Professional Practice Scenario

Managing Conflicts Between RDs & Substitute Decision-Makers

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Both the substitute decision-maker and the Registered Dietitian have a professional responsibility to act in the best interests of clients. To manage conflicts with substitute decision-makers, dietitians must have a clear understanding of the rights and responsibilities of the substitute decision-makers and of their own responsibilities.

A client presented with severe dysphagia secondary to a stroke and had a PEG tube inserted for enteral feeding. The client's wife is the substitute decision-maker who objects to the idea of her husband having nothing by mouth because it diminishes his quality of life. Despite a barium swallowing assessment indicating a significant risk of aspiration, the client has been receiving a full plate of food at lunch at the wife's request.

Jane, the RD assigned to the client, tried to meet with the wife to discuss the risks of oral intake, but the wife refused further discussion. The client has already received treatment for respiratory distress, possibly the result of aspiration from oral intake. All members of the healthcare team agree with the recommended treatment of nothing by mouth and some have questioned the wife's capacity to effectively act as the client's substitute decision-maker. Concerned for the client's well-being, Jane contacted the College for guidance with this situation.

The College receives inquiries from RDs, like Jane, who feel clients are at risk when their treatment recommendations have been refused by a client's substitute decision-maker. Dietitians can manage this conflict by understanding the rights and responsibilities of the substitute decision-maker and their own professional responsibilities in working in the best interests of their clients. These are clarified below.

THE RIGHTS AND RESPONSIBILITIES OF THE SUBSTITUTE DECISION-MAKER

The *Health Care Consent Act* stipulates that substitute decision-makers must always act in the best interests of the person on whose behalf they are making decisions. According to section 21(2) of the *Act*, "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;
(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."[1]

Substitute Decision-Maker's Right to Refuse Treatment

A substitute decision-maker has the right to refuse treatment if they are acting in the client's best interests. RDs may find it difficult to accept these decision(s), especially when these wishes may not follow their own values and beliefs. It may also be challenging for RDs to accept a substitute decision-maker's decision when managing the ethical issues associated with end of life care. In the same way that RDs must accept the treatment decision of their client, RDs need to respect the wishes of the substitute decision-maker provided the refusal is informed.

PROFESSIONAL RESPONSIBILITIES OF RDS

Ensure Informed Consent or Refusal

In order for substitute decision-makers to act in the client's best interests, they must have adequate information to ensure informed consent or refusal of treatment. RDs have the responsibility to ensure they have communicated appropriate information regarding nutrition care options to the substitute decision-maker.

As outlined in section 11(2) of the *Health Care Consent Act*, informed consent or refusal includes the following:[1]

- Reasons for the treatment
- The nature of the treatment
- Who will be providing the treatment
- Risks and side effects
- Alternatives to the treatment
- Consequences of declining the treatment
- Questions from the substitute decision-maker are addressed

Minimize Risk to the Client

The client's best interests should always be at the forefront of an RD's mind. To the extent possible, RDs have the professional responsibility to minimize or remove risk to their clients. In Jane's case, effective risk minimization may be working with other healthcare team members to determine a feeding strategy that reduces the risk of aspiration; simple adjustments of the bed height or seating positioning may help to lessen aspiration risk.

Clearly Document Refusal of Treatment

If the substitute decision-maker has been given all the information required to enable informed consent and refuses the recommended treatment, RDs must clearly document the refusal in the client's health record. Make sure you have recorded:

1. the results of your assessment and your recommendations;
2. your discussions of these recommendations with the substitute decision-maker;
3. the substitute decision-maker's refusal of consent for the recommendations;
4. your revised plan (as applicable), which makes recommendations for the safest implementation of the wishes of the substitute decision-maker.

It is also advisable that RDs communicate this information with the health care term.

THE RD STILL FEELS THAT THE SUBSTITUTE DECISION-MAKER IS NOT ACTING IN THE CLIENT'S BEST INTEREST. ARE THERE OTHER OPTIONS?

An RD may feel that the substitute decision-maker is not acting in the client's best interest and is putting the client at risk. Under these circumstances, health care practitioners can apply to the Consent and Capacity Board, an independent body created by the provincial government of Ontario under the *Health Care Consent Act*, which addresses the arbitration of matters relating to capacity, consent, civil committal and substitute decision-making[2]. Section 37 of the *Act* states that a health care practitioner can apply to the Consent and Capacity Board if they believe that the substitute decision-maker does not have the capacity to give consent or is not complying with the principles given in section 21(2).

In this scenario, if Jane and her team determine they have reason to believe that the substitute decision-maker is not acting in the client's best interests or are themselves not capable of giving consent, they should consult their hospital administration and/or legal counsel before making a formal application to the Consent and Capacity Board. If a formal

application is made, the Consent and Capacity Board would hold a hearing to determine whether or not the substitute decision-maker has the capacity to give consent or has complied with their responsibilities to act in the client's best interests.

If the Consent and Capacity Board determines that the substitute decision-maker did not comply with their responsibilities under the *Health Care Consent Act*, 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 applying to the Consent and Capacity Board and what to expect in a hearing, consult the information sheet: *Applying to Determine Whether or Not the Substitute Decision Maker has Complied with the Rules for Substitute Decision Making*. (http://www.ccboard.on.ca/english/publications/documents/formg.pdf).

References:

1 *Health Care Consent Act*. (1996). Available from: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm

2 Government of Ontario. (2005). Consent and Capacity Board *About Us*. Available from: http://www.ccboard.on.ca/scripts/english/index.asp

NEED TO KNOW

- Both the substitute decision-maker and the RD have a responsibility to act in the best interests of clients. To manage conflicts with substitute decision-makers, dietitians must have a clear understanding of the rights and responsibilities of the substitute decision-makers and of their own responsibilities
- A substitute decision-maker has the right to refuse treatment if they are acting in the client's best interests. RDs need to ensure that consent or refusal to nutrition care is informed and that they have clearly documented the substitute decision-maker's refusal to treatment. When treatment is refused, RDs must work to ensure that risk is minimized to their client.
- Healthcare providers may apply to the Consent and Capacity Board if they believe a substitute decision-maker is not acting in the client's best interest. The Consent and Capacity Board may direct the substitute decision-maker to act in the client's best interest or appoint a replacement.

2009 Registration Renewal

Completing your 2009 Annual Renewal may have taken you a little longer this year because of the changes required to collect information for the *Health Professions Database* project.

Many of the questions on this year's form were either new or had potential answers that were different from previous years. As a result, your renewal form was not pre-populated with the information that we already have on file. Having members complete a few extra questions during renewal saved the College from having to input the data manually, which would have resulted in significant expense.

The 2010 Annual Renewal will be more convenient, because the renewal form will contain the information that you have provided this year and you will only be asked to correct or update any changes.

We thank you for your patience and understanding during this transition year.