

“This is really long term”

Identified version

“This is really long term”: the experiences, issues and needs of the long-term suicide bereaved

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Abstract

This study aimed to examine experiences, issues and needs of suicide bereaved people beyond the initial two years post-suicide. Interviews were conducted with 22 people with a median of four years after the suicide. The mixed methods interview consisted of qualitative questions and four psychometric measures of grief and trauma. It was found that participants were still impacted in terms of grief and trauma. Many were able to identify a shift in their grief 2 to 6 years afterwards and this shift was assisted by individual counselling and/or group experience. The authors suggest specific recommendations for counselling and groupwork intervention.

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Literature Review

People respond to loss or traumatic loss differently. The available research suggests that people vary significantly in the length and severity of their grief reactions (e.g. Bonanno, 2004). Most people will be highly distressed within the first days of a major bereavement and the majority will experience acute symptoms for some months or longer and then gradually improve and move towards a baseline level of functioning within 1 to 2 years of bereavement (Bonanno & Boerner, 2008). A minority of people, usually between 1 to 10 per cent will have chronic symptoms of distress for years after the loss, which has been labelled Prolonged Grief Disorder (PGD) (Prigerson, Vanderwerker & Maciejewski, 2008) and, more recently, in the Appendix to DSM5 as Persistent Complex Bereavement Related Disorder (PCBRD) (American Psychiatric Association, 2013). But the vast majority of people after a period are able to proceed with their daily functions and activities. Most are able to adjust to a loss over time in an adaptive way. It is generally agreed that the pain associated with bereavement decreases with time (Ott, Lueger, Kelber & Prigerson, 2007).

The death of a significant other to suicide is a particular form of loss. There has been debate in the literature as to whether people who are bereaved by suicide are more likely to be affected at a deeper level, and more negatively by the death than those who have lost a loved one to other forms of death (Jordan, 2001; Flynn, 2008; de Groot, De Keyser & Neeleman, 2008). The features of suicide bereavement that make it different from other forms of bereavement have been outlined by a number of researchers. The most recent and comprehensive review of this issue has been done by Jordan and McIntosh (2010a), in which they examined the common features of suicide bereavement to determine whether these are supported by the existing research evidence. They found that the following features were supported by research evidence: 1) abandonment and rejection; 2) shame and stigma; 3)

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concealment of the cause of death as suicide; 4) blaming; and 5) increased self-destructiveness or suicidality. They also ascertained that the following features were not currently supported by sufficient research evidence, but were supported by clinical experience and the anecdotal accounts of survivors: 1) guilt; 2) anger; 3) a search for an explanation and a desire to understand why; 4) relief; 5) shock and disbelief; 6) family system effects/ social support issues/ social isolation; 7) activism, obsession with the phenomenon of suicide, and involvement with prevention efforts (pp.30-33).

Given that those bereaved by suicide are likely to be affected in particular ways and may be impacted more negatively, does this mean that the trajectory of their grief response will be longer and more severe as compared to survivors of other losses? McMenemy, Jordan & Mitchell (2008) conducted a needs assessment survey with a sample of 63 with a mean time of 47.2 months (four years) since the suicide. They reported their findings (Jordan, 2001; McIntosh, 2003), which were consistent with past research, suggesting that the trajectory of suicide bereavement can be prolonged and difficult, characterised by a range of issues in the practical, psychological and social domains.

The most direct evidence on this question of trajectory seems to come from the series of studies done by Feigelman, Gorman and Jordan called the Feigelman Survivors of Child Loss survey which has now published in its totality as a book (Feigelman, Jordan, McIntosh & Feigelman, 2012). The third study in this series (Feigelman, Jordan & Gorman, 2007) looked at grief difficulties among suicide survivors as a function of elapsed time since death, amongst a range of other variables. They found that particular factors (a history of repeated suicide attempts and a negative relationship with the deceased prior to death) “... were associated with greater grief difficulties during early years of bereavement, although not when subjects were five or more years past the date of death” (Jordan, Feigelman,

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McMenamy & Mitchell, 2010, p.119). Their data also indicated “... that between three and five years usually marked a turning point”, which was defined as “... a time when acute grief difficulties accompanying the suicide loss began to subside” (Jordan et al., 2010, p.119). The period of 3-5 years after death is a time period for recovery which is generally longer than that observed from normative bereavement. Feigelman, Gorman & Jordan (2007), in an earlier study, incorporated an evaluation of common helping resources including at differing lengths of time since the loss. They found the use of all resources declined as time since the death increased (Jordan et al., 2010, p.120).

