

Article

The Function of Ritualized Acts of Memory Making after Death in the Neonatal Intensive Care Unit

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Abstract: (1) Background: Some infants die shortly after birth, leaving both parents and nurses in grief. In the specific setting where the data were collected, the bereaved parents receive a scrapbook made by the nursing staff in the NICU, and a box made by a local parent support group. Making a scrapbook and a box when an infant dies in the NICU can be regarded as ritualized acts. The aim of this study is to explore the functions of these ritualized acts of making a scrapbook and memory box when an infant dies in the NICU. (2) Methods: Focus group interviews were performed with experienced nurses in the NICU, and with members of a parent support group. Reflexive thematic analysis was used to interpret the data. (3) Three main themes were constructed: “Making memories”, “showing evidence of the infant’s life and of the parenthood”, and “controlling chaos”. (4) Conclusions: Through the ritualized acts of making scrapbooks and boxes, nurses and members of the parent support group collect and create memories and ascribe the infant with personhood, and the parents with the status of parenthood. In addition, the ritualizing functions to construct meaning, repair loss, relieve sorrow, and offer a sense of closure for the makers of these items.

Keywords: memory making; function of ritualized acts; ritualization; neonatal intensive care unit (NICU); new-born; death; bereaved parents; nurses; parent support group; existential



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1. Introduction

When infants die shortly after birth, parents are left in shock and grief (Berry et al. 2021), and nurses can also experience sorrow (Gibson et al. 2018). Birth shares some of the experiential and existential qualities of death (Wojtkowiak and Crowther 2018). Beginning and ending of life, experienced as biologically radical, are entangled. These two transitions can illuminate each other in the sense that presence of death can be more distinct when life begins, and life more distinct when death approaches (Prinds et al. 2019).

1.1. Memory Making in the NICU

When an infant dies shortly after birth, parents leave the neonatal intensive care unit (NICU) without their child, and nursing interventions become important (Pueyo et al. 2021). In the specific Norwegian NICU where the data collection was carried out, it has over the last decades become common to make scrapbooks when an infant dies. The book is an ordinary A5 size writing book where the nurses write in second person singular (“you”) to the infant, reporting medical information about the treatment, but also sometimes including a self-made text, or a poem. Photos of the infant and its parents are usually included in the book, as well as ink foot- or handprints on a cartoon, hair, and EKG electrodes. In addition to this, foot- and handprints are made with plaster, and given to the parents when they

leave the NICU. Comparable practices are also known from other studies. Memories are made through photos taken by parents or staff, or through the creation or collection of mementos in a memory box containing objects of significance (Pueyo et al. 2021; Thornton et al. 2019). The making of footprints with ink, foam or alginate plaster is another way to create remembrances (Levick et al. 2017). Physical and tactile items such as blankets, clothes or a clay footprint, which were directly connected to the infant can also hold special significance (Thornton et al. 2020). It is known from other studies that parent support groups sometimes provide bereaved parents with a support package when an infant dies (Aho et al. 2014). This is also true for our context. A local parent support group for bereaved parents provide the hospital with a support package which takes the form of a box filled with brochures of information together with various items. The box has space also for objects which belonged to the infant if the parents wish to keep these. In agreement with the hospital, the box is handed out by the nurses in the NICU when bereaved parents leave the hospital.

In general, when an infant dies in the NICU, health professionals can act as ritual inventors and experts when supporting bereaved parents (Jørgensen et al. 2021). Memory making through the creation of a scrapbook and memory box can be regarded as ritualization when an infant dies in the NICU. In line with this, we wanted to investigate what functions the ritualization by nurses and members of the parent support group might have. The research question was: what are the functions of the ritualized acts performed by nurses and members of the parent support group in the course of an infant's death in the NICU?

1.2. Theoretical Framework

“Ritual is as old as humanity” (Grimes 1995, p. xxiv), and rituals have been studied for decades. The ethnographer van Gennep (1960) was the first to identify that in all cultures there are ceremonies that mark an individual's transition from one status to another within a given society. These rites are connected to birth, maturity, reproduction, and death. Because of the importance of these rites, he called them rites of passage. After further studies, he also found it meaningful to subdivide them into rites of separation (preliminal rites), transition rites (liminal rites) and rites of incorporation (postliminal rites) (van Gennep 1960, pp. 10–11). The different ceremonies' essential purpose was to enable the individual to pass from one defined position to another (van Gennep 1960, p. 3). Building on van Gennep, the anthropologist Turner further developed the concept of liminality, and argued that being in the transition phase means that you are no longer classified and still not yet classified (Turner 1996, p. 511). This indicates that the liminal phase is an ontological and socially insecure and unstable position to be in (Grimes 2000, p. 6; Jørgensen et al. 2021, p. 3). We can also consider it as a critical phase because it raises the question whether one will be accepted and incorporated into the new state or not. Building on the insights from van Gennep and Turner, ritual theorists today investigate how rites of passage are practiced and experienced around the world. Grimes, the founder of the interdisciplinary field of ritual studies, is for instance interested in how people “[. . .] can fruitfully reflect on their own experiences of passage” (2000, p. 8). The performative and individual sides of rituals have, in this way, gradually become more emphasized, cf. the following broad definition: “Very generally, ritual is any activity—sacred or secular, public or private, formal or informal, traditional or newly created, scripted or improvised, communal or solitary, prescribed or self-designed, repeated or one-time only that includes the symbolic expression of a combination of emotions, thoughts, and/or spiritual beliefs of the participant(s) and that has special meaning for the participant(s)” (Castle and Phillips 2003, p. 43).

