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Developing taxonomy and mapping concepts of shared decision making to improve clinicians understanding

Abstract

Background: Shared decision making (SDM) is a complex process, which is poorly understood by many clinicians. Health care policy worldwide advocates for SDM in all health care settings. A taxonomy and mapping of SDM was developed.

Aim: The aim of the taxonomy and mapping is to help clinicians better understand the concepts related to SDM in health care.

Methods: An internet search was conducted, which was not limited to the scientific literature in order to include the broadest conceptual definitions possible. Searching continued until there was saturation. Identified concepts were discussed with scholars and authors from government agencies.

Findings: A taxonomy of the concepts was developed, which were further mapped to illustrate SDM in practice.

Conclusion: Illustration and discussion of the concepts of SDM in an Australian context should increase understanding by clinicians.

Keywords: shared decision making, concepts, taxonomy, mapping

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Summary of relevance

Problem: Shared decision making (SDM) is poorly understood by most clinicians in Australia and has rarely been observed in practice.

What is already known: The process of SDM has been previously described but the conceptual basis which underlies practice has not.

What this paper adds: Describing the various components of SDM may increase clinicians knowledge of SDM in practice, in particular, concepts which may mitigate against implementation.

Introduction

Shared decision making (SDM) is the process of clinicians and patients participating jointly in making a health care decision, having discussed evidence based treatment options (including no treatment), the possible benefits and harms of each option, taking into consideration the patients individual preferences and values.[1] Various approaches have been described in the literature to help clinicians implement the process in practice[2,3] as well as tools developed to assist both clinicians and patients.[4] Some authors believe SDM implementation in practice has been very slow,[1] despite policy which advocates for it in all healthcare settings.[5] Many misconceptions and misunderstandings about what constitutes shared decision making persist regardless of attempts by authors to clarify or dispute them.[1]

Shared decision making is based on important moral, ethical and legal imperatives aimed at developing a genuinely patient-focused health system[6] in which individual self-determination and autonomy are desirable goals.[7] Research on shared decision making demonstrates many patient benefits, such as improved safety,[8] improved outcomes[9] and better informed patients who make less costly choices about treatment.[5] Despite this compelling evidence, some clinicians believe it is too time consuming to implement in practice.[10] This is a valid concern, given the time poor environments of many health care settings,[11] but research evidence indicates that this concern is unwarranted.[12] Other critics of shared decision making suggest that patients don't want to be involved in decision making or lack the ability to do so.[13] Again, these are valid concerns, and caution needs to be exercised in determining a patient's willingness and readiness to be involved in decision making.[14] Health literacy is cited as a major barrier in a patient's ability to be involved in shared decision making, as low health literacy can limit both understanding of health information and treatment outcomes.[15] Current estimates indicate that only 41% of the Australian population have the required level of health literacy to share in complex decisions about health treatment.[16] Intervention, such as patient decision aids have shown promise in ameliorating health literacy barriers.[17]

Initially shared decision making focused on the medical practitioner/patient dyad,[18] but more recent commentary proposes that it is relevant to all clinicians, in all disciplines.[18] The inclusion of shared decision making in health care policy also indicates the intention that shared decision making should be implemented in all health care settings. Nurses are critical members of the health care team[19] and practice in all settings. As such, nurses are viewed as the key to widespread implementation,[19] and it seems inevitable that the task of embedding shared decision making will be expected of nurses. Limited training on shared decision making is available in Australia, either for nurses or any other clinicians.[1] If nurses are to be in the frontline of health care change, it essential they have a thorough understanding of shared decision making, and the basic concepts and principles related to the process.

The concepts of shared decision making are complex and multi-dimensional.[20] Given this complexity, a taxonomy and mapping of the concepts related to SDM was developed. The purpose of the taxonomy and mapping is to adequately illustrate and describe the concepts of shared decision making and thereby enhance understanding. Taxonomy deals with complexity of information by building structure of data.[21]

Methodology of taxonomy development

An internet search of the term shared decision making was undertaken July-October 2015 and yielded scholarly articles and government policies from many countries and disciplines. The aim of this search was not to analyse the various sources in terms of reliability and validity, bias or methodological processes, but to glean an overview of the concepts related to shared decision making. Key concepts from the initial search were discussed with scholars in the field of shared decision making, authors of government documents and articles as well as clinicians in health care. Many of the concepts overlapped and many new concepts were raised through discussion with others. A secondary search of all references was also undertaken. Searching and discussion continued until there was saturation of the concepts-meaning no new ideas or vital information emerged from any sources. Utilising authors and clinicians provided an additional way to assess saturation, by them describing their ideas and experiences.