Typically, both the available research and intervention focus on the immediate period after the loss. Generally this time period is between six months and three years afterwards e.g., Seguin et al. (1995); Farberow et al. (1987; 1992a; 1992b). This trend is typified by the series of longitudinal studies done by Farberow and his collaborators who researched spouse-suicide survivors over a two and a half year period.

Jordan et al., (2010) contended that interventions are likely to be needed to be available for longer than the short-term and crisis oriented response that is typically offered by professionals and communities following a suicide, particularly for those who are deeply affected by the death (Jordan et al., 2010, p.129). The authors’ counselling experience at (name of program) would support this view. Jordan et al. (2010) also point out that “... people bereaved by suicide may need different types of services at different points in their bereavement trajectories, and that “one size does not fit all” in terms of services” (p.129).

Despite this short-term focus, researchers and therapists alike have suggested that: 1) the trajectory of suicide bereavement is likely to be longer than other types of losses; 2) the intensity, as well as the duration, of people's distress will exceed those found in other types of

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losses (Jordan, 2010, p.185); and 3) therefore a range of interventions will need to be available to people.

Therefore, it would seem to be appropriate from both a research and intervention perspective to examine the longer term experiences, issues and needs of this group with a particular focus on the 2 to 6 year period, given that within this time period a shift seems to occur for many people. Jordan and McIntosh (2010b), in discussing the time criterion for survivorship, suggest that it is ultimately an empirical question that is best answered by solid research on the types and duration of various bereavement trajectories after suicide, as well as their relative frequencies in the general population of those exposed to suicide (pp.7-8). They also recommended as part of a research agenda for suicide survivors that there is a need to study separate groupings of survivors by kinship relationship (McIntosh & Jordan, 2010c, pp.512-513).

The existing research has not provided guidance in answer to the following questions:

- 1) what are the experiences and issues for those bereaved by suicide for two years or more?
- 2) what are their needs?
- 3) what are the implications of these needs and issues for the type and nature of interventions for this group?

These research questions were addressed in the present research study. This study was conducted using former and current clients of the (Name of program) who met the criterion of having been bereaved by suicide for at least two years. By implication, all of them had received some intervention from (Name of program), whether in the form of individual

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counselling or group work, or a combination of these. Therefore, the sample automatically had an inbuilt bias in that the participants had received some sort of intervention through (Name of program). In line with one of Jordan and McIntosh’s 2010 recommendations, the study also sought to incorporate a range of survivors with varying kinship relationships.

Method

Participants

This study analysed data from cross-sectional interviews with suicide bereaved people who are clients or former clients of a specialist suicide bereavement program. Interviews were conducted between August 2012 and January 2013.

There were 22 participants, with the majority being women (16, 73%), as compared to men (6, 27%). The mean age was 52 years, with the oldest being 70 years of age and the youngest 20 years of age. Seventy-seven per cent (17) of participants were between the ages of 46 and 65 years.

All were bereaved by suicide, with nine (39%), having lost a child; seven (30%) a sibling; five (22%) a partner or spouse; one (4%) a parent, and another friend. (There was a total of 23 deceased as one participant lost a husband and a sister to suicide.) In terms of time elapsed since the death, the median was 4.25 years. The longest time was 8.8 years afterwards and the most recent was two years.

The majority of participants (20, 91%) described their ethnicity as Australian. The majority (13, 59%) had completed a university degree, with only six (27%) having completed high school or less. Most were in professional or managerial occupations (17, 77%). Their household income was relatively high with a mean of \$87,000 per annum and a median of

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\$62,000 per annum. (In comparison in December 2012, according to NATSEM (National Centre for Social and Economic Modelling, 2013), the median Australian household income was \$43,100.) In terms of religious affiliation, the largest category described themselves as having no religious affiliation (9, 41%), with the next most frequent category being Catholic (6, 27%).