When it comes to understanding the function of rituals, the findings from the social anthropologist Brottveit (2003) are relevant to this study as he has studied grief and death rituals in a cross-cultural perspective. He points to three main functions: (1) Therapeutic function—make the unreal real, relieve the grief and repair the loss. (2) Cosmological

function—give death a meaningful frame and define the deceased’s new place and identity. (3) Social function—redefining the roles and resume normalcy. In the present article, we elaborate mostly on the first and third functions. An ordering function of rituals is emphasized by Driver, Professor of Theology and Culture: “In its ordering function, ritual performs the world, bringing it from chaos and the limbo of potentiality into actualized (actionful) form” (Driver 2006, p. 136).

It is common to distinguish between ritual and ritualization; a ritual is often conceived as a text or a formula that is used in a religious context or in other contexts where something needs to be expressed symbolically. Carrying out the ritual means enacting the ritual script and making it as vital as possible in a performative act. By ritualizing, we mean symbolic activities people take part in in order to derive meaning. For ritualizing, people can use written rituals, but they can also create new symbolic activities that they use in their meaning-making efforts (Danbolt and Stifoss-Hanssen 2017, p. 355). According to the religious studies scholar Catherine Bell, ritualization must be understood in connection with context, as it “[...] always takes place within a larger and very immediate sociocultural situation” (Bell 1992, p. 100).

The academic study of ritual is complex and gives insights into a field “[...] upon which multiple viewpoints are focused” (Grimes 1995, p. xxvi). In the discussion, it will become evident that we interpret our data material in light of ritual and ritualization theory. However, we are not investigating rituals and ritualization within traditional religious contexts. Our interest lies in understanding what functions the ritualized acts performed in the course of an infant’s death in the NICU have. The terminology “ritualized acts” is taken from Bell (1992, p. 140) who goes beyond former definitions of ritual in defining ritual as “the production of ritualized acts”. In line with her understanding, we investigate practices surrounding birth and death in the NICU and regard these as ritualized acts. To understand the functions of these practices, we are indebted to classical works in the field, but even more to recent works on rituals and ritualization around birth and death, and especially to the works of Jørgensen et al. (2021) and Wojtkowiak (2018, 2020). The aim of the study is therefore to explore the functions of the ritualized acts of making a scrapbook and memory box when an infant dies in the NICU.

2. Materials and Methods

The study has a qualitative, explorative design. The interview guide was designed to explore experiences, practices, and reflections.

Our overall analytic approach has been hermeneutical. The parts and the whole of the data material have been interpreted in light of each other in order to gain a “thick” description (Geertz 2017, pp. 3–33). Insights from hermeneutics have been applied both in the search for understanding the research participants’ experiences, practices, and reflections, but also in our search for understanding each other’s professional backgrounds as researchers, and how these impact our interpretations of the data set. According to the German philosopher Hans-Georg Gadamer, being aware of one’s own preunderstandings and prejudices are vital in the act of interpreting, as prejudices are present in all understanding (Gadamer 2011).

A hermeneutical approach can include various methods, and in this study, it is combined with the method of reflexive thematic analysis. Reflexive thematic analysis aims at constructing and categorizing essential themes which form the data, and at the same time emphasising the active role of the researcher in this process (Braun and Clarke 2006; Braun et al. 2019, p. 848).

2.1. Sample and Data Collection

This study was conducted in a hospital in the Southern part of Norway. The participants lived in the same area. Data were generated through three focus group interviews with altogether 12 participants (eleven women and one man). The data collection was carried out with two groups of nurses, and one group of members of a parent support group.

Five members were recruited by contacting the parent support group, but only three turned up at the date of the focus group interview. Although they were few, they provided us with substantial data on the topic. The other participants were nine experienced nurses working in a level 3 NICU. To give all nine participants sufficient time to speak, two focus group interviews were performed. In order to anonymise the participants alias names were used.

The first author was the primary investigator in terms of obtaining the right permissions to undertake the study, and of recruiting participants to the three focus group interviews.

2.2. Interviews

The main objective in the focus group interviews was to examine the functions of the ritualized acts of making a scrapbook and box.

Through the group discussions, the specific experiences and practices were reflected on from nurses and members of the parent support group. These provided us with new knowledge about how memory making in this sense can be seen as forms of ritualized acts. The same interview guide was used for both groups, but questions were slightly adjusted to fit the specific group in focus. The interview guide was made based on the recommendations of [Krueger and Casey \(2015, pp. 44–46\)](#). The guide was organised with an opening question where the participants briefly presented themselves. The next introductory question dealt with how the idea about making a scrapbook and memory box came into being. The transition question pursued how the participants experienced the work with the respective items to be included in the scrapbook and memory box. The key question examined the contents of the scrapbooks and memory boxes, respectively, and the significance and meaning the contents had to the research participants. The ending question was directed towards the participants' understanding of rituals and ritualization.

All three researchers were present at all focus group interviews. One researcher was moderator, while the others asked additional questions and summarized the discussions. The interviews were recorded and transcribed verbatim by the researchers. All groups were interviewed once, and each interview lasted approximately one hour and thirty minutes.

