

Decision-making capacity in an age of control

“...when you grow old, you will stretch out your hands, and someone else will gird you, and bring you where you do not wish to go.”
John 21:18

Clinicians know that elderly people do not fear death so much as the process of dying. Because modern therapies are more effective at relieving pain, emotional angst and moral bewilderment, control over the process itself has emerged as the salient concern. This defence of the need to be in control is particularly apparent among elderly people with dementia. Thus, it is odd that in adult medical care, we have adopted such an all-or-nothing approach to decision-making by adults with impaired capacity.

Modern medicine has removed control from the hands of the patient and placed it into the hands of the professional. Physicians prefer to treat every problem thoroughly without taking quality of life into consideration. Thus, patients who will die within the next year frequently receive treatment for mild, asymptomatic hypertension, hyperglycemia or hyperlipidemia. Alternatively, we choose the path of least resistance. Rather than providing a secure and caring environment for patients with dementia, we chemically restrain them, robbing them of their remaining dignity in the process.

Our colleagues in pediatrics, who face an equally limited decision-making capacity among their patients, have taken a more nuanced approach based on the following principles: children have dignity, intrinsic value and a right to medical treatment that serves their best interests; children should be involved in decisions that affect them; information should be presented truthfully and with sensitivity; decision-making should be interdisciplinary and collaborative; and the best interests of individual children should be of primary concern.¹ We at *CMAJ* are surprised that such principles are not considered for adults with diminished decision-making capacity.

Physicians primarily caring for elderly patients could be guided not only by these principles, but also by 2 concepts that guide pediatric practice. First, the concept of assent recognizes children to have partial decision-making skills and, thus, to have some authority over their own health care. Elements of assent include the patient being aware of the nature of the condition and of what to expect with each action, the physician clinically assessing the patient's understanding and the presence of influencing factors including pressure, and the physician soliciting the patient's willingness to accept the plan.² Second, the concept of voluntariness maintains that the decision-maker should not be manipulated or coerced and that there is always an option to change one's mind.

These principles and concepts could be adapted easily for adults with diminished capacity. Their adoption would be predicated on a better defined assessment of the capacity for decision-making, which would involve institutions and health care practitioners first moving away from all-or-nothing decisions.

Capacity for decision-making should be much more specific to the decisions at hand and should be reassessed frequently.

One of the ways to ensure more targeted capacity assessments would be to expand the number of categories considered for evaluation. Specifically, we should determine a patient's competence to decide within the 4 following categories: legal and financial matters, health care management (investigation or intervention), behaviours and bodily functions. To be sure, it is common to determine competency in the first 2 domains separately. And we have begun to respect patient decisions on the behaviour front. For instance, some institutions make allowances for patients who smoke, or who like to drink or go for walks outdoors. Physical restraints are used much more judiciously; however, drug restraint is still lamentably prevalent.

But choices about bodily functions seem to be the last bastion of institutional control and convenience. True, there is a move from the use of indwelling urinary catheters toward the use of diapers, but this has not made the business of emptying one's bowels any more human. Perhaps we need to offer the choice of a daily enema at a time and a place that better preserves dignity. There is growing acceptance that not every person with dementia wants or needs to eat more.³ Artificial feeding ought to be considered as only an option; sometimes natural eating, even when there is a moderate risk of aspiration, will be the best option. Overriding patients' decisions regarding bodily functions should only occur in the presence of convincing justification.^{3,4}

Health professionals should be mindful that capacity for decision-making is not predicated upon the patient's age or type of disease. It is a function of the person and the decision at hand.

We suggest that decision-making capacity be determined more precisely. No orders should be written until there is an explicit entry in the case record, similar to records of allergies or drug reactions, specifying the person's decision-making capacity in each of the 4 domains listed previously. Exercising control, no matter at how visceral a level, may be the last remnant of our ability to retain our humanity.

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