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The limits of shared decision making

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The foundation of shared decision making (SDM) is the view that people should be aware of relevant choices, and that their personal views, priorities and preferences are relevant factors when determining action. The degree to which people wish to engage in decisions will vary, as will the level to which they will be made aware that decisions exist, or become informed about the relevant information.¹ There is increasing interest in SDM, an ethical imperative,² and supporting evidence that well-designed tools help people compare options and make more informed choices.³ We as authors, are strong advocates of SDM, and think the approach can be applied widely, perhaps more widely than many health professionals think possible.^{4 5}

Nevertheless we have identified situations where we consider there to be clear limits to SDM, where wider interests can override the priority given to individual preferences. While we think individual priorities and preferences should be respected where possible, there are situations where other factors determine decisions.⁶

We feel it is essential to make these situations clear. SDM can be too easily dismissed as an impossible ideal if we do not acknowledge that the approach has limitations. In addition, delineating exceptions will serve to illustrate the demarcation between what can be thought of as the pinnacle of patient-centred care and situations where the approach is rightly constrained by ethical, professional or societal factors.⁵

First, let's agree that decisions come in different forms: some are conscious and episodic, as in 'Shall I have this procedure?'. Some are the result of commitment decisions, such as when agreeing to take medication for a long-term illness.⁷ Others go unnoticed in conversations, such as when a clinician suggests a solution and results in assumed acceptance. Such subtle decisions may well occur because of deference to an expert or an unwillingness to disagree.⁸ SDM makes the process of determining decisions more explicit,⁹ and in healthcare the skills of supporting people to become aware, consciously deliberate, and arrive at better-considered decisions, whether for irreversible or continuous actions, are of utmost value. The steps suggested to achieve SDM have been extensively described elsewhere.¹⁰

It therefore follows that SDM can be applied to a wide range of situations. When there is no evidence that any one management option is considered superior to another reasonable option, then SDM could be seen as a *necessary* approach. This situation has been described as one where

clinical equipoise exists.¹¹ Indeed, it might even be considered unethical not to provide information about alternatives in such situations.^{12 13}

More common, however, is the situation where a range of options exist and where the extent of evidence, and its quality, varies considerably, exacerbating uncertainty.¹⁴ Sometimes the evidence is sparse or poor, or points in different directions, yet there are reasonable options, including the potential watchful waiting or taking no action. Sometimes there is good evidence and high certainty, but even so there are important trade-offs to consider, such as side effects, or other burdens and costs. In these scenarios, individual preferences will contribute to an assessment of what action to take.

To the degree that it is reasonable to compare options, these situations also qualify as having clinical equipoise.¹⁵ SDM is necessary because there will always be a need to consider harms alongside benefits, and critically, the weighting of those factors will vary according to the priorities and preferences of people who will live with the consequences of decisions made, and the trade-offs they are willing to make.

However, there are also situations where taking a shared approach to decisions is not possible, although this does not rule out the need to provide empathetic care. There are limits to SDM, and the goal of this article is to be clear about the type of situations where SDM faces limits and where other strategies will need to be considered.

Limits on SDM will occur when:

- Wider interests override individual wishes
- Evidence of benefit is insufficient or absent
- Lowered decisional capacity is present
- Profound existential uncertainty exists.

Wider interests override individual preferences

One of the clearest situations which puts severe limits on SDM is where an individual's preference overrules the responsibility of clinicians for the safety of the individual or the well-being of the broader population.

Antibiotics for self-limiting illness A good example of this situation is where antibiotics are being requested for self-limiting illness.¹⁶ This scenario may occur when a parent feels a child needs an antibiotic for a viral illness. There is of course plenty of room to negotiate, to educate, and to offer the option of watchful waiting, pending more developments. We lack a good term for this respectful form of arbitration. But there is no genuine clinical equipoise in this situation:

antibiotics would not improve the child's health and may increase antibiotic resistance. Prescribing antibiotics because they are requested by people does not fulfil the test that reasonable options can be offered and described.

