

A peer-reviewed version of this preprint was published in PeerJ on 25 June 2015.

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Basile ML, Thorsteinsson EB. 2015. Parents' evaluation of support in Australian hospitals following stillbirth. PeerJ 3:e1049
<https://doi.org/10.7717/peerj.1049>

Parents' evaluation of support in Australian hospitals following stillbirth

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The present study evaluated the level of support and satisfaction among parents of stillborn babies in Australian hospitals. One-hundred and eighty-nine mothers and fathers completed an online survey designed by the researcher based on the guidelines designed by the Perinatal Society of Australia and New Zealand. Support was inconsistent with guidelines implemented only 55% of the time, on average. Areas of support regarding creating memories, birth options and autopsy were most problematic. A significant positive correlation was found between support and satisfaction and there is indication that there has been some increase in support and satisfaction over time. There has been a significant increase in both support and satisfaction since the release of the guidelines in 2009. Creating memories was regarded by parents as the most influential to their grief. It is recommended that health professionals review guidelines and seek feedback from parents as to how they can improve the support they provide.

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Parents' Evaluation of Support in Australian Hospitals Following Stillbirth

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Abstract

The present study evaluated the level of support and satisfaction among parents of stillborn babies in Australian hospitals. One-hundred and eighty-nine mothers and fathers completed an online survey designed by the researcher based on the guidelines designed by the Perinatal Society of Australia and New Zealand. Support was inconsistent with guidelines implemented only 55% of the time, on average. Areas of support regarding creating memories, birth options and autopsy were most problematic. A significant positive correlation was found between support and satisfaction and there is indication that there has been some increase in support and satisfaction over time. There has been a significant increase in both support and satisfaction since the release of the guidelines in 2009. Creating memories was regarded by parents as the most influential to their grief. It is recommended that health professionals review guidelines and seek feedback from parents as to how they can improve the support they provide.

Keywords: Stillbirth, babies, guidelines, Australian, hospitals, support, satisfaction, PSANZ

Parents' Evaluation of Support in Australian Hospitals Following a Stillbirth

Scope of the Problem

A stillbirth, as defined in Australia, is the death of a baby before or during birth at 20 weeks or more gestation, or with a birth weight of at least 400 grams (Li, Zeki, Hilder, & Sullivan, 2013). In 2011, there were 2,200 stillbirths in Australia providing a rate of 7.4 stillbirths per 1,000 total births (Li et al., 2013).

Stillbirth is a unique loss in that it encompasses the loss of a person, loss of parenthood, and the loss of future hopes and dreams (Boyle, Vance, Najman, & Thearle, 1996; Fetus and Newborn Committee, 2001; Kowalski, 1983; Robinson, Baker, & Nackerud, 1999). This devastating loss is compounded by the lack of acknowledgement, validation, and support in the community (Bennett, Litz, Lee, & Maguen, 2005; Kowalski, 1983; McGreal, Evans, & Burrows, 1997). The grief may extend into future pregnancies and can last from months to years (Hutti, 2005). Mothers of stillborn babies are up to three times more likely to develop anxiety and depression, and suffer significantly higher levels of psychological distress compared with mothers of living infants (Boyle et al., 1996; Rådestad, Steineck, Nordin, & Sjögren, 1996). Feelings of shock, guilt, anger, anxiety, emptiness, loneliness, and helplessness are often expressed as families are ill prepared to deal with the intensity of their grief (Boyle et al., 1996; Callan & Murray, 1989; Flenady et al., 2014).

The Perinatal Society of Australia and New Zealand (PSANZ) have developed evidence-based guidelines to assist health professionals in providing relevant support for bereaved parents (Flenady et al., 2009). In an attempt to ensure that support in Australia is consistent and meeting the needs of bereavement parents a thorough evaluation must take place. The current study aims to explore levels of support and satisfaction in hospitals across Australia, and to shed light on any areas of support that need improvement.

1 **Background**

2 Before the 1960's grief associated with stillbirth was unrecognised in the nursing
3 literature (Brabin, 2004). Stillborn babies were taken away and disposed of without any
4 parental involvement and discussion of the loss discouraged (Lasker & Toedter, 2007). Over
5 the past 40 years there has been an increase in studies assessing the impact of loss through
6 stillbirth which has created a shift in hospital practices which now encourage bereaved
7 parents to acknowledge and work through their loss (Leon, 1992).

