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Information provision in life-threatening illnesses: comprehensive framework

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ABSTRACT

Background In life-threatening illnesses, open information provision can benefit patients and families. However, not all patients prefer to have all information. There is a lack of clinical guidance on how to handle patient preferences for non-disclosure.

Aim To develop a conceptual framework and practical guidance for clinicians regarding the spectrum of patients' information provision preferences with a focus on when patients do not desire to have full information.

Methods Multidisciplinary expert stakeholder meeting.

Results 20 expert stakeholders from various disciplines and continents participated in the expert meeting. Based on the qualitative results, a conceptual framework was created. Our framework highlights that information is never value-free but attains value via healthcare provider and patient/family factors, including how information is interpreted by clinicians and patients/families. In this process, ethical and sociocultural tensions can arise, such as between patient and family autonomy, that can influence harmful effects of the attained value of information along several axes such as empowerment versus disempowerment. To mitigate tensions and minimise harm, our framework produces practical guidance for clinicians such as making a connection and having an open attitude.

Conclusions Our framework has clinical, research and policy implications and can be further refined and tested. Ultimately, it serves as a starting point to reduce social and cultural inequities in end-of-life care information in a global context.

WHAT WAS ALREADY KNOWN?

⇒ Open information provision can precipitate distress.

⇒ Clinicians lack guidance about handling preferences for non-disclosure.

WHAT ARE THE NEW FINDINGS?

⇒ Our framework highlights how information attains value.

⇒ We present recommendations to mitigate tensions arising in this process.

WHAT IS THEIR SIGNIFICANCE?

Clinical

⇒ Our guidance helps promote more equitable information provision.

Research

⇒ Our framework provides opportunities for refinement/testing.

INTRODUCTION

'Help, or at least do not harm' lies at the heart of medicine. While clinician communication can positively influence patient well-being,[1 2] many complaints related to end-of-life care are associated with communication deficits.[3–5] Suboptimal communication undermines person-centred decision-making, patient experiences and care outcomes[6] and causes or exacerbates mistrust, especially in the minority groups.[7–9]

For those communicating with people living with life-threatening illnesses, the line between helping and harming is most fragile when considering *open information provision*. The 2022 Lancet Value of Death Commission highlights the importance of 'essential' clinician–patient conversations, as 'a right for all people and families who wish it' (p. 864).[10] Indeed, potential benefits of open information provision include better psychological outcomes,[11] person-centred care,[12] less aggressive treatment[13] and fewer complicated bereavement outcomes.[13] However, for those who do not wish it or are ambivalent about full disclosure of information, potentially harmful effects of unreserved open information provision are both psychological, for example, anxiety or depression[11 14], and existential, for example, potentially losing optimism.[15]

We need to better understand and mitigate the potential harms of unsolicited information provision for those who might not or do not prefer it.[16] Insight and guidance are required on how clinicians should best approach information sharing with those who do not wish it, for whom preferences fluctuate or for whom information preferences are unclear. Despite acknowledging the importance of tailoring information to a patient's preference, current guidelines do stress the importance of open information provision.[6 17] When clinicians' perspectives differ from those of patients and their families, this can also lead to clinician distress.[18 19] This issue may become amplified against a backdrop of clinicians globally increasingly caring for more diverse people with life-threatening illnesses.[20 21]

We, therefore, convened a stakeholder meeting where attendees' views were used to inform the development of a conceptual framework and practical guidance for clinicians regarding the spectrum of patients' information provision preferences, with a focus on when patients do not desire full information. This guidance is intended to inform clinical practice and serve as a starting point for researchers interested in the circumstances when patients do not prefer full disclosure. It will be useful for policymakers interested in developing or extending policy to improve equitable care provision and patient outcomes among those affected by life-threatening illnesses.

METHODS

We organised an international, multidisciplinary expert stakeholder meeting and used thematic analyses to qualitatively synthesise the results. Based on these outcomes, we devised a conceptual framework and practical guidance.

