AN EXPLORATION OF THE EMOTIVE EXPERIENCES AND THE REPRESENTATIONS OF FEMALE CARE PROVIDERS WORKING IN A PERINATAL HOSPICE. A PILOT QUALITATIVE STUDY

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Abstract

Congenital anomalies are the principal cause of neonatal mortality in the United States. Families who decide to continue gestation and reject termination of pregnancy benefit from the experience of Perinatal Hospice (PH). There are no current studies that show if there may be positive outcomes for care-providers as well. The first step is exploration of their emotive experiences and representations beyond burnout or stress disorders and the possible negative outcomes. With this aim, semi-structured interviews were conducted with 10 specialists. An Elementary Context analysis was performed with T-Lab software. Providers experience positive elements even though they work in a painful reality and face the possibility of 'failure' of medical science or the loss of a patient. They declare themselves to be satisfied and do not demonstrate deep suffering or particular psychophysical disorders. They consider their job as a 'gift'. There is a lack of research exploring the encouraging aspects of their work, such as coping strategies or positive emotions.

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Introduction

Congenital anomalies remain the leading cause of neonatal mortality in the United States (Almli et al. 2020). Many life-limiting conditions can be diagnosed before birth as a result of medical advances in fetal assessment (Breeze and Lees 2013). In the case of a diagnosis of a life-limiting or terminal condition, the medical staff will talk through options with the parents, including therapeutic abortion. Termination of pregnancy is considered to be a less distressing option and a benevolent attempt to protect the family members because, by limiting attachment, it is believed that potential pain can be prevented (Munson and Leuthner 2007; Koopmans et al. 2013). For the same reason, until a few years ago, parents were separated from their stillborn babies to minimize potential trauma (Lasker and Toedter 1994). A pregnancy also always carries some risks to the health and well-being of the mother. Furthermore, many do not always understand why a mother may prefer to proceed with a pregnancy and labor that may be complex and emotionally heavy.

Nevertheless, there are many families who actively elect to carry on the pregnancy (see, for example, Dahò 2020). In these cases, it is important to establish a personalized plan of care for each member of the family and for the infant. The diagnosis of a life-

limiting condition can be a terrible news for many future parents because their expectations are altered (Walker et al. 2008; Côté-Arsenault and Denney-Koelsch 2011). Initial emotional reactions may include shock, deep sadness, disappointment, and disbelief, along with anger, guilt and shame, mixed with feelings of hope (Statham et al. 2000; Badenhorst et al. 2006; Munson and Leuthner 2007). The situation is complex especially in the presence of siblings as parents must address their wellbeing and explain that their younger brother or sister may not be born, or could survive only for a very short time. So it is important to attend to the needs of all family members following the antenatal diagnosis. Likewise, continued support after the infant's death is encouraged, as recovering from the psychological impact of a perinatal death has been reported to take as long as 5 to 18 years (Gravensteen et al. 2012). The death of a child around the time of birth is considered, in fact, one of the most profound, stressful events an adult may experience (Bonanno and Kaltman 2001). It can lead to emotional distress, major depression, post-traumatic stress disorder (PTSD) and complicated grief (Lichtenthal et al. 2004; Stroebe et al. 2008; Côté-Arsenault and Denney-Koelsch 2011). Furthermore, a higher likelihood of divorce has been reported for parents whose child dies prematurely (Gold et al. 2010; Shreffler et al. 2012). This distress

may interfere negatively with the bond with other offspring, and may impact decisions about future children as parents could 'reject' a new pregnancy for fear of new traumas (Lisi et al. 2008; Cacciatore et al. 2009; Cacciatore and Flint 2012). However, although many programs for bereavement support have been established in recent years, families declare a lack of support and compassion by society, including experiencing isolation, disapproval, and pressure to terminate (Kobler et al. 2008; Côté-Arsenault and Denney-Koelsch 2011; Guon et al. 2014).

