

Seeing and holding baby: Systematic review of clinical management and parental outcomes following stillbirth

ABSTRACT

Background In 2009 there were an estimated 2.6 million stillbirths worldwide. In the United States, a 2007 systematic review found little consensus about professional behaviours perceived by parents to be most helpful or most distressing. In the United Kingdom a bereaved parents' organisation has highlighted discordance between parental views and clinical guidelines that recommend clinicians' do not encourage parents to see and hold their baby. The objective of this review was to identify and synthesise available research reporting parental outcomes relating to seeing and holding.

Method(s) We undertook a systematic review. We included studies of any design, reporting parental experiences and outcomes. Electronic searches (PubMed, PsychINFO) were conducted in January 2014. Three authors independently screened and assessed the quality of the studies, before abstracting data and undertaking thematic analysis.

Results We reviewed 741 records and included 23 studies (10 quantitative, 12 qualitative, 1 mixed-method). Twenty-one studies suggested positive outcomes for parents who saw or held their baby. Increased psychological morbidity was associated with current pregnancy, choice not to see their baby, lack of time with their baby and/or insufficient mementos. Three themes were formulated "Positive effects of contact within a traumatic life event", "Importance of role of health professionals"; and "Impact on Mothers and Fathers: Similarities and differences".

Conclusions: Stillbirth is a risk factor for increased psychological morbidity. Parents' seeing and holding their stillborn baby can be beneficial to their future wellbeing. Since 2007, there has been a proliferation of studies that challenge clinical guidelines recommending clinicians do not encourage parental contact.

Keywords: review, stillbirth, seeing and holding

Word count: 3,998

1 **Seeing and holding baby: Systematic review of clinical management and**
2 **parental outcomes following stillbirth**

3

4 **Background**

5 Worldwide, in 2009, approximately 2.6million stillbirths occurred(1). In recent years,
6 the United Kingdom's (UK) Royal College of Obstetricians and Gynaecologists
7 (RCOG)(2), National Institute for Clinical Excellence (NICE)(3), the American College
8 of Obstetrics and Gynaecology (ACOG)(4), and the Perinatal Society of Australia and
9 New Zealand (PSANZ)(5) have all issued new clinical guidance relating to the
10 management of stillbirth. These guidelines include references to what is known about
11 care practices that may help bereaved parents cope at the time and in the years
12 following a stillbirth. The trauma of giving birth to a stillborn baby is known to greatly
13 impact parents and their surrounding family(6,7). Seeing and/or holding the baby is
14 part of a number of psycho-social interventions around the time of stillbirth that may
15 improve parents' short and long-term wellbeing(7). Other examples of interventions
16 include adjustments to the physical environment, counselling, and making mementos,
17 such as hand and foot prints. The attitudes and behaviour of clinicians' around the
18 time of birth can greatly influence parents' decision-making.

19

20 In the UK, approximately 4,000 babies are stillborn each year(8). Current RCOG
21 guidelines state 'carers should avoid persuading parents to have contact with their
22 stillborn baby, but should strongly support such desires when expressed'(2), at the
23 same time as national guidance recommends; 'mothers whose infants are stillborn or
24 die soon after birth should not be routinely encouraged to see and hold the dead
25 infant'(3). The publication of the latter guidance sparked a high profile 'seeing and

26 holding your baby' campaign by the UK Stillbirth and Neonatal Death charity(9). In
27 June 2010, following discussion with the Guideline Development Group a clarification
28 statement was released, but to date the guidance remains the same. It is based on
29 evidence published before 2009, which suggests that seeing and holding the baby is
30 not beneficial for everyone(3).

31

32 Compared to the volume of research into the aetiology and prevention of stillbirth there
33 are relatively few studies investigating parental experience of stillbirth. In 2007, Gold
34 published a systematic review of parent experiences of interactions with health
35 providers' following stillbirth(10). That review examined numerous aspects of parents'
36 experience, including interactions with staff, contact with the baby and the creation of
37 mementoes. The author found that interactions with health professionals have
38 profound effects on parents and concluded that health professionals may benefit from
39 increased training in bereavement support. The review was inconclusive in relation to
40 the benefits of parents seeing and holding their stillborn baby. In 2013, a Cochrane
41 Review of 'Support for mothers, fathers and families after perinatal death' also
42 concluded that the evidence of the potential detrimental effect of seeing and holding a
43 deceased baby remains inconclusive(11). The Cochrane Review acknowledges that
44 the sensitive nature of the topic makes developing trials difficult and rigorous research
45 designs other than trials should inform practice in this area.

46

47 The rationale for the present review builds on Gold's(10) concern that there is little
48 consensus about which behaviours are most helpful or harmful for bereaved parents
49 at the time of stillbirth. In the UK this is evident in current guideline recommendations

50 for seeing and holding, which run contrary to the suggestions of bereaved parent
51 groups(9,12). Seeing and holding is the explicit focus of our review. It aims to address
52 the question *“What is the evidence of benefit and harm for parents seeing and holding
53 their baby following stillbirth after 20 or more completed weeks of pregnancy?”*

54

55

56 **Methods**

57 The study design was a systematic review informed by the principles of narrative
58 synthesis. At the time of writing there is on-going debate about how best to synthesize
59 research using different methodologies in meaningful ways, which draws from a
60 number of approaches(14,15). Our approach follows the systematic steps common to
61 many of these approaches but is not directly aligned to any particular one. In
62 accordance with Gold(10) the present review set out to systematically collect and
63 summarise all articles containing relevant data.

