

Perinatal palliative care after a stillbirth – Midwives' experiences of using Cubitus baby a tool to keep the dead body cold

Abstract

Background: Approximately 450 babies are stillborn every year in Sweden. Usually, the parents stay at the hospital two or three days after the birth and have the baby in their room. Due to the importance of keeping a dead body cold, the routine followed until recently has been to separate the baby from the parents in the evening and place the baby in a refrigerator during the night. With the goal to improve the dignity for the baby and the family a tool was developed. Cubitus baby, a special designed cot with cooling blocks, was implemented at all 47 delivery wards in Sweden during 2013-2014. The aim of the study was to investigate the midwives experiences of using the tool when supporting parents after the stillbirth.

Methods: In total 154 midwives answered a questionnaire. Responses to a single open question about their experience using Cubitus baby were analyzed by using content analysis. **Results:** Four categories with two subgroups in every category were identified: *A feeling of dignity* with subgroups: A good feeling in working with grief; Design and function; *Caring cooling* with subgroups: The cooling function; A cold baby; *Time for fairwell* with subgroups: Time together; Time to oneself decide; *A satisfying feeling for the parents* with subgroups: Parents and Cubitus baby; A possibility for bonding. **Conclusion:** Not needing to separate parents and baby unnecessarily is to be viewed as a meaningful benefit resulting from use of Cubitus baby. The midwives found that this practice provided a more dignified and worthwhile form of care as they no longer had to move the dead baby to a refrigerator. **Clinical implication:** There is no need to separate the baby from the parents during their stay at the hospital. In modern perinatal palliative care it is not justifiable to place a dead baby in a refrigerator.

BACKGROUND

In Swedish maternity wards it has been standard practice until recently to place the dead baby in a refrigerator, in a cold-storage room, or to transport the body to a cold room during the night and even part of the day when the parents are in the hospital. If the parents wanted to be with the baby a staff member brought the baby to the parents and then later returned the baby to the refrigerator or storage location, something that could happen several times during the day.

Cubitus Baby, a helpful device that keeps the dead baby at the right low temperature, is now in use at delivery wards in Sweden so that parents and baby no longer need to be separated from each other unnecessarily. In this study we wanted to investigate the midwives' experience with using this device as part of a new care routine.

Researchers in the USA (Wool et al. 2016) report that perinatal palliative care is well suited as an approach to providing care for parents who have learned that their baby has died in the uterus. Perinatal palliative care refers to the care that health-care providers can provide in helping the pregnant woman and father in making the transition to parenthood. Even if some parents cannot return home

with a living baby, they have experienced becoming parents (Munson & Leuthner, 2007). Perinatal palliative care can be given before the start of delivery, during the delivery, and even after the birth. If the child is stillborn it is the parents who need palliative care according to Sumner and Kavanaugh (2006).

Van Hoover and Holt (2016) state that midwives are well suited to provide palliative care. Working with women giving birth has some similarities with working with dying patients; both stages are a natural part of life. O'Connell, Meaney and O'Donoghue (2016) found that the parents whose child was stillborn and had been given care by a midwife with previous substantial experience with the stillborn were satisfied with the care they had been given. Parents appreciated it when the midwife talked directly to them and treated the baby with the same sensitivity, dignity and respect given to a living baby; this helped the parents to draw closer to their own baby (Peters et al., 2015). It can be challenging to create calm and secure atmosphere around the parents and their child right in the middle of the care that otherwise is being carried out at a maternity unit where babies' cries and sounds from women giving birth are a part of daily life (O'Connell, Meaney & O'Donoghue, 2016).

In Sweden in 2015, 427 children were born dead after 22 completed weeks of gestation, corresponding to 3.7 stillbirths per 1,000 births. The majority (2/3) of these deaths occurred in late pregnancy. About 90 % of all intrauterine deaths in Sweden occur before labour starts. With the goal to improve the dignity for the baby and the family a tool was developed and implemented at all 47 delivery wards in Sweden during 2013-2014. *Cubitus baby*, a specially designed cot with cooling blocks looks like a baby bed with high sides and it has a cover that that can be completely closed or be left partially open at the head of the bed. The bedding is white padded cloth. The bed in this device is made with sheet and blanket; concealed under a white inner protective layer are pockets for the coolant blocks that can be changed as needed. The coolant blocks may also be placed on the cover.

