1.4 Substitute Decision-Making

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Educational Objectives

1. To appreciate the basis of substitute decision-making in health care.
2. To appreciate how substitute decision-makers may be identified in a health care context.
3. To appreciate the scope of substitute decision-making.
4. To appreciate the circumstances under which a health care team may seek to limit a substitute decision-maker's authority to make health care decisions.

Case: "No Pain Medication for Mother, Thank you Very Much!"

We have secured permission from University Publishing Group to re-print the case study. An elderly woman suffering from shortness of breath was brought to the emergency department by her daughter. She had an elevated temperature and seemed confused and disoriented. Her medical history indicated that she had suffered a cerebrovascular accident approximately one year ago. On admission, it was noted that the woman had a gangrenous foot and ankle and a mottled leg up to, and above, her knee. Later, on the ward, the nursing staff noticed that when they moved the patient she appeared to be in considerable pain. They recommended analgesia and the attending physician concurred. The patient's daughter, however, who was her only child and only living relative, refused to allow any pain medication. The daughter was the patient's legally recognized substitute decision-maker. The daughter, a retired pharmacist, said that analgesia would shorten her mother's life. Further, she informed the staff that her mother had an unusually high pain threshold. She noted that her mother had never used any freezing at the dentist and when she had suffered a bad burn on her arm she never took anything for the pain. Caregivers tried to negotiate with the daughter, but to no avail. She emphatically stated: "No pain medication for Mother, thank you very much!"

The patient's condition deteriorated. The daughter met with her mother's surgeon and was told that her mother's gangrenous leg was reaching a critical point (i.e., sepsis). The daughter agreed to amputation surgery to prolong her mother's life. Following the amputation surgery, the anaesthetic was wearing off and staff approached the patient's daughter about giving the patient post-surgical analgesia. Once again, the daughter adamantly refused.

Questions

1. What ethical foundation or principles underlie health care decisions made by a substitute decision-maker?
2. In practice, how are substitute decision-makers identified?
3. What is the scope of the task undertaken by substitute decision-makers?
4. When may a health care team seek to interfere with or limit a substitute decision-maker’s authority to make health care decisions?

Discussion

Q1. What ethical foundation or principles underlie health care decisions made by a substitute decision-maker?

Individuals are presumed to be competent to make health care decisions. The legal and ethical presumption that capable individuals are entitled to make important decisions about their health and well-being is grounded in the medical principle of respect for persons. While the obligation to meaningfully involve "competent" persons in health care decisions can be seen as an expression of respect for their autonomy, it is perhaps most appropriate to view the meaningful inclusion of patients in health care decisions in a broader context. Here, rather than focusing solely on another's autonomy, the broader principle of respect for persons not only includes respect for another's capacity to be self-directing, but also recognizes our ethical and legal obligations to persons who may be vulnerable or who are no longer able to participate in a meaningful way in decisions about their health care.

Those who were once able to participate in a meaningful way in decision-making about health care may have lost
Q2. In practice, how are substitute decision-makers identified?

"Substitute decision-making" refers to those decisions taken by third parties on behalf of others who lack decision-making capacity. In practice, the identification of a substitute decision-maker is often quite informal and reflects what might be best characterized as "custom." If a previously capable person has not formally appointed anyone to act on his/her behalf, the now incapable patient is typically represented by a spouse, partner, adult children, relatives or friends who are available and willing to assist with health care decisions. In the majority of cases, this "custom" works; no conflict exists regarding who should represent the patient, and there is no difference of opinion regarding what counts as appropriate in the treatment and care of the patient. In these situations, family members are often routinely consulted when patients lose decision-making capacity. Family members or significant others are commonly viewed by caregivers as acceptable substitute decision-makers because they know the patient well and want to do the right thing for their loved one.

The identification or appointment of a substitute decision-maker may also be more formalized. In such situations, the once-capable person may have previously appointed an individual(s) to act as a proxy decision-maker(s). Substitute decision-makers may be named in an advance directive or, depending on the province or jurisdiction, they may be identified in a legislated hierarchy of substitute decision-makers (e.g., in consent/substitute decision-making legislation enacted by the particular province or territory).

In practice, it is not uncommon for family members or intimates of the patient to present themselves to the health care team and inform the team that they have a "power of attorney." In most provinces and jurisdictions, a power of attorney authorizes a third party to oversee the financial affairs of an incapable person. A power of attorney does not typically confer any legal or moral authority to make health care decisions.

Q3. What is the scope of the task undertaken by substitute decision-makers?