8 Once health professionals realised that attachments were formed before birth during
9 pregnancy the significance of loss through stillbirth was recognised (Fetus and Newborn
10 Committee, 2001; Leon, 1992; Robinson et al., 1999). As early as the 1970's Yates (1972)
11 described how mothers of stillborn babies found it helpful to talk about their experiences and
12 how naming the baby was important to them. Additionally, Lewis (1979) found that when
13 hospital staff facilitated mourning there was better adjustment to bereavement.

14 From a psychoanalytic perspective, mourning involves a process of understanding the
15 memories, thoughts, and feelings surrounding a loss both on a conscious and unconscious
16 level (Lewis, 1979). It has been explained by Leon (1987) that interactions with the baby and
17 the creation of concrete tokens of remembrance are at the very essence of parental mourning.
18 Not only is the baby to be mourned but also the lost hopes and wishes for a future together,
19 "it is the loss of one who will never be rather the loss of one who once was" (Leon, 1987, p.
20 194).

21 There is now great value placed on viewing, naming, and holding the baby to
22 formulate an identity and validate the pregnancy and death (Aldridge, 2008; Bennett et al.,
23 2005; Bonnette & Broom, 2011; Callan & Murray, 1989; Chance et al., 1983; Fetus and
24 Newborn Committee, 2001; Hammersley & Drinkwater, 1997; Leon, 1987).

1 It is now commonplace to encourage families to take photographs of the deceased
2 baby as a means of creating an identity for which the baby can be remembered and mourned
3 (Godel, 2007). Photographs give the baby social status as a family member and portrays them
4 as a valued individual as well as helping the parents recognise their roles as mother and
5 father, which is often left unrecognised (Godel, 2007).

6 **Individualised Support**

7 It has been recommended that health professionals understand the significance of the
8 loss for each unique family as a way to offer appropriate support which should be “open,
9 sensitive, and nondirective, and ultimately tailored...” (Lafarge, Mitchell, & Fox, 2013, p.
10 933). Culture, religion, and traditions influence the way people mourn and sensitivity to the
11 variety of beliefs and behaviours may help to facilitate bereavement (Bennett et al., 2005;
12 Callan & Murray, 1989; Chance et al., 1983; Chichester, 2005; Cowchock et al., 2011; Fetus
13 and Newborn Committee, 2001). It is also important that health professionals do not allow
14 their own personal beliefs to interfere with a family’s style of grieving (Chichester, 2005;
15 Flenady et al., 2014; Mahan & Calica, 1997). Understanding the diversity of behaviours,
16 practices, and beliefs held by different cultures will assist with supporting families, although
17 it is advised that assumptions should never be made based on a family’s appearance
18 (Chichester, 2005). Some families may adhere to cultural norms while others may choose to
19 honour their baby in a unique way (Chichester). Hospital chaplains can be used as a source to
20 provide culturally sensitive support and health professionals should seek advice from families
21 as to how they would like to remember and mourn their baby (Chichester).

22 Similarly, it is important to recognise the different coping styles and grief patterns
23 between mothers and fathers (McGreal et al., 1997). In a pilot study assessing sex differences
24 following miscarriage or stillbirth different rates and forms of grieving were found between
25 mothers and fathers affecting communication and heightening feelings of vulnerability

1 (McGreal et al.). It has been found that fathers feel their grief is less significant in the eyes of
2 hospital staff and therefore often feel overlooked and dissatisfied with treatment (Bonnette &
3 Broom, 2011). Mothers have even remarked how their partners were adversely affected by
4 feeling excluded within the hospital post-loss (Sanchez, 2001). In a study by Säflund and
5 Wredling (2006) mothers and fathers were found to rate the behaviour of the physician
6 differently, with fathers finding them to be more insensitive than mothers. In the vast
7 majority of research in this area it is common to see only the reactions of mothers
8 documented (Callan & Murray, 1989). Bonnette and Broom (2011) describe how the
9 recognition and validation of fatherly grief is often overshadowed by the view they are
10 merely supportive partners.

11 **Assessing Support**

12 In 1982, Forrest, Standish, and Baum (1982) conducted a randomised trial comparing
13 mothers that received routine hospital care against mothers that received planned support
14 (based on guidelines), and counselling. Planned support and counselling was found to
15 appreciably shorten the duration of distress of bereaved mothers (Forrest et al., 1982).
16 However, there is some concern about how protocols and guidelines are handled and applied
17 (Hutti, 2005; Leon, 1992). It is recommended that care be taken to respect the individual
18 wishes and needs of the family as standardization of bereavement care runs the risk of
19 disrupting a family's unique style of coping (Bennett et al., 2005).