When *Cubitus baby* was delivered (as a non-profit project) to the maternity wards it was accompanied by a folder with instructions on how this helpful device was to be used. In the folder there was a questionnaire that the midwives were encouraged to complete after they had used the device. Depending on the size of the maternity ward there were between five and ten questionnaires in the folder along with a postage-paid reply envelope.

AIM

The aim of the study was to investigate the midwives' experiences of using the device Cubitus baby when supporting parents after the stillbirth.

METHOD

Study design

Questionnaires to all midwives at all maternity wards in Sweden, the questionnaire was completed after the midwives had used Cubitus baby while caring for parents whose child was stillborn. The questionnaire simply asked the participants to report what they had experienced with this sentence as a guide: "Here you can describe your own impressions of how Cubitus baby functioned and you believe the parents experienced having access to this aid." In addition to this open question the midwife could indicate the length of time Cubitus baby was used for each baby during the period in which care was given. All the completed questionnaires that had come in to the research group by 1 January 2017 constitute the basis for this study

Data processing

The analysis was begun by reading several times each of the texts that the midwives had written about their experiences using Cubitus baby in caring for the parents. Then meaning-bearing units in the text were marked. A total of 261 meaning-bearing units were identified that were sorted into categories and then entered into Excel. After that, the meaning-bearing units were condensed, text in each category was gone through again, and the texts were sorted into subcategories. These categories constitute the headings in the presentation of the results (Malterud, 2012).

RESULTS

A total of 154 completed questionnaires were returned to the research group; midwives at seven of 47 (15 %) of the maternity clinics did not return any questionnaires. The shortest time that Cubitus baby had been used at a hospital was three hours (n=3) and the longest time was 11 days (n=1) when a family took their baby home with them in Cubitus baby. An additional two families chose to take their babies home for 48 and 21 hours respectively. One family used Cubitus baby for nine days while they remained in the hospital. Most often the device was used in the hospital for between one and three days, one day (n=36), two days (n=50), three days (n=29). The device was most often placed in the parents' bed. In a few cases Cubitus baby was placed in another room that the parents could visit when they wanted to.

The open question was left unanswered in 44 questionnaires and four questionnaires with answers were excluded since the answers did not bear upon the aims of the study. The analysis resulted in four categories with two subgroups in every category: *Feelings of dignity* with subgroups, Satisfactory feelings in working with grief, and Design and function; *Caring cooling* with subgroups The cooling function and A cold baby; *Time for farewell* with subgroups Time together and Time to make your own choice; *Satisfying feelings for the parents* with subgroups The parents and Cubitus baby and A possibility for bonding. The number in parentheses after each quotation indicates the questionnaire from which the quotation was taken.

Feelings of dignity

Satisfactory feelings in working with grief

Having something to help them when they are working with parents filled with sorrow due to the death of the baby was what midwives had been looking for. They wrote that Cubitus baby is fantastic, a resource and something that it feels good to be able to use. Some of them expressed their thanks stating that Cubitus baby had contributed to a good experience with this type of care. Dignity was a word that was used often, the midwife felt that it was dignified that the child could lie in Cubitus baby and that it was dignified for the parents to be able to see the child in that environment.

A significantly much greater feeling of dignity in these situations. (2)

An incredibly fine and good aid in a difficult situation. (128)

Design and function

The midwives described Cubitus baby as soft, beautiful, tranquil, respectful, and inviting and that the design was smooth and neutral. The device felt nice to use and to show to the parents. The midwives described how they arranged the bedding and tried to make it cozy around the baby with blankets and the sheet. Depending on how large the child was they tried to adapt the bedding so that the bassinet was appropriate even for a very small child. The midwives expressed positive views about the simple cooling function.

Looks very cozy around the child! (116)

Caring cooling

The cooling function

The midwives reported that Cubitus baby maintained the cooling well and that the cooling blocks remained cold for a long time. Some reported that they

changed every 18 hours and others every 12 hours. The cooling function performed well even during warm summer days when it was extra warm in the room. The midwives reported that the children had remained in good condition during the time they were in the care of parents and midwife and that thanks to Cubitus baby they remained in good condition longer than in the past when the baby was moved back and forth between the refrigerator and the parents' room. One of the midwives reported that the big sister of a stillborn sibling had helped her change the cooling blocks. They viewed changing the freezer packs as a part of care giving when they could express caring for the baby.