2.3. Analysis

Reflexive thematic analysis according to [Braun and Clarke \(2006, 2019; Braun et al. 2019\)](#) was used to construct, describe, and interpret themes. According to Braun and Clarke, a reflexive thematic analysis consists of six phases: (1) All researchers read through and became familiar with the data. (2) Initial codes were generated, based on a deductive approach. The researcher made these codes, respectively, and agreed about which were most relevant. (3) The dataset was searched for themes based on temporary themes. The first author developed temporary themes, and these were discussed with co-authors. (4) The temporary themes were further scrutinized and reorganized. (5) The themes were developed around topics aiming to provide a diversity of meanings. The team of researchers discussed and examined the themes and the dataset throughout the entire process. (6) Finally, the article text was written ([Braun and Clarke 2006; Braun et al. 2019, pp. 852–57](#)). Meaning-based patterns were conceptualized to themes. The patterns of meaning were found after exploring, developing and examining the dataset. The data was developed using latent thematic analysis. Latent thematic analysis was used as we sought for a broader, more implicit meaning. The themes were regarded as pattern of shared meaning supported by a core concept ([Braun and Clarke 2019](#)). We sought to offer a comprehensive and convincing interpretation of the given data. Our professional background as chaplains and nurses, in addition to our interest in ritualization, influenced the process.

2.4. Ethical considerations

As topics around death and life can touch upon existential issues in the individual, we formed our interview guide in a way which allowed the individual to protect themselves and not share more than they wanted to share in the course of the focus group discussion. The study followed the Helsinki declaration ([World Medical Association 2018](#)), and the participants were granted confidentiality. The Norwegian Centre for Research Data (NSD) approved the study (ref. no: 697560). The participants received written and oral information explaining the aim of the study and gave their written consent to take part in the study.

3. Results

3.1. Making Memories

3.1.1. There Was a Life

A decade or two ago, one of the nurses in the ward initiated the making of the scrapbooks. This practice has ever since been performed. The nurses start on the scrapbook immediately after an extreme premature and/or critical ill infant is admitted in the NICU, or when a long stay is expected. Nurse Fiona explains:

“We try to start taking photos quite straight away when the infant is admitted, if we think it is very premature or seriously ill.”

The motifs may be the incubator, medical equipment, the infant, and the parents. The infant’s weight, length, head circumference and the parents’ names are added. The scrapbook can at this stage be regarded as a celebration of the birth. However, the seriousness of the situation signals that what starts out as a diary of a new-born life, becomes a memory book if the infant dies. They start writing to the infant using second person singular (“you”). However, if the infant dies, the nurses continue writing to the infant, but then have the parents and potential siblings in mind when it comes to content. Nurse Mona says:

“Most times, we write to the infant during the whole stay. If the infant dies, I write to the infant, then finally to the parents.”

They may describe that the infant’s condition is critical. Other times they try to find suitable poems appropriate to the situation with the intention of comforting the parents and siblings. The pages are decorated with various stickers and photos. As parents may forget what happened when the infant was seriously ill, the scrapbook is intended to help them to remember. Nurse Gina explains:

“It becomes like a journey through the NICU, through life, if life ends at the ward. There was a life.”

When it comes to the box, one of the members of the local parent support group initiated the making of the memory boxes. The group wanted bereaved parents to be provided with better information and grief care than they experienced when they lost their child. One of the members of the parent support group had the idea of using a box for the purpose of collecting information and mementoes. In addition to brochures with information, the group decided that the box should contain a small teddy bear, a laminated poem and a small transparent jewelry bag with symbolic items: a candle, a security pin, an angel, and a heart.

3.1.2. Not Leaving the Hospital Empty-Handed

The scrapbooks and the memory boxes are tactile objects. The members from the parent support group hoped that the memory box would be a touchable memory. Beth, who herself had experienced loss, says:

“I am very concerned that you should not leave the hospital empty-handed . . . I found it very difficult; I call it something touchable, something that you can show to others.”

The nurses emphasize the scrapbook as a physical evidence of the infant's life. Nurse Hannah explains:

"The scrapbook is something that you hold, and that is what they [the parents] have left."

The nurses try to create memories when there is no hope for an extended life. They make a testimony of the time the family had together, even when life is very short. They collect and make other tactile memories as blankets, haircuts, hand- and footprint on paper and in plaster. They also save the pacifiers and other things that have been close to the infant. Nurse Linda states:

"Even the shortest lives will get [a book]; we always manage to complete the books."

The nurses emphasize the importance of photos chosen for the scrapbook. They try to capture different scenarios as soon as possible when an infant arrives. Sometimes they start when the infant gets the initial treatment. The photos should reflect important moments in the family. Milestones such as the parents holding or bathing the infant for the first time, or grandparents or siblings visiting are such moments. When the parents are present, pictures of the infant grabbing the parents' finger, or parents' and infant's hands together are other important moments to capture, according to the nurses. Special characteristics such as for instance long eyelashes are perpetuated. Nurse Mona wants to capture this and:

"... to take a photo of the love and the longing ..."

When an infant is admitted in the NICU, this in itself means that the parents are experiencing a severe crisis. Some mothers may not be able to visit their new-born infant due to their own critical condition. The parents' time together with the infant is sometimes very limited. The nurses try to highlight the bonding between infant and parents. Olivia explains:

"I remember it well as it was on Christmas Eve. The parents had dressed up and the father wore a tie. The infant was so weak that he could not grab. When the father holds the infant, he grabs the tie. I took a photo of the three together. I heard that they used the photo as Christmas card."

