

# ‘It was a blanket of love’: How American and Italian parents represent their experience of perinatal hospice through the use of metaphors



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**Abstract:** The loss of a child is one of the most profoundly stressful events an adult can experience, but perinatal hospice may be an important resource for the family's wellbeing. The aim of this study was to understand how a group of American and Italian parents of infants affected by life-limiting or terminal conditions and treated with personalised comfort measures represents, with a metaphorical statement, the experience of perinatal hospice care. Thirty five questionnaires were collected and included 13 parents from Italy and 22 from the US. Parents represent their experience as positive and rich with lovely family moments and, although it is also a hard path, they consider it as an important gift. Other metaphors elected were related to spirituality and transcendence, underlying the need of parents to express and share their spiritual values and beliefs. Finally, parents also perceived an overall support from care providers and felt as if they were part of the same family.

**Keywords:** hospice, palliative care, death, grief, metaphor

## Introduction

Death at the beginning of life is difficult to understand, both by individuals who are directly affected by it and by those who are external to it. Death at the beginning of life is, in fact, an event that distorts the normal natural order of the life cycle. It is not a coincidence that in many languages there is not even a word to indicate the ‘parent who loses a child’ during perinatal age because it is a circumstance that is often destined to remain private and does not have a precise position in society. The loss of a child is one of the most profoundly stressful events an adult can experience (Bonanno & Kaltman, 2001) and perinatal palliative care is an emerging field which aims to provide care for the dying babies and their bereaved parents. However, despite the growing acceptance of the significant impact of neonatal

and perinatal loss, this event is still poorly addressed. Many families declare, in fact, a lack of compassionate support by society, including experiences of disapproval, isolation and pressure to terminate (Kobler, Limbo, & Kavanaugh, 2008; Côté-Arsenault & Denney-Koelsch, 2011; Guon, Wilfond, Farlow, Brazg, & Janvier, 2014)

For this reason, the option of perinatal hospice within a neonatal intensive care unit (NICU) has been seen in the last years as an important resource for the families. The purpose of perinatal hospice is to welcome a newborn affected by a medical condition not compatible with life beyond hours or days with or without life support and satisfy their needs, by giving them love, comfort, nutrition/hydration, and palliative care/painkillers. Some examples of this condition are anencephaly, renal agenesis, limb-body wall syndrome, or where the burden of intensive care may

exceed the benefits in terms of length of survival, such as in cases of trisomy 13 or 18. Parents actively elect to give birth to their infant suffering from a condition defined as not compatible with life, in order to spend their brief life with them. Although the deep pain that affect parents saying farewell to their child, the vision or the direct contact with them, as well as the creation of memories, may help, in fact, to reduce psychological disorders, such as anxiety and depression (Cacciatore, Frøen, & Rådestad, 2008; Erlandsson, Warland, Cacciatore, & Rådestad, 2013). Other studies have described, instead, parents' experiences regarding their journey at a perinatal hospice, reporting also significant positive thoughts and outcomes, beyond their deep sorrow (e.g. Lathrop & VandeVusse, 2011; Côté-Arsenault & Denney-Koelsch, 2011, 2018; Limbo & Lathrop, 2014; Waugh, Kiemle, & Slade, 2018). These studies were qualitatively based but parents were not asked to share their experiences using a visual storytelling technique, like electing a metaphor, in all of them. Metaphors are, in fact, evocative expressions that should always be included during narrative data collection, because they capture the hidden meanings which individuals assign to personal thoughts and experiences. Rosenblatt (1983) also adds that several studies conducted with bereaved families reveal that family members are often unable to speak openly of the loss, and they may instead use a metaphor to express their feelings.

