Documentation of Capacity and Identification of Substitute Decisionmakers in Ontario

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Abstract: Documenting capacity assessments and identifying substitute decisionmakers (SDMs) in healthcare facilities is ethically required for optimal patient care. Lack of such documentation has the potential to generate confusion and contention among patients, their family members, and members of the healthcare team. An overview of our research at the Ottawa Hospital and issues that influence the consistency of documentation in the Canadian context are presented here, as well as ideas for the mitigation of these issues and ways to encourage better documentation.

Keywords: capacity assessment; substitute decisionmaking; healthcare consent; documentation; Canadian bioethics; advance directive

Introduction

A common theme in ethics consultations is disagreement between patients\families and the care team regarding the plan of care, especially as it relates to end-of-life care. What can complicate matters in these situations is a lack of clear documentation regarding patient decisionmaking capacity, patient wishes for care, and identification of an appropriate substitute decisionmaker. Without a clear understanding of these critical pieces of information, providers often struggle to meet basic ethical and legal standards that support respect for patient autonomy and appropriate care planning. It is commonly held and supported that healthcare providers may assume that their patients have the capacity to make decisions for themselves, unless there is evidence to suggest otherwise.[1,2] When this assumption can be made, there would be no need to formally assess patient capacity, but there should be clear documentation to indicate the providers' understanding of that capacity. The decisionmaking process becomes more complex when there is evidence to indicate that a particular patient's decisionmaking capacity is compromised in some way.

If there is reason to believe that a patient lacks capacity, an assessment must be done by the provider proposing the treatment. When patients are determined to lack decisionmaking capacity, a substitute decisionmaker (SDM) must then be identified to provide or refuse consent on the patient's behalf. All Canadian provinces and territories have legislation in place to protect patient rights in healthcare decisionmaking, including situations in which the patient may be incapacitated.[3] In Ontario, the criteria for assessing decisionmaking capacity and a hierarchy of SDMs are presented in the Health Care Consent Act (HCCA). For patients to have decisionmaking capacity, they must meet the standards of understanding and appreciation as set out in the HCCA in relation to a particular treatment or placement decision. Thus, patients can be capable with respect to one treatment decision and incapable with respect to another at the same point in time. Based on these criteria, patient capacity can also fluctuate over time; even over the course of a

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single day. In the event that patients are found to lack capacity, a SDM must be identified. In some cases, a patient may have previously indicated a preference for his or her SDM in the form of a power of attorney for personal care document, or by informally asking that a particular individual be approached for consent in the event of the patient's incapacity. In cases in which a SDM has not been identified by the patient, the HCCA describes a hierarchy of persons eligible to provide consent, as well as the rules for such decisionmaking.[4] Although capacity assessment and SDM identification are understood to be ethically and legally required in order to both respect patient autonomy and provide appropriate care, the actual frequency with which either or both of these processes is documented is not well known. Lack of such documentation has the potential to generate confusion and contention among patients, their family members, and members of the healthcare team.

Why Document Decisionmaking Capacity and SDMs?

Ethically, clear documentation of decisionmaking capacity and identification of the appropriate SDMs are significant for a variety of reasons. Primarily, this documentation supports respect for patient autonomy by recognizing the right of capable patients to make their own decisions, while also preventing incapable patients from consenting to treatment and interventions that are beyond their capacity to understand. By clearly documenting assessments of capacity and identifying SDMs, clinicians ensure that this information is accessible to the entire interprofessional team. There are often multiple clinicians involved in a single patient's care, particularly in the acute care environment, with staff physicians rotating on and off service, nursing staff going on and off shift, and other health professionals interacting with the patient. This environment is ripe for miscommunication and misunderstanding, especially if clinicians have only an informal understanding or impression of a patient's capacity or of the person identified as his or her SDM. Without appropriate documentation, there is a real risk that the different clinicians may not know if patient capacity is in question; this could result in obtaining consent inappropriately or obtaining consent from an inappropriate SDM. Given that the medical record is the recognized repository of clinical knowledge and history for the patient, this documentation must be properly chronicled so that all team members can have up-to-date, accurate information.

