Whose Decision is it Anyway?

Abstract

One of the most challenging and at the same time hopefully rewarding activities is to be the substitute decision maker (SDM) for someone important to you such as a parent. The assumption is by designating a child or children to be one’s substitute they will make the right decisions and keep your wishes or best interests at the centre of the decision-making. This unfortunately is not always the case and for a variety of reasons some of which are just a misunderstanding of the legislation and the meaning of the Health Care Consent Act some SDMs start making decisions based on their personal preferences and biases and not of the person they are meant to represent. This can lead to varying degrees of conflict sometime so serious that health care professionals may explore the steps that might be needed to remove the SDM from the role and find a more appropriate substitute. This is not something one likes to do and with proper explanation it usually can be avoided. The most important point is that the patient must always be the centre of the decision-making process.

Keywords: Substitute-decision-maker, capable patient, consent, Public Guardian

The daughter was quite adamant, “I do not want my niece visiting my mother. She always was and continues to be a bad influence on her. It does not matter what my mother says, I’m in charge now. Since her stroke on top of her Alzheimer’s disease, she is clearly not able to make decisions of importance for herself”. The nursing staff in particular was quite upset by this statement which was made a few hours after the niece had left after what seemed to be a very warm and friendly visit with patient whose eldest daughter was her legal Substitute Decision Maker (SDM). “Moreover, the daughter continued, I am not happy with the food being served my mother as the dietician does not seem to understand the importance of a low cholesterol diet which
my mother needs since her stroke and in fact the well-known dangers of meat in a person’s diet with my mother’s risk factors”. After the nurse brought that information to the dietician which had come to a head when the daughter removed the food tray containing beef stew which the mother clearly indicated from the menu presented to her the previous day that she wanted for lunch.

The dietician when discussing the issue with the daughter pointed out that at 92 years old despite a stroke which in fact was due to an embolus due to atrial fibrillation rather than an underlying serious problem with elevated cholesterol levels, the focus should be on the mother’s wishes and quality of life rather than any theoretical minimization of risk factors by dietary means. The daughter’s response was quite forceful, “I know what is best for my mother and as her Substitute Decision Maker it is my decision at this point and not hers since she is no longer capable of making her own decisions”.

The nurses were quite upset as were the dietician when the daughter said, “from this time forward I am going to determine what my mother eats and since I really believe in a primarily vegetarian diet with perhaps the occasional addition of fish or eggs and some milk for cereal or occasional yogurt. For years I tried to convince my mother that she should change her diet to a healthier one that I am now describing but she would talk about her Polish origins and her love for beef and chicken when prepared in the ‘old country’ way and would not budge in her dietary beliefs not matter how much I would show her articles about how unhealthy her diet was. As for her niece, she always took my mother’s side and I would not be surprised that she would try and sabotage my instructions which I think would be to the detriment to my mother’s well-being.”

The social worker was called in to discuss the issue with the daughter. “You know your mother seems to enjoy visits from her niece and since she will likely be institutionalized until she dies, whenever that might be, as many social contacts that she enjoys would be very important to nurture and she seems to show all the signs directly and indirectly of enjoying her niece’s visits.” The response of the daughter was quite belligerent towards the social worker, “I do not care what you think is good for my mother, you do not have power of attorney for personal care (SDM) I do so it is my call and that is that. If you go against my wishes I will report you to administration and if necessary I will take action to make sure that my wishes and expectations are heeded.”

After a period of open hostility from the daughter it became clear that the mother was not happy
with some of the decisions and made it known to the dietician that she wanted some meat or chicken and pointed to her roommate’s dish when there were traditional Eastern European cabbage rolls being served and indicated that she wanted some as was the case when chicken wings were being served some days later. She was asked by the social worker if she missed not seeing her niece and with clear nodding of her head indicated that this was the case and seemed to be puzzled as why she stopped visiting.

