Complex Issues & Consent to Treatment

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PRACTICE SCENARIO

Anna, a 75 year old woman with esophageal cancer has been transferred to a palliative care unit. Up until this point, Anna has been capable of making her own treatment decisions. Her recent medical decline has lead to bouts of confusion, with episodes of deep sleep and occasional unconsciousness. She has extensive family support including her adult twin children, six grandchildren, and several brothers, sisters, and cousins (her husband passed away five years ago).

The Winter 2013 issue of *résumé* reviewed the basics of consent to clarify the fundamental concepts of the *Health Care Consent Act (HCCA), 1996*. The scenario above addresses three complex issues surrounding consent to treatment:

1. Establishing a substitute decision-maker;
2. Conflicts between substitute decision-makers; and
3. End-of-life care.

1. ESTABLISHING A SUBSTITUTE DECISION-MAKER

Under the HCCA, a client must provide informed consent for treatment. If a client is not capable of providing informed consent, a substitute decision-maker must be identified to make decisions on the client's behalf.

Where a substitute decision-maker has not yet been established, section 20(1) of HCCA provides the hierarchy of who is eligible to provide act as a substitute for a client. As a last resort, section 20 (5) specifies that the *Office of the Public Guardian and Trustee* can also take on the responsibilities of a substitute.[1]

"List of persons who may give or refuse consent

1. The incapable person's guardian of the person, if the guardian has authority to give or refuse consent to the treatment.
2. The incapable person's attorney for personal care, if the power of attorney confers authority to give or refuse consent to the treatment.
3. The incapable person's representative appointed by the Board under section 33, if the representative has authority to give or refuse consent to the treatment.
4. The incapable person's spouse or partner.
5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to the treatment in the place of the parent, this paragraph does not include the parent.
6. A parent of the incapable person who has only a right of access.
7. A brother or sister of the incapable person.
8. Any other relative of the incapable person."
9. The *Office of the Public Guardian and Trustee, Ontario,* as a last resort.[1,5]

In order for someone to act as a substitute decision-maker they must be willing, capable and available.[2] In-person availability is not mandatory, provided the substitute decision-maker can be contacted in a timely manner via any

means such as phone, email, text or video conferencing. In most cases, a family member, as outlined in the HCCA hierarchy above, would automatically have the right to make these decisions on behalf of the client. A person established as a client's *Power of Attorney for Personal Care* (POAPC) takes precedence over any family member for consent to treatment decisions. Personal care includes health care, nutrition, shelter, clothing, hygiene and safety.[3]

In this scenario, there was no pre-established power of attorney, therefore, the health care team assigned Anna's twin children the role of the substitute decision-makers. They agreed to share this responsibility and, as per the requirements of the HCCA, also agreed to act in the best interest of their mother, take into consideration the values and beliefs that their mother held while still capable and involve their mother (as best as possible) in any decision-making.

Consent and Capacity Board

Where a client does not have any family or other assigned substitute decision-maker, someone else (e.g., a client's friend) may apply to the *Consent and Capacity Board* (Board) to be appointed as the client's representative for personal care decisions. This process requires submitting an application to the Board followed by a hearing.[4] At the hearing the applicant will be asked to present information to help the Board decide whether they should be appointed as the substitute decision-maker for the incapable person.

Office of the Public Guardian & Trustee, Ontario

If there is no family member or representative available to be appointed as a substitute decision-maker, the health practitioner who is proposing the treatment or the health care provider overseeing a client's care (e.g., case manager) is responsible for contacting the *Office of the Public Guardian and Trustee, Ontario*. Staff of the *Public Guardian and Trustee* will then take on the responsibilities of a substitute decision-maker and make informed care decisions on the client's behalf once they have confirmed that the client is indeed incapable and that no other substitute is available. The *Office of the Public Guardian and Trustee* is called to act on behalf of a client only when there are no other legal substitutes available.[2,5]

2. CONFLICTS BETWEEN SUBSTITUTE DECISION-MAKERS

Making decisions about the health care of a family member can often be difficult. Because of the sensitive nature of making treatment decisions on behalf of another person, varying opinions may arise. Where there are disagreements about whether to give or refuse consent between two or more equally-ranked substitute decision-makers (e.g., two children), section 20(6) of the HCCA specifies that the *Office of the Public Guardian and Trustee, Ontario* shall make the decision in their place.[1]

Anna's twin children attended a meeting with the health care team to discuss their mother's prognosis. They were asked whether they wish to pursue any further treatment including options for tube feeding, and/or hydration administered intravenously.

