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Parents' experiences of losing an infant of multiple birth during perinatal or neonatal period

Literature review

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The purpose of this final thesis was to describe parents' experiences of losing an infant of multiple birth during perinatal or neonatal period. The aim of this literature review was to develop the expertise of health care professionals working with bereaved multiple birth parents, especially those who work in perinatal and neonatal units.

Systematic search was conducted from databases CINAHL, MEDLINE and PUBMED. Manual search was used to maximize the bibliography of this literature review. Total of 10 research articles were chosen.

Results implied that losing an infant of multiple birth was a complex and life-changing experience. Parents had mixed emotions; they were happy for their survivor(s) and simultaneously grieved the death of the other multiple(s). Losing one of the multiples caused fear, anxiety and worry over the rest of the multiples, and difficulties in bonding with the survivor(s). However, the survivor(s) could also be a source of comfort and strength. Parents were also grieving the loss of the special status of being a multiple birth parent. Parents faced the grief of losing their multiple through different circumstances: the funeral, going back to the NICU to see the survivor(s), interacting with health care professionals who are unaware of their situation, seeing other twins or higher order multiples, looking at their photos and other mementoes.

Parents felt like other people could not understand their loss and often came across as insensitive. Relationships between parents, as well as friends and other family members may have altered after the loss. Parents listed emotions they experienced surrounding the subject of losing an infant of multiple birth: sorrow, grief, despair, irritability, anger and guilt. They felt isolated and that they were expected to grieve in a certain way or hide or delay their sadness. They were left asking questions and looking for reasons. After some time had passed, parents may have talked about acceptance, personal change and growth from the experience.

There is a good amount of research in general conducted about this topic, but an evident lack of research regarding nursing practices. More research on the phenomenon of losing one infant of multiple birth is a necessity for understanding the unique aspects of it.

Keywords	multiple birth, grief, loss, bereavement, parents

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Tekijä(t) Otsikko Sivumäärä Aika	Jenni Hyvärinen ja Roosa Salmi Vanhempien kokemukset monikkolapsen menetyksestä perinataali- tai neonataalivaiheessa – Katsaus kirjallisuuteen 37 sivua + 3 liitettä 18. huhtikuuta 2017
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Tämän opinnäytetyön tarkoituksena oli kuvailla vanhempien kokemuksia monikkovauvan menetyksestä perinataali- tai neonataalivaiheessa. Kirjallisuuskatsauksen tavoitteena oli kehittää hoitotyön ammattilaisten ammattitaitoa työskentelystä monikkovanhempien parissa, jotka ovat menettäneet yhden monikkolapsistaan. Erityisesti niiden, jotka työskentelevät vastasyntyneiden parissa.

Opinnäytetyön aineisto kerättiin systemaattisesti CINAHL, MEDLINE and PUBMED tietokannoista. Aineiston maksimoimiseksi, kirjallisuutta haettiin myös manuaalisesti. Aineistoksi valikoitui 10 tieteellistä artikkelia.

Tuloksista ilmeni, että monikkovauvan menetys oli vanhemmille monimutkainen, elämää mullistava kokemus. Vanhemmat kokivat ristiriitaisia tunteita; he olivat iloisia selviytyneestä vauvasta/vauvoista mutta samanaikaisesti surullisia menetetystä vauvasta/vauvoista. Monikkovauvan menetys aiheutti pelkoa, ahdistusta ja huolta selviytyvistä monikkovauvoista, ja lisäsi haasteita varhaiseen vuorovaikutussuhteeseen selviytyjän kanssa. Usein selvinnyt monikkovauva oli kuitenkin lohdun sekä voiman lähde vanhemmille. Vanhemmat myös surivat menetettyä mahdollisuutta olla monikkovanhempi. Vanhemmat kohtasivat surunsa monissa eri tilanteissa, kuten hautajaisissa, vastasyntyneiden teho-osastolla vieraillessaan selviytyneen vauvan/vauvojen luona, vuorovaikutuksessa sairaalan henkilökunnan kanssa ja muita monikkolapsia nähdessään sekä katsellessaan kuvia ja muistellessaan menehtyneitä vauvoja.

Vanhemmat kokivat, että muut ihmiset eivät ymmärtäneet heidän menetystään ja vaikuttivat tunteettomilta vanhempien menetystä kohtaan. Ihmissuhteet vanhempien, kuten myös muun perheen sekä ystävien kanssa saattoivat muuttua menetyksen jälkeen. Vanhempien listaamia tunteita, koskien monikkolapsen menetystä, olivat: suru, epätoivo, ärtyisyys, viha ja syyllisyys. Vanhemmat kokivat olevansa eristyksissä ja heidän edellytettiin joko surevan tietyllä tavalla tai piilottaa tai viivästyttää suruaan. He jäivät pohtimaan kysymyksiä ja miettimään syitä miksi heille kävi niin. Kun aikaa kului, vanhemmat saattoivat puhua hyväksynnästä, henkilökohtaisesta kasvusta ja muutoksesta tapahtuman vuoksi.

Monikkolapsen menetystä ilmiönä on tutkittu, mutta tutkimuksesta koskien hoitotyön ammattilaisten työtehtäviä on selvä puute. Monikkovauvan menetystä käsittelevälle tutkimukselle on tarvetta, jotta ilmiön ainutlaatuiset puolet tulisivat tutuiksi.

Avainsanat	monikkoperheet, suru, menetys, vanhemmat

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1 Introduction

This thesis is conducted in cooperation with the project VauvaSuomi. VauvaSuomi is a Finnish registered association, which works to promote the wellbeing of families with infants, and their goal is to get the infant's "voice" heard in the Finnish society (Mäkelä 2016). VauvaSuomi was established about two years ago. They work to spread information of good early interaction and the importance of interaction, and their effect on neurological development and later human growth and development. (VauvaSuomi 2017.)

In the past 10 years, multiple births have accounted for 2.7-3.1 percent of all births in Finland (THL 2015; THL 2016). The majority of multiple births are twins: approximately 800 twins are born each year. Higher order multiples are quite rare in Finland. Each year there are approximately 10 triplets born and quadruplets are born more infrequently. The last two sets of quadruplets were born in 2014 and 1994. Last quintuplets were born 1977. (Suomen monikkoperheet ry n.d..)

Studies have shown that parents losing one infant in multiple pregnancy experience the loss as deeply as parents losing an infant in a singleton pregnancy. Parents will feel the same level of concern equally towards all infants in multiple pregnancies as they feel toward one infant in a singleton pregnancy. (Paananen Pietilä, Raussi-Lehto & Äimälä 2015: 507.) In case of death of one multiple, the parents may be grieving two things: the death and losing the special and unique status of being multiple birth parents (Bryan 1999: 187).

The aim of this thesis is to develop the expertise of health care professionals working with bereaved multiple birth parents, and to provide information of the phenomenon of losing a multiple infant from parents' perspective. Therefore, the purpose of this literature review is to describe parents' experiences of losing an infant of multiple birth during perinatal or neonatal period.

2 Multiple birth and neonatal death

We have narrowed our topic into infants of multiple birth in perinatal and neonatal period. The term perinatal mortality includes stillborn infants and death occurring before the age of 7 days (THL 2016). In literature, the term multiple birth have been used to describe birthing of two or more infants. The term to describe multiple birth of three or more infants is higher order multiple birth. Perinatal period starts from the 23rd pregnancy week and ends when the infant reaches the age of 7 days. Neonatal period is known as the infant's first 28 days. (Paananen et al. 2015: 339.)

2.1 Multiple birth statistics in Finland

The average length of a singleton pregnancy is 39-40 weeks, for twin pregnancy it is 36-38 weeks, triplet pregnancy 32-33 weeks, quadruplets 30-31 weeks and quintuplets 29-30 weeks. Infants born before week 37 of gestation are called preterm and infants born before 32 weeks of gestation are called very preterm. 60% of twins are born prematurely and over 90% of all triplets and all other higher order multiples are born prematurely. Being born as a premature infant decreases the odds of surviving. Prematurity has been the cause of death of infants during neonatal period in 70% of the cases in Finland. All risks associated with pregnancy are more common in multiple birth pregnancies than singleton pregnancies. (Paananen et al. 2015: 459, 500-504.)

Since there are more risks during multiple birth pregnancies than with singleton pregnancies, the risk for perinatal death with the multiples is also greater than with singletons (Paananen et al. 2015: 500-504). It can be seen from the THL (2015) statistics of perinatal mortality in 2013-2014, that the mortality rate of twins or triplets and quadruplets is relatively higher than singletons. In singleton pregnancies, 3.4 infants (per 1000 infants) died during perinatal period. The mortality rate was much higher with twins, 14.2 infants (per 1000 infants) died. When comparing these two to the triplets and quadruplets' rate of 65.2 infants (per 1000 infants), the number is relatively higher. The conclusion is that death among multiple birth pregnancies is relatively more common than in singleton pregnancies. Figure 1 illustrates the perinatal mortality in 2013-2014 of all infants in singleton and multiple birth pregnancies.

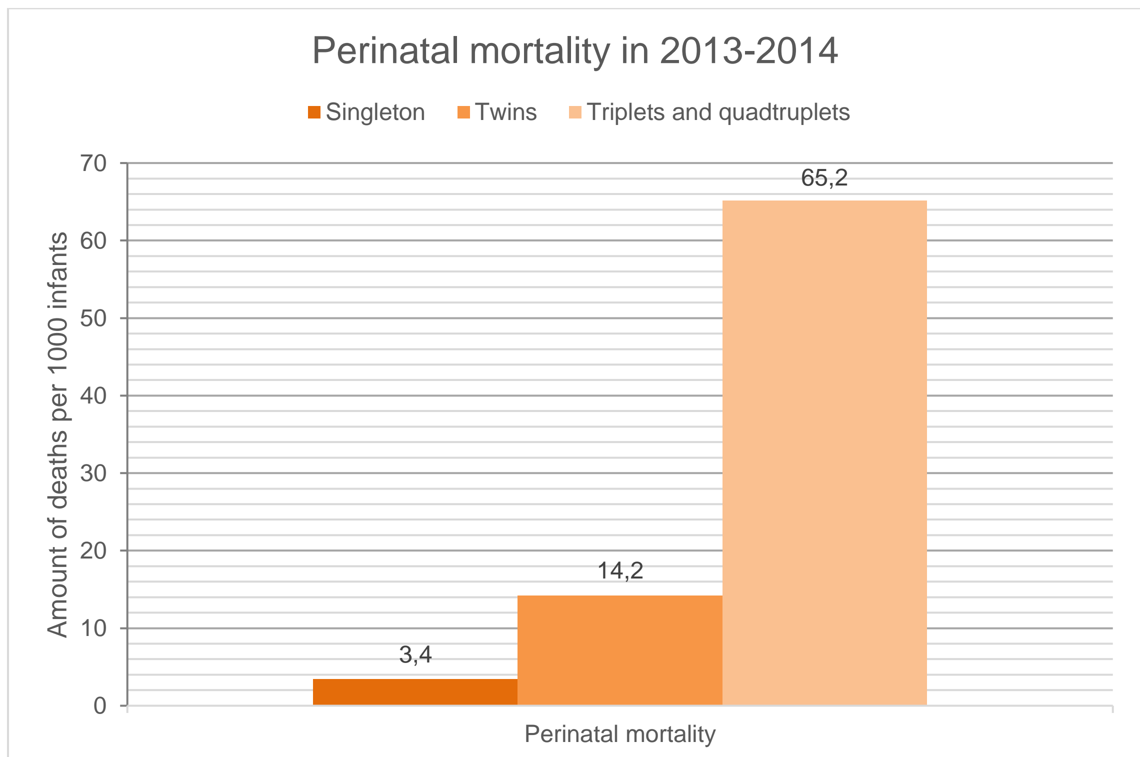
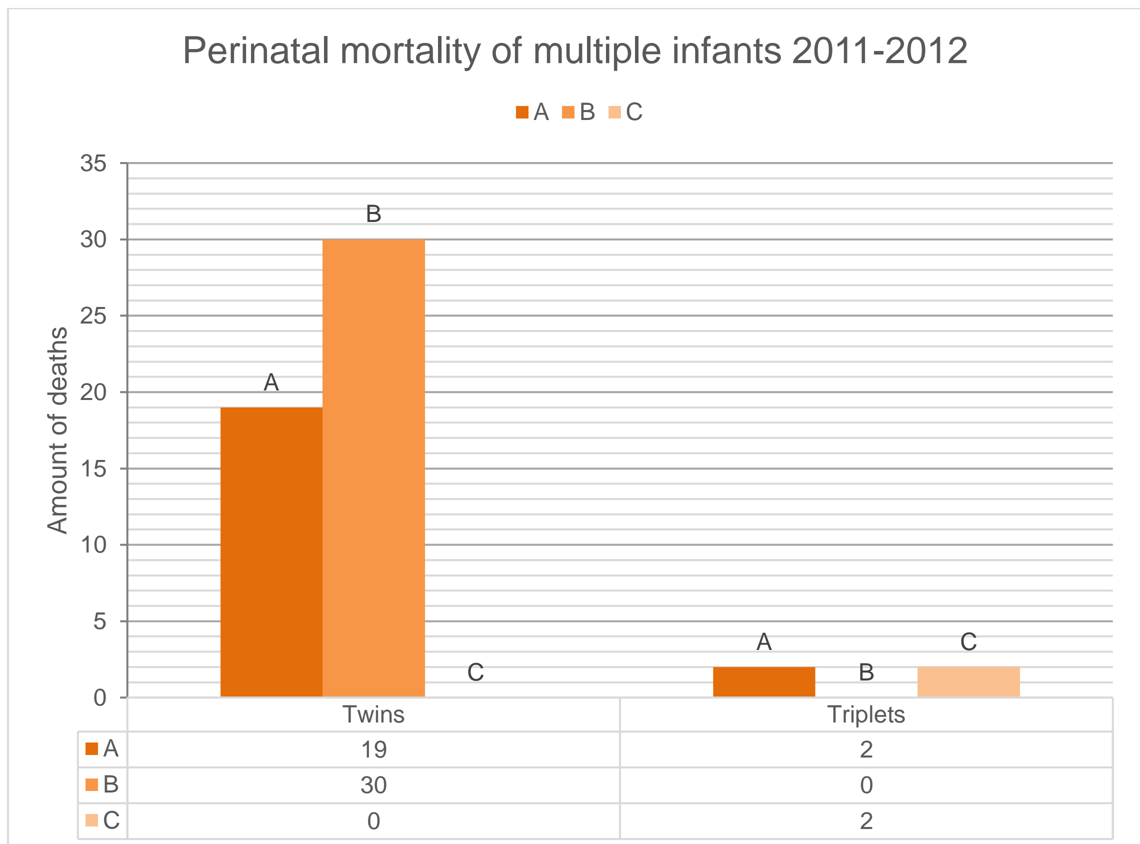


