Critical care providers' support of families in bereavement: a mixed-methods study

Soutien des familles en deuil par les intervenants aux soins intensifs : une étude de méthodes mixtes

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Abstract

Purpose *When people die in intensive care units (ICUs), as many as half of their family members may experience a severe grief reaction. While families report a need for bereavement support, most ICUs do not routinely follow-up with family members. Clinicians are typically involved in supporting families during death and dying, yet little is known about how they work with families in bereavement. Our goal was to explore how clinicians support bereaved families, identify factors that facilitate and hinder support, and understand their interest and needs for follow-up.*

Methods *Mixed-methods study of nurses and physicians working in one of nine adult medical-surgical ICUs in academic hospitals across Canada. Qualitative interviews followed quantitative surveys to reflect, expand, and explain the quantitative results.*

Results *Both physicians and nurses perceived that they provided empathetic support to bereaved families. Emotional engagement was a crucial element of support, but clinicians were not always able to engage with families*

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because of their roles, responsibilities, experiences, or unit resources. Another important factor that could facilitate or challenge engagement was the degree to which families accepted death. Clinicians were interested in participating in a follow-up bereavement program, but their participation was contingent on time, training, and the ability to manage their own emotions related to death and bereavement in the ICU.

Conclusions *Multiple opportunities were identified to enhance current bereavement support for families, including the desire of ICU clinicians for formal follow-up programs. Many psychological, sociocultural, and structural factors would need to be considered in program design.*

Résumé

Objectif *Lorsque des personnes décèdent dans une unité de soins intensifs (USI), jusqu'à la moitié des membres de leur famille pourraient souffrir d'une réaction émotionnelle grave. Bien que les familles rapportent le besoin d'un soutien en cas de deuil, la plupart des USI ne font pas un suivi de routine avec les membres de la famille. Les cliniciens sont traditionnellement impliqués dans le soutien aux familles pendant la mort et le décès, mais nous ne connaissons que peu de choses concernant leur travail avec les familles en deuil. Notre objectif était d'explorer la façon dont les cliniciens viennent en soutien aux familles en deuil, d'identifier les facteurs qui facilitent ou entravent le soutien, et de comprendre leur intérêt et leurs besoins en matière de suivi.*

Méthode *Nous avons réalisé une étude par méthodes mixtes auprès du personnel infirmier et des médecins travaillant dans l'une de neuf USI médico-chirurgicales pour adultes dans des hôpitaux universitaires du Canada. Des entretiens qualitatifs suivaient des sondages quantitatifs afin de refléter, approfondir et expliquer les résultats quantitatifs.*

Résultats *Selon leur perception, les médecins et le personnel infirmier fournissent un soutien empathique aux familles en deuil. L'implication émotionnelle a été identifiée comme étant un élément crucial du soutien, mais les cliniciens ne sont pas toujours capables de s'impliquer auprès des familles en raison de leurs rôles, de leurs responsabilités, de leurs expériences ou des ressources de l'unité. Un autre facteur important qui pourrait faciliter ou au contraire entraver leur implication est la mesure dans laquelle les familles acceptent la mort. Les cliniciens seraient intéressés à participer à un programme de suivi de deuil, mais leur participation dépend de leur temps, de leur formation et de leur capacité à gérer leurs propres émotions liées à la mort et au deuil à l'USI.*

Conclusion *De nombreuses cibles ont été identifiées pour améliorer le soutien actuel aux familles en deuil, y compris le désir des cliniciens de l'USI de disposer de programmes formels de suivi. Il faudra toutefois tenir compte de nombreux facteurs psychologiques, socioculturels et structurels dans la conception de tels programmes.*

Death is common in the intensive care unit (ICU), and can have a profound impact on family members (FMs) and staff. As many as half of FMs of ICU decedents may experience a severe grief reaction (SGR) with intense yearning or separation distress, as well as emotional, cognitive, and functional impairment lasting months to years.[1] SGR is distinct from other psychiatric illnesses, and is associated with declining health, increased use of healthcare resources, and even death.[2,3] While families of deceased patients report a need for bereavement support[4,5] and critical care societies have identified bereavement support as clinical and research priorities,[6-8] most ICUs do not routinely follow-up with families to identify and support those with SGR.