The majority of the 23 decedents were male (21, 91%), with only two females (9%). Their median age was 36 years with the oldest being 66 and the youngest 14 years of age.

Measures

Each participant had a face-to-face interview. These interviews utilised the following instruments: 1) a semi-structured interview schedule to obtain qualitative data and 2) four psychometric measures to assess a range of dimensions.

Questions in the semi structured interview schedule included:

- 1) Background information including: age; gender; ethnicity; education level; household income; religious affiliation; occupation; who had died; their relationship to the deceased; and the length of time since the death.
- 2) Their narrative of the person’s suicide i.e., responses to the question: can you tell me something about the person and their suicide?
- 3) What are the current issues for you as a result of being bereaved by suicide? Can you tell me about them?
- 4) How do these differ from the issues for you earlier in your bereavement?
- 5) What services have you utilised since that time? How helpful were they?

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- 6) What do you think you need now? In what ways, do you think this/or these things would be helpful?

The four psychometric measures were:

- 1) The abbreviated version of the Grief Experience Questionnaire (GEQ) (Barrett & Scott, 1989; Bailey, Dunham & Kral, 2000) was used to measure grief difficulties. This is a 16-item scale which had also been used in this abbreviated form by Feigelman, Jordan and Gorman (2009).
- 2) The Prolonged Grief Disorder Inventory (PGD Inventory - Revised) (Prigerson et al., 2009) which consists of 12 items used to determine if a participant had indications of Prolonged Grief.
- 3) The 15 item Impact of Events Scale (IES) (Horowitz, Wilner & Alvarez, 1979) was utilised as a measure of Post Traumatic Stress Disorder (PTSD).
- 4) A brief index of personal psychological problems. This was designed and utilised by Feigelman, Jordan and Gorman (2009) in their study. A range of other screening questions, were used to ascertain other dimensions including depression, a self rating of emotional/mental health, and the impact of mental health difficulties on days lost to work or housework within the last month, and life satisfaction. Summing together the responses on these four questions produced a total score (Mental Health Problems score) which enabled participants to be located on a continuum from 0 to 4.

Procedure

Pilot testing of the interview schedule and measures was conducted with a long-term suicide bereaved person who was also a volunteer group facilitator at the program. She gave valuable

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feedback about the content and process of the interview which assisted in refining in its final form.

Ethical approval for the study was obtained in September 2012 from the ethics committee of the agency in which the program is located.

Notice of the study was provided in the program’s newsletter, and people were invited to participate. They had to meet the criterion of being bereaved for at least two years. People readily volunteered to be participants. There was no coercion or inducement to participate. Participants were assured that data from the study would only be reported in an anonymous form. They were also informed in advance of the interview that in participating in this study, they would be recalling possibly painful and traumatic past events. If any ill effects were observed, the research interviewer would refer such participants to their own counsellor at the program for appropriate follow-up, support and counselling. This was not necessary during the study.

Interviews were conducted by the then current counsellors at the program. The interviewers did not conduct interviews with anyone who was a current or former client.

In terms of analysis of the data, following transcription of the interview material (by an external secretarial service person who signed a confidentiality agreement), thematic analysis was conducted of the qualitative data, as well as content analysis for some questions. For the quantitative psychometric measures, basic descriptive statistics were done. The Excel computer package was utilised for the latter analysis.

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Results

Of the 22 participants in this study, eight (37%) were not participating in any program activities at the time of interview. Six (27%) were still receiving counselling through the program, whilst four (18%) attended groups of varying kinds run by the program. Four (18%) were volunteers with the program.

The quote contained in the title of this article (“This is really long term”) comes from one of the participants interviewed for this study. It encapsulates the long-term nature of the bereavement experience for virtually all of the participants. The impact of the person’s suicide was still clearly profound at four or more years after the death. All participants were able to readily provide detailed accounts of the deceased person, their life and circumstances of their suicide in the initial part of the interview. This included a number who had found the deceased and for many of them the trauma of that experience had stayed with them.