20 Hospital support, or lack thereof, appears to have a significant impact on grief
21 resolution (Gold, 2007; Kirkley-Best & Kellner, 1982). Parents are able to recount distress
22 caused by negative experiences many years after the event showing how crucial it is that the
23 level of support is meeting the needs and expectations of parents (Cacciatore & Bushfield,
24 2007; Downe, Schmidt, Kingdon, & Heazell, 2012; Lafarge et al., 2013). In a recent study by
25 Crawley, Lomax, and Ayers (2013), mental health outcomes of bereaved mothers could be

1 predicted by the degree of perceived professional support received. Similarly, Hammersley
2 and Drinkwater (1997) found that recognition of loss and empathy by others to be powerful
3 factors in alleviating pathological reactions to stillbirth.

4 With hospital guidelines now in place there has been call for more studies to examine
5 the level of support currently offered as well as measuring levels of satisfaction (Bennett et
6 al., 2005; Cacciatore & Bushfield, 2007; Callan & Murray, 1989; Erlandsson, Säflund,
7 Wredling, & Rådestad, 2011; Gold, 2007; Lasker & Toedter, 2007; Wing, Burge-Callaway,
8 Clance, & Armistead, 2001). While some studies indicate that support within the hospital
9 setting is satisfactory (Bennett, Litz, Maguen, & Ehrenreich, 2008; Conry & Prinsloo, 2008;
10 Geerinck-Vercammen & Kanahi, 2003; Lafarge et al., 2013) there is evidence that more
11 consistent support is needed (Cacciatore & Bushfield, 2007; Cacciatore, Schnebly, & Froen,
12 2009; Conry & Prinsloo, 2008; Gold, 2007; Lasker & Toedter, 2007; Simwaka, de Kok, &
13 Chilemba, 2014).

14 Support from health professionals and the opportunity to create memories have been
15 documented as the most important factors in the way parents define their hospital experience
16 (Conry & Prinsloo, 2008; Downe et al., 2012; Lafarge et al., 2013). Forrest et al. (1982)
17 found that almost half of mothers felt that support within the hospital settings could be
18 improved and where care was judged as satisfactory flexibility had been mentioned as an
19 important factor.

20 Lasker and Toedter (2007) completed one of the largest longitudinal studies assessing
21 parents' satisfaction with hospital care in the United States. They found that parents who
22 received support were more satisfied than parents that did not. Although having more support
23 did not lead to greater levels of overall satisfaction. They suggest this is because quality of
24 support is also a determinant of satisfaction and grief alleviation. Harper and Wisian (1994)
25 have also documented a significant positive relationship between satisfaction and the use of

1 most recommended interventions. Variation in the support offered by different health care
2 professionals has also been reported, with doctors often being described as not meeting the
3 emotional needs of parents (Cacciatore et al., 2009; Erlandsson et al., 2011; Gold, 2007). In
4 Australia, Brabin (2004) discusses how the Stillbirth and Neonatal Death Support (SANDS)
5 organisations have reported a shift over the last 20 years with less complaints of hospital
6 support and an increase with the satisfaction of care.

7 Very little research of a quantitative nature has been employed to assess parents' level
8 of support and whether the support received is satisfactory. The majority of studies have also
9 used very small sample sizes and have evaluated only one hospital service. Furthermore, only
10 a limited number of studies have assessed the experiences of both mothers and fathers. No
11 studies have examined the support offered in Australian hospitals and whether parents of
12 stillborn babies have found such support satisfactory. Additionally, limited studies have
13 examined differences in support and satisfaction following the introduction of the PSANZ
14 guidelines. The current study aims to address these shortcomings.

15 Although designed to be non-prescriptive, the PSANZ guidelines have been used by
16 the current study as a benchmark to examine the support offered to parents of stillborn babies
17 in Australian hospitals. Guidelines are designed to provide knowledge to health professionals
18 by describing generally recommended practice and to enhance the quality of bereavement
19 care (Flenady et al., 2009). Support is used in the current study as the collective term to
20 include the hospital practices and interventions (guidelines), relevant to stillbirth under the
21 following categories: respect, information, autopsy, birth options, hospital stay, creating
22 memories, and aftercare. By examining levels of support and satisfaction it is hoped that the
23 research will shed light on any areas that need improvement.