The metaphor, from the ancient Greek μεταφορά (metaphérō), is a rhetorical figure that involves a transfer of meaning. It is a figure of speech by which we replace one term with another in a sentence, with the aim of creating images with a strong expressive charge (Lakoff & Johnson, 1980). The analogy and the simile are similar to the metaphor and consist of combining two images or situations, different and apparently without a logical connection. However, if we say '*you are strong and brave like a lion*' that is a simile while saying '*you are a lion*' is a metaphor. Through metaphors, we evoke images that cannot be reduced to the literal meaning of the expression we want to use. Thus, it permits individuals to express complex thoughts or feelings, and especially those regarding topics such as pain, death, or other experiences with the same nebulous subjective nature. For this reason, metaphors are equally common in literature as in the psychological or medical setting (e.g. Froggatt, 1998; Arroliga, Newman, Longworth, & Stoller, 2002; Richardson & Grose, 2009; Casarett et al., 2010; Southall, 2013).

According to Bucci (1999), the human mind is composed of a verbal code, a symbolic and also a sub-symbolic one. The latter ones are more easily captured by images rather than words because they are based in our unconscious, which, according to psychoanalysis, works through images rather than words. Thus, pictures and images, as well as visual storytelling, are used by therapists to help individuals

elaborate traumas, cope with grief or depression, and to promote the resilience and the adaptive reconstruction of emotional elements (Graves, 2009). Several studies suggest also that the use of pictures and images in the clinical setting, included abstract paintings, help individuals relive and recall memories, emotions, and past experiences so that they can be better understood (Kövecses, 2000; Fetterman, Bair, Werth, Landkammer, & Robinson, 2016). However, metaphors are used in the therapeutic setting also, outside the psychoanalytic world. For instance, Barker (1985), building on the work of Milton Erikson, uses the metaphor with individuals suffering from different clinical problems, in order to discover an affective component of the personality that is hardly reachable. Instead, Andolfi and Angelo (1988), in a manner consistent with the Milan family therapy model and the Palo Alto School's studies, report using metaphorical speech during family therapy sessions, in order to enter into the family's myths, transmit messages that transcend the literal contents of a family's narrative, and introduce new information that can facilitate the creation of healthier family interactions, myths or beliefs.

It is also well known that the use of metaphors in grief therapy helps facilitate the healing process. Metaphors can be expressed by the therapist, the person, or they may co-evolve in the process of therapy. For instance, they can be used in order to understand how the loss is being perceived by the person, such as whether they judge themselves as a victim of the circumstances, or whether they experience some degree of control. Finally, the so-called metaphoric imagery work can be useful in devising appropriate interventions or in suggesting the right alternative ways of responding to the event (Nadeau, 2006; Carson, 2009; Umphrey & Cacciatore, 2014).

In light of what has been reported so far about on metaphors, and given that the subjects of this study are parents coping with the loss of a baby, the author of this paper thought that the use of metaphors and imagery could be a way to learn more and penetrate deeper into their experience regarding perinatal hospice care. Furthermore, it was an opportunity for parents to share their feelings and, by making the 'invisible visible', come to a deeper understanding of themselves and their experience.

## Aim

The aim of this study was to understand how a group of American and Italian parents of infants affected by life-limiting or terminal conditions and treated with personalised comfort measures represent, with a metaphorical statement, the experience of perinatal hospice care.

## Methods

This is a qualitative explorative study of American and Italian parents of infants diagnosed during pregnancy or

immediately after birth with a life-limiting or terminal condition and who elected the perinatal hospice option. Infants were born in the unit and treated with personalised comfort measures including family/infant bonding, warmth, hydration/nutrition, and pain/discomfort management. A total of 52 questionnaires were mailed from 2013 to 2016 to parents (18 Italians and 34 Americans) who elected perinatal hospice option, and at least three months after the event but not over one year. Two of the clinics/hospices involved were from Italy, and two were from the US. Research meets the ethical guidelines, including adherence to the legal requirements of the study country.