Unscheduled opiate prescriptions A similar wider set of responsibilities also exists when an individual who has an addiction to drugs such as opiates requests additional medication outside an agreed schedule or agreement. A particularly difficult situation occurs when people are visiting many clinics seeking prescriptions for opiates, often on the same day, and they are at risk of selling or distributing the drugs to others. Such requests do not represent situations of clinical equipoise. As in the previous example, exploring context issues will be critical. What is motivating the demand? What are the risks of supplying the drugs compared with the benefits? Is prescribing likely to support crime? There are contingencies available to clinicians, such as negotiating an agreement or coming to a compromise, recognising that point-blank refusal can lead to conflict and potential harm.¹⁷ Nevertheless, SDM cannot proceed in such fraught situations.

Vaccine hesitancy The resistance to the use of vaccines provides a complex example of where wider public interest might be viewed to override the preferences of individuals. From a population perspective the emergence of either herd immunity, or the likely reduced spread of a harmful virulent vector, is viewed as argument enough for taking a persuasive approach to vaccination. Offering financial incentives to clinicians to vaccinate a significant percentage of children, or denying access to school or continued employment are examples of persuasive efforts to limit the freedom to decline vaccination. Such incentives can be debated of course. Nevertheless, SDM faces limits when strong public health arguments prevail, at least from the perspective of health professionals who place a high priority on the wider societal benefits of immunisation methods. However, there are also arguments to support taking an adapted SDM approach to vaccine hesitancy. In vaccine hesitancy, the provision of good information coupled with the development of trust in a longitudinal series of interactions may be an effective strategy.¹⁸

Absence of or insufficient evidence of benefit

Scientific evidence for or against a course of action is a key determinant of how clinicians frame decisions in discussions with patients, although the influence of peers and accepted norms are arguably just as important.¹⁹ In some situations, for a range of reasons, increased attention is frequently given to the absence of evidence of net benefit, especially when the evidence is of low quality or contradictory.

There are three common situations where this may be the case.

When there is no evidence

For many options there is little to no research available to allow comparison. However, it is not unusual for patients to have strong prior beliefs about the need for a specific treatment or a test. The clinician may need to become better informed, or may already be aware that insufficient evidence exists, or that there is likely harm, and that acquiescing risks the prospect of delaying effective treatment. Both these scenarios require skilful negotiation for either more time to search for information or to provide reasons why the request for the option may be declined, especially if the option likely brings harm or an unjustified use of resources. Such discussions are made more complex when patients are exposed to media that promote novel healthcare developments. Honesty and transparency can guide communication, however, a consensus is

often difficult to achieve. This situation is often one where clinical equipoise does not exist, and therefore places limits on SDM.

Scientific evidence of inferiority

Clinicians may also be *unwilling* to consider SDM when evidence exists in favour of some options compared with others, or where situations have high stakes and the use of effective treatment is considered imperative or is widely viewed as a standard of care, even if individual patient preferences vary. Clinicians report feeling a moral and professional obligation to recommend superior versus inferior options in such situations.²⁰ They may feel the need to follow clinical guidelines and harbour concerns that they will be viewed as either incompetent or negligent for not adhering to professionally held norms. There is evidence that the willingness of clinicians to practice SDM varies, especially in the face of strong clinical practice recommendations.²⁰

Cost-effectiveness and regulatory restraints

Some countries restrict access to therapies that do not meet agreed-on thresholds of cost-effectiveness or place restrictions to effective care on other grounds (i.e., abortion bans). Conversely, some forms of screening, such as newborn screening, may be mandated by the law. Moreover, people may be required to undergo medical screening to participate in sports or to access certain types of work activities. Decisions about whether to offer such alternatives to individuals are therefore explicitly guided by societal or system-level decisions. While clinicians may opt to become patient-advocates and guide them to uncover a path forward together, this falls outside the scope of conventional SDM.

