Do professionals disempower bereaved people?

Grief and psychosocial intervention

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THIS PAPER ADDRESSES AND CHALLENGES those who are against the medicalisation of grief. I was prompted to revisit this old controversy[1] by the findings of my recent research on experiences of parents bereaved of a child through SIDS, suicide or accident[2], looking at how the parents' lives were affected and what support they received from their own networks and from professionals. Although these parents struggled with serious problems, they received limited professional help and, most importantly, far less than they would have liked[3,4]. This has important implications for those developing strategies for professional assistance to bereaved populations.

The following questions frame the debate on current strategies for professional assistance to bereaved populations.

• Should people facing a life crisis be able to handle the situation themselves, with help from their social networks, or should they have professional assistance and, if so, what should determine the nature and extent of this intervention?

• Does the availability of professional assistance empower or disempower people in a psychosocial crisis?

Before attempting to answer, I will refer to some basic concepts and illustrate them with brief descriptions of the reality of traumatic bereavement. Then, I will let bereaved parents voice their needs for help to inform the discussion.

Medicalisation and empowerment

The concept of medicalisation can be expressed as a tendency towards 'defining behaviour as a medical problem, or illness, and mandating or licensing the medical profession to provide some type of treatment for it'[5].

It has been assumed that once people are defined as 'patients', they are necessarily made powerless[1,6,7] and, to prevent people from being disempowered, we should free the patient from the doctor and, by extension, from the psychologist, the therapist, the psychiatrist, and so on.

Thus the arguments of those who criticise medicalisation are linked to a debate about autonomy and empowerment, which aims at restoring power and control to patients (often renamed consumers or users). Thompson[8] defines empowerment as 'The process of giving power to clients in whatever ways possible – resources, education, political and self-awareness and so on'. Thus, empowerment becomes a goal, an escape from a suppressed position, and at the same time, a method to achieve social change, ie it is both an ideology and a methodology[9].

The psychosocial situation of traumatically bereaved parents

The Norwegian nationwide Support and Care study[4] looked at parents after the sudden death of an offspring by either suicide (under 30 years old),

SIDS (under 2 years old) or accident (under 18 years old). A year and a half after the death, most of the bereaved parents reported serious physical, social, and psychological problems. In

total 232 parents were studied and 60% scored high levels of psychosocial and physical symptoms as mapped by the General Health Questionnaire (GHQ).

The study found psychic distress in the parents reflected in somatic symptoms, anxiety and insomnia, social dysfunction and severe depression that might lead to long-term impairment of their quality of life. The results also showed that 52% of the parents suffered from high levels of post-traumatic distress as measured by the Impact of Event Scale (IES). Thus, they experienced unwanted thoughts and images (intrusion reactions), strong anxiety and negative emotional reactions (arousal reactions), as well as denial of the event and its consequences (avoidance reactions).

Finally, a large proportion (74%) of all the parents in the study scored highly for complicated grief reactions[4] as mapped by the Inventory of Complicated Grief (ICG). This measure, which identifies symptoms which are distinct from bereavement-related depression, showed that parents were preoccupied with thoughts of their child, searching and yearning for it, experienced disbelief about the death and were stunned by, and had difficulties in accepting it. The post-traumatic stress also resulted in an existential crisis that challenges bereaved individuals' assumptions about their existence in the world, and made great demands on their capacity to confront and handle what had happened, cognitively as well as emotionally[10, 11].

There was also a profound tendency among this group of bereaved parents to withdraw and isolate themselves from others. This self-isolation seems to be linked to loss of energy and feelings of guilt and self-blame[4]. As seen in other studies, the social and emotional withdrawal acted as a barrier to accepting offers of social support, and professional assistance[4, 12, 13].

These results are in line with previous findings of serious and long-lasting psychosocial problems after bereavement[10, 14, 15, 16, 17, 18]. An important question then was whether the bereaved parents, with the help of their social network, were able to cope with the tremendous existential, psychological and social difficulties they experienced. And, if not, did they ask for help?

The parents' view of their support needs – professional or network?

When parents in the Support and Care study were asked what kind of help they needed, 88% emphasised that it was not a question of either formal assistance (professional) or informal support (social network)[3]. In line with similar studies[19, 20, 21], they argued that they needed both, because each form of help met different needs.