To convene the international and multidisciplinary expert stakeholder group, the core group (LMvV, AS, BP, JK, FB) approached international key expert stakeholders with specialist interests in medicine, palliative care, health communication, medical/cultural anthropology, bio-ethics and patient representation. Expert stakeholders were invited to attend a 2-day online meeting (February 2022) to help develop a conceptual framework and practical guidance for clinicians around information provision across a spectrum of information preferences. 20 experts (online supplemental table 10) represented countries located in Asia, Africa, South America, Europe and North America. Before the meeting, attendees were requested to write a reflection on the conditions under which information provision might cause unintended harm, and how preferences for non-disclosure might be best approached. The reflections were circulated among the group.

The topics and dilemmas identified in the expert reflections, supplemented by scoping of the literature, were synthesised and grouped into three discussion themes for the online meeting (online supplemental table 2). They included: (1) disclosure and non-disclosure: potential harm of open information provision; (2) indirect language and implicit/tacit knowledge: indirect and emphatic communication and (3) 'big' dilemmas: medical oaths, the right to know and autonomy. A final group discussion identified the initial elements that would contribute to the framework. Results of multidisciplinary and plenary discussions were captured on 'Miro' boards (https://miro.com/) and Word files.

creation of framework

Following the 2-day meeting, the core group followed principles of thematic analysis[22] to qualitatively analyse the findings. Two authors (LMvV, AS) re-read the Miro boards, expert reflections and the preparation notes for the meeting (step 1) and commenced the development of initial themes (step 2). Following further discussion (involving JK), these themes were refined to form the initial framework (step 3). This was discussed with the wider group of experts (step 4) to prevent one-sided interpretations of the data,[23] which was followed by a face-to-face meeting (LMvV, AS, JK) to finalise the conceptual framework (step 5). Lastly, the results section was written (step 6).

RESULTS

The analysis resulted in a conceptual framework for information provision across a spectrum of information preferences (figure 1).

The framework is based on three key principles:

1. Information provision holds value within a clinical and sociocultural context and a relational context that includes healthcare providers, patients and their families

Information was defined as data that can be interpreted and communicated. In the communicative space in which clinicians, patients and their family members interact, information is never value-free. The value that this information, for example, a test result, attains depends on the healthcare provider; the manner of communication; the patient and family; and the clinician–patient relation. The expert group distinguished five dimensions of value creation in the process of information provision.

Clinical and sociocultural dimensions:

(1) *The process of interpretation by a healthcare provider*. For example, a medical test result is being interpreted.