Lowered decisional capacity

It is perhaps obvious that SDM is not appropriate where an individual has lost the capacity for making decisions.²¹ This could be transient, as in loss of consciousness or the influence of drugs, or prolonged, as when cognitive decline is present. Decisional capacity is also a gradient and may vary over time, so clinicians can benefit from the assistance of time and repeated assessments to establish the threshold at which SDM with people who have insufficient cognitive capacity remains appropriate.²¹ It may well be that others can act as proxies and represent the views of the individual. Parents are asked to act as proxies for children, where the interest of the child may need to be represented by others.

These situations and the levels of involvement possible are special cases that deserve more detailed consideration elsewhere. Nevertheless, such cases should remind us that even for proxies, or for people who we deem as having sufficient decisional capacity, that the quality and simplicity of information are critical. Our capacity to process information can be severely compromised when we are under stress, realising that a close relative is seriously ill and may not recover. Health professionals tend to overestimate people's ability to assimilate and process information, especially in high volume or complexity.

Profound existential uncertainty

It is also clear that profound uncertainty and serious illness can lower decisional capacity, and place limits on SDM. A pulmonologist describes her difficulty counselling people with incurable lung cancer. She notes that an increasing number of second-line treatment options are available: they are efforts to delay cancer progression rather than offer a cure. Sometimes these treatments lead to remission but more commonly the treatments lead to severe, painful side effects and do not substantially delay progression. However, individual responses to treatments vary and are unpredictable. Nonetheless, despite the

uncertainty, the offer of more treatment is viewed optimistically, although this optimism may be misplaced. There is evidence that many clinicians make strenuous efforts to provide information about these complex agents that is barely digestible. At the same time, the inherent uncertainty clouds the prognosis that death could be close, although impossible to predict.²² Euphemistic language often amplifies optimism. Rational comprehension is undermined by fear and emotion and so decisional capacity is severely compromised.^{14 23}

Clinicians tend to resort to guidelines, perhaps guided by attempts to make decisions that are, in their view, in the best interest of the person. For example, with incurable lung cancer, Landmark *et al* describe this uncomfortable process as one of competing authority to decide.²⁴ Clinicians try to give ill individuals deontological authority, whereas when seriously ill, individuals point to the clinicians' epistemological authority.²⁴ Even clinicians who are skilled communicators in such situations will regularly experience that attempts at SDM seem to overwhelm

people. Patients, in times of great need and uncertainty, often want to trust the expertise of others. Eagerly involving seriously ill people in decisions can put their well-being at risk.^{25 26}

Possible solutions

Clinicians inevitably meet these situations, and often, they are compounded by concern, stress and emotion, at individual and family levels. There are no simple solutions. However, we advocate the use of approaches that will likely save time in the long term, by building trust, preserving dignity and bolstering autonomy where possible. These approaches are summarised in the table below [table 1](#).

Conclusion

Considering the historical underappreciation of the need for patient involvement in their care, there is a need for more SDM. While evidence may help, it might not be enough. It is widely reported that many interventions in medicine do not have strong

Table 1 Suggested approaches when shared-decision making is inappropriate or difficult

