

# The Lifekeeper Memory Quilt: Evaluation of a Suicide Postvention Program

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The Lifekeeper Memory Quilt Project, implemented by the Salvation Army (Suicide Prevention-Bereavement Support Services) in Australia in 2008, aimed to provide support for those bereaved by suicide and to create greater public awareness of suicide. To evaluate participants' satisfaction with this project, 82 bereaved individuals completed surveys and 30 completed an interview. Results indicated that the Quilt was helpful in assisting participants in their bereavement. The Quilt project gave participants an opportunity to reflect on the life of their loved one and provided a space for them to grieve without fear of negative social reactions.

Suicide is one of the major causes of premature deaths internationally and ranks 15th as a cause of death in Australia (Australian Bureau of Statistics [ABS], 2012). It is estimated that almost 1,000,000 people worldwide die by suicide each year (World Health Organization, 2012). In Australia, there were 2,273 reported deaths by suicide in 2011, accounting for six suicides per day (ABS, 2013). For each person who completes suicide, many people are bereaved, and they reportedly receive limited or less than adequate support (Mitchell, Sakraida, Yookyung, Bullian, & Chiappetta, 2009; Peters, Murphy, & Jackson, 2013).

Those bereaved by suicide, not only experience a myriad of feelings related to the grieving process, such as unhappiness, loss, and isolation, but also feelings of guilt, confusion, rejection, shame, anger, trauma, and stigma. For instance, some survivors may be left in a

quandary with many questions still unanswered and an overwhelming sense of guilt for not intervening sooner, and others may have been traumatised by the experience or feel abandoned, rejected and angry at the thought of being left behind on their own (Young et al., 2012).

Survivors of suicide are subject to much more social stigma than those bereaved by other forms of death (Feigleman, Gorman, & Jordan, 2009) and this stigma may hinder the healthy progression of the grieving process and result in maladaptive responses to grief (Aguirre & Slater, 2010), such as complicated grief (Young et al., 2012). *Complicated grief* is defined as “the failure to return to pre-loss levels of performance or states of emotional well-being” (Prigerson et al., 1995, p. 23). Furthermore, stigma represents a barricade to seeking support and initiating the healing process for persons bereaved by suicide, causing them to encounter animosity, judgement, and superficial support (Aguirre & Slater, 2010). In addition, individuals bereaved by suicide are at high risk of suicide themselves, and experiencing complicated grief can heighten this risk (Aguirre & Slater, 2010; Ram, Darshan, Rao, & Honagodu, 2012). The level

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Received 31 January 2014; accepted 29 July 2014.

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of closeness one had to the individual predisposes the suicide survivor to an increased risk for complicated grief (Mitchell, Kim, Prigerson, & Mortimer-Stephens, 2004).

Being able to communicate with others, in some form, about a loved one is key to recovery and healing, but many people bereaved by suicide report that it is often extremely challenging to openly talk about the cause of death (Young et al., 2012). There is no definitive, best postvention strategy for survivors, but it is clear that bereavement support strategies should be diverse (Andriessen, 2009). One such postvention program, the Lifekeeper Memory Quilt initiative, may provide an outlet for recovery and healing for those affected by suicide and reduce the incidence of further suicide. Young et al. (2012) explained “[o]ften it is helpful to see others who have ‘survived’ the suicides of their own loved ones, and eventually it may even be helpful to have the opportunity to help others” (p. 182).

In 2008 the Salvation Army (SA), Hope for Life Suicide Prevention and Bereavement Support, launched a national Lifekeeper Memory Quilt initiative. The project invited families bereaved by suicide to submit via email or post a photographic tribute and a 25-word narrative about their loved one who had died by suicide. Using the photos and narrative, a SA volunteer created memorial quilts. In addition to the inaugural quilt, Hope for Life developed five state-based quilts that are available for community suicide prevention and postvention awareness events. The Lifekeeper Memory Quilt has two objectives: (a) to provide a sensitive and fitting memorial to enable bereaved families to celebrate and remember the lives of their loved ones; and (b) to raise awareness of the impact of suicide with the hope that this awareness prevents further suicides.

Although anecdotal evidence from participants showed overwhelming support for the initiative, a formal evaluation of this postvention strategy had not previously been conducted. Further, there is limited evidence available to guide optimal timing for the implementation of such strategies (McDaid, Trowman, Golder, Hawton, & Sowden, 2008). Though it is seldom accomplished, evaluation is crucial to ensure accountability and to identify both successful and ineffective aspects of the postvention strategy and promote improved outcomes (Andriessen & Kryszynska, 2012). Without formal evaluation, the sustainability of such initiatives is threatened in terms of capacity to attract community and financial support (Roberts & McGilloway, 2011; Schut & Stroebe, 2011). The aim of this study was to evaluate satisfaction with the Quilt project.