Figure 1. Perinatal mortality in 2013-2014

2.2 Perinatal mortality in multiple births

In the hospital, multiples are named in the order of birth alphabetically. For example, first born is an A infant and second born is a B infant (Kiviniemi n.d.). In the year 2015, perinatal mortality in singleton births was 3.7 per 1000 infants, in twin births perinatal mortality was 13.6 per 1000 and in triplets it was 208.3 per 1000. (THL 2016: table 15). It is clear that because the risk of prematurity is higher with multiple pregnancies, the perinatal mortality is also higher in multiple pregnancies.

Looking deeper into the multiple birth perinatal mortality, it can be seen that 49 twins died during perinatal period from 2011 to 2012, 19 of which were A infants and 30 B infants (THL 2013: table 22). This shows that there are families in Finland living with only one surviving twin. From 2011 to 2012, four triplets died during perinatal period, two of which were A infants and two C infants (THL 2013: table 22). This clearly shows that some of the triplet families in Finland are raising only one or two of the infants and lost one or two during perinatal period. Figure 2 illustrates the perinatal mortality of multiple birth pregnancies during the years 2011 and 2012.



	Twins	Triplets
A	19	2
B	30	0
C	0	2

Figure 2. Perinatal mortality in multiple infants 2011-2012

Perinatal mortality in twins from 2013 to 2014 was similar to that of 2011 to 2012. 44 twins died during perinatal period between 2013 and 2014, 18 of which were A infants and 26 B infants (THL 2015: table 22). From 2013 to 2014 three of higher order multiples died. One was A infant, one was B infant and one was C or D infant (THL 2015: table 22). It is not clear whether all the deceased infants are part of the same triplet or one of the quadruplet born multiples. It can be seen that also during the years 2013 and 2014 many parents of twins only got one of their newborn twins home after the birth. Figure 3 illustrates the perinatal mortality of multiple birth pregnancies during the years 2013 and 2014.

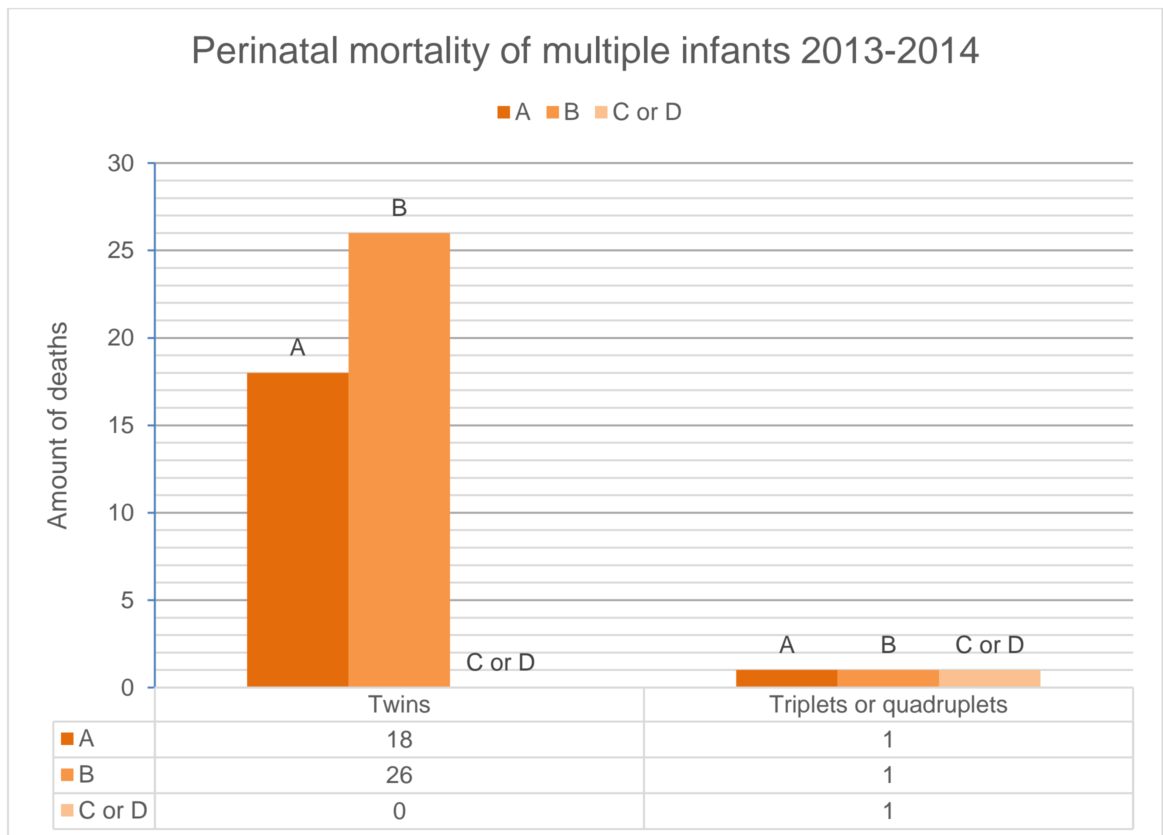


Figure 3. Perinatal mortality in multiple infants 2013-2014

Losing a multiple infant is a rare but sad reality for some parents in Finland, as can be seen from the statistics. Since it is such a unique experience, it is important that also these parents are taken into consideration by the health care staff. Previously written literature of the multiple birth parents' experiences is described next.

2.3 Losing an infant of multiple birth

Parents grieving the loss of one infant in multiple pregnancy may come across as not being thankful for the surviving infant or infants of multiple birth to some friends, family members and health care professionals. This is the case often when the infant has been stillborn or died soon after birth (Bryan 1999: 187). Parents who lose one infant of multiple birth often do not get as much sympathy as they would had they lost all the multiples, even though losing one multiple is felt exactly same as losing any child. The grief is deep and can be more complex than when losing a singleton. (Bryan 2002).

In case of death of one multiple, multiple birth parents may be grieving two things; the death and losing the special and unique status of being parents of multiples. Parents can

also have mixed feelings because they are simultaneously grieving their loss but are also happy for their surviving infant. (Bryan 1999: 187).

Mothers can see the dead infant in the living one or ones in the case of monozygotic (identical) multiples. This can have a negative effect on the mother responding to the surviving infant. They may avoid the surviving infant altogether. Mothers of multiples may even place blame on the living infant for the death of the other infant. They may think that the surviving infant caused the death of the other co-multiple(s). (Bryan 1999: 195-196.)

2.3.1 Health care staff and bereaved multiple birth parents

Parents should see and hold the dead infant when there is a body available. Parents or medical and health care professionals should take pictures of the deceased infant alone and of all the multiples together. Staff should also encourage the parents to take other mementoes such as foot prints of their deceased infant. This will benefit the grieving process of parents as well as the surviving multiples, and later on give memories to the surviving multiple or multiples. It is suggested that parents should name their deceased multiple like any other child. (Bryan 1999: 190-195; Kivikko, Kokko & Kumpula 2011.)

When it is known that one infant will die, the surviving multiple should be placed together with the dying infant if it is not medically contraindicated. Parents' should be encouraged by staff to spend time with the dying multiple. Often in these cases parents' attention and time is dedicated to the dying multiple because of the pressure by medical professionals. If the parent's attention is forced, it may have a negative effect on the relationship with the surviving infant and therefore they should not be pressured. Sometimes in these cases mothers have become isolated and angry towards the surviving multiple. This has resulted in child abuse towards the surviving infant in some cases. Some parents have been grateful to have the time and memories spent with the deceased. (Bryan 1999: 190-195; Kivikko et al. 2011.)

Even though one multiple has died, the parents will still consider the living ones as part of the whole multiple (Bryan 1999: 199). Some parents may become aggressive or even refuse to interact with people who mistakenly call their survivors for example as twins when in fact they were triplets at birth (Bryan 2002). In case of death of an infant, health care professionals should refer to the surviving multiples as they would if all survived.

Triplets with only one living infant are still triplets. It is important for health care professionals to understand the uniqueness of multiple births and respect the fact that the parents are parents of multiples even in case of death of one or all infants. (Kivikko et al. 2011.)

2.3.2 After the loss

Parents who lose an infant of multiple birth often put their grief on hold and focus on the survivor or survivors. This is often the case when the surviving infant is having similar problems as the deceased and is in critical condition. Parents are so invested and worried about them that they do not have space and time to grieve. (Bryan 2002.)

After losing one infant of multiple birth it can be hard for the parents to come in contact with complete sets of multiples. These parents with an incomplete set of multiples, should not be kept side by side with complete sets of multiples in the hospital. (Pector & Smith-Levitin 2002.)

Bryan (1999: 199) noted that many studies have shown that in multiple pregnancies the fetuses are in contact and respond to other fetuses in the womb. He suggests that parents should be made aware of the fact that they should tell the surviving infant that they are part of a multiple set even if the lost infant died in the womb. The deceased multiple can and should be a part of the family's normal life to aid with the grieving process. Parents should also talk about the deceased to begin the grieving process. It is also better for the surviving multiples' own grieving process and acceptance.