Important motifs are when parents and infant are physically close, such as when the parents hold the infant or touch the baby after death has occurred. Nurses emphasize that they try to take photos before the infant's color changes and make sure the parents hold the infant before it becomes cold. The participants emphasize the concreteness of the scrapbook and the boxes. It is a reminder and a memory of the life and death of the infant.

3.1.3. The Ambiguity of Making and Collecting Memories

The nurses are well aware that memories are not always desired, and that they can even hurt the parents. Gina means:

"Well, I think that none of the parents have expected or know that we are making a scrapbook. In a way, it is something that we inflict on them."

The nurses do not know whether the scrapbooks can make the pain of the loss remain longer, prevent the parents from moving on, or if it at all relieves the pain. At the same time, they know that even if the parents find it difficult to look in the scrapbook straight after the death of their infant, they may appreciate it after some time. They know that some parents do not look at the book for years.

When taking photos, the nurses are physically very close to the parents and the infant. They may feel that they disturb the time the family have together. They persuade the parents to hold their dead infant and take photos. Olivia refers to an experience where she guided the parents to hold the dead baby:

"So, I asked whether we pushed them [the parents]; sometimes I feel we take too many photos, that we are too much around them, and encourage them to hold

the infant. [The answer was] if you had not told me to hold the infant, I would not have done it."

The parents' cultural background influences how parents meet the death of their infant. Mona found it difficult to provide an immigrant couple with what she thought was a dignified ending when they did not want any memories to be collected or created:

"It happened very suddenly and the parents did not want to hold the infant, to have photos; anything. The infant should just be forgotten."

The members of the parent support group do not meet the bereaved parents, as the parents receive the memory box via the nurses in the NICU. The participants from the parent support group do not know whether the contents of the box are helping the bereaved parents. Regardless, they have heard that some parents experienced that the symbolic contents of the jewelry bag enabled them to get in touch with their emotions. They are at the same time aware that some of the nurses remove the jewelry bag before giving the box to the parents and interpret this as a sign of different preferences. Beth realizes in her own grief that good intentions from other people are not always easy to contain:

"... I also know that things were said with a good intention. However, I just cannot take it. So I think we are at our most vulnerable state."

The members of the parent support group are aware of that what they perceive as support for bereaved parents is not always welcomed. Beth and Anne have for instance met parents in their private settings who neither wanted to receive a box nor photos of the dead infant. This reaction was unfamiliar to them, but they realize that not everyone wants the kind of grief care that is intended by the box.

3.2. *Showing Evidence of the Infant's Life and of the Parenthood*

3.2.1. Bringing Infant and Parents Together

Some parents have a limited time to bond when the new-born infant dies shortly after birth. The nurses nevertheless try to encourage the bonding, and to personify the infant when writing in the scrapbook. Nurse Gina explains:

"... I always mention the parents when writing, that mother and father have stayed with you a lot. Moreover, mother comes with her milk."

As the NICU is an unknown and unfamiliar setting for the parents, the nurses urge them to touch, to become acquainted with and to see their infants behind all the medical equipment. When the nurses realize that the infant is dying, they find it important to highlight that the parents had a relation to the infant, even if the infant's life was very short. Some parents are holding the infant the first time after it is dead. This may be the only moment the parents and infant share privately together. The nurses try to facilitate bonding in this situation. Nurse Pia underlines:

"To create a relation, so that the parents get a feeling that they bonded to the infant; afterwards; when they hold; that they are a family."

To capture the infant's look, photos are taken of the dead body from different angles. The scrapbook shows that the parents actually had some experiences with the infant, as nurse Fiona says:

"To show ... that there was an infant, which the parents can be acquainted with in a way, through the scrapbook. They may not be able to take photos themselves or describe what they lived through ... "

The parents may find it hard to grasp that they actually had an infant. Knowing that they have the scrapbook with the memories may help the parents to realize what happened:

"You have a proof. You have something physical, not only an infant that disappeared." (Pia)

3.2.2. It Is a Closure

When the infant is dead, the nurses finish the scrapbook. It is a last farewell to the infant and the parents. The nurses emphasized that it was important for them to write some greetings in the book. Gina says:

“It is a closure for me. Moreover, a start of the parents’ sorrow, if it can help them start. In addition a summary over what happened.”

When writing, they prefer to sit alone in a room, away from the ward and the noise. They regard the finishing of the book as their last act of care towards the infant and its family. Gina continues:

“ . . . a last act of caring that you are giving . . . that you want it to be some words that are good to read afterwards.”

The nurses realize that they are among the few people who knew the infant and sometimes they are very close to the parents. If an infant dies whom they have been involved with, they find it frustrating if they are unable to write some last words in the scrapbook. The nurses’ memory making may not be finished when the parents leave the ward for the last time as the parents or other relatives often agree to come back and collect the memories. Linda underlines the importance of closure:

“I think they understand that we need to say goodbye. We have been a part of their life in the NICU.”

3.3. Controlling Chaos

3.3.1. Contribute When Parents Are in Their Worst Crisis

The nurses as well as the members of the parent support group explain that they want to help parents getting through an existential crisis. The members of the parent support group hope that they can provide some practical help and comfort with the boxes. After Beth had lost an infant, she asked herself:

“Can I turn this into something good? Can I do something that will let others—they will not have less pain—may come through the experience in a better way?”