Frontline ICU clinicians, including physicians and nurses, are routinely involved in supporting bereaved FMs during death and dying. Many would value the opportunity to meet with families after the patient's death to offer further bereavement support, if provided with adequate training and time.[4,9] In related work, our group and others have studied the burden and predictors of SGR among bereaved FMs in the ICU.[1,10] Although distress, depression, post-traumatic stress disorder, and burnout are well described among ICU clinicians,[11-14] little is known about how clinicians are affected by death, dying, and bereavement and how they support bereaved families.[15-19] In this study, we used a mixed-methods approach to understand how ICU physicians and nurses view bereavement support, how they provide such support to families, and what factors facilitate and challenge their support. We also sought to explore their interest and needs for offering more formal, programmatic follow-up with bereaved families. A better understanding of bereavement support may help ICU clinicians improve and extend the support they provide for grieving families, while simultaneously meeting clinicians' needs in providing such support.

Methods

Study design and setting

We conducted a mixed-methods exploratory study of nurses and physicians working in one of nine adult medical-surgical ICUs within university-affiliated hospitals in Ontario and Alberta, Canada.[20] The study

Table 1 Demographics of survey participants

Demographic	Nurses (*n*=290)	Physicians (*n*=42)
Age (yr), Mean (SD)	36 (10.4)	46 (8.4)
Female sex	224 (85%)	11 (28%)
Religion		
Christian	161 (56%)	14 (33%)
Other	15 (5%)	4 (9%)
Non-religious	86 (31%)	17 (42%)
No answer/decline	24 (9%)	7 (17%)
Spiritual		
Very	47 (17%)	4 (10%)
Somewhat	116 (41%)	12 (30%)
Minimally	70 (25%)	11 (28%)
No	37 (13%)	10 (25%)
Years of clinical experience workworkoExperience		
0–9	143 (49%)	3 (8%)
10–19	67 (23%)	18 (50%)
20–29	42 (14%)	9 (25%)
30+	21 (7%)	6 (17%)

Data shown as *n* (%) unless otherwise indicated; SD = standard deviation

was approved by the institutional research ethics boards in participating sites. All participants signed informed consent.

Quantitative survey

Participants were surveyed to assess perceptions of grief reactions, psychiatric symptoms, and social distress experienced by bereaved families; their comfort in supporting the bereaved; their current involvement in bereavement support; and clinicians' willingness to participate in a future screening and support program for FMs at their institution. The survey was developed by the authors based on domains from the Inventory of Complicated Grief-Revised and Social Difficulties Index and refined based on sensibility and pilot testing according to accepted methodology.[4,21] The questionnaire included ten total questions, with some multiple choice options for respondents to estimate frequencies. There were also free text response options for questions about facilitators, barriers, and learning needs. (The questionnaire is available as Electronic Supplementary Material [ESM]).

Intensive care unit physicians and nurses at participating sites were eligible. The survey was distributed electronically to all ICU staff physicians at each study site with two reminders two weeks apart, and on paper to all nurses working on two consecutive shifts in the ICU at each site (with no reminders). This hybrid approach was used in our previous single-site survey to maximize our response rate.

Qualitative interviews

Physicians and nurses who indicated their interest in an interview on the survey were considered. We used purposive sampling[22] to recruit a heterogeneous group of clinicians with a wide-range of ICU experience. Given the number of sites involved, we aimed to include two physicians and three nurses from each site with goals of achieving both thematic saturation and site- and demographic variation.

Semi-structured interviews were most often conducted in person, in non-clinical areas in the workplace. Three interviews took place over the phone or outside the hospital according to participants' requests. The primary author (C.K.) constructed the interview guide and refined it after discussions with team members (J.D., T.S.) (The interview guide, Electronic Supplementary Material). C.K. interviewed the participants in Ontario and A.R.O. interviewed participants in Alberta; C.K. also joined the first two interviews in Alberta by Skype. The interviews lasted between 20 and 70 min, and were audio-recorded and transcribed verbatim. NVivo 10 (QSR International, Victoria, Australia) was used for qualitative data management.