The issue was brought to the primary physician who received the same reply from the daughter with the same veiled threat that should she not get her way with her mother’s care she would take legal, administrative or regulatory action. The primary care physician discussed the issue with her unit consultant, department head and administrative advisor and eventually it was decided to ask for an ethics consultation as the first step and then if that could not resolve the issue seek legal input from the facility’s lawyer.

The physician in his report to the team was quite concerned and told them, “she is quite fixated on her ‘right’ to make decisions for her mother and seems pleased that finally after no many years of her mother ‘not taking her advice’ she can now control her mother’s care and well-being. She sees this not only has her ‘right’ but her duty as her mother’s caregiver and SDM. I offered to have her meet with the ethicist and team and she refused once again threatening to take action against anyone that interferes with what she sees as her legal right and ethical/familial duty.

After the unit’s administrator was apprised of the issue, he arranged a meeting with the daughter which she used to state her position strongly and again assert her willingness to take legal action against “anyone” who interfered with her wishes and intentions. Rather than succumbing to what by this time everyone believed was a *modus operandi* of threats and bullying, the administrator told her that she was free to take whatever legal action she wanted but that he could not on behalf of her mother’s ethical need for respect for autonomy and beneficence and as part of protecting her from potential harm, he would be happy to deal with the issue within a legal framework if that is what she wished. In the meanwhile he told her that she would be receiving a letter from the hospital lawyer outlining the framework of action under Ontario’s Health Care Consent Act. The letter would obtain the organization’s position on what those that care for her mother in the various professional and ethical duties and obligations were willing to do to make sure that her mother will be properly looked after in the most professional and ethical and

**Key Point**

*Involve the incapable patient, to the extent possible, in discussions with the substitute decision-maker. Consider the wishes of the patient as much as possible especially when the health care risks or not high*
humane way possible.

According to the administrator who reported back to the team of health care professionals, the daughter seemed to be taken aback by the fact that there was not acquiescence to her belligerent and threatening attitude, and indicated that she would “fight” all attempts to take away from her what she saw as her right, even when the administrator left her with a copy of the Ontario Health Care Consent Act.

A few days later the daughter was asked to attend a meeting with the administrator and the facility’s lawyer as well as the unit’s director of nursing, senior social worker and the centre’s ethicist. The daughter was informed that she was welcome to bring a lawyer with her but she declined saying that “she knew her rights”. In the meeting whose level of conflict was kept at a minimal due to the calming effect of the social worker who reiterated time and again that everyone there was there for the same purpose which was to best serve the needs and wishes as well as they were known of the patient. The first time this was expressed by the social worker the daughter clearly bristled but calmed down when it became clear that no one at the meeting was prepared to enter an aggressive and accusatory stance with her.

It was explained to her the content of the Health Care Consent Act and she was given a copy with certain sections highlighted for her so that she could understand and if necessary discuss with her lawyer if that person was not a specialist in health law what the issues were for which she might have problems defending her position should her case be taken for adjudicative resolution such as to the Consent and Capacity Board. The salient features are ones that primary care physicians should be familiar with in order to address important issues that might come up when Substitute Decision Makers flout their “rights” when decisions are being made that are felt by my health care professionals to not be in the best interest of their patients.

Often the issues that appear to be in conflict do not actually fall under the purview of the Health Care Consent Act and the role of the SDM as they are not actual treatments according to the Act and therefore lie outside the decision-making role of the SDM. In fact the only items that an SDM can make decisions about unless they are court appointed SDMs which was not the situation in this particular case and is not that common, are treatments, admission to a Long-term care facility and personal assistance services. The Act contains the following important points and definitions:

“treatment” means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related
purpose, and includes a course of treatment, plan of treatment or community treatment plan, but does not include,

(a) the assessment for the purpose of this Act of a person’s capacity with respect to a treatment, admission to a care facility or a personal assistance service, the assessment for the purpose of the Substitute Decisions Act, 1992 of a person’s capacity to manage property or a person’s capacity for personal care, or the assessment of a person’s capacity for any other purpose,

**Presumption of capacity**

A person is presumed to be capable with respect to treatment, admission to a care facility and personal assistance services. 1996, c. 2, Sched. A, s. 4 (2).