64

65

66 **Search Strategy and Selection Criteria**

67 After initial scoping of the topic, a search strategy was designed to locate studies, of
68 any methodological design, reporting parental views and experiences of seeing and
69 holding their stillborn baby. All electronic searches were undertaken in January 2014,
70 with an English language and human subjects restrictions imposed. No date restriction
71 was placed on the search. Searches used the key words covering the main search
72 domains including “seeing” OR “holding” OR “contact” AND “perinatal death” OR
73 “pregnancy loss” OR “fetal death” OR “stillborn” OR “stillbirth” AND “grief” OR

74 “bereavement” OR “psychology”. The search strategy prioritised sensitivity over
75 specificity to aim for completeness, which necessitated screening a large number of
76 articles. Searches were conducted using PubMed and PsychINFO databases. We
77 chose PubMed over Medline as it is inclusive of Medline, is more up-to-date and has
78 a wider scope (including life science journals). We chose PsychINFO as the leading
79 database for behavioural sciences and mental health. A handsearch was carried out
80 using references obtained from the relevant papers. Two authors (EO, JG) initially
81 reviewed all of the included papers independently, then together with the lead author
82 to reach a final agreement on inclusion by consensus. Primary research papers
83 reporting maternal and/or paternal data, following a stillbirth after 20 completed week’s
84 gestation were included. As there is no standardised definition of stillbirth(1) we
85 imposed the lowest gestational limit used in clinical management(16). Included
86 manuscripts had to be available and written in English. The full list of exclusion and
87 inclusion criteria is shown in Figure 1.

88

89 **Quality Assessment**

90 Articles that met the inclusion criteria were independently assessed by three authors
91 (EO,JG,CK) to minimise bias. Quality appraisal of quantitative studies was carried out
92 using checklists from the Critical Appraisal Skills Programme (CASP) Toolkit(16).
93 Checklists formed from this process were used to grade papers into categories A, B,
94 C or D, with group A representing papers of the highest quality. Papers were assigned
95 a group according to how many criteria it not fulfilled; e.g. Category A contained papers
96 that had not fulfilled 0-1 of the marked criteria whilst Category D contained the papers
97 that had not fulfilled ≥ 6 criteria. More weight was given to the presence of precise

98 results than to presence of possible bias, as this is present in some form in most
99 studies. Qualitative appraisal was conducted according to the checklist described by
100 Walsh and Downe(17) and articles were graded according to Downe and
101 Simpson(18). A grade of A was allocated to papers which had no or few flaws where
102 the study credibility, transferability, dependability, and confirmability is high; B, some
103 flaws, unlikely to affect the credibility, transferability, dependability, and/or
104 confirmability of the study; C, some flaws which may affect the credibility,
105 transferability, dependability, and/or confirmability of the study; D, significant flaws
106 which are very likely to affect the credibility, transferability, dependability. One study
107 that reported quantitative and qualitative data was assessed by combining two
108 relevant checklists. Any differences in the authors' appraisals resulted in a re-read of
109 individual papers and a decision was reached in unison by three authors. The final
110 grading is listed in Table 1.

111

112 ***Analysis and Synthesis***

113 This review generally adheres to the reporting strategy recommended by the Preferred
114 Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)(19). However,
115 not all recommendations were feasible given the wide degree of heterogeneity both
116 within and across research traditions. None of the quantitative studies were suitable
117 for meta-analysis - Table 2 summarises their outcome measures, analytic strategies,
118 and key findings. Instead this review replicates the reporting structure of Gold's
119 systematic review with studies summarised narratively by tradition (quantitative or
120 qualitative) and synthesised in relation to three overarching themes(10). The themes
121 are ""Positive effects of contact within a traumatic life event", "Importance of role of

122 health professionals”; and “Impact on Mothers and Fathers: Similarities and
123 differences”. These themes were formulated based on consensus agreement by all
124 authors about shared and discrepant findings across all included studies.

125

126

127 **Results**

128

129 ***Search Outcomes***

130 The search strategy yielded 735 results containing quantitative, qualitative and mixed
131 methods papers. Six additional records were identified through other sources (hand
132 searching and reference lists). A total of 637 records were independently screened
133 and excluded by title or abstract. One hundred full-text articles required assessment
134 for eligibility. These processes resulted in 706 exclusions, leaving 31 articles requiring
135 assessment for methodological quality. Eight papers were excluded at this point.

136

137 ***Description of included studies***

138 A total of 23 papers are included in this review(20-42). They incorporate 10
139 quantitative papers(20-29), 12 qualitative papers(31-42) and one mixed methods
140 study(30). Nine studies originated from Sweden, five from the United Kingdom, five
141 from the United States, one from Canada, one from Norway, one from Australia and
142 one from Japan. The earliest included paper was published in 1983(31). Fourteen of
143 the studies were published in or after 2007(24-30,36-42). This figure includes seven
144 of the 12 qualitative studies(36-42). In total, the 23 studies involved 4,529 participants,

145 including controls. Four Swedish studies(21,22,24,27), three US studies(30,36,38)
146 and two UK studies(23,26) included data from the same individuals who were followed
147 up in a subsequent study or different aspects of data from the same study were
148 reported in separate papers. Three studies(32,33,40) looked solely into male
149 perspective following stillbirth with a further three examining the experience in
150 couples(20,34,42). Marital status was reported in ten studies.(20,21,23,26,29,32-
151 34,37,42). Although all papers included information on seeing and holding stillborn
152 babies, eight of the studies did not state the number of participants that saw their
153 stillborn baby(30,33,34,36-39,42) and 10 did not state whether participants had held
154 their baby(30,31,33-39,42). In the remaining studies, 4,680 had seen and 3,927 had
155 held their stillborn baby following birth or in the immediate postnatal period.

156

157 **Seeing and holding: Positive effects of contact within a traumatic life event**

158 With the exception of two quantitative papers(23,26), all other papers reported positive
159 outcomes and experiences of parents' contact with their stillborn baby (20-22,24-42).
160 Five quantitative papers(21,23,26,27,29) commented on possible adverse outcomes
161 for the mother following contact with their stillborn baby. Only two studies reported
162 associations(23,26). Both of these studies were authored by the same UK team and
163 involved the same participants. The first study(23), a retrospective case-control study
164 involving 65 pregnant women with a history of previous stillbirth found a narrowly non-
165 significant ($p=0.06$) association between seeing and holding, length of time since loss
166 and third trimester depression in current pregnancy. In this study 17 women did not
167 see their stillborn baby; 14 saw but did not hold their stillborn baby, and 34 had held
168 their stillborn baby. Compared to controls, all women who had experienced a stillbirth

169 had significantly greater post-traumatic stress disorder (PTSD) in the third trimester of
170 a subsequent pregnancy, irrespective of whether or not they had seen or held their
171 stillborn baby. The second study(26) was a seven year follow-up of study of the same
172 participants that reported an association between mothers having held their stillborn
173 baby, case-level PTSD and subsequent partnership breakdown. Whilst the first
174 study(23) shows evidence of psychological hardships during future pregnancies,
175 another study(25) suggests that these associations may be transient; resolved when
176 a subsequent pregnancy ends with a live birth.