24 The present study aims:

- 1 1. To assess the level of perceived support parents are receiving (as determined by the
2 PSANZ guidelines) and the extent of parent satisfaction.
- 3 2. To identify if the introduction of the PSANZ guidelines has significantly increased
4 levels of support and parent satisfaction, and whether there is a negative correlation
5 between years since birth and support and satisfaction.
- 6 3. To examine the extent to which support is positively correlated with parent
7 satisfaction and to explore which areas of support parents perceive to be most
8 influential to their grief.
- 9 4. To determine if fathers are receiving a lower level of support and are less satisfied
10 than mothers.

11 Method

12 Participants

13 Participants were at least 18 years old and were parents of stillborn babies born in an
14 Australian hospital. A stillbirth occurs when a baby dies at 20 weeks or more gestation, or
15 with a birth weight of at least 400 grams. Participants were asked about gestation but not
16 birth weight. Two participants were excluded that gave birth on or before 12 weeks gestation
17 where it was reasonable to assume they had a miscarriage as opposed to a stillbirth. One-
18 hundred and forty-eight participants were excluded who did not attempt or complete the
19 survey as well as one participant who gave birth outside of Australia.

20 The sample consisted of 181 women (95.8%), six men (3.2%), and two (1.1%)
21 providing no sex information. Age ranged from 18 to 65 years ($M=34.9$, $SD=7.6$). The
22 majority of participants were married/de facto (84.1%) and generally well educated with
23 41.8% having completed a university degree or higher.

24 Years since birth ranged from zero to 40 years ($M=5.0$, $SD=6.4$) and time of birth
25 ranged from 16 to 42 weeks gestation ($M=30.5$, $SD=7.5$). Location of birth covered all states

1 and territories across Australia: New South Wales (32.3%), Victoria (28.6%), Queensland
2 (18.0%), Western Australia (9.0%), South Australia (5.8%), Australian Capital Territory
3 (2.6%), Tasmania (2.6%), and Northern Territory (1.1%). According to the data collected by
4 Australia's Mothers and Babies 2011 (Li et al., 2011) this is a fairly accurate cross-section of
5 the population. Participants in the study gave birth in 96 different hospitals across Australia
6 with 82.5% being public and 17.5% being private. One-hundred and thirty-three participants
7 were admitted as public patients (70.4%), 54 were admitted as private patients (28.6%), and
8 two did not report patient admission status (1.1%). A total of 174 (92.1%), of the pregnancies
9 were single, with 14 (7.4%), being a multiple pregnancy, and one (0.5%), participant failing
10 to report. Of the multiple pregnancies, nine participants reported a loss of one baby, while
11 five reported a loss of more than one.

12 **Materials**

13 Participants volunteered to complete the Stillbirth Support Survey designed by the
14 researcher. The survey consisted of 12 demographic and topic-specific questions followed by
15 50 questions assessing support as per the PSANZ guidelines. Here support was measured
16 under the following categories: respect, information, autopsy, birth options, hospital stay,
17 creating memories, and aftercare. Participants were presented with a statement and asked to
18 answer on a 5-point scale (1=*strongly disagree* to 5= *strongly agree*). Example items include:
19 "My cultural/religious beliefs, traditions and practices were respected by hospital staff," "The
20 information I received was delivered in a sensitive manner," and "I was provided with an
21 opportunity to bathe my baby/babies." Participants were asked how satisfied they were with
22 the overall level of support on a 7-point scale (1=*very dissatisfied* to 7=*very satisfied*), and
23 then asked which area(s) of support they felt were most influential to their grief process
24 (respect, information, autopsy, birth options, hospital stay, creating memories, aftercare, and

1 other). The support and satisfaction measures were collapsed for Aim 1 to ease with the
2 interpretation of results.

3 No reportable measures of reliability and validity are available for the Stillbirth
4 Support Survey. Questions were based directly on the published PSANZ guidelines which are
5 intended as generally recommended practice for Australia and New Zealand (Flenady et al.,
6 2009).

7 **Procedure**

8 The study was conducted with the approval of the Human Research Ethics Committee
9 of the University of New England, Australia, approval number HE14-149. Participants were
10 recruited online via Facebook where approval was sought from page administrators for a link
11 to the Stillbirth Support Survey to be posted on the page. Pages were selected by searching
12 key words such as “stillbirth,” “stillborn,” and “pregnancy loss” and any linked and
13 suggested pages on the chosen pages were also explored. The pages included closed groups,
14 open groups, non-profit organisations, communities, charity organisations, and public figures.
15 Of the 27 pages approached seven agreed to participate. The link was voluntarily shared on
16 other pages, recommended to specific individuals, and displayed on one counselling website.

