal relationship between doctors and patients as an independent variable in the context of the diffusion of innovation such as new drugs. Doctors who were found to exhibit a more positive attitude toward an equal and active role for the patient in his/her relationship with the doctor were more likely to adopt new clinical practices than those who were not. One interview included a particularly forceful expression of a stand in favor of the patient’s equality: “The doctor should not be mystical. He should consider the patient as an equal partner—as intelligent as himself—and give the patient a chance to help the doctor by trying to figure out problems together. The patient should have the freedom and the chance to say what he thinks about a certain therapeutic approach.” Interestingly, among several types of innovating behavior examined, acceptance of a more equal doctor–patient relationship was the only behavior associated with greater general satisfaction with modern developments in medical practice by the participating doctors. By 1982, a more equal doctor–patient relationship had moved to being a primary research target (i.e. dependent variable of interest). A US Presidential Commission on medical decision-making ethics recommended shared decision making as the “appropriate ideal for patient–professional relationships that a sound doctrine of informed consent should support” [19]. The Commission’s survey revealed that 56% of physicians and 64% of the public felt that increasing the involvement of patients would improve the quality of care, with physicians citing compliance and cooperativeness as the main reasons. Embedded in a shift toward patient involvement and advocacy, shared decision making is increasingly prevalent in health literature [20]. In light of the current trend in patient-centered care and the potential systemic advantages exposed by current shared decision making research, more and more countries are deciding to orient their policy decisions around the patient [4]. The history, relevance and general tendency of patient-centered care and shared decision making clearly demonstrate that shared decision making is not a passing fad, and will play an increasingly important role in the way we think about our health and our relationship with care.

2.2. Myth #2: In shared decision making, patients are left to make decisions alone

The myth that the patient is left alone to make the treatment decision is not supported by the extensive systematic reviews on models of shared decision making and contradicts its core elements [9,10]. Shared decision making is an interpersonal, interdependent process in which the health care provider and the patient relate to and influence each other as they collaborate in making decisions about the patient’s healthcare [21]. The idea of balance and respect between the two partners is fundamental to shared decision making and one of its main purposes is to take advantage of both parties’ expertise [22,23]. The degree to which the decision is shared (i.e. whose expertise is explored the most in the medical encounter) varies widely in terms of the condition, the treatment options and the sheer personality of the actors involved, with self-efficacy systematically being a high predictor of engagement in shared decision making [24]. A widely-recognized review of 161 conceptual definitions of shared decision making has identified that clinicians’ recommendations and knowledge were essential to shared decision making [9]. The clinician is involved in every step of the decision-making process, from identifying that a decision needs to be made, presenting the evidence and counseling the patient to implementing a strategy with which both parties feel comfortable. Furthermore, an increasing number of studies highlight the important role of the patient’s family members (or other companions) when making a health decision and these findings impact the way we measure and conceptualize shared decision making [25,26]. Shared decision making is not, in fact, abandoning patients to make decisions alone, but is rather striving to optimize their expertise in the most supportive environment possible.

2.3. Myth #3: Not everyone wants shared decision making

The preferred and assumed role of patients in the decision making process is often assessed in shared decision making studies and varies according to patients’ characteristics and the clinical situation. However, the evidence suggests a clear desire on the part of patients for more information about their health condition [27]. In a systematic review of optimal matches of client preferences about information, decision making, and interpersonal behavior, findings from 14 studies showed that a substantial number of clients (26–95%, with a median of 52%) were dissatisfied with the information given, and would have preferred a more active role in decisions concerning their health, especially when they understood the expectations attached to this role [27]. Moreover, a time trend is observed: the majority of respondents preferred sharing decision roles in 71% of studies dated 2000 and later, compared to only 50% of studies dated before 2000 [28]. This argument may stem from the fact that assuming an active role in the decision-making process remains particularly difficult for vulnerable patient populations [27]. Although such vulnerable patients systematically report less interest in shared decision making, they are the ones who may stand to benefit most from it. If we do not want to exacerbate inequities when implementing shared decision making—that is, only improve outcomes for those who can most easily share decisions, such as the more educated—the process should be at least recommended for all patients, with adaptations to suit individual ability and interest [29,30]. Indeed, a number of studies have shown that even among patients who prefer a more passive role, those who are actively involved in decision making derive the most clinical benefits [27,31,32]. In fact, patients’ reluctance to engage in the decision-making process may not reflect a true lack of desire to be involved, but rather a lack of self-efficacy [33]. Therefore, it may be possible to develop tailored interventions to foster shared decision making with vulnerable populations [34]. Ethical and moral principles require that we search for new ways to engage these reluctant patients in shared decision making rather than abandoning the attempt.