3 Purpose of the literature view and research question

The purpose of this literature review is to describe parents' experiences of losing an infant of multiple birth during perinatal or neonatal period. The literature chosen for review are studying the phenomenon of losing an infant of multiple birth from parents' perspective. The ultimate aim is to collect and gain knowledge, and with that, develop the expertise of health care professionals working with bereaved multiple birth parents, especially those who work in perinatal and neonatal units.

The primary research question of this literature review is: What are the experiences of parents following the loss of a multiple during perinatal or neonatal period?

This question is not too broad and it focuses on the parents' experiences in multiple births. This research question is answered by analyzing literature using qualitative content analysis. This includes identifying themes from the chosen articles (Tuomi & Sarajärvi 2009: 95). The intent of this literature review is to find out what special themes arise from the parents' experiences of losing a multiple.

4 Descriptive literature review and content analysis

4.1 Data search

The keywords that were used in data searches are derived from the topic of the thesis. In this case search words were "multiple birth", twin*, triplet*, parent*, death, loss, bereavement, grief and stillbirth. Search words were combined with Boolean operators OR and AND. Databases CINAHL, MEDLINE and PUBMED were used to search articles covering the topic. The searches from database CINAHL, MEDLINE and PUBMED can be seen in Appendix 1. Eight articles were included from database searches. Rest of the articles (2) were frequently cited in the chosen articles and they were found by manual search using reference lists.

Finnish databases such as MEDIC were also searched but no articles were found.

4.2 Data collection

The guidelines by Polit and Beck (2010) and Aveyard (2010) on how to collect and analyse the chosen articles were followed. As described earlier, multiple data searches with appropriate keywords were completed in order to find relevant articles and publications.

As suggested by Polit and Beck (2010: 171), primary sources were preferred in this literature review, since they contain first-hand knowledge. However, a previous literature review on the topic - which is always a secondary source – proved to be a valuable source of information to expand the bibliography. Some relevant sources of information were found from the reference lists of the chosen research articles.

This literature review is first and foremost descriptive, but it has a systematic approach. Searching for, critiquing and synthesizing literature was completed by adapting the Cochrane Collaboration's method of systematic literature review. According to Aveyard (2010: 13) and Polit and Beck (2010: 170), a reliable, valid and good quality systematic literature review is detailed, carefully designed and includes all appropriate and available literature on the topic. This literature review does not meet all the strict requirements of the Cochrane Collaboration method, but the intent was to follow the steps to keep the literature review as logical as possible.

The first step was to present a research question. The aforementioned research question was derived from the broad project VauvaSuomi and the topic of interest: experiences of parents who have lost one or more infants of multiple birth during perinatal or neonatal period. The type of literature to look for was identified - in this case only research articles - that have provided answers to the research question.

The second step was to develop a searching strategy in order to find research articles. Aveyard (2010: 69) describes the searching strategy that was used in this literature review. The search terms were logical and relevant, and most importantly, derived from the research question. All relevant databases were used to search for articles with the search terms defined earlier. On top of this electronic search, most frequently cited sources and reference lists were manually searched to find the maximum amount of literature on the topic.

Data searches yielded a lot of articles so something had to be done to narrow down the articles that were found. Inclusion and exclusion criteria were stated to assess the relevance, quality and validity of the searched literature. Aveyard (2010: 71) guided the process of identifying the inclusion and exclusion criteria in order to keep the focus on the research question and discard irrelevant sources of information. The inclusion and exclusion criteria are listed below, in Figure 4.

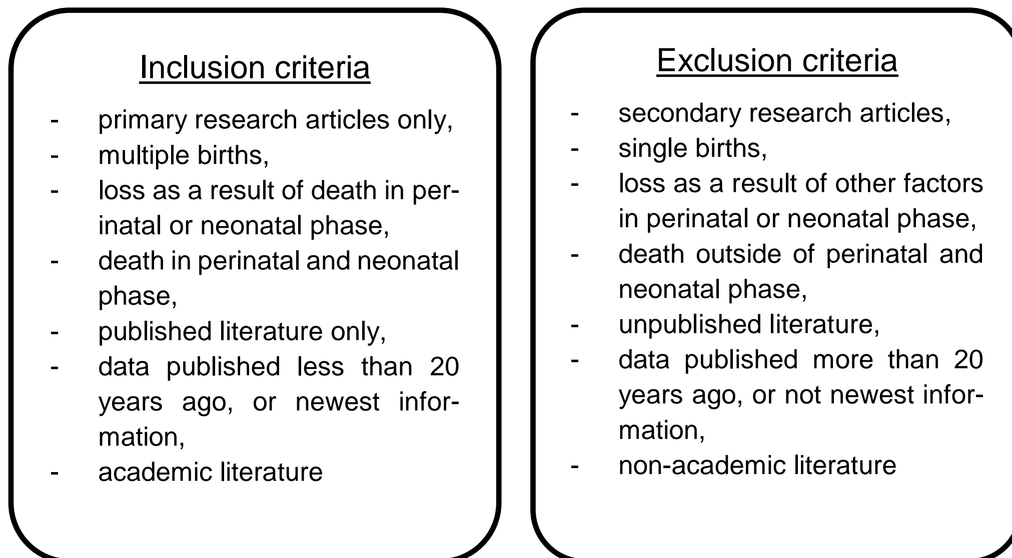


Figure 4. Inclusion and exclusion criteria.

Finally, the findings of the included literature were analysed as follows, combined together and reported in this literature review. The results of the analysed articles are described under Findings.

4.3 Data analysis

This research is a literature review about the experiences of parents who have lost one or some of infants of multiple birth during perinatal or neonatal period. Only qualitative research articles were reviewed, and therefore a qualitative content analysis was completed.

A total of 10 articles were identified for this literature review. Table 1 lists the research articles chosen for this literature review. Three articles were from England, two from North America and Australia, one from Denmark, one from Ireland and one from Israel. Articles were published between 1999 and 2016. All of the chosen articles answered the research question about parents' experiences. Two articles discussed only mothers' experiences but they were included since they were relevant for this literature review and answered the research question. All (n=10) of the articles contained qualitative data. More detailed descriptions of the chosen research articles and the main findings can be found from Appendix 2, Article analysis.

Table 1. List of articles used in this review

1	Aagaard, H., Storm, I. & Klitgaard, J. (2016) Losing one twin in the NICU - A case study of the parental experience. Journal of Neonatal Nursing 22, 153-158.
2	Goggin, M. (2011) The lived experience of parents following the death of a twin in peri-natal/neonatal period. Doctoral thesis
3	Grady, K.L. (2012) Parenting a Lone Twin: When One Twin Dies. Doctoral Dissertation
4	Meaney, S., Corcoran, P. & O'Donoghue, K. (2016) Death of One Twin during the Peri-natal Period: An Interpretative Phenomenological Analysis. Journal of Palliative Medi-cine October 2016, ahead of print.
5	Netzer, D. & Arad, I. (1999) Premature singleton versus a twin or triplet infant death: parental adjustment studied through a personal interview. Twin Research 2(4), 258-263.
6	Pector, E.A. (2004a) How bereaved multiple birth parents cope with hospitalization, homecoming, disposition for deceased and attachment to survivor. Journal of Perinatol-ogy 24, 714-722.
7	Pector, E.A. (2004b) Views of bereaved multiple birth parents on life support decisions, the dying process and discussions surrounding death. Journal of Perinatology 24, 4-10.
8	Richards, J., Graham, R., Embleton, N. D., Campbell, C. & Rankin, J. (2015) Mothers' perspectives on the perinatal loss of a co-twin: a qualitative study. Pregnancy and Child-birth 15 (143).
9	Swanson, P., Pearsall-Jones, J. & Hay, D. (2002) How mothers cope with the death of a twin of higher multiple. Twin Research 5(3), 156-164.
10	Swanson, P., Kane, R., Pearsall-Jones, J., Swanson, C. & Croft, M. (2009) How couples cope with the death of a twin or higher order multiple. Twin Research and Human Ge-netics 12(4), 392-402.

After gaining enough data, planning of the analysis started. Before organizing and ana-lysing anything, a decision was made to only look for similarities across the studies. The purpose was to describe the findings of the chosen articles, not compare them with each other. Some of the articles were comparing the experiences of mothers and fathers, and differences of experiences between multiple birth parents and singleton birth parents. Only the findings regarding multiple birth parents were included and no comparison to singleton birth parents were made. Comparison between the experiences of mothers and fathers was not done. Simply the experiences of multiple birth parents were de-scribed. Only after deciding what to look for, could systematic marking of the elements of interest begin.

The qualitative content analysis is inductive, which means that the themes are derived from the data, not according to a previous theoretical framework. The marked elements or analysis units - in this case only direct quotes of words and phrases - were chosen keeping the research question in mind. The labour was divided for two and work was done apart, conversing and consulting each other throughout the analysis process.

Marking the words or phrases in the literature, that are directly linked to the research question, was the first step to start mindfully organizing the data. The articles were printed out and colour coded to make it visible which direct quotes were said by multiple birth parents. The quotes from each article were inserted into a Google Docs file, where a colour for each article was chosen. This also made it easy to go back and retrieve all the relevant content from the data. The quotes and impressions were reduced into short sentences to make it easier to start clustering the information. It was quickly realized that some analysis units were lengthy and they needed to be cut down into smaller units. This was done making sure that the quotes were still in context and understandable.

Clustering and creating categories was the next step of organizing and analysing the data. Once direct quotes were shortened, initial categories were created in two different Google Docs files. At this point, both created initial categories which derived almost directly from the data. It was decided to use similar categories and themes that were found as headings or subheadings across the research articles. This was found very helpful, and this thematic analysis was used as a guideline to create the final categories.

Work was completed apart from each other in Google Docs files but the results were shared after initial grouping was finished. The initial categories were quite similar to each other and it was decided to combine and refine them. The intent was to create fairly concrete categories in order to describe the phenomenon as systematically as possible. The guideline by Polit and Beck (2010: 467), which stated that a category or theme is relevant when it has emerged from the data at least three or four times, was followed. Thus, categories for analysis units that were reported less than three times in the data have not been created. The final categories had multiple shortened sentences from different articles, in different colours. This is how it was visible that each category had at least three analysis units, preferably in three different colours.

Through the analysis process, it was noticed that some of the analysis units related to more than one categories and after consulting each other, systematic organization of the data was completed without compromising the validity of our literature review.

After creating the categories, upper categories that form theoretical concepts and more abstract conclusions had to be done. However, fairly concrete upper categories were identified here as well. Moving from direct quotes to shortened impressions, to categories which are under a theme. An example of this content analysis is presented in Table 2.

Table 2. Example of content analysis

Direct quotation	Simplified expression	Sub category	Generic category	Main category
"There are a lot of mixed emotions ahm… surrounding it is not as simple as you have lost a baby and that is it when it comes to twins you have a constant reminder not as if you haven't got a constant reminder if was just a singleton baby but because it is a twin… there's something missing ahm… you don't… you want to celebrate... You've got to try to be positive for the… surviving twin on his or her birthday as well Christmas but at the same you have got the other emotion of… of the loss of one ahm."	Trying to be positive for the other but still feeling the loss of one.	Simultaneous joy and sorrow	Mixed emotions	Parents' experiences surrounding the death of a multiple infant
"When one died, a part of me died, too. I was no longer a mother getting ready to raise twins."	I was not a multiple birth parent anymore.	Losing the status of multiple birth parents	Multiple losses	
"When they do their rounds everyday they'd come around and they would go this is [Baby Boy] twin one of twins and [Baby Girl] was twin two…"	Staff referring to the surviving twin as a twin even though the other one had died.	Acknowledging multiple birth status	How health care staff was perceived	Parents' interactions with other people
''… the common thing people would say to you over and over again, at least you have one and he's healthy and you have him and you want the smack them in the head. You understand because they don't know what else to say. You just want to smack them… you do not think that I am happy and very thankful that I have him...? But it doesn't take away from the fact that I don't have her...''	At least you have one.	Negative interactions with other people	Interactions with other people	

For example, the simplified expression ‘at least you have one’, which was found in almost every article, was inserted into the sub category ‘negative interactions with other people’, which is under the generic category ‘interactions with other people’. The final categorization and thematic analysis is written under Findings. A table of the categorization can be found in Appendix 3, Categorization.