17 Potential participants that followed the link were forwarded to the Stillbirth Support
18 Survey powered by Qualtrics software (Qualtrics, 2014). An *information* sheet was initially
19 provided followed by an online implied *consent* form where potential participants could
20 choose to proceed or exit the study. If participants chose to proceed then they were given
21 survey instructions before going on to complete the Stillbirth Support Survey. If a participant
22 had experienced more than one stillbirth from separate pregnancies questions were to be
23 answered based on the most recent experience. If a particular question was not relevant or if
24 participants could not recall if something did or did not happen they were advised to leave the
25 item blank. To reduce the risk of emotional trauma participants were reminded that they were

1 able to withdraw from the survey at any stage and information for bereavement counselling
2 was made available at the beginning and end of the survey.

3 **Statistical Analysis**

4 A total of 339 participants followed the link to the survey with 189 participants
5 retained after applying the exclusion criteria. Using a 2:1 ratio for female to male participants
6 and combining an effect size of $f = 0.5$ with a power level of 0.95 and alpha of 0.05, a power
7 analysis performed on G*Power 3.1.9.2 (Faul, Erdfelder, Lang, & Buchner, 2007) suggested
8 a sample size of at least 198 participants will be required to perform analyses between
9 groups. The current study failed to recruit enough male participants to determine if
10 differences exist between mothers and fathers.

11 Pearson's correlation coefficient and independent t -tests were used to analyse the
12 data. Assumptions of normality, independence, and homogeneity of variance were met for the
13 "satisfaction" and "support" variables. Due to positive skewness and kurtosis of the "years
14 since birth" variable a $\log+1$ transformation was conducted as per Field's (2005)
15 recommendation. There was little difference between results for raw and transformed data
16 thus raw data results were retained for ease of interpretation.

17 **Results**

18 **Perceived Support (Aim 1)**

19 Descriptive statistics were used to assess levels of perceived support (as determined
20 by the PSANZ guidelines). Participants that indicated either *agree* or *strongly agree* on
21 support items were combined to determine the rate to which guidelines are taking place in
22 Australian hospitals.

23 A total of 76.7% of participants reported that respect was given to their baby/babies
24 and 71.0% indicated respect was given to their cultural/religious beliefs. Grief was validated

1 by hospital staff 74% of the time and 66.5% of participants felt supported to reach their own
2 decisions regarding care for themselves and their baby/babies.

3 As indicated by participants, provision of information varied: Hospital staff provided
4 information to both parents (73.0%) sensitively (75.2%), honestly (75.7%), and clearly
5 (67.7%) using appropriate terminology (78.6%) delivered in a quiet, private place (81.5%).
6 Information was also provided at an appropriate time (58.2%) with written fact sheets
7 (66.5%) and there was adequate time to consider information (55.5%), ask questions (63.5%),
8 and to grieve silently (68.8%). Hospital staff ensured both parents understood information
9 provided (69.2%) and spoke of the baby/babies in sensitive terms (75.7%).

10 Support regarding autopsy also varied: 63.0% of participants reported they were
11 provided with verbal and written information regarding options for a post-mortem; 66.3%
12 were made aware that results could take months to return and that nothing adverse may be
13 reported; 58.4% received information in a quiet, private place; and 52.4% felt comfortable
14 with the person delivering information and could competently answer questions. Only 11.1%
15 of participants knew the person taking their baby/babies to the autopsy and only 6.3% were
16 given the opportunity to meet the pathologist and assured their baby/babies would be treated
17 with respect. A total of 28.3% of participants reported that they were given the option to
18 see/hold their baby/babies after the autopsy.

19 In total 31.7% of participants reported they were given relevant information regarding
20 delivery and 45.4% were provided with a choice to remain in hospital or return home prior to
21 delivery. A total of 40.5% of participants were provided with information on the benefits and
22 consequences of each type of delivery (natural vs. caesarean section) with 31.4% of
23 participants offered a choice in birth options.

24 Various aspects of the hospital environment varied among participants: although only
25 13.1% of participants were asked which ward they would like to be placed in, a total of

1 93.1% reported that they were provided with a private room; 55.0% indicated they were away
2 from the busiest part of the ward; 39.9% had a symbol placed on their door; continuity of care
3 was indicated by 60.3% of participants; 85.7% had time available with their baby/babies;
4 57.1% had a staff member available to collect/return baby/babies as desired; 59.8% were
5 informed that there was no urgency to leave the hospital; and 57.2% had a social worker
6 provide support, counselling and information.