Data analysis

Participant characteristics and survey responses were calculated separately for nurses and physicians and compared between groups using a t-test for continuous

Table 2 Demographics of participants in interviews

Characteristics	Nurses (*n*=21)	Physicians (*n*=13)
Female	17 (80 %)	4 (30 %)
Age (yr), mean (range)	43 (25–58)	46 (36–62)
Religion		
Christian	11 (52 %)	7 (54 %)
Other	1 (4 %)	1 (8 %)
Non-religious	8 (38 %)	4 (30 %)
Spiritual		
Very	0 (0%)	2 (15 %)
Somewhat	11 (52 %)	4 (30 %)
Minimal	6 (28 %)	4 (30 %)
No	3 (14 %)	2 (15%)
Years since degree, mean (range)	21 (4–39)	20 (9–39)
Time spent with direct patient care		
1–25%	1 (4 %)	1 (8 %)
26–50%	2 (9 %)	9 (43 %)
51–75%	2 (9 %)	1 (8 %)
76–100%	14 (67 %)	2 (15 %)

Data are presented as *n* (%)

variables and Chi squared tests or Fisher's exact tests for categorical variables, all using R 3.3.2. The qualitative thematic analysis was iterative and inductive.[23] Three investigators (C.K., J.D., T.S.) coded the first five transcripts independently to determine major themes and identify areas for additional inquiry. C.K. analyzed the remaining transcripts to refine the coding scheme using the constant comparison method. Following coding, qualitative and quantitative findings were juxtaposed to explore how qualitative findings reflect, expand, and explain quantitative results.

Results

Between May 2015 and July 2016, 42 of 78 physicians (54%) and 290 of 710 nurses (41%) completed surveys, for a total of 332 of 788 eligible participants (42%) across the nine sites in Ontario and Alberta (eTable 1, Electronic Supplementary Material). We also interviewed 13 physicians and 21 nurses across the same sites (eTable 2, ESM). Participant demographics are provided in Tables 1 and 2.

Intensive care unit clinicians supporting families in bereavement

Quantitative survey results

Approximately half of clinicians (50% nurses, 57% physicians) reported being comfortable or very comfortable supporting bereaved families (eTable 3, ESM). More than 80% reported supporting families at the time of death. Although 31% of nurses and 55% of physicians noted that they often/always assessed whether FMs wanted to discuss (after the patient died) events that occurred in the ICU before the patient died, fewer than 6% reported following up in the days or weeks after death.

Qualitative interview results

Nurses and physicians suggested families' bereavement "doesn't start at the moment the patient died, but it starts before," (eTable 4, ESM). Many recognized that interactions with families prior to and following death could have important impact on families' bereavement. They agreed on the importance of starting conversations early "rather than at the end" to explain the disease and therapeutic processes, and to enhance understanding "of what has happened, what is happening, and what is likely to happen to that person."

Clinicians recognized that while they were habituated to the dying process in the ICU, the experience "may be traumatic to the lay person." They expressed that it was important to reassure families that the patient was not experiencing pain nor suffering when death was imminent. A nurse elaborated that reassurance "[gives families] a peace of mind."

Participants used language intentionally to "provide comfort" to families. One nurse discussed how a colleague "helped her find the right words" to comfort a mother losing her young daughter: "Just tell her everything's going to be okay and that you're going to see her again sometime." When she used those words, the mother "had visibly become more relaxed."

In many ICUs, nurses tried to "make [families] feel comfortable" by following their wishes: "whatever they need I will follow through." They allowed FMs to lie beside their loved one, or followed their requests about how to brush patients' hair, adjust blankets, or play music. One nurse added, "You just give them the time that they need with the patient," along with space and privacy when possible. Both physicians and nurses admitted that their support was part of a "multidisciplinary team effort" that involved other clinicians as well, including social workers and chaplains.

None of the study ICUs had a systematized follow-up plan with bereaved families at the time of interviews, although some clinicians reported that they reached out to bereaved families after they left the hospital. A few attended funerals if they had developed a strong rapport with the family. Some physicians claimed that they reconnected with families at follow-up meetings arranged to discuss autopsy results or quality of care experiences. These meetings were usually family-initiated. Some physicians occasionally made an effort to initiate follow-up with FMs who appeared to be coping poorly at the time of death. Such meetings were oriented around information sharing rather than bereavement, but physicians acknowledged that they could be "an important part of the bereavement process." Physicians tried to reflect on and resolve FM questions, and also "to absolve [FMs] of guilt."