5 Findings

The research articles used in this literature review studied the experiences of parents from parents’ perspective. Many of the articles had similar results to each other and supported the previous literature on the topic. The two main themes - Parents’ experiences surrounding the death of a multiple infant and Parents’ interactions with other people – and sub themes or generic categories are described. Main points of these experiences are described in the next subheadings.

5.1 Parents’ experiences surrounding the death of a multiple infant

5.1.1 Mixed emotions

Experiencing the loss of an infant and simultaneously praying for the life of another infant was an emotional struggle for the parents (Goggin 2011; Pector 2004a; Grady 2012). Some parents felt so extremely sad that they could not bear to feel any joy for the survivor (Grady 2012; Goggin 2011). Overall the experience was bittersweet and the parents were confused by their feelings, they were not sure what they could or should feel (Goggin 2011; Meaney, Corcoran & O’Donoghue 2016; Pector 2004a). When feeling both sorrow and joy, many parents felt guilty for being happy for the survivor or survivors (Goggin 2011; Pector 2004a).

> “I literally felt like I was going to split in two... when you have a twin die, it’s incredible; it feels so horrible to be taking any joy from it. I wouldn’t never step back there in a million years, I’d rather go back to junior high again than do that.” (Grady 2012:66)
>
> “Because we didn’t get to know James I think that made it much easier because if James had survived and he died later in hospital, I think that would have been terrible, terrible. Even though it was very sad for us and we mourned, it was like a weird feeling because I was happy to have Joseph and I was terrible sad to have ah not to have James. “ (Goggin 2011:106)

Conflicting emotions were often present when deciding to withdraw care and life support. *"I couldn't let her lay there and suffer out of my own selfishness" (Pector 2004b:6).* Parents felt that they did not want their infant to suffer but, on the other hand, they needed them to be alive for their own comfort (Goggin 2011; Pector 2004b). *"you do want them to go because you know it is obviously better for them not to suffer but you also want to be selfish and keep them here" (Goggin 2011:165).*

Many parents began feeling happy for their survivor or survivors after a while but were disturbed by the feeling that something was missing. The survivor was a constant reminder of what was lost for some parents and therefore when they were happy and looked at their survivor, they remembered that there was supposed to be more than that. (Grady 2012; Goggin 2011; Meaney et al 2016.)

> "I remember it was coming up to Christmas and we put him into the car and I looked at him in the rear view mirror and. [feeling] a huge sense of loss, something missing. " (Meaney et al 2016:3)
>
> "There are a lot of mixed emotions ahm… surrounding it is not as simple as you have lost a baby and that is it when it comes to twins you have a constant reminder not as if you haven't got a constant reminder if was just a singleton baby but because it is a twin… there's something missing ahm… you don't… you want to celebrate... You've got to try to be positive for the… surviving twin on his or her birthday as well Christmas but at the same you have got the other emotion of… of the loss of one ahm." (Goggin 2011:135)

Some parents pressured themselves to not be allowed to grieve since they had a live multiple and had to smother their grief (Swanson, P., Kane, Pearsall-Jones, Swanson, C. & Croft 2009; Swanson, Pearsall-Jones & Hay 2002). *"I was not permitted to grieve since I had a live twin" (Swanson et al 2009:398).* Parents were also feeling pressured by other people and staff members to hide their grief or to grieve in a certain way (Pector 2004a; Swanson et al 2009; Swanson et al 2002). *"She kept pursuing … telling me I had to go through a grief process in a certain way" (Swanson et al 2002:161).*

It was common for parents to wonder why it had to be their infant who did not get to live. (Swanson et al 2009; Meaney et al 2016; Goggin 2011; Grady 2012). These kind of thoughts and questions were difficult and draining for the parents because they knew that they can never be answered (Grady 2012). When the bereaved parents saw other multiples, they would feel upset and sad to know that someone else got to keep all of their multiples, knowing they could not (Goggin 2011).

> "I often find tears in my eyes and wonder and ask 'why couldn't I have both of mine?' when I know that's not a question that can be answered." (Grady 2012:83).

> "When I heard other couples and both their babies survived, I would get very upset about that, when couples come in and I'd say to Ben well how come, why? that's not fair why can't I have the two babies, you know and I, I used to get very upset…" (Goggin 2011:125-126)

The emotions felt when seeing other sets of multiples are discussed in the next chapter.

5.1.2 Multiple losses

When parents lose an infant, there is one big difference between parents of singletons and parents of multiples. Multiple birth parents will also lose their special status of being a multiple birth parent.

When the parents found out that they were having multiples, it made them feel special (Richards, Graham, Embleton, Campbell & Rankin 2015; Grady 2012). When parents encountered the loss of one multiple they had to grieve their lost possibility of being a multiple birth parent (Pector 2004a; Grady 2012; Goggin 2011). *"When one died, a part of me died, too. I was no longer a mother getting ready to raise twins." (Pector 2004a:716).* Some parents thought that they were destined to be multiple birth parents and therefore felt that it was unfair and something was stolen from them when, in the end, they did not get to be multiple birth parents (Grady 2012; Pector 2004a).

> "…I did wish that I would have another set of twins. I do not know how I would have survived the pregnancy but I do feel like I was gypped out of being a twin mom." (Grady 2012:67)

> "I was excited…I felt, how can I put it…I felt special. I felt special to be carrying two babies, you know, I really wanted my two babies who, I seen two babies on that scan, I wanted two babies." (Richards et al 2015:4).

Some parents said that when one of their multiple died, they still saw themselves as multiple birth parents even though no one else could see it (Grady 2012). Surviving multiple was seen as a constant reminder of what could have been for some parents (Pector 2004a; Goggin 2011; Meaney et al. 2016; Swanson et al. 2009).

> "Being a parent of a twin is still somewhat out of the ordinary. After all, most babies are single births. But with my loss, I knew that I was the mother of twins, yet no one could see that." (Grady 2012:67)

It was common for parents to have strong emotions when coming in contact with other multiples, when they were not able to parent all of their own (Goggin 2011; Grady 2012). *“I used to be angry about them having twins and how come I didn’t have twins…” (Goggin 2011:148).* Many parents hated seeing other multiples and felt that it was excruciating and brought up all the painful memories of their loss (Pector 2004a; Swanson et al 2002; Richards et al 2015; Grady 2012; Goggin 2011).

> “My heart hurts when I see twin babies.” (Swanson et al 2002:161)
>
> “Trample[d] in to see the twins, triplets, etc. and gush over the babies. I would just turn my back and cry to myself.” (Pector 2004a:716)
>
> “It was so devastating, and it’s still, 4 years later, still so hard to see twins and everything…” (Grady 2012:79)

In addition to the parents losing their special status, parents grieved the special relationship that their survivor lost. Parents feared that their survivor would be missing out being raised as a singleton when in fact he/she had been a part of a multiple set at the beginning (Goggin 2011; Grady 2012). Some parents felt that their survivor would feel the absence of their deceased co-multiple and grieve the loss. For some parents, it was difficult to see their survivor as something else than a multiple. (Grady 2012.)

> “…it’s bittersweet, because I have this great son, he’s wonderful and he’s amazing, but you know, he had a sister and he doesn’t know really at all about his sister... I do feel that Nick and Stacey had a relationship too and I feel like they did know that there was somebody else in there with them, in some way. But I don’t know... I know there is all this research done about twins – that they know the other twin is gone, a grieving process as a baby. Like something is missing... it’s so hard to go there, to think about that. “ (Grady 2012:79-80)

5.1.3 Having a survivor

After losing a multiple, parents were adjusting to new circumstances of parenting the survivor or the survivors. They often feared that the survivor would also die. (Netzer & Arad 1999; Grady 2012: 82; Pector 2004a). Some parents were overwhelmed and almost paralyzed with the fear of death that they would delay bonding with the survivor or avoid bonding altogether (Pector 2004a).

> “I would tell myself to stop because I didn’t want to bond with this baby that I thought I would lose too. “(Pector 2004a:716).
>
> “...I was just sure that she was going to die. I mean, how did we just manage to get her out of the situation full term, alive, and she did everything early, she walked at eight months. She talked, and I always thought that was just so I would worry less,

> instead of doing things on the later side as we may have expected. I worried and worried, and I know people say…'all parents worry that their child will die… you know, everybody sneaks in to see if they are still breathing.' I want to say it's just different, and how can I know that? How can I know that? No one else was freaking on the same level that I was freaking." (Grady 2012:82-83)

Parents were also afraid of what the future might bring for the survivor, whether there was a possibility of disability and different challenges in growth and development in the survivor's future (Netzer & Arad 1999; Grady 2012). For some parents, the uncertain future was more upsetting than the death of their multiple (Netzer & Arad 1999). *"The unknown future of my other two infants was more frightening than the feeling that they may die." (Netzer & Arad 1999:261)*

The surviving multiple helped parents with their grief (Goggin 2011; Pector 2004a; Grady 2012). The survivor or survivors was a source of comfort for the parents in the unthinkable situation (Netzer & Arad 1999; Goggin 2011; Pector 2004a; Grady 2012). Having at least one survivor gave the parents a reason to get up in the morning and go see the new-born (Netzer & Arad 1999; Richards et al 2015; Goggin 2011). Other parents said that the survivor was what kept them from falling apart because the survivor did not deserve to be left alone in the NICU (Pector 2004a; Goggin 2011).

> "…I have Henry like I said he's just amazing to call him a consolation is insulting to him but he kind of was you know he's what got me through the event of losing James you know cos Henry forced me to keep going and of course I'd already got Joseph (older sibling)." (Goggin 2011:143)
>
> "You do have trying moments but when you have a twin that passed away and you have a twin that's left you just have to keep on going. Because if you fall apart what's there for him?" (Goggin 2011:129)

5.1.4 Death as experienced

Being present at the multiple's death was important for the parents. Holding their multiple and letting them die peacefully in the parent's arms was a source of comfort for many parents. When the presence of parents at the death was not possible it was extremely important that at least supportive staff members would be there. Parents were relieved to know that their infant was surrounded with loving and supportive staff at his/her death and afterwards (Meaney et al 2016; Pector 2004b). In case of more than one multiple's death, it was comforting for parents to know that in the end their deceased multiples were together in the afterlife. (Pector 2004b).

> "It was the hardest thing I have ever, ever done but I couldn't let him die alone. Supportive staff is vitally important when you have to remove a child from life support. Leaving him in NICU after death was easier because I knew he was in loving hands, even if they weren't mine. " (Pector 2004b:7-8)

The reason that some parents felt that their infant's death was a horrible experience was the sum of many things. Lack of support from staff was one of the main things which contributed to the negative experience. Some parents would reject any attempts of support from staff members after the death. These parents had lost their trust in the staff because of the way their multiple's death was handled. Some parents wished that they could have been in a calm environment at the time of death of their multiple and not have staff coming in and out of the door. Some mothers said that it was common practice to give a single room for the bereaved mothers but it made them feel isolated and left alone without any support (Richards et al 2015). (Goggin 2011).

> "…it was such a horrible experience… It has, it really has affected me badly, (voice shaky/ trembling) yes it has… it has…I mean when I was holding Dominic waiting for him, because obviously we pulled the tube out and then went into the Quiet Room to hold him while he was going to sleep…and … my… complaint was…that I wasn't left alone with him…just to let him go. I had people coming in, nurses coming in every 10 minutes… ahm… just checking his heart 'Oh he is not gone yet' his heart is fading 'I'll be back in another 10 minutes. You don't want that, you just want to be left alone, you know he is going to die…die…you just want…just let me hold him in peace... I personally lost all faith in the hospital… not so much the nurses… ahm… more the… ahm the head of the people really… why didn't they intervene sooner… why…I was treated the way I was treated… people coming in… well one person coming in every 10 minutes." (Goggin 2011:110-111)

Accepting the death of a multiple helped the parents in their bereavement. Accepting that there was nothing left to do also helped the parents to make the decision about withdrawing care (Pector 2004b). Some parents had difficulties to understand how serious their multiple's condition was until hearing from someone who had been in the same situation and actually lost their infant, which made the parents accept the possibility of death (Goggin 2011). Some parents found comfort in accepting that their bereavement would be a long and difficult journey which they had to go through (Grady 2012).

