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Grief and loss: The needs of the whole population

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Abstract

Grief and loss is an issue for the whole community. A whole-of-population approach is needed in order to ensure optimal outcomes for people at risk of traumatic grief. Such an approach will need to be interdisciplinary, and provide a focused approach for a research agenda to improve health outcomes.

In a public health context there are three key constructs that can help inform this process – prevention, screening, and a framework for evaluating any intervention. In grief and loss, unless a clear relationship can be defined between identification of people at high risk of traumatic grief, interventions offered and improved health outcomes (in the broadest sense of ‘health’) then current service models will not be able to focus limited resources on people who most need them.

The development of an active research agenda with real ownership to deliver improved grief and loss services is urgently needed in order to influence policy and resource decisions.

When considering grief and loss in the community, there is clearly an enormous impact with long term health consequences for many people. As we consider the consequences of grief and loss at a whole-of-population level – its costs to individuals, to relationships, to families, to the health system (especially in the setting of traumatic grief that may present at a time much later than the loss was experienced) and the economy – we need to consider an approach which attempts to truly address the needs of the whole community. Unless we adopt a population approach we are likely to miss key opportunities to improve the well being of the whole population as people grapple with loss and its associated grief.

To conceptualise such an approach, it is necessary to adapt aspects of population-based health intervention and service planning. Three key issues need to be considered – types of adverse outcome prevention, the role and definitions of screening, and how to ensure that the whole population is included in the denominator as we seek to explore people who may need highly skilled support as they deal with traumatic grief (Horowitz, 1997; Raphael, 1990). Each of these three key issues are related and cannot be considered in isolation.

Importantly, their relationship to grief and loss is a construct with which to explore the strengths and weaknesses of the current approaches to grief and loss.

The problem

How does the ownership of grief and loss translate into

clinical practice? Every clinician (from all of the health and social sciences) seems to lay claim to grief. At the same time, no one lays claim to being the voice for ensuring adequate services for people with complex grief. Without a key advocate within the health or social systems, grief and loss are likely to continue to languish at their current level of service provision and research. At a population level, who in the community, and more explicitly the health system, is ultimately responsible for ensuring that the grief and loss needs of the community are properly assessed and adequately met? It could be argued that a lack of ownership in the area of loss and grief may lead to a lack of accountability. In turn, this may lead to major gaps that are not being addressed currently in research, education and service provision. Ultimately, a single voice must be created in order to improve the outcomes for people facing loss and grief.

An approach

Prevention

A construct that can inform an approach to grief and loss is the concept of prevention. Prevention has often been divided into three levels – primary, secondary, and tertiary (Hensrud, 2000). Although there are some differences in definitions and their application, the key issue is that there are different times along any trajectory in which interventions can potentially modify the long term outcomes that can be achieved. Primary prevention is when there is no identified problem but long term outcomes can be improved by early intervention for people who are identified as being ‘at risk’ of an adverse outcome. Secondary prevention is when the adverse outcome is present but not causing overt or symptomatic problems. Tertiary prevention is minimising the impact of an established adverse course or event.

Within this construct, interventions for grief and loss are all in the context of tertiary prevention – the recognition of established traumatic grief where there is an attempt to minimise the effect that this is having on the person. Ideally, earlier recognition of an ‘at risk’ population – people who have experienced loss and grief and who are more likely than other people to go on to adverse outcomes as a result – is preferred, so that tailored support can be offered to avoid the full impact of traumatic grief. Such a process, even at the secondary prevention level requires tools that can also identify people who do not need additional support. There is a need for ‘screening’ to help address the identification of people at high risk.

Screening

For screening to be effective there are several key issues that are assessed (Talley, Frankum & Currow, 2000). The issue for which screening is taking place should have:

- a 'pre-symptomatic' phase that is detectable by the screening tool
- an intervention which if used in this 'pre-symptomatic' phase changes the natural history of the issue for which screening is taking place

Additionally, the screening test must be:

- inexpensive
- easy to administer
- acceptable to the people who are being screened
- ideally the screening tool will be both highly sensitive and specific (although this is rarely possible)
- feasible
- effective

There is currently no established nexus between risk assessment, intervention and ultimate outcomes in grief and loss. Many people experiencing grief and loss will do so as part of life's expected encounters. The idea of risk assessment is of relevance to try to identify people for whom:

- grief and loss have had such an impact that their day-to-day lives continue to be severely compromised in the long term
- no specialised support is needed

Such identification is only of relevance if early recognition of people who are experiencing traumatic grief can change the long term outcomes by more timely support. If we compare the criteria for screening with the current state of knowledge of grief and loss, the first two criteria above fail to be met; no tool to identify an 'at risk' population for traumatic grief, and no data to support that those whose lives are most compromised by grief and loss can have the course of this changed by earlier recognition than we currently achieve.

As we look to assessment of grief and try to distinguish it from traumatic grief, we can do so, but with hindsight. Screening is ultimately about early identification of people at greater risk of adverse outcomes - impaired health (in its broadest definition), premature death. The other criteria for screening are not achieved either with currently available tools.

