



# Navigating disagreement and conflict in the context of a brain-based definition of death

## Se frayer un chemin entre désaccords et conflits dans le contexte d'une définition cérébrale du décès

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**Abstract** *In this paper, we discuss situations in which disagreement or conflict arises in the critical care setting in relation to the determination of death by neurologic criteria, including the removal of ventilation and other somatic support. Given the significance of declaring a person dead for all involved, an overarching goal is to resolve disagreement or conflict in ways that are respectful and, if possible, relationship preserving. We describe four different categories of reasons for these disagreements or conflicts: 1) grief, unexpected events, and needing time to process these events; 2) misunderstanding; 3) loss of trust;*

*and 4) religious, spiritual, or philosophical differences. Relevant aspects of the critical care setting are also identified and discussed. We propose several strategies for navigating these situations, appreciating that these may be tailored for a given care context and that multiple strategies may be helpfully used. We recommend that health institutions develop policies that outline the process and steps involved in addressing situations where there is ongoing or escalating conflict. These policies should include input from a broad range of stakeholders,*

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including patients and families, as part of their development and review.

**Résumé** Dans cet article, nous discutons des situations dans lesquelles un désaccord ou un conflit survient dans le contexte des soins intensifs en ce qui concerne une détermination de décès selon des critères neurologiques, y compris le retrait de la ventilation et d'autres assistances somatiques. Compte tenu de l'importance pour toutes les personnes impliquées de déclarer une personne décédée, un objectif primordial est de résoudre les désaccords ou les conflits de manière respectueuse et, si possible, de préserver les relations. Nous décrivons quatre catégories différentes de raisons causant ces désaccords ou conflits : 1) le chagrin, des événements inattendus et le besoin de temps pour accepter ces événements; 2) les malentendus; 3) la perte de confiance; et 4) les différences religieuses, spirituelles ou philosophiques. Les aspects pertinents du milieu des soins intensifs sont également identifiés et discutés. Nous proposons plusieurs stratégies pour gérer ces situations, en étant conscients que celles-ci peuvent être adaptées à un contexte de soins donné et que plusieurs stratégies peuvent être utiles à appliquer. Nous recommandons que les établissements de santé élaborent des politiques qui décrivent le processus et les étapes nécessaires pour faire face aux situations où il y a un conflit en cours ou qui s'intensifie. Dans le cadre de leur élaboration et de leur examen, ces politiques devraient inclure les commentaires d'un large éventail d'intervenants, y compris les patients et les familles.

**Keywords** conflict · critical care · determination of death · disagreement · ethics

Many situations in critical care/intensive care units (ICUs) are difficult to navigate for patients, substitute or surrogate decision makers (SDMs), family, and health care teams. These situations include emotional responses, considerations related to prognosis, and decisions about whether to continue or withdraw medical interventions.<sup>1-3</sup> The desire to respect a patient's expressed end-of-life wishes, values, or best interests, and challenges related to communication and understanding in a complex, changing, stressful environment is also included.<sup>4-6</sup> Some of the most challenging and distressing situations are those in which there is disagreement or conflict between an SDM and family, and the health care team in relation to a *brain-based definition of death* (BBDD) and the *determination of death by neurologic criteria* (DNC).<sup>7,8</sup> This disagreement or conflict may also extend to questioning the removal of ventilation and other somatic support following DNC.<sup>9-11</sup>

While there have been and will continue to be efforts to increase awareness and understanding of BBDD and DNC, disagreement or conflict will likely occur in a pluralistic society, such as Canada, and reasonable accommodations in some instances will be appropriate.<sup>12-14</sup>

We note upfront that there are many associations with the terminology of “disagreement” and “conflict.” Many of these associations are predominantly negative, in that situations of disagreement and conflict are often described as creating distress and interfering with making decisions or providing appropriate care (which may include withdrawal of medical interventions or removal of somatic support). This framing of conflict also typically suggests that it is experienced by the health care team or individual clinicians and the SDM and family as “being against each other,” which contributes to feelings of frustration, sadness, or anger. Accordingly, there is a need both to unpack the reasons that may underlie these situations of conflict and to develop and use approaches that address these situations in ways that are compassionate, respectful, and fair, and hopefully will contribute to finding a way forward together.

In the next section on Methods, we provide an overview of the key values and principles that inform and provide the foundation of this work. This is followed by a detailed discussion of four different categories of disagreements or conflicts that may arise, along with several suggested strategies for resolving them.<sup>10,15</sup> These are not meant to be read in isolation but are meant to highlight different ways of understanding and navigating disagreements or conflicts that may occur in relation to BBDD and DNC. In the following section, we then discuss some additional relevant aspects of the critical care setting for navigating disagreements or conflicts well. The final section of this paper addresses the possibility of reasonable accommodations and the role of policy in providing a clear process and next steps in situations where navigating conflict has become particularly challenging.