Leech et al.[22] provide a rationale for using multiple sources which does not limit the review to scientific literature. The rationale includes increased rigour through expansion of themes and ideas and triangulation of findings. Utilising multiple sources allows the researcher to better understand the phenomena being studied. Greene et al.[23] assert that practitioners and scholars, as well as popular media provide legitimate representation and understanding, especially where there is convergence and corroboration of concepts. The aim of the taxonomy development was not scientific inquiry or systematic review, but a broad approach to increase understanding, and facilitate mapping of the inter-related concepts. Ethical approval was not applicable as human research was not conducted.

Findings

The taxonomy of concepts of SDM in health care and the sources from which they are derived is shown in Table 1. The first objective of the taxonomy was to map the concepts that constitute the SDM process. Both person-centred care (PCC) and informed consent are the essential elements of SDM and the relationship in shared decision making is shown in Figure 1. This approach is helpful in identifying and illustrating the basic elements of the SDM process. The basic conceptualisation of the SDM process ignores the other concepts found in the taxonomy, which influence a clinicians' ability to practice SDM. This was further mapped to illustrate how all concepts balance to allow smooth transitioning in SDM in practice, and the importance of each concept in achieving balance. This is shown as a SDM concept wheel in Figure 2. The major concepts in SDM practice, and how the sub categories of each of these influence SDM practice in reality are further discussed, to help clinicians understand their impact.

Table 1 Taxonomy of the concepts related to Shared Decision Making in health care.

Major concept	Sub category	Sources
Consent	Informed consent, implied consent, tacit consent, paternalism, therapeutic privilege.	Websites, scientific studies, policy documents, communication with authors of studies and policy, observation in context, professional experience.
Person-centred care	Autonomy, beneficence, choice, values and preferences, advanced care planning, self management support.	Websites, scientific studies, policy documents, professional experience.
Evidence based practice	Variations in care.	Scientific studies and abstracts, communication with authors, discussion papers, professional experience.
Health literacy	Decision aids, patient characteristics of age, education, health conditions and ethnicity.	Websites, scientific studies, policy documents, communication with authors of studies and policy, observation in context.
Law, regulation and policy	Guardianship and advocacy, privacy.	Websites, discussion papers, scientific studies, observation in context, professional experience.
Training and Education		Scientific papers, discussion papers, policy documents, communication with authors of Policy.

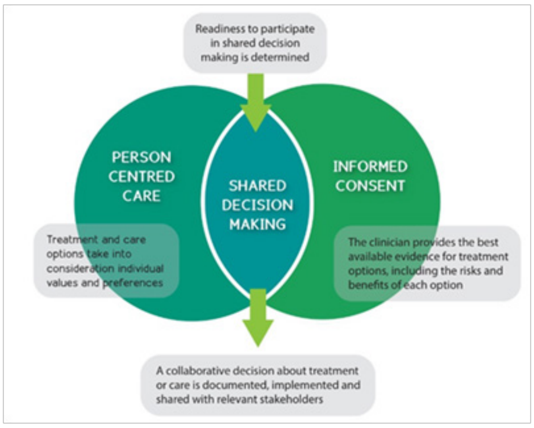

Figure 1 Concept map of the process of SDM.

Figure 2 The wheel of SDM practice.

Discussion of concepts and sub categories

Consent

Consent is a key concept in the provision of health care which has legal, ethical and practical dimensions. In practical terms, informed consent is the process by which a health care clinician informs a patient of their treatment options including risks and benefits.[24] Shared decision making extends the concept of informed consent beyond the simple transfer of information,[6] though informed consent alone does not result in shared decision making, just that the patient has arrived at a decision based on information provided by the clinician.[25] Shared decision making has been described as a broader concept of consent.[6] Frequently informed consent is limited to a juridical exercise in naming all the risks as quickly as possible-a ritual in which a patient signs a piece of paper, authorising or limiting treatment. Little attention is paid to the patient's human identity, their values, what makes life worth living and what devastation may make it reasonable to let life end.[26]

Consent in health care settings refers predominantly to either implied or expressed consent. Expressed consent is understood to be written or oral consent, usually witnessed, and obtained when treatment carries an appreciable risk or there is a legal requirement to do so.[27] Expressed consent can be given by patients without any exchange of information that is meaningful to the patient, unlike informed consent, which includes the receipt of information about the nature and purpose of the intervention and expected outcomes.[28] Some critics propose that expressed consent is a legal undertaking aimed at reducing a clinicians liability rather than aiming at autonomous authorisation of an intervention.[29]

