Promoting health care decision-making capabilities of adults with intellectual and developmental disabilities

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Promoting participation of patients and their caregivers in health care decisions is central to person-centred care.[1,2] Family physicians in Canada are required by law to obtain informed consent for health care interventions from patients who are assessed to have decision-making capacity or from their legally designated substitute decision makers if patients are assessed to lack such capacity. People with intellectual and developmental disabilities (IDD) and others with similar cognitive and adaptive impairments, however, might need to be accommodated by care providers or to arrange decision-making support by committed and trusted caregivers who know them well in order to make informed health care decisions.[3] The United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD),[4] which Canada has ratified, recognizes the right of people with disabilities to have the supports that they need to realize their equal standing with others before the law. The "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines" also support this as an ethical right.[5] Legal policies in only a few provinces and territories of Canada (namely British Columbia, Alberta, Manitoba, Prince Edward Island, and Yukon) currently enable adults with IDD to exercise this right through some form of supported decision making.[6] Family physicians in other parts of Canada, however, can promote supported decision making of such patients when substitute decision makers cooperate. In this case, the family physician first makes adjustments to accommodate the patient and then arranges supported decision making to elicit the patient's life goals and preferences and help the patient to apply these to the health care decision. The family physician also facilitates discussion among the patient, caregivers whom the patient trusts, and the patient's substitute decision maker to arrive at a shared decision.

Case

Terry is a 52-year-old man with IDD in the moderate range (ie, mental age equivalence of 6 to 9 years). He has cerebral palsy, seizures, and dysarthric speech. You have been his family physician for a year. Terry comes to your office with 2 long-time group home workers. You know from previous visits that Terry usually communicates with the help of these caregivers as interpreters. Terry's only family member is a cousin who lives in another Canadian province. He is Terry's court-appointed guardian and substitute decision maker for health care matters. A recent note from Terry's urologist confirms that Terry has stage II bladder cancer. The note also states that the urologist assessed Terry not to be capable of deciding on medical care options, which you suspect was owing to Terry's difficulties communicating. The urologist telephoned Terry's cousin to discuss 2 options: either surgery, which is a potentially curative intervention for similar patients, or a palliative approach, with a prognosis for Terry of death within 2 years. The urologist and Terry's substitute decision maker had rejected the surgical option.

For Terry's visit to your family practice, you schedule more time, adapt your language to Terry's level of functioning, and engage the caregivers accompanying Terry to interpret his ways to communicate as usual. With their help, you assess that Terry understands that his cancer is life limiting and that he definitely wants to live well for as long as possible. You also ascertain that Terry needs help to judge the relative benefits, burdens, and risks of various medical care options in light of his goals and preferences. Terry indicates that he trusts the caregivers who are present to discuss these medical care options with him. They eventually express Terry's decision for the surgical option, which best aligns with his goals and preferences. You determine that Terry is able to understand and appreciate the various medical intervention options with the help of his supporters. This allows him to maintain an active role in decision making. You offer to engage with Terry's cousin and urologist on his behalf.

Discussion

This case illustrates how the framework of the UNCRPD, which acknowledges interdependency in decision making and equal standing before the law, can be implemented. The capability of being active and involved in health care decision making of adults with IDD depends on various factors: the type and complexity of the decision, the context in which decision making takes place, the decision-making capabilities that the person has, and the possibilities for adapting to the patient's needs

and arranging decision-making support. Therefore, a range of scenarios can be encountered. In each case family physicians should adequately assess whether the patient with IDD might need to be accommodated and whether he or she can make certain decisions if there are available supporters who can reliably interpret the patient's will and preferences and apply them to the decision. Some patients with IDD are able on their own to communicate, understand information, and appreciate possible benefits and burdens of various interventions, and be guided by their goals and preferences to select medical interventions. This is more likely if they are familiar with the health issue or if interventions are not too complex. Other patients might be capable of directing decisions as long as there are trusted people who can reliably interpret what matters to them (ie, their goals and preferences) and help them apply them to consider the relative benefits, burdens, and risks of medical care options. Still other patients are unable to participate very much or at all in the decision-making process, even with accommodations, or they might lack decision-making supports, or are unable to express their will and preferences in a way that another person can reliably interpret. Such patients, however, might have life histories that can inform their substitute decision maker's decision. For still others, the family physician might also need to be attentive to possible vulnerabilities of the patient. These include suggestibility and learned compliance or a history of impulsive or compulsive behaviour. They also include inappropriate taking over of decision making by supporters or substitute decision makers.