Other obstacles that families sometimes face derive from the hospital context and the interaction with health workers (Chitty et al. 1996; Côté-Arsenault and Denney-Koelsch 2011). Difficulties in the relationship with care providers may emerge because of defense mechanisms, such as avoidance (Maguire 1985), that care providers sometimes use. The role of a hospice specialist has been often reported in the literature as a complicated and multifaceted role with frequent complex emotional exposures (e.g. Broom et al. 2014; Seed & Walton 2012). Thus, achieving emotional distance has even been described as a particular skill that helps to avoid long-term negative consequences for health workers who face the dying on a daily basis including a high level of stress or discomfort that may lead to development of Burn-out (Broom et al. 2014; Fox 2006). The expression 'burn-out' in the psychological field was introduced for the first time by Freudenberger (1974). Later it was developed more extensively by Maslach and Jackson (1981), who also built a scale of measurement: the Maslach-Burnout-Inventory (MBI). Through this questionnaire, they highlight the three main factors of the burn-out phenomenon: emotional exhaustion, depersonalization, and personal involvement. Presence of burn-out, or high level of stress in care providers, and especially for those working in intensive care hospital units, has been well documented and is known to also affect negatively the emotional well-being of families and patients (Embriaco et al. 2007; Reader et al. 2008; Braithwaite 2008). Because of burn-out, the health worker can develop (or worsen) medical conditions such as cardiac (Kawachi et al. 1995; Boggild and Knutsson 1999), sleep (Spiegel et al. 1999), gastrointestinal (Caruso et al. 2004), or dysfunctions of the Central Nervous System (Peterson and Demereuti 2008; Reader et al. 2008; Rotenstein 2018). They could also develop (or worsen) psychological disorders, such as major depression, anxiety, or fatigue (Embriaco et al. 2007; Raggio and Malacarne 2007; Rotenstein et al. 2018). This discomfort may interfere with work performance. In fact, significant errors in practice, more workplace accidents, and greater absenteeism have been reported in health workers with documented burn-out (Braithwaite 2008; Rotenstein et al. 2018). Finally, it is distressing for most humans to witness a dying child. When death occurs, care providers may prefer to avoid contact with the family. Furthermore, many did not enter this profession to care for those who are dying (Nuzun et al. 2014), making it difficult for them to accept the perceived failure of saving a life. Death is also a subject that often raises difficult and ethical questions.

However, care providers, despite their best intentions, often do not know how to manage these particular cases because of the absence of definite healthcare protocols. Postnatal management and palliative care guidelines are rare (Bhatia 2006; Moro et al. 2006; Engelder et al. 2012; Breeze and Lees 2013), and only in the past few years have there been documented programs of Perinatal Hospice (PH) that

included recommendations to support bereaved families (D'Almeida et al. 2006; Weinhold 2007; English and Hessler 2013; Miller et al. 2014). These programs have many points in common, from which it is possible to deduce the essential elements of perinatal hospice. These include: the presence of a multidisciplinary team; clear and empathic communication to parents through several meetings; development of a Prenatal Birthing Plan; attention to the basic needs of the child; attention for all members of the family (social support); creation of memories (e.g. Memory Box); and promotion of bonding between parents, siblings, and infant.

All these points are important and essential because research and clinical psychology demonstrate that, if the family is assisted properly, all family members can proceed more easily and to the reorganization of their lives and through psychosocial rehabilitation. There are, in fact, many studies (Cacciatore et al. 2009; Cacciatore 2010; Rådestad et al. 2011; Lathrop and VandeVusse 2011; Dahò 2020) that affirm that 'good care' carried on through the partnership of several health workers and starting from the prenatal diagnosis, is crucial for the long-term welfare of families. However, there are no current studies that report, instead, about how the possible positive outcomes of "perinatal hospice practice" may be experienced by health care workers. There are, in addition, only a few investigations to date (e.g. Bruce & Davies 2005; Kehoe 2006; Sinclair 2011; Harris 2013), that explore their emotional experiences beyond burn-out syndrome and its negatives impact, or other psychological outcomes such as acute stress reactions or Post- Traumatic Stress Disorder (PTSD).

Aim

The aim of this pilot study is to explore the representations and the emotional experiences of the providers who work in a Perinatal Hospice program within a Neonatal Intensive Care Unit (NICU) based in New York City.