177

178 Four of the quantitative studies included in this review reported either no significant
179 difference in anxiety or depressive symptoms of parents who had seen or held their
180 stillborn baby compared to those who had not(21,24) or, increased risks of mental
181 health outcomes associated with no contact(27,29). Rådestad et al(21) found that
182 increased anxiety and depression was associated with a lack of tangible tokens for
183 remembrance and not seeing the baby for as long as parents had wished. Contact
184 with the baby in itself did not cause an increase in symptoms. Crawley et al(29) also
185 found that making memories was not associated with adverse outcomes for parents,
186 but rather a lack of memories and barriers to talking about the experience of stillbirth
187 was significantly associated with mental health outcomes. Another paper, Cacciatore
188 et al(25) reports amongst non-pregnant women who saw their stillborn baby, lower not
189 higher, levels of anxiety and depression were present. Among pregnant women
190 assessed during a pregnancy after the stillbirth there was an increased risk of anxiety
191 and a tendency towards depression.

192

193 One study conducted in the US in 1994(21) reported that 95.5% of parents that had
194 seen their baby thought it was essential. A more recent international survey (n=2,292),
195 where the majority of respondents were from the US (72%), reported amongst the 95%
196 of women who saw their baby, 99.7% were glad to have done so; and amongst the
197 90% of women who had held their baby 99.5% of mothers were glad to have done so.
198 Amongst the women who did not see or hold their baby 80% regretted this, even
199 though the decision was their choice. Further insight into the complexities of the
200 choices available to individual parents at the time of stillbirth is offered by Rådestad et
201 al(27) who report a beneficial effect of having held a stillborn baby after 37 gestation
202 weeks, whilst the effects between 28-37 weeks are uncertain. The qualitative studies
203 offer more detailed insight into these complexities. They suggest that parents perceive
204 contact positively, even if they are initially reluctant to see or hold their baby.

205

206 A recurring finding across the quantitative and qualitative papers was that parent's
207 view seeing and holding as helpful to come to terms with their loss. Contact following
208 the birth was the only time they had to create memories of their child. One
209 quantitative(25), one mixed method(30) and three qualitative studies(32,35,37)
210 addressed participants having regrets about decisions made following stillbirth. The
211 main focus of regret was not seeing and holding their child as well as not creating
212 enough tangible memories, for example, photographs and footprints. In a paper by
213 Trulsson et al(35), all women had seen their baby with three of these finding the
214 experience frightening at first but ultimately comfortable and none of the participants
215 regretted seeing their baby. Many parents expressed regret with regard to the length
216 of time spent with the infant in the hours following the birth(21,24,30,34,35,38,39).
217 Where mothers reported not being with the infant for as long as wished, the risk of

218 developing symptoms of depression or anxiety were found to have increased seven
219 fold three years post-delivery in one study(22). Qualitative findings from five
220 studies(30,34,35,38,39) support this.

221

222 **Importance of role of health professionals**

223 Many studies reported parents' gratitude for the support they were given by health
224 professionals around the time of stillbirth. Nine papers suggested the scope for
225 increased guidance by health professionals to help parents decide whether or not to
226 see and hold their baby. Six of these were qualitative studies(31,33,34,35,36,42) and
227 three were quantitative(25,27,28). A recurrent finding in the six qualitative
228 papers(31,33,34,35,36,42) highlighted that in this time of grief, some parents preferred
229 the health care professional to lead them to a decision that was "right." Across three
230 decades and two continents if the midwife described the baby as beautiful, women felt
231 validated as a mother and as a result were more likely to see their infant(31,39,41).
232 One quantitative study described how a lack of healthcare support resulted in women
233 being four times less likely to hold the stillborn(27), underlining the influence of
234 professionals in decision making. Two papers(25,28) examined the way in which staff
235 facilitate seeing and holding and the parental impact. Erlandsson et al(28) studied 668
236 participants who responded to how the baby was presented at birth. The group who
237 were assumptively offered the baby (with no prior discussion), most commonly
238 reported that they were not at all frightened ($p=0.02$) or uncomfortable ($p<0.01$) seeing
239 the stillborn compared to the group who were asked. In addition, there was a trend
240 that mothers felt more natural and good if the baby was offered to them without being
241 asked, however this was not statistically significant ($p=0.07$). The study by
242 Cacciatore(25) with a large study sample of 2,292, found that those who were

243 assumptively given the child had significantly less depression symptoms than those
244 who were offered as a choice ($p=0.035$).

245

246 Parents felt that they were treated inadequately when healthcare professionals
247 appeared dismissive of their stillborn baby. Behaviours that were appreciated by
248 parents were acknowledging the child, calling the stillborn child by their name and not
249 treating the child like an object but rather a live baby. Decreased satisfaction with
250 professionals was found to be associated with an increase in PTSD and depressive
251 symptoms in parents(29). Four studies(31,33,40,41) specifically mentioned about
252 creating mementoes even if parents refused the offer at the time. Many parents stated
253 that in hindsight, they were glad the midwife had created mementoes and kept them
254 in the patient's notes so that the decision made after birth was not final.

255

256 In the study by Trulsson et al(35), five participants reported that on diagnosis of
257 stillbirth, verbal communication deteriorated and parents expressed the feeling of
258 isolation. It was noted that options should be provided both orally and in writing as it
259 is difficult for parents to take in information when receiving bad news. Parents in one
260 study suggested the need for discussing options before the birth such as bringing a
261 camera and how the stillborn body may change post-delivery(38).

