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Supporting the bereaved in greatest need: We can do better

Wendy G. Lichtenthal, PH.D.

Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, NY

Guest Editorial

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Author for correspondence:
Wendy G. Lichtenthal, Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center, 641 Lexington Avenue, 7th Floor, New York, New York 10022. E-mail: lichtenw@mskcc.org

Introduction

The disturbing truth is that following the loss of someone significant in their lives, those who struggle, those who may benefit from professional support the most, are often the ones who do not end up getting help. This is not unique to the context of bereavement, but given the increased risk of downstream physical and mental health challenges that grieving individuals face (Kirby et al., 2018; Marziliano et al., 2018; Prigerson et al., 2009) and the importance of continuity of palliative care through bereavement, the bereaved demand our attention.

It is well-established that many individuals find their way through the pain of loss without the need for intervention (Bonanno and Kaltman, 2001; Jordan and Neimeyer, 2003). For an important group of individuals, though, the challenges are debilitating and persistent (Prigerson et al., 2009). And yet, for several reasons, many of which are touched on in the current issue of *Palliative & Supportive Care*, too many of those who are struggling ultimately do not access professional support (Aoun et al., 2015; Breen et al., 2014a; Cherlin et al., 2007; Lichtenthal et al., 2015a).

The reasons for this are multifactorial, and several of these are touched on in the articles by Kirby et al. (2018) and Hudson et al. (2018), both in this issue. There are characteristics of the patients or clients themselves that play a role, there are factors related to professionals and our approaches that may play a role, and there are, sadly, innumerable systems factors at play (Lichtenthal, 2017).

Hudson et al. (2018) do an outstanding job of addressing several of the challenges that impede sound bereavement aftercare through their proposed standards for bereavement support and their recommendations for implementation of these standards. They do so with humility, highlighting that their proposal is a work in progress and pointing to the areas in need of additional research. Indeed, there are numerous ways that I agree the field needs to advance in order to "do better" in supporting the bereaved and to give the implementation of such standards a fighting chance. Namely, we need to improve screening efforts, reduce barriers to accessing support, improve our ability to assess the bereaved, improve the fit and efficacy of therapies, disseminate and implement empirically supported grief interventions, establish standards of care (as Hudson et al., in this issue propose), increase the workforce of grief specialists, and minimize burnout of these providers (Lichtenthal, 2017).

Improve screening

First, we need to figure out how to better and more systematically identify those who will be in the greatest need of support, capitalizing on family members' accessibility while patients are receiving care, a point Hudson et al. (2018) emphasized. Doing so will allow providers to triage the limited resources and time that most organizations have available to dedicate to bereavement aftercare. Screening family members for their risk of bereavement-related mental health challenges both before and after the patient's death can help reduce the many instances of family members falling through the cracks. Implementing a screening process in healthcare settings also allows an initial connection to mental health providers, offering an entrée into the system, should grievers feel the need for further support. Furthermore, screening can minimize overdiagnosing and underdiagnosing bereavement-related mental health challenges, because understanding an individual's risk profile can help a clinician better interpret presenting symptoms and determine whether additional support is indicated (Roberts et al., 2017a).

Our group's efforts in this area have focused on developing a brief, clinically useful, self-report measure that is transdiagnostic, not only assessing predictors of prolonged grief, as is often the focus (Hudson et al., 2018; Patel et al., 2018), but also of bereavement-related depression and posttraumatic stress (Roberts et al., 2017a). We have used patient-reported outcome measure development methods to obtain feedback on this tool, referred to as the Bereavement Risk Inventory and Screening Questionnaire (BRISQ), because of the need for sensitively-worded and comprehensible screening items when approaching those whose loved one is seriously ill or who are grieving (Roberts et al., 2017a, 2017b). Examining the validity and reliability of the BRISQ as well as those instruments described by Hudson et al. (2018) through large-scale psychometric studies

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will be essential. And, it would be helpful to consider these screening tools as living documents that can revised as we learn more about prospective risk factors through other investigations (Burke and Neimeyer, 2013; Roberts et al., 2017a). Once more rigorous studies of screening tools establish those that are psychometrically sound, the field will need to determine how to best implement such assessments in various clinical settings to ensure their uptake and to better understand when to screen and how frequently (as some risk factors are dynamic; Roberts et al., 2017b).