> "I had never known anyone who had lost a baby and ahm although I was telling everybody via text and phone call that I had given birth at 23 weeks and that it was grim and that they would probably both die it wasn't until Joan looked me in the eye and told me that she had lost her first girl a year ago and this was her second attempt and Sian was very ill and I actually suddenly realised and that it really was possible quite almost definitely going to happen, it's kind of weird you know busy telling everybody, acting as if I'd totally accepted the fact that this but I don't think I still actually believed it until you know she said." (Goggin 2011:122)

Removing their infant from life-support was a decision some parents had to make. Parents needed the staff to be supportive, sensitive and caring when talking about the decision to withdraw care. It was important for the parents that the staff was the first to bring up the option to withdraw care and not the parents. Critical and pressuring opinions from staff members were not appreciated and caused additional sorrow. Parents needed time to make the decision. At this moment, many parents felt that they needed their infants to be alive but did not want them to suffer, as discussed earlier. (Pector 2004b; Goggin 2011.)

> “And then once I had calmed down a bit and I’d gone into the nursery to speak to him that’s when I was pressured to ‘Oh it’s gonna be the kindest thing to pull the tube out, you need to let him go now, you don’t want him to suffer no more’ and I knew that I didn’t need to be reminded… I just wanted… they … need to give you time. That’s what it is all about, they just need to give you time to get over the initial shock, which I know you never do...” (Goggin 2011:112)
>
> “The consultant did explain there was no rush to make a decision… but it felt like it was quite clear and I’m grateful to her for the fact that she made it quite clear… that she felt we ought to give proper consideration to letting him go and not prolonging it and I’m glad she did that because I don’t know how I would have been able to make the decision if she hadn’t have been so clear cut and one of the many things that I struggled with later when I went over it the following 48 hours is that nobody ever really repeated it. I understand people can’t tell you what the right decision is I and realise that. It would be nice to have some more reassurance because you feel very lonely making that decision.” (Goggin 2011:127)

On the whole, withdrawing care was a complicated and hard decision to make. It required time and support from staff. When parents felt that their decision was not supported, they regretted their decision afterwards and were left wondering if they made the right choice. (Pector 2004b; Goggin 2011.)

> “It’s all about quality of life isn’t it it’s just that you never expect to have to do that with a human life you know to make that kind of a call… and no one can be sure what the right decision is you know so you’re left to make it.” (Goggin 2011:127)
>
> “It’s like the decision wasn’t really mine. If I could own it and face it I might not always wonder ‘What if’.” (Pector 2004b:7).

Some parents felt the need to tell others about their surviving infant’s deceased co-multiple or co-multiples to people at the beginning, but after years had passed they said that the need grew smaller and smaller. These parents also felt that it was not socially acceptable to talk about deceased children because people do not want to talk about it. Parents struggled with the fact that the subject made people uncomfortable. (Grady 2012.)

> "It was tough when people would compliment me on how cute Brent was. Sometimes I wanted to just blurt out 'he's a twin!' because I felt like he was missing out on so much with people assuming he was a singleton." (Grady 2012)

Bereaved multiple birth parents had the need to be acknowledged as multiple birth parents and they needed people to acknowledge that their infants had existed (Grady 2012). It was very important for parents that their deceased multiple was acknowledged while they had their survivor or survivors (Meaney et al 2016).

> "… And there was just such a real attachment to here [maternity hospital] because this is where she was because this is where she existed, this is where she was so real and you know they just made her so, her life her life, you know and they made it very real and that was so special." (Meaney et al 2016:3)

Memories of the deceased multiple or multiples were important to parents, every moment spent with them was valued by the parents (Pector 2004b; Meaney et al 2016; Grady 2012). They also felt that their grieving process was easier to handle because they had had these precious moments and memories (Goggin 2011; Pector 2004b). Some parents felt that since they did not have many memories with the deceased multiple, what they had lost was a potential of a person (Goggin 2011).

> "I think were you to lose a living person who'd lived then you have more memories and you have more joy so there must be I mean I don't know because I haven't done it but I would have thought there must be more sadness too because you know what you've lost I don't necessarily know what I've lost because I haven't had it, so I've lost a potential..." (Goggin 2011:139)

Parents felt that they should have some memories to treasure from the time of the death or the last moments of their deceased multiple or multiples. There were some parents who never got any information about the last moments and they would have desperately wanted to know. (Pector 2004a; Richards et al 2015; Goggin 2011.)

> "Even their birth is a blank. How did the boys lie? Did they cry? How did they look? What did my doctor think when he pulled them out? … What was said? Who cut their cords? Who cleaned them and who rushed them to intensive care? … I have nothing of my boys and need to know every minute of their little bit of life." (Pector 2004a:717)

The surviving multiple was also a part of the parents' memory of the deceased, especially with identical multiples. Parents thought that it was assuring to have the identical multiple or multiples to grow up because in some sense they got to see the possibility of what the deceased twin would have looked like (Goggin 2011; Grady 2012; Pector 2004a). *"I find*

helpful actually, ahm because I do at least, I think its part of the memory thing I do know what she would have looked like." (Goggin 2011:150).

Pictures of the deceased or all of the multiples together had a big role in parents' memories. Parents who did not have any mementoes said it was their biggest regret (Richards et al 2015). *"…that's my biggest regret, I've got nothing" (Richards et al 2015:8).* Parents felt that the pictures of all the multiples together would also mean a lot to the surviving multiple or multiples in the future. Some parents could not bear to look at the photos of their deceased multiple and said that they have not looked at the photos after the death. It was important to have mementoes of what was lost and something concrete to hold and show to other people (Pector 2004a; Pector 2004b; Goggin 2011). (Goggin 2011.)

> "A wonderful nurse suggested that we each hold our sons [one living and one deceased] at our survivor's bedside and took the only family pictures of all 4 of us. We were scared to hold our survivor on a vent, only 5 days old. It was probably the best suggestion ever made to us. We treasure those pictures." (Pector 2004b:8)
>
> "You can't smile for the photo can you(cries) something felt very odd and I'm still not entirely sure how I feel about it but equally of course if we didn't have them there these photos we'd have nothing to show he'd ever been here, well his birth certificate." (Goggin 2011:141)

Many parents held funerals for their deceased multiple or multiples (Goggin 2011; Grady 2012; Richards et al 2015). Some parents who chose to have their child cremated, regretted the choice afterwards and wished they would have buried them and had a tomb stone for them (Richards et al 2015; Pector 2004a).

> "I just got rail, not railroaded but swept along with what they generally do, I just got railroaded into going for a cremation with nothing…and it's just…I just think, I think that, I was given the options, you can have a burial. It was just kind of 'this is what people do' and you, when you're just in a bit of a daze, I just think you go along with what people say…" (Richards et al 2015:8)

Parents who had experienced a stillbirth were thankful for the hospital that they had the opportunity to plan and arrange the funeral before the actual birth (Richards et al 2015; Goggin 2011). Some parents waited and postponed the funeral until they knew that the rest of the multiples would survive or, if not, they could bury them all together (Pector 2004a).

5.2 Parents' interactions with people

Health care staff was an essential part of the parents' experiences of losing a multiple infant since it happened in a hospital surrounded by health care staff. Other people such as relatives, friends and strangers also played a part in the bereaved parents' lives throughout their grieving process. These parents wanted and needed support from people in general (Goggin 2011).

> "I think in the long term, for me it would have been more helpful had somebody mentioned Isla and asked me about her, about how I was feeling about losing her or about William and how I was." (Goggin 2011:130)

Parents' interactions were divided into two generic categories: interactions with health care staff and interactions with other people. Both of them have multiple sub categories which are discussed in the next two subheadings.

5.2.1 How health care staff was perceived

After the death of one or more multiples, acknowledging their survivor being part of a multiple set was really important for the parents. They wanted the staff members to know, but mostly to acknowledge that their other multiple or multiples had died (Richards et al 2015; Goggin 2011; Pector 2004a). Acknowledging their survivor's multiple birth status made parents feel that the deceased multiple or multiples actually had existed and it gave them comfort beyond words (Richards et al 2015; Meaney et al 2016; Pector 2004b).

> "When they do their rounds everyday they'd come around and they would go this is [Baby Boy] twin one of twins and [Baby Girl] was twin two… " (Meaney et al 2016:3).
>
> "They [health professionals] always wrote on the board… like in [NICU] they'd always write the name and then 'twin 1' or 'twin 2' underneath and they said, they asked us if we wanted that to be done or not done you know, so they were thinking about how [we felt]… I think what you didn't want was, you know, as soon as [deceased twin] had died was everyone just treating [surviving twin] as if he was a singleton, because he wasn't." (Richards et al 2015:4)

Parents said that they wanted the staff to know this without the parents explaining and highlighted the importance of multiple birth status being told at handovers and reports. In higher order multiples, it was important to talk about the right multiple set. (Richards et al 2015; Goggin 2011; Aagaard, Storm & Klitgaard 2016). When the staff was not

aware or would not acknowledge their infant's multiple birth status, it was always noted by the parents. Having to explain that their infant was a survivor to the staff was causing additional grief and anxiety for the parents. The staff members who were not aware of the multiple birth status were perceived being less good at their job. (Richards et al 2015; Goggin 2011; Aagaard et al 2016; Grady 2012.)

> "What I found really annoying was that I had to keep repeating my story to the nurses who were looking after [twin]. I had never met them before. Now in a hand-over, that is really very important that they know that [survivor] was a twin and I'm very delicate…it would have been in my notes." (Richards et al 2015:6)
>
> "I have certainly experienced many times that people [nurses] have asked, 'is this your first child?'. Try reading our record! But it became very clear that the longer we were admitted to the NICU, the further back the new nurses had to read to realise that he had had a twin." (Aagaard et al 2016:156)
>
> "I think the great thing about notes being read which would have saved a lot of grief, I think it is unnecessary, it is hard to talk about it at the time, feeling emotional and ahm its, it would be helpful if people had read the information." (Goggin 2011:107)
>
> "Especially on a night shift, I found that was when they [nurses] just didn't, just didn't seem to care. They were like…they just go in for a social and I used to come home nervous." (Richards et al 2015:6)

On the other hand, staff members, who knew and acknowledged the multiple birth status, were perceived being better at their job. Parents often trusted these staff members more and were not anxious leaving their survivor at their care. These encounters with the staff were a source of positive memories for the parents. (Richards et al 2015; Meaney et al 2016; Pector 2004b; Goggin 2011.)

> "They were there for me, I just felt like, I felt so close to them, I really, really did and I felt like ahm, they were even crying with me and that's why I felt so connected to them because I felt they felt my pain, they weren't just ahm there doing their job basically and saying well I am very sorry but it is just one of those things, but they were really wonderful and they were holding me and supporting me in all the ways that I thought that I would have wanted at the time." (Goggin 2011:110)

When staying in the neonatal intensive care unit, some parents had more challenges to attach to their surviving infant or infants. Since the survivor was in an incubator and often had restrictions, for example a breathing tube, the infant simply couldn't be picked up and held by the parents. This made some parents feel that it was not their baby, but hospital's baby instead. Some parents became detached from their infant since they could not pick them up. Many parents felt that it did not occur to the nurses that the parents could feel like this, and so the nurses were not helping the parents form an attachment to their survivor (Aagaard et al 2016; Richards et al 2015). Some parents felt

that even when their survivor died, he/she still was more of the hospital's baby than their own (Pector 2004b). (Aagaard et al 2016; Richards et al 2015; Pector 2004b.)