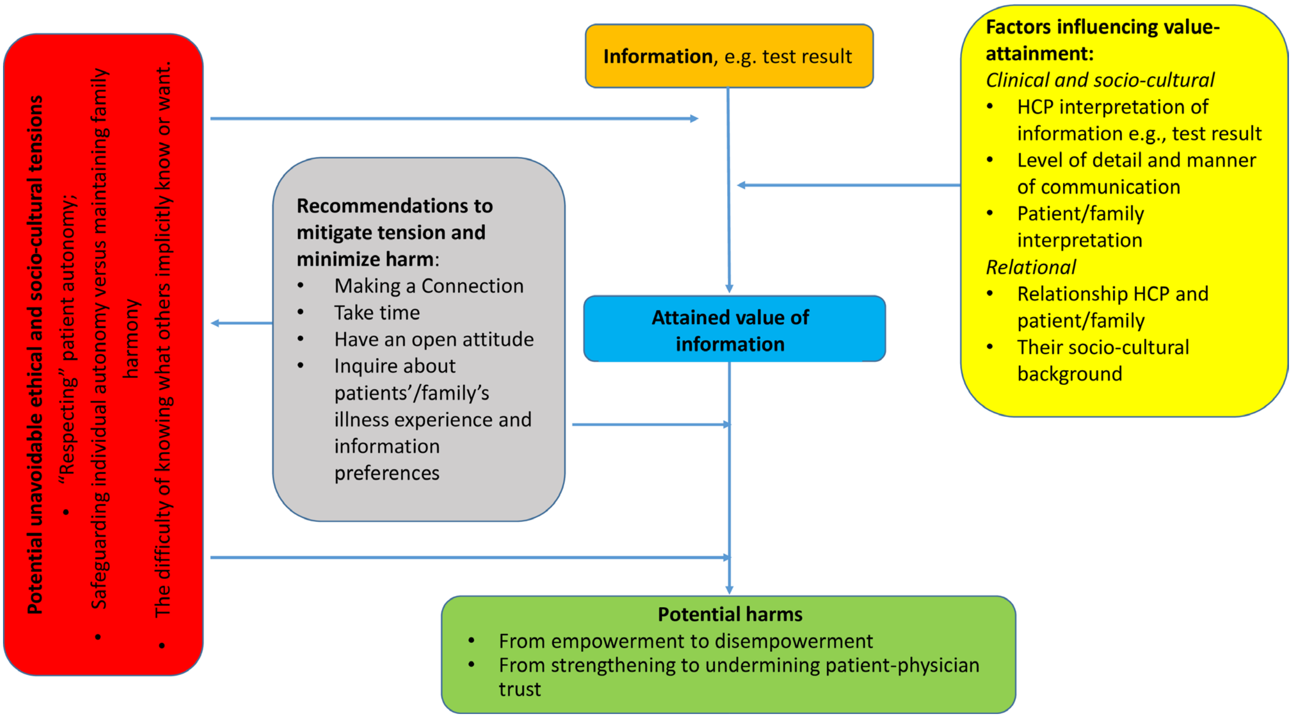

Figure 1 Conceptual framework. HCP, healthcare providers.

(2) *The level of detail and manner in which information is communicated by healthcare providers*. Clinicians can either provide full information, select information, or gradually disclose information depending on the topic discussed; for example, are there many treatment options to discuss or is the aim to discuss that someone will die? The level of detail should be seen as a continuum; clinicians can provide information in various manners; for example, being more implicit and indirect or more explicit (eg, saying ‘time is short’ instead of ‘dying’), and making use of body language (eg, eye contact).

(3) *How information is interpreted by patients and their families*. The information provided by clinicians is only part of the information that is accessible to patients and families. Other sources might include their social network or the internet.

Relational dimensions:

(4) *The healthcare provider–patient/family relationship*. This relationship influences how information is perceived and which information is preferred (patients may interpret information differently from a trusted clinician). Family dynamics may also play a role in how information is navigated and which information is shared (families may wish to act as mediators).

(5) *Their respective sociocultural backgrounds*. Culture plays a significant role in how information is preferred and how it is interpreted. For example, in some cultural settings, indirect language can be immediately understood (clinicians might talk about symptoms without referring to a diagnosis) and direct information may be considered rude. Religious beliefs may also play a role, for example, the idea that the divine gives and takes life and that death should not be announced by a physician.

2. Potential unavoidable ethical and sociocultural tensions may arise in the process in which information attains value

While bad news has the potential to cause unavoidable harm, there are three domains (coming from competing ethical frameworks) in which potentially unavoidable tensions can arise in the process in which information attains value, which can cause further harm.

(1) *‘Respecting’ patient autonomy*. Autonomy is not universally valued, and in making decisions, people always relate to others. Autonomy can clash with medical protocols, but can also come with too much responsibility—in some cultures sharing responsibility is desired (eg, so the patient cannot be ‘blamed’ for the decisions made) and autonomy can be a burden. There may be friction between the ‘medically correct’ decision (non-maleficence) according to healthcare providers and meeting the patient in their ‘right’ decisions (the palliative care approach). This creates the core tension as to whether full information is always required to achieve patient autonomy, or whether it is rather about asking patients what their information preferences are, that instils autonomy (eg, full disclosure might not be best for everyone).