Much of a clinicians work is undertaken with implied consent, either by words or behaviour of patients that imply permission for treatment, examination or investigation.[27] An example of implied consent is voluntarily attending a medical appointment, being examined for the chief complaint and accepting and filling a prescription.[29] A real gap lies in determining where implied consent ends and paternalism begins. Paternalism is described as a clinician assuming a dominant role, based on their expertise.[25] A paternalistic model of care neglects to incorporate patient preferences, the clinician is viewed as the authority whose directives the patient should or must comply with.[25] There are legal limitations to consent which protect clinicians and where paternalism is justified. The law recognises therapeutic privilege in instances where delaying treatment presents real risk to patients. In emergency medicine, consent is legally presumed and there is no onus on the treating clinician to obtain informed consent.[30] Some authors propose that therapeutic privilege is rarely justified and should be an extremely rare exception in most health care settings.[31]

Tacit consent is closely aligned to implied consent, and was first described in the political literature in the 1600's.[32] Tacit consent could be argued to be the premise of care and treatment for those admitted to a health care facility. Tacit consent is concerned with citizenship that residing in a country implies that one agrees with the authority of that country. This principle ignores the ability of a person to change their situation, and Hume[33] provides the following analogy. A person who is carried onto a ship involuntarily now finds himself subject to the commands of the captain. His only alternative is to throw himself into the stormy sea. A person remaining on the ship cannot be interpreted to be consenting to the authority of the captain; he is merely attempting to avoid the terrible cost of getting off the ship.

Many people admitted to residential aged care settings, face a similar dilemma to that described by Hume. Although they may not agree with some of the care or treatment delivered in the facility, it is better than the alternative, namely expulsion from the facility. Continued residence, or failure to object, is interpreted as tacit consent to care and treatment. There is a great deal of evidence that people in residential aged care comply with care and treatment simply to avoid any repercussions of objecting.[34,35]

Patient centred care

Patient-centred care (PCC) has been defined as an approach to care that consciously adopts the patient's perspective.[36] PCC is based on the premise that autonomy and self determination are desirable goals for patients. Self determination theory is the intrinsic tendency to protect and preserve our own wellbeing, while autonomy describes individual freedom and self governing qualities.[13] A health care culture of PCC has been shown to be essential to the uptake of SDM.[11] Shared decision making has been described as the pinnacle of PCC[7] and is viewed as a strategy that incorporates patient centred principles into standards of care.[37] Because PCC is so essential to shared decision making, it may be confused as being one and the same. SDM and PCC share the characteristic of respecting patient values, needs and preferences, the difference however, is that it is possible to have patient centred care without evidence based practice, but not shared decision making without evidence based practice. Respecting and complying with a patient's wishes, as would be expected in PCC, neglects to consider if their decision has been informed by evidence of risks and benefits.

Like PCC, self management support is often confused with shared decision making. Self management support (SMS) also known as health coaching and motivational interviewing, is the cornerstone of the National Chronic Disease Strategy.[38] While much of the SMS process mimics that of SDM, such as eliciting patient preferences and values and optimising patient empowerment[39] frequently evidence based information is neglected in the SMS encounter. SMS and SDM also share the notion that patients are active partners in care and balances good clinical practice with the principles of beneficence and justice.[40] Beneficence is defined as promoting what is best for patients and justice as equal access to the same care.[41] It should be acknowledged that paternalism may also be rooted in the principle of beneficence. Elwyn et al.[13] acknowledge that justice and autonomy can be compromised in SDM when a patient's health literacy is poor, or when poor cognition or language differences are present. Concerns about health literacy are a common concept in SDM literature.

Advanced care planning (ACP) is intended to ensure that the patient's wishes remain the focus of decisions made about their care, when they lack the capacity to do so. ACP is defined as a process of reflection, discussion and communication that enables a person to plan for their future medical treatment for a time when they are not competent to make or communicate decisions for themselves.[42] Frequently ACP includes end-of-life treatment. One study found that clinicians spent a median time of one minute discussing end-of-life options with patients.[43] This suggests that there is no real regard for true partnership or the ideal of SDM. Limitations to treatment and ACP are promoted as being a support to patient autonomy, yet studies have found that patients and families that document their preferences show no improvement in control over their treatment or correspond with future care preferences.[44] Australian studies also show that physicians have a poor understanding of the law in relation to end of life care,[45] which presents a legal risk to their practice. Like SMS, some ACP models or practice may also neglect to introduce evidenced based information to help patients or their families reach decisions. Lack of evidence based information in ACP has been shown to result in decisional regret for families or proxy decision makers,[46] or an unwillingness to be involved in SDM.[47,48]