The issues and experiences they detailed in the interviews were extremely varied. Current issues for them could be categorised as follows: 1) My life has life has changed profoundly and will never be the same again – 11 participants; 2) changed family dynamics – 6; 3) a lack of understanding from others and a feeling of being excluded – 3; 4) fears about the future – 2; and 5) a capacity to become emotional at times – 2. (Tallies total more than 22 as some participants listed multiple issues.)

Results of measures

Three measures were administered to participants as part of the research interview. These were: 1) the Grief Experience Questionnaire (GEQ); 2) the Prolonged Grief Disorder Inventory (PGD Inventory – Revised) and 3) the Impact of Events Scale (IES).

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The correlation between the GEQ scale and the PGD scale was .74 and .48 with the Impact of Events Scale. The correlation between the PGD scale and the Impact of Events Scale was .61.

Insert Table 1 here: (Table 1: Results of participants’ scores on 3 measures (GEQ, PGD and IES scales))

The means were slightly above the mid-points for each of the three measures. No participants scored the minimum possible score on any of these three scales. It would appear that many participants were still impacted by their grief, but not to the extent of meeting the criteria for being diagnosed with Prolonged Grief Disorder or Post Traumatic Stress Disorder. The ranges in the scores on these measures showed considerable variation from those with low scores who were doing quite well overall to those with relatively high ones who were experiencing more difficulties. This range was also reflected in the standard deviations for each of the measures.

Results of other measures

1) *Index of personal psychological problems* was a 4 point scale with 4 = “very good” / “excellent” in terms of mental/emotional health. The mean and median was 3 (“good”). 2) On the *Screening question for depression*, 12 of the 22 (55%) participants reported feeling depressed. 3) Participants were asked about the *days of work missed within last month*, with only 7 (32%) having missed any days at all. The mean response was 1.5 days. 4) *Life satisfaction question*. Both the mean and median responses were 3 (somewhat satisfied). Of all 22 participants, nine (41%) rated themselves as satisfied “a lot”; seven (32%) as “somewhat”; five (23%) as “a little” and only one (5%) as “not at all.” 5) *Mental Health Problems score* was a total of the 4 previous measures to derive a score from 0 to 4, with the higher the score the greater number of problems. The mean score was 1.4 and the median was 1 and the standard deviation of 1.29. Fifteen (68%) of the participants scored one or more. Of

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these, 6 (40% of the 15) scored 1; 3 (20%) scored 2; 5 (33%) scored 3; and 1 scored 4. Seven (32%) scored zero on the scale.

Fourteen of the 22 participants (63%) were able to identify a shift in their grief having taken place, but eight (37%) were not able to do so. The time period of such a shift varied considerably for participants. Three participants each thought it had occurred at one and two years respectively, with one participant thinking it had occurred at 3 years; another at 3-4 years; another at 4 years; one other at 6 years; and another at 7 years. Eight participants could not identify when it had happened. If time periods are combined, six of the 14 (43%) thought that time period for the shift was between 2 to 4 years, and nine between one and four years. The remaining two participants thought it had occurred at 6 and 7 years respectively.

There was also considerable variation in the way that participants described the nature of this shift as Table 2 reflects.

Insert Table 2 here (Table 2: Participants’ descriptions of nature of shift).

Various descriptions of the shift were used by participants. There appeared to be a number of common elements in these discussions. Having a sense of agency or control over the grief, either by the bereaved person assuming these themselves and/or with the aid of the emotional work entailed in individual counselling and/or participation in a therapeutic group or via using self-care strategies. The lapse of time since the suicide was also considered an element for some participants in the shift. The other category mentioned was the impact of another life crisis or major change for the person which seemingly acted as a means of distracting them from their grief.

Examples of participants’ comments about this included the following:

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I think the four year mark for some reason was very important to me. It's like ... you go through a period where you are thinking about him every 10 seconds... I remember at about four years thinking: I didn't actually think about it for the past five hours.

Some were able to say what assisted them to make this shift e.g.

It is one of the things that is never going to go away and there will always be issues that come up that take you back. It's never going to be put aside and you are never going to get over it. You learn to accommodate. You get stronger. For me the only way I got stronger was to be able to talk about it, to come to group things, to be able to have counselling. To me it's talking about it and processing it.

