An Unrecognizable Pain: Neonatal Loss and The Needs of Fathers

Gláucia Maria Moreira Galvão
School of Medicine
Federal University of Minas Gerais, Brazil
E-mail: gmmgbh@gmail.com

Denise Streit Morsch
Clinical Psychologist, Consultant for Humanized Care for the Newborn
Kangaroo Method, Ministry of Health, Rio de Janeiro, Brazil
E-mail: denisemorsch@yahoo.com.br

Eduardo Carlos Tavares
Medicine Department of PUC-Minas, Betim, Minas Gerais, Brazil
E-mail: eduardoctavares@gmail.com

Maria Candida Ferrarez Bouzada
Department of Pediatrics, School of Medicine
Federal University of the State of Minas Gerais, Belo Horizonte, Brazil
E-mail: bouzada@medicina.ufmg.br

Steven Eric Byrd
Department of Society, Culture, and Languages
University of New England, Biddeford/Portland, Maine, USA
E-mail: sbyrd@une.edu

Abstract

Objective: Verify the mourning and paternal suffering in the context of perinatal death, through interviews with the mothers that suffered a gestational loss.

Methods: This study has a qualitative, longitudinal, and prospective research realized through two semi-structured interviews with parents who lost children with less than 22 weeks of gestation at the high-risk maternity ward at a public hospital, in Belo Horizonte, Brazil, from February-October 2019. In the interviews, a vital trait was paternal suffering, as evidenced by the mother’s speech. This matter brought the authors attention.

Results: The interviews in this study show evidence that men need to be tended regarding the time of neonatal loss. The women’s interviews expressed the suffering of their companions and demonstrated how they wished to share their pain with them during their period of mourning. The mothers provide evidence that they feel the need of their partners during gestational loss.

Conclusions: Paternal suffering following neonatal loss is often ignored and forgotten about. Further research and directives of support, including supporting neonatal loss as part of the healthcare system, and meaningful steps to ensure quality treatment, are essential for making progress in this overlooked area.

Keywords: Mourning, Professional Training, Neonatal Death, Disenfranchised Grief.
1. Introduction

Neonatal loss is a topic that warrants attention, as it carries with it significant emotional pain, for the mother as well as for her partner. Also, it has the potential of creating future problems in the conjugal and family relationship. Such issues include emotional outbursts and an overall lack of interest in life, which can affect the other children of the family and work – and involve both the mother and her partner (Brasil, 2017). Recent scholarship has raised awareness on this issue, which is mostly invisible in modern-day society but is one which carries significant emotional suffering for the families involved (Frøen et al., 2016; Heazell et al., 2016; Horton & Samarasekera, 2016; Aguiar & Zornig, 2016).

The impact and consequences of losing a child for the parents, families, healthcare professionals, and society should not be ignored. They should instead be examined both in the neonatal period as well as subsequent periods. The adverse effects, particularly in the mental health of the parents, can be alleviated through empathetic practices and personalized interventions, practised in a sensitive and individualized manner (Heazell et al., 2016).

Neonatal loss encompasses, in addition to the suffering associated with the loss of the baby that the couple planned and desired, secondary losses that can intensify the mourning process, even when it occurs in the first weeks of pregnancy. These secondary losses can cause changes in the family structure that was in the planning stages. These include: losses in the opportunity of parenting; losses in stature or social identity associated with pregnancy and life in general; losses in the feeling of security and a sense of control over life; losses in self-esteem and of control over one’s body (Aguiar & Zornig, 2016; Callister, 2006; Heustis, Jenkins & Wolfelt, 2005).

Studies generally indicate that mothers tend to show more emotion and go through a more intense period of mourning and a more significant number of emotional manifestations (Aguiar & Zornig, 2016; Brownlee & Oikonen, 2004; Fonseca et al., 2010). This is attributed to the stronger physical bond to the baby, above all when the loss occurs in the first months of pregnancy and therefore having the additional emotional overload of physically going through the loss of the child. That is, being the person physically attached to the baby, mothers can feel a heightened sense of guilt, feeling personally responsible for the loss, even when there is no clear medical explanation for it. Fathers tend to show more controlled responses during the mourning process, feeling the need to "be strong" and "take care" of his spouse. In general, men get back to their daily routines and professional lives more quickly than women (Callister, 2006; Heustis et al., 2005). Moreover, men are guided to such conducts, given that there are no worker rights protections for them in these situations, as well as general social and cultural norms governing their behaviour. Considering these gender disparities in the mourning process (designated as "incongruous mourning"), the loss of a child can accentuate tensions in conjugal relations (Callister, 2006) if not given proper attention by the family, by society, and by healthcare professionals.

Hence, the present study aims to verify paternal mourning through interviews of mothers, as well as through the accounts of some of the fathers present during the interviews with the mothers.

2. Methodology

This case study is one of qualitative, longitudinal, and prospective research realized through two semi-structured interviews with parents who lost children with less than 22 weeks of gestation at the high-risk maternity ward, Maternidade Odete Valadares of the Fundação Hospitalar de Minas Gerais, in Belo Horizonte, Minas Gerais, Brazil, during the months of February-October 2019. In the interviews, one of the noteworthy traits was paternal suffering, as evidenced by the mothers, as well as by the fathers themselves that were present during the second round of interviews. These caught the authors' attention to this topic.

The initial contact with the participants was realized during their admittance to the maternity ward, during the first 24 hours following their neonatal loss. The first interview was also conducted during this period, whereby the
patients’