> "Because when your baby's in an incubator, what's your natural thing to do? You can't just pick your baby up and cuddle her, you can't just do what you want to do with your baby so you do get a little bit detached and then you, and then you feel guilty because you don't have that attachment. I don't think it occurs to the nurses that you don't feel like your baby is yours." (Richards et al 2015:9)

Supportive staff members were valued and important to the parents. It was important to offer support or emotional help but not force it. The most important thing was to be present. Parents felt that right timing and good chemistry with the staff members was a key aspect of providing support (Goggin 2011; Pector 2004a). It was important to let the parents know that they could talk to the staff if they wanted to (Richards et al 2015). Sometimes getting support from staff was easier because they were strangers to the parents (Pector 2004a). *"Sometimes it is easier to get strangers to help. You can't really tell a family member no thanks… without upsetting them." (Pector 2004a:717).* Supportive staff was vitally important and helped parents with their bereavement. Some parents found most comfort from the words spoken by the staff in regular conversations, at times, when the staff might not have intentionally offered support (Goggin 2011). (Meaney 2016; Richards et al 2015; Pector 2004b.)

> "I just loved her [nurse]…she took me under her wing as soon as I got in that hospital…you know and she just, I felt like I didn't want to let her go home that night, I just wanted her to stay with us…she's just lovely and I trusted her implicitly." (Richards et al 2015:6)

> "I probably got more emotional help and support from unwitting members of the nursing team who would just say something based on their experience and it would actually provide me with quite a lot of comfort even if that hadn't been their intention." (Goggin 2011:116)

Often the parents felt that the nurses were sensitive towards the parents' needs and talented at providing support as well as emotional help. Doctors were often perceived to be less supportive, not understanding and busier. Some parents felt that nurses should be the ones providing support and comfort, and supporting parents was not the doctor's job (Richards et al 2015). Nurses were perceived as the ones to be present and have time to listen to the parents. (Richards et al 2015; Goggin 2011; Pector 2004b.)

> "The nurses were very supportive…the doctors I don't think so much, but only because they do ward rounds and they have to assess what is in front of them there and then and they are doing such an important thing aren't they really, that's kind of not relevant to them. I think the nurses are very good, they'd sit and listen to you talk until the cows came home which is brilliant." (Richards et al 2015:5)

> "What I got a lot of… the doctor at the time really quite upset me… she often said to me, 'At least you've still got one', and that was one of the worst things that anyone could possibly say. 'You've still got [surviving twin] though' and I know I'm really grateful I still have [surviving twin]... And it was really quite upsetting. I knew that she didn't mean it in any nasty way." (Richards et al 2015:4)

Some parents said that it did not matter what people said at the time of the death of the multiple because they were in a shock and nothing could alleviate their pain (Richard et al 2015; Goggin 2011). *"At that particular time you have just lost, lost a twin there is nothing anything anybody can do for you" (Gogging 2012:129).* Many parents said that they do remember everything, negative and positive, that was said to them during their experience of losing a multiple infant (Goggin 2011; Pector 2004a).

> "Well I think it's to do with, I don't know what it's to do with, shock that you're in at the time, so how people treat you is incredibly important actually and what they say and how they say it." (Goggin 2011:139)

Some parents wished that there would have been one staff member to be assigned to provide emotional support whenever needed (Pector 2004a). Being in the NICU environment made parents feel uncomfortable. Parents said that they needed to know what all the equipment around their infant was. Staff members who failed to communicate with them, made the parents feel anxious and lose trust in the staff. Some parents said that the peeping noises in the NICU were making them uncomfortable since they thought every peep would mean that there was something wrong. It would have given the parents more comfort, a sense of security and trust in the staff, if the staff had communicated with them about the alarms. Staff members who were able to make the parents feel safe and trust in their care were valued (Goggin 2011). (Aagaard et al. 2016.)

> "... As a parent you are uncomfortable with the alarms. They always make you uncomfortable - and if the nurse just neglects them, it doesn't exactly create a sense of security" (Aagaard et al. 2016:156)
>
> "I mean it is just such a miracle… that's what I thought so yea I definitely felt very, very safe with everybody and I trusted everybody I knew that whatever happened… if he did die everybody would have tried their best to keep him alive." (Goggin 2011:109)

Staff members who failed to acknowledge the survivor's or survivors' multiple birth status were seen as insensitive, as described earlier. Nurses who did not offer any support were seen as simply showing up to do their job and leaving it at that (Richard et al 2015).

> "It's just they (nurses) they can be seen to be like 'it's just a job' you know. Some of them on Special Care Baby Unit was just like that and just like, 'it's just their job' you know. They come in and they do their job and go'." (Richards et al 2015:5)

Some parents said that after a bad experience of how staff handled their deceased multiple, the parents were more reserved with new staff members they encountered (Richards et al 2015; Pector 2004b; Goggin 2011).

> "I wasn't very pleased with the way things were handled with Dominic the same night he died as well ahm… so that obviously pushed me away from the support that if I wanted any, I wouldn't have taken it ahm…because it was such a horrible experience." (Goggin 2011:110)

Some parents said that one staff member kept mixing their multiples and called their survivor by their deceased multiple's name and it was seen as a very insensitive thing to do (Richards et al 2015). Overall nurses were seen as supportive members of health care staff. Parents' experiences with staff members regarding the death of their multiple was described earlier in the chapter Death as experienced.

5.2.2 Interactions with other people

Some parents felt that only other multiple birth parents could understand their loss. Losing a multiple is a unique thing and only after having experienced the uniqueness of it first hand, people can begin to understand the depth of losing one. Other multiple birth parents were seen as supportive by some bereaved multiple birth parents. (Grady 2012; Goggin 2011).

> "She knows more than me what it's like because has twins and I don't so I think at the time she was very upset and probably more upset than a lot of my friends because I think she knew, she knew you know and I didn't know and she did what I had lost ahm so yeah she has, she's a very good friend." (Goggin 2011:121)
>
> "...sometimes Moms with twins do really get it, they know they don't have a baby and a spare, so they understand that you haven't been given the "bonus" kid. And they can much more put themselves in the situation, 'what would it be like if I didn't have one of my kids,' but a lot of people they just don't understand the kind and types of joys of the whole thing is." (Grady 2012:70-71)

Parents might have difficulties to interact with other multiple birth parents, because they often had strong negative feelings when they came in contact with other multiples, like discussed earlier under the heading Multiple losses. Support groups and classes mostly meant for singleton parents were tough for the bereaved multiple birth parents. Support

groups for bereaved parents were seen more stressful than helpful because of the survivor. Some parents were told that bereaved multiple birth parents do not go to the bereaved singleton parents' support groups because the survivor is an issue (Goggin 2011). (Grady 2012.)

> "They would always open with a question for the Moms; a lot of times it was "what do you remember on the day they were born?... if the regular person running the class saw me coming she would avoid that question. There was one set of newborn twins that never came back again after I spoke. I was honest." (Grady 2012:73)
>
> "...I remember we broke into an argument one day because someone said to me 'I don't understand why are you here, you have a baby.' And then the other people started yelling at her – 'how can you say that, she lost a baby, that's why she's here.' I felt that I had to defend myself; it never occurred [to me] that I was there for any other reason other than the fact that my son died, he's a different person than the other one. I was such a problem... I thought 'my God' the amount of emotion and energy in that group, I almost felt like it was a responsibility to go there for the other people, but it wasn't really helping me." (Grady 2012:69)
>
> "I went to try and get information about the TAMBA support group and there was a SANDS lady there and she was actually saying you they don't get people coming to the meetings for the very reasons that I was saying, she said and she thought if people turned up and they had a surviving baby they... I think people do perceive that you have got one baby ahm… to me it doesn't lessen it at all." (Goggin 2011:125) (TAMBA=Twins and Multiples Births Association; SANDS=Stillbirth and Neonatal Death Society, Goggin 2011)

Some relatives and friends were seen as supportive and helpful by the bereaved parents (Goggin 2011). Despite people's best efforts to be supportive, sometimes careless words could be hurtful and in difficult situation like this one, it can be tough for the relatives and friends to understand and support the bereaved parents (Goggin 2011).

> "Basically I think because they (parents) are too scared at the prospect of it not being okay for me you know, but sometimes that's not… but they were great, and they have been great all year, saying to me all the time 'We're here if you want to ring up and yell at someone or sob at someone we're here and no, they've been fantastic." (Goggin 2011:119)
>
> "You know everybody tries to make you feel better because they love you and they want to look after you but it's not, they don't always say the right thing and ah you know. My sister has got two boys as well and we both wanted a girl and I remember her saying 'Oh God, don't moan at least you've got your daughter'… and ahm she loves me to death and we are very close you know from her point of view I'm sure that is really what she sees but, it's harder than that." (Goggin 2011:118-119)

It was common for other people to not quite understand the depth of multiple birth parents' grief (Netzer & Arad 1999; Grady 2012; Goggin 2011). It was difficult for the parents when other people would not acknowledge their loss of a multiple (Goggin 2011). The

importance of acknowledging multiple status was described in the previous heading concerning interactions with health care staff. Acknowledging the multiple status is as important with health care staff as it is with other people.

> "I don't know how to explain to people that it never gets any better. Its like having your soul ripped out, there's always the presence and people look at my family and think we look happy and to a certain extent [we are] . . . we'll never really be complete, there will always be this missing piece. That's what it's like for me." (Grady 2012:93)
>
> "Henry's family don't acknowledge… I find it quite difficult… I don't really understand it but ... when we lost Isla… his Mum is a twin ah… I thought she would have quite a good understanding but she… she didn't understand at all and was quite surprised at how I had taken time off work and ... was surprised we had a funeral and things like that… which she didn't say directly to me … but I … I … know that she did… and so… I suppose I find that… a quite hard to understand." (Goggin 2011:146)

Other people not understanding the situation resulted in many parents' getting their feelings hurt. It was very common for someone to say "at least you got one" to the grieving parents which was perceived to be a very insulting thing to say (Netzer & Arad 1999; Swanson et al 2009; Swanson et al 2002; Grady 2012; Pector 2004a; Goggin 2011; Richards et al 2015). Many parents also perceived being told that they can have other children was very insulting and insensitive (Swanson et al 2009; Netzer & Arad 1999; Swanson et al 2002).

> "...I've taken offense to people who have said "well at least you got one" or "now you have your set (meaning a girl and a boy)"... like my surviving twin was a consolation prize? The insensitivity of people, even those close to our family, has been the hardest over the years." (Grady 2012:76-77)
>
> "I think I felt that no one said the right thing, but I don't think anyone could have said the right thing to me, (laughs). Cos everybody said 'At least you've got one' you know 'At least she you know 'Oh life would have been a nightmare with four children under four' all of which were things that I was thinking myself you know, of course, one I would much rather have one daughter than no daughter." (Goggin 2011:126)

Many mothers felt that men have different experiences with having a stillborn baby than the mothers. Mothers said that it was because the fathers are not carrying the baby and do not feel the baby growing and moving. Mothers also knew that they had a unique relationship with their infant while they were in the womb. Some mothers knew that the infant would recognise the mother's voice and smell if they had been born alive (Grady 2012). Some mothers even felt that their loss was greater than the father's loss because their attachment formed to the unborn (Goggin 2011). Mothers also felt that the loss did not become a reality for the dads until at the time of the birth or neonatal death when the

body was present. On the other hand, some mothers did not think that the death was real until they saw the body (Goggin 2011). (Grady 2012; Meaney et al 2016.)

> "…Even my husband, he doesn't really understand what it's like to carry the pregnancy around…the physical stress of knowing that my body was responsible for carrying, nurturing these two children, one who was to die, a huge responsibility... he said that he knew that this was horrible and he knew I was going through hell and he couldn't figure out how to access it, what to do, how to access me, how to help me, and that he felt very helpless because he just couldn't figure out what to do. Coming through this thing... we all do the best we can... I've never felt angry with him [husband] for not understanding. He did his very best, and he was a real support. I carried Jason and I know that when I drank chocolate milk, he moved a lot. I knew where his head was, right here, and I could tell [husband] those things but it's not the same. I think that's true, it doesn't become real until the baby is born... they can't feel the baby move, and so forth. "(Grady 2012:90-91)

Going through the loss of a multiple infant can be different for the mother and the father. It can also spark blame and guilt between the parents. Some mothers said that their husbands blamed them for the death of multiple (Swanson et al 2009; Swanson et al 2002). *"My husband blamed me for not having a scan that the doctor did not order" (Swanson 2009:398).* Many mothers also blamed themselves and were feeling guilty because they were the ones to carry the child (Swanson et al 2002; Grady 2012). Almost every parent was looking for someone to blame in this difficult situation.