## METHOD

### Participants

Participants were 82 suicidally bereaved people (54.67% response rate) who returned either a hard copy or

completed an online survey. Most (75) were women, with 75% being over 45 years of age. Approximately two-thirds (54; 66%) lost a child to suicide, 11 (13%) a sibling, 10 (12%) a spouse/partner, and 5 (7%) a parent. Two participants (2%) did not complete the question related to their relationship with the deceased. The age of the deceased ranged from 13–76 ( $M = 32.24$ ,  $SD = 14.45$ ). The final page of the survey allowed participants to provide contact details if they wished to participate in an interview. As a result, 30 people consented to participate in a telephone interview. These 30 were bereaved for between 8 months and 15 years ( $M = 5.96$ ,  $SD = 3.74$ ).

### Materials

Using the Help Is at Hand questionnaire (Hawton et al., 2011), the chief investigator developed 16 items measured on a 5-point format ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). With two negatively worded items reverse coded, scores could range from 16 to 80, with higher scores indicating more positive attitudes about the Quilt project. Items included whether the Quilt assisted participants with their bereavement journey, dialogue with their family about their loss, remembering and memorialising loved ones, and promoting public awareness. Separate questions about demographics, how long after bereavement they participated, and whether they perceived the timing to be apt, were included on the survey.

These 16 items of the Participants’ Evaluation of Quilt (PEQ-16) scale had a Kaiser-Meyer-Olkin measure of sampling adequacy value of 0.88, indicating the data were well suited for principal component analysis. The analysis yielded a one-component solution that explained 48.09% of the variance. Component loadings of all 16 items ranged from 0.46 to 0.83, all of which were above the 0.3 component loading threshold. Cronbach’s alpha was 0.92.

### Procedure

The SA representative who had overseen the Quilt project mailed a letter that included a participant information sheet outlining the study, a consent form, a list of counselling services and the present survey. Following completion of surveys, two of the present authors who have substantial experience in interviewing vulnerable populations interviewed the 30 consenting people via phone, with interviews averaging 30 min in duration. The telephone interviews began with, “Tell me about your experiences of participating in the Quilt project.” Open-ended prompt questions were used if required to ensure participants’ narrative responses addressed the aim of the research (see the Appendix).

The research was approved by the University Human Research Ethics Committee. All interview participants were allocated a number to prevent them being identified by name. Participants were informed of the voluntary nature of the study and were assured that no member of the SA would know whether or not they chose to participate. They were also informed that decisions regarding participation in the study would not impair any existing or future relationships between themselves and the researchers and/or the SA.

Qualitative data were audiorecorded, transcribed verbatim and thematically analyzed by two of the authors independently. Final themes were decided when consensus was reached.

## RESULTS

The mean for PEQ-16 scale was 69.64 ( $SD = 9.08$ , range = 42–80) with a nonnormal distribution scores. This mean showed high satisfaction with the project with average answers indicating either agreement or strong agreement that participants were satisfied with the Quilt project. About 80% participated in the program over a year after their loss while the other respondents enrolled in the Quilt project between 1 to 12 months of their loss. Over half (48%) reported that a year after their loss was the best time to be participating in the Quilt project. Overall, approximately 92% who completed the survey rated the Quilt project to be helpful or extremely helpful.

Using the Spearman's rho to test for associations between Quilt project satisfaction and participants' demographics, how long after bereavement they participated, and whether they perceived the timing to be apt, those who perceived that this was the best time to be participant in the Quilt project were significantly more satisfied ( $r = 0.34$ ,  $p = 0.006$ ). There was no other statistically significant relationship between satisfaction and participants' characteristics.

Analysis of the qualitative data revealed the following four themes: healing, creating opportunity for dialogue, reclaiming the real person, and raising public awareness. The four themes illuminate how the Quilt assisted participants in their bereavement and provides insights into why they engaged in the Quilt program. These themes are illustrated below with verbatim quotes from participants' transcripts.

### Healing: "It's Given Me My Power Back"

Participants conveyed that the Quilt facilitated their grief journey ("I think it's given me my power back,

power to move on, power to be able to get on with my life," Participant 1), and they appreciated the support they received ("I found the Quilt project as healing and very supportive," Participant 19).