Exemplified scenarios (age in brackets)	Suggested approaches
Wider interests override individual preferences	
Vaccine hesitancy: Samira and Yael do not want their child (1) to receive a vaccine that is effective to reduce the severity of cases and transmission of a potentially lethal disease. They are worried about potential long-term side effects. Moreover, they are vaccine-hesitant and they prefer not to get vaccinated at all. While at the moment there have been no outbreaks, legal mandates have been introduced requiring vaccination for admission to the local school.	A clinician might proceed by declaring that although it is normal to offer options where reasonable, situations exist that put limits on choice. One approach is to explain her responsibility to society at large and to follow professional or legal standards, before making an effort to motivate the parents to consider vaccination. A possible approach, closer to SDM, is to explore, listen, inform and take time to build trust, avoiding persuasion.
Absent or insufficient evidence of benefit	
Absence of evidence: Samantha (37) wants to try a herbal preparation as a treatment for her severe depression, anxiety and panic attacks. Her clinician finds no evidence supporting its use, although no report of serious harmful effects. At the same time, the clinician worries that Samantha will not agree to more effective therapy and there are grounds to be concerned about suicide.	Absence of evidence: Honest discussions would highlight the uncertainties surrounding the use of a herbal preparation that has no evidence of benefit, and voice a parallel concern that Samantha needs effective treatment. Where people wish to use approaches that have no supporting evidence of benefit nor serious harm, clinicians may want to advocate for a combined approach by suggesting the addition, where feasible, of known effective therapy.
Scientific evidence of inferiority: Michael (53) has multifactorial high cardiovascular risk and according to guidelines he should be take active steps plus medications to reduce the risk of myocardial infarction and stroke. However, Michael is focused on his cholesterol levels and wants to try chia seeds, an approach where there is no evidence of effectiveness.	Scientific evidence of inferiority: Patients that wish to use treatment that has lower effectiveness than safer alternatives put limits on SDM. The ability to uphold the existence of clinical equipoise is challenged. As in other similar situations, a possible approach is to explore, listen, inform and take time to build trust, as a way to guide Michael to take steps to lower his risk.
Cost-effectiveness and regulatory restraints: María wants her son (2) to receive a new drug for his congenital condition, considered a rare disease. Her paediatrician informs her by letter that the novel drug is not covered by her health insurance due to cost-effectiveness issues. She has thought of going to a lawyer. Her primary care clinician is aware of the policy decision, and while willing to be her advocate, is careful not to raise her hopes that she could reverse policy decisions of this nature.	Cost-effectiveness and regulatory restraints: Declarations that novel therapies are not judged to be cost-effective are increasingly commonplace and set limits on SDM. Discussions at individual levels are helpful when they explain the scientific evidence and the deliberations and trade-offs that led to the policy-level decisions.
Lowered decisional capacity	
Ramón (75) has deteriorating cognitive impairment. He has previously told his clinician of his preference to delay surgery for an expanding abdominal aneurysm. Now, the aneurysm has reached a diameter where surgery may be indicated, but the balance between the risk and the benefit from surgery is small. The surgeon fears that Ramón has lost the capacity to declare an informed preference, and is uncertain about how to proceed.	Lahey <i>et al</i> ²¹ suggest a tailored approach based on an assessment of decisional capacity and availability of a surrogate. If, in this situation, Ramon is considered to have lost capacity, then engaging a surrogate would be the right approach, where the surgeon would also need to convey Ramon's previously declared preference as part of the decision process. Absent a surrogate, directive guidance supported by ethical advice would be an alternative.
Profound existential uncertainty	
Jane (63) has incurable lung cancer. Her clinician explains that there are additional second-line expensive treatments that may, for some people, lead to a temporary remission, although more commonly, the treatments lead to severe, painful side effects that may lower her quality of life. The clinician, carefully explaining the complex trade-offs, admits that it is impossible to predict with certainty which of these two outcomes Jane will experience. Jane, already anxious, says that her priority is to spend her last days peacefully.	Moving away from explicit decision-making to solace, support and guidance may be more appropriate for Jane. In these situations, evidence shows that people value multiple brief conversations that acknowledge emotions and explore priorities in the face of declining health.

evidence of effectiveness,^{27 28} and that more research to determine clinical effectiveness is required. In addition, evidence from randomised trials cannot be easily applied to individuals with different characteristics, and such evidence definitely lacks information about the context, priorities and preferences of individuals.²⁹ We, therefore, contend that the need for SDM is *increasing* given the increasing complexity of therapeutic potential coupled with comorbidity.

Nevertheless, as we outline, there are situations that limit when decisions can, or should, be shared.³⁰ Clinicians have a duty of care to the people they advise, and, in our view, to involve them carefully in decisions: they also have obligations to their profession, to society and to science. It helps to be clear when those other obligations take precedence and therefore limit the use of SDM.

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