Health literacy

Health literacy is broadly defined as the skills to access, understand, appraise and apply health information in order to make judgements about health care.[49] Health literacy is a relatively new concept that originated from the field of public health in relation to health education, health promotion and primary prevention.[50] Low health literacy can limit a patients understanding of health information and treatment outcomes and is a barrier to participation in shared decision making.[51] Current estimates indicate that only 41% of the population in Australia have the required level of literacy to share in decisions about complex health treatment.[16] Despite this, there is evidence that clinicians over estimate patient levels of health literacy.[52] The reasons for low health literacy are multi-factorial, but many relate to patient characteristics such as low socioeconomic status, differing cultural backgrounds or health conditions such as dementia.[53] Patients with low education, income or cultural backgrounds other than English may feel too intimidated to openly express their preferences or negotiate with a clinician.[54]

There is little guidance for clinicians on how to accomplish shared decision making for populations with low health literacy,[13] though for this reason, much of the research has focused on patient decision aids. Treatment decision aids are an educational intervention which provide a structured way give patients detailed information about treatment and choices.[25] Clinical trials show that patients find decision aids useful in 'digesting information'.[55] However, earlier studies found that decision aids had trivial effect on patient empowerment.[56] While there has been over 500 decision aids developed,[4] evidence suggests routine use is low[57] and few address the needs of lower health literacy.[58] The quality of decision aids vary, rapidly outdate as new treatments become available and may not be readily accessible or available.[55] While decision aids may offer hope of simplifying SDM, more research is required to determine the benefits of decision aids in shared decision making.

Age, although it may not be related to health literacy, is also recognised as being a barrier to shared decision making, with older age being more predictive of being accepting (and indeed expecting) of clinicians making decisions on their behalf.[59] Patients who have not been exposed to a SDM model shun making decisions when given the opportunity.[14]

Evidence based practice

Shared decision making has been described as the nexus of communication and evidence based practice (EBP).[13] and the relationship between SDM and EBP has become increasingly recognised.[1] The process of SDM with patients includes clinicians providing evidence of various treatment options, which means SDM is dependent on clinicians having up-to-date, high quality evidence.[13] There is argument that clinicians, with patient consent, should only put into practice what has been learned from research.[60] The use of EBP in SDM may be problematic for a number of reasons. Clinicians may encounter situations where no evidence yet exists, or is subject to rapid change. In addition, EBP may require new skills of the clinician, including literature searching and evaluation of the literature.[61] Thorough searching for research evidence may be time consuming, and iterative as new evidence emerges. Evidence based guidelines and decision aids do exist for a number of conditions, but not all, and many patients present with multi co-morbidities, which complicate treatment decisions. There is also tension, and ethical dilemma's for clinicians when patients choose a path that is clearly not in their best interests based on the available evidence.[62]

One of the benefits of utilising EBP is to eliminate unwarranted variations in care. While variations in care may be a result of patient preference,[63] paradoxically, SDM appears to reduce variations in care.[4,64] Variations in health care that cannot be explained by patient need or preference, raises questions about quality, efficiency and equity, as well as appropriateness of care (Australian Government 2015). Variations in practice that are not a result of patient preference may indicate wasteful practices that do not serve the best interests of the patient.[65] Variations in care may mean that some patients are missing out on effective care or having tests and treatments that are unnecessary or those risks outweighs the benefits.[66] The complexity lies in determining the key reasons behind variations in care.

Training and education

There are several key challenges to widespread SDM, the first of which is training for clinicians.[67] Currently there are few training opportunities for clinicians available in Australia.[67] Like SMS, it involves a huge shift in clinician behaviour, from paternalistic models of care to patients as partners in care.[68] Towle[14] proposes that clinicians need explicit frameworks and competencies to embed SDM in practice because it goes beyond communication skills typically taught in undergraduate studies. However, there is evidence that even clinicians trained in SDM still fail to implement it, citing time constraints as a barrier[10] Other authors describe the process required for SDM,[3] but also acknowledge the poor uptake by clinicians. This suggests that even if widespread training in SDM for clinicians were available, there must be organisational scope to implement it into practice.