Method

Participants

Participants included 10 females (average age 47) employed in a Perinatal Hospice (PH) established at a non-faith-based hospital of New York in 2007. The sample captured the entire staff of specialists and is composed of: three physicians, three nurses, two social workers and two child life consultants. They had a minimum of 3 years to almost 10 years of work experience in the perinatal hospice. Yet, their experience at a common Neonatal or Pediatric Intensive Care Unit (NICU or PICU) is longer.

Although the entire team has many meetings with the family, and works toward the same goal (e.g., to ensure the well-being and comfort of the newborn and family), each specialist differs in the method of approach and role. The physician, for example, primarily deals with the physical health of the child, guaranteeing the patient remains stable and in the absence of pain through medical tests and the administration of drugs. The physician is also accompanied in these procedures by the nurse, who, is also in closer contact with the parents. Indeed, the nurse teaches parents a variety of techniques to allow them to have more physical contact with the child and facilitate the creation of a bond. For example, the nurse teaches them to change the diaper inside the incubator or crib, to feed the baby with a tube,

or utilize kangaroo care. The role of social workers is slightly different, as they support parents emotionally, through counseling sessions, or even logistically, helping them to find temporary accommodation if they come from outside the city, or vouchers for parking or the hospital canteen. Finally, the Child Life consultant interacts generally with the siblings of the infant, to help them elaborate what is happening and process around the potential of death.

Procedures

Since each participant plays a different role within the hospice, it was thought to deepen the emotional and experiential aspect of their work through semi-structured interviews. The aim of the interview was to explore the representations and the emotive experiences of the specialists of the hospice in order to capture the common aspects, despite of the differences of role and tasks. In particular, interviews served to explore in general the job experience, roles, motivations, emotional reactions, and the personal relationships with the families and newborns. Participants could reply freely as there were no time limits. The interview included 7 questions, was conducted singularly in their hospital unit in a comfortable room and it took approximately 15 to 30 minutes. Before starting, it has been asked the permission to take part of the study and for the publication of the results. The conversations were then audio-recorded and then transcribed faithfully.

Data analyses

The goal was to understand the common elements of the narratives and representations of the Perinatal Hospice experience (referred by subjects also as "Comfort Care") rather than the specific comments by each participant. According to the work of Cortini and Tria (2014), there are three possible ways of approaching textual or narrative material. The first has the focus on the way in which speeches have been told, that is, how it was performed and what metaphors or peculiar words were used. A second method suggested aims to analyze the references made – e.g. the number of repetitions of specific words and of word associations. Finally, a third way consists in a mixed method that takes advantage of both the qualitative and quantitative perspectives. In this paper, it was conducted a thematic analysis selecting the mixed method, that takes care both the number of repetitions and the words used. Indeed, they both may play an important role in the text analysis.

In order to do this, the materials produced were submitted to a linguistic-textual analysis using the T-Lab statistical software (Lancia 2004). The use of so-called Computer-Assisted Qualitative Data Analysis Software (CAQDAS), of which T-Lab is also a part, as well as allowing the rapid manipulation of large amounts of data, it offers the advantages of increasing the rigor and reliability of the analyses. This software allows a synthetic representation of the corpus main themes by creating a few thematic clusters, permitting to do an analysis of the content (Lancia 2004).

In this case, the set of transcriptions of the interviews constituted the corpus in analysis. The entire corpus was first submitted to a revision of the dictionary on a linguistic and a semantic basis. In particular, the attention was focused on the identification of *multi-words* (headwords included), the elimination of less important grammatical elements (like prepositions, conjugations etc.), the correction of some linguistic inaccuracies not

recognized by the software, and the disambiguation of cases of semantic ambiguity. Finally, some similar words have been collected into a single category, as they were conceptually identical definitions, although they were expressed with different words (for example, the words "*quiet death*" or "*peaceful death*" used by providers to describe their perception regarding the infant's death, where unified into the locution labelled "*quiet-peaceful death*").

