Early studies of bereavement and Cruse Bereavement Care

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Abstract: In this article Cruse Life President Colin Murray Parkes describes the early days of Cruse and how pioneers brought about the science of the care of the dying and bereaved, tracing the development of grief counselling and the body of Cruse volunteers who provide today's invaluable work.

The aftermath of World War Two prompted many developments in the health and social services. These included the use of volunteer 'counsellors' in marriage guidance and other fields. They also fostered innovations by three very remarkable women who broke the taboos around death, dying and bereavement to create a new science and a revolution in the care of dying and bereaved people.

Former British nurse then social worker, Cicely Saunders (1918–2005), who fell in love with a dying patient, learned how to face death and to talk about it to other dying patients. She trained to become a doctor and founded St Christopher's, the first modern hospice.

A young Swiss/American psychiatrist, Elizabeth Kubler Ross (1926–2004) '…hated psychiatry. It was the last on my list of specialties. But we needed something to pay the rent and put food on the table' (Kűbler-Ross, 1997b, p. 112). She was fired for neglecting her job as a psychiatry lecturer while devoting too much of her time to researching and writing a book *On death and dying* (1969). The accounts of her interviews with dying people opened the door to communication about death and enabled her great number of readers to witness the success of her tender care. Sadly her distrust of doctors kept her isolated from the professionals who were building a new science of palliative care. From the 1980s she was heavily involved in work with HIV sufferers.

We come last to another social worker Margaret Torrie (1912–1999) who with Alfred, her psychiatrist husband, started the organisation *Cruse Clubs for Widows* in 1958 in her home in Richmond, Surrey. This was a time when few women worked outside the home and, by the time their children had grown up and left home, they found themselves alone and without meaning and direction in their lives. Cruse was set up to foster the recovery and empowerment of widows as reflected in the name of Margaret's book *Begin again, a book for women alone* (1970) which is crammed with practical advice and suggestions.

I had the privilege of knowing each of these pioneers and playing a part in the subsequent development of the enterprises they initiated. As a young psychiatrist I worked with psychologist, psychiatrist, and psychoanalyst John Bowlby at the Tavistock Clinic and Institute (the 'Tavi') where, over 14 years, we undertook innovative studies that gave rise to attachment theory. Robertson and Bowlby (1952) described the phases of grief of children separated from parents and we subsequently found similar phases in the grief of many adults after the death of a spouse (Bowlby & Parkes, 1970). While these early studies now seem simplistic, they identified grief as a process rather than a state and triggered the flood of research that followed.

I joined the board of *Cruse Clubs for Widows* in 1963 and enjoyed chairing an occasional Mother's Group for women with children, most of them teenagers who had lost a father. Their grief, and that of their mothers, complicated their growing autonomy and undermined their security. In due course we were able to invite the youngsters to attend their own groups.

At St Christopher's Hospice we set up a service for bereaved people using volunteer counsellors who I selected,

DOI: 10.1080/02682621.2019.1679476

trained and supervised. To evaluate our work I used a questionnaire to identify clients who, in the Harvard Bereavement Project, had been found to be at risk of problems in recovering from bereavement. In order to evaluate this work we assigned those at medium to high risk at random, to either proactive support by the counsellors or, as a control group, the pre-existing open door from which very few had sought our help. Our follow-up confirmed the predictive value of the risk assessment questionnaire and the value of our use of outreach by specialist volunteers to those at risk (Parkes, 1981).

Meanwhile, in 1966 I had responded to a disaster in Aberfan, in one of the mining valleys in South Wales. The linear village was next to a coal mine and in a valley beneath a range of mountains on which waste from the mine had been dumped in a series of tips. After heavy rain, one of the tips turned into an avalanche of black slurry, four times the weight of water, which cannoned down the mountainside destroying half the village school and 20 houses. The world watched on television as the miners dug in the ruins, but there were few survivors. 106 children and 38 adults died.