Finally, we should be mindful of the fact that our estimates of risk (and of the prevalence of clinically significant symptoms) and frankly, most bereavement studies, are likely biased, because those who are struggling the most often decline research participation. For example, a healthy selection bias was suggested in the study described by Kirby *et al.* (2018). Bereaved caregivers' perceptions of bereavement support, which was characterized as appropriate for those who were "falling apart," seemed to reflect that participants in their study were generally coping adaptively with their respective losses (Kirby et al., 2018). Though not without their struggles, by and large, participants in that study did not appear to represent those in greatest need. In contrast to their findings, in a study of parents bereaved by cancer, we found that nearly 50% of parents indicated a desire for coping assistance and 22% had clinically significant levels of depression, anxiety, or prolonged grief symptoms (Lichtenthal et al., 2015a). Unfortunately, a substantial proportion of these parents—around 40% of parents in both cases—were not being met. In other words, around 40% of parents said they wanted services but were not using them, and around 40% were clinically symptomatic and were not using services.

Reduce barriers to accessing care

This brings us to the next area in need of more clinical and research attention: the reduction of access-to-care barriers. So let us imagine that we have identified a grieving individual who seems at risk for mental health challenges in the wake of her loss. We inform her about available resources, inviting her to use both universal and specialized services. What happens next to this intensely distressed, debilitated individual who may have lost her main source of support—perhaps the person who helped schedule her medical appointments? Is she likely to make an appointment with a counselor? The bereaved face similar barriers to accessing mental health services that all individuals may face, such as transportation, time, and finances (depending on their country's healthcare system). What we recognize clinically, and something for which our group has found some empirical support, is that the pain of grief itself is also a significant barrier to accessing care. In our study of bereaved parents, in fact, it was the number one barrier: 64% of bereaved parents who wanted or needed services but were not accessing such support reported it being "too painful" as a barrier to service use (Lichtenthal et al., 2015a). Kushner and Sher (1991) described this phenomenon as "treatment fearfulness," defined as apprehension related to expectations about engaging in treatment and being exposed to "the very things that they fear most" (p. 198). In line with this, we found that bereaved parents with elevated prolonged grief symptoms were nearly seven times more likely to indicate that a barrier to getting help is that it is just too painful to talk about their loss (Lichtenthal et al., 2015a).

To address this barrier, whenever possible, enlisting the help of those who have been in a similar position can be invaluable. For example, our group has used video-recorded testimonials to assist in outreach for a grief intervention trial targeting parents bereaved by cancer (Lichtenthal et al., 2017). Having someone who has suffered the same loss engaging in outreach efforts may also be a powerful way to help address the fearful bereaved individual's concerns.

Given the emotional and logistical barriers of returning to the institution where their child was treated, we also deliver counseling via videoconferencing to bereaved parents, doing our best to ensure that we are conveying the warmth, presence, compassion, and attunement that is necessary for effective grief counseling (Lichtenthal et al., 2017). In fact, telemedicine may have a variety of applications in maintaining continuity of palliative care of families through bereavement, from screening, to connecting bereaved individuals with one another, to individual counseling.

The qualitative study by Kirby et al. (2018) noted that another barrier to service use is the public image of grief support, suggesting that we can do better "PR" for bereavement aftercare. We also realize that many people who are interested in bereavement services struggle to find competent specialized support. Palliative care services should of course provide this kind of specialized support, but it is not always logistically feasible for family members to access the care that is offered. The identification of local specialized referrals can be facilitated by pooling knowledge in shared databases of trained providers and widely publicizing these databases or search engines (Lichtenthal, 2017). We need to know who has grief specialty training and where we can find them.