## Methods

The members of one of the subgroups of the Legal and Ethics Working Group (C. S., K. L. A., M. H., A. K., R. Z. S., T. P.) developed the key questions and areas of focus for this paper. An extensive literature search was conducted using several search terms (e.g., disagreement, conflict, end of life, critical care, ICU, withdrawing, strategies, communication) across several different databases (e.g., PubMed, CINAHL, PsychINFO, EBSCO, and Philosopher's Index). Theoretical analysis and critical reflection on core ideas, key positions, relevant values and principles, and a range of possible and actual cases/

situations further informed an iterative discussion-based consensus process. This process included additional discussion with other members of the Legal and Ethics Working Group, as well as contributions from authors on related papers (N. B. M.), and a member of the guideline development panel (A. H.). Overall feedback and direction from the guideline development panel were also incorporated into this work.

### *Values and principles*

It was acknowledged early on in this work that there are several ethical values and principles that provide a foundation and guidance for navigating disagreement and conflict. At the broadest, these include those that underlie the Canadian health care system, professional practice, and codes of ethics,<sup>16</sup> and the organ and tissue donation and transplantation system.<sup>17,18</sup> The curated list of ethical values and principles in the [Table](#) emphasize those that are particularly relevant in situations where BBDD and DNC may be contested. As with many difficult issues, tensions between these values and principles exist (e.g., between respecting persons and stewardship of health care resources).<sup>11</sup> These tensions add to the moral distress that all may experience in situations of disagreement or conflict, even while recognizing that those involved may weigh and prioritize the relevant values and principles in different ways.

The first set of values and principles is substantive (i.e., provides the *basis* upon which decisions should be made), while the second set is process oriented (i.e., provides guidance about *how* decisions should be made). It is recognized that these values and principles are Western focused; disagreement about some of these values and principles may be a source of conflict in and of itself as well. Nevertheless, our intent here is to reflect a commitment to democratic values and processes for navigating disagreement or conflict in a Canadian context. These values and principles are particularly important when considering what strategies may be most appropriate to employ when disagreement or conflict is not obviously resolvable.

### **Reasons why disagreement or conflict may arise and related strategies**

The purpose of the following is to identify some of the reasons why SDMs and family may disagree with BBDD and DNC, along with potential strategies that may assist health care providers in navigating these types of disagreements or conflict. While specific strategies are identified in connection to each reason, several strategies

could be used in tandem and across the range of situations of disagreement or conflict described below. Additional strategies are included in the following sections of this paper.

These four categories of reasons for some disagreements or conflicts are presented separately here for the purposes of clarity and description. In practice, these sources of disagreement or conflict may overlap or coexist in specific situations, or, as time passes, some reasons contributing to disagreement may be addressed (e.g., such as the emotional processing aspects) while others may become more prevalent (e.g., such as the religious or spiritual considerations). Being familiar with these different categories of reasons should assist with exploring what is happening with a particular SDM and family and with checking one's own assumptions about what is the "root cause" of a specific disagreement or conflict.

The role of communication in facilitating the development of a good relationship with the SDM and family is vital. While this is something that should be strived for in every clinical encounter, it becomes even more important in the context of disagreement or conflict. Several strategies suggest ways in which to approach, adjust, and/or revise how and when information is shared to help increase the likelihood of communicating well. These strategies are also about conveying empathy and respect, particularly in situations where disagreement or conflict is present. Finding ways as health care providers to share power—e.g., by offering SDMs and family opportunities to perform important rituals, say goodbye, or be present for the DNC clinical examination—can go a long way to maintaining and even rebuilding relationships that may be strained. And, in the context of a sometimes rapidly changing environment like the ICU, talking with SDMs and family about things like what typically happens in this setting, who is involved in providing care for their loved one, along with what discussions will likely occur (e.g., updates, some topics might involve hard or uncomfortable decisions) can also provide a basis for developing a good relationship with SDMs and family, and for navigating any disagreements or conflicts, should they arise.