At the end, the lemmas used for the analysis were 237; the minimum frequency threshold of the lemmas, in order to be selected and included in the analysis, was kept at 4. The lemmas were inserted then in T-Lab and an Elementary Context analysis was performed. This technique, through the integration of various algorithms, generates clusters that allow to represent the data in a synthetic way. Clusters are generated by the software using similarity criterion, so that elements within each cluster are strongly connected among themselves and, at the same time, different from the elements of the other clusters. T-LAB performs an automatic clustering consisting of two principal steps: a co-occurrence and a comparative analysis. Thus, this method allows to compare the two corpus subsets and to determine (1) the most frequently used words in each subset and (2) the words solely used in one subset but not in the other. The visible outcomes of this procedure are (A) a table of list words and variables that occur within each cluster with their respective chi-square values; (B) text extracts characterized by the same patterns of dense words.

For what regard the point (A), while clusters are generated by the software, their labeling is decided by the researcher. The labelling process is based on the comprehension both of the words and variables, and of the text extracts that characterize each cluster. Thus, the title given to each cluster is clearly related to the contents as it summarizes the most recurrent theme for that specific cluster based on the highest frequency and chi-square test value of the words. When approaching instead the point (B), given that T-lab already recognized, clustered, coded, and mapped the data, the researcher can present the text extracts selected by the software as the most relevant in a cohesive manner to provide their underlying meanings. In this case, given that the attention of the author was on the emotive experience, they were selected, read and analyzed only the extracts provided by T-lab that contained the key words related to the emotions or feelings reported by participants.

Results

Six different clusters have been generated from the thematic analysis of the elementary contexts conducted on the corpus of the interviews.. The figure (**figure 1**) shows the distribution of the six clusters in the factorial space and offers an insight of the similarities and differences among the clusters.

The clusters are illustrated in detail in the following paragraphs in order of greater variance.

Cluster number 3: 'The team: tasks and responsibilities' (23,63% of variance)

Cluster number 3 is characterized by terms such as *'team', 'work', 'my_role (in the Comfort Care unit)'*. This cluster refers to the health operators' role within the team (*'Child_Life', 'social_worker', 'doctor', 'nurse', 'therapist', 'specialist'*) and their main tasks (*'support_family', 'help_family', 'explain', 'help_parents', 'involve', 'give_idea', 'listen', 'teach'*). During the interviews, the speech of the providers focused mainly

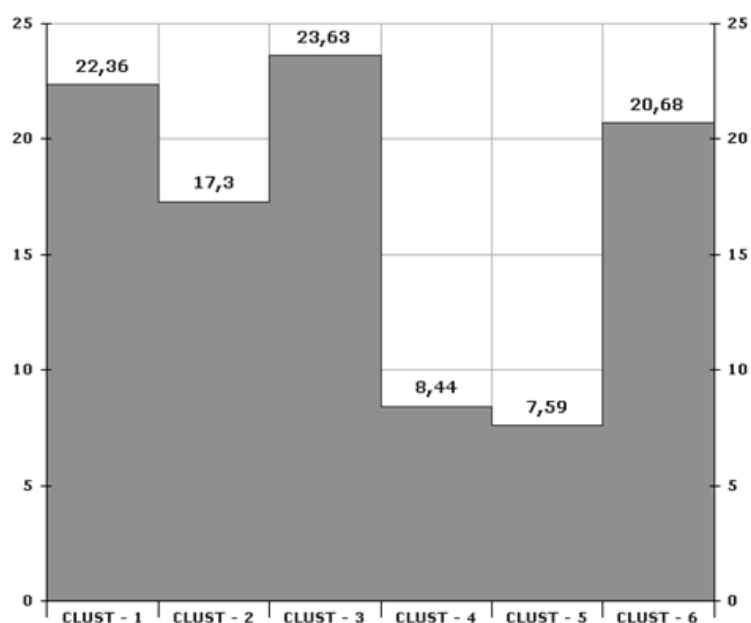**Figure 1.** *Distribution of the six clusters in the factorial space*