Parents were asked to sign their consent for participating in the study, and then were asked general demographics questions. They were asked to briefly describe the medical condition of the newborn and to express through '*an image, a symbol or a metaphor the experience of perinatal hospice*'. Another optional open question asked if participants wished to add anything else about their baby's comfort care experience. 35 complete questionnaires were returned, and included 19 mothers and 16 fathers, 13 from Italy and 22 from the US. 17 parents did not complete the questionnaire for the following reasons: wrong family contact; language barrier; declined participation. Italians parents' age ranged from 26 to 46 years with a mean age of 35.3 years. The race of participants was 100% Caucasian. Religion affiliation was Christian for most of them (89.6%), while others declared to be atheist (10.4%). American parents' age ranged from 23 to 42 years with a mean age of 31.7 years. Race was predominantly Caucasian (63%), followed by Hispanic (20%), Asian (12.6%) and Black-American (4.4%). Religious affiliation signed was Christian for most of participants (62%), followed by Jewish (16.3%), Muslim (9.9%), and other religion (6.1%). Some of them declared to be atheist (5.7%). The newborns' prenatal diagnoses included: trisomy 18 to 13 (12 cases), hypoplastic left heart syndrome (eight cases), bilateral renal agenesis and/or dysplasia (five cases), anencephaly (five cases), limb-body wall syndrome (two cases), other complex or multiple congenital or genetic anomalies (three cases).

The data was analysed following a broad-based interpretation of metaphor which included similes and analogies because individuals often do not make the distinction among similar rhetorical figures. The 35 surveys have been divided into the two groups and have been coded as *M* or *F* to indicate if mother or father, *Ita* or *Am* to indicate if belonging to the Italian or American group, following an Arabic number to identify the specific subject (e.g. *M.Ita.2*). The Italian answers were translated faithfully by an official translator. All the data was later analysed according to the method for thematic analysis outlined by Braun and Clarke (2006). First, the data was read several times. Then initial codes were generated from aspects of the data which appeared more interesting and suitable

according to the broad-based interpretation of metaphor. (Surveys there were not considered suitable were excluded). Third, the various codes generated in step 2 were collated into potential themes which seemed to explain larger sections of the data. Finally, clear definitions and names were generated for each refined theme.

At the end, metaphors have been freely interpreted in order to highlight the power of the meaning of the image chosen that goes beyond the literal meaning itself. In order to do so, the author, who is a clinical and family psychologist with experience in perinatal hospice, also consulted some books of symbolism, philosophy and mythology (e.g. Battistini, 2002; Fornari, 2006). Later, interpretations were discussed with a neonatologist with long experience of perinatal hospice care and with two other psychotherapists.

## Results

Even though 35 questionnaires were collected, the author identified 29 metaphors considered suitable according to the broad-based interpretation of metaphor (six answers were eliminated for the following reasons: the answer was judged incomplete or not suitable). The metaphors, related to parents' experience in the perinatal hospice or comfort care unit, were collected into five key themes labeled *Family time*, *Protection*, *Spirituality*, *Gift* and *Path* (see Table 1).

### Family time (eight statements)

The largest theme, labeled *Family Time*, describes parents' experience as a highly positive quality time spent in a large family. As shown in Table 1 they state: '*comfort care [the name of the programme] is a family (M.Ita.18)*' and '*it was better than family (F.Am.11)*'. They added also that '*it was like being in a family (M.Am.5)*', or like '*spending time with family (M.Am.12)*'. They especially emphasised that care providers took care of them and their offspring as if they were members of the family: '*It was like we were in a family because it was like they were caring for their own daughter, niece or granddaughter (F.Am.3)*'; '*everyone involved loved our daughter like she was his or her own (M.Am.9)*'. Parents also felt loved, supported and hugged like at home: '*It is a place full of love and peace like in a family (M.Am.16)*'; '*It was like a hug (M.Am.15)*'; '*It was a big hug (F.Ita.12)*'. Parents appreciated this time spent with the loved ones and were grateful for the kind attention they received from everyone involved.

