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Recovering from stillbirth: the effects of making and sharing memories on maternal mental health

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Abstract

Objective: This study examined whether the experience of creating and sharing memories of their babies is associated with mothers' mental health after stillbirth, taking account of factors previously shown to be important. **Background:** Mothers of stillborn babies are usually offered the opportunity to spend time with and create memories of their babies. However, evidence on whether this leads to better mental health outcomes is equivocal. One possible explanation is that the impact of making memories is mediated by the extent to which women subsequently share these memories. **Methods:** Cross-sectional questionnaire study. Mothers (N = 162) of stillborn babies completed online questionnaires of how memories were made and shared, satisfaction with memory making and sharing, professional and social support, and symptoms of depression, anxiety and PTSD. **Results:** The majority of mothers made and shared memories. The number of different memory making activities was not associated with mental health outcomes. However, the degree to which mothers shared their memories was associated with fewer PTSD symptoms. Regression analyses showed that good mental health was most strongly associated with time since stillbirth, perceived professional support, sharing of memories and less wish to talk more about the baby. **Conclusion:** This study confirms research showing that time since stillbirth and perceived professional support is associated with better mental health following stillbirth and for the first time shows the importance of opportunities to share memories of the baby. Variation in sharing opportunities may contribute to inconsistencies in the association between making memories and mental health following stillbirth.

Keywords: stillbirth; stillborn, maternal health, mental health, making memories, sharing memories

Introduction

Stillbirth occurs in 1 in 200 pregnancies in the UK and these rates have changed very little over recent decades (Flenady et al., 2011). Most prospective parents are not prepared for the possibility of stillbirth (Layne, 2003), so it is a shocking and highly emotional experience that can impact negatively on the mental health of all family members, particularly the mother (e.g., Badenhorst, Riches, Turton, & Hughes, 2006; Boyle, Vance, Najman, & Thearle, 1996; Cacciatore, Schnebly, & Fróen, 2009; DeFrain, Martens, Stork, & Stork, 1990; Rådestad, Steineck, Nordin, & Sjögren, 1996; Turton, Hughes, Evans, & Fainman, 2001; Vance et al., 1995). Even in high-income countries where professional psychological support is available, the incidence of depression, anxiety and posttraumatic stress disorder (PTSD) symptoms is about 20% in mothers of stillborn babies (Fróen et al., 2011).

Research has revealed a number of factors that influence the association between stillbirth and mothers' subsequent mental health including time since the baby died (Cacciatore, Rådestad, & Fróen, 2008; Engelhard, van den Hout, & Arntz, 2001; Turton et al., 2001), gestational age (Engelhard et al., 2001), professional support (Murray & Callan, 1988), social support (Cacciatore et al., 2009; DeFrain, et al., 1990; Turton et al., 2001) and subsequent pregnancy (Cacciatore, Rådestad et al., 2008; Turton et al., 2001). There is an extensive but less consistent literature on the influence of opportunities to create memories of the baby (Hughes & Riches, 2003). Until the 1970s, stillborn babies were usually removed quickly, so parents had no opportunity to see or hold them. The suggestion that a lack of contact might inhibit mourning and lead to psychological

difficulties (Lewis, 1976) subsequently led to mothers being encouraged to make memories by, for example, seeing and holding their babies and keeping mementos.

Research has shown that mothers value spending time with their stillborn babies (e.g., DeFrain et al., 1990; Rand, Kellner, Revak-Lutz, & Massey, 1998) and creating mementos such as photographs (Godel, 2007; Riches & Dawson, 1998). However, research on the impact of memory making is inconsistent with some studies finding adverse effects (e.g., Hughes, Turton, Hopper, & Evans, 2002; Turton et al., 2001; Turton, Evans, & Hughes, 2009) and others finding positive effects (e.g., Cacciatore, Rådestad et al., 2008; Rådestad et al., 1996; Surkan, Rådestad, Cnattingius, Steineck, & Dickman, 2008). For example, Hughes et al. (2002) found better mental health outcomes both during and one year after a subsequent pregnancy for mothers who did not see or hold their stillborn infants. Furthermore, Turton et al. (2009) found that partnership breakdown and PTSD re-experiencing symptoms were associated with mothers having held their stillborn babies. In contrast, Rådestad et al. (1996) reported that not having mementos and not seeing their babies for as long as they wished led to more anxiety and depression symptoms in mothers following stillbirth. Similarly, Cacciatore, Rådestad et al. (2008) found that mothers who had seen and held their stillborn babies had lower anxiety and depression symptoms unless they were pregnant in which case their depression symptoms were lower but their anxiety symptoms were higher. This increase in anxiety in subsequent pregnancies is commonly observed in women who have experienced stillbirth (Turton et al., 2001). Such findings have important implications for professional practice. In the UK, research suggesting adverse effects of seeing and holding their stillborn babies on mothers' long-term mental health (Hughes et al., 2002)