When asked about what their current needs were participants gave a variety of responses, as seen in Table 3 below.

Insert Table 3 here (Table 3: Current needs of participants)

The majority of participants identified either ongoing contact with the program (9, 41%) or contact with other suicide bereaved people (7, 32%). Three (14%) reported that they did not require help at the present time, and two (9%) thought they needed in-depth counselling work.

Some participants were able to articulate clearly what they needed as illustrated by the following comments:

I think you need ongoing affirmation with people and ... to be able to talk to people still about it is really important ...I mean really say what I want to say about it, and

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that rarely happens with friends and family. So it's good ... ongoing contact with people who've been in the same sort of situation.

I just think it's a helpful thing to be with people, like people with like feelings, and life experiences, and just try and learn a little bit more from each other how to deal with things ... just to help you to work things out yourself.

The ongoing and severe nature of the effects of suicide grief is vividly illustrated in the following quote from one of the participants (bereaved for three years): “So I feel like I have a chronic illness ... I have the same symptoms. I have memory loss, I have reduced ability to cope with stress, I'm tired during different times of the day...Mainly to do with concentration and stress.”

Discussion

Whilst the significant impact of someone close to a person taking their own life has been documented at its early stages, its impact and its trajectory in the longer term has been under-researched. The present study's 22 participants were clearly affected by the suicide four or more years after the event as illustrated by the mean level of their scores on the three psychometric measures of grief (CEQ), prolonged grief (PGD) and trauma (IES). However, there was considerable variation in the scores with quite a wide dispersion in the range of scores on these measures. Many participants were doing well on these three measures, whilst a number, albeit smaller, could be said to be struggling with the grief and trauma four or more years after suicide.

On the positive side, there were many signs of resilience and growth which amongst participants. For example, close two thirds of participants saw themselves as having good or

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better levels of mental/emotional health. Over two thirds also had not missed any days from work or household duties in the past month because of mental health difficulties. It was noteworthy that 73% ($n=15$) of participants rated their satisfaction with life as “somewhat” or “a lot.” Just under a third (32% - 7) scored zero on the Mental Health Problems score levels (indicating that they perceived that they had no mental health problems at all.)

A minority of participants were apparently experiencing difficulties, as indicated by the following findings: 12 of the 22 (55% or over half) of participants reported feeling depressed; five (23%) rated themselves as only being “a little satisfied with life”, and one has “not at all satisfied”; the same numbers and proportions were evident in scores on the Mental Health Problems score with five (23%) scoring three (three problems) and one scoring 4.

Those participants who reported doing less well relative to others in the study sample tended to be characterised by: 1) being more recently bereaved i.e. those six participants who scored 3 or 4 on the total Mental Health score had a mean of 3 years since the death as compared to those who scored 0 or 1 on the same measure who had a mean time of 5 years since the death; 2) having ongoing and complex issues in their lives, as well as dealing with the suicide of someone close to them; 3) they tended to be strongly attached or dependent on the person who had suicided; 4) tended to be relatively isolated with few significant social supports; and 5) may have been acting as carer for the deceased prior to their death.

In contrast, those who were doing relatively better tended to: 1) be bereaved for a longer period of time; 2) were not dealing with other ongoing and complex issues in their lives; 3) tended to benefit from strong and consistent sources of social support; and 4) had not acted in a carer role for the deceased.

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Based on previous research, there was an expectation that there would be an identifiable turning point in participants' grief between three or five years after the death. Only slightly over half of the participants (59% - 14) were able to identify such a shift in their grief. For the other nine participants, there was no identification of any such shift, which either indicated it had not been experienced, or if it had, these participants were not able to identify it. Of those who had not had perceived such a shift, it could be thought that it may await them in the future or not come at all. Even if such a shift was identified, there was considerable variation in the time after the suicide that it took place, with three participants being unable to identify when it had occurred. Of the remaining 11 participants, the median time that elapsed was two years after the death. This time period ranged from one year through to 7 years.

Unfortunately, these findings do not really provide confidence in predicting for suicide bereaved people when such shift is likely to occur for them.

Participants in this study confirmed that they had ongoing needs, even though their grief was more long-term. Eighteen of the 22 participants (82%) either wanted continuing contact with a specialised suicide bereavement counselling program (at a range of different levels) or contact with other suicide bereaved people.