Factors influencing providers' bereavement support and emotional engagement

Quantitative survey results

Nurses (56%) and physicians (44%) perceived that bereaved families needed emotional support. Nurses (88%) were more likely than physicians (69%) to report often/always providing emotional support to families at the time of death.

Qualitative interview results

Interview participants expanded on how they engaged emotionally with bereaved families, and discussed relational facilitators and challenges, as well as sociocultural and structural barriers to bereavement support. Physicians acknowledged nurses' crucial role in responding to families' emotional demands. Nurses were perceived to be "at the best spot" to "develop rapport" with families. Their position at the bedside intricately linked them to families, while physicians could easily "remove [themselves] physically from difficult situations."

Clinicians' personal bereavement experiences were important facilitators for supporting bereaved families. By recalling "how people have comforted" them in their own loss, participants found they could "reciprocate to the families" they served in the ICU.

Similarities between families and clinicians also facilitated emotional engagement. For example, shared sociocultural backgrounds and speaking "the same language" were noted to enhance empathetic engagement. The relationship between patient and family was also said to evoke their own familial ties, and fostered connection. For example, a nurse discussed how a child dealing with her father's death triggered him to think of his own daughter, helping him console the child. Conversely, providers found it more difficult to engage with families whose life experiences might be different. For example, a nurse without children found it hard to "know what to say" to parents losing their children.

Certain situations evoked providers' concern for families. For example, when FMs left the ICU alone after their loved one died or if they were in obvious distress, participants wondered whether there was "someone who can be there for them." These concerns prompted some physicians to invite families for a follow-up meeting.

Many perceived that emotional support "depends a lot on where the family is at." It was much easier to support families who accepted their loved one's impending death. In contrast, families' lack of acceptance about the patient's death and dying was regarded as a barrier to support. A physician, for example, articulated her difficulty understanding families' intense emotions for highly predictable deaths: "I have a hard time to wrap my mind around why that would cause so much distress." Families' lack of acceptance could also lead to negative emotions towards clinicians, such as "anger" and "almost abuse," and this was reported as another obstacle to bereavement support. In these situations, nurses felt they were "harming the patient," experienced frustration, "and had to disengage from the family."

Clinicians identified significant sociocultural and structural barriers to supporting bereavement, including

language. Many providers reflected on how hard it was "to find the right words" to comfort families. They were sometimes concerned that common supportive statements did not recognize family emotions, and preferred to avoid them. Instead, they recommended other practices, such as allowing the family to spend time with the deceased.

Another observed barrier to bereavement support was limited time. One nurse described, "our interactions with families are relatively brief because it's usually only for the time they spend in the unit after the patient died." Time was also curtailed by unit policies around bed turnover and the assigned tasks that clinicians had to complete for the deceased. Typically, nursing time was limited by needing to prepare for new patient admissions: "I was still talking to the mother but had to prepare another room, and would come back and kept on having to apologize." Availability of interprofessional support from spiritual care and social work was limited after hours and on weekends.

Finally, space was perceived as a challenge in the ICU. Participants elaborated on how they had to cultivate privacy for bereaved families. It was disruptive when people were laughing and talking at other bedsides in close proximity, and although nurses "put signs up, so people will notice, you have to be vigilant in going around and saying, can you keep it down?"

Conditional interest in providing further bereavement support
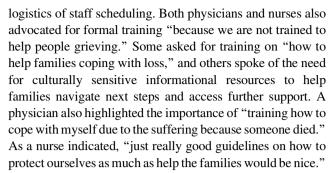
Quantitative survey results

In the surveys, 82% of respondents expressed interest in receiving formal training to provide bereavement support, and 40% of nurses and 50% of physicians were willing to provide emotional support to families as part of a formal program if given adequate time and training.