The members of the parent support group have experienced chaos following the loss of an infant. In this chaos they had to make a lot of choices, and experienced they did this on a poor basis. They had missed information about practical tasks, and about how they could make informed decisions about burial place, funeral ceremony, tombstone, etc. Anne explains further:

“I wish I had got a box with information and all the brochures. Because you fumble in the dark—where to start?”

In their view, it should not be random what bereaved parents are informed about. The parents, who live through a severe crisis, should be able to make choices based on balanced information. Charles stresses that the information needs to be the same to everybody:

“You never plan to bury your infant . . . so in a way you get a choice: “You can do it in this way or that” and “this is allowed” . . . that the information reaches everybody and that they get the same information.”

The nurses understand that working with the scrapbook is part of their task and a way of caring for parents and infant. In addition to helping the parents, working with the scrapbooks and memory collection was a very meaningful task for them. Mona explains:

“You are doing a very important job in that situation, when you gather infant and parents and make memories. You feel that you are quite privileged . . . that you are coming so close to someone that is in such a situation. Through making memories, you feel that you are doing a good job.”

The nurses accentuate that when the infant’s life was short, they were among the few people that knew the infant:

“The parents share their infant with us in a way.” (Linda)

Writing the scrapbook and creating memories could be exhausting when the infant was seriously ill as they had many other duties in a hectic and critical situation. However, contributing when being among the few who knew the baby felt like an obligation.

3.3.2. Is It a Ritual?

We are aware that it is our task as researchers to interpret the collected data material. However, we were curious about the participants' own reflections about what they are doing might mean, and thus asked them at the very end of the interviews whether they had ever thought that the work they do can be seen as some form of ritualization. Although most participants had not reflected on this previously, they seemed to reflect there and then on this way of understanding their acts. The nurses pointed at the intended function of the book to help bereaved parents with the transition from life to death, and with personifying the infant also for friends and family, and they underlined that the scrapbook was a way of making the infant visible:

“We take photos and create memories; so it has to be visible.”

It also becomes evident that the closeness with the infant does something to the nurses, and that the work with the book makes sense also in their process of coming to terms with their own loss. Fiona and Gina point to the function the making of the scrapbooks have for themselves:

“It is our ritual”. “It is something that we give to them. It is our ritual.”

Some nurses saw some relations to more traditional rituals in broader society. Gina explains that the scrapbook can resemble a condolence protocol, and Olivia had asked the chaplain to write some words in the scrapbook. The parents appreciated the gesture as the same chaplain had baptized their infant. Mona sees some similarities with a condolence protocol, but does not think that the scrapbook as such is a condolence protocol:

“You write more personally than just condolence; it is something more.”

The members of the parent support group hope that the box could help bereaved parents when they experience the transition from life to death, from hospital to home, and in the grieving process. They were aware that some parents do not use the box while others would put it in a visible place in the home. Whether the term ritualization could be used about the making of memory boxes, some participants were hesitant, as they were not sure about the content of the term and mixed it with the term sacrifice. Beth, on the other hand perceived the act of preparing boxes as some kind of ritualization, and picked up on something she had said earlier about the need for help in the transition from life to death, and also in making the unreal real:

“I mentioned the concreteness, to have something to show, to have something to talk about.”

4. Discussion

“People know what they do, and they know why they do what they do, but they do not know what what they are doing does.” (Foucault quoted in [Bell 1992](#), p. 108).

A recent study indicates that rituals taking place in the NICU establish the human potentiality of the infant, as well as offer the bereaved parents' status as mother and father of the infant ([Jørgensen et al. 2021](#)). What are the functions of the ritualized acts performed by nurses and members of the parent support group in the course of an infant's death in the NICU referred to in this article? In the following, we will try to answer this question within the theoretical framework of rituals and ritualization.

4.1. The Making of Scrapbooks and Boxes as Ritualized Acts

In our interpretation, both healthcare professionals and members of the parent support group perform ritualized acts when they make the objects scrapbooks and boxes (cf.

Grimes 1995, p. 28). In fact, they act as ritual experts when they invent the scrapbook and the box (Jørgensen et al. 2021). They have not been asked by their respective organizations to make these in the course of an infant's death in the NICU—they have invented these acts as they see a need for bereavement care (Thornton et al. 2019). However, the hospital setting enables nurses to develop such ritualized acts and give the members of the parent support group the opportunity to provide the hospital with a box to be handed out to parents when an infant dies in the NICU. In our interpretation, the making of scrapbooks and boxes are ritualized acts intended for bereaved parents, but they also carry meaning for the ones who perform these acts. As this study did not investigate how the scrapbooks and boxes were experienced on the receiving end, we can only suggest the intended meaning from the makers' side, and the meaning experienced for those who make the scrapbooks and boxes, respectively.

4.1.1. Ritualization as a Way of Constructing Meaning for the Bereaved Parents

"Rites of passage are ways of embodying meaning [. . .]" (Grimes 2000, p. 9). The task of a ritual is to acknowledge life-changing events, and to potentially transform the participants (Wojtkowiak 2018). In our material, it is our clear impression that the nurses and members of the parent support group regard their making of scrapbooks and boxes, respectively, as something which is urgently needed and which have the potential to make a difference for the bereaved parents: "Ritual and meaning-making processes are not causally driven but driven by the 'meaningful'" (Wojtkowiak 2018). In the interviews it became clear that the scrapbook and box have the intention of guiding the bereaved parents in the transitions they go through both as parents, and on behalf of their dead infant (Jørgensen et al. 2021). As the makers of these items through memory making "[. . .] form the body of the child into a person or human potential" (Jørgensen et al. 2021), this is intended to create meaning for the bereaved parents. In their ritualized act they are "[. . .] cocreators of the ontological status of the child" (Jørgensen et al. 2021). In addition, they are cocreators of the social status of parenthood. This will be further elaborated on below.