Conclusions to be drawn from this study should not be overstated given the nature of the sample used. The sample was self-selected in that the participants chose to volunteer for the study for their own particular reasons. A number of the participants reported that taking part in the interview for the study was beneficial for them. Others appeared to participate as a means of expressing their gratitude to the program.

The demographic features of the sample indicated that it may not have been representative of those bereaved by suicide. That most participants were women is consistent with pattern of

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gender differences in suicide i.e., 4:1 ratio of men to women who suicide (Australian Bureau of Statistics, 2014), thereby making it more likely the women will form the majority of partners who are bereaved. The majority of participants had completed a university degree, were in professional or managerial occupations and had relatively high household incomes. All of these features are probably consistent with the means used to advertise the study i.e. through electronic or hard copy of the program's newsletter.

This study sought the views of participants as to how they were functioning currently, but also asked them to recall how they were functioning immediately after the suicide. This retrospective component of the study is a significant consideration, given the median length of time since the death was four years. This passage of time may have affected the accuracy of recall by participants, particularly given the likely severity of their grief and trauma immediately after the death.

In terms of current needs, the majority of participants wanted to have continuing contact with the program or contact with other suicide bereaved people (16 out of 22 = 73%) or further counselling (2). These numbers represent 18/22 or 83% overall. Only four (out of 22 - 17%) said they did not require help now or did not know what their current needs were.

These findings provide some indication of future direction for intervention and services from programs for long term bereaved people. While such programs clearly have as their focus providing assistance to people bereaved by suicide in the immediate crisis and the acute and short term, it is important not to lose sight of those longer term in the provision of services.

The findings of this study suggest the following recommendations: 1) ensure that people are aware that they are welcome to have continuing contact with the program on a long-term basis without feeling it is creating dependency or drawing on scarce resources. Programs

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should ensure that they are aware of the long-term effects of suicide grief on people who should not feel excluded and/or stigmatised by services. The availability of continuing services could take the form of: a) the ready availability of counselling and b) specific groups for the longer term bereaved. The latter would be open groups with the capacity for participants to attend the group as they felt the need. Such a group would benefit from facilitation from a trained peer supporter, alongside a professional counsellor.

2) As well as these more formal options, programs could provide opportunities to people to gather together more informally to join together for sharing, affirmation, understanding, comfort and connection e.g. discussion with other similarly bereaved people, taking part in suicide prevention walks, and social events. Programs should always be mindful of providing flexibility in order to meet bereaved people's needs (Ryan, 2012).

This study began to explore the nature of longer-term suicide grief, but ideally, future research should take the form of a longitudinal study that could follow participants for up to 10 years. They would be interviewed at a minimum of six monthly intervals using both psychometric measures of grief and trauma, as well as in-depth qualitative methods, as a means of tracking them through their grief journey.

In conclusion, it seems from the findings that suicide grief does not disappear. It is always there, but its nature changes. It needs acknowledgement and affirmation, and for some, specific intervention with counselling and/or group work which programs need to be mindful of providing.

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TABLES

Table 1: Results of participants’ scores on 3 measures (GEQ, PGD and IES scales)
(n=22)

<i>Measure</i>	<i>Midpoint of scale score</i>	<i>Mean</i>	<i>Range</i>	<i>SD</i>
GEQ	40	44.3	26-66	10.01
PGD	27.5	30.4	15-42	8.4
IES	30	35.5	16-49	9.6

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Table 2: Participants’ descriptions of nature of shift (n=14)

Acceptance/becoming used to the situation	3
Another life crisis/change diverts focus away from grief	3
Doing emotional work in counselling or group	2
Passage of time combined with emotional work	2
Passage of time alone	1
Passage of time, plus self care	1
Having an explanation of the suicide plus doing group	1
Taking control of grief	<u>1</u>
	14

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Table 3: Current needs of participants (n=22)

Continuing contact with program	9
Contact with other suicide bereaved people	7
Do not require help now	3
Need for in-depth counselling work	2
Do not know	$\frac{1}{22}$

Martin Ryan – 8-11-2015