### *Reasons for not accepting or acknowledging BBDD and DNC*

#### 1. GRIEF, UNEXPECTED EVENTS, AND NEEDING TIME TO PROCESS THESE EVENTS

Many situations involving DNC are precipitated by an unexpected, traumatic event that causes the patient's death, meaning these situations are relevantly different from those in which patients have been previously diagnosed with a

**Table** Values and principles

<b>Substantive</b>	
Respect for persons	Fundamental for establishing how all are to be treated; includes dignity and respect for autonomy
Trust	A belief in the reliability and/or ability of another; key aspect of therapeutic relationships
Compassion	Sensitivity and responsiveness to the suffering of others
Pluralism	Recognition of the validity/value of different systems of beliefs
Equity, diversity, inclusion	Integrating antiracist and antioppressive approaches in health care and providing health care based upon the medical needs of the individual
Humility	Maintaining an openness with others in relation to their beliefs and the facets of their identity that matter most to them (e.g., cultural, gender, age, etc.), <sup>42</sup> including reflecting on one's own beliefs and identity
Duty of care	As part of a fiduciary relationship, to provide care in accordance with standards
Patient- and family-centered care	Focuses on how care is designed and delivered from the perspectives of patients and families
Professional integrity	Is the ability to practice in line with one's professional standards
Stewardship	Making the best use of available resources
Trauma-informed practice	Supporting safety, choice, and control as part of integrating an understanding of past and current experiences of violence and trauma in health care
<b>Procedural</b>	
Consistency	Making decisions in similar, predictable ways in similar circumstances
Flexibility/responsiveness	Ensuring that decisions consider relevant differences in context
Procedural justice	The use of fair processes to address conflict and make decisions
Transparency	Communicating both about the process and content of decisions

disease or illness, where both the patient and SDM have had time to adjust to this news and process what is happening. First, there is the initial distress of the event (e.g., car accident, drowning, cardiac event, or drug overdose). Second, many of these situations often involve persons who are relatively young, and this may add to the difficulty of accepting what has happened. Third, there may also be difficulty with acceptance given that, while health care providers are informing them that their loved one has died, their physical appearance may give the impression otherwise (this may contribute to misunderstanding as well, see below).<sup>19</sup> Patients who meet the requirements of DNC often appear to be in a deep sleep and feel physically warm to the touch.<sup>20</sup> For these and other reasons, SDMs and family may have difficulty processing, accepting, and/or acknowledging the death of their loved one. They are in a new circumstance, and they have to adjust to new information, potentially new health care providers, and process their own grief.<sup>21</sup>

There is often a high focus on technical procedures in a complex, fast-paced setting like an ICU. These aspects of care are essential and a necessary aspect of the care that is provided for patients. Nevertheless, the technical focus may sometimes “crowd out” or tend to have the effect of deprioritizing discussions with SDMs and family, including addressing their grief. This may contribute to not establishing a good connection with the SDM and

family initially and on an ongoing basis. This could potentially contribute to heading “down the path” of disagreement or conflict when this may have been avoidable. Taking advantage of opportunities to develop or improve the relationship with the SDM and family by providing openings to discuss what they may need, not only in terms of information but also emotional support, will be useful and most often welcome. For some SDMs and family, the use of silence—i.e., “sitting in silence” together—can be a powerful way of connecting and being present with them.

In the pediatric context, this also includes being alert to whether the SDM and family are struggling with what a “good parent” should do in this circumstance and/or whether accepting DNC means giving up on one’s child. These questions or concerns have been identified in other pediatric settings as well.<sup>22,23</sup> Likewise, in the adult setting, SDMs and family can struggle with guilt about “letting go” or following a loved one’s wishes as well as wondering about being a “good daughter or son.” Thus, engaging the SDM and family in discussion about these potential concerns can be very helpful as part of addressing their grief; it also opens the possibility of sharing the burden of decision making.

The above emphasizes the importance of tailoring communication strategies to the needs of the SDMs and family, taking cues from them about what may be most

needed and useful. Every case in which a patient dies is unique, and there will often also be interfamily dynamics at play. This means health care providers may need to use different strategies even among a single patient's family.

When thinking of how to bridge the need for SDMs and family to process what has happened, six strategies include:

1. Provide SDMs and family with information in a safe setting. For many, this will be a setting that is private, but for others it may mean staying close to their loved one. Accordingly, it may be helpful to ask, "where would you feel most comfortable speaking together?"
2. Provide SDMs and family with information early in the process. Before undertaking DNC and the confirmation tests, inform them that their loved one may have died.<sup>19,24</sup>
3. Ensure frequent contact with SDMs and family such that they have the opportunity to process their grief, the information shared with them, and have time among themselves to consider and raise any questions.<sup>25</sup> As appropriate, sharing that other families have similarly struggled may assist with normalizing what they are experiencing.
4. Enable SDMs and family to have support present during clinical conversations. These support persons may be identified by the SDMs and family and/or may include the offer of support such as social work and spiritual care.<sup>19</sup> It may also mean using telehealth to include other family members or support persons in key discussions.
5. Offer the opportunity for SDMs and family to be present while undertaking the clinical tests for DNC if this would be helpful or desired.<sup>19</sup>
6. Appreciate that different SDMs and family will have different informational needs and requests. This may include repeating information that was previously shared, providing information in different formats (e.g., verbal, written), addressing grief, and responding to other needs, such as guidance about how to explain what has happened to extended family or friends.<sup>19,26</sup>