Qualitative interview results

Interview participants also expressed interest in a follow-up program for FMs, but questioned whether families would want to reconnect with clinicians and "what it will do to them." In contrast, a few had no interest, because, as one physician noted, "it was a little bit outside of what I like to do." Those interested raised the question of who the best person would be for the role. Many physicians argued that "closure can only be provided by the treating physician who was there at the time of death." Others, however, contemplated whether it should be the clinician who has been involved in the care or someone else, especially if "things were a bit antagonistic during their stay."

To participate in a potential follow-up program, providers discussed the need for allocated time and the complicated logistics of staff scheduling. Both physicians and nurses also advocated for formal training "because we are not trained to help people grieving." Some asked for training on "how to help families coping with loss," and others spoke of the need for culturally sensitive informational resources to help families navigate next steps and access further support. A physician also highlighted the importance of "training how to cope with myself due to the suffering because someone died." As a nurse indicated, "just really good guidelines on how to protect ourselves as much as help the families would be nice."

While clinicians found bereavement support meaningful, many nurses and physicians discussed their own "array of emotions" around death and bereavement, and acknowledged that "we're not made of steel…, we're human." They remarked that "this is not easy for anybody," "it's tough on [clinicians] too." The emotional toll of death and bereavement work affected their sense of self and well-being. One physician explained, "it takes me probably several days to actually be myself again" after being on call for a week. Another spoke of the need to "look after my mental health a lot because I think it's a huge challenge in our job." They also recognized the potential reciprocal negative consequences on families, as clinicians' emotional exhaustion could affect the care they provided: "you can't help others if you can't help yourself."

Participants noted the limited institutional resources available to them through which they could access emotional relief from the intensity of their experiences. Some nurses recommended situational support, such as debriefing when confronting difficult events. One nurse spoke about the need to take breaks from the bedside when "it becomes too much emotionally." Administrative solutions were also suggested, for example, charge nurses could "ensure that the nurse gets time away from the patient," while adequate coverage was provided. Most importantly, both nurses and physicians emphasized the necessity for cultural change. A physician explained:

"We have to change the culture to enable people to be upset by something and for that to be alright. You would have to enable a paradigm shift in how people perceive emotions and coping with death and stress in order to be able to institute some of these programs and for them to be effective. You've got forward-thinking educators and residents but it will take another twenty years or a generation for the whole culture to change."

Discussion

Our results describe how both physicians and nurses perceived that they support bereaved families in the ICU. Focusing on bereavement support and assessing interest in

a formal follow-up program for FMs allowed these clinicians to reflect on the pivotal role of emotions at work that convey not only how they support families' intense emotions during this period but also how they manage their own emotional lives as they repetitively confront death, dying, and bereavement.[24] We identified multiple factors that facilitate and challenge how clinicians attend to grieving families' emotions, and found that nurses' and physicians' ability to engage with families is dependent on their roles, responsibilities, and experiences, and on unit resources. Another important factor that clinicians perceived can facilitate or challenge emotional engagement is the degree to which families had accepted death. This study reveals that clinicians generally find end-of-life and bereavement work meaningful, and many are interested in participating in a follow-up bereavement program, if provided with time and training. Participation is also contingent on clinicians' ability to manage their own emotions. Therefore, practical and cultural changes are necessary to help them feel better prepared and supported in bereavement work.

Intensive care unit clinicians described grief as a process that begins prior to death,[6-8,15,25,26] and highlighted the similarities and differences between nursing and medicine in a range of bereavement support practices. Nurses and physicians reported that they typically provide support at different time points in bereavement. Nurses are in a unique position at the bedside, and experience an intense, sometimes prolonged exposure to family grief. Physicians confront family emotions more sporadically; they often lead early conversations with FMs, may be less present during emotional situations in end-of-life care, and again play an important role at follow-up meetings in the period after death, if they occur. If grief manifests before death and clinicians already support bereaved families during death and dying, leveraging existing ICU clinicians to provide extended bereavement support after a patient's death may be of benefit.[4,9]

Previous studies have explored the crucial role of nurses in emotional work,[15,16,18,27,28] and the division of emotional labour between nurses and physicians in clinical care.[23,28,29] This study expands the literature on the emotional aspects of physicians' work[30] and explores how both nurses and physicians perceive their care for bereaved families in the ICU.[17,19] We found that emotional labour is inherent in both medical and nursing work, and that it may not be appropriate to associate this labour with only one profession.[17,24]