Another said that the Quilt fostered personal resilience in providing a positive outcome for their grief: "I felt better about myself that I actually did something. I'm a big believer in that, actions do speak louder than words, and I couldn't do much and I felt really, really helpless at the time anyway" (Participant 15).

Despite acknowledging that the Quilt helped them with their bereavement, participants recognised that part of this recovery required them to revisit the past and reflect on painful memories. For example:

It was emotional and therapeutic in a way as well. I get the opportunity to see my daughter's photograph, see her smiling face. Being able to talk about it, and have the memories that I can have or share with other people in the memories of our children. (Participant 13)

It just brings everything back. You have to relive everything. The sadness of seeing our son as one of those faces. You go back to asking why and if only and—yeah. (Participant 6)

### Creating Opportunity for Dialogue: "It's a Good Way to Open a Conversation"

Because of the negativity and stigma surrounding suicide, participants reported multiple difficulties in commencing and maintaining conversations related to the suicide deaths of their family members. They perceived the Quilt to be helpful in generating dialogue, as one participant said, "Because it's a visual medium. It's a good way to open a conversation" (Participant 20).

Participants conveyed they had substantial difficulty in talking about their loved ones and this reluctance limited them in seeking and receiving appropriate support in their bereavement. The narratives of participants below highlight how participants perceived the helpfulness of the Quilt in talking about their loved ones: "[The Quilt] has been helpful because I've talked to people, I've shown them the pictures of the Quilt to those that knew my [loved one]. I think it's made people around me more aware about what's going on" (Participant 26). As well as the Quilt facilitating discussion with those outside the family, participants also reported that it assisted in opening up family dialogue. For example, "It gave a chance to talk to the kids a little bit even though they're not very talkative and open about it. To have more of a positive thing that they can contribute to" (Participant 18).

The Quilt made participants feel connected with others bereaved by suicide. They felt a sense of community with other participants of the Quilt project and

described a sense of mutual understanding with others who had lost loved ones to suicide. Because of this mutual understanding one participant stated, “There was a connection, there was somehow a link. I felt safe in doing that process” (Participant 1).

Further elaborating on the connectedness they felt with others bereaved by suicide, another participant stated, “Unless you’ve also been bereaved through suicide, you don’t really get it. There’s always empathy but even other people bereaved by other sudden deaths, they don’t quite get it” (Participant 30).

As well as sharing a common understanding between all individuals bereaved by suicide, some participants conveyed the importance of having the opportunity to speak with someone mourning the loss of a similar person in their lives.

I met this lady that had also lost [her husband] and so it was a chance to I suppose speak to another widow in that respect because it’s difficult to talk about your loss of a husband when other people have lost a child. So it made you realise you’re not alone. (Participant 18)

Participants conveyed that they did not just feel connected with bereaved others in terms of being understood, but in understanding them and feeling for people in their grief. This capacity for empathy toward others bereaved by suicide is highlighted in the following narratives. “I know that I’m not the only one out there now, there’s lots of people out there that are dealing with the same thing. I feel for everybody involved, I really do” (Participant 26).

As well as providing the opportunity to connect with others bereaved by suicide, the Quilt was perceived by participants as valuable in facilitating a connectedness with the memories of their deceased loved ones. The following illuminates the ability of the project to promote connectedness and in turn assist the bereaved in navigating their grief:

Seeing the Quilt there it’s like I’m now starting to feel he’s with me on my journey. It was like I was totally alone. But now to actually acknowledge that he was part of my life, it’s like this is not wasted. There’s sort of an energy that comes with it. (Participant 1)

#### Reclaiming the Real Person: “The Opportunity to Remember Them in a More Revered Way”

When a person dies by suicide, discussion tends to focus on the suicide, reducing the person to the act while at the same time dismissing everything else about his or her life. Participants felt that irrespective of who their loved ones were or what they had previously done, the act of

suicide became the focus and their loved ones were forgotten. For example,

My son was still at school when he died. At the end of the year when the yearbook came out, there was not one single mention of my son. Now if he’d died in a car accident or had cancer or died of anything else, there would’ve been a memorial page to him or something. I was incensed, but I felt really, really bad for his friends. They were the ones who were most hurt and angry that it was like he never existed. (Participant 30)

Participants talked about the Quilt as a vehicle that allowed them to honor and value their loved ones and acknowledge the life they had lived, rather than the means by which they had died.