## 2. MISUNDERSTANDING

There are many factors that may impact and influence whether, when, and how SDMs and family understand that their loved one has died, including how this has been determined. Being cautious with respect to assumptions about what should be familiar to or known by SDMs and families, based on such things as education levels or their respective vocations/occupations, is essential.<sup>27</sup> For example, there may be situations in which a health care provider is engaging with a family that includes doctors or nurses and for whom additional information and support

will be highly needed and appreciated, whereas other similarly situated families may require much less information and support. Communication strategies to reduce the likelihood of misunderstanding should consider characteristics of the SDM and family, such as the degree of familiarity with the Canadian health care system, preferred language, and hearing or visual impairments.<sup>28</sup> Key contributors to misunderstanding—and thereby to disagreement or conflict—include mixed messages about the meaning of BBDD, about how DNC is conducted, and about the impact of confounding factors.<sup>19,24</sup> Clear communication, tailored as much as possible to the needs of particular SDMs and families, will help minimize the possibility of misunderstandings about these core concepts. This could also include explaining why their loved one's appearance may be different from what the SDM and family might expect (as noted above).

If the involved health care team members do not feel prepared or supported in having these types of discussions with SDMs and family, this can also contribute to misunderstanding (and to disagreement or conflict). Approaches to help prepare and support the health team may include additional training and skill building for team members for navigating conflict as well as, more specifically, increasing understanding and awareness among the team about BBDD and DNC, and developing a common, consistent set of language, phrases, and descriptions that are used by the team when discussing BBDD and DNC.<sup>19,29</sup>

For example, this may mean switching descriptions from "the prognosis is poor" and "things are looking bad" to "your loved one/child may have already died or may be dying" when it is certain or highly probable that the patient has died or that the patient will proceed to die and meet the requirements for DNC.<sup>19,29</sup> The words "dying," "died," and "dead" tend to be clearer in terms of meaning. Other ways of sharing information may include phrasing along the lines of: "We'll do everything we can now to give your loved one a chance and will assess to see if there are signs of life in a few days' time" and "When someone dies, this is what typically happens next (e.g., removal of the ventilator ...)."<sup>19,29</sup> Consider switching descriptions from "life support" to "ventilator-dependent breathing" or from "patient" to "loved one" to help make the distinction between persons who are alive and receiving ongoing critical care, from those who already have died.

Overall, things like continuing (or not) to chart, how a loved one is referred to, and what changes in the routines surrounding a loved one before and after DNC may occur, provide signals to SDMs and family about what is happening—and to the potential for misunderstanding. Taking advantage of these openings to share the "big" picture, put things in context, and share what to expect with



SDMs and families can be quite helpful. One would be remiss not to acknowledge that these situations involve SDMs and families experiencing a highly stressful event that typically causes immense grief, as discussed above. This grief can greatly impact the dynamic between health care providers, SDMs, and family in conjunction with the possibilities for misunderstanding(s) outlined.

Five strategies to reduce misunderstanding include:<sup>30</sup>

1. Conduct short conversations regarding information. After discussing each aspect of the patient's situation, stop and ask the SDM and family if they have any questions. While information must include medical information, relay it in a manner that the general public can understand.<sup>19</sup> Too often, health care providers desire to relay all of the information at once regarding a patient, but the SDM and family may only be listening, hearing, or comprehending certain aspects. Breaking down conversations can be useful to gauge how SDMs and family are understanding the information being relayed. Given the complexities of BBDD and DNC, pacing information, signaling what is coming next, and addressing questions and concerns can make a significant impact on understanding and in building a good relationship with the SDM and family.
2. Use interpretive or translation services. While it is generally recommended that a professional interpreter or translator should be used in these situations, there are many circumstances where a health care provider who speaks the language may be called upon or that there may be interfamily interpretation. In general, having an unbiased interpreter or translator increases the chance that accurate information is being relayed, which can be particularly important in cases where DNC will occur. Involving the interpreter or translator in a planning meeting or ensuring that they are appropriately briefed about the upcoming discussion with the SDM and family, as possible, may also assist with increasing accuracy and clarity.
3. Provide and use educational aids and assists to increase the chance of informational dissemination.<sup>19</sup> For example, showing visuals or imaging to SDMs and family can help show the lack of brain function of the patient (noting that this also requires sufficient explanation about what one is looking at and looking for to assist in allaying questions). Substitute or SDMs and family can also refer back to educational materials later.
4. Repeat information, as often as needed. It can be important to have more than one family representative in meetings, as family can then discuss this information among themselves as well. Often in family meetings, there will be different individuals

who process different aspects of the medical information being shared.