Table 1. *Cluster number 3*

LEMMA	CHI SQUARE	EC IN CLUSTER	EC IN TOTAL
Team	49.627	17	19
Work	31.277	18	27
Child_Life_1	29.084	18	28
My_role	28.338	13	17
Social_worker	21.645	9	11
Child_Life	21.645	9	11
Support_family	16.437	10	15
Role	13.659	27	68
Specialist	13.151	4	4
Medical_doctor	12.463	20	46
Role	12.16	5	6
Nurse	10.121	15	33
Help_family	9.261	8	14
Explain	9.261	8	14
Therapist	8.994	4	5
choose_this_ profession	8.211	12	26
help_parents	6.933	5	8
Involve	6.319	4	6
Give_idea	5.95	3	4
Listen	5.95	3	4
Teach	5.95	3	4
Specialization	5.95	3	4

on an in-depth explanation of their activity, as requested by the researcher.

Cluster number 1 'The moment of the death of the child' (22,36% of variance)

After a brief illustration of the team and its tasks, the speech of the health operators focused mainly on the moment of the child's death. They described the atmosphere breathed at that time and what actually happens. This cluster contains words such as: '*hold_in_arms*', '*watch*', '*peace*', '*quiet-peaceful_death*', '*mother*', '*support*', '*die*', '*accept*', '*heart*', '*love*', '*safe*' and '*relationship*'. This cluster is characterized also by the reflections that specialists make about the death of these children and the practice of Comfort Care.

Cluster number 6 'The journey of the parents' (20,68% of variance)

Table 2. *Cluster number 1*

LEMMA	CHI SQUARE	EC IN CLUSTER	EC IN TOTAL
Hold_in_arms	55.594	15	15
Quiet-peaceful_death	27.507	9	10
Watch	20.233	7	8
Death_topic_	18.104	10	15
Peace	17.733	5	5
Nurse	10.16	16	38
Realize	9.773	4	5
Mother	7.106	13	32
Support	6.959	4	6
Die	6.748	27	85
Social_worker	6.677	14	36
Acept	6.493	3	4
Heart	6.493	3	4
Love	6.493	3	4
Safe	5.937	5	9
Relationship	4.167	3	5

Table 3. *Cluster number 6*

LEMMA	CHI SQUARE	EC IN CLUSTER	EC IN TOTAL
Death	23.369	10	14
Fight	19.597	5	5
Not_permit_baby_die	19.597	5	5
Put_in_the_shoes	15.61	4	4
Continue	11.329	5	7
Compassion	10.961	4	5
Offer	7.939	4	6
Experience_of_lost	7.321	3	4
Before_birth	7.321	3	4
Last	7.321	3	4
they_want_baby_to_live	7.321	3	4
Hospital	5.571	7	16
Circle	4.816	3	5
Suffer	4.341	4	8
Care	4.319	5	11

This cluster focuses on one hand on the description of the families and it includes some of the hardest moments reported by parents such as the time of the choice and the loss. This cluster contains, in fact, headwords like: *'death', 'fight', 'not_permit_baby_to_die', 'continue', 'last', 'they_want_baby_to_live', 'experience_of_lost', 'suffer'*. On the other hand, this cluster highlights the emotional support offered to the parents and it is composed of words like: *'put_in_the_shoes', 'compassion', 'offer', 'before_birth', 'hospital', 'circle', 'care'*. Providers have been working since the time of the diagnosis to help parents to face the painful experience of loss and farewell or, to use one of their expressions, to *'close the circle'* with compassion and empathy.

Cluster number 2 'Representations and emotive experiences of the specialists' (17,3% of variance)

This cluster is composed of the following lemmas and locutions: *'beauty_elements'* (elements of beauty), *'humanity', 'positivity', 'medical_therapy',* *'professional', 'illness', 'patient', 'my_work', 'sick', 'expect', 'short_life', 'cases', 'different', 'together', 'be_touched', 'cure', 'succeed', 'sadness'*. It is impressive the strong presence, especially in the first positions, of positive words *('beauty_elements', 'human', 'positivity', 'together', 'be_touched', 'succeed')*. The expression *'be affected'* concerns something that has surprised or touch emotionally. These words are next to more negative terms that refer to the professional experience such as: *'illness', 'patient', 'sick', 'brief_life', 'pain', 'sadness'*. There are also lemmas like *'medical_therapy', 'professional', 'my_work', 'cases', 'different', 'cure'*.