(2) *Safeguarding individual autonomy versus maintaining family harmony*. In some cultures, autonomy is more centred on the unit of the family. Consequently, there may be a clash between the patient and family (eg, the patient may want to talk about a matter while the family does not), within families, and between the family and clinicians (families might want to filter

information while clinicians feel obliged to inform patients). This has the potential to create tension about where autonomy is situated and who controls the distribution of information.

(3) *The difficulty of knowing what others implicitly know or want*. There may be different ways in which people are aware of their situation even when information is not presented to them directly. It may be impossible to know exactly what others know or want if direct language is not used, and even asking directly about patient preferences might result in patients providing an answer they feel healthcare providers or families want to hear. This creates the tension of not knowing what the patient knows and how they want to be communicated with.

3. Potential harms associated with information provision can occur along two axes

Potential harms from the attained value of information can occur along two axes:

(1) *From empowerment to disempowerment*. Information is multilayered. It can inform and empower. However, it can also threaten an individual's worldview and lead to an existential crisis (moral injury), endanger family and social relations, and signal a lack of respect.

(2) *From strengthening to undermining patient–healthcare provider trust*. While information can create trust, it can also undermine the relationship. Information is sometimes shared under the notion that it is 'good' for patients. However, patients may experience this as 'truth-dumping', which can undermine their trust in a healthcare provider.

Recommendations on how tensions may be mitigated and harms minimised

We propose the following recommendations to mitigate tensions and minimise harms associated with information provision. Central to these recommendations is that a trusting relationship must be built and continually invested in over time. The recommendations commence from the basis of being open to the social and cultural diversity of patients and families and the importance of building a relationship.

- Make a connection

Clinicians need to invest in making a connection with patients and their families. This enables them to know what kind of information to share and how. To foster a trusting relationship over time, specific communication elements and behaviours are essential: awareness of and the use of subtleties (eg, sensing the atmosphere, reading the patient); making use of empathic behaviours including the acknowledgement of emotions and making people feel seen as a person (eg, by remembering some details of their everyday lives) while using small talk and expressing non-abandonment ('I will stay with you'); being authentic; and trying to find common ground.

- Take time

Relationships are built over time and through repeated interactions. This also enables staged disclosure, as presenting all information at once can harm the trusted relationship. Time is not only about duration but also about its depth.

- Have an open attitude

Clinicians need to be open to the social and cultural diversity of patients and be aware of how information can impact the patient and the patient-family dynamics. If this is not done, it can cause conflict and loss of trust between the clinician and the patient and their family. For example, in some sociocultural settings, patients might lose their jobs if it becomes widely known that they are incurably ill.

- Inquire about the patient's/family's illness experience and information preferences

Healthcare providers may—repeatedly—ask about information preferences. However, sometimes patients may find this difficult to know or to express, or their answer aims to please the healthcare provider. Therefore, asking first about the patient and their family's illness experiences (how they present the problem) can help to understand how they wish to be informed. It might also be useful to assess social 'pressures'—what other factors influence how a person desires to take on information.

DISCUSSION

Based on an expert stakeholder meeting, we aimed to develop a conceptual framework and practical guidance for healthcare providers regarding information provision across a spectrum of information preferences, with a focus on when patients do not desire full information. The framework—informed by globally diverse perspectives—highlights that information is never value-free but attains value via multiple clinician and patient/family factors. During this process, ethical and sociocultural tensions may arise which can lead to the sharing of information causing harm along two axes. To mitigate tensions and minimise harm, our framework provides practical guidance when informing patients in serious illness situations. This framework can be further refined and tested.

Information neither exists in a void nor is always an undiluted 'good'. This does not mean that clinicians who are uncomfortable with or uncertain about providing information should use this as an excuse to make unilateral decisions to withhold information. It does, however, mean that clinicians should be aware that information attains value by individual clinicians' and patient/families' interpretation, their communication and their relationships.