5. Develop and implement processes to help ensure that consistent messages are provided to the SDM and family. This may include, for example, having a bedside nurse present at family discussions so that they are aware of what information has been shared and/or having an ICU staff member present when outside clinical staff meet with the SDM and family.

### 3. LACK OF TRUST

A significant consideration regarding BBDD and DNC is that SDMs and family may not trust health care systems, health care institutions, or health care providers. Reasons for this distrust may include 1) negative experiences with current health providers, institutions, or systems; 2) negative experiences with health care providers, systems, or institutions in the past, either the SDM's or family's own experiences or other experiences that the SDM is aware of;<sup>31</sup> 3) institutional racism and/or previous discrimination;<sup>32</sup> 4) previous diagnoses or health care encounters in which an SDM and family may have been told that their loved one would not survive, would not improve, or would die within a period of time in which that did not occur; and 5) the imbalance of power between the SDM and family, and the health care team—which is particularly pointed in the context of DNC, including the sharing (or not) of information and deciding what tests are done (or not) and when.

Negative experiences in which SDMs and families do not trust health care providers, systems, or institutions are not unique to the situations under consideration in this paper and are a constant reality in health care. These experiences could be based on the current admission to hospital or on previous situations and often leave a lasting impression on individuals. Lack of trust based on negative experiences is difficult to overcome because individuals may not bring this forth in current conversations (especially considering the power imbalance). Trust is difficult to earn and easily lost. Unfortunately, in critical care generally and in situations where there may be dispute about BBDD and DNC, the opportunity for a long-standing relationship with an SDM and family to build this trust is usually not available. Thus, transparency and honesty from the beginning of care are of utmost importance in (all) interactions with SDMs and family. These “opening moments” and first conversations with SDMs and family can set the tone for what follows.

Transitions or rotations among the attending physicians and other team members may also affect continuity of care or perceptions thereof by the SDM and family and may

impact the possibilities for trust. Paying attention to whether there will be rotations among the health team members at key junctures, such as who conducts the DNC and/or the removal of ventilation and somatic support, may be particularly important. Determining who on the team may be able to have key discussions with the SDM and family over time, serving as a primary point of contact, will often be very helpful. In some instances, this may mean involving the medical lead for the unit or another person in a related leadership role to facilitate this continuity and to provide additional support for those involved.

With respect to a lack of trust that stems from experiences of racism and oppression, this also means critically examining the ways in which care is provided overall from a place of humility and with a patient- and family-centered perspective. This includes making changes that can further contribute to increasing trust, such as implementing trauma-informed practice (see Table). While health care teams and health institutions are becoming more diverse over time in Canada, we recognize that these settings are still predominantly populated with persons who are White/settlers and that, for many from equity-deserving groups, health care institutions are associated with historical and current trauma(s). When the stakes are high—as they are with determining if a person has died—the impact and influence of this broader context on the relationship, and communications, between the SDM, family, and health care team must be considered and addressed as much as possible to help prevent and facilitate navigating any disagreement or conflict. As health care institutions become increasingly committed to reconciliation with Indigenous communities, this may provide additional mechanisms through which trust can be cultivated with SDMs and families.

Six strategies for (re-)building trust include:<sup>33</sup>

1. Acknowledge previous experiences the SDM, family, or patient has had and highlight the differences in circumstances as appropriate. This can be done by asking SDMs or family if they have ever had a similar experience or experience within a critical health care situation.
2. Listen actively to SDMs and families and validate their feelings and concerns.<sup>34</sup> This includes being attentive to issues, among others, that may relate to transitions in the health care team and/or the need for a primary point of contact.
3. Invite spiritual health, Indigenous health, social work, or ethics resources into conversations with the SDM and family. If the spiritual and/or cultural partners or resources are external to the health institution, it may be helpful to discuss mutual expectations and understandings of what the invitation into these

discussions means and may involve. This may also be something to explore with the SDM and family with respect to their interest in these forms of support and what their respective role(s) may be.