262

263 ***Mother and Fathers: Similarities and Differences***

264 Stillbirth is a process that both mothers and fathers go through. However, the
265 physiological aspects of the process are felt most by the mother and perhaps
266 understandably most literature focuses on the experiences and outcomes of stillbirth
267 on mothers. However, in this review, six of the included studies(32,33,37,39-41)

268 contain information on reactions of fathers during stillbirth. Participants in three papers
269 stated that fathers go through the same feelings of shock, grief and denial on receipt
270 of the news of their child's death as mothers(32,33,39) suggesting the need for a
271 similar level of psychosocial care for fathers as for mothers(39). Men in one paper(40)
272 expressed feeling a need to 'get rid' of the baby as soon as possible following
273 diagnosis of intrauterine death, a reaction that was echoed by women in a paper by
274 Trulsson et al(22). As has been demonstrated with mothers, males were grateful for
275 staff support of their parenthood, including the treatment of their baby(33,40) and
276 tokens of remembrance, which were cherished as tangible proof that the child had
277 existed(32,33,40). In one paper(33) fathers expressed fear for their partners delivering
278 the stillborn baby and seeing the baby after birth. In three studies(32,33,37) fathers
279 were found to feel the need to support their partners, as women appear more visibly
280 upset, rather than address their own emotional needs during this incredibly traumatic
281 time for both parents.

282

283 **Discussion**

284 This review sought to answer the question "what is the evidence of benefits and harms
285 in relation to parents seeing and holding their stillborn baby?" A similar systematic
286 review was published in 2007(10). We identified a proliferation of papers specifically
287 concerned with seeing and holding that have been published in the intervening years.
288 We found almost all included studies (21 out of 23) reported positive benefits for
289 parents who had seen or held their baby. Five studies suggested the potential for
290 harm, with two reporting an association. One of these two studies(23) was particularly
291 influential in challenging the then norm for clinicians to encourage parents to see their
292 stillborn baby, which led to a shift in clinical guidelines(2,3). Two subsequent studies

293 have explicitly challenged the findings of that study(24,25). The earlier review by
294 Gold(10) was inconclusive in relation to the benefits of parents seeing and holding
295 their stillborn baby, as was a more recent Cochrane Review(11). Our findings suggest
296 that seeing and holding the stillborn baby is beneficial, the role of healthcare
297 professionals in facilitating actual decision-making is key, women who have seen or
298 held their stillborn baby should have additional support in any future pregnancies, and
299 clinical management needs to take account of both parents' needs. These findings
300 support the suggestion that good practices identified by family support groups should
301 be included in professional guidelines. Specifically the principles of good practice set
302 out by SANDS in the UK(12) and the unified position statement on contact with the
303 baby published by the International Stillbirth Alliance(43).

304

305 Future guideline development should take into account that seeing and holding is
306 beneficial for many parents when considered as part of positive memory making.
307 Caring for parents experiencing stillbirth is known to be one of the more difficult
308 aspects of maternity professionals roles(44-49). This review(20-42) adds weight to
309 Gold's(10) principal finding that interactions with health professionals have profound
310 effects on parents with perinatal losses. Many studies report interactions with
311 healthcare professionals as the determining influence as to whether or not parents
312 saw or held their baby. Current clinical guidelines place responsibility for the decision-
313 making surrounding seeing and holding with the parents(2,3). However, quantitative
314 and qualitative studies included in this review show some parents express the need
315 for increased guidance in making difficult decisions following the diagnosis of stillbirth,
316 directly challenging some current guidelines. We suggest the balance of evidence has
317 shifted for two reasons; an increase in studies in this area (of any design) and in

318 particular an increase in the number of robust qualitative studies. Traditionally
319 qualitative studies have not featured in medicine's hierarchies of evidence that are
320 used in the formulation of clinical guidelines. However, qualitative research and
321 synthesis is now routinely assessed for quality in similar (albeit philosophically
322 different) ways as quantitative research and efforts to secure its inclusion in evidence
323 based medicine are gaining momentum(50,51). The present review differs from the
324 recent Cochrane Review (11) in both its question and methodology. The focus of the
325 Cochrane Review was broader with the explicit objective of determining the
326 effectiveness any form of intervention on parents and families who experience
327 perinatal death. This review specifically focused on seeing and holding. The inclusion
328 criteria for the Cochrane review were randomised controlled trials, whereas this
329 review, following Gold (10), did not exclude studies on design alone. As previously
330 highlighted in the introduction, the sensitive nature of this topic makes developing trials
331 difficult and other rigorous research designs should also inform practice.

332

333 Another development since Gold(10) is that the experiences of fathers during
334 pregnancy, childbirth and the immediate postnatal period have received increasing
335 research attention(53). This review included six studies of fathers experiences of
336 stillbirth, four of which were published since 2007(37,39-41). Male reactions to stillbirth
337 appear to be very similar to that of women and psychosocial care should be directed
338 at fathers at the same time as mothers. It has been found to be important to
339 acknowledge the male in his role as a father and provide an opportunity for them to
340 speak about the birth away from their partners whom they feel obliged to support. In
341 the UK current RCOG guidelines' already acknowledge mothers, partners and siblings
342 are all impacted and their reactions may be very different.

343

344 The results of this paper must be interpreted in light of its limitations. Future search
345 strategies could be enhanced by searching a more exhaustive list of electronic
346 databases including EMBASE and others with non-English language coverage such
347 as African Journals on-line (AJOL) and LatIndex. It is an important limitation of this
348 review that it excluded non-English language papers. We also employed strict
349 exclusion criteria in respect of gestation age. Three papers were excluded because
350 they did not state gestational age(54-56). A further six papers were excluded because
351 results were not categorised by gestational age and the authors were unable to
352 determine the results corresponding to births >20 weeks gestation(57-62). This review
353 is suggestive of the importance of individual factors including gestational age on the
354 variable benefits of seeing and holding for parents. Further research is required. The
355 strengths of this review include a systematic search strategy and rigorous critical
356 appraisal. It contributes to an emotive and controversial area of maternity practice in
357 which professional and parent interactions fundamentally impact short and long-term
358 outcomes for families.

359

360

361 **Conclusion**

362 Stillbirth is a risk factor for increased psychological morbidity. Since 2007, there has
363 been a proliferation of studies that challenge clinical guidelines recommending
364 clinicians do not encourage parental contact. This review suggests parental contact
365 with their stillborn baby is beneficial for many parents future wellbeing. This finding
366 runs contrary to some current clinical guidelines, but resonates with the practice
367 recommendations of bereaved parents' organisations.