led to controversial advice suggesting parents should not be routinely encouraged to see and hold their stillborn babies in some of the documents in the 2007 National Institute for Health and Clinical Excellence guideline on antenatal and postnatal mental health (Schott & Henley, 2009).

One possible explanation for the inconsistent findings is that it is not the opportunity to make memories per se that affects mental health, but whether mothers have the opportunity to share and process these memories afterwards. If a lack of opportunities for sharing memories is associated with poor adjustment, variation in such opportunities may contribute to the inconsistent evidence on making memories. To date, no research has examined the relationship between opportunities to share memories and maternal mental health following stillbirth.

There are several reasons to suggest sharing memories following stillbirth might be beneficial for maternal mental health. First, sharing memories is usually considered beneficial as part of the grieving process (Kubler-Ross & Kessler, 2005; Stroebe & Schut, 1999). Second, birth is a major life event that impacts on a mother's identity and sharing their birth story aids the integration of the experience into a mother's life narrative. This is important for mothers bearing live infants (Callister, 2004) and may be even more so following stillbirth. This is because, as Cacciatore, DeFrain, and Jones (2008) pointed out, stillbirth is an example of ambiguous loss (Boss, 1999). This leads to ambiguity in the mother's identity - she is both 'mother', the baby was born and is psychologically present, and 'not mother', the baby is physically absent. Sharing memories may help women resolve the ambiguity and adjust their identity to include the baby and their role as mother in a healthy way.

While mothers might want to share their memories following stillbirth, they may find it difficult to do so. This is partly because they have few memories to share, partly because others do not consider their loss and grief to be as legitimate as that following the death of any other child and do not appreciate their need to share, and partly because, if they do try to talk about their babies, others find it uncomfortable and avoid the topic (e.g., Cacciatore, 2007; St John, Cooke, & Goopy, 2006).

The aim of this study was thus to examine the relationship between mothers' opportunities to make and share memories of their babies and their mental health following stillbirth and how this relates to the association with other factors already known to have an influence, namely time since the baby died, gestational age, and professional and social support.

Method

Design

A cross-sectional online study examining the associations between making and sharing memories after stillbirth and mothers' anxiety, depression and PTSD.

Participants

Participants were mothers of stillborn babies (N = 162). Inclusion criteria were that women were at least 18 years old and gave birth in the UK in the past 10 years to a baby of at least 20 weeks gestation¹. Women were excluded if they were currently pregnant, or if their stillborn baby had a live born twin. One hundred and eighty-nine participants were recruited via websites supporting parents who had experienced perinatal loss, mostly from the Stillbirth and Neonatal Death (Sands) charity website (n = 141). Attrition meant 27 women only partially completed the questionnaires, leaving a final sample of 162.

Materials and Procedure

A questionnaire was designed for this study to collect information about mothers' experiences of making and sharing memories and perceived support following stillbirth. In section 1, mothers responded (yes/no) to a 19-item checklist of what their memories might include (e.g., seeing, holding, or bathing the baby) with an option to specify other ways they had created memories. Some of the items were based on those used by Surkan et al. (2008). In section 2, five items asked how they felt about making the memories on a 5-point scale (strongly agree to strongly disagree) e.g., I wish I had made more memories. Using the same rating scale, section 3 asked three questions about information, care and support from health professionals (e.g., I felt supported by health *professionals following my baby's death*) and three questions about support from the mother's partner, family and friends. Section 4 asked about the frequency of a variety of opportunities for sharing memories (never, once, occasionally (2 or 3 times), frequently) using a 19-item checklist covering talking to others, sharing photographs and keepsakes, and writing about the baby (e.g., I have talked about my baby with my family). Section 5 used a 5-point rating scale to ask three questions about how they felt about sharing their memories (e.g., I wish I could talk more about my baby). Open-text questions invited women to provide more information relating to their experience. These data are to be reported elsewhere (Brierley-Jones, Crawley, Lomax, & Ayers, submitted).