What Does the Literature Say?

There is paucity in the literature with regard to whether decisionmaking capacity is being documented and SDMs are being identified in the medical record. In a sample of 105 patient charts in a critical care unit in Toronto, Ontario, researchers found documentation of patient decisionmaking capacity in only 3.8 percent of cases. In the same study, SDMs were explicitly identified in only 10 percent of charts.[5] From an ethics perspective, such low numbers raise the question of who was making decisions for incapable patients and whether they had legitimate authority to do so under the HCCA.

In another recent retrospective cohort study of 17,744 mental health admissions in England, Penelope F. Brown et al. found documentation of capacity assessments in only 9.8 percent of cases. Furthermore, the researchers found reference to the

actual criteria for determining capacity in only 14.7 percent of these cases in which capacity was documented. This study examined documentation of capacity assessments in the context of the Mental Capacity Act being introduced in 2007 and found that this new legislation did not appear to have any "decisive and immediate effects on practice but provoked anticipatory change."[6] These results are concerning, given that one might reasonably expect significantly higher rates of capacity assessments (although not necessarily incapacity) in patients admitted for mental health reasons.

Another chart review by Anna Glezer et al. at Massachusetts General Hospital looked at documentation of capacity and identification of SDMs.[7] The authors reviewed the medical records of 38 patients with altered mental status, finding that only 15 had a SDM identified in their records. In looking at consent for lumbar punctures, the authors also determined that 25 of the 33 available consent forms were signed by substitute decisionmakers. In only 3 of these 25 cases was there any reference to decisionmaking capacity, although there was enough information to infer a lack of capacity in 21 of 25 cases. Of the 8 patients who signed their own consent, none had documentation of decisionmaking capacity. However, the authors state that in 3 of these 8 cases there was enough information to infer that these patients had capacity. Ultimately, the authors conclude that in most cases clinicians establish an informal understanding of patient decisionmaking capacity without ever documenting it. This raises the question of how such informal understandings of patient capacity are communicated throughout the interprofessional team. If the primary method of communication to other team members is via the medical record, then not recording these informal understandings creates an information vacuum. In other words, to quote an old adage, "if it wasn't documented, it didn't happen."

Our Findings

Our own research at the Ottawa Hospital revealed better documentation in general but with large gaps.

We reviewed a convenience sample of 100 patient charts, all of whom died as inpatients in the six-month period between July and December 2011. Formal documentation of capacity was found in only 14 cases. We determined in our review that in 41 of the remaining 86 records, no documentation of capacity was required or to be expected, because the patients in these cases were presumably capable, or obviously incapable. Provincial legislation presumes capacity in the absence of evidence to the contrary, and these 41 people met that standard. However, in the remaining 45 percent of cases, there appeared to be a genuine lack of clarity about whether or not patients were capable, without any corresponding documentation to guide providers.

Sixty patients in our sample of 100 had a SDM identified, and the average length of time from admission to SDM identification was four days. Given that almost all patients had previous contact with the hospital, in the form of either an inpatient admission or visits to clinics based at the hospital, it was interesting that it took so long to identify a SDM and that many people never had a SDM documented. There could be many reasons why this occurred, including time constraints, perception that the patient and/or family did not want to discuss SDM choice, patient refusal to discuss SDM choice, or physician discomfort with discussing the

identification of a SDM. Unfortunately, these reasons do not legitimately negate the need for a SDM to be identified.

Determining a patient's level of decisionmaking capacity and identifying a SDM relatively quickly on admission is good practice, given that disease progression could impact the ability of patients to make healthcare decisions on their own. Ethically, this gap in both the timing and frequency of identification of a SDM raises questions as to whether providers are promoting patient autonomy by involving them in discussions related to substitute decisionmaking, or whether they are simply defaulting to whoever is perceived as the appropriate SDM once the patient has lost capacity. Such situations can lay the groundwork for complex ethical and legal dilemmas related to appropriate decisionmaking.