### Protection (seven statements)

The second largest theme, labeled *Protection*, describes parents' experience as something that physically protected them from falling apart or 'drowning'. For instance, they stated it was like '*an umbrella that tried to protect the baby and the family (M.Am.13)*'; '*a bandage that helped*

**Table 1.** The five key themes

<p><b>Family time – total statements: 8</b></p> <p>It was like being in a family (M.Am.5)  It was like spending time with family. We felt like everyone involved loved our daughter like she was his or her own (M.Am.12)  It was like if we were in a family because it was like they were caring for their own daughter, niece or granddaughter (F.Am.3).  It is a place full of love and peace like in a family (M.Am.16)  It was like a hug (M.Am.15)  It was better than family (F.Am.11)  Comfort care is a family (M.Ita.18)  It was a big hug (F.Ita.9)</p>	<p><b>Protection – total statements: 7</b></p> <p>I would describe my experience of comfort care as an umbrella that tried to protect my baby and my family (M.Am.13)  Perinatal hospice was like a bandage that helped to heal (F.Am.4)  Perinatal hospice was a blanket of love and support through a difficult time (M.Am.6)  It was an accompaniment that treated the terminally ill but also took care of the parents' soul (M.Ita.8)  Comfort care was a pillow (M.Ita.9)  Perinatal hospice was love, awareness, and accompaniment (F.Ita.10)  It was sunshine (M.Ita.11)</p>
<p><b>Spirituality – total statements: 6</b></p> <p>A little angel settled in locked baby serving some high-concealed purposes. I felt the radiant sensation of purification, submission, modesty exercising grief but the feeling of mystical highly unique amendment (M.Am.1)  The Creator of these poor little babies has certainly shown me a glimpse of His special plan and attention by arranging such an extraordinary unit (M.Am.3)  I felt the protection of angels. In comfort care, there were angels (M.Am.7)  Perinatal hospice was a miracle, a blessing (F.Ita.5)  Comfort care was a place where I got to meet my precious angel (M.Am.10)  It was like a beautiful and calming corridor between this world and the "next world" (M.Am.14)</p>	<p><b>Gift – total statements: 4</b></p> <p>It was such a gift to me (M.Am.2)  I would describe my experience with a butterfly. The butterfly does not count the years but the instants: for this reason, its brief time is enough for it and it is grateful for that gift (M.Ita.18)  Comfort care is a gift (F.Am.1)  It was a gift full of surprises (F.Ita.6)</p>
<p><b>Path – total statements: 4</b></p> <p>It was a love, pure, unadulterated longing for goodness and beauty path (F.Am.2)  Perinatal hospice experience was being immersed in a deep sea (M.Ita.4)  It was a bike ride (F.Ita.7)  A mountain trip (F.Ita.8)</p>	

to heal (F.Am.4); 'a blanket of love and support through a difficult time (M.Am.6)'; 'a pillow' (M.Ita.9) or 'a sunshine (M.Ita.11)'. This theme emphasises the extreme sense of care, protection, and support they felt from providers and everyone involved. They added also: 'It was an accompaniment that treated the terminally ill but also took care of the parents' soul (M.Ita.8)' and 'perinatal hospice experience was love, awareness, and accompaniment (F.Ita.10)'. This theme seems to be connected to the previous one: again the sense of familiarity and deep connection established with care providers emerges. Yet, in the present theme, the point of view is focused more on the feelings of being protected and helped physically and emotionally, rather than on being hugged and loved like in a family.

### Spirituality (six statements)

In the third theme, labeled *Spirituality*, the parents' representations were more closely related to spirituality and transcendence than to care and love. Parents expressed their beliefs that there is something beyond death and that

the experience of disease and the death of a little child is part of an unknowable project, an expression of God's will. For instance, they said: 'The Creator of these poor little babies has certainly shown me a glimpse of His special plan and attention by arranging such an extraordinary unit (M.Am.3)'; 'It was like a beautiful and calming corridor between this world and the "next world"' (M.Am.14). They also described also the hospital facility as a place with 'angels'. In addition, they added a description of their spiritual experiences. For instance, 'I felt a radiant sensation of purification ...' (M.Am.1)'; 'I felt the protection of angels (M.Am.7)', and it 'was a miracle, a blessing (F.Ita.5)'.