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Additionally, they realised that there were some problems that a social network neither could, nor should, be expected to handle, eg PTSD, family communication problems, or difficulties connected with lack of information. The bereaved parents felt they could not burden those close to them with their worst thoughts of guilt or shame, traumatic flashbacks or problems of a personal nature, and indicated a strong need for professional assistance as a supplement to social support.

Professional support: the parents' preferences

When asked to describe what professional help they would ideally like, the bereaved parents asked for:

● early help

● support from trained personnel

● information about the event and reactions that may arise

● a chance to meet others who had experienced a similar situation

● more help for surviving children

● help over time

In the main, this fits in with the scarce research in this field[3, 12, 15, 19, 20, 22].

What do governments of western countries provide?

In most countries with welfare states, local authorities are responsible for meeting the needs of the bereaved

population. However, there is a huge variation in local authorities' strategies for helping after sudden, traumatic deaths.

Our study found that 85% of the communities in Norway offer some kind of immediate help (eg priest, medical practitioner, nurse), but parents lack ongoing support for themselves and their children, and only 13% of the communities provide long-term (a year or more) contact or follow-up[3, 15]. Why do bereaved populations not get the professional help that is available and needed? Are modern ideologies and strategies related to the facts?

Current strategies defining the limits of professional assistance

In our study[3, 15], four different strategies for psychosocial assistance after traumatic deaths were identified among the 321 local communities in Norway.

Prevention strategy
This aims to prevent dysfunction initially through early crisis intervention and then long-term follow-up adapted to the individual or the family. These services are provided without the bereaved having to ask for them. The strategy emphasises the need to normalise the situation and minimise recovery time in collaboration with the bereaved by reducing distress and restoring function in individuals, families and local communities[23]. As well as involving professionals, it is also considered important to mobilise the resources of the bereaved, the support of their social networks and others who have experienced similar kinds of loss.

Treatment strategy
This acknowledges the serious impact of the traumatic event, but operates a policy of 'wait and see, and intervene if necessary'. An important principle is that atrocities in people's lives should be handled by the 'natural' healing capacities of the individual, together with social networks. Professionals should not act until a problem arises and, usually, this means a manifestation of traditional medical symptoms. The strategy fits in with traditional medical practice assuming that bereaved people act upon, define and

present their problems to professionals, and actively ask for help.

Ignorance strategy

This reflects the fact that many countries, as well as some professionals in Norway, are still ignorant of the psychosocial impact of traumatic events, or do not give it priority among all the other demands on the resources of local authorities. As psychosocial crisis intervention is a relatively new practice, compared with psychology and medicine, there is great variation in how knowledge of this field is distributed worldwide.

De-medicalisation strategy

This involves no psychosocial intervention for ideological reasons rather than the reasons mentioned under the two last headings. Although the traumatic impact and hardship for the bereaved are acknowledged to a certain extent, this ideology asserts that violent tragedies are part of normal human life. The best help is provided by the bereaved themselves and those close to them, and professionals may make things worse. This thinking is very often implicit, though not verbalised, among community workers, or it is put forward as a matter of 'values', 'priorities' or 'attitudes' to psychosocial assistance. A heated debate in Norwegian newspapers instigated by a senior professor in psychiatry exemplifies one extreme of this strategy. Under such headlines as 'Crisis-psychiatry makes things worse', 'Crisis-psychiatry – cosmetic medicine', and 'Crisis-psychology as industry', professional crisis intervention was equated with the removing of wrinkles, shaping noses, enlarging breasts, and bleaching teeth[24]. The professor upset many bereaved people, and provoked strong resistance from professionals in the field.

Strong elements of opposition to medical intervention are evident in the second and fourth strategy, but is this justified? There is an obvious discrepancy between those whose aim, as they see it, is to defend the patient against the constraints of professional involvement, and the bereaved in our study who asked for professional help. Bereaved people can end up being disempowered by the very people who are convinced they are empowering them.

When an empowering philosophy results in disempowerment

How does this paradox arise? It seems to me that the opponents of medicalisation are taking too wide and too theoretical a view of the debate and, indirectly, acting to protect traditional medicine. It is important to avoid overgeneralising about grief, and instead put more effort into separating sad, but ordinary, experiences from those that often lead to serious clinical illness. A main concern of the critics of medical intervention has been the hypothetical problem of a growing army of experts who would focus on risks of everyday life, resulting in medicalisation of normal processes and a potentially reduced tolerance of deviance, but the experience of populations bereaved by traumatic death is far removed from the norm.