As our study looked strictly at documentation, there were several limitations. One such limitation was that we had no ability to identify whether SDMs were utilized appropriately—that is, whether they were making decisions only when the patients had lost the ability to do so for themselves, or whether the treating teams were using the SDMs rather than involving the capable patients in conversations about their care. This has significant implications for both patient autonomy and informed consent. Another limitation is that we had no means to verify whether the person identified as the SDM actually *was* the SDM as per the regulatory requirement. It is entirely possible that in some cases the SDM was identified incorrectly. A final limitation was that we did not look specifically at whether SDMs followed the rules for substitute decisionmaking laid out in the Health Care Consent Act. This issue is touched on in a study by Mohana Ratnapalan et al., in which the authors note that although a treatment plan had been discussed with substitute decisionmakers, there was not always "a justification for the plan in relation to the patient's previous wishes."[8] Similar concerns are also highlighted by Eva C. Winkler, W. Hiddemann, and G. Marckmann.[9] This should be an area of further investigation.

What Resources Exist to Help Patients and Clinicians?

There are various regulations in provincial legislation across Canada that codify the rights of patients and the responsibilities of healthcare providers in determining capacity and seeking consent from SDMs.[10] Each province or territory has generated legislation to this effect, with notable differences among them. For example, some jurisdictions have not stipulated a hierarchical list of SDMs in the event that a SDM is not identified by the patient via either an advance care directive or another accepted institutional format. Manitoba, for example, does not currently have an act or code that deals with persons who become incapable over the course of a normal lifespan or disease progression; it only recognizes a process for SDM selection for incapable persons who have mental health issues. There are recommendations being made to change this legislation, and there are requirements for updating the legislation of other provinces.[11] It could be that legislation such as the HCCA no longer meets the needs of the people for whom it is intended. Understanding law as a basic ethic, legal documents should be regularly reviewed to reflect new evidence, changes in professional practice, or changes in society, so that they do not become out of date or irrelevant.

Alberta has the most recently updated legislation, with the new Adult Guardianship and Trusteeship Act (AGTA), implemented in 2009. There is an

accompanying Web site[12] for this legislation that provides forms and instructions for when a capacity assessment should be done and when to designate a SDM via a personal directive (PD). It even has an online registration process so that individuals can register the fact that they have a PD, and physicians can access this online registry to determine if one of their patients has such a directive and, if so, who his or her SDM is. Unfortunately, the PD itself is not made available through this registry. This does, however, offer a realistic alternative to relying on patients to bring hard-copy PDs to a hospital, and it certainly provides greater consistency than querying patients and family members during a hospital stay. It is also respectful of the increasing interest in electronic recordkeeping that reflects the movement of our society to managing documentation—including healthcare documentation—electronically or online.

Many hospitals or regional health centers have created documents that outline the basic information from relevant legislation and provide links or printed material for patients and clinicians to refer to. However, the fact that documentation is created does not mean that it necessarily reaches the people it needs to; there are no statements that explicitly require such documentation to be placed in a patient's medical record.

What Are the Barriers to Capacity Documentation and SDM Identification?

Ease of access to documents that are written for the lay person is necessary for the general public to understand the relevance of capacity assessment and SDM identification. In Canada, there is a national approach to universal access to healthcare, but the actual regulation of care is provincial. It would be difficult to envision an agreement between all provinces for such documentation that would manage expectations for patients in all jurisdictions in relation to capacity assessments and identification of SDMs. As an example, standardization of practice that has been successfully implemented at a national level can be seen in the Patient Self-Determination Act in the United States.