Although there are lots of tools that purport to help assess risk, most do so when the person is recognised as experiencing traumatic grief. When traumatic grief is identified, there is little agreement among the caring professions about how to best help this person. What can reasonably be done to improve the short and long term emotional and physical function of someone experiencing traumatic grief? A key research priority then must become establishing that by early identification, the ultimate outcomes for people with complex or traumatic grief can be modified by earlier intervention. Tools to assess traumatic grief and loss are of little importance if the ultimate course of grief for this person cannot be improved.

Populations

Another construct with which the current status of grief and loss can be examined is an evaluation model (Richardson, Wilson, Nishikawa & Hayward, 1995). Within a whole-of-population evidence-based paradigm, this would include looking at:

- The population who are at risk of loss and grief, including those who may be at high (or very high) risk of traumatic grief and how to identify these people
- The intervention or support that is offered in order to improve outcomes
- The control (or in the case of grief and loss, the natural history of the experience)
- The ultimate outcomes that people hope can be achieved as a result of the intervention

Population

In the broad context of the community, the population most affected by someone's death is often identified by kinship rather than relationship. Family relationships have their own challenging dynamics in end-of-life care (Kissane, McKenzie, Forbes, O'Neill & Bloch, 2003). At a community level, the 'closer' the person is, the more likely the perception that they will grieve. This has several caveats. The first is that the person who is closest to the person dying may also have had the most warning of this loss, particularly in the palliative setting. Secondly, it assumes that the proximity to the person actually correlates strongly with the grief that will be experienced. Different people have different coping mechanisms, honed by life's experiences. This raises the issue of 'connectedness' - the actual relationship between the person who has died and the person who is grieving. This is not the 'on paper' relationship but about how these two people related to each other in life. How we elicit this closeness ('connectedness') becomes a crucial issue. It would be reasonable to acknowledge a personal communication to Dr Paul Dunne of the Tasmanian Palliative Care Service for the question he asks clinically of people who are facing a life-limiting illness - "Who is the person most likely to be affected by your death?" This question generates surprising answers. It is also a question that people respond to in a way that suggests that it is something they think about. It is often not the spouse or caregiver but someone such as a grandchild for whom the impact is perceived to be the greatest.

Caregivers are a special population (Jepson, McCorkle, Adler, Nunah & Luke, 1999). The many roles that caregivers need to take on (nurse, housekeeper, clearer, cook, confidant, lover, friend, secretary) for people with a life-limiting illness are broad and demanding. The relationship between the caregiver and the person with a life-limiting illness can often reach a new level of intimacy at a time of intense contact and raw emotions. The longer the caregiving role, the more likely that there will have been major changes in lifestyles to accommodate the caregiving role (Jepson, McCorkle, Adler, Nunah & Luke, 1999). Ceasing that role therefore has significant implications as the person tries to "move on" with their life. For more than 40

years, the specific morbidity and increased mortality associated with the primary caregiver who is caring for someone at the end of life has been recognised. The spousal caregiver is at particular risk of early death themselves when the caregiving role has been completed (Parkes, 1970). What has not translated from that recognition is an ability to predictably change the health outcomes, including survival, for people facing the health impact of the caregiving role. We at least recognise this role and its associated risk to health.

Another recognised risk factor is in people who have had cumulative loss, particularly in the face of unresolved grief. Within the broad constructs of 'traumatic grief' this is one area where there is agreement on the risk generated (Raphael & Middleton, 1990; Jacobs, Mazure & Prigerson, 2000; Horowitz, Siegel, Holen, Bonanno, Milbrath & Stonson, 1997). Recognition of risk and the ability to improve the course or outcomes of the experience is still lacking.

Health professionals, especially those working with people at the end of life are themselves a group at risk of cumulative loss. In reality self-care programs are not well supported in health or social services nor is it the culture of many of the caring professions to foster good self care. This deficit is an ongoing challenge given the community's investment in training, supporting and relying on health professionals.

Intervention

As we consider interventions, what is done, when it is done, who initiates it, and finally who provides intervention, are all variables in the equation.

The timing of assessment for risk of complex grief becomes crucial. At a population level, can one distinguish early in the course of grief those people whose experience will develop into traumatic grief and those who are more likely not to (Raphael, 1977)? The clinical analogy is the fact that thousands of people attend their general practitioners every day in Australia with a headache, but the skill is picking the one patient who has meningococcal disease from the thousands who have almost identical headaches. Likewise with grief (Jordan & Neimeyer, 2003), the symptoms and signs are going to be very similar early in the clinical course for people who are going to cope with their loss with no external support and those who eventually are identified as having traumatic grief. Should we simply wait until traumatic grief declares itself, should we wait a period of time and then try to apply a screening tool so that the tool's sensitivity is improved, or should there be a rigorous attempt to define very early in the course of grief those people who are most at risk of traumatic grief? Such a process is important if we are trying to direct resources to people who most need them, and protecting people from interventions that they do not need (Jordan & Neimeyer, 2003). Screening, by definition, is about assessment of whole populations to improve health outcomes. Can this be achieved in the next decade for traumatic grief?

