

Shared decision making: patients have a right to be informed about possible treatment options and their risks and benefits

Rosca Ana, Krones Tanja, Biller-Andorno Nikola

Institute of Biomedical Ethics and History of Medicine, University of Zurich, University Hospital Zurich, Switzerland

Historically, physicians liked to refer to the so-called therapeutic privilege when withholding information they considered too distressing for their patients. A broad interpretation of this principle allowed physicians to inform or not inform patients at their discretion. These days are long gone. The therapeutic privilege is explicitly rejected by organisations such as the American Medical Association [1]. The code of the Swiss Medical Association emphasises the duty to inform patients, although it still leaves some room for interpretation as to how much information physicians think their patients can bear and how their patients should best be informed [2].

More recently, the concept of shared decision making (SDM) as a guide to patient-centred information and care has become prevalent in Switzerland [3–5]. The concept was at the centre of the recent “Excellence in Patient Care” symposium hosted by the Collegium Helveticum and organised by the University of Zurich, the University Hospital Zurich and the University Hospital Basel [6].

SDM can be defined as an interpersonal, interdependent process in which physicians, patients and their caregivers relate to and influence each other as they collaborate to make decisions about a patient’s healthcare [7]. The process becomes relevant whenever the risks and benefits of more than one treatment option need to be compared.

The SDM model proposed by Jurgen Kasper and his team (fig. 1) describes the generic core of the SDM process. Since its early days in the 1990s [9], SDM has reached beyond the dyad of patient and healthcare professionals to include specialised nurses, specialist physicians and other healthcare professionals. It has been suggested that SDM best practice should involve “team talk”, “option talk” and “decision talk”, with the aim of improving the process of deliberation and collaboration between all the parties involved [10]. At the “team talk” level, all the involved healthcare professionals deliberate the medical options for treating the patient. The “option talk” takes place with the patient and includes one or more talks with the GP, nurses and/or clinical specialists, while the final “decision talk” takes place between the patient and the healthcare professional who will deliver the treatment. This complex model is a valuable aspirational goal that can overcome numer-

ous challenges, both procedural and conceptual, in real-life clinical settings.

From a provider perspective, it could be argued that in many instances there is no need to negotiate with the patient, as there are guidelines that tell physicians what should be done. This might be true in “black” situations, when there is high-quality evidence that an intervention is likely to do no good or even more harm than good. In these cases the intervention would not be appropriate. Negotiations might also seem unnecessary in “white” situations, when an intervention is likely to do more good than harm, although in these cases the patient must still consent to the treatment and may well reject it no matter what the guidelines say. However, it has been argued that the large majority of clinical evidence is “grey” [11]: the evidence is either lacking, supports more than one option (equipoise) or of low quality. In such scenarios, decisions should be preference-sensitive, i.e. they should depend on personal judgments concerning how the benefits and risks should be weighed.

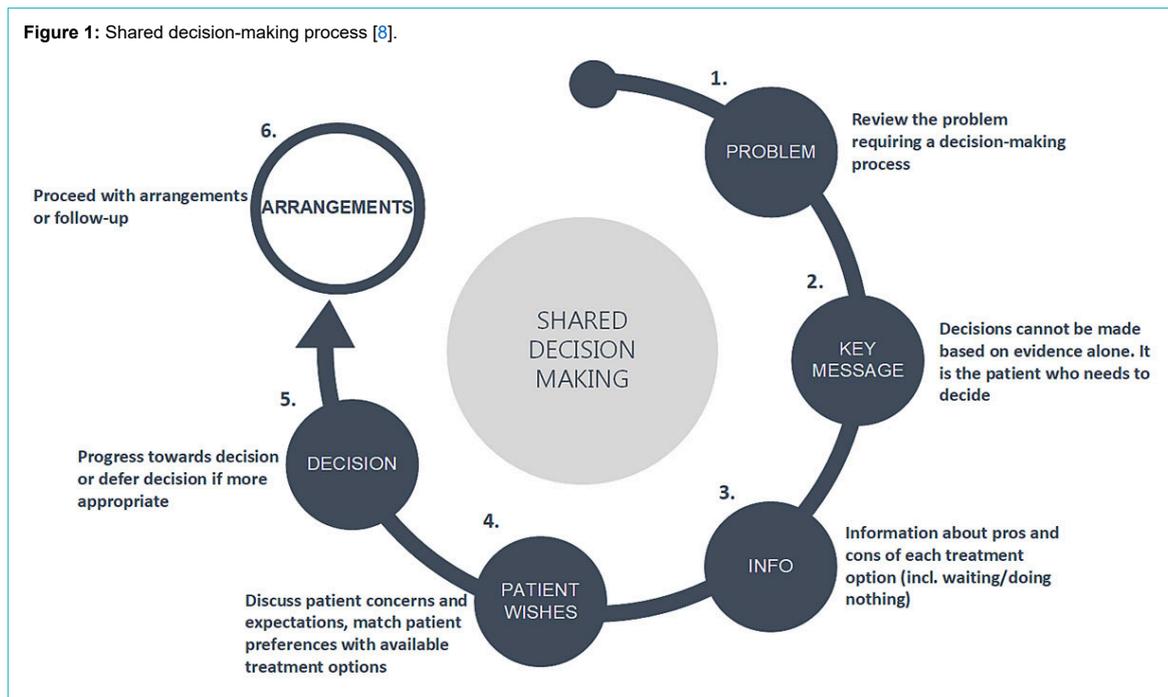
Furthermore, some patients may not want their physicians to interfere with what could be seen as a private choice. And indeed, just as physicians can decline non-emergency treatments they do not feel comfortable offering, competent patients have the right to be left alone when making healthcare decisions. In most cases, however, patients will seek personalised information, and often personal counselling and advice as well, from their physicians.