Also, because Canada is a cultural mosaic, patients in our healthcare facilities are extremely culturally diverse. Accommodating such cultural differences with regard to decisionmaking can be difficult, even when legislation and ethical guidelines are present. When clinicians, patients, and families come face to face, there is no amount of legislation or support that can mitigate all potential conflicts arising from varying cultural or religious beliefs. This might partly explain why there are more informal capacity assessments and why identification of SDMs is suboptimal.

In addition, physicians and other health professionals regularly move between cities and even provinces, so it is likely that they carry previously learned ideas and behaviors with them; this may include understandings of legislation or clinical practices from mentors and institutions. Orientation of new physicians to an institution should require an introduction to the appropriate processes for capacity assessment and SDM identification within that province. Provision of information and resources to support good clinical practice needs to be consistent, and the access to them needs to be easy. It is interesting, for example, that few of the Web sites for the provincial colleges of physicians and surgeons have links to provincial legislation on capacity assessment and SDM identification; the Canadian Medical Association also does not provide links to provincial legislation on this issue. There are currently no acknowledged best-practice guidelines that exist in

the literature for discussion of SDM identification and assessment of capacity with patients in Canada or other Western countries. More consistent training for clinicians and strong cross institutional processes can aid in supporting these discussions that need to take place between clinicians and their patients.

What Is Needed?

The following list illustrates what is needed to improve the current state of affairs.

1) We need better public engagement. Most non–healthcare professionals have only a cursory understanding of these issues. To meet this need, we are currently developing literature to engage and inform the public, with the goal of increasing the frequency of completion of advance directives and identification of SDMs. This could easily be expanded to a national level.
2) Greater consistency or a standard of training for physicians to document both capacity and SDM identification would improve communication among the patient, clinician, family members, and healthcare team. Even clinicians can have difficulty interpreting, understanding, and adhering to applicable legislation such as the HCCA, particularly when they don't receive any specialized education and training on the subject. To address this need, we have

    a. Carried out applied research to gather data on what is actually occurring
    b. Taken the results of this research to develop programming to educate physicians and other providers on the subjects of decisionmaking capacity and identification of SDMs

3) Empirical evidence is also required in order to understand the true frequency of documentation, the nature of documentation, and how decisions are being made in the presence or absence of such documentation. To date, anecdotal evidence and secondary analyses suggest that documentation is definitely not consistent. In order to understand how to change or improve a process, it is important to have a concrete understanding of how the current process works. Similar to what we have done, organizations should aim to address this need by undertaking continuous quality improvement (CQI) initiatives by gathering the evidence needed to change practice and promote necessary changes.

Conclusion

Based on the literature, there is no reason to believe that practices are significantly better beyond the borders of Ontario, within Canada, or even internationally. Although healthcare falls under provincial jurisdiction in Canada, the guidelines and legislation are sufficiently similar across the country to suggest that providers in different locations are struggling with similar issues. These similarities also lend themselves to taking a more global view of these issues and illustrate that pan-provincial organizations such as the Canadian Medical Association could take a leading role in effecting change.

Our own research findings ultimately suggest that although SDMs are being identified in many patient charts, documentation is definitely not at the level that

it could be, and care providers are not explicitly documenting capacity nearly as frequently as they should. Because the HCCA upholds a presumption of capacity and makes no requirement to document the capacity status of a patient, healthcare providers may have established an informal sense of the patient's capacity without seeing a need to document it, as stated earlier. This is problematic because these informal impressions may be inaccurate.[13,14,15] Detailed chart documentation is part of good clinical practice, and there is room for improvement in this area, especially in the explicit documentation of patient capacity. With the ongoing focus on patient-centered care and the promotion of patient autonomy in Canada, good communication and documentation is as critical in this area as it is in communicating disease progression or symptomology. Without regulatory or professional bodies making this issue a priority, there continues to be significant risk that patients' wishes are not being respected, that persons who are not legitimate SDMs are making decisions, and that incapable patients are providing their own consent.

Notes

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