Other authors suggest that education for patients should be a priority, proposing that a bottom-up approach is more likely to be effective, where patients come to the clinical encounter expecting that they will be involved in the decision making process.[38] Education for patients should include understanding that there is opportunity to take part.[69]

Law, Policy and regulation

SDM is ubiquitous in both Australian and international health care policy.[70] These conflicts with some government directives and laws, such as childhood immunisation and euthanasia, which presents obvious difficulties for clinicians in practicing SDM and for which there are no clear resolutions.

Most research to date has focused on the traditional patient/clinician dyad[18] There are additional challenges to utilising SDM for patients with cognitive deficits,[71] where decision making must include surrogate decision makers such as guardians. Guardianship is a longstanding legal doctrine, where it falls to the government to protect those who can't protect themselves. Proxy decision makers can be appointed by law to make decisions on behalf of others incapable of making their own decisions.[66] A person may legally document their desired decision maker prior to losing capacity. Studies have found

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that when appointing a guardian or proxy decision maker, there should be structured conversations about values and preferences to ensure the guardian in properly informed.[72] This same study recommended that these interactions should be safeguarded with oral, written and video recorded information to be used for future decision making. Caution should be taken in the decisions made by guardians if their relationship is that of caregiver, especially if there are economic burdens associated with care.[73]

There is no clear regulatory guidance, that in the absence of a legally appointed representative, that caregivers or family members are permitted or ethically suitable to make decisions on the patient's behalf.[51] Strictly speaking only the court or someone appointed by the court may consent to care and treatment when the patient lacks the capacity to do so,[27] though clinicians often treat, or withhold treatment with the approval of family members. Studies have found that the views of surrogates and patients are often discordant.[74] The appointment of proxy decision makers also raises issues with privacy.

The Guardianship Act specifies that the person with authority to make decisions on the behalf of someone without capacity is only justified to access information that has a direct bearing on the decision to be made to protect their right to privacy. Control of who knows or see's things about one's self is an important concept in autonomy.[75] Where there is no capacity for an individual to make decisions, this complicates the principle of respect for autonomy. The physician's primary responsibility is to the patient.[76] Hardwig[77] posits that, while proxy decision makers must guard against undue emphasis on their own interests, undue emphasis on patients' interests should also be avoided, which requires the 'whole story' of a patients' health.[78] Argue that issues of privacy in shared decision making are rarely a concern in non western countries, as patient-doctor triads are the norm for all consultations.

There is evidence that patients and clinicians underestimate the risk associated with various interventions.[1] Shared decision making, especially in its fullest sense of utilising research evidence, substantially mitigates risks as well reducing inappropriate tests and treatments.[79] There are numerous studies which indicate that clinicians have poor statistical literacy which either prevents them from communicating risks and benefits of treatment and screening options or communicating misinformation to patients.[80,81] Shared decision making allows patients to weigh up benefits and harms of various options[67] and there is evidence that patients tend to make more conservative choices.[1] Whitney et al.[29] propose a matrix of consent, citing that informed consent and shared decision making is essential where treatments propose risk, where there is more than one choice of treatment and the outcomes of treatment are uncertain. Whitney et al.[29] also propose that the higher the risk to patients, the greater the time that should be spent in shared decision making, exploring patient values, preferences and needs and those of the family. Some authors propose that shared decision making is often viewed as a risk management tool, used by clinicians to limit their liability.[82] Although not its intention, shared decision making can reduce the risk of malpractice allegations, if the research evidence is correctly communicated to patients.[83]

While some clinicians argue that discussing risks as part of shared decision making might create undue anxiety, studies have demonstrated that fully informed patients were not more anxious.[84] Some authors propose that shared decision making should be evaluated by patient outcomes, and subsequent reduced risks to patients.[85]

Conclusion

Taxonomy as a tool is applied for information conceptualization and organization, and the development incorporates all concepts and their relationships.[21] The taxonomy of shared decision making shows that it is complex, and may explain why there is confusion about what constitutes the process of shared decision making. Many of the concepts, such as evidence based practice and person centred care are widely embedded in everyday practice, however it is the amalgamation of all the concepts that constitutes SDM.

Many clinicians argue that they already practice shared decision making, though evidence suggests it has rarely been observed in practice.[86–89] These discordant views may indicate that clinicians have a poor understanding of what constitutes SDM or may indicate that the process of SDM is too prescriptive or too complicated to use in practice. Developing taxonomy and mapping concepts of SDM may assist clinicians to better understand the complexity of SDM.

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Conflict of interest

The author declares no conflict of interest.

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