Cluster 4: 'The support to the members of the families' (8,44% of variance)

This cluster is characterized by words such as *'father', 'talking', 'family_member', 'born', 'mother', 'explain', 'decision', 'providers', 'siblings', 'attempt', 'grandfather', 'meet'*. This cluster refers again to the attentions offered to each family member. Health

Table 4. *Cluster number 2*

LEMMA	CHI SQUARE	EC IN CLUSTER	EC IN TOTAL
Physician	59.572	22	35
Beauty_elements	25.567	12	21
Humanity	19.45	4	4
Positivity	19.45	4	4
Medical_Therapy	19.45	4	4
Professional	19.45	4	4
Illness	14.036	4	5
Patient	13.437	10	22
My_job	11.823	5	8
Sick	11.823	5	8
Expect	11.823	5	8
Short_life	11.336	8	17
Cases	9.57	5	9
Different	9.57	5	9
Together	9.468	3	4
Be_affected	9.468	3	4
experience_with death	6.651	13	42
Cure	6.391	5	11
Succeed	6.188	4	8
Sadness	6.188	4	8

Table 5. *Cluster number 4*

LEMMA	CHI SQUARE	EC IN CLUSTER	EC IN TOTAL
Father	33.262	7	14
Speak	22.812	6	14
Family_member	18.509	4	8
Born	10.54	7	29
Mother	8.644	7	32
Relationship_with_parents	8.544	5	19
Explain	7.805	4	14
Decision	7.504	3	9
Providers	6.418	6	29
Siblings	6.091	4	16
Attempt	5.398	4	17
Granparents	4.937	2	6
Meet	4.487	3	12
families_description	4.253	4	19

workers do not speak longer in general of 'families', but of fathers, mothers, siblings or grandparents. The speech of the providers, strongly centered on the assistance of families, turned in favor of the needs of the single individual. In addition, this cluster emphasizes the activity of the family members involved in meetings and making decisions.

Cluster 5: 'The human experience in a perinatal hospice' (7,59% of variance)

The last cluster summarizes the main characteristics of the Comfort Care management and its peculiarities. In fact, they are listed some of the experiences lived in the unit, beyond the care aspect. The cluster consists of the following lemmas: *'photography'*, *'make_memories'*, *'walk'*, *'honor_child'*, *'experience'*, *'meet_baby'*, *'time'*, *'memories'*, *'go_through'*, *'process'*, *'department'*, *'NICU'*, *'gift'*, *'pictures'*, *'people'*, *'work_with'*, *'receive_presents'*, *'be_born'*. In the photography-rate category have been included all the themes and lemmas related to the photography such as: *'photos_of_child'*, *'photos_with_family'*, *'photographers'*, *'cameras'*, *'take_photos'* etc. The same has been done with the locution *'make_memories'* (which are: handprints, footprints, art creations, objects belonged to the child, etc.).

Discussion

The six clusters allow a complete and effective picture of perinatal hospice (PH) management (also named by participants as "Comfort Care"). The fact that T-Lab has selected six clusters underlines the complexity of the practice and the multiplicity of components that must be taken into account when creating a perinatal

Table 6. *Cluster number 5*

LEMMA	CHI SQUARE	EC IN CLUSTER	EC IN TOTAL
Photography	30.662	5	9
Make_memories	26.751	5	10
Walk	26.34	3	4
Honor_child	25.232	4	7
Experience_CC	19.987	3	5
Meet_baby	18.101	4	9
Time	15.773	3	6
Be_Honored	14.446	6	21
Memories	12.78	3	7
familes_description	11.412	7	31
Go_though	10.425	2	4
Process	7.643	2	5
Unit	6.626	4	17
NICU	5.939	4	18
Gift	5.811	2	6
Pictures	5.811	2	6
People	5.456	3	12
Work_with	5.33	4	19
Receive_presents	4.522	2	7
Be_born	4.381	5	29
emotions	4.381	5	29

hospice program. The specialists focused especially on their roles and responsibilities, on the moment of the child's death, and on the descriptions of the families they meet. Providers also spoke about their personal emotions and feelings, and about other activities and experiences within the unit (e.g. making memories).