**Exception**

A person is entitled to rely on the presumption of capacity with respect to another person unless he or she has reasonable grounds to believe that the other person is incapable with respect to the treatment, the admission or the personal assistance service, as the case may be. 1996, c. 2, Sched. A, s. 4 (3).

**Wishes**

A person may, while capable, express wishes with respect to treatment, admission to a care facility or a personal assistance service. 1996, c. 2, Sched. A, s. 5 (1).

**Capacity depends on treatment**

A person may be incapable with respect to some treatments and capable with respect to others. 1996, c. 2, Sched. A, s. 15 (1).

**Capacity depends on time**

A person may be incapable with respect to a treatment at one time and capable at another. 1996, c. 2, Sched. A, s. 15 (2).

**Principles for giving or refusing consent**

A person who gives or refuses consent to a treatment on an incapable person’s behalf shall do so in accordance with the following principles:

1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.

2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person’s best interests. 1996, c. 2, Sched. A, s. 21 (1).

**Best interests**

In deciding what the incapable person’s best interests are, the person...
who gives or refuses consent on his or her behalf shall take into consideration,

(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;

(b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and

(c) the following factors:

1. Whether the treatment is likely to,
   i. improve the incapable person’s condition or well-being,
   ii. prevent the incapable person’s condition or well-being from deteriorating, or
   iii. reduce the extent to which, or the rate at which, the incapable person’s condition or well-being is likely to deteriorate.

2. Whether the incapable person’s condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.

4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed. 1996, c. 2, Sched. A, s. 21 (2).

**Offence: misrepresentation of wishes**

No person shall knowingly misrepresent wishes someone has expressed with respect to treatment, admission to a care facility or a personal assistance service. 1996, c. 2, Sched. A, s. 83 (1).

**Penalty**

A person who contravenes subsection (1) is guilty of an offence and is liable, on conviction, to a fine not exceeding $10,000. 1996, c. 2, Sched. A, s. 83 (2).

**Offence: decision contrary to wishes**

A person who knowingly contravenes paragraph 1 of subsection 21 (1), paragraph 1 of subsection 42 (1) or paragraph 1 of subsection 59 (1) is guilty of an offence and is liable, on conviction, to a fine not exceeding $10,000. 1996, c. 2, Sched. A, s. 84 (1).

**CPSO Interpretation**

The interpretation of the Health Care Consent Act by the College of Physicians and Surgeons of Ontario (CPSO) makes it clear to physicians that they have duties to determine that the SDM is acting properly when fulfilling their roles. The considerations to determine this position include the following statements from the CPSO policy statement on Consent to Treatment
A physician must consider whether the substitute decision-maker is complying with the principles set out in the HCCA. If a physician is of the view that the substitute decision-maker is not acting in accordance with the HCCA, he or she can call the Office of the Public Guardian and Trustee.

Even when there is a substitute decision-maker, a physician must still involve the patient. The College advises the physician to take the following steps:

1. Tell the incapable patient that a substitute decision-maker will assist the patient in understanding the proposed treatment and will be responsible for making the final decision.

2. Involve the incapable patient, to the extent possible, in discussions with the substitute decision-maker.

3. If the patient disagrees with the need for a substitute decision-maker, or disagrees with the involvement of the present substitute, the physician must advise the patient of his or her options. These include finding another substitute of the same or more senior rank, and/or applying to the Consent and Capacity Board for a review of the finding of incapacity.