4.1.2. Is This Kind of Ritualization Related to Traditional Rituals in the Societal Setting?

The invention of new rites never happens in a vacuum: "Even if our desire is to create new rites of passage, we do so with the materials at hand, with the stuff of our cultures and traditions" (Grimes 2000, p. 4). As we interpret the findings within the theoretical framework of rituals and ritualization, a timely question is whether or not the act of making a scrapbook and a box reveals reference to any traditional rituals surrounding life and death? In the Norwegian context, there is no traditional birth or death ritual which directly underpins the practice of making a scrapbook and a box in the course of an infant's death. However, there exists a ritualized act in Norwegian society of placing a condolence protocol at a table outside a ceremonial room, or at another adequate site when significant people die, or when ordinary people die suddenly. In such cases the condolence protocol can be signed by all who are present. In the interviews, it was explained that after the death of an infant, also other than nurses may write in the scrapbook. The book seems to undergo a transition from being a diary of the infant's life written by the nurses, to becoming something similar to a condolence protocol where for instance the hospital chaplain can write a last greeting. When it comes to the box, the societal custom of placing the dead body in a coffin before the funeral can give associations to the small box. However, the members of the parent support group actively try to avoid this association by not providing the hospital with white boxes. Another association to a traditional ritual is Medieval Norwegian graves where archaeologists have excavated material objects placed together with the dead body. The box can give associations to this custom as belongings of the infant is put into the box. A difference though is that the box is not buried with the child but preserved by the bereaved parents. What is evident is that these new forms of ritualization presented here seem to negotiate with existing or traditional rituals in a complex way (Bell 1992; Wojtkowiak 2020).

4.2. *The Intended Function of the Ritualized Acts from Those Who Make the Scrapbook and Box*

What is the intended function of the scrapbooks and boxes? Although the ritualized acts from nurses and members of the parent support group interviewed here did not follow guidelines from the hospital or the national support group, their specific way of assisting bereaved parents and families with memories is also seen elsewhere: “The collection of mementos, such as photographs, personal items, clothing, of footprints, has also become common in practice and is recommended throughout perinatal and neonatal palliative care guidelines” (Thornton et al. 2019, p. 352). Studies have showed that the care strategy of collecting memories from the infant “[...] is one of the principal interventions that have been developed to date” (Pueyo et al. 2021). Being provided with objects of significance allows the bereaved parents and siblings to still maintain a connection to the family member who is dead—in their processing of the loss (Levick et al. 2017; Pueyo et al. 2021).

Whether or not these intentions are achieved at the receiving end is not investigated in this project. However, the interviews revealed a feeling of ambiguity, both in nurses and members of the parent support group of making and collecting memories for bereaved parents (see Section 3.1.3). This shows an awareness of also potential negative outcomes of ritualization: “Rites can not only fail to achieve what they purport to do, they can also become a means of oppression, so we cannot afford to view them through a fuzzy, romanticized lens” (Grimes 2000, p. 7).

4.2.1. Ritualization as a Way of Making Memories

Both the scrapbook and the box are regarded by nurses and members of the parent support group as ways of creating, collecting, and preserving memories about the lost infant. The loss of an infant transforms a “[...] usually joyous life transition into pain and heartbreak” (Berry et al. 2021, p. 26). Both nurses and members of the parent support group describe the act they perform as having the meaning of making memories about the infant. The memory making is regarded an important part of bereavement care for the parents. As many parents feel unprepared to create mementoes with their infant, they need guidance through the process of making memories (Thornton et al. 2019). The reason why memory making is seen as important by the participants is not clearly defined in the interviews. However, it seems to be connected to the social integration of the new-born who is now dead into family and society (Thornton et al. 2019), and on a deeper level to give the child an ontological status as a human being, and not leaving the hospital empty-handed: “memories became fundamental as parents could take only these with them, not the baby they were expecting” (Thornton et al. 2019). By making memories of the child, the short life is given meaning (Levick et al. 2017), and the parents are intended to be helped in their processing of the loss. This is achieved through the collection of tangible items (Pueyo et al. 2021; Thornton et al. 2019). As already said, in the box there is space for clothes, blanket and other items which belonged to the child. The book contains photos, poems, documentation of what the infant has undergone medically, and texts written in second person singular. Together with hand and/or footprints, all this literally functions to show the footprint the infant made on earth. As both members of the parent support group and the nurses emphasize the need to make memories, this underlines that the liminal phase in which both infant and parents find themselves risk the danger of social invisibility (Jørgensen et al. 2021). To avoid this social invisibility, and to help parents and infant into their new statuses, memories are collected and preserved. The collected items also make it possible for people outside the closest family to get to know the new-born, its short life on earth, and the impression the baby left (Thornton et al. 2019, 2020).

