



## Substitute decision-making for cognitively impaired older people

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About 10% of elderly residents in chronic care facilities are tube-fed. Yet there is persuasive evidence that common beliefs about tube-feeding cannot be supported: tube-feeding is *not* similar to spoon-feeding, it is *not necessarily* indicated in patients with aspiration pneumonia, swallowing evaluations are *not* very helpful in selecting patients for tube-feeding, and when artificial nutrition and hydration are withheld or withdrawn patients do *not* have a painful death.<sup>1</sup> So why are patients tube-fed?

In this issue (page 1705) Drs. Susan L. Mitchell and Fiona M.E. Lawson report on their timely study of decision-making for long-term tube-feeding in cognitively impaired elderly people.<sup>2</sup> Their study raises a number of crucial issues around substitute decision-making and the ethics of tube-feeding and suggests that some physicians may be failing patients and their substitute decision-makers by not informing them of research findings that contradict popular beliefs about common interventions. Is it possible that these physicians are unaware of such disputes or that they choose to disregard them?

Mitchell and Lawson interviewed 46 substitute decision-makers who had agreed to tube-feeding for their elderly dependents and found that 78.3% had some sort of discussion with the primary care physician, the consultant who inserted the feeding tube, or a resident or intern. The substitute decision-makers stated that the medical benefits most often mentioned to them were the prolongation of life and the prevention of aspiration. However, Mitchell and Lawson cite studies that do not support these claims. Perhaps the 22% of participants in their study who had had no discussion with medical personnel were better off after all: at least they had not been misled. In all, 39% of the substitute decision-makers in the study felt that the physician had made the decision alone, and 28% indicated that the doctor had shared the decision. Yet only 13% were not closely related to the patients. It seems highly spurious to suppose that the other 87% had so little knowledge of their family values and preferences that they would have lacked confidence in their own judgement unless they had been otherwise advised or persuaded.

Advance directives or living wills would certainly be of help to substitute decision-makers, but the limitations of

living wills should be recognized. Singer<sup>3</sup> recommends giving specific directives about health care and personal matters. In addition, he advises that a person appoint a trusted friend or family member to act as proxy or substitute decision-maker. Several provinces already make legal provision for such a person to be recognized, and others are likely to follow suit. Singer appropriately highlights the importance of frank discussion with a person appointed as proxy. Mitchell and Lawson asked the substitute decision-makers in their study whether the patients had communicated their wishes for long-term tube-feeding, but we do not know how well informed any of them were of the possible consequences. Without knowledgeable discussions it is difficult to conceive of substitute decision-makers having any confidence that the decisions they make consistent with the wishes of their dependents. Even if a person has carefully followed Singer's instructions related to possible treatment decisions, the proxy may be faced with a complex situation that does not readily fit the template.

Mitchell and Lawson did not include in their analysis the substitute decision-makers who declined the option of tube-feeding. A comparative study might be revealing on a number of counts. Were these proxies better informed of their dependents' wishes? Mitchell and Lawson cite 3 studies in which the patients' advance directives were not considered and 1 in which the substitute decision-makers' perceptions of the patients' wishes were at odds. The patients in their study were described as being incapable of medical decision-making at the time of tube placement, but they do not mention how this was determined or documented. It is sadly the case that patients who decline apparently straightforward procedures are sometimes considered incompetent because their decisions are based on experiences deemed by others to be irrational.<sup>4</sup> A similar disregard of some patients' wishes in the present study cannot be ruled out without further inquiry.

Regardless of the disputed benefits of the procedure, 78% of the substitute decision-makers in Mitchell and Lawson's study felt "a moral obligation" to permit tube-feeding. One wonders what the basis of such obligation might be. It could be the duty to pursue medical interventions when there is the possibility of preserving life. But if



there is no evidence that tube-feeding prolongs life, then moral obligation may be misplaced and skewed. It seems more appropriate to question the efficacy of earlier decisions and interventions that have led to the need for an alternative to oral feeding. Could there be a moral duty to desist from intervening in what would otherwise be an end-of-life event if the quality of that life, including the ability to enjoy food, is going to be in question?

Dying, which used to be familiar and routine and a relatively simple and public ritual, has become, for the most part in contemporary Western society, something that few people, even physicians, encounter in their early years. Death has become something unusual and unexpected, a process that is increasingly complex and so private that it is not to be talked about except in hushed tones. It is a part of life that has largely been removed from the family home to the institution, where it takes place out of sight. It has become an event that is almost indecent.<sup>5</sup> Callahan<sup>6</sup> suggested that this state of affairs arose because we were seduced into thinking that technology has the power to eliminate death altogether. In Mitchell and Lawson's study the question of tube-feeding arose in most cases after an acute neurologic episode. They do not mention whether the substitute decision-makers had talked about death and dying and its meaning or desirability for their dependents. Even the participants committed to prolonging life at all costs might have had second thoughts had they been adequately informed about the potential outcomes of the proposed intervention at the onset of the acute episode. For example, swallowing problems are common in survivors of stroke, and tube-feeding may be recommended for a patient who is not receiving adequate nutrition because of such a problem. Substitute decision-makers may not be aware that the options for the continuing care of tube-fed patients are quite restricted. Only chronic care hospitals will provide complex continuing care.<sup>7</sup> For example, an elderly parent who has been happily settled in a retirement home but becomes dependent on tube-feeding will not be able to return to that environment. Mitchell and Lawson refer to, but do not elaborate on, the considerable expense to the health care system associated with tube-feeding. Clearly one expense must be the blocking of acute care beds by tube-fed patients waiting for suitable placements in chronic care facilities.