The role of a hospice specialist has been often reported in the literature as a complicated and multifaceted role with significant and complex emotional exposures (e.g. Broom et al. 2014; Seed and Walton 2012). In particular, Trier (2006) states that hospice nurses are often reluctant to talk about their own emotional experiences because they report that they are not accustomed to share these feelings. In the studies of Harris (2013) and Melvin (2012), health workers point out a lack of emotional support for themselves, yet, a large part of the literature on this topic emphasizes the need for health workers to become aware, clarify, and verbalize the emotional challenges met at work (Bruce and Boston 2008; Li and Arber 2006; Melvin 2012). Also in the present study, a number of specialists acknowledged difficulty verbalizing their emotional life, probably because they were not accustomed to reflect and express these feelings. Indeed, also the T-lab clusters did not emphasize the emotional aspect (except for cluster 2), as workers provided fewer words and time describing this component. For this reason, in this section of the paper, the emotional factor will be discussed more deeply.

The study of Nuzum and colleagues (2014), that explores specifically the emotions of perinatal hospice care providers, states that obstetricians feel negative emotions with stillbirths. Also in the present study health workers manifested sadness and pain. For example, they stated:

'There is that sadness that we cannot save everyone' (Nurse 2)

'It was painful to accept that after of all these weeks of praying, of hoping, of trying every possible thing that

we could do for her, it wasn't going to work' (Nurse 1)

However, in addition, to the obvious emotions of pain and sorrow expressed by most providers when facing the death of the patient, Bruce and Boston (2008) found that the emotional impacts for hospice professionals were also associated with feelings of guilt and dissatisfaction, which were often rooted in unrealistic expectations of providing the optimal care for the dying. In contrast to this research, participants in the present study, did not express guilt or dissatisfaction despite being aware of the painful reality they work in and the 'failure' of medical science. In contrast, they were able to find positive elements and to experience positive emotions such as satisfaction, happiness, joy, compassion and tenderness.

'In these cases there is a satisfaction just identifying these points of beauty and positivity that there are always. It is a different kind of satisfaction, but the fulfillment of my human needs -that is to be happy as a doctor in the situation-, happens in all cases' (Physician 1)

'It is as if Comfort Care offered a chance to be a doctor to the full without experiencing the experience of failure' (Physician 1)

'The most beautiful moment I have ever seen is when the mother is holding her child and she knows the time is limited. You feel sad, but it is not that depressing sad… it is just beautiful: you see a mother loving on her baby and the siblings holding the child… it is satisfying, it feels settling and it is rewarding. I guess you would never put happiness in a context of death but you feel like you are doing something right; it makes you feel good inside.' (Physicians 2)

Their serenity is surprising. There is no anger, disappointment or fear like has been reported in other studies (e.g. Nuzum, 2014). They are honored to meet the newborn and do this job with a role they consider as a '*gift*' because it allows them to reflect on the meaning of life and on the importance of human bonds.

'*I actually see as a blessing to be able to be there when they go through that profound experience. I feel honored that I can know their baby's life*' (Social Worker 1)

'*I personally feel that it is a gift, that I benefit as much as I help anyone. It is a privilege for me to do this work because I cannot give the family what they want the most, but I can care for this child, I can care for them as a family, help them… let them know that their child did not die alone*' (Nurse 1)

This finding is similar to those from past studies in which participants described working with the dying as an honor and as a way to affirm life that also encouraged them to appreciate more fully their own lives (Kehoe 2006; Harris 2013). Hospice professionals also find that witnessing the dying on a daily basis can lead to personal and professional growth and development (Bruce and Davies, 2005; Kehoe 2006; Sinclair 2011).