References

1. Cousens S, Blencowe H, Stanton C, Chou D, Ahmed S et al. (2011) National, regional, and worldwide estimates of stillbirth rates in 2009 with trends since 1995: a systematic analysis. *The Lancet* 377: 1319–30.
2. Royal College of Obstetricians and Gynaecologists. Late Intrauterine Fetal Death and Stillbirth. Guideline No.55. 2010.
3. National Institute for Health and Clinical Excellence. Antenatal and Postnatal Mental Health. Clinical Guideline 45. 2007.
<http://www.nice.org.uk/nicemedia/live/11004/30431/30431.pdf> (accessed 24 Feb 2014).
4. American College of Obstetricians and Gynaecologists. Management of Stillbirth. Guideline No. 102. 2009.
5. Flenady V, King J, Charles A, et al. (2009) PSANZ clinical practice guideline for perinatal mortality. Version 2.2 April 2009.
www.stillbirthalliance.org.au/guideline1.htm (accessed 2/5/14).
6. Bennett SM, Litz BT, Lee BS, Maguen S. The Scope and Impact of Perinatal Loss: Current Status and Future Directions. *Professional Psychology: Research and Practice*. 2005; 36(2):180–187.
7. Cacciatore J. (2011) Psychosocial Care in Spong CY (ed) *Stillbirth: Prediction, Prevention and Management*. Blackwell, Chichester. Pg 203-228.
8. Confidential enquiry into maternal child health. *Perinatal mortality 2008: England, Wales and Northern Ireland*. London: Centre for Enquiries into Maternal and Child Health, 2010.

9. Stillbirth and Neonatal Death Charity (SANDS). Bereavement Care Report (2010). <http://uk-sands.org/sites/default/files/SANDS-BEREAVEMENT-CARE-REPORT-FINAL.pdf> (accessed 3 March 2014).
10. Gold KJ. (2007) Navigating care after a baby dies: a systematic review of parent experiences with health providers. *Journal of Perinatology* 27: 230-237.
11. Koopmans L, Wilson T, Cacciatore J, Flenady V. (2013) Support for mothers, fathers and families after perinatal death. *Cochrane Database of Systematic Reviews*. Issue 6. Art. No.: CD000452.
12. Kohner N, Henley A (2001) *When a baby dies: The experience of late miscarriage, stillbirth and neonatal death*. Routledge, Abingdon.
13. Mays, N., Roberts, E. and Popay, J. (2001) Synthesising research evidence. In: Fulop, N., Allen, P., Clarke, A. and Black, N. (eds). *Studying the organization and delivery of health services*. London: Routledge.
14. Noyes J, Booth A, Hannes K, Harden A, Harris J, Lewin S, Lockwood C (editors), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. Version 1 (updated August 2011). Cochrane Collaboration Qualitative Methods Group, 2011. Available from URL <http://cqrmg.cochrane.org/supplemental-handbook-guidance>.
15. Li Z, McNally L, Hilder L, Sullivan E (2011) *Australia's mothers and babies 2009, Perinatal statistics series no.25 Cat. No. PER 52*. Sydney: AIHW National Perinatal Epidemiology and Statistics Unit.
16. Critical Appraisal Skills Programme (CASP). *CASP Checklists*. 2013. <http://www.casp-uk.net/#!/casp-tools-checklists/c18f8> (accessed 3 March 2014).

17. Walsh D, Downe S. Appraising the quality of qualitative research. *Midwifery*. 2006;22:108-119.
18. Downe S, Simpson L, Trafford K. Expert intrapartum maternity care: a meta-synthesis. *Journal of Advanced Nursing*. 2007;57(2):127–140. doi: 10.1111/j.1365-2648.2006.04079.x
19. Moher D, Liberati A, Tetzlaff J, Altman DG. (2008) The PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PLoS Med*2008;6:e1000097.
20. Lasker JN, Toedter LJ. Satisfaction with hospital care and interventions after pregnancy loss. *Death Studies*. 1994;18:41-64.
21. Rådestad I, Steineck G, Nordin C, Sjögren B. Psychological complications after stillbirth-influence of memories and immediate management: population based study. *BMJ*. 1996;312:1505-1508.
22. Rådestad I, Nordin C, Steineck G, Sjogren B. Stillbirth is No Longer Managed as a Non-event: A Nationwide Study in Sweden. *BIRTH*. 1996;23(4):209-215.
23. Hughes P, Turton P, Hopper E, Evans CDH. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet*. 2002; 360: 114-118.
24. Surkan PJ, Rådestad I, Cnattingius S, Steineck G, Dickman PW. Events after Stillbirth in Relation to Maternal Depressive Symptoms: A Brief Report. *BIRTH*. 2008;35(2):153-157.
25. Cacciatore J, Rådestad I, Frøen F. Effects of Contact with Stillborn babies on Maternal Anxiety and Depression. *BIRTH*. 2008; 35(4):313-320.

26. Turton P, Evans C, Hughes P. Long-term psychosocial sequelae of stillbirth: phase II of a nested case-control cohort study. *Arch Womens Ment Health*. 2009;12:35-41.
27. Rådestad I, Surkan PJ, Steineck G, Cnattingius S, Onelöv E, Dickman P. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery*. 2009; 25:422-429.
28. Erlandsson K, Warland J, Cacciatore J, Rådestad I. Seeing and holding a stillborn baby: Mothers' feelings in relation to how their babies were presented to them after birth-Findings from an online questionnaire. *Midwifery*. 2013;29:246-250.
29. Crawley R, Lomax S, Ayers S. Recovering from stillbirth: the effects of making and sharing memories on maternal mental health. *Journ Reprod Inf Psych*. 2013;31(2):195-207.
30. Cacciatore J. Effects of support groups on Post Traumatic Stress Responses in Women experiencing Stillbirth. *OMEGA*. 2007; 55(1):71-90.
31. Lovell A. Some questions of identity: Late miscarriage, Stillbirth and Perinatal Loss. *Soc. Sci. Med*. 1983; 17(11): 755-761.
32. Worth NJ. Becoming a Father to a Stillborn Child. *Clin Nurs Res*. 1997;6(1):71-89.
33. Samuelsson M, Rådestad I, Segesten K. A Waste of Life: Fathers' Experience of Losing a Child Before Birth. *BIRTH*. 2001; 28(2):124-130.
34. Säflund K, Sjögren B, Wredling R. The Role of Caregivers after a Stillbirth: Views and Experiences of Parents. *BIRTH*. 2004; 31(2):132-137.
35. Trulsson O, Rådestad I. The Silent Child-Mothers' Experiences Before, During, and after Stillbirth. *BIRTH*. 2004;31(3):189-195.