4. Seek a formal second opinion inside or outside of the current health institution (see further discussion in “Role of policy,” strategy number 2, below).
5. Ask the SDM and family if they have a family doctor or nurse practitioner (or other regular health provider) with whom they have a good relationship, and whether it would be helpful to connect with this clinician.
6. In particularly complicated situations in which trust seemingly cannot be built, it may be appropriate to identify or find another health care provider who may be able to connect with the SDM and family. These may also be situations in which policies (discussed below) can assist with providing guidance as to next steps and setting expectations.

#### 4. RELIGIOUS, SPIRITUAL, OR PHILOSOPHICAL DIFFERENCES

Some SDMs and family have beliefs that are either formally or informally grounded in religion or spirituality that come into conflict with BBDD.<sup>35,36</sup> While there are documented religious practices that do not support the notion of BBDD, many SDMs and family may not connect their rejection of BBDD with a formalized religion or spiritual practice. While their beliefs may not align doctrinally with formal spiritual or religious beliefs, this lack of doctrinal consistency does not thereby negate their beliefs. Nevertheless, it can make it more challenging for health care providers who may then associate a rejection of BBDD on religious grounds as inaccurate. When SDMs or families reject BBDD (or refuse testing for DNC) based on religious, spiritual, or other philosophical beliefs, it is often more challenging for health care providers as they want to respect the beliefs of the patient, the SDM, and family while simultaneously balancing that the patient has died, and ongoing medical interventions are futile and should be removed. In these situations, health care providers may experience moral distress due to these conflicting values and beliefs and may also (come to) feel that continued somatic support is disrespectful to the body of the deceased person.<sup>12</sup>

While there are individuals who will reject BBDD based on religious, spiritual, or philosophical beliefs, there are also individuals who may not outright reject these concepts but may invoke miracle language. The use of miracle language, and hope for such a miracle, is not uncommon in clinical care settings, particularly in critical or end-of-life situations.<sup>37</sup> It may be helpful to explore what the expression of a hope for a miracle means for an SDM

and family<sup>37,38</sup> even in situations where a patient is DNC and there is objectively no chance of recovery. Such a declaration may be indicative of spiritual or religious beliefs or may simply be an expression of a wish that things could be different, while still accepting what has happened. Miracle language also could be a mechanism to create a separation between the SDM and family from the health care team and may overlap with or indicate a lack of trust, as discussed above. Appreciating that individual health care providers may feel uncomfortable engaging in miracle language conversations, it is often worthwhile to consult allied health providers (such as spiritual care providers) who may be able to engage further with the SDM and family in relation to discerning the basis for the miracle language, and whether there are religious, spiritual, or philosophical beliefs that underlie their questions or concerns about BBDD.

Drawing on other supports and resources within the team or health institution can also sometimes facilitate a “restart” in establishing a connection with the SDM and family. This can convey the value placed on the relationship with them, even in the midst of ongoing disagreement. Rather than expecting “the other side” (the SDM and family) to come to agree with everything that is happening or to shift their beliefs to now accept BBDD, consider what can be agreed to for next steps as a mechanism for moving forward. Distinguishing, for example, between the ending of the “clinical journey” for the patient and the spiritual or relational journey that may be ongoing may be helpful for an SDM and family to agree to the removal of ventilation and somatic support while feeling respected in their beliefs.

Some SDM and family beliefs may be focused on end-of-life rituals that accompany transitions from life to death and not be in direct opposition to BBDD. For example, an SDM and family may agree that the patient meets the criteria for DNC from a clinical perspective; however, they may also hold a conviction that religious and spiritual practices must occur in order for their loved one to peacefully transition to an afterlife. Or the SDM and family may want to find ways to respect or uphold the end-of-life wishes expressed by the patient. Thus, being careful about what one assumes in relation to a disagreement or conflict based on religious, spiritual, or philosophical beliefs is vitally important. Being curious about and seeking to better understand what is at issue for an SDM and family may identify opportunities for agreement. This may include ways for the SDM and family to feel respected and empowered by having some level of control in a situation where SDM and family often feel powerless or limited in what they can contribute or do in honor of their loved one.

Four strategies in scenarios in which an SDM and family are raising religious, spiritual, or philosophical concerns regarding BBDD include:

1. Discuss with the SDM and family their beliefs and the beliefs of the patient.
2. Involve allied health providers or outside spiritual practitioners to further explore and enable these discussions. Ensuring that these persons have a grounding in the concepts of BBDD and DNC will be helpful in providing a foundation for these conversations.
3. Acknowledge and explore the use of miracle language to learn more about its meaning for an SDM and family (e.g., is it spiritually based or an expression of a wish that things could be different?).<sup>37,38</sup>
4. Identify ways to support/enable the SDM and family in practicing their beliefs with or over the patient, such as performing key rituals related to end of life and transitions between life and death.