### Gift (four statements)

The fourth theme has been labeled *Gift*. Even though this is a small theme, some parents described their experience as a *gift*. It seems unrealistic, given that their newborn passed away, but they valued as a gift the time they spent with their babies. 'I would describe my experience with a butterfly. The butterfly does not count the years but the

*instants: for this reason, its brief time is enough and it is grateful for that gift (M.Ita.18)*'. They also probably felt loved and supported enough to consider this experience in a positive manner. They said, for example: *'It was such a gift to me (M.Am.2)*'; *'Comfort care is a gift (F.Am.1)*'; *'It was a gift full of surprises' (F.Ita.6)*.

### Path (four statements)

The fifth theme is labeled *Path*. Even though this is a small theme, it is significant because the metaphors selected describe in summary the experience considering both the beauty of it and its complexity. Parents stated that it was: a *'love, pure, unadulterated longing for goodness and beauty path (F.Am.2)*'; *'being immersed in a deep sea (M.Ita.4)*'; *'a bike ride (F.Ita.7)*, and *'a mountain trip (F.Ita.8)*'.

### Discussion

From a group of 35 American and Italian parents of infants, affected by life-limiting or terminal conditions and treated with personalised comfort measures, 29 metaphors were identified relating to the experience of perinatal hospice. The metaphors were collected in five themes: *Family Time*, *Protection*, *Spirituality*, *Gift* and *Path*.

The *Family Time* theme is the most present, as the majority of parents describe their experience as highly positive quality time spent in a large family. The perinatal hospice became like a second home not only because their newborns spent most of their life or even their entire life there (infants often live only for a few minutes or hours), but also because of the familiar and comfortable atmosphere they immediately perceived and the deep connection established with the staff. They especially talked about a *'big family'* because they considered care providers as new family members:

*'It was like we were in a family because it was like they were caring for their own daughter, niece or granddaughter (F.Am.3)*'.

*'It was a place full of love and peace like in a family (M.Am.16)*'.

The second most quoted theme, *Protection*, is composed of metaphors that highlight the sense of protection and healing perceived by parents. Some of the expressions used were: *'an umbrella that protected the family'*, *'a bandage that helped to heal'*, *'a blanket full of love and support'*. These images remind one of a kind mother taking care of her vulnerable and sick offspring. However, in this case, parents have been cared for and kept comfortable by the staff of the hospice. As a mother stated, summarising well this concept:

*'It was an accompaniment that treated the terminally ill but also took care of the parents' soul (M.Ita.8)*'.

The spiritual theme was also present since some statements alluded to a further existence beyond earthly life or other spiritual elements.

*'It was like a beautiful and calming corridor between this world and the "next world"' (M.Ita.14)*.

At the end of life, themes such as death, the purpose of life, the purpose of life and the dimension of the transcendence become more urgent questions and are also emphasised by patients or caregivers (Balboni et al., 2009; Shin et al., 2017). According to recent studies, spiritual care should be considered an essential component in providing comfort to NICU families because spiritual leadership, during one or more meetings, was shown to help families move toward positive religious and spiritual coping, avoid religious distress, and strengthen their overall wellbeing (Rosenbaum, Smith, & Zollfrank, 2011; Snodgrass, 2012; Brelsford & Doheny, 2016). Searching for the meaning of what happened seems to be, in addition, a critical element for the psychological adjustment or healing of grief (Lichtenthal, Currier, Neimeyer, & Keesee, 2010). Finally, people who profess stronger spiritual beliefs may resolve grief more rapidly than people without spiritual beliefs, and are less likely to develop a complicated and ineffective grieving process (Walsh, King, Jones, Tookman, & Blizard, 2002; Paloutzian & Park, 2013; Hayward & Krause, 2014).