They are not remembered in the way you would like them to be because of the trauma around the way they have died. This actually gives us the opportunity to remember them in a more revered way and to honour them. (Participant 19)

Participants conveyed that they participated in the Quilt project in order to diminish or combat stigma: “The Quilt was one way of being able to talk more openly about suicide by showing people photos and talking about the Quilt, it’s a way of being able to discuss suicide and try and de-stigmatise it” (Participant 6).

Participants thought that the stigma that surrounds suicide denied them memories of their loved ones. Participation in the Quilt project provided them with the opportunity to remember their loved ones and validate the existence of the decedents. For example, “We thought it was a good way to commemorate our daughter as a real person, that people, besides our friends who actually knew her, could see that she’s a real person, not just a statistic” (Participant 23).

As well as facilitating the reclaiming and normalizing of the lives of their loved ones, participants appreciated the opportunities for reflection and remembrance provided by the Quilt. The following narratives represent participants’ recognition of the way the Quilt assisted in provoking memories of happier times in their lives with their loved ones: “Having the opportunity to put 25 words together about your loved one as a reflection on who they were, I found that a really beautiful process. I could think about the positives in my daughter’s life” (Participant 19).

#### Raising Public Awareness: “Instead of Just Numbers These Are People”

One of the main reasons participants gave for engaging in the Quilt project was that they wanted to make a difference. As highlighted in the narratives below,

acknowledging and recognizing suicide was a common goal for all participants. They wanted to highlight that those depicted on the Quilt were husbands, wives, sons, and daughters and very much loved by the bereaved person: “People need to know that instead of just numbers these are people; that they had a life and they’re very precious to those they’ve left behind” (Participant 12).

Apart from recognizing and acknowledging the extent of suicide, participants hoped that their contribution to the Quilt would create public and private dialogue to promote suicide prevention: “So this is an opportunity to be able to try and inform the public and the need to talk about suicide and for people who may be vulnerable and maybe hopefully then prevent somebody from taking their own life” (Participant 13).

One of their main objectives through participation was to highlight the fact that individuals who complete the act of suicide are not atypical of the general population. As one participant stated:

It’s out there and it’s in our community and it’s happening every day, families are getting that knock on the door, that phone call, every day and it’s-by putting a face that’s a human face to these people. It’s not just the people that are dealing with it, it’s there for everybody to see, that it can happen to anybody. (Participant 9)

Further to raising community awareness of the indiscriminate nature of suicide, the following participant’s narrative encourages support and understanding from others regarding the reasons people feel they need to end their own lives.

Knowing that it was helping—that somehow it was a contribution for other people as well and getting things out there in the open. It’s not shameful or anything like that. It’s just—they’re just at the end of their tether basically and people have to understand that. (Participant 12)

To create public awareness, participants anticipated that the Quilt would be displayed. There were varying degrees of uncertainty within participants’ narratives regarding the current and future use of the Quilt. They wanted the Quilt to reach the public but were mindful that there needed to be an appropriate context in which it was displayed.

I would actually like to see it on permanent display, in a subtle way that people would actually have to seek it out. The obvious way to use it is to have it at things like survivors’ day, suicide prevention day, where people—it’s in a public forum but people know that that’s why they’re going to that, they’re going to talk about suicide. (Participant 30)

All participants hoped that the Quilt could be used in public forums to educate communities and promote discussions around suicide. For example,

I think it’s a very positive thing and I hope that it will be used as a teaching tool... Seeing those happy, smiling faces of the people, on that Quilt, they were cut down before they even reached their potential. They were stripped of a life and their families bear that scar forever. (Participant 3)

## DISCUSSION

Present participants perceived that they were denied the opportunity to grieve because their loved ones died by suicide. This finding resonates with participants of a study by Feigelman et al. (2009) who highlighted ways in which the responses of others made them feel stigmatised. These responses included avoidance of discussion relating to the deceased person and the absence of empathy regarding participants’ loss, including giving insensitive advice. Such advice included telling participants “it’s time to move on,” which is invalidating and offers no consolation for the survivor. Responses such as this described by both present participants, as well as Feigelman et al.’s (2009), reflect the social disapproval attached to death by suicide, as well as impose blame on the family which leads to informal isolation. In addition, being denied the opportunity to discuss the death of their loved one, further complicates the grieving process by inhibiting the bereaved person’s capacity to make sense of their loved one’s death (Trickey, 2009).