2.4. Myth #4: Not everyone is good at shared decision making

Shared decision making is not an inborn talent but consists of specific behaviors that can be taught. It is useful to describe the behaviors expected by both patients and clinicians, notably during a shared decision making encounter [35]. Using socio-cognitive theories, interventions that act on the determinants of shared
decision making behaviors, such as decision aids, can enable these specific behaviors. Decision aids are client-mediated interventions for changing clinicians’ practices [36]. A Cochrane systematic review of 115 studies on patient decision aids found that they reduce the proportion of people who remain passive or undecided in decision making and facilitate the adoption of shared decision making by providers. They have also been shown to reduce the overuse of options not clearly associated with benefits for all, while potentially enhancing the use of options clearly associated with benefits [17]. Also, according to two systematic reviews on interventions to improve the adoption of shared decision making by healthcare providers [13,37], interventions targeting both patients and clinicians are more likely to increase shared decision making as reported by both patients and clinicians than those that solely focus on clients or solely on healthcare providers [38,39].

2.5. Myth #5: Shared decision making is not possible because patients are always asking me what I would do

A recent study by Mendel and colleagues compared patients’ preferences for treatment before and after receiving their physician’s advice. They found that 48% of a sample of patients receiving treatment for schizophrenia and 26% of a sample of patients receiving treatment for multiple sclerosis followed the advice of their doctor and chose a treatment option that went against their initial preference [40]. In other words, the doctor proposing a course of action can lead patients to make decisions that do not match their fundamental values and preferences. Using socio-cognitive theories, we have conducted studies that explore how the doctor influences the patient’s desire to engage in shared decision making. We found that patients change their decision making for other psychosocial variables at the patient level, the variable most significantly associated with the patient’s intention to engage in shared decision making was the physician’s attitude toward it [33]. This suggests that patients respond to the doctor’s enthusiasm, or lack of it, for sharing decisions, and that a significant number of patients may go against their treatment preference if they follow the clinician’s advice without participating in the decision making process. As mentioned previously, the role of patients in decision making represents a set of specific behaviors that are modifiable like any other health-related behaviors [41]. Provided that the clinician has a positive attitude toward shared decision making, patients can learn these new skills and become increasingly confident in their ability to engage in this process with their healthcare provider.

2.6. Myth #6: Shared decision making takes too much time

Any change that is proposed for the busy clinical context is always assumed to add more time to the consultation [42]. Time constraints are among the most frequently reported barriers to clinical change, including to shared decision making [12,42]. However, no evidence has yet been produced to support the claim that shared decision making takes too much time. A 2014 Cochrane systematic review analyzed 115 decision aids, ten of which were embedded in interventions that measured consultation lengths. Two studies found that shared decision making interventions took longer than usual care; one found that it took less time than a traditional consultation, and six found no statistically significant difference in consultation lengths [17]. The Cochrane review showed that the effect of decision aids on length of consultation varied from ~8 min to ~23 min (median = 2.5 min). Therefore, decision aids have a variable effect on length of consultation, and there is a need to further reflect on which contexts are associated with longer duration, shorter duration and no impact.