When discussing options, benefits and harms, uncertainties, and preferences, physicians should engage with their patients as partners. In an SDM process, patients communicate their individual and often unpredictable preferences; they share their knowledge about their health and body while considering medical information and the provider’s preferences. The physicians try to align patient preferences with the available evidence and, if relevant, their own stance. If their patient’s choice is not compatible with what they consider responsible care, they do not need to offer it.

This process is particularly important and challenging in the case of multimorbid patients, in which one decision can have an impact on more than one treatment process. One important reason why SDM is not yet easily applic-

Correspondence:

Prof. Nikola Biller-Andorno, MD, PhD, Institute of Biomedical Ethics and History of Medicine, Centre for Medical Humanities, University of Zurich, Winterthurerstrasse 30, CH-8006 Zurich, [biller-andorno\[at\]ibme.uzh.ch](mailto:biller-andorno[at]ibme.uzh.ch)

Figure 1: Shared decision-making process [8].

able to multimorbid patients is the low inclusion rate of this patient group in clinical trials [12, 13]. Because of the limited evidence for multimorbid patients, SDM often cannot do justice to the complexity of treating this group. Another challenge is that addressing multiple issues at the same time can be overwhelming for both the patient and the physician. One approach to this problem is to address just one aspect of care at a time. There are, for instance, decision aids for diabetes that allow patients to decide which aspect of their complex medical care (like lowering blood sugar, lowering blood pressure, lowering the glycosylated haemoglobin, weight control) they want to focus on during a particular visit [14]. This could also mean that during that visit only one single aspect (e.g., weight control) will be discussed. Over time, all these aspects will be addressed and clarified.

The complexity of treating multimorbid patients increases when more healthcare teams are involved. This also increases the complexity of SDM implementation. All participants (including the patient and/or, if applicable, their surrogate) must have the chance to share their own preferences and to hear those of the other parties involved. This kind of complex, interdisciplinary approach is rarely easy to implement [15], and requires the top-down support of system and process changes. There are examples which show that an interdisciplinary approach is feasible and not overly resource intensive. The existence of various expert boards (e.g., tumour or heart boards) can serve as a starting point for the implementation of an interdisciplinary and interprofessional SDM process. The aim of such boards is to determine the best available treatment for individual patients. If the patient expresses a strong preference for a specific treatment plan, this will be considered during board discussions. An interdisciplinary SDM best practice would create enough opportunity for jointly discussing the preferences and needs of the patients and their surrogates (if necessary), as well as the expertise and preferences of the involved physicians (including those from other disciplines).

If this is not possible, the preferences of each of the involved parties should be collected and brought up during interdisciplinary board meetings.

General practitioners (GPs) can play an important role in ensuring that the preferences of all patients, including multimorbid ones, are given due consideration. GPs usually have a holistic view of their patients' existing conditions, have usually had prolonged contact with them and are usually acquainted with their preferences regarding the various treatments of their comorbidities. They can therefore focus not only on a specific treatment but on the general goals of care, and best summarise and transfer to the specialised clinicians the information required for making decisions. If the SDM process is performed by GPs, the preferences of their patients concerning one treatment will already be balanced against other existing conditions. The systematic reporting of patient preferences – regarding both goals of care and treatment options – can help both GPs and specialised physicians deliver individualised care.