I helped recruit, train and support a local social worker, Audrey Davey, as well as a small team that included Derek Nuttall, a gentle minister with social work training. Derek supported a group of bereaved teenagers and so impressed the community that he was chosen to chair the community association that was set up to restore morale and plan the way ahead for this multiply bereaved community. At that time post traumatic stress disorder had not been discovered and it would be misleading to pretend that we solved all of the problems of the bereaved, but Derek played an important part in a series of community conferences focused on ‘the way ahead’ and Aberfan soon took the lead in community development in the Welsh valleys (Ballard & Jones, 1975). My research with the medical officer of health, Ron Williams, showed an increase in the birth rate in Aberfan that, in the four years after the disaster, gave rise to the birth of an extra 132 children, 17 more than were lost in the disaster (Parkes & Williams, 1975).

When, five years after the disaster, Derek decided that it was time to leave Aberfan, he accepted the offer of a post as regional officer for Cruse, rallying support and organising new branches across the UK. Alfred Torrie died in 1972 and I took his place as chairman. When, four years later, Margaret retired, she handed over the reins of director to Derek.

It was time for change, not only because, with the loss of our place in the Torrie’s mansion, we had to raise sufficient funds to move into new premises, but also because we had become aware that, while women in general were becoming more independent, problems were threatening the mental health of a wider range of bereaved people. A *Cruse in Crisis* appeal enabled us to fund new premises in Richmond and to cope with the growing numbers of branches and individuals who sought our help. To signal the change we changed the name to *Cruse Bereavement Care*.

Child psychiatrist Dr Dora Black joined the Board and helped to train our volunteers to work with children. With Derek, we were able to extend the work to all bereaved people who sought our help; they included many who had been exposed to traumatic, sudden or untimely bereavements of the kind that are common in disaster areas. As a result, most of our more experienced volunteers were well qualified to help people bereaved by disaster. Both as trainers and by adding advice and support to local resources, we were able to respond to the Bradford Football Club Fire in July 1985, the capsize of The Herald of Free Enterprise outside Zeebrugge harbour in March 1987 and the bombing of Pan Am flight 103 over Lockerbie in December 1988.

In 1982, with Dora Black and I as editors, we started an in-house journal, *Bereavement Care,* to provide education and support to our volunteers. This proved so successful that we decided to offer it to all who help bereaved people and to include academic articles that would pass the criteria of ‘peer review’. It was this element that, 10 years ago, persuaded Routledge to publish an online version and we were able to turn *Bereavement Care* into the international journal that it is today.

The turn of the century saw the publication of several meta-analyses of random allocation studies of bereavement counselling, in which bereaved people were assigned at random to counselling or none. Sadly they showed little or no statistically significant differences in psychiatric symptoms on follow up (Forte, Hill, Pazder, & Fuedtner, 2004; Currier, Neimeyer, & Berman, 2008). This was assumed to mean that bereavement counselling was ineffective but closer study suggested another explanation. First it became clear that most bereaved people do not need or benefit from psychological therapy outside their existing family and social support systems. Grief is an aspect of love and those who are loved by one person are usually loved by more than one. Viewed in this light a brief attachment to a counsellor was unlikely to provide more than a glimpse of the longer term attachments that most of us need to feel safe in the world. Second, most of the early counselling was based on the assumption that most problems in bereavement were caused by the inhibition or repression of grief. An important study by Schut et al in 1997 showed that this problem was most prevalent in bereaved men and that these were the ones most likely to respond to traditional methods of counselling. Most women, on the other hand, had little difficulty in expressing grief and may even have been harmed by traditional methods of counselling. They responded better to cognitive approaches focused on finding new meanings in life. We had been giving the right treatment to the wrong people.

Of course, even this explanation was simplistic. Since that time service providers have been on their mettle and a number of studies have confirmed Henk Schut's conclusion that '…the more complicated the grief process…the better the chances of bereavement intervention leading to positive results' (Schut et al., 2001). Between them these studies covered many of the problems that cause people to seek help from bereavement services. They also indicated that there is no one kind of intervention that will solve all problems. Some of the successful interventions involved a particular treatment, others more than one form of help; some were given to groups of clients, others to individuals; some included medications, others did not; some were cognitive therapies, others emotive. From now on it would be necessary to provide a variety of solutions carefully matched to a variety of problems.