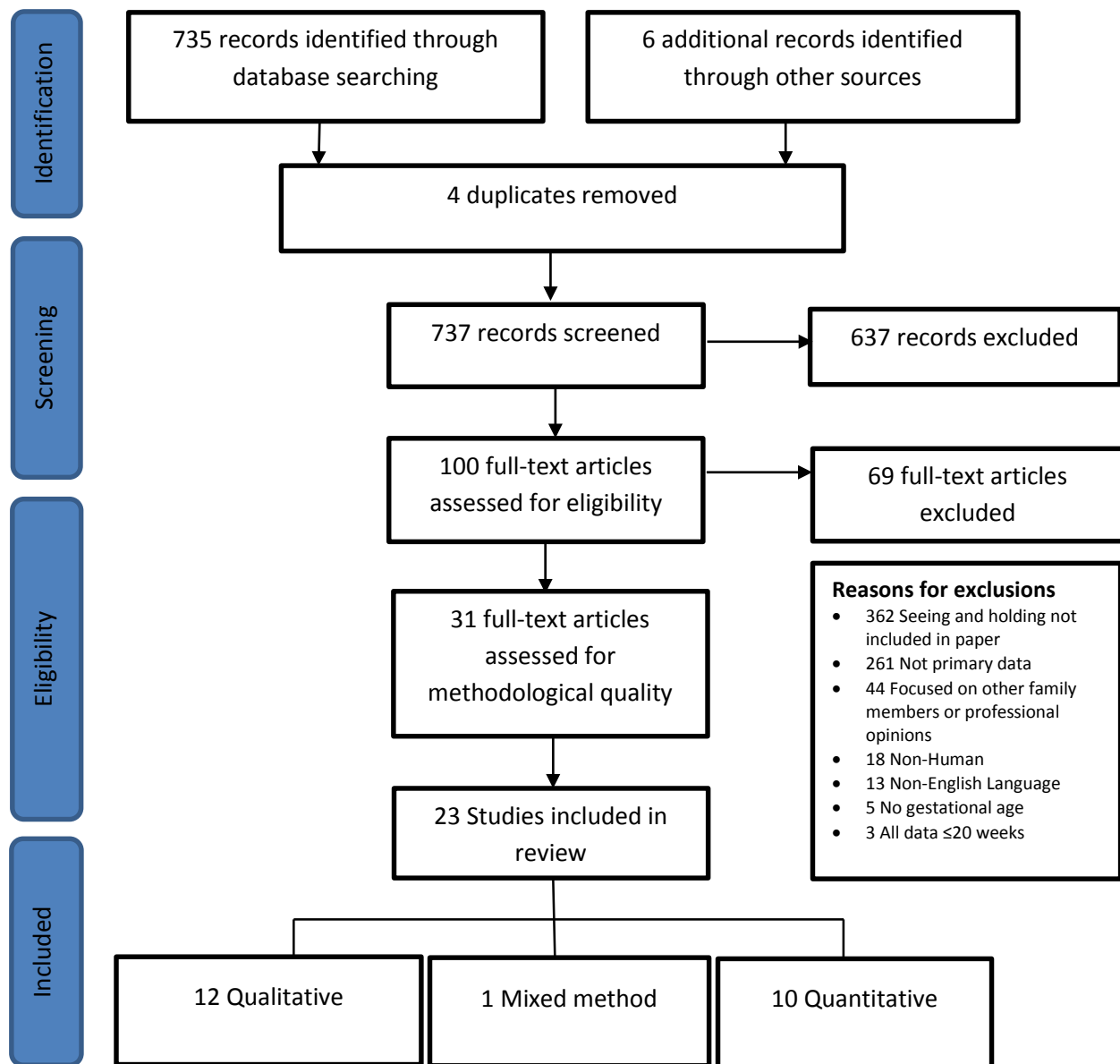
36. Cacciatore J, Bushfield S. Stillbirth: The Mother's Experience and Implications for Improving Care. *Journal of Social Work in End-of-Life & Palliative Care*. 2007;3(3):59-79.
37. Yamazaki A. Living with Stillborn Babies as Family Members: Japanese Women who experienced Intrauterine Fetal Death after 28 weeks gestation. *Health Care for Women International*. 2010; 31:921-937.
38. Cacciatore J. The Unique Experiences of Women and Their Families After the Death of a Baby. *Social Work in Health Care*. 2010;49:134-148.
39. Lathrop A, VandeVusse L. Affirming Motherhood: Validation and Invalidation in Women's Perinatal Hospice Narratives. *BIRTH*. 2011;38(3):256-265.
40. Cacciatore J, Erlandsson K, Rådestad. Fatherhood and suffering: A qualitative exploration of Swedish Men's experiences of care after the death of a baby. *Int Journ Nurs Stud*. 2013;50:664-670.
41. Lee C. 'She was a person, she was here': The experience of late pregnancy loss in Australia. *Journ Reprod Inf Psych*. 2012; 30(1):62-76.
42. Downe S, Schmidt E, Kingdon C, Heazell AEP. Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. *BMJ Open*. 2013; 3:e002237. Doi:10.1136/bmjopen-2012-002237.
43. Warland J, Davis DL, et al (2011) Caring for Families Experiencing Stillbirth: A unified position statement on contact with the baby. An international Collaboration.
44. Jonas-Simpson CF, Pilkington B, MacDonald C, McMahon E. (2013) Nurses' Experiences of Grieving When There Is a Perinatal Death. *SAGE Open*. DOI: 10.1177/2158244013486116 (Accessed 19 May 2014)