### **One’s own role: reacting and responsibility**

There may also be times in situations of disagreement or conflict where things escalate because of the behaviors, comments, or (in)actions of the health care providers. While this may occur in other care situations in the ICU, this may be more likely when there are differing perspectives on the meaning and implications of BBDD and DNC. Disagreements about religious, spiritual, or philosophical beliefs may sometimes be experienced as an affront to the professionalism or experience and training of the involved health care providers. The lack of trust may be taken quite personally rather than recognizing this may stem from previous experiences with the health care system. Disagreement or conflict may exacerbate feelings of powerlessness or loss of control, not only for an SDM and family but also for the involved health care providers. As such, health care providers may potentially react more strongly and in negative or less helpful ways in situations of disagreement or conflict, especially if they are already overly stretched with demands.

Due to the high degree of stress and burnout in critical care, those who work in this setting “may ... be manifesting maladaptive responses to their own daily stressors in and out of the hospital.”<sup>28</sup> This may then constrain or limit the likelihood of navigating disagreement or conflict well with SDMs and families. There is no simple solution to these possible contributing factors to disagreement or conflict. They do speak to the need for awareness of one’s own style<sup>39</sup> and approach to conflict, and whether or how some of the abovenamed stressors and



perceptions about the relationship with an SDM and family, judgements about their beliefs, or level of understanding may be influencing what is happening. It also means taking responsibility and being accountable to SDMs and families for one's own behaviors and actions, much in the same way that there are expectations outlined for how SDMs and families ought to behave in the ICU setting (e.g., visiting hours, number of family members in the unit at one time).

Putting in place and drawing on additional support for health team members in these situations will also help address moral distress, anxiety, and burnout—whether directly related to BBDD- and DNC-related conflict or not. This support may include department leadership checking in with the team after a difficult meeting and/or providing opportunities for teams to debrief during and after challenging cases. It may also mean checking in with the nursing staff directly to help address issues and provide support on a day-to-day basis. If available, an in-house psychologist may be able to offer individual or team-based sessions as well. As appropriate, making the organization aware of challenging situations and seeking additional guidance may be helpful—especially if, as outlined below, there may be a need to activate or follow the processes outlined in a policy regarding accommodation.

### Accommodations?

Even when there has been excellent communication and a genuine attempt to find a way forward together, a divergence in views between a health care team and an SDM and family may continue, escalate over time, or seem unresolvable. As noted above, and as discussed in other papers in this Special Issue,<sup>12–14</sup> these situations may be more likely to arise when there are fundamental differences in religious, spiritual, or philosophical beliefs between the SDM, family, and health care team about BBDD and DNC.

To show respect for diversity within a pluralistic society such as Canada, attending to what may be appropriate from the perspective of reasonable accommodations, including processes related to such accommodations, becomes legally and ethically important. Along with the relevant legal backdrop for considerations related to reasonable accommodation,<sup>13</sup> it is also worth noting that discussions about what is or is not possible to do are intertwined with, and ought to include, considerations of power and privilege. While there is a clear need for a definition of death within the clinical setting,<sup>13</sup> the ways in which specific situations of difference are addressed, how SDMs and families with differing views are treated, and what efforts are undertaken by health care teams and health institutions to come to some form of resolution say much

about how we understand our obligations to each other as part of a pluralistic, democratic society.<sup>12</sup>

### The role of policy

One mechanism that can assist in upholding these commitments is through health institution policy. When there is ongoing and/or escalating conflict, a more structured or formalized approach for managing these situations can be particularly beneficial. This structured approach should be described in health institution policy. This policy should include input from a broad range of stakeholders, including patients and families, as part of its development (including revisions and/or review).<sup>12</sup>

Various benefits that may stem from having such a policy include, but are not limited to, the following. First, the existence of this type of policy indicates that conflicts are taken seriously. The institution's goal is to work with SDMs and families to, hopefully, find a way forward together. Second, a policy like this helps with establishing parameters for all involved about what options may exist for addressing the conflict and what may happen over time. This facilitates openness and transparency and may assist with subsequent discussions about the relevant steps and available options. Third, this type of policy can help ensure that all involved are treated fairly through the use of a consistent approach (e.g., by following the steps outlined in the policy). A consistent approach to addressing conflict can still allow for a flexible response. This could be by providing options that enable tailoring for different care situations where there is conflict (e.g., after DNC, in what instances would all somatic support continue and even escalate versus when would somatic support only be maintained at the current level?). Or, flexibility could be included by providing different steps, but not requiring that every single option be canvassed if these are not needed nor appropriate.