Anna's twins agreed that they did not wish to pursue tube feeling but could not agree on whether to pursue hydration administration intravenously. One child felt that this would be prolonging her mother's life and that her mother wouldn't agree to that. The other felt that without adequate hydration, her mother would suffer in her end-stages of life. It was noted that their mother did not have a living will.

According to the HCCA, Anna's twins were equally-ranked substitute decision-makers. Because they could not agree, the *Office of the Public Guardian and Trustee, Ontario,* was contacted to make a decision.

3. END-OF-LIFE CARE

End-of-life/palliative care decisions should always respect client-centred decision-making and engage the client in exploring treatment options. It is the goal that clients or their substitute decision-makers actively participate in choosing the best available options, based on informed discussions and any known goals, values and beliefs of the client.[6]

Treatment decisions can vary depending on the client's condition and the amount of treatment that the client or their substitute decision-maker wishes to accept, refuse, or even withdraw. Ongoing communication is crucial to ensure optimal end of-life decision-making.[6]

Family Involvement

"Family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends."[6] The client or substitute decision-maker determines who will be involved in the care decisions and who will be present at the bedside. It is the responsibility of the health care team to know with whom they may share information about a client's health status. Just because a family member is present in the room or at the bedside, doesn't warrant implied consent to disclose personal health information.

The representative from the *Office of the Public Guardian and Trustee, Ontario,* consulted with Anna's children, other family members, the health care team, and also did extensive research regarding hydration and end-of-life care. After much deliberation and discussion with all those involved, the representative decided not to pursue any further treatment for Anna. Comfort measures were provided and Anna passed away peacefully four days later, with much of her family at the bedside.

Ethical Issues for RDs

RDs must respect the end-of-life decisions made by a client or their substitute decision-maker even when the decisions to accept, refuse or withdraw treatment are not in agreement with their own ethics, values and beliefs.

If an RD and/or health care team feel that the substitute decision-maker is not acting in the client's best interest and is putting the client at risk, they can apply to the *Consent and Capacity Board*. If the Board determines that the substitute decision-maker did not comply with their responsibilities under the HCCA, the Board can direct them to do so. If the substitute decision-maker is deemed not to have the capacity to give consent or does not comply with the Board's direction, another person may be appointed. For more information on *Managing Conflicts Between RDs & Substitute Decision-Makers*, refer to the Fall 2009 issue of *résumé*.

1. ***Health Care Consent Act*. (1996).** http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm#BK24
2. **Office of the Public Guardian and Trustee, Ontario.** (2012). *Powers of attorney and "living wills" questions and answers.* http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/livingwillqa.pdf
3. **Office of the Public Guardian and Trustee, Ontario.** (2000). *A Guide to the Substitute Decisions Act.* http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/pgtsda.pdf
4. **Consent and Capacity Board.** (2013). *Applying to Be Appointed a Representative to Make Decision(s) with Respect to Treatment, Admission to a Care Facility and/or Personal Assistance Services* (Form C). http://www.ccboard.on.ca/english/publications/documents/formc.pdf
5. **Office of the Public Guardian and Trustee**, Ontario. (2012). *Making Substitute Health Care Decisions, The Role of the Public Guardian and Trustee, p. 3.* http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/ISBN-0-7794-3016-6.pdf
6. **College of Physicians and Surgeons of Ontario**. (2006). *Decision-making of the end of life.* http://www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/End%20of%20Life.pdf

FREE Valuable Resource for RDs!

Electronic Health Library

The College recently attended a valuable webinar provided by the *Allied Health Professional Development Fund* (AHPDF) on navigating their *Electronic Health Library*. A medical librarian demonstrated how to find relevant journal articles from several databases with full printable text. The webinar also showed how to refine literature searches, and email, save and cite journal articles in applicable reference formats.

The College requires RDs to practice in an evidence-based manner. One of the essential components of evidence-based practice is finding the best available evidence to enable knowledgeable and informed decisions. The AHPDF *Electronic Health Library* provides free journal article access for RDs in Ontario.

For more information on future webinars and to access the *Electronic Health Library*, visit: https://www.ahpdf.ca/