45. Wallbank S, Robertson N. (2013) Predictors of staff distress in response to professionally experienced miscarriage, stillbirth and neonatal loss: A questionnaire study. *International Journal of Nursing Studies*. 50:1090-1097.
46. Roehrs C, Masterson A, Alles R, Witt C, Rutt P. (2008) Caring for families coping with perinatal loss. *Journ Obstet Gynae Neonatal Nurs*. 37(6):631-639.
47. Chan MF, Lou FL, Zang YL, Chung YF, Wu LH et al (2007) Attitudes of midwives towards perinatal bereavement in Hong Kong. *Midwifery*. (3):309–21.
48. Gold KJ, Kuznia AL, Hayward RA. (2008) How physicians cope with stillbirth or neonatal death: a national survey of obstetricians. *Obstet Gynecol*. 112:29–34.
49. Downe S, Kingdon C, Kennedy R, Norwell H, McLaughlin MJ et al (2012) Post-mortem examination after stillbirth: views of UK-based practitioners. *Eur J Obstet Gynecol Reprod Biol*. 162:33–7.
50. The Joanna Briggs Institute Levels of evidence and Grades of Recommendation of Working Party. Supporting Document for the Joanna Briggs Institute Levels of Evidence and Grades of Recommendation. The Joanna Briggs Institute [Internet] 2014. Available from: www.joannabriggs.org
51. Glenton C, Colvin CJ, Carslen B, Swartz A, Lewin S et al (2013) Barriers and facilitators to the implementation of lay health worker programmes to improve access to maternal and child health: qualitative evidence synthesis. *Cochrane Database of Systematic Reviews* 2013, Issue 10. Art.No.: CD01414. DOI 10.1002/14651858.CD010414.pub2.

52. Royal College of Obstetricians and Gynaecologists (1995) Report of the RCOG working party on the management of perinatal deaths. London: Chameleon Press.
53. Steen, M., Downe, S., Bamford, N., & Edozien, L. (2011). Not-patient and not-visitor: a metasynthesis of fathers encounters with pregnancy, birth and maternity care. *Midwifery*, 28(4), 422-431.
54. Kelley MC, Trinidad SB. Silent loss and the clinical encounter: Parent' and physicians' experiences of a stillbirth – a qualitative analysis. *BMC Pregnancy and Childbirth*. 2012;12:137.
55. Kuti O, Ilesanmi CE. Experiences and needs of Nigerian women after stillbirth. *Int Journ Gynae Obs*. 2011;113:205-207.
56. Bonnette S, Broom A. On Grief, fathering and the male role in men's accounts of stillbirth. *Journ Soc*. 2011;48(3):248-265.
57. Thompson S, Estrada M, Yonekura M. Factors affecting psychological adjustment to fetal death. *Am J Obstet Gynecol*. 1987;157(2):254-257.
58. Bach Hughes C, Page-Liberman J. Fathers experiencing a perinatal loss. *Death studies*. 1989;13(6):537-556.
59. Kavanaugh K, Hershberger P. Perinatal loss in Low-Income African American Parents. *JOGNN*. 2005;34:595-605.
60. Cahen L, Zilkha S, Middleton RN et al. Perinatal moratility: Assisiting parental affirmation. *Amer. J. Orthopsychiat*. 1978;48(4):727-731.
61. Kellner KR, Donnelly WH, Gould SD. Parental Behaviour after Perinatal Death: Lack of Predictive Demographic and Obstetric Variables. *Obstet Gynecol*. 1984;63(6):809-814.

62. Rand CSW, Kellner KR, Revak-Lutz et al. Parental behaviour after perinatal death: twelve years of observations. *J Psychosom Obstet Gynecol.* 1998;19:44-48.

Figure 1: Process of article selection with inclusion and exclusion criteria



- Inclusion Criteria:**
- Human data
 - English Language
 - Full manuscript available
 - Maternal and/or paternal viewpoints
 - Gestational age >20 completed weeks
 - Unplanned Loss (no termination of pregnancy)
 - Must include “seeing” and “holding”

- Exclusion Criteria:**
- Not written in the English language
 - Does not contain “seeing” and “holding”
 - All data involving stillborns of <20 weeks gestation
 - Not primary data
 - Viewpoints of other family members

Table 1: Summary of Included Studies

	Year	Location	Number of participants	Gestational Age	Length of time since Stillbirth	Method Used	Quality Grading
<i>Quantitative Studies</i>							
Lasker and Toedter (20)	1994	USA	138	≥27 weeks n=22	Followed up at 2 months, 1 year and 2 years following loss	Longitudinal cohort study	B
Rådestad et al (21)	1996	Sweden	636 (314 stillbirth cases)	≥28 weeks	≤ 4 years	Case-control study	A
Rådestad et al (22)	1996	Sweden	636 who participated in (21)	≥28 weeks	≤ 4 years	Postal questionnaire	C
Hughes et al (23)	2002	UK	125 (65 stillbirth cases)	≥18 weeks	Not stated	Case-Control Cohort study	C
Surkan et al (24)	2008	Sweden	314 women who experienced stillbirth and participated in (21)	≥28 weeks	3 years	Postal questionnaire	B
Cacciatore et al (25)	2008	International	2,292	≥20 weeks	Not stated	Web-questionnaire	A
Turton et al (26)	2009	UK	51 controls and 52 cases who participated in (23)	≥18 weeks	Not stated	Nested Case-Control	C
Rådestad et al (27)	2009	Sweden	314 women who experienced stillbirth and participated in (21,22 and 24)	≥28 weeks	≤ 4 years	Cohort Study	B
Erlandsson et al (28)	2013	Sweden	840	≥22 weeks	≤1989 (n=119) 1990-1999 (n=106) 2000-2010 (n=574) Not stated (n=41)	Web-questionnaire	A
Crawley et al (29)	2013	UK	162	≥20 weeks	≤ 10 years	Web-questionnaire	A
<i>Mixed-Method Study</i>							
Cacciatore (30)	2007	USA	47	≥20 weeks	Within 1 year (n=10) 1-2years (n=10) 2-5 years(n=17) 5-10 years (n=7) ≥10 years (n=3)	Web-questionnaire	B