Improve assessment

Once a person is willing to meeting with a grief specialist, how do we understand what she needs? Does she need anything at all? What do clinicians perceive when they assess psychological symptoms in the context of a significant loss (Dodd et al., 2017; Lichtenthal et al., in press)? We recently conducted a study of mental health clinicians and found that those who received a brief tutorial on prolonged grief disorder (PGD) were over four times more likely to correctly diagnose the individuals who depicted PGD (Lichtenthal et al., in press). We further observed that educating clinicians about PGD result did not result in them pathologizing normative grief, a common concern about establishing bereavement-related diagnoses in existing diagnostic manuals (Davis et al., 2018). That is, clinicians who received the PGD tutorial were not more likely to diagnose normative grief as PGD (Lichtenthal et al., in press). This suggests that training really can help. If we help clinicians in training programs and through continuing education opportunities learn how to distinguish different types of reactions in bereavement, they will know how to better help. If we do not get the assessment right, then we do not get the treatment right, and that is how the belief that "no one can help" is cultivated (Lichtenthal et al., 2015a). That is when we see individuals drop out of treatment.

'We also would do well to more carefully consider assessment issues in our research. Participants in our grief investigations have anecdotally shared how variable their grief experiences are, and how their answers to our questions—whether through self-report or through clinical interview—are highly dependent on when you "catch them." This has important implications for our basic science investigations of grief phenomena as well as our interpretations of treatment outcome studies. Contemporary theories of grief acknowledge this movement and variability (Stroebe & Schut, 2010). Thus, we need to begin to think outside of the box with our use and timing of standardized questionnaires that ask participants to recall how they have been recently feeling, perhaps revising instructions, or including ecological momentary assessment or diary approaches (Eisma et al.,

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2017; Monk et al., 2006; Myin-Germeys et al., 2018), so that our assessment tools account for these assessment challenges.

Improving therapeutic fit

What else can we do to make sure those who need help get it? Well, we can improve the fit of the treatments available. We have found that the most frequently cited reason bereaved parents discontinued therapy was because they felt it was not working, with 36% of parents indicated this was an issue in one study of bereaved parents (Lichtenthal, 2017). To improve fit, stakeholder input is key (Lichtenthal et al., 2017; Snaman et al., 2017). Although research has demonstrated the efficacy of several therapeutic approaches, including pharmacotherapy interventions, none are universally efficacious (Boelen, 2016; Boelen et al., 2011; Bryant et al., 2017; Kissane et al., 2006; Mancini et al., 2012; Sandler et al., 2010; Shear et al., 2016). We realize one size surely does not fit all. We need to have thoughtful adaptations for different populations and different clinical issues. For example, at the Weill Cornell Medicine Center for Research on End-of-Life Care directed by Drs. Holly Prigerson and Paul Maciejewski, our group is now adapting established cognitive-behavioral and acceptance-based approaches into a brief intervention for caregivers of noncommunicative patients in intensive care units (Kentish-Barnes & Prigerson, 2016; Marziliano et al., 2018). We also need more moderator analyses conducted to determine for whom a given grief intervention approach is most beneficial.

Disseminate and implement empirically supported interventions

Research to date has focused on intervention development and establishment of treatment efficacy. Many pilots and smaller scale studies have been conducted. But we need more large-scale trials and replication studies. And as the evidence base of efficacious grief interventions grows, we need to get the word out. Bereavement intervention researchers will need to develop expertise in dissemination and implementation research methods. Palliative care and bereavement professional organizations can promote use of and training in these approaches. Existing treatments need to be disseminated, following training models for grief interventions that have garnered empirical support (e.g., the Family Bereavement Program through the Arizona State University REACH Institute, The Center for Complicated Grief at the Columbia School of Social Work).