The urologist's role. In this case, the urologist's lack of familiarity with Terry and his manner of communicating highlights the appropriateness of collaborating with another health care professional, such as Terry's family physician, or with group home workers who have assisted Terry with daily care and who are more familiar with Terry and his ways of communicating. Before contacting Terry's substitute decision maker, the urologist could ask Terry whether he would like any of these people, or someone else, to be present at a meeting to discuss medical care options.

The guardian or other substitute decision maker's role. The court-appointed guardian, in this case Terry's cousin, does not know him well. He is entrusted with the responsibility by law of making decisions on behalf of Terry that are in Terry's best interest. Because you assessed Terry to be capable of making this particular decision with the assistance of supporters, his guardian should be encouraged to enable him to do so. Even if Terry were assessed to not be capable of either independent or interdependent supported decision making, there are often signs, such as a life history, that can illuminate the kind of person Terry is and his goals and preferences for care. These can inform medical care. Approaching the situation in this way would ensure that Terry remains at the centre of this decision.

The family physician's role. It is important for the family physician first to provide accommodations that will help Terry to convey and learn information relevant to this decision. Some examples include giving Terry options for the timing of appointments and ensuring an environment that reduces sensory overload, stress, and anxiety; adjusting communication to Terry's level of understanding (mental age equivalence of 6 to 9 years old or a grade 2 level); using visual cues and aids; and asking Terry whether he would like his group home caregivers, or someone else, to be included in assessing him and discussing his care options. A recent tool developed by the Developmental Disabilities Primary Care Program in Ontario describes these and other kinds of accommodations.[7]

The caregivers' roles. The caregivers in this case played a key role in providing Terry with decision-making assistance, such as by interpreting the way he communicates. They also supported his decision making by eliciting his goals and preferences and helping him to apply these to choose an intervention that best aligned with them. Terry understands that he has a life-limiting illness and that he wants something to be done so that he can live as well and as long as possible.

Facilitating supported decision making. In Canada, this approach of supported decision making can be used as an alternative to substitute decision making. It is legally authorized in different forms only in British Columbia, Alberta, Manitoba, Prince Edward Island, and the Yukon.[8] If Terry were to live in a Canadian province or territory that does not yet legally recognize supported decision making and arrangements, his guardian would need to be involved to authorize the decision. In this situation, the role of the family physician is to be an advocate for Terry and a collaborator in providing patient-centred care. Because, in this case, Terry's guardian does not know Terry well and made a decision for Terry without consulting him or others who knew him better, the family physician can offer to facilitate a discussion involving Terry, his guardian, and his caregivers. If agreement cannot be reached on Terry's best interest, then the family physician can refer them to a legally instituted body that adjudicates disputes regarding substitute decisions.

Promoting capabilities of adults with IDD to make independent or supported decisions is a fundamental goal of patient-centred care. For assessing such capabilities, the 2018 IDD guidelines recommend using a tool that is adapted to adults with IDD.[5] The Developmental Disabilities Primary Care Program has recently developed such a tool, as well as a related tool to promote safety in decision making by identifying factors that might undermine these capabilities.[7,9]

Conclusion

Adults with IDD have a range of decision-making capabilities that vary with the type of decision. Many adults with IDD, as well as those with cognitive and adaptive impairments, can exercise their right to make health care decisions independently with accommodations or interdependently when they are provided with decision-making support.

The right is recognized by the UNCRPD and affirmed by the 2018 IDD guidelines. Promoting decision-making capabilities of adults with IDD is also part of the CanMEDS–Family Medicine roles of family physicians to be advocates and collaborators for patient-centred care.[10]

Tools to assess decision-making capacity must be adapted to adults with IDD to assess their need for accommodations and decision-making supports, as well as factors that undermine their decision-making capabilities.

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Competing interests
None declared

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