Qualitative Studies

Lovell (31)	1983	UK	22 mothers 10 stillbirths	20-27 weeks	Not stated	Interview	C
Worth (32)	1997	Canada	8 fathers	26-41 weeks	3months-5years, 3 months	Interview	B
Samuelsson et al (33)	2001	Sweden	11 fathers	33-42 weeks	5-27 months	Interview	B
Saflund et al (34)	2004	Sweden	24 couples 7 mothers	≥28 weeks	4-6 years	Interview	A
Trulsson and Rådestad (35)	2004	Sweden	12 mothers	≥24 weeks	6-18 months	Interview	B
Cacciatore and Bushfield (36)	2007b	USA	47 mothers	20-32 weeks (n=13) 33-36 weeks (n=12) ≥37 weeks (n=22)	Within 1 year (n=10) 1-2years (n=10) 2-5 years(n=17) 5-10 years (n=7) ≥10 years (n=3)	Questionnaire	B
Yamazaki (37)	2010	Japan	17 mothers	28-40 weeks	1-6 years	Interview	A
Cacciatore (38)	2010c	USA	47 mothers	20-32 weeks (n=13) 33-36 weeks (n=12) ≥37 weeks (n=22)	Within 1 year (n=10) 1-2years (n=10) 2-5 years(n=17) 5-10 years (n=7) ≥10 years (n=3)	Questionnaire	B
Lanthrop and VandeVusse (39)	2011	USA	15 mothers	28-36 weeks	1-2 years (n=5) 2-4 years (n=3) 5-9 years (n=7)	Interview	A
Cacciatore et al (40)	2013	Sweden	131 fathers	>22 weeks	0-4 years (n=99) 5-10 years (n=32)	Questionnaire	A
Lee (42)	2012	Australia	14 mothers	20-24 weeks (n=9) 25-37 weeks (n=4) 1 non-responder	3-4 months	Questionnaire	B
Downe et al (43)	2013	UK	22 mothers 3 couples	24-42 weeks	1-9 years	Interview	A

Table 2: Quantitative Studies: Heterogeneity of Study Designs, Analytical Strategies and Outcomes Measures

Author/Year/ Country	Focus	Design and Methodology	Analytic Strategy	Main Outcome Measures	Findings
Lasker and Toedter, 1994, USA(20)	Interventions at time of loss and associated outcomes	Longitudinal cohort study with interviews at 2 months, 1 year and 2 years following loss	Hypothesis testing with results reported by four groups - pregnancy loss, early fetal loss (16-26 weeks); late fetal loss (>27 weeks) and neonatal death	Satisfaction with general care at time of loss; satisfaction with specific intervention at time of loss; and grief outcomes over course of two years following loss	Parents' who experienced late fetal loss (27+ weeks) who saw, touched/held or spent time alone with baby were significantly more satisfied than those who did not. There was no significant difference between those who did not see or did not touch/ hold baby at an earlier gestation.
Rådested et al, 1996, Sweden(21)	Factors that may predict long-term psychological complications	Retrospective case-control study using national birth records and epidemiological methods	Multivariate linear and other regression modelling techniques	Anxiety related and depression related symptoms at around four years following loss	Not seeing baby for as long as the mother wished was associated with increased risk of anxiety related and depressive related symptoms, suggesting that meeting and parting is important and should be strengthened to diminish the risk of long term psychological complications.
Rådested et al, 1996, Sweden(22)	Maternal views	Postal questionnaire responses obtained as part of the above study (21)	Simple descriptive statistics	Not applicable	One third of women stated staff should have been more active in helping them meet their baby, but some (unclear how many) felt staff tried to force them to see and hold their baby when they were not ready for it.
Hughes et al, 2002, UK (23)	Is seeing and holding beneficial to psychological health of mother and next-born child?	Part of wider case-control study	Inferential statistics	Maternal symptoms of depression, anxiety, and PTSD during 3 rd trimester of pregnancy	Women who had held their stillborn baby were more depressed than those who only saw the infant, while those who did not see the baby were least likely to be depressed. Women who had seen their stillborn infant had greater anxiety and higher symptoms of PTSD than those who had not.
Surkan et al, 2008, Sweden (24)	Associations between infant bonding, maternal actions, and depressive symptoms	Retrospective case-control study using national birth records and epidemiological methods	Multivariate linear regression modelling techniques	Time between delivery and seeing baby, held and/or caressed baby, time with baby, staff at delivery	Factors related to maternal depressive symptoms at 3 years' follow up were mother not being with the stillborn baby as long as desired, later birth order of the stillborn, and no subsequent pregnancy during the first 6 months after the event.
Cacciatore et al, 2008, International, (25)	Seeing and holding and risk of anxiety	Web questionnaire	Multivariate linear and other regression modelling techniques	Anxiety and depression-related symptoms	Seeing and holding the stillborn baby are associated with fewer anxiety and depressive symptoms among mothers of stillborn babies than not doing so, although this beneficial effect may be temporarily reversed during a subsequent pregnancy.
Turton et al, 2009, UK (26)	Seven-year follow-up of (23)	Nested case-control study	Inferential statistics	Depression, post-traumatic stress disorder (PTSD) and partnership breakdown	Significantly higher levels of PTSD persisted in stillbirth group amongst women who had case-level PTSD seven years earlier. Partnership breakdown was associated with having held stillborn and having had case level PTSD.

Rådested et al, 2009, Sweden (27)	Long term outcomes of mothers who have or have not held their stillborn baby	Postal questionnaire responses obtained as part of above study (21)	Inferential statistics	Anxiety, depression and wellbeing	Holding a stillborn baby born after 37 weeks was found to be beneficial, whereas the effects of holding a baby born between 28-37 gestational weeks were uncertain. The attitude of staff influenced whether or not the mother held her stillborn baby.
Erlandsson et al, 2013 (28)	Way caregivers offer opportunities to see and hold impacts mothers	Web-questionnaire	Simple descriptive and inferential statistics	Maternal views	Mothers presented with their stillborn baby as a normal part of birth (without being asked if they wanted to see) felt more natural, good, comfortable and less frightened than those who were asked to choose.
Crawley et al, 2013 (29)	Creating and sharing memories following stillbirth and maternal mental health	Web-questionnaire	Regression analyses	Maternal views and symptoms of depression, anxiety and PTSD	All mothers saw their babies and nearly all held them with wide variations in mental health scores. There was no association between making memories and PTSD, anxiety or depressive symptoms, but sharing memories was associated with fewer symptoms of PTSD.