The baby maintained a low temperature even though it was midsummer. The freezer packs maintained the low temperature for a long time. (17)

Easy to change the freezer packs, but you do not need to make much of this, big sister helped with this. (69)

A cold child

The need to keep the stillborn baby cold had been previously experienced by the midwives as something stressful. They had to take the child from the parents and put the baby in the refrigerator or cold room. Several midwives said that it was nice not to have to move the child and disturb the parents and also that the baby could remain lying in Cubitus baby while the parents arranged the blankets and teddy bears. Some of the midwives stated that the parents kept their distance from the cold baby and found it difficult to take the child when the baby felt so cold. The midwives said that they had explained in advance for the parents that the child had to be kept cold and that it therefore would not be so difficult for the parents when they held their baby.

Didn't need to worry about having to put the child in a refrigerator (which otherwise can be a stress factor). (84)

Time for farewell

Time together

The midwives noted that it felt completely natural that the baby got to be with its parents during the entire time when a new born living child would be with its parents, without interruptions caused by taking the child to the cold room. Relatives came by to visit and the dead baby was there in a natural way the whole time. Some parents chose to take their baby home, and the midwife wrote that without Cubitus baby this would not have been possible. One couple put Cubitus baby in a baby carriage and took a walk with their child. The midwives said that the parents were grateful for the time they got to be with the baby

and that they themselves could decide when it was time to take that final farewell.

Cubitus baby was a pre-requisite for the parents to have the baby at home right up to the funeral. (12)

The felt that it was a positive experience for them, personally, to have the time needed to say farewell. (20)

They had Cubitus baby in their own bed and could therefore have the child there even when they were resting/sleeping. (36)

Time for them personally to decide

The midwives felt it was good that thanks to the aid the parents got the chance to bond (draw close) to their stillborn baby in a way they personally chose. The midwives reported that there were parents who wanted to see their baby for a while and then wanted the child in Cubitus baby to be placed in another room. Some parents wanted to have their baby with them during the day and then let the child be with health-care staff during the night.

Cubitus was placed in a separate room, the patients did not want to have the baby in with them. But they did go in several times to their baby. (91)

In some cases the parents had gone home and had then come back to the hospital to look at the baby during the time the child had remained in Cubitus baby at the hospital. The parents said that it was comforting to know that the baby was still there while they go return home for a while. Several midwives noted that it was possible for the parents themselves to decide how close they wanted to be to their child. Some couples had said that they did not want to touch the baby but still wanted to have the child close by so that it could lie in Cubitus baby in the room during the entire time care was being offered. Some others wanted to see the baby but not be too close. The midwives said that they felt it was good that the child could still be there even when the parents did not want the baby to be in the room where they were staying.

The parents liked Cubitus Baby. They wanted the baby to lie there untouched. (99)

A nice feeling for the parents

The parents and Cubitus baby

A number of midwives observed that the parents appreciated Cubitus baby even in the midst of their sorrow. Parents had said to the midwives that the bassinet looked nice when the baby lay there bedded down. The midwives described Cubitus baby as a resource for the parents and that it had contributed to a good experience for them. Even family members had positive thoughts about this aid.

They thought it felt nice with Cubitus baby. (41)

The parents were very much satisfied with Cubitus baby. (63)

A possibility for bonding

Some of the midwives noted that they experienced Cubitus baby as helping the parents to become connected to the baby (bonding). The bassinet made it possible for them to be close to their child and to create a natural parent-child situation. The parents picked the baby up out of the bed themselves, put their own blankets and teddy bears in the bed, and took pictures of the child lying in Cubitus baby.

DISCUSSION

Not needing to unnecessarily separate parents from baby was seen as a meaningful benefit with Cubitus baby. The midwives felt that they were able to provide a more dignified kind of care when they no longer needed to place the child in a refrigerator.