4.2.2. Ritualization as a Way of Personifying the Infant and Making Parenthood Real

When a child is born, parents and child undergo transitions: Parents grow into their new status as parents, and the child enters into family and society and gets the status of a new member of these settings (Wojtkowiak 2020; Jørgensen et al. 2021). When death occurs shortly after birth, the infant is deprived of this socialization process, and the parents’

process of evolving into the status of parenthood is disturbed. Both parents and infant are left in a liminal state. As already said, the liminal phase is an ontological and socially insecure and unstable position to be in (Turner 1996, p. 511), and also a critical phase because it raises the question of whether one will be accepted and incorporated in the new state or not (Grimes 2000, p. 6; Jørgensen et al. 2021, p. 3). The infant is in a double liminality as both new-born and dead, and two transitions are thus needed—an integration into family and society, and an integration into “the land of the dead” (Jørgensen et al. 2021). As in other western secularized societies (Wojtkowiak 2018), also in Norway, informal and formal ritualized acts are performed to visualize that a newly born child belongs to something bigger than only the immediate family: people pay visits and give complements, they provide the baby with presents, and after some days, weeks or months baptism, name giving, or circumcision may occur (Wojtkowiak 2020). When an infant dies in the NICU, this transition into family and society is impossible to complete, and infant and parents are left in a liminal space.

In our interpretation, the ritualized acts from the nurses and members of the parent support group have several functions. First, the brochures and symbolic items included in the box document parenthood. Second, the way the scrapbook documents the infant’s life through text and photos gives the infant the status of a human being belonging within family and society (Thornton et al. 2019). The documentation also “[...] honors the relationship between the new-born and the family” (Thornton et al. 2019). In addition, the fact that somebody outside the closest family have seen the infant and made a relation with the child adds to giving the infant the status of a human being. The scrapbook and box together are intended to serve to personify the infant, to make parenthood visible and real, and function as an attempt to help parents with the integration into society at the same time as they leave the child among the dead.

4.2.3. Ritualization as a Way of Making Order out of Chaos, and Making the Unreal Real

All human beings are aware that it belongs to the human condition that we all one day will die. However, parents who experience the loss of an infant are confronted with the unpredictability of life, and the shocking experience when death comes in proximity to birth and happens unexpectedly: “When birth brings death, it is a paradox, and dead new-borns are potentially very frightening—they remind us of the fragile boundary between life and death and disturb the cherished narrative of linear progress” (Jørgensen et al. 2021). In such a chaotic situation, it is difficult for the parents to take in what has happened, and from the focus groups interviews it is evident that the nurses function as guides along the road of making order out of chaos (Driver 2006, p. 136) and making the unreal real (Brottveit 2003). However, how do they help the parents to define and comprehend a human being who had a very short time on earth? As part of the nurses’ status as ritual experts (Jørgensen et al. 2021), the interviews revealed that parents are intended to be helped when they experience uncertainty and fear about what they are allowed to do with the dead baby (Jørgensen et al. 2021). The members of the parent support group shared the feeling of not being at home in the hospital setting and at the same time going through a shocking experience when they lost their children. They regarded the healthcare professionals to be in the position of defining what is culturally accepted in this liminal situation. Through encouraging parents to bond with the dead baby, and through the making of the scrapbooks, the nurses intend to assist parents in taking in what has happened, give words to their experiences, and as such gradually assist the bereaved parents in making the unreal real.

4.3. *The Experienced Function of the Ritualized Acts for Those Who Make the Scrapbook and Box*

What function does the making of scrapbooks and boxes have for those who make them? “Rituals are by all means embodied enactments of meaning [...]. What is more, rituals aesthetically translate reality into symbolic form” (Wojtkowiak 2020). Although Wojtkowiak here talks about rituals which are performed in a social, collective setting, much of the same is true for the acts referred to here and performed by nurses and members

of the parent support group. Traditional religious rituals have decreased in contemporary Western, secularized societies, and new ways of meaning making are enculturated (Wojtkowiak 2020). In our data material, it is evident that the need for ritualization becomes pressing when birth and death occur close in time, and “[t]hese new rituals are introduced by those who are at the center” (Wojtkowiak 2020). The ritualized acts are targeted towards the individuality and uniqueness of the dead infant (Wojtkowiak 2020). The book is made different from infant to infant, capturing the distinct circumstances around the individual. The sense of community around the ritualization discussed here—which is pertinent when traditional rituals are performed—is captured to some extent by the nurses as they all share the experience of losing an infant at the ward. The community side and social collaboration (Wojtkowiak 2018) is also imminent in the ritualized act from the members of the parent support group as they together fill the boxes with contents. Not having experienced appropriate bereavement care themselves (Thornton et al. 2020) make them eager to create something valuable for others.

4.3.1. Ritualization as a Way of Constructing Meaning for Nurses and Members of the Parent Support Group

Neonatal care has over the years improved due to technological development. However, when death still occurs close to birth, what can help nurses and parents then? According to Grimes, “Technology without ritual (or worse, technology *as* ritual) easily degenerates into knowledge without respect. [. . .] It matters greatly not only *that* we birth and die but *how* we birth and die” (Grimes 2000, p. 13, his emphases). In our interpretation, the ritualized act of making the book functions as a way of attempting to make meaning of what the nurses live through at work (cf. Levick et al. 2017), and to get in touch with “[. . .] the rhythms of the human life course” (Grimes 2000, p. 3). The nurses establish a relation to the infant and the parents, and they go through a process of grief when an infant dies in the NICU (Gibson et al. 2018). This shared sorrow between parents and staff in the hospital becomes visible in the book, and the book functions as a place for collective healing between parents and nurses (cf. Levick et al. 2017).