7 Hospital staff informed 42.3% of participants of the length of time they could spend
8 with their baby/babies and 17.0% were given the option of staying in the hospital or taking
9 their baby/babies home. A total of 55.7% of participants were informed about what to expect
10 in terms of the appearance of their baby/babies, 37.1% were made aware that there was no
11 urgency to arrange and funeral, and 42.5% were informed a baptism/blessing could be
12 arranged if desired. Opportunities to create memories varied among participants: 35.1% were
13 provided were an opportunity to bathe their baby/babies; 86.7% had staff provide hand and
14 footprints, identification bracelets, photographs and cot cards, etcetera; and 57.7% had staff
15 make suggestions for the creation of memories.

16 Support pertaining to after care also varied among participants: 42.0% were informed
17 about milk production and was given the option of a lactation consultant, 82.3% were made
18 aware of post-pregnancy changes and the need for a post-birth check-up, 53.5% received
19 information and referrals to other relevant health professionals, 76.5% were informed of the
20 legal requirement to arrange a funeral and given options for funeral arrangements, and 37.2%
21 were told what to expect in terms of the grief journey.

22 **Parent Satisfaction (Aim 1)**

23 Descriptive statistics were used to assess the amount of satisfaction among parents of
24 stillborn babies. In total, of the 189 participants, 64.0% reported satisfaction with their overall

1 level of hospital support. There were 30.2% reports of dissatisfaction and 5.8% of
2 participants remained neutral.

3 **The Effect of the PSANZ Guidelines on Support and Satisfaction (Aim 2)**

4 The PSANZ guidelines were published in 2009 so the participants were split into two
5 groups based on if participants gave birth before or after the release of the material. Mean
6 scores for support and satisfaction are provided in Table 1.

7

8

9 Table 1

10 Mean Scores on the Stillbirth Support Survey

Measure	Births from 1974-2008 (<i>n</i> =56)		Births from 2009-2014 (<i>n</i> =132)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Respect (4)	3.67	1.08	3.98	1.01
Information (13)	3.39	1.04	3.83	0.93
Autopsy (7)	2.81	0.83	3.19	0.80
Birth options (4)	2.68	1.07	3.03	0.96
Hospital Stay (9)	3.10	0.93	3.60	0.85
Creating Memories (8)	2.84	0.92	3.18	0.83
Aftercare (5)	3.10	1.01	3.48	0.96
Total Support Score (50)	3.12	0.87	3.51	0.75
Satisfaction (1)	4.09	2.17	5.11	1.97

11 *Note.* Support scores could range from 1 (*strongly disagree*) to 5 (*strongly agree*), and
12 satisfaction scores ranged from 1 (*very dissatisfied*) to 7 (*very satisfied*). Number of items for
13 each measure is displayed in parentheses.

14

15

16 On average, parents that gave birth after 2009 reported greater support ($M = 3.51$, SE
17 $= 0.07$), than parents giving birth before 2009 ($M = 3.12$, $SE = 0.12$), $t(186) = 3.12$, $p < .001$
18 with a small to medium sized effect $r = .22$ ($r = 0.10$ [small], $r = .30$ [medium], and $r = .50$
19 [large]; Field, 2005). Similarly, parents that gave birth after 2009 also reported higher
20 satisfaction ($M = 5.11$, $SE = 0.17$) than parents who gave birth before 2009 ($M = 4.09$, $SE =$

1 0.29), $t(186) = 3.16$, $p < .001$ with a small to medium sized effect $r = .23$. A description of
 2 satisfaction frequencies and percentages between groups is provided in Table 2.

3
 4
 5 Table 2
 6 *Satisfaction Frequencies and Percentages*

Satisfaction	Births from 1974-2008 ($n=56$)		Births from 2009-2014 ($n=132$)	
	Frequency	%	Frequency	%
Very dissatisfied	8	14.3	11	8.3
Dissatisfied	10	17.9	10	7.6
Somewhat dissatisfied	8	14.3	10	7.6
Neutral	4	7.1	7	5.3
Somewhat satisfied	5	8.9	19	14.4
Satisfied	11	19.6	34	25.8
Very satisfied	10	17.9	41	31.1

7
 8

9 **Support and Satisfaction over Time (Aim 2)**

10 Pearson's correlation coefficient was used to determine whether there was a negative
 11 relationship between support, satisfaction, and years since birth. Support was negatively
 12 correlated to years since birth, with a coefficient of $r = -.33$, which was also significant at $p <$
 13 $.01$. A negative relationship was also documented between satisfaction and years since birth
 14 ($r = -.31$, $p < .01$).