Both sociocultural and structural factors can facilitate and challenge bereavement support. Our analysis shows that demographic similarities and similar familial ties between clinicians and FMs can foster emotional engagement, and that clinicians' personal bereavement experiences can help them relate and respond to families' emotions. Conversely, differences along these same lines can hinder engagement. By reflecting on these similarities and differences, clinicians may be able to recognize opportunities to provide more compassionate support to all FMs in the ICU.[31-34]

Clinicians had a difficult time confronting intense family distress in particular situations that they associated with families' lack of acceptance of death and dying. These were often situations that clinicians perceived as easily explainable from their biomedical perspective. When families, for example, had difficulty coming to terms with what for clinicians was highly predictable death, they could not make sense of families' emotions, leading to disengagement from families. These findings show that clinicians sometimes correlate rational understanding with emotional acceptance of death, even though the relationship between the two is complex and therefore their informational support may be limited. Echoing the request articulated by some study participants, we endorse the need for culturally sensitive psychosocial education, particularly to complement the narrow biomedical world view of some clinicians, and to enhance all clinicians' deeper understanding of bereavement and its management and to strengthen their strategies to build a therapeutic alliance with families.[31,35,36]

Clinicians' interest in potential formal follow-up programs was contingent on adequate time and training, as well as on their own emotional well-being. While they found empathetic engagement with bereaved families to be meaningful and rewarding, they also experienced the complex challenges evoked by emotional labour. Although many called for practical solutions, some also expressed ambivalence about whether families would actually welcome a post-death ICU follow-up, echoing the results of other studies.[37] Most, however, recognized the cultural shift that is necessary in the ICU, whereby clinicians would feel better supported in their bereavement work. The published literature on the impact of death and dying on nursing, for example, reaches similar conclusions.[28] We join those who advocate for the integration of palliative and critical care that recognizes clinicians' educational needs as well as their needs for better emotional support.[38-40]

This study is novel in its' national scope and mixed-methods approach to understanding clinicians' perspectives and experiences of supporting bereaved families of ICU decedents. The limited qualitative sample size at each site precludes comparing findings across centres. Future work exploring institutional variation could shed light on whether and how particular organizational structures and cultures influence bereavement support. This study is also unique in its inclusion of both nurses and physicians, but

Table 3 Opportunities and suggestions

To enhance bereavement support for FMs	To better support clinicians in their work with bereaved FMs
Start conversation with FMs before the death occurs	Offer culturally sensitive education for clinicians on bereavement and support, building therapeutic alliance with families, and coping with multiple deaths
Reassure FMs that their loved one is not suffering	Arrange situational team debriefs after difficult deaths and/or bereavement support situations
Use comforting and honest language	Offer coverage to allow a prolonged break after supporting dying patients/bereaved families
Respect FM's wishes when possible	Encourage clinicians to acknowledge their emotions after death and bereavement and seek emotional support
Provide space and privacy for FMs with the dying patient/the deceased	
Provide time for FMs with the dying patient/the deceased	
Use signage to notify other staff that someone is dying/has died	
Request interprofessional support	
Arrange to follow-up with FMs	

FM = family members

limited in its exclusion of other healthcare professionals, such as social workers, mental health professionals, or spiritual care providers. Future research could examine bereavement support from other ICU clinicians' perspectives. Finally, our research draws attention to the well-being of critical care providers and its importance for the provision of bereavement support. Nevertheless, we did not evaluate the formal and informal, unit- or hospital-based resources available to clinicians through which they could access emotional relief and support. Understanding whether and how they influence clinicians' distress and burnout is an important direction for future research.

Conclusion

Physicians' and nurses' compassionate approaches to care aim to moderate family emotions around death, dying, and bereavement, with the potential to impact long-term family bereavement and well-being. Our findings identify multiple opportunities to enhance current bereavement support, including the development of a formal follow-up program (Table 3). If grief starts before death, leveraging existing ICU staff to provide bereavement support not only before death but also after death may be of benefit. While ICU clinicians appear willing to participate in this capacity, many psychologic, sociocultural, and structural factors will need to be considered in designing such programs and training clinicians to offer follow-up to families for bereavement support.

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