We found that the midwives were satisfied with not needing to separate parents from their baby. Cubitus baby could keep the dead body cold. Previously the midwives would feel stressed by having to take the baby from the parents and go with the child to the cold room or put the child in a refrigerator. In the study by Fenwick et al. (2007) the midwives reported that it was important for them to be able experience feelings of satisfaction in the care of stillborns when the opposite response left them feeling stressed and frustrated. The midwives in the present study reported that that Cubitus baby contributed to providing the parents with a nice experience in the midst of their sorrow. Fenwick et al. (2007) found in their study that midwives were satisfied with their work when they could give the parents a good feeling in spite of the sorrowful situation (Fenwick et al., 2007). As a result of this new way to work, the midwives in the present study felt that a family who had lost a child could

come closer to their child at the rate that they wanted and that they got the time they needed to say goodbye to the child. In a study of perinatal palliative care the midwives reported that it was very nice to take care of parents and their stillborns (Fenwick, Jennings, Downie, Butt & Okanaga, 2007). This gave them a feeling of satisfaction in being able to take care of these families and a chance to use their experience to be able to support the parents and make the difficult moment less traumatic. The midwives created possibilities for the parents to be present and care for their child (Fenwick et al., 2007). A study by Rådestad et al. (1996b) found that mothers who got to be with their stillborn baby as long as they wished after the birth experienced less anxiety three to four years after the event. O'Connell, Meaney och O'Donoghue (2016) found in their study that the women found it very meaningful to have time with their stillborn children and have a moment to create a memory. The family should be able to get help in creating a quiet atmosphere in which they can say goodbye in peace (Rådestad et al., 1996b).

In our study the midwives said that they were able to provide more dignified care when they no longer need to place the dead baby in a refrigerator. Munson och Leuthner (2007) note that one of the most important goals of perinatal palliative care is to enable the parents to feel like parents of the new born baby even if the baby is stillborn. Perinatal palliative care is a concept that has not yet taken hold in Sweden. Midwives with their special knowledge are the ones who are best suited to take primary responsibility for the perinatal palliative care that should be a matter of course in every maternity ward (Peacock, Price & Nurse, 2015). Peters et al. (2015) state that midwives need specific training in taking care of parents and the stillborn baby and it must also be made possible for them to be given support in facing their own feelings that may arise during this work. That midwives need additional training in perinatal palliative care is emphasized by Peacock, Price and Nurse (2015) as well as by O'Connell, Meaney och O'Donoghue (2016).

Methodological considerations

Those selected for the study were midwives who had assisted at a stillbirth and who had used Cubitus baby in caring for the parents after the stillbirth. Thus there are varied impressions expressed in connection with their having used a new means for providing care for parents who had lost their new born baby. The midwives who participated in the study may have been especially interested in this kind of care; they all had substantial experience in contrast with, for example, midwives who have just finished their training and who might find this kind of care as somewhat frightening, at least at first. This might possibly have been a factor in shaping the overwhelmingly positive attitude toward Cubitus

baby expressed in the replies. The midwives texts were rather short and the method of analysis sticking close to the text that was used in this study was felt by us to be adequate. Thus no special effort was made to identify any underlying opinions (Malterud, 2014). Because the analysis had an inductive approach we were unconditionally able to go through the texts without and predetermined theories in the background.

Conclusion

To not need to unnecessarily separate parents from child was emphasized as being a meaningful advantage of Cubitus baby. The midwives felt that this provided a more dignified form of care when they no longer had to place the dead child in a refrigerator.

Clinical applicability

In modern perinatal palliative care it is not dignified to place a dead baby in a refrigerator or to separate the parents and the baby by taking the baby to a cold room.

The analyses of data was done by midwifery student Karin Henley Listermar, supervised by PhD student Taina Sormunen at Sophiahemmet University.

Cubitus baby is developed by Ingela Rådestad





Cooling blocks ensure that the temperature is kept low, they are totally 12 and easy to change when necessary. Cubitus Baby can be used in the hospital and makes it possible for the parents to keep the baby in their room for a longer time. Cubitus baby can maintain the baby at below room temperature and it is not necessary for the parents to be separated from their child. Cubitus baby can also be used if the parents want to take their baby home before the funeral. And it can also be used as a coffin. You can buy Cubitus baby from *Fonus* in Sweden (Cubitus baby costs about 300 Euro).

<https://www.begravningsprodukter.se/main.aspx?page=articlelist&gid=105>