When the parents are handling their bereavement in different ways, it brings challenges into their relationship. It can bring up anger and resentment. Parents are going through a unique situation and need the other one's support and understanding. Some mothers felt that even though the father was not able to fully understand, he was still providing support, which was hugely important for the mother (Grady 2012; Goggin 2011). Anger towards the other parent can be caused by not participating to the funeral, going to see the survivor in the NICU or not being supportive (Goggin 2011). Some parents felt that difficulties in their relationship, which were brought up by the loss of a multiple, caused a lifelong battle because the grief does not end (Meaney et al 2016).

> "Because [Husband] was my rock during the pregnancy he firmly believed everything was going to be ok but then afterwards his world fell apart. So I felt that how we dealt with it, with each other the hardest part. Because you never go through, we've never been through anything this significant together." (Meaney et al 2016:3)

> "…it hasn't been easy because it shows up the biggest differences between us… and you know he definitely felt that his loss was as awful as my loss over the twin whereas I felt it was definitely worse for me, awful as if was for him, you know I had to have the operations, I had to give birth do it all, so it had to be worse for me but he never recognised that… and still doesn't really recognise that… I ended up saying to him 'But lovely you know, it's alright I know how awful it's been for you but it's been terrible and blah blah blah' and I never felt that he really turned around

> and did that for me. It kind of, so you know it has been a problem but it's a problem that we have talked about and are aware of it and I wouldn't say it's gone away." (Goggin 2011:119-120)

Parents also noticed differences in their ways of thinking about the likelihood of multiples' survival. Some parents had different beliefs of what would happen. Often one parent believed in the survival and the other one did not. The parent who was sure of the survival would also be supportive and positive towards the other parent. In these circumstances, when the parents were faced with the death of a multiple, the parent who believed in the survival often took the loss more intensively. (Meaney et al 2016.)

> "I think that was the big thing, big difference between myself and [Husband]... That I was preparing all the time for one good and one disabled baby of some sort. He wasn't. [Husband] was never preparing for that second child. To him that child was always, was never going to survive. Like he's real matter of fact. Once we were told really that it wouldn't, he put that out of his head. Whereas I always had the kind of. Whereas I always thought it would. Well, I always, I always thought it was a possibility." (Meaney et al 2016:3)

Some parents felt that going through the stressful experience of losing a child together, made their relationship stronger than before (Goggin 2011).

> "We definitely became much, much closer because of it, we were so lucky because we, we were warned in advance you know this is very stressful on couples, couples can break up. I think our relationship was quite strong in the beginning so I think that having this happen, you know was very helpful that we were solid already and that stressful situation didn't break us up." (Goggin 2011:153)
>
> "I think in some ways it has made us stronger cos I think…that's a positive part of it is that you know we went through… a really difficult time and we got through it… so I think, you know, I think that's a strength if you like." (Goggin 2011:153)

6 Discussion

The purpose of this literature review was to describe parents' experiences of losing an infant of multiple birth during perinatal or neonatal period. The aim was to develop the expertise of health care professionals working with bereaved multiple birth parents, especially those who work in perinatal and neonatal units. The research question for this literature review was: What are the experiences of parents following the loss of a multiple during perinatal or neonatal period? The parent's experiences studied in the research articles described in the Findings section are discussed.

6.1 Phenomenon of losing a multiple infant

When looking into previous literature on this subject, similar themes were found as in this literature review. Previous literature suggested that when losing an infant of multiple birth, parents are losing some additional things such as losing the multiple birth parent status (Bryan 1999: 187). This theme also arises in this literature review. Parents felt as if a part of them was lost when the infant died. They were grieving the fact that they were no longer getting to raise twins or higher order multiples.

In previous literature, the grief of losing a multiple infant was described as complex and deep (Bryan 2002). Bereavement of losing a multiple infant was found to be multifaceted and sometimes indescribable, as well as in this literature review. Parents felt as if no one could understand their loss, except for those who had experienced the same loss.

It was also found in previous literature that other people might not understand the phenomenon of losing a multiple infant (Bryan 1999: 187). This theme was strong in this literature review and it was found that because of it, other people might come across hurtful towards the parents. Other people would say insensitive things as “at least you have one”, implying that they should be happy about their survivor and forget the deceased. The findings suggest that some thoughtless words can have a big impact on the parents. Especially the saying “at least you have one” was seen very hurtful. Thoughtless words can have a negative impact on the relationship between the health care staff and parents. Nurses need to be patient-sensitive when talking about multiples since the misuse of words can bring additional sorrow for parents.

As in previous literature on the topic, this literature review found that parents could see their dead infant when looking at their surviving co-multiple. Unlike Bryan (1999) had studied, there was no evidence of mothers blaming their survivor for their co-multiple’s death. However, they were reminded of their deceased infant, especially around birthdays and other milestones, like starting school.

Pictures of all the multiples together brought up memories of those treasured moments around the death of their infant, helping parents with the grieving process. Some felt that the survivor would also benefit from seeing pictures of all of them together as infants. However, some parents didn’t even dare to look at the pictures, because it was too painful. This literature review supported the statement from previous literature (Bryan 1999;

Kivikko et al. 2011) that mothers may lose the attachment or relationship with the survivor, or have difficulties or refuse bonding with the survivor.

Time dedicated to the dying infant was important to the parents and it was suggested that staff should encourage the parents to spend time with the dying multiple, even more than with the surviving multiple (Kivikko et al. 2011). As in previous literature on the topic, this literature review found also that parents were grateful for the time spent with the deceased one or ones and those memories were treasured. It is clear that the staff should encourage them to do so but in a way that does not put pressure on the parents.

Parents felt acknowledged when they were treated as multiple birth parents even when there was only one survivor. As it was suggested by Bryan (1999) health care staff should refer to the parents as multiple birth parents, and use the right terms when talking about the multiples. Health care staff who would talk about their multiples with the right terms were seen as more compassionate and better at their job than the ones who would misuse the terms. Parents would also feel the need to tell people that their survivor was a part of a multiple set, not a singleton.

As it has come across in previous literature, the parents would put their grief on hold, and concentrate on the survivor(s) (Bryan 2002). Findings of this literature review supported this. The parents would not be able to grieve over their lost infant at the time of death, because they were preoccupied with the care of their other infants who may or may not survive. Some parents even felt pressured to hide their grief or grieve in a certain way.

It was found in previous research, that it may be hard for parents to come in contact with complete sets of multiples (Pector & Smith-Levitin 2002). Some parents would feel anger towards parents who got to keep all their babies. They were asking themselves “why couldn’t I have both of mine?” (Grady 2012: 83). As Pector and Smith-Levitin (2002) suggested, health care staff should not keep complete sets of multiples next to bereaved multiple birth parents.

As future nurses, we hope to be supportive and sensitive health care professionals if we ever come in contact with bereaved multiple birth parents. We hope that the knowledge gained from this literature review is beneficial for us in our professional careers, as well as in our personal lives.

6.2 Implication for clinical practice and suggestions for further research

There is evidently a good foundation of researches conducted of this topic, but not necessarily regarding concrete nursing practices. More research on the phenomenon of losing one infant of multiple birth is a necessity for understanding the unique aspects of it and to help health care professionals working with these bereaved multiple birth families.

This subject is very sensitive and concerns a small population of people, especially in Finland. Therefore, it is understandable that conducting a research studying this subject in Finland can be a challenge. It could be more worthwhile for health care professionals to take a look into the parents' experiences of losing a multiple infant and to reflect on it. How are these situations handled in Finland? How is it perceived in health care? How are these parents taken into account and differentiated from singleton parents?

Since these articles were not written in Finland it is not clear what the state of practice with bereaved multiple birth families is in Finland. Kivikko, Kokko & Kumpula (2011) have written a guideline for professionals on how to support families who have lost a multiple infant. This guideline summarizes quite well the phenomenon of losing a multiple infant.

7 Ethical considerations and validity, limitations

7.1 Ethical considerations

This literature review has been completed working ethically throughout the whole process. The articles that were chosen are not inflicted with bias, but they have been chosen using a critical appraisal tool. Objectivity and a neutral attitude towards the articles has been a challenge but the intent was to report the results of the articles correctly and completely without any kind of deceit. In a literature review, it is important to give credit to the research articles and make sure they are referred to appropriately (Tuomi & Sarajärvi, 2009: 132-133.) Written products are completed according to Metropolia's guidelines.

7.2 Validity, strengths and limitations

Validity of the research articles was assessed using Aveyard's (2010: 91) tool to critically assess references. The headings of the articles of our initial data search were read through and irrelevant articles were discarded. The inclusion and exclusion criteria (see Figure 4) were implemented and the abstracts of the remaining articles were read. Other irrelevant articles were discarded according to the abstract and final articles were found, read through carefully and assessed critically to determine their usefulness. Then the references' priority towards the research question was assessed. All of the chosen articles (n=10) are of top priority, since they answered the research question: What are the experiences of parents after losing an infant of multiple birth during perinatal or neonatal period?

The articles were assessed as good quality. The authors are published researchers and experts in their fields, or they are studying the field (doctoral theses). The research articles included description of used methods and the limitations of their studies. The chosen articles and publications were published within the last 20 years in reliable medical and nursing journals. As noted earlier, all of the chosen articles are relevant to this literature review.

There are lots of critical appraisal tools available and a tool recommended by Aveyard (2010: 91) which can be used to assess all types of references was used. This tool consists of a set of questions which can be found in Figure 5. (Woolliams, Williams, Butcher & Pye 2009 cited in Aveyard 2010: 97.)

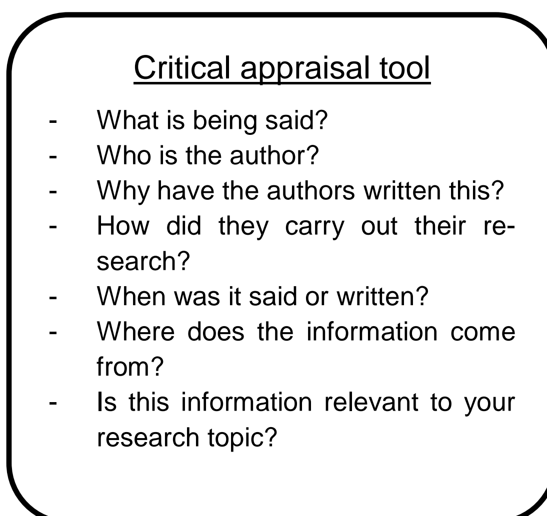


Figure 5: Critical appraisal tool by Woolliams et al 2009.

There are a number of strengths in this literature review. Well detailed plan and guidelines of executing a literature review were followed quite rigorously. No risks were taken in order to not compromise the validity and quality of this literature review.

The data searches covered every possible, accessible database, so it is likely every top priority article was found. On top of this database search, the final collection of articles included research articles found from reference lists, maximizing the bibliography. All in all, the final data collection was comprehensive.

However comprehensive the data search was, there is a possibility of bias in this research. The search terms include a negative emotion: grief. Although it is likely that this is the main feeling after losing one or more of the multiples, there is a possibility that positive emotions are not presented in full extent. The reason these search terms were used was based on previous literature and the themes arising from the initial data searches.

Another limitation that has to be brought forth is the lack of experience and prior knowledge of conducting a research and completing a literature review. A lot of effort has been put in to write a good quality literature review in the time span allocated to complete this thesis. Awareness of personal prejudices, opinions, experiences and previous knowledge of this subject has to be taken into consideration, since they might have affected the research. The intent was to stay as objective as possible.