For the members of the parent support group, the making of the box help them in their own re-working and digestion of their private loss and doing this together increases social cohesion (Wojtkowiak 2018). Through providing others in a similar situation with what they missed, they experience to perform a meaningful act to others, but also to themselves.

The quote which opened the discussion section deals with peoples’ ritualized practices, and how they can be interpreted: “People know what they do and they know why they do what they do, but they do not know what what they are doing does” (Foucault quoted in Bell 1992, p. 108). In our interpretation, what they are doing are ritualized acts, and these acts do something to the bereaved parents, but also to themselves. Their invention of rituals surrounding an infant’s death underlines that birth and death are major transitions in life, which require not only practical procedures and information, but ritualized actions. The birth and death of an infant is not only a private tragedy but is an event that is intimately interwoven with existential, social, and cultural webs of meanings (Wojtkowiak 2020; Prinds et al. 2019). The examples of ritualization studied here seems to be a necessity for the participants: “The grounds of ritualization as a human necessity are ecological, biogenetic, and psychosomatic. We cannot escape ritualization without escaping our own bodies and psyches and thus rhythms and structures that arise on their own” (Grimes 1995, p. 42). What the participants do (cf. Foucault) effects not only to the bereaved parents and themselves, but also to society’s understanding of life and death.

4.3.2. Ritualization as a Way of Repairing the Loss, Relieving the Sorrow and Making a Closure

As the transition from life to death had no official ritual attached to it in the NICU, the ritualization was invented to attend to the major life events in an adequate way. Although not stated explicitly, this was perhaps done to avoid the state Grimes describes in the following quote: “Unattended, a major life passage can become a yawning abyss, draining

off psychic energy, engendering social confusion, and twisting the course of the life that follows it" (Grimes 2000, pp. 5–6).

As already mentioned, nurses can experience similar grief responses as family members, in addition to stress and physical and emotional exhaustion when infants they have cared for die (Gibson et al. 2018). That healthcare professionals are personally and professionally affected by their close relations to patients, is known also from other studies (Ådland et al. 2021). For the nurses in our interview material, we interpret the ritualized act of making the scrapbook as a way of digesting what they have experienced and witnessed (cf. Levick et al. 2017, p. 458). As nurses in the NICU are sometimes the only ones who have seen the infant awake, the only ones who have given the infant milk, and the only ones who have given the baby a bath—they have been responsible for holding the life in their hands and feel connected to the infant through this relation (Levick et al. 2017). Through the actual making of the scrapbook the nurses rework and process the suffering and sorrow they go through after having witnessed the death of an infant they had a relation to. In our interpretation, the ritualized act of making the book creates an "aesthetic distance" to the event, and "offers a contained way of expressing emotions" (Wojtkowiak 2018). Through this ritualized act they make a closure for the relation with the infant who died, and they try to enable themselves to move on to the next admission. Although the practices referred to here do not take place in an open, communal setting as rituals often do, the acts are still performed within a specific time and place, they have a concrete beginning and end, and this makes them a unique event every time the acts are performed (Wojtkowiak 2018).

For the members of the parent support group, much of the same applies. The loss of an infant is experienced as a traumatic and life-altering experience which affects them for the remainder of their lives (Berry et al. 2021). As perinatal loss experiences are often difficult to recognize for friends, family and colleagues (Berry et al. 2021), the members of the parent support group find solace in meeting one another in the group setting when they fill the boxes with contents. Through the making of the box, the members process their own loss, and feel a sense of relieve of the sorrow as they are in a space where their emotions and reactions are recognizable and contained.

5. Conclusions

The question of this article was: what are the functions of the ritualized acts performed by nurses and members of the parent support group in the course of an infant's death in the NICU? We have sought to answer this question within the theoretical framework of rituals and ritualization.

From the focus group interviews, it is evident that the ritualized acts have a dual function. First, the scrapbooks and boxes are intended to create memories, and to help the parents not to be stuck in the frightening unstable liminal phase, but to help them move over to a phase where their status as parents is confirmed, and the dead new-born is socially recognized. Second, the interviews made it clear that the ritualized acts of making scrapbooks and boxes have a function also for those who make them. These ritualized acts serve to help both nurses and members of the parent support group to construct meaning, repair the loss, relieve the sorrow and to make a closure, in other words: to digest what it means to have been in a relation to a human being who died.

6. Recommendation for Practice and Future Research

The making of scrapbooks after the death of an infant is, in our interpretation, a ritualized act invented by nurses in the NICU. The practice of making rituals when something is at stake has followed humankind throughout history (Danbolt and Stifoss-Hanssen 2017). Studies have showed that nurses experience personal grief after the death of an infant in the NICU (Gibson et al. 2018), and a recommendation for practice is thus to provide a framework in the NICU to help nurses interpret and understand what it means and takes to be exposed to death at work.

There is need for future research to evaluate how bereaved parents experience interventions after death in the NICU, such as those described here: a scrapbook and a box. This is important in order to provide bereaved parents with interventions designed in response to their needs and values (Thornton et al. 2019), and to avoid oppression and other negative outcomes (Grimes 2000, p. 7). More research is thus needed on how culture, religion, and spirituality influence parents' preferences for bereavement care (Thornton et al. 2019). Being sensitive to these areas is paramount in memory making practices as "cultural, religious, and spiritual practices are elements that are inherent to the grieving process and can constitute an effective coping mechanism in the event of a perinatal loss" (Pueyo et al. 2021).

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