Two further conclusions can be drawn from all of this work. On the one hand it seems that most bereaved people do not need and will not benefit from routine referral to a bereavement organisation. In a cash-strapped world this is good news. On the other hand, the minority of bereaved people who are unusually distressed, unsupported, or have complicated reactions to bereavement, will usually benefit from the right kind of support. There is no 'one-size-fits-all' type of counselling that is needed by all bereaved people. Therapists and bereavement organisations need to match the solutions to the problems.

Cruse Bereavement Care was not included in the meta-analyses, most of which were carried out in the USA, but we could no longer assume that our popularity with the bereaved people whom we set out to help was a reliable indicator of its worth; after all most bereaved people do find that their grief diminishes over time. In the new millennium, two studies of Cruse Bereavement Care have shown satisfactory results from support given by our volunteers. The first involved people with learning disabilities who had suffered a major bereavement while in residential care (Dowling, Hubert, & Hollins, 2003). A randomised group of residents who received the support of bereavement volunteers from Cruse and a similar local organisation got better results than the comparison group who received the support of residential staff, despite the fact that the latter had themselves received training in bereavement care.

The second study was a fascinating quasi-random allocation study by Newsom et al. (2017) of Cruse Bereavement Care in Scotland. Under pressure from their principle funder, the Scottish Government, Cruse in Scotland had become independent from the management of Cruse UK in 2001. Newsom et al studied two groups of bereaved people both of whom had obtained high scores on a measure of bereavement-related distress. 156 had received six sessions of counselling aimed to provide '..a flexible, bereavement-specific counselling intervention, combining elements of a number of established therapeutic methods including cognitive behavioural therapy…, person-centred counselling…, and the psychodynamic approach'. They were compared with a control group of 188 similarly distressed people who had not received counselling. Only when the scores were compared six months after the ending of counselling did the researchers find that the scores of the counselled group had continued to improve while improvement in the control group had tapered off. These differences reached statistical significance. Perhaps, during the period of counselling, many participants had shared thoughts and feelings that had been repressed. Inevitably their level of distress increased and it was only after the intervention had come to an end that they gradually relaxed and began to discover the benefits of the counselling.

By this time the advent of the British Association for Counselling and Psychotherapy (BACP) was creating a profession of paid counsellors. Cruse was able to provide many of their trainees with work experience in the field of bereavement. At the same time we stopped using the term 'counsellor' for our trained volunteers. Despite this most of our trained volunteers know more about the problems of bereavement than most medical, nursing and social work professionals. I remain proud of both the volunteers and staff of Cruse Bereavement Care who are now welcomed for their contribution to the international and national conferences that they attend.

At aged 91 I grow old, my short-term memory is failing and I no longer trust myself to treat psychiatric patients. On the other hand old age has given me the time and opportunity to reflect on some of the lessons that life has taught me including the nature and logic of love. Some of these lessons have been covered in the four editions, now with Holly Prigerson, of *Bereavement: Studies of grief in adult life* where, from the outset, we recognised that grief is the price we pay for love.

And it can be a high price. In Rwanda the genocidal killings were triggered by the assassination of the Hutu president. Asked why Hutu men and women killed their Tutsi neighbours one woman explained, 'I suppose we just loved our president too much'. Of course there is more to genocide than a perversion of love but there may be a measure of truth in this shocking thought.

Psychiatry and psychology are concerned to explain the logic of irrational, illogical behaviour including the large grey area between normality and mental disorder. Neurophysiologists have found that when people suffering from prolonged grief disorder, who may continue to pine for a lost person for many years, are shown a picture of that person, they show a distinctive pattern of activity in their brains that resembles the response of a drug addict to a picture of the syringe that will assuage their longing (O'Connor et al., 2008; Wise, 1998). Is seems that we are beginning to discover that some mental distress takes place because 'you're not sick, you're just pining'.

In 2001 Cruse joined with family liaison officers from the Metropolitan Police to support the families of British people flown to New York after 9/11; in 2005 our volunteers joined with the Red Cross to support families following the London bombings and, most recently after the fire in the Grenfell Tower. We have grown up and learned a lot since the early days. ■

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