In summary, SDM is a key concept in the process of working towards high-quality, patient-centred care for all patient populations. It is relevant not only for current care decisions, but also for advance care planning, and it is needed particularly during times of crisis such as we are seeing currently with COVID-19: while we rightly focus on saving lives and protecting the vulnerable groups of the elderly and the chronically ill, we should always ensure that we not only do not neglect patients, but that we also do not impose on them treatments that they do not want. When dealing with a frail patient who has contracted pneumonia due to an unexpected infection (e.g., COVID-19), discussing in a sensitive, professional way how far treatment should go if the situation gets worse (intensive care, intubation, reanimation etc.), is a perfect illustration of shared decision making.

Disclosure statement

No financial support and no other potential conflicts of interest relevant to this article was reported.

References

- 1 Withholding Information from Patients. American Medical Association. Available at: <https://www.ama-assn.org/delivering-care/ethics/withholding-information-patients>. (Accessed: 16th March 2020)
- 2 Foederatio Medicorum Helveticorum (FMH). Statuten und weitere Reglemente: Standesordnung der FMH. Available at: <https://www.fmh.ch/ueber-die-fmh/statuten-reglemente.cfm>. (Accessed: 2020 March 16)
- 3 FMH Zentralvorstand / Comité central de la FMH. Die Position der FMH. «Choosing Wisely»: Weniger Leistungen für mehr Nutzen. *Schweiz Arztsztg*. 2017;98(05):144–5. doi: <http://dx.doi.org/10.4414/saez.2017.05276>.
- 4 Vincent C, Staines A. Verbesserung der Qualität und Patientensicherheit im schweizerischen Gesundheitswesen. Berne: Bundesamt für Gesundheit; 2019
- 5 Michaud PA, Jucker-Kupper P, members of the Profiles Working Group. PROFILES; Principal Objectives and Framework for Integrated Learning and Education in Switzerland. 2017.
- 6 Santa Claus Symposium | ETH Zürich Videoportal. Available at: <https://video.ethz.ch/speakers/collegium-helveticum/digital-societies/santa-claus.html>. (Accessed: 2020 March 16)
- 7 Légaré F, Adekpedjou R, Stacey D, Turcotte S, Kryworuchko J, Graham ID, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev*. 2018;7:CD006732. doi: <http://dx.doi.org/10.1002/14651858.CD006732.pub4>. PubMed.
- 8 Kienlin S, Nytrøen K, Stacey D, Kasper J. Ready for shared decision making: Pretesting a training module for health professionals on sharing decisions with their patients. *J Eval Clin Pract*. 2020;26(2):610–21. doi: <http://dx.doi.org/10.1111/jep.13380>. PubMed.
- 9 Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med*. 1997;44(5):681–92. doi: [http://dx.doi.org/10.1016/S0277-9536\(96\)00221-3](http://dx.doi.org/10.1016/S0277-9536(96)00221-3). PubMed.
- 10 Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, et al. A three-talk model for shared decision making: multistage consultation process. *BMJ*. 2017;359:j4891. doi: <http://dx.doi.org/10.1136/bmj.j4891>. PubMed.
- 11 Lomas J, Lavis J. Guidelines in the Mist. Hamilton, Canada: McMaster University Centre for Health Economics and Policy Analysis. 1996.
- 12 Hanlon P, Hannigan L, Rodriguez-Perez J, Fischbacher C, Welton NJ, Dias S, et al. Representation of people with comorbidity and multimorbidity in clinical trials of novel drug therapies: an individual-level participant data analysis. *BMC Med*. 2019;17(1):201. doi: <http://dx.doi.org/10.1186/s12916-019-1427-1>. PubMed.
- 13 Buffel du Vaure C, Dechartres A, Battin C, Ravaud P, Boutron I. Exclusion of patients with concomitant chronic conditions in ongoing randomised controlled trials targeting 10 common chronic conditions and registered at ClinicalTrials.gov: a systematic review of registration details. *BMJ Open*. 2016;6(9):e012265. doi: <http://dx.doi.org/10.1136/bmjopen-2016-012265>. PubMed.
- 14 Diabetes Medication Choice. Available at: <https://diabetesdecision-aid.mayoclinic.org/app/diabetes?lang=EN&v=m>. (Accessed: 2020 January 23)
- 15 Washington KT, Parker Oliver D, Gage LA, Albright DL, Demiris G. A multimethod analysis of shared decision-making in hospice interdisciplinary team meetings including family caregivers. *Palliat Med*. 2016;30(3):270–8. doi: <http://dx.doi.org/10.1177/0269216315601545>. PubMed.