With increasing globalisation and more possibilities to care for patients and families who have different cultural ways of comprehending illness and healthcare, recognition of differences that make a difference is vital.[24] The cultural dimensions postulated by Hofstede[25 26]—for example, power distance, collectivism versus individualism, short- vs long-term orientation—may guide further investigation of how clinicians, patients and families share and interpret information and the acculturation that occurs in a more global world. Previous studies have documented tensions that arise during the process of information provision on the side of clinicians and patients/families, including clinicians struggling with how to inform and care for patients from other cultural or ethnic backgrounds[27] and patients from minority groups experiencing suboptimal communication.[28–31] Our framework builds on this, suggesting that in clinical reality it might not be realistic to believe tensions can always be avoided and provides deeper insight into factors contributing to potentially unavoidable tensions. Moreover, from a unique interdisciplinary and global perspective, we make recommendations for how to mitigate tensions when they arise. It is easy to see how tensions arise if clinicians are trained to and legally required to fully inform patients,[32–34] which is the norm in many Western countries, while in other cultural contexts, it may be inappropriate to openly talk about death[35 36] or treatment withdrawal.[37] Our suggestions for building connection and trust—for example, by listening to patient narratives, creating time and inquiring about illness experiences—to mitigate arisen tension, build upon previous studies[6 38–40] and should be seen in the light of patients from minority ethnic backgrounds receiving suboptimal levels of empathic communication,[41] which can compromise the principle of patient safety. Moreover, our framework shows that these behaviours illustrate the importance of both cultural humility (life-long commitment to self-evaluation and critique to redress clinician–patient power imbalances)[42] and providing cultural safety (addressing power dynamics while centering on patient's rights so that patients feel safe when receiving care).[43] This is especially important during the non-judgmental enquiry about information preferences and/or illness experiences before providing information. It is even possible to make tensions explicit as an approach to invite patients and families to share their information wishes and views. One could argue that these elements are central to 'good palliative care', with a recent scoping review indeed recommending the inclusion of palliative care experts to explain medical information understandably.[44] However, this approach should be ingrained in the whole healthcare system and among all practitioners.

Our conceptual framework and recommendations have clinical, research and policy implications. At a clinical level, our guidance may help promote more equitable information provision and level-up care provision for all people facing life-threatening illnesses. While for clinical-experts, individual elements of our framework might be known, our meeting has consolidated these elements and their inter-relations together in a unique interdisciplinary and multilayered conceptual framework, which provides a deeper insight into when and how tensions arise which are not always avoidable, and how they might be mitigated. By doing so, we hope our framework can help clinicians understand and anticipate critical tensions which may be associated with harm.[45] For researchers, this framework should be further refined and tested in clinical practice, for example, by using Delphi processes, to encourage urgent studies to better understand implicit communication[46 47] and effective practices of finding common ground where discordant views are present.[40] Lastly, at a policy level, they support the local adaptation of guidelines and policy initiatives. A good example hereof is the cultural adaption of advance care planning, in which recent work demonstrates the importance of native language, clear information, and the possibility of relational autonomy or delegating autonomy to others.[48 49]

This project had limitations. First, we invited experts from various disciplines and countries. However, we do acknowledge that some views might be missing, notably those from policymakers. We wish to include their perspectives in the next step of translating the guidelines into policies tailored to diverse demographic and sociocultural contexts. Second, our conceptual framework has not been empirically tested, and follow-up studies should test the framework or its separate elements.

To conclude, our conceptual framework highlights that the value of information provision in life-threatening illnesses is influenced by clinicians, patients and their families. Healthcare providers can mitigate potentially unavoidable ethical and sociocultural tensions and harm that arise in this process through several concrete behaviours. Ultimately, we hope this framework holds the potential to assist in reducing social and cultural inequities in end-of-life information and care provision in a global context.

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