2.7. Myth #7: We’re already doing shared decision making

One of the most surprising comments reported over and over again regarding shared decision making is that integrating the patient’s values and preferences into their health decisions, as well as considering the best medical evidence, is already occurring. Yet a systematic review of 33 studies assessing shared decision making in clinical practice using observer-based outcomes indicates that it has not yet been adopted in clinical practice (mean score on OPTION = 23 ± 14%) [16]. This failure to adopt shared decision making does not appear to be a systematic refusal on the part of clinicians. First, there may be a lack of understanding of all the facets of shared decision making. Second, there may be some confusion between shared decision making and the more broadly defined patient centered approach. Third, in the minds of some healthcare professionals, the mandatory informed consent process may be synonymous with shared decision making. In other words, clinicians may already partly engage their patients, but they do not engage them enough [43].

2.8. Myth #8: Shared decision making is easy! A tool will do

Notwithstanding the performance of patient decision aids, they usually do not differ significantly from usual care with regard to satisfaction with decision making, anxiety, and health outcomes, thus confirming that implementation of shared decision making may not equate solely with the delivery of decision aids to clients [44]. As defined by the International Patient Decision Aid Standards (IPDAS) Collaboration, patient decision aids are “tools designed to help people participate in decision making about health care options. They provide information about the options, and help patients to construct, clarify, and communicate the personal values they associate with the different features of the options. They provide structured guidance in the steps of decision making” [45,46]. In contrast, shared decision making is a process consisting of a series of specific behaviors on the part of the patient and of the health provider. A 2013 study by Lloyd and colleagues revealed that normalizing shared decision making in practice takes more than support devices, and will stem from a common understanding of shared decision making [44]. In other words, tools may facilitate shared decision making, but true clinical behavior change in terms of shared decision making entails adopting a more complex set of clinical behaviors.

2.9. Myth #9: Shared decision making is not compatible with clinical practice guidelines

Clinical practice guidelines (CPGs) are “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances” [47]. It may appear that the involvement of patients in their decisions could be problematic if their preferred course of treatment contradicts a CPG recommendation. Unfortunately, many doctors are instructed to implement CPGs without individualizing the information on benefits, harms and trade-offs of a treatment. CPG developers are increasingly expected to involve patients and integrate their preferences, but this rarely happens [48–50]. In light of this apparent incompatibility, we have assessed the simultaneous adoption of two behaviors (adopting CPG recommendations and engaging in shared decision making) using socio-cognitive theories. We found that physicians’ intentions to adopt one of the behaviors had no clinically significant effect on their intention to adopt the other, and concluded that using CPGs and engaging in shared decision making are not inherently mutually exclusive clinical behaviors [51]. This evidence dispels the myth that a physician has to choose between engaging the patient in
shared decision making and following CPG recommendations. Time trends are likely to show that both behaviors are equally important in the decision making process and can be successfully combined.

2.10. Myth #10: Shared decision making is only about the doctors and their patients

Until recently most shared decision making models were limited to the physician–patient dyad, yet care is increasingly planned and delivered through interprofessional healthcare teams [52–56]. In a systematic review addressing barriers to implementing SDM in clinical practice, the majority of participants (n = 3231) across 38 studies were physicians (89%), thus indicating little perspective beyond the physician–client dyad [12]. However, as a 2005 report by Marshall and colleagues stated, “in a world of multi-disciplinary care and substitution of medical inputs wherever appropriate, it would be timely for studies to test methods of enhancing patient involvement in decisions shared with other health-care providers” [57]. In light of changing morbidity, decision processes are inevitably going to be modified, and therefore shared decision making needs to adapt to this reality. Studies on team-based approaches to shared decision making are rapidly changing the way we view care, its delivery, and thereby the decision making process. A German train-the-trainer program has already been implemented in practice and has shown to be acceptable and advisable for bridging interprofessionalism and shared decision making [58]. In addition, we have updated our international scan of SDM training programs for health providers [15], and as of 3 January 2014, four out of 99 shared decision making training programs target more than one type of health professional (http://bit.ly/TatkAz). A shared decision making intervention designed for interprofessional healthcare teams could improve quality of care, reduce practice variations, and improve the fit between what clients want and what they receive across a larger spectrum of care contexts. This in turn has the potential to reduce professional silos, improve the integration of healthcare services and enhance continuity of care [59,60]. Therefore, it is inadequate to qualify shared decision making as restricted to one patient and their doctor. Although more research in this field is needed, the existing evidence acknowledges the importance of multiple actors.