There are two ways of approaching this issue. Screening in this context may be about 'needs' –

deficits that will identify this person as being at risk of long term adverse outcomes. The other approach is to focus on the strengths of the person in doing a risk assessment – their social network, their coping strategies and mechanisms, their previous experiences with grief and loss, the relationship they had with the person who died. For people with well defined strengths at a time of screening, it may be that no further evaluation is needed. If those strengths are not identified, then there may be the need for future assessment of that person to identify early evidence of traumatic grief. The identification of people who are likely to benefit from additional professional support because it will improve their overall well being is a key responsibility for health services.

Does one accept that a person may not have integrated the experience of loss into their personhood in six months, 12 months or 24 months? What about the person who, at 24 months, has not returned to the previous level of function, is still struggling to make connections with other people or to reestablish normal patterns in life? Whose responsibility ultimately is it to ensure that that person receives adequate help? When should that help start? What should that help look like and does it make a difference?

How do people access professional support when they are not coping with loss? If our system relies on people recognising that they are not coping, are we missing the people most at risk of long term health problems for loss and grief? The 58 year old widower with no children, having buried his partner of 34 years – the first funeral he has ever attended - whose only coping mechanisms for difficult times has been to work harder, with no identified social network, is at risk of very poor health outcomes. This person is unlikely to refer himself for professional support. Conversely, there is a chance that people with loss and grief who do self-refer are the people, by definition, who are more likely to cope with loss and for whom professional support may be of little real benefit in changing the course of their grief. People who are able to self-identify, find appropriate services locally and access those may not be the target group who would best benefit from these services. Self-referral of people may well be missing significant public health opportunities to improve outcomes for people who by their nature, and the nature of their grief and loss, cannot identify themselves as being likely to benefit from help.

If referral is to occur, to whom should that be? The challenge is that there is an assumption in many areas of the community that the process of providing good bereavement care is relatively simple and quite generic. In professional practice, the complexity is identifying people with straightforward and uncomplicated needs for whom a large number of professionals may equally provide excellent support and hence excellent outcomes. By comparison however, there may be people with extremely complex needs whose needs are only going to be met by one specific discipline or even subdiscipline when that person's needs are properly evaluated and identified. As such, it begs the question

what background health professionals working in this area should have? Most professions within health lay claim to aspects of bereavement care, or even the ability to provide complete care from single disciplines or subdisciplines. Clearly, the complexity of needs for at least a small group of the population are such that a true interdisciplinary approach is needed across lots of philosophical paradigms in order to come to a place where complex needs can be evaluated and addressed.

Is there ever going to be a 'generic' bereavement position within health that has its own training program and development program? Given the complexity of need in loss and grief, probably not. What needs to be urgently achieved is agreement about how to recognise and best support people with traumatic grief in order to maximise their health outcomes. For this, interdisciplinary assessment is a key requisite that is rarely part of practice.

Control

In this construct, the 'control' is the natural history of loss and grief. The history of loss and grief without professional support is context specific. Each culture and each community deal with grief and loss differently. For each person, the response to grief and loss will change as their life experiences develop. There are cultural impacts as well as life journey impacts in this process. It means however that the natural history against which interventions will be judged is difficult to define. That judgement comes down to the simple question – have we improved outcomes when we compare this to providing no intervention? It also then begs the question – have we worsened outcomes as a result of that intervention? This is not a neutral process and whatever we do (or do not do) may affect outcomes in one of three ways: improving, worsening or making no impact whatsoever.

Outcomes

Can we improve the care of people at risk of complicated grief? To do so will require the recognition of people whose experiences and life skills identifies them as needing extra support – support that cannot be offered by their own social support network. Directing resources to the people who most need and will most benefit from support becomes an imperative for people managing scarce resources. Within a broad construct those with more complex needs are going to need far greater support and intervention with the hope of improving their outcomes. The Pareto principle suggests that much of the resource should go to a relatively small group of people (Pareto, 1896-7). There may even be a very small group of people who despite intervention have no demonstrable improvement in outcomes.

Identifying early someone at risk of complicated grief may, in a public health context, also be an opportunity to improve subsequent experiences with loss and grief because new coping skills have been developed. The net impact may go well beyond the person who had contact with a professional. There may be benefits to

the people in the grieving persons own support network. An opportunistic approach of health promotion says that any contact with health services should be taken as an opportunity to improve the total health and health outcomes for that person in the context of their life. If we are serious about such a public health approach to grief and loss, we will have to adequately resource research programs to define the relationship between risk, intervention, and outcome.

Ultimately, the whole population's health is at risk if grief and loss are not owned within services and within a research agenda that is interdisciplinary. Such a program has as its ultimate goal a community whose capacity to deal with these issues is strengthened by timely support, education and, at times, professional support.

Who needs to take responsibility for the grief and loss needs of the whole Australian population? To date, no clinical entity within the Australian health context actually takes that ownership. Until the health disciplines and the social sciences can come to an agreement on the broad basis for such a process, an agenda for future development will be difficult to develop or deliver. Such a hiatus continues to put at risk the health of a vulnerable group within our community.

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