As the parents who took part in our research pointed out, people are offered immediate treatment and routine follow-up after a heart attack or a broken leg, but when they experience a huge life-crisis, resulting in both physical and psychosocial problems, there is no service for them. One asked: 'Why is it so much more important to rely on natural healing processes for emotional scars than physical scars?' Obviously, far less suffering is tolerated in somatic medicine than in the psychosocial field before medical intervention is acceptable. When theorists tell people that they do not need help, this is not simply arrogant and disregarding of the voices of those they purport to protect, but also displays a singular ignorance about the situation of the traumatically bereaved.

According to its critics, one of the most serious results of medical intervention is a reduction in people's capacity for taking responsibility for their own lives and health, making them powerless and dependent[5, 25, 26]. Looking at our research, it is hard to see how an individual's autonomy could be reduced as a result of professional crisis support. There is a far greater risk of traumatised groups being overpowered by their own reactions, isolation, and lack of support, than by interventions aimed at helping them to regain control over their lives. Opponents of medicalisation ignore the fact that

"It is important to put more effort into separating sad, but ordinary, experiences from those that often lead to serious clinical illness"

traumatised populations who seek help are, in many ways, the best experts when it comes to their own experiences. As claimed by Williams and Calnan[27], lay voices are important in providing a much needed empirical check or balance to broader theoretical claims and contentions, and substantially more empirical research on user groups should be conducted[28].

According to Hughes and Patterson[29], a 'sociology of impairment' is an important step towards increasing the awareness and sense of control of individuals who need professional help. If there was increased awareness of the psychological injuries that result from trauma and how they impact on individuals, and these problems were seen by society as important, traumatised groups could more easily be helped on their own terms.

Conclusion

By claiming to protect the individual from being powerless and dependent on professionals, opponents of medicalisation prevent people in psychosocial crisis from accessing professional help. In disregarding the voices of those it intends to protect, there is a great risk that well-intended theorising facilitates disempowering rather than empowering processes. The consumer perspective, based on a holistic and subjective concept of health, should be taken more seriously so that professionals listen to the bereaved who claim that, rather than deskilling them, professional help would give them the means to move forward with their lives. ●

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BOOK REVIEW

Dying, Death and Bereavement 2nd edn

Inge Corless, Barbara Germino, Mary Pittman
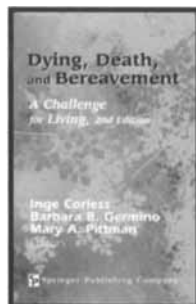
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The first edition (1995) of this book will be well known to many working in palliative care. For the second edition, the editors have gathered a very impressive list of authors, mainly from the USA, distinguished contributors in their fields.

The book is an anthology, a collection of chapters collated into five sections, on death, dying, bereavement, related issues, and the future of palliative care. Individual chapters deal with a wide variety of topics, such as death education, legal and ethical issues, and the role of healthcare workers. Each section begins with a personal account that helps to ground the following academic chapters within a reality frame and remind us why people come to work in this field in the first place.

There is much that will be of interest to palliative care workers but, for those working with people after a death, the section on grief and bereavement will be more relevant. Here, the chapter on the bereavement process by Mullan, Skaff and Pearlin looks at this highly complex issue and the requirement of the bereaved person to restructure major life domains. Silverman's chapter considers social support and mutual help, drawing from her experiences of working with widows and widowers. Lamers gives an account of the needs of children, including a list of resources, and Davies provides what I found the most useful contribution to this section, a thorough overview of the field of sibling bereavement. The section ends with a short chapter from Wessel on the loss of a pet.

The one issue I have with this book is the paucity of references to experience outside the North American setting. For example, in the chapter on helping bereaved children – my own field – there are no references that I could find to work by non-USA authors apart from Bowlby. At risk of sounding petty, I feel that for a book to have real relevance to a practitioner audience outside of the USA some recognition has to be paid to the work of writers from other continents, especially as most of them write in English. That said, however, this is a book rich in expertise, a good source of information and a valuable contribution to the field, and I would recommend it to readers of *Bereavement Care*. ●

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