Although the *Gift* and *Path* themes were the smallest, they were highly significant because, in them, parents pointed out how grateful they were for this journey within the perinatal hospice:

*'It was a gift full of surprises' (F.Ita.6)*.

Thus, even though it was a hard and painful path they considered it as a gift. However, these metaphors are also double-edged because, while on one hand there is the awareness of following a pleasant path (such as a bike ride or a mountain trip) there also emerges, on the other hand, a sense of difficulty and tiredness. In fact, both activities can be hard and tiring. Finally, also the metaphor of *'being immersed in a deep sea'* recalls something relaxing but scary at the same time (a deep sea is dark, too).

In the free comment session some parents reported their gratitude. They emphasised that they were thankful to have had the opportunity to bond with their babies and take care of them, exercising their parental role and therefore gaining something positive from the tragic experience of bereavement.

*'We are just so grateful for the care our baby received and to have met him' (F.Am.15)*.

## Conclusion

This explorative qualitative study shows that parents of infants with life-limiting conditions and short life expectancy who elect to carry on the gestation represent their experience in a perinatal hospice or comfort care unit as positive and full of lovely family moments. Although it is also a hard and painful path, they consider it as an important gift. Other metaphors were closely related to spirituality and transcendence, suggesting the need or desire of some parents to express and share their religious or spiritual values and beliefs. Parents also perceived overall support from care providers and felt as if they were part of the same family. In perinatal hospice each baby is acknowledged as an individual and is treated as such in the context of their own family although they will not survive, thus parents are very grateful for knowing that their infant's life has been profoundly respected and loved.

The study has some limitations. For example, participants were not asked to explain the metaphor or image they reported. Thus, further studies would benefit from organising interviews or focus groups with parents, instead of sending surveys, to get deeper feedback. Another limitation is the small number of participants, especially from Italy, where perinatal hospices are rare. However, in spite of these limits, findings suggest the essential role of care providers in supporting parents coping with grief, and that religious and spiritual views can be sources of support for individuals as well. Spirituality plays an important role in the elaboration of painful experiences and should be considered an essential component of care in perinatal hospice programmes, even though parents do not ask for it or may declare to be atheist (Meert, Thurston, & Briller, 2005; Caldeira & Hall, 2012; Brelsford & Doheny, 2016). In Italy, for example, the 'spiritual care' role or department within hospitals do not exist, and many American clinics still do not provide this service. This study also maintains that meeting the infant, despite some malformations, may contribute not only to reduced negative bereavement outcomes such as anxiety and depression, as reported by some studies (e.g. Cacciatore et al., 2008; 2009; Rådestad, Westerberg, Ekholm, Davidsson-Bremborg, & Erlandsson, 2011), but can also alleviate the anxiety experienced during pregnancy about the baby's appearance that is sometimes imagined as 'monstrous' (Kuebelbeck & Davis, 2011). In fact, there were no negative metaphors or comments related to the aspect of the baby. However, this correlation needs more investigation. In terms of follow up, further research is indeed needed on how this might impact on bereavement experiences over time, including their level of anxiety, depression, and social adjustment. In order to do this, it is suggested to use both validated scales and interviews. Another further exploration should also include a deeper analysis of the possible cultural differences in parental

experiences between Italians and Americans, as well between mothers and fathers.

Finally, care providers, social workers, and counsellors should be aware of the power of the metaphorical speech or visual storytelling and how to introduce it in their practice to support individuals, as suggested also in other studies (e.g. Fazio, 1992; Denshire, 2002; Arroliga et al., 2002; Casarett et al., 2010). Deeper studies on the use of metaphorical statements are also warranted to estimate in which particular cases this different kind of communication can be considered as necessary, and when not, and its efficacy within the therapeutic setting. ■

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