Symptoms of depression and anxiety in the previous month were measured with the Depression, Anxiety and Stress Scale, DASS-21 (Henry & Crawford, 2005; Lovibond & Lovibond, 1995). PTSD symptoms in the last month were measured using the Posttraumatic Stress Symptom Scale (Foa, Riggs, Dancu, & Rothbaum, 1993) adapted to

ask women only to report symptoms in relation to the stillbirth. Demographic and birth details were measured by self-report.

Following ethical approval, the survey was available online for six months (February to July 2010). Participants gave informed consent before completing the questionnaires.

Results

Sample characteristics

Sample characteristics and birth details are shown in Table 1.

Table 1

Making and Sharing Memories

The number of different activities included in memories of their babies ranged from 4 to 16 ($M = 10.5$, $SD = 2.8$). Table 2 shows the percentage of mothers reporting different memory making activities.

Table 2

The number of different ways mothers shared their memories ranged from 1 to 19 ($M = 13.9$, $SD = 3.6$). The percentage who engaged in different memory sharing activities at least occasionally is shown in Table 3.

Table 3

Satisfaction with memory making and sharing opportunities and with professional and social support is shown in Table 4. Rated satisfaction with social support was significantly higher than satisfaction with professional support ($t(161) = -7.57$, $p < .001$).

Table 4

Making Memories, Sharing Memories and Mental Health

Women in the sample had a range of symptoms of PTSD (range 0-51, M = 20.6, SD = 12.6), depression (range 0-42, M = 20.9, SD = 13.4) and anxiety (range 0-42, M = 14.3, SD = 11.2). Table 5 shows correlations between mental health measures, memory variables, time since the baby died, gestational age, professional and social support. Preliminary analyses showed items measuring satisfaction with making and sharing memories were not internally consistent (Cronbach's $\alpha = .01$ and $.19$ respectively) so could not be summed and used as subscales. Therefore Table 5 includes items from these scales that were significantly associated with mental health variables (I wish I had made more memories and I wish I could talk more about the baby). The correlations were used to determine which potential predictor variables to include in the regression analysis for each of the mental health measures. To adjust for the possibility of Type 1 errors, only correlations where the effect size r exceeded $.1$ (small effect) were included (Cohen, 1992). This method was chosen in preference to choosing variables on the basis of significance because effect sizes are a more accurate reflection of effects than significance (e.g., Nakagawa 2004; Perneger 1998).

Table 5

The lack of a relationship between making memories and mental health meant it was not possible to establish whether this was mediated by sharing of memories. Instead, a stepwise multiple regression analysis was conducted for each mental health measure to identify which of the independent variables identified as potential predictors from the correlation analyses (effect size $>.1$) were most strongly associated with PTSD, depression and anxiety symptoms. Predictors entered into the regression analysis for PTSD were time since the baby died, age of the baby at birth, professional support, social

support, the number of ways memories were shared, the rated wish to have made more memories and the rated wish to talk more about the baby. For anxiety, the predictors entered into the regression analysis were the time since the baby died, the age of the baby at birth, professional support, the rated wish to have made more memories and the rated wish to talk more about the baby. For depression, they were the time since the baby died, professional support, and the number of ways memories were shared. The results of these three separate multivariate linear regression models are shown in Table 6.

Table 6

For PTSD symptoms, four variables accounted for 24.4% of the variance. These were rated professional support ($R^2 = .10$, $p < .001$), time since the baby died ($\Delta R^2 = .09$, $p < .001$), the variety of ways memories had been shared ($\Delta R^2 = .03$, $p = .02$), and the wish to talk more ($\Delta R^2 = .02$, $p = .03$). PTSD symptom scores decreased with time since the baby died, greater satisfaction with professional support, and more sharing of memories; and increased in women who wished to talk more about their babies. Beta values suggest that time since the baby died and perceived professional support had the largest associations with PTSD symptom scores. For depression symptoms, two variables accounted for 10.2% of the variance. These were time since the baby died ($R^2 = .05$, $p = .003$) and professional support ($\Delta R^2 = .05$, $p = .004$). Depression scores decreased with time since the baby died and with more professional support. Anxiety symptoms were also associated with two variables that accounted for 7.7% of the variance. These were wishing to talk more about the baby ($R^2 = .05$, $p = .007$) and time since the baby died ($\Delta R^2 = .03$, $p = .02$). Anxiety scores were higher with less time since the baby died and in women who wished to talk more.

Discussion

This study is the first to investigate the relationship between the way mothers share memories of their babies and their mental health following stillbirth. Mothers most commonly shared memories of their babies by talking to others. Around 90% or more had talked to their partners, families and friends. Photographs and keepsakes had been shared by more than half of the mothers with sharing decreasing as social distance increased, and more than a quarter had written about their babies. Memory sharing measures predicted mental health outcomes in this sample along with two factors that have been shown to be important in previous research; time since the baby died and professional support. Our finding that symptom scores for the three mental health measures decreased over time is consistent with research reported by Cacciatore, Rådestad et al. (2008), Engelhard et al. (2001) and Turton et al. (2001). The association between perceived professional support and lower PTSD and depression scores supports previous research emphasising the need for supportive professional guidance after stillbirth or the sudden death of a child (Janzen, Cadell, & Westhues, 2004; Lovell, 1983). Our findings do, however, contradict Cacciatore et al.'s (2009) conclusion that social support was more important for reducing maternal anxiety and depression following stillbirth. In our study, mothers reported more social than professional support and it was the degree of perceived professional support that predicted mental health outcomes.

Memory making activities that were reported by at least 90% of mothers were seeing their baby, naming their baby, arranging a funeral, holding their baby and creating a memory box. Consistent with previous researchers, we found that mothers valued creating memories of their babies and most wished they had more memories (Cacciatore,

2007; DeFrain et al., 1990; Godel, 2007; Rand et al., 1998; Riches & Dawson, 1998).

When considering whether mothers should be encouraged to see and hold their stillborn babies, it is notable that all mothers saw their babies and nearly all held them, yet mental health scores varied widely, and in this sample there was no association between making memories and PTSD, anxiety or depression symptoms. In contrast, sharing memories was associated with fewer symptoms of PTSD. It is possible then that one reason for the inconsistency in evidence associating memory making and mothers' mental health following stillbirth (e.g., Hughes et al., 2002; Turton et al., 2009; Cacciatore, Rådestad et al., 2008; Rådestad et al., 1996) is that no account was taken of how far mothers were able to share their memories.

PTSD decreased as more memories were shared and both PTSD and anxiety were associated with wanting to talk more about the baby. The cross-sectional nature of the study means that it is not possible to make claims about causation. This means that while it is possible that sharing memories is helpful in reducing anxiety and PTSD symptoms, it is equally possible that low levels of anxiety and PTSD facilitate memory sharing. Nevertheless, just as healthy recovery from other kinds of bereavement is associated with sharing memories of the deceased (Stroebe & Schut, 1999), the same is true of bereavement following stillbirth. Although talking about loss is not considered universally beneficial (e.g., Baddeley & Singer, 2010; Pennebaker, Zech & Rimé, 2001; Stroebe et al., 2002), our study shows that sharing memories is associated with good mental health following stillbirth.

There are good reasons why few opportunities to share may be associated with poorer maternal mental health following stillbirth. One is that the resulting silence is not

chosen but imposed by external circumstances (Scott, 2011). Another is that a lack of sharing may make it harder for a woman to adapt her narrative identity to include the baby and the role of mother in a healthy way. As Fivush (2010) argues, it is more difficult to integrate an experience of trauma into a coherent narrative identity if others are not willing to hear and validate the story of that experience. Furthermore, in cognitive models of PTSD (e.g., Ehlers & Clark, 2000), a lack of integration of trauma memories into autobiographical memory is associated with re-experiencing symptoms of PTSD. This may go some way to explain the association between greater memory sharing and fewer PTSD symptoms. Memory sharing may facilitate the elaboration and contextualisation necessary for trauma memories to be integrated successfully (Krans, Naring, Holmes, & Becker, 2009). Tangible reminders of the baby's existence, like photographs and mementos, may also help parents to integrate the child into their life story and validate the parental role (Riches & Dawson, 1998).

Before drawing conclusions, several methodological issues need to be considered. First, we acknowledge that the study's cross-sectional design means that while the results of our study show that good maternal mental health following stillbirth is associated with sharing memories, we cannot make claims about the causal relationship between the two. Furthermore, it is acknowledged that in the time since the experience of stillbirth (up to ten years previously) mothers will have experienced many other minor and major life events that are likely to have influenced their mental health scores. This is particularly likely for the measures of depression and anxiety symptoms where the standard DASS instructions to indicate symptoms in the past month were used unlike the PTSD measure in which mothers were asked to rate their symptoms in relation to their experience of

stillbirth. Second, whilst we recruited a comparatively large sample of women, they were predominantly white and well-educated so results may not generalise to women from minority ethnic groups or with lower educational attainment. Recruitment from a charity offering support for mothers following stillbirth may mean women in this sample had more symptoms and/or a greater need to share their experiences than other mothers of stillborn babies. Furthermore, because none of the women in this sample had no memories of their babies it is difficult to know whether the lack of effect of making memories on mental health found here would remain if women who chose not to make memories were included. Future research should attempt to address this, although pragmatically this could be difficult, as the making of memories reflects current healthcare practice in the UK.

These methodological issues need to be born in mind when considering the clinical implications of this research. Interventions to improve the mental health of mothers who have experienced stillbirth are important aspects of good professional care following the loss of a baby. The challenge for professionals is to provide mothers with choices based on sound evidence in a sensitive and timely fashion under difficult circumstances, achieving the right balance between beneficial guidance and harmful persuasion (Rådestad et al., 2009). The finding that making memories is not associated with mental health outcomes suggests the practice of giving babies to their mothers to see and hold may not be as negative as some studies suggest (e.g., Hughes et al., 2002; Turton et al., 2009). The first 30 minutes after birth is the best time for mothers to see and hold their babies while they are still soft and warm, a time when mothers are often in shock, sometimes unwell, and unsure what to do. Rådestad and Christoffersen (2008)

suggested a stillborn baby should be handed to the mother in the same way as a live baby because to ask parents whether they want to hold their baby creates doubt. The challenge is to reconcile such considerations with parents' right to choose and to resist being overzealous in encouraging memory making (Lundqvist & Nilstun, 1998; Lundqvist, Nilstun, & Dykes, 2003; Rádestad et al., 1996). The association between maternal mental health and memory sharing suggests it may be helpful to encourage mothers to share memories of their babies. If this is not possible within their immediate support networks, then support groups can be helpful (Cacciatore, 2007). If talking is not an option, mothers could be encouraged to share through writing. Although Pennebaker et al. (2001) reported that not all studies have found that writing is helpful following bereavement, they suggested it is beneficial when the death is sudden and unexpected and when talking is not an easy option because of social constraints; all circumstances typical of stillbirth.

In conclusion, this study shows that poorer mental health of mothers up to ten years following stillbirth was associated with less time since the baby died, less reported satisfaction with professional support, fewer memory sharing activities, and a wish to talk more about the baby. No association was found between mental health and memory making. However, there was a relationship with memory sharing. This finding is novel and has the potential to offer some explanation for the previously conflicting findings regarding the effect of making memories on mental health following stillbirth. We suggest that high quality care of mothers following stillbirth involves interventions to improve their mental health as well as opportunities for them to create and share memories of their babies.

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Footnote

1. Although the UK's Stillbirth Definition Act (1992) defines stillbirth as 24 weeks gestation and over we included six women whose babies were born between 20 and 23 weeks. This is because there is no consistent international definition of stillbirth by gestational age (Mullan & Horton, 2011; Spong, Reddy, & Willinger, 2011) and these mothers identified their births as stillbirths.

Table 1

Sample characteristics (N = 162) and birth details

	No.	%
<hr/>		
Marital status		
Married or living with partner	150	93
Single or separated	11	7
Ethnic group		
Caucasian / British	153	95
Other (African, Afro-Caribbean, Asian)	5	3
Level of education		
Secondary school education	45	28
Further education, degree or higher degree	117	72
Number of children before stillbirth		
0	99	61
1 or more	60	37
Number of children since stillbirth		
0	88	54
1 or more	69	42
Type of birth		
Spontaneous vaginal	34	21
Induced vaginal	113	70
Elective caesarean section	4	3
Emergency caesarean section	10	6
Baby died		
Before labour began	134	83
During labour	28	17

Age of mothers (years)	
Range	18-47
Mean (SD)	32.9 (5.9)
Gestational age of baby (weeks)	
Range	20-43
Mean (SD)	35.4 (6.1)
Median (interquartile range)	38.0 (32.0-40.1)
Time since loss of baby (months)	
Range	0.25-120
Mean (SD)	27.9 (29.4)
Median (interquartile range)	18.5 (4.4-42.0)

Table 2

Percentage of mothers making memories in different ways

Saw baby	100
Named baby	97
Funeral	94
Held baby	93
Created memory box	90
Photographs	83
Family saw baby	75
Scattering ashes / visiting grave	74
Created scrapbook / photo album	65
Other	65
Hand / foot prints	62
Visited in chapel of rest	43
Lock of hair	41
Dressed baby	24
Friends saw baby	17
Bathed baby	9
Videos	8
Took baby home	2

Table 3

Percentage of mothers sharing memories in different ways at least occasionally

Talked with:	
Partner	97
Family	96
Friends	89
Midwife	71
Internet support group	66
Colleagues	66
Doctor	54
Counsellor	40
Face-to-face support group	33
Shared photographs with:	
Partner	79
Family	68
Displayed at home	59
Friends	57
Shared keepsakes with:	
Partner	70
Family	58
Friends	43
Written about baby:	

Diary	37
Letter/poem	36
Internet	25

Table 4

Mean satisfaction with making and sharing memories, and perceived professional and social support following stillbirth (range = 1-5)

	Mean	(SD)
<hr/>		
Making memories		
The time with my baby helped me make good memories	4.4	(1.0)
My memories of my baby are strong	4.4	(1.0)
I feel I spent enough time with my baby	2.7	(1.4)
I wish I had made more memories	4.2	(1.1)
I wish I had not made these memories	1.3	(0.6)
Sharing memories		
I feel comfortable talking about my baby	3.9	(1.2)
Talking about my baby has been helpful	4.5	(0.7)
I wish I could talk more about my baby	4.2	(1.0)
Support following baby's death		
Mean professional support	3.5	(1.2)
Mean social support	4.2	(0.9)

Table 5

Correlations between mental health measures and potential predictors (N = 162)

	1	2	3	4	5	6	7	8	9	10
1. PTSD										
2. Anxiety	.63*									
3. Depression	.68*	.71*								
4. Time since baby died	-.29*	-.20*	-.23*							
5. Age of baby at birth	-.15*	-.11*	-.09	.11*						
6. Professional support	-.32*	-.13*	-.21*	-.03	.04					
7. Social support	-.12*	-.07	-.03	-.15*	.09	.39*				
8. No. ways memories made	-.04	.02	.00	-.09	.17*	.14*	.32*			
9. No. ways memories shared	-.15*	-.01	-.10*	-.19*	.14*	.12*	.25*	.42*		
10. Wish made more memories	.11*	.13*	.07	.10*	.08	-.35*	-.18*	-.09	.01	
11. Wish to talk more about baby ^a	.27*	.21*	.06	-.09	-.02	-.31*	-.15*	.01	.02	.29*

^a n = 161; * r > .1

Table 6

Summary of multivariate regression models for symptoms of PTSD, anxiety and depression

	B	SE B	β	p
<u>PTSD</u>				
Professional support	-2.63	.74	-.26	= .001
Time since baby died	-.14	.03	-.32	< .001
No. ways memories shared	-.63	.25	-.18	= .013
Wish to talk more about baby	2.09	.95	.16	= .03
<u>Depression</u>				
Time since baby died	-.11	.03	-.24	= .002
Professional support	-2.34	.81	-.22	= .004
<u>Anxiety</u>				
Wish to talk more about baby	2.28	.89	.20	= .011
Time since baby died	-.07	.03	-.18	= .02

Variables excluded from the regression models were: PTSD - age of the baby at birth, social support, wish to have made more memories, Anxiety - age of the baby at birth, professional support, wish to have made more memories, Depression - number of ways memories were shared.