These social judgments toward suicide and survivors of suicide not only complicate the grieving process, they also increase the risk of survivors developing a phenomenon known as complicated grief. Complicated grief, in turn, increases the risk of survivor suicide thereby emphasising the importance of postvention strategies, such as the Quilt project, and raising awareness of and support for survivors of suicide (Aguirre & Slater, 2010). Further, the more stigma that suicide survivors encounter, the greater that grief is exacerbated and the need for support and postvention increases (Feigleman et al., 2009).

Interactions experienced by participants throughout their involvement in the Quilt project were in stark contrast to those they encountered in the general community. By its very design the Quilt project provided a space free from stigma, judgment, and negative social reactions that encouraged bereaved people to discuss their loss from suicide. This opportunity is significant in light of findings of previous research that identifies stigma as being strongly related to suicide ideation among survivors (Cvinar, 2005).

As well as ameliorating, to some extent, the effects of stigma related to their loved ones’ suicide, the Quilt



project provided a milieu of understanding and acceptance. The importance of suicide survivors being understood and accepted is emphasized in previous research that has found that they experience greater levels of societal rejection than those bereaved by other causes of death, which further complicates their grief (Cvinar, 2005; Maple, Edwards, Plummer, & Minichiello, 2010; Sveen & Walby, 2008). Resonating with a study by McMenamy, Jordan, and Mitchell (2008), participants of the Quilt project described feeling connected with others and appreciated the opportunity to share the stories of their loved ones in a nonjudgmental environment. This finding suggests that the Quilt project can offer multiple benefits to those who engage with it.

Furthermore, results suggest that participation in this intervention was perceived as being most helpful when it occurred more than one year post bereavement. Timing of postvention programs is critical with on-scene intervention being quite helpful in ensuring suicide survivors engage in follow-up support programs/interventions within the next few years (Szumilas & Kutcher, 2011). Like the Quilt project, the Australian StandBy Response Service, a community postvention service, identified significant benefits of their program including lower levels of suicidality within the initial two years following the loss. The participants who engaged in the program, compared to those that did not, also reported greater work productivity and efficiency and a reduction in the usage of health services, which has additional economic benefits for health systems (Andriessen & Krysinska, 2012).

Postvention strategies, such as the Quilt project, have the potential to play an essential role in bereavement support, suicide prevention, and improved public awareness of the issue, with suicide survivors placed at the forefront of the initiative. It is vital to listen to those whose loved one died by suicide and understand their needs to be able to provide effective postvention strategies (Andriessen & Krysinska, 2012). As Andriessen and Krysinska explained, “[j]ust as suicidology without the involvement of survivors would be poor suicidology, suicide prevention without survivors would be poor suicide prevention” (p. 29).

A major limitation of this study was that the sample was predominantly made up of women. As men and women have been reported to grieve in different ways (Stroebe, 2001), findings from this research may not necessarily be applicable in informing suicide bereavement support for men. Also, participants were not representative of all people bereaved by suicide, with over 75% being over the age of 45. A further limitation to this study was that people who participate in Quilt projects are not necessarily representative of all suicide survivors; and although over 50% of those who participated in the Quilt project responded to the survey,

those who did not respond may have a different perspective regarding the benefits of the project for bereavement support.

Individual participants’ experiences of being involved in the Quilt project were varied, but the vast majority considered the Quilt to be an effective postvention strategy. Included in the most valued aspects of participation was the opportunity to have their experiences validated by others who had endured a similar loss. As well as personal benefits gained from the Quilt project, participants recognized its potential in raising community awareness. Therefore, in part, their reasons for participation included a desire to prevent the act of suicide and reduce the stigma surrounding it.

## ACKNOWLEDGMENTS

The Salvation Army had no role in the design of the study or the collection, analysis, and interpretation of data. Alan Staines from the Salvation Army contributed to writing and critical reading of the manuscript and agreed with the decision to submit the manuscript for publication.

## FUNDING

This study was funded by The Salvation Army.

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## APPENDIX: INTERVIEW QUESTIONS

### Initial Question

- Can you tell me about your experience of participating in the Lifekeeper Memory Quilt Project?

### Possible Prompt Questions

- Can you tell me why you decided to participate in the Quilt project?
- Can you tell me what you found helpful about the Quilt project?
- Tell me what you found difficult about the Quilt project.
- Have your thoughts and opinions about the Quilt changed over the last few years?
- Has your involvement in the Quilt project impacted on your grief journey? If so how?
- How do you view the Quilt project impacting on your family?
- Did the Quilt project assist in communication with members of your community?
- Tell me how you would like to see the Quilt used.