Typically, substitute decision-makers are only called upon to act in that capacity when patients are understood to be temporarily or permanently incapable of representing themselves. Substitute decision-makers are expected to faithfully communicate the known wishes or preferences of the person they are representing regarding treatment and care. In circumstances where substitute decision-makers are asked to assist with decision-making, it is essential that they accurately convey to care providers any known wishes or preferences the patient may have shared while competent.

If an incapable patient's wishes are not known, the substitute decision-maker is expected to collaborate with care providers and make decisions that are seen to be in the person's best interests. This is often easier said than done. Not infrequently, differences between care providers and families (or other substitutes) will depend on differing perceptions of the patient's true interests, when all things are considered.

Some of the challenges of substitute decision-making become more apparent as one moves away from explicitly communicated or transmitted decisions to more opaque and challenging contexts. In general, one might distinguish three types of substituted decisions: transmitted decisions, hypothetical judgments and guardian judgments.

Transmitted judgments are those in which a previously capable person has clearly communicated wishes or preferences with respect to the specific health care decision under consideration. Hypothetical judgments are those formed by substitute decision-makers when the now incapable person has never explicitly expressed a wish or preference about the particular situation under consideration. However, in such instances, substitute decision-makers, or others of goodwill who have known the patient, can agree that a particular assessment about what ought to happen comports or "fits" with the person's known values and beliefs.

The most challenging and difficult decisions taken by substitute decision-makers are so-called "guardian"
judgments. In these situations, substitute decision-makers have no direct knowledge of the patient's wishes or preferences, either because the person has never said anything or because the patient, such as an infant, has a limited or no history in the world; there is no biographical evidence that communicates a preference or from which to construct a decision. In the case presented, the patient's daughter believes she is accurately representing her mother's wishes with respect to pain medication. This is based on her long-standing relationship with her mother and her intimate knowledge of her mother's actions in past health care circumstances. As there are no other family members or intimates available, it is difficult to secure collateral evidence to substantiate the daughter's claim that her mother would truly not have wanted any analgesia.

Q4. When may a health care team seek to interfere with or limit a substitute decision-maker's authority to make health care decisions?

From an ethical and legal perspective, there are situations where it is defensible to place limits on the authority of substitute decision-makers. As noted, substitute decision-makers are expected to faithfully represent the known wishes or preferences of the persons entrusted to their care. It is important to recognize that the authority of substitute decision-makers with respect to decision-making is not power "...for family members to do as they wish with the body and personality of their dependent relative." In the case presented, the patient's daughter insists that her mother had told her earlier that she would not want pain medication. While the care providers do not challenge the veracity of the daughter's statement, they do question whether the situations described by the daughter, such as no freezing during routine dental examinations and no pain medication in the care of a burn, translate to the current clinical situation "a gangrenous leg."

As events actually unfolded, the care providers became more convinced that it was inappropriate to withhold pain medication. They were acutely aware of the patient's pain and discomfort, as well as the considerable moral distress this evoked among the staff themselves. The patient's daughter continued to believe she was faithfully representing her mother's views and insisted that her mother would not want to receive pain medication, even post-amputation.

Care providers need to be cautious about how they act in the face of reservations they may have about substitute decision-makers who appear to be "harming" those they represent. In such circumstances, there is a clear obligation on the part of care providers to communicate their concerns to appropriate department heads, service chiefs or managers. In the face of a difference or disagreement regarding the best interests of an incapable person, to resort to unilateral decision-making or summarily dismissing substitute decision-makers is not ethically defensible. If there are serious concerns about the quality of a substitute's decisions, it is imperative that appropriate third parties be involved to assist with mediation and conflict resolution. If the differences cannot be satisfactorily resolved in a manner that first and foremost protects the vulnerable patient, care providers will have to explore options in their health care facility, city, province or territory to legitimately challenge the authority of the substitute decision-maker and/or to identify another category of substitute decision-maker (e.g., a public trustee).

Finally, in practice, an additional complication may emerge when individuals in the health care team find themselves divided in their assessments of the quality or content of a substitute decision-maker's direction. In these circumstances, some caregivers may be prepared to act on the substitute's decision, while others may feel compromised by what they are being asked to cooperate with professionally. In ethical terms, one might describe this threshold as the difference between "I do not support this direction, but I am willing to cooperate with it" and "Not only do I not agree with this direction, but I cannot cooperate with it." In such a situation, health care professionals may have to consider transfer of care after securing appropriate protection for the vulnerable person.

What we intended originally was a scenario where a physician at the 'threshold' described above has one of two options available: (i) provide the care or interventions requested or (ii) provide for the safe transfer of care to another medical colleague as per professional college guidelines.

References

Further Reading

- Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill: "it was just out of the question". *Journal of the American Medical Association* 2005; 293: 1374-81.