Further, if there is input from patients and families from diverse perspectives as part of developing this policy, this may help with increasing trust in such a policy. This aspect of policy development may be particularly important for some SDMs and families who might raise questions about the validity or appropriateness of the policy and the measures it includes. Input could also include consulting with spiritual and religious leaders, such as Indigenous Elders, imams, rabbis, priests, etc.<sup>12</sup> In addition, this approach to developing policy is in line with *Accreditation Canada* standards and their emphasis on collaboration with patients and families as part of people-centered care.<sup>40</sup>

Seven strategies this policy could include as part of a structured approach to situations of conflict are:

1. Establish whether transfer of care to another attending physician would be appropriate. This option may depend on both the health institution and context and must consider the aforementioned rotation of ICU coverage.
2. Seek a formal second opinion from inside or outside of the current health institution. This may be particularly useful in situations where trust between the health care team and the SDM and family has broken down or has not been established. To help increase trust in the relative independence of the second opinion, consider what process should be undertaken for determining who provides this second opinion, including whether the SDM and family could be involved in selecting this person (e.g., from a list of qualified clinicians). It may also be appropriate to ensure that the SDM and family have the opportunity, if they wish, to meet the clinician providing the second opinion.
3. Require formal ethics consultation and/or consultation with other resources/supports within the health care institution.
4. Provide guidance about any delays in removing ventilation and other somatic support. Delays may include allowing additional time for such things as arranging for a formal second opinion, waiting for a family member (or relevant other) to travel to be present for DNC and/or the removal of ventilation and other somatic support, and/or providing time for the SDM and family to consider their options. It may be appropriate for such a policy to provide guidance for what the timeframe for a delay may typically be, i.e., a matter of days. It is anticipated that this timeframe may be extended or shortened in some situations, and the policy should be clear about how decisions ought to be made in these instances, including by whom and at what level within the institution. If the timeframe is to be shortened because of the medical resources being urgently needed to safeguard the life or health of another patient, this decision should be made at the institutional level and not at the bedside (in line with how other allocation decisions are made about limited resources, including in times of crisis, such as a pandemic). It is noted that delays in withdrawing treatment or removing ventilation and somatic support also happen in situations where there is no disagreement or conflict. As such, including guidance for delays in this type of policy—whether directly in relation to a situation of conflict or not—is important for showing consistency in approach as well to help ensure fairness between and across different types of care situations.
5. Continue medical management of the patient during any delays. Depending on the nature of the delay and

the particular care situation or type of conflict occurring, there may be scope for considering escalation of some forms of somatic support (mechanical ventilation settings, cardiovascular support, cardiopulmonary resuscitation [CPR]<sup>41</sup>) or to maintain the current forms with no escalation of interventions (e.g., no CPR, no antibiotics for infection, no escalation of mechanical ventilation settings).

6. Proceed with ancillary testing either if the SDM/family requests this or to provide additional information for the SDM that may assist with understanding DNC.<sup>24</sup>
7. Offer the option of transfer of care to another institution (if such an opportunity exists; this may include transfer to other countries/jurisdictions). The SDM and family may also opt to pursue this option on their own.

There may be other strategies that a health care institution may wish to include that the above list is not exhaustive. Throughout, the emphasis should be on continuing to (attempt to) engage in discussion with the SDM and family to help maintain or re-establish some form of connection, even in the midst of conflict. Ultimately, if situations where there is conflict cannot be addressed informally or through one or more of the approaches suggested in previous sections, having a policy to provide support and guidance about next steps that is more structured both in terms of available options and related processes for making decisions can be helpful.

## Conclusion

Even while the definition of death and the criteria for its determination will be updated over time,<sup>24</sup> the significance of declaring a person dead remains for all involved. In many, if not most, of these situations, there is agreement with the determination of death and the sequence of events that will follow. In other situations, there may be disagreement or conflict. Fortunately, this frequently can be navigated successfully through one or more of the above-described strategies. In more limited circumstances, there may be a need to draw upon the guidance provided by health institution policy to move forward more formally when there is ongoing and/or escalating conflict. It is hoped that these situations remain limited, appreciating the toll that such situations can take. Fundamentally, finding and employing mechanisms to resolve these situations of conflict in ways that are respectful and, as much as possible given the circumstances, relationship preserving remains an overarching goal.

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