2.11. Myth #11: Shared decision making will cost money

The issue of cost is of great importance to policy makers. Some critics argue that shared decision making is being driven by a consumer-oriented decision-making model, giving policy makers cause to worry that more shared decision making across the healthcare continuum will increase the demand for unnecessary, costly, or harmful procedures and will undermine the equitable allocation of healthcare resources. However, a recent systematic review found no studies reporting increased spending associated with the use of patient decision support interventions [61]. Synthesis of the evidence is difficult due to the diversity of the study designs and methods, and the same review noted that the few available studies reporting savings to the healthcare system showed only moderate economic assessment quality and high risk of bias. Moreover, a critical appraisal of the literature on this topic must take into account the concepts of overuse, underuse and misuse of treatment options and diagnostic procedures [62]. For example, as the Cochrane review on decision aids shows, in the context of overuse, patients being more active in the decision making process may be associated with the reduction of costly interventions when less costly ones are available with similar outcomes [17]. Lastly, given the length and the intensity of some shared decision-making training programs [15], will it be sustainable to implement shared decision making across the whole healthcare continuum? What will be the cost to do so? In short, there is an urgent need to increase the robustness of the evidence base regarding the cost of shared decision making given the strained budgets for healthcare in many healthcare systems.

2.12. Myth #12: Shared decision making does not account for emotions

Shared decision making involves emotions, which are complex psychosocial reactions that include cognitive appraisals, action impulses and somatic reactions [63]. Emotions are sources of expressive behavior, conscious experience and physiological activation [64], all of which are involved in the decision making process. Contrary to popular belief, emotions do not necessarily act in opposition to cognitive reasoning [65]. Instead, an ongoing negotiation takes between the two as they react to environmental stimuli [66]. Although it appears that the majority of the literature on shared decision making has not yet clearly integrated the contribution of emotions to the process, a few models have been explicit about it. For example, the authors of one such model posit that decision making processes that are more unilateral are loaded with more negative emotions than those that are more bilateral [67]. More recently, an international, interdisciplinary group of 25 individuals met to deliberate on core competencies for shared decision making and agreed that there were two broad types of competencies that clinicians needed: relational (emotional) competencies and risk communication competencies [68]. Entwistle and colleagues suggest that many health care practices affect patients’ emotional autonomy by virtue of their effects “not only on patients’ treatment preferences and choices, but also on their self-identities, self-evaluations and capabilities for autonomy” [69]. Therefore, it is expected that future years will bring increased interest in the intersection of emotion and shared decision making as they act together to forge effective patient–healthcare provider relationships.

3. Conclusions

In spite of the many myths surrounding shared decision making, it is a feasible, suitable and adequate means to approach the clinical encounter in the 21st century. It will not solve all the problems of the world, or even those in the healthcare system, but it may help address some. Shared decision making is one of the many components needed to optimize the use of scarce resources in healthcare. More and more health systems will pursue integrating patient-centered approaches in their priorities for the future, and shared decision making will likely be a crucial part of this paradigm shift [4]. However, incorporating shared decision making into clinical practice will remain a challenge and even more so if some of the myths are not recognized as such and if robust evidence is not produced to either confirm or refute those that persist.

3.1 Practice implications

Shared decision making will require careful consideration from both clinicians and patients, with incentives and education on either side of the clinician’s desk [21]. However, it is definitely here to stay, and policy makers do well to pay attention to it.
Conflict of interest

None.

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