The authors do not mention whether tube-feeding was ever stopped once the patient's medical status had stabilized or whether that was ever discussed as an option. Yet the neuromuscular biomechanical swallowing problems that these patients experienced are not so different from those of residents in other long-term-care facilities and nursing homes, where the presenting problems are frequently associated with dementia, as indicated in the United States, where tube-feeding of this population is common.<sup>8-10</sup> In one Canadian study 87% of residents in a nursing home exhibited mealtime difficulties associated with a decline in physical, mental and behavioural status.<sup>11</sup> Widely accepted alternative interventions to tube-feeding involved meal texture modification, compensatory postures, food administration techniques and direct

therapeutic procedures. The residents who required the highest level of feeding assistance actually consumed the greatest amount of food. Perhaps tube-feeding is not the only way of ensuring that cognitively impaired people with swallowing problems will get adequate nutrition; however, patients require careful assessment, and there must be adequate staff and procedures in place to meet their special needs. In Mitchell and Lawson's study most of the substitute decision-makers questioned the improvement in the patient's quality of life that resulted from tube-feeding. It is perhaps a moot point to suggest that the personal contact and time involved in being fed by a concerned person is preferable to having formula fed through a tube. This could be a case of technology and expediency taking the place of caring human contact.

Mitchell and Lawson suggest that when substitute decision-makers have not had adequate direction from their dependents, decisions should be based on the patient's best interests, by weighing the possible medical outcomes against perceived values and preferences. Quality of life and functional status were considered most relevant. Quality of life is a very subjective judgement. Unfortunately, Mitchell and Lawson did not explore with the 54% of participants who stated that they would not wish to be tube-fed themselves what their reasons might be or whether their opinions had changed in the light of their experience. Perhaps one way of ascertaining the effects of tube-feeding on quality of life would be to survey younger, cognitively intact patients who have chosen tube-feeding but have been able to return home with support from family and home care services.

Who should educate the public on the crucial issues involved in substitute decision-making, and when should this take place? It appears that in Mitchell and Lawson's study most of the information was given and the decisions were made in the acute care setting, with the attendant atmosphere and pressures to reach decisions quickly. Rational decisions will frequently be overridden in such emotionally charged circumstances. Our technologically based and democratic society continues to advance our rights to long and healthy lives. The corollary is the need for an informed public that appreciates the responsibility that we each have to ourselves and to one another. Physicians certainly need to be informed adequately if they are to be worthy of the trust put in them by patients and proxies, but they cannot be all things to all people. In the matter of tube-feeding, there are other members of the health care team, such as speech-language pathologists, occupational therapists, dietitians and social workers, who may be better equipped to discuss the implications and potential outcomes with a substitute decision-maker. As a matter of health promotion, there is an opportunity for ethicists to question current practices and to assist members of the public in their critical review of common interventions before a situation arises. As responsible citizens, we must ensure that the parameters of our best interests are well understood and appropriately constrained by those we appoint to make decisions for us.



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# Oral isotretinoin: prescribers beware

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Oral isotretinoin (Accutane<sup>TM</sup>) has become widely used in the treatment of acne since its arrival on the Canadian market in 1983. This is because it is uniquely effective in the treatment of disabling, intractable cystic acne. It was clear from the outset that this treatment came with a price. Oral isotretinoin is highly teratogenic and must never be given during pregnancy.<sup>1</sup> However, by approximately 1 month after cessation of therapy, when the drug is no longer in the circulation, the risk of fetal malformation is the same as at baseline.<sup>2</sup>

The use of oral isotretinoin in women of childbearing age became a concern because of the potential for these patients to become pregnant during therapy. Since 50% of pregnancies are unplanned, a great deal of effort was invested in trying to prevent pregnancy during isotretinoin therapy. The most effective approach, currently in use in the United States and Canada, is a multipronged communication strategy called the Pregnancy Prevention Program, which was developed by the manufacturer of Accutane<sup>TM</sup> and the US Food and Drug Administration.<sup>3</sup>

In this issue (page 1719) Drs. Gordana Atanackovic and Gideon Koren of the Motherisk Program in Toronto describe the cases of 4 women who became pregnant while taking oral isotretinoin therapy.<sup>4</sup> Because the goal of the

Pregnancy Prevention Program is a zero pregnancy rate during oral isotretinoin therapy, these cases represent a failure in the responsible use of the drug. It is not known how many failures occur in Canada, but even 4 cases are enough to draw our attention. The report by Atanackovic and Koren highlights the inherent risk in giving oral isotretinoin to young women who may not fully comprehend the risk of teratogenesis or strategies for pregnancy prevention.

Mitchell and colleagues<sup>3</sup> conducted a survey to assess the effectiveness of the Pregnancy Prevention Program. They found that most pregnancies during oral isotretinoin therapy occurred in women who were taking oral contraceptives concurrently with the isotretinoin. Surprisingly, these women were well counselled, remembered being informed about pregnancy prevention and yet became pregnant because of normal contraception failure. The Pregnancy Prevention Program has enrolled approximately 400 000 patients since 1989 and is now enrolling patients at a rate of 50 000 per year (Dr. Allen Mitchell, Director, Slone Epidemiology Unit, Boston University, Boston, MA: personal communication, 1999). This is estimated to represent almost half the women of childbearing age using oral isotretinoin in the United States. More than half of the