4. Reasonably assist the patient if he or she expresses a wish to exercise the options outlined above in paragraph 3.

After meeting with the daughter it was made clear by the lawyer and the attending physician that if the daughter was dealing with issues which in fact were not part of the Health Care Consent Act as they were not “treatments” according to the definition of the Act and therefore her opinion would have no influence on the actions about which she wanted to intervene– specially who could visit her mother, and what she could eat. She was told that her instructions in these areas would be ignored and that her mother could make such decisions on her own without input from her daughter. If there were a legal undertaking by the daughter, the facility lawyer indicated that they would be prepared to engage legally using the wording and implications of the Health Care Consent Act and their fiduciary duty to protect and care for her mother who was a patient of the hospital.

The daughter indicated that she would get legal assistance to counter this option and was told she was most welcome to do so and if necessary the facility’s lawyer would be happy to discuss the situation with her lawyer and outline what the expectations were for her to be at this point when what she
was intruding in were not part of the her role as SDM and what the facility would expect of her according to the law should situations occur when true treatments were required and when the mother could not participate in such decisions and what the daughter based her substituted decision upon. They suggested that any health care lawyer who understood the Health Care Consent Act would council her to change her approach to the care of her mother.

The daughter left the meeting in a very defiant state and a letter outlining the content of the meeting was sent to her as a registered letter reiterating the expectations that the facility had of her in her role of SDM which would have no impact on who could visit (i.e. the niece) as such a decision was not a “treatment decision” and there was no indication that preventing such visits was in the mother’s general, social, psychological and familial best interests and that the mother should be allowed to eat what she wanted as there was nothing to suggest that such choices were of the nature “treatments” and her autonomy in the choice of food had to be respected unless what was being asked for was clearly egregious in the nature of the choices.

Ten days letter the daughter asked to meet with the lawyer and the same group who attended the first meeting and indicated that she

---

**SUMMARY OF KEY POINTS**

Even when there is a substitute decision-maker, a physician must still involve the patient. The College advises the physician to take the following steps:

1. **Tell the potentially incapable Patient who is still able to understand that a substitute decisionmaker will assist in understanding the proposed treatment and will be responsible for making the final decision presumably based on the person’s previous expressed wishes or best interests.**

2. **Involve the incapable patient, to the extent possible, in discussions with the substitute decision-maker. Consider the wishes of the patient as much as possible especially when the health care risks or not high**

3. **If the patient disagrees with the need for a substitute decision-maker, or disagrees with the involvement of the present substitute, the physician must advise the patient of his or her options and rights under the legislation. These include finding another substitute of the same or more senior rank, and/or applying to the Consent and Capacity Board for a review of the finding of incapacity or in extreme cases to take over care decisions.**

4. **Reasonably assist the patient if he or she expresses a wish to exercise the options outlined above in paragraph 3.**

had consulted with her lawyer who suggested that she had best alter her approach to her mother’s care and she was prepared to review the issues for which there was friction and see what she could do to fulfil the expectations that she felt were her duties and at the same time respect the law. The first that she was asked to do in that direction was phone her mother’s niece (in essence her cousin) and invite her back for visits, without any preconditions. It was also suggested that she meet with the dietician and the doctor to discuss her medications and diet in terms of her wishes and her health status based on the known parameters of risk and benefit for a woman in her mother’s condition and at her age and what her mother was able to indicate she wanted for herself.

As she left the meeting the daughter in a very restrained manner ventured that perhaps her attitude and position prior to the meetings was a bit severe and perhaps she did not fully understand the concept of the SDM’s privilege for fulfilling that role and the emphasis being on the best interests of the patient rather than the wishes and beliefs of the SDM. Over the following month, the situation had resolved itself and the daughter was transformed into a cooperative and in essence a most devoted family member and devoted SDM who from time to time needed a reminder and some assistance as to where the focus had to be when difficult decisions had to be made for her mother’s on-going care.

References

Always ask the SDM what is the basis of a decision that is being made—known previous wishes or a reflection of known previous values.

2) When an SDM starts using terms like I want or I believe that, or my mother never really understood—be aware that the SDM may not be reflecting their loved one’s wishes or values—then it is time to explore.