Given the findings discussed so far, the question that arises is: how can this result in such hard work and unique environment? The providers interviewed do not have in their hospitals a support structure in which they can process the personal and professional impact of death or other work-related stressors, nor have they received specific training about perinatal hospice. Thus, one hypothesis is that they probably found one or more adaptive coping strategies that enhance their resilience. Philosopher Frode Nyeng (2006) states that every person has his own way of dealing with both emotions and death, depending on cultural and social factors. Surely, personal cultural background and religion beliefs help because they facilitate the search for the meaning of what has happened, a critical element for the psychological adjustment or healing in the case of grief or loss (Lichtenthal et al. 2004). Other coping strategies that they might use include the presence of an external support system (e.g. external counselor or therapist, support from the community etc.), an optimal work-life balance (despite the long night-shifts or emergency-calls), or the inclination to think they have made a difference in the lives of these babies and their families. Despite the coping strategies, it is also possible that the contact and view of the baby and the joy experienced when assisting a birth, together with all the positive memories collected during the infants' life, may help them to cope with this loss, as well as it helps parents. It is important to add that the gravity of the health condition of the infants does not often permit them to reach the end of the gestation or to survive during the labor. Thus, when the death does not occur immediately and the baby is alive, it is a day of intense joy for everyone involved, including the team of workers, because death is not a foregone conclusion. The same happiness is prolonged every minute, hour or day of survival because no one can predict for how long this baby will survive. This fact may explain also why they feel honored to participate in such an intimate important event (the birth and life of a child that only a few will meet) or to feel satisfied. When instead health workers have to provide therapeutic abortion, the atmosphere and setting is completely different and may also have a different impact on their emotional experience.

Limits and applications of the study

So far, there are no studies that show the potential positive outcomes of perinatal hospice practice on health care workers' psychological well-being. This was the first pilot qualitative study that explored this

hypothesis with results limited by the small number of subjects from only one perinatal hospice program that did not permit to analyze the role of other variables such as age and years of work. Another limitation, is that all subjects interviewed were females. Thus, further investigations should explore the representations and emotive experience of both males and females within a larger group of participants, in order to emphasize any differences between the two groups.

Given that the majority of studies highlight clinical factors, the focus often revolves around aspects related to the disease and discomfort, rather than on the most functional elements. Thus, data that pertain to this study are important because they show that it is possible to see the beauty and be happy or satisfied, in a context where positivity and feelings are not a primary focus overall leaving many to suspect frequent Burn-out or similar stress related disorders. There is, therefore, a need for more balanced investigations, exploring all aspects of emotional reactions on a continuum from burnout and stress to meaningfulness and high satisfaction with employment in these settings as well as exploring all coping strategies automatically put in place by care providers to prevent certain problems, as well the elements that permit clinical staff to maintain their work throughout the years. Another line of research should deepen the hypothesis that meeting the baby may help specialists to cope better with subsequent death, making, perhaps, a comparison between this experience and therapeutic abortion, and/or between two groups of staff workers. These reflections may help to find the best cognitive strategies that can support health workers to cope better with their work reality in order to prevent the development of particular stress related disorders.

Finally, another suggestion is to provide opportunities for open discussion and emotional debriefing since the first trainings highlighted the positive aspects within this work environment. This strategy may help to enhance the resilience of new health workers and help them to adapt, grow and construct meaning or narratives from stressful and painful experiences.

Conclusion

The aim of this pilot study was to explore the representations and the emotive experiences of 10 female care providers who work in a perinatal hospice. Six different main themes emerge from the thematic analysis of the elementary contexts conducted on the corpus of the interviews.

Describing their role, the health operators spontaneously highlighted more of their experienced joys and, in general, all the positive elements that they meet, rather than those experienced as negative. This is unusual, because this subset of health workers has always been considered as at risk for symptoms related to stress and/or Burn-out syndrome. This discomfort is much more elevated for those who have frequent contact with the death of human beings. In this case, instead, not only do the specialists of the perinatal hospice declare high personal satisfaction with their work, they do not demonstrate deep suffering or psychophysical disorders, despite the obvious stressful experiences they encounter daily.

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