Other strengths of this literature review include staying true to the data. Staying true to the data was achieved by reading and re-reading the articles, both together and separately. Continuous conversations and consulting each other ensured that both were on the same page. Revisiting the articles throughout the analysis process was essential to prevent incorrect or incomplete reporting of the findings.

8 Conclusion

Losing an infant of multiple birth is a life-changing experience. Parents had mixed emotions; they were happy for their survivor(s) and simultaneously grieved the death of the other multiple(s). Losing one of the multiples caused fear, anxiety and worry over the

rest of the multiples, and difficulties in bonding with the survivor(s). However, the survivor(s) could also be a source of comfort and strength. Parents were also grieving the loss of the special status of being a multiple birth parent. Parents faced the grief of losing their multiple through different circumstances: the funeral, going back to the NICU to see the survivor(s), interacting with health care professionals who are unaware of their situation, seeing other twins or higher order multiples, looking at their photos and other mementoes. Parents were reminded of their lost multiple by seeing their survivor, especially in the case of identical multiples, birthdays and even by the comments of other people.

Parents felt like other people could not understand their loss and other people often came across as insensitive. There were insensitive comments towards the parents from friends and relatives and even from health care professionals. Relationships between parents, as well as friends and other family members may have altered after the loss. Parents listed emotions they experience surrounding the subject of losing an infant of multiple birth: sorrow, grief, despair, irritability, anger and guilt. They felt isolated and that they were expected to grieve in a certain way, or hide or delay their sadness. They were left asking questions and looking for reasons. After some time had passed, parents may have talked about acceptance, personal change and growth from the experience.

We hope this literature review will give insight of multiple birth parents and loss to other nursing and midwife students. With the knowledge gained from this literature review, we hope health care professionals who encounter bereaved multiple birth parents could provide compassionate and patient-sensitive care for them.

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Database search

Table 3. Database search

Database	Key Words	Hits	Limitations	Articles retrieved	Articles chosen
CINAHL	"multiple birth" AND death OR loss OR bereavement OR grief	48	Research article Peer reviewed	31	2
CINAHL	"multiple birth" OR twin* OR triplet* AND death OR loss OR bereavement OR grief or stillbirth* AND parent*	90	Research article Peer reviewed	34	3(4)
					= 3 articles
MEDLINE	"multiple birth" AND death OR loss OR bereavement OR grief	4	-	-	-
PUBMED	"multiple birth" AND death OR loss OR bereavement OR grief or stillbirth* AND parent*	46	-	-	4
PUBMED	"multiple birth" OR twin* OR triplet* AND death OR loss OR bereavement OR grief or stillbirth* AND parent*	423	-	-	7
					= 7 articles

After removing identical articles: TOTAL of 8 articles + 2 from hand search = 10

Article analysis

Table 4. Article analysis

Title, Author and Publication place	Purpose	Country	Sample	Data collection and analysis	Main findings
Aagaard, H., Storm, I. & Klitgaard, J. (2016) Losing one twin in the NICU - A case study of the parental experience. Journal of Neonatal Nursing 22, 153-158.	Study the parents' experience of losing a prematurely born twin and to understand more on how parents can be supported by the nursing staff.	Denmark	2 participants: First time parents of premature twins born before 26 weeks of gestational age.	A qualitative case study, in-depth interview after discharge from the hospital in May 2014. Thematic content analysis	Three major themes; difficulties understanding the verbal and cultural discourse within the NICU, relation between nursing staff and parents, the struggle to become an active parent OBS! Only two participants, not generalizable
Goggin, M. (2011) The lived experience of parents following the death of a twin in perinatal/neonatal period. Doctoral thesis	Study the parents' experiences of losing a twin to gain understanding on the phenomenon. By means of identifying what influences their experiences, what made it worse and what helped, parents' advices for medical professionals and what follow up care parents need.	England	7 participants: 6 mothers and one father. Death of the twin happened from 6 months up to 6 years ago.	Two semi-structured interviews.	Experience was found to painful and lasting. Bereavement stayed in the parents' minds and part of their lives for a long time even against their desire. Parents' felt that support was not available since almost nobody could understand their loss which made them feel isolated. Losing a twin has made some these parents' different persons and they found hidden strength in themselves. Professional support was mostly needed and wanted by parents.
Grady, K.L. (2012) Parenting a Lone Twin: When One Twin Dies. Doctoral Dissertation	Explore the parents' experience of raising only one twin. By means of identifying how grief affected the daily activities, how the parents got by simultaneously grieving other twin	England	9 participants: 7 mothers and 1 parents (mother and father) of surviving twin. Death of the twin happened 4-24 years ago.	Interviews in-person, via phone or via email. The mother and father pair was interviewed together.	Parents felt that their experience of losing a twin has made them different but mostly better persons. Many parents never thought that they child could die but after their experience are more aware that it could happen again.

	and attaching to the surviving twin and how this affected the parents.				Parents found different ways to honour both twins and it was said to lifelong journey to grief. Every milestone of the surviving infant brought back memories. Parents felt that talking about their lost twin was a taboo. OBS! Long time (4-24 years) time since the death of a child added depth to the experiences.
Meaney, S., Corcoran, P. & O'Donoghue, K. (2016) Death of One Twin during the Perinatal Period: An Interpretative Phenomenological Analysis. Journal of Palliative Medicine October 2016, ahead of print.	Explore the parents' experiences in case of death of one twin in the perinatal period.	Ireland	9 participants: 1 mother and 4 couples (mother and father). All parents of twins. All Irish	In-person interviews. All but one couple were interviewed alone.	Losing one twin made parents feel conflicting emotions such as simultaneous sorrow and joy. Overall it was agonising and extremely difficult for the parents. Some parents were outraged, in cases where one twin had good change and one was terminally ill, that terminating one fetus was not possible for them in Ireland
Netzer, D. & Arad, I. (1999) Premature singleton versus a twin or triplet infant death: parental adjustment studied through a personal interview. Twin Research 2(4), 258-263.	Explore the parent's adjustment phase after losing an infant of multiple birth, one of twins or triplets, and to compare it to those who lost infant of singleton birth.	Israel	36 participants: 18 parents (mother and father) of which 9 parents of singletons and 9 of multiples of which 4 parents of twins with one survivor, 3 triplet parents of one survivor, and 2 triplet parents of two survivors. These infants were born during 1990-1993.	Parents were interviewed via mail or phone 1-4 years after the loss of an infant. Duration of interview was 1,5–3 hours.	Not any big differences between multiple birth and singleton birth parents. Both had similar coping mechanisms. Parents had hard time getting empathy and felt that only people with similar experiences could understand.

Pector, E.A. (2004a) How bereaved multiple birth parents cope with hospitalization, homecoming, disposition for deceased and attachment to survivor. Journal of Perinatology 24, 714-722.	Uncover the parents', who lost an infant of multiple birth, experiences on support, disposition decisions, how they attached to the surviving multiple(s), discharge from the NICU and coping afterwards.	North American	140 participants: 70 parents (mother and father). These infants were born between late 1980's to 2001.	Narrative email survey with quantitative and qualitative analysis.	Half of the parents had difficulties in forming an attachment to the surviving infant. Parents had negative experiences with health care professional, for example wrong use of words such as twins and not acknowledging the deceased infant. 1 out of 3 parents had difficulties in coping, they felt that they needed more support than what they got. Returning to back to work to NICU was extremely hard for the parents and it was said to bring up bad memories.
Pector, E.A. (2004b) Views of bereaved multiple birth parents on life support decisions, the dying process and discussions surrounding death. Journal of Perinatology 24, 4-10.	Explore the parents', who lost an infant of multiple birth, experiences with resuscitation, life-support discussions, death process and talking about death with health-care professionals	North American	71 participants: 67 mothers and 4 fathers. These infants were born between late 1980's to 2001.	Narrative email survey	Most parents felt that decision making about end of life care was done very well with the parents. They were informed and respected. Parents wo did not obtain any memories (pictures) of the deceased, said it to be their biggest regret. 23 out of 27 parents said that death news should not be given via the phone and only face to face.
Richards, J., Graham, R., Embleton, N. D., Campbell, C. & Rankin, J. (2015) Mothers' perspectives on the perinatal loss of a co-twin: a qualitative study. Pregnancy and Childbirth 15 (143).	Explore the mothers' experience of losing a twin and to gain deeper understanding of the phenomenon.	England	14 mothers of twins	A qualitative study involving semi-structured interviews.	Medical staff who acknowledged their twins were appreciated. On the contrary when medical staff made mistakes, mothers remembered it. After the loss, mothers felt that for the most part the medical staff acknowledged their lost and were sensitive towards mothers' feelings. After the loss mothers reported feeling conflicting feelings, feeling joy

					but simultaneously feeling sorrow. Some talked about being traumatized. Mothers said that they focused fully on the surviving infant the therefore putting their grief on hold which eventually even years after their grief was let out stronger. Many said that focusing on the surviving infant helped them to be strong. Nurses who did not provide any emotions were seen just there to do their job and less trusted to taking care of their surviving infant.
Swanson, P., Pearsall-Jones, J. & Hay, D. (2002) How mothers cope with the death of a twin of higher multiple. Twin Research 5(3), 156-164.	Study the nature of bereavement of mothers of multiples, how mothers experience and cope with the death of a twin or higher order multiple to gain understanding how the support of these parents could be improved.	Australia (New Zealand)	66 mothers of multiples who lost one or more of their twins, triplets or quadruplets, comparison to 138 singleton mothers who lost their infant	Retrospective and current Beck Depression Inventory II (BDI-II), retrospective Perinatal Grief Score (PGS) short version Interview in storytelling form with additional stimulus questions Focus groups after collecting and analysing data	Mothers reported high levels of anxiety and grief when multiples died in utero in the second and third trimester as well as those who took part in the decision to turn off life support of their new born Grief lessens over time Early bonding was difficult and some resisted it Disenfranchised grief (67%) Lives were transformed with the experience, positive changes What was most and least helpful and recommendations for others who have lost a multiple
Swanson, P., Kane, R., Pearsall-Jones, J., Swanson, C. & Croft, M. (2009) How couples cope with the death of a twin or higher order multiple.	Compare the differences between mothers' and fathers' emotions and expression of grief and coping with losing an infant of multiple birth	Australia	104 participants: 52 parents (mother and father) who had experienced the death of at least one member of a multiple birth (twin or higher order	Retrospective and current Beck Depression Inventory II (BDI-II) and retrospective Perinatal Grief Scale (PGS) short version	Current BDI-II scores lower for both parents than retrospective scores, though mothers scored higher than fathers in both All PGS subscales were higher for mothers than fathers

Twin Research and Human Genetics 12(4), 392-402.			multiple) with at least one survivor of that birth (births between 1999 and 2004)	Separate, unstructured interviews in storytelling form with some structured queries Strength of spiritual beliefs Format to assess current and retrospective abilities Focus group after collecting and analysing the data	Helpful and hurtful themes for both parents and mother and fathers separately Mothers expressed that their lives changed substantially, fathers not that much unless mother's grief was unending

Categorization

Sub category	Generic category	Main category
Simultaneous joy and sorrow	Mixed emotions	Parents' experiences surrounding the death of a multiple infant
Being happy but missing something		
Feeling that grief was not allowed		
Looking for reasons and unanswered questions		
Losing status as multiple birth parents	Multiple losses	
Strong emotions when in contact with multiples		
Surviving multiple losing the special relationship with their co-multiple		
Fear for the survivor	Having a survivor	
Comfort from the survivor		
Strength from the survivor		
Being present at death	Death as experienced	
Death was a horrible experience		
Acceptance		
Withdrawing care		
Need to talk about death		
Memories		
Acknowledging multiple birth status	How health care staff was perceived	Parents' interactions with other people
Hospital's baby not mine		
Supportive staff members		
Insensitive staff members		
Positive interactions with other people	Interactions with other people	
Negative interactions with other people		
Relationship between parents		