Establish standards

The establishment of standards and guidelines helps us raise the bar. If we aim higher, we may still experience misses, but we will do better than we are doing now. Standards should be realistic, taking into account the state of the science and reasonable resources (Hudson et al., 2018). For example, we proposed a set of standards for bereavement follow-up following the death of a child to cancer; it suggests a bare minimum of a single contact by the healthcare team to the grieving parents (Lichtenthal et al., 2015b). Although we would ideally like to see more follow-up than that, it is a practical start.

But how can we ensure such standards are accepted and implemented? Hudson et al. (2018) offer a model for doing so by incorporating a pathway to implementation that accompanies their proposed guidelines. We have to be mindful of the gaps between guidelines and actual practice and think carefully about what might make compliance with the standards more challenging (Aoun et al., 2017). We also need to appeal to institutions and organizations for the needed resources (e.g., funding, training).

Increase the workforce and minimize burnout

At least one reason for the gap between standards and practice is related to staffing. Who is going to carry out the work suggested by the standards (e.g., regular bereavement outreach)? We need to increase the workforce, and importantly, we need to increase the trained workforce (Hudson et al., 2018). A simple search of general therapist databases will reveal a surprising number of clinicians who list "grief" as a topic area in which they are expert. Although there is no denying the value of clinical experience, there is an expectation that clinicians who include grief among their specialty areas have specialized training in this field (Ober et al., 2012), and trained grief specialists are at a premium.

It is imperative to create a culture that helps individuals feel that if they go to someone with presumed expertise in grief and loss, those individuals are trained and competent providers. This goes hand-in-hand with establishing standards-standards that not only mandate training for all palliative care and bereavement support providers (Hudson et al., 2018), but that also specify what this training should be (per discipline) and that establish the need for an accrediting body that can oversee the quality of training programs. As mentioned earlier, obtaining grief support is often a person's first experience with psychotherapy, and we often get one shot to demonstrate that psychotherapy can be helpful. If a griever meets with someone lacking the training to work with the bereaved, she may become disenchanted with therapy and decide not to return for help in other times of need. This may be especially important for those struggling more; we found that parents who lost a child to cancer and who reported higher levels of prolonged grief symptoms were three times more likely to indicate that feeling that no one could help was a barrier to actually getting help (Lichtenthal et al., 2015a).

Another way to increase the workforce is to train volunteers, which Kirby et al. (2018) suggested to enlarge the capacity of the community to support the bereaved. As we know, for many bereaved individuals, supporting others who have experienced similar losses is a way to make meaning of their pain and struggles (Lichtenthal et al., 2010). We recognize how meaningful it can be for a bereaved individuals to support others in need of support, and how helpful it can be to connect to others who "get it" (Snaman et al., 2017). As others have done, our group developed a parent-to-parent program that involves training bereaved parents further out from their loss to support those more recently bereaved (Lichtenthal et al., 2013). Extending reach in this way can be invaluable.

Finally, it is important to do what we can to minimize burnout in the workforce and to promote self-care (Breen et al., 2014b). Sadly, the amount of space dedicated here may parallel the amount of time dedicated to such efforts. Yet its significance cannot be understated. It is a relatively small and select group of individuals who chooses a career in palliative care and bereavement support, and these individuals need to be nurtured and should have protected time and resources for self-care (Boerner et al., 2017; Breen et al., 2014b; Chan et al., 2015).

Hudson et al. (2018) characterized bereavement support as "the forgotten child" of palliative care. One could argue that this reflects the lack of a single discipline championing advances in bereavement clinical care, research, and policy. Perhaps advancements in the field have been slowed because bereavement care is so multidisciplinary and diffuse, even more so than the broad field of palliative care,

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with no one group devoting resources to moving the field forward. The waters may have also been muddied as different professional groups—including but not limited to social work, psychology, psychiatry, palliative medicine, chaplaincy, and nursing—learn one another's languages. It is time to transform the complexities of our subfield into its greatest strength. It is time to synthesize varying perspectives and use them to advance bereavement support, learning from one another so that we can, indeed, do better.

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