15 **Relationship between Support and Satisfaction and Influences on Grief (Aim 3)**

16 Pearson's correlation coefficient was also used to determine if there was a positive
 17 relationship between support and satisfaction. A significant relationship was found, $r = .89$, p
 18 $< .01$.

19 Descriptive statistics were used to explore which areas of support parents perceived to
 20 be most influential to their grief, see Table 3. Over half of the participants reported creating
 21 memories, respect, and hospital stay to be the most influential.

22

1 Table 3
 2 *Categories Parents Perceive to be Most Influential to their*
 3 *Grief (N = 189)*

Measure	Frequency	%
Creating Memories	142	75.1
Respect	125	66.1
Hospital Stay	110	58.2
Aftercare	86	45.5
Information	84	44.4
Autopsy	36	19.0
Birth Options	34	18.0
Other	22	11.6

4

5 **Differences between Mothers and Fathers (Aim 4)**

6 Independent *t*-tests were used to determine whether fathers are receiving lower of
 7 support, and are less satisfied, than mothers. Although fathers did report greater support ($M =$
 8 3.57 , $SE = 0.42$), than mothers ($M = 3.38$, $SE = 0.06$), the difference was not statistically
 9 significant $t(185) = 0.57$, $p = .57$. Similarly, fathers reported higher satisfaction ($M = 5.50$, SE
 10 $= 0.76$), than mothers ($M = 4.77$, $SE = 0.16$). However, this difference was also not
 11 statistically significant $t(185) = 0.84$, $p = .40$.

12

13

Discussion

14 The current study aimed to assess the level of support parents are receiving (as
 15 determined by the PSANZ guidelines) and the extent of parent satisfaction. Over the last 40
 16 years Australian hospitals have been providing some relevant support to bereaved parents of
 17 stillborn babies however, much improvement is needed. While some guidelines are being
 18 demonstrated in up to 93.1% of cases, others are rarely displayed (as low as 6.3%). On
 19 average, guidelines are being implemented just over 55% of the time. Overall, areas of
 20 support that are the strongest include respect, information, hospital stay, and after care; with
 21 birth options, creating memories, and autopsy being the lowest scoring categories on average.
 22 It is evident that there is considerable variance in terms of support with some bereaved

1 parents being offered specific interventions and practices while others are not. For instance,
2 some parents are missing out on important information, opportunities with their deceased
3 baby/babies, and options regarding their care. Overall, of the 189 participants that gave birth
4 between 1974 and 2014, 64% reported satisfaction with the overall level of support.

5 As expected, a significant increase in both support and parent satisfaction was found
6 since the publication of the PSANZ guidelines in 2009. Further support for guidelines has
7 been found in Oxford where the duration of distress was noticeably shortened with the
8 introduction of guidelines and counselling (Forrest et al., 1982).

9 Of the participants that gave birth prior to 2009, 46.5% reported some degree of
10 dissatisfaction compared to only 23.5% of participants that gave birth after 2009. Although
11 this is a marked decrease, this means that almost one in four bereaved parents leave the
12 hospital not only mourning the loss of their child, but disappointed with the support provided
13 to them at one of the most difficult times of their lives. These findings are not dissimilar to
14 other recent studies which have reports of support still being inadequate, inconsistent, and
15 unsatisfactory for some bereaved parents (Bonnette & Broom, 2011; Cacciatore & Bushfield,
16 2007; Conry & Prinsloo, 2008; Downe et al., 2012; Erlandsson et al., 2011; Lafarge et al.,
17 2013; Simwaka et al., 2014). Distress caused by negative experiences can be long-lasting
18 which indicates how crucial it is that all bereaved parents are adequately supported
19 (Cacciatore & Bushfield, 2007; Downe et al., 2012; Kirkley-Best & Kellner, 1982; Lafarge et
20 al., 2013).

21 As hypothesised, support and satisfaction were negatively correlated with years since
22 birth. This suggests that there has been some improvement of support, and higher rates of
23 satisfaction, over time. These results confirm reports that there have been far fewer
24 complaints and greater satisfaction among parents of stillborn infants in Australia over the
25 last 20 years (Brabin, 2004). Midwives have embraced training opportunities (Brabin, 2004)

1 so it is hoped that as health professionals continue to become more experienced and
2 knowledgeable, improvements will continue to be seen.

3 As hypothesised, a significant and strong, positive relationship between support and
4 parent satisfaction was documented. It seems likely that as health professionals are adhering
5 to the guidelines provided by PSANZ, greater satisfaction is seen among bereaved parents.
6 However, a direct causal relationship cannot be determined by the present study. In the
7 United States, Harper and Wisian (1994) also documented support for guidelines with
8 satisfaction increasing with most recommended practices. Although the guidelines are
9 designed to be non-prescriptive, the results suggest that following the recommendations by
10 PSANZ may have a positive impact on bereaved parents.

11 The study also sought to explore which areas of support parents perceive to be most
12 influential to their grief. Three quarters of participants deemed creating memories (time with
13 baby/babies, mementos, and baptism/blessing) to be the most influential area of support.
14 Around half of the participants also reported respect (for baby, parents, and cultural/religious
15 beliefs), hospital stay (environment, support of staff), after care (maternal changes, support
16 services, referrals, and expectations of grief), and information (timing, delivery, mode, and
17 terminology) to be most influential to their grief. These results support previous research that
18 claim the creation of quality memories to be highly valued among bereaved parents (Bonnette
19 & Broom, 2011; Conry & Prinsloo, 2008; Crawley et al., 2013; Godel, 2007; Lafarge et al.,
20 2013; Lasker & Toedter, 2007). Additionally, the quality of memories has been found to
21 dictate whether the experience was viewed as either positive or negative (Downe et al.,
22 2012). The creation of memories further assists in creating an identity for the deceased as
23 well as validating the pregnancy and the loss (Aldridge, 2008; Bennett et al., 2005; Bonnette
24 & Broom, 2011; Callan & Murray, 1989; Chance et al., 1983; Fetus and Newborn
25 Committee, 2001; Hammersley & Drinkwater, 1997; Leon, 1987). Furthermore, sharing

1 memories has been associated with less symptoms of post-traumatic stress disorder (Crawley
2 et al., 2013).

3 With such a high value placed on creating memories by parents and the associated
4 benefits to mental health (Crawley et al., 2013; Rådestad et al., 1996) it is a concern that this
5 category was one of the lowest scoring in terms of support. This highlights that considerable
6 changes need to be made by health professionals to ensure that support is consistent, relevant,
7 and meeting the needs and expectations of bereaved parents.

8 It was hypothesised that fathers are receiving a lower level of care and are less
9 satisfied than mothers. The sample did not contain an adequate number of fathers to
10 determine if differences exist. It has been documented that while women are more expressive,
11 men tend to exert more control over their emotions and are expected to keep their feelings to
12 themselves (Stinson, Lasker, Lohmann, & Toedter, 1992; Wing et al., 2001). Such attitudes
13 may have impacted self-inclusion rates among fathers in the current study. Furthermore, it
14 has been reported that finding a sense of belonging is the foremost coping strategy used by
15 mothers of stillborn babies (McGreal et al., 1997). It may be that more mothers than fathers
16 sought out the selected pages on Facebook (where the survey was advertised) as a way of
17 connecting with others and dealing with their grief.

18 **Limitations**

19 The sample may have been skewed given that it was predominantly younger, female,
20 married, and well-educated. All participants also had internet access. Future research should
21 seek to engage a more diverse and representative sample. The use of some online support
22 groups used for recruitment may have introduced bias. Participants were asked to comment
23 retrospectively so there is also the potential for recall bias in the rating of experiences.
24 However, it appears that although parents were informed to leave items blank if they could

1 not remember or were unsure, many were still able to recount experiences from many years
2 ago.

3 It is possible that participants may have previously been satisfied with hospital
4 support until completing the Stillbirth Support survey. Participants may have been unaware
5 of specific interventions and practices that could have been offered which in turn may have
6 lowered their original perceptions of the support they received. Future research in this area
7 could evaluate satisfaction at the beginning and end of questionnaire to determine if
8 perceptions are altered.

9 **Conclusion**

10 Although support for bereaved parents in Australia has improved since the
11 introduction of the PSANZ guidelines it is clear that hospitals are not implementing them
12 fully. Parents in the current study reported higher levels of satisfaction when hospitals were
13 following the recommendations. Creating memories was regarded as the most influential area
14 of support by most participants however, it was one of the categories most lacking support. It
15 is recommended that health professionals within the hospital setting review guidelines that
16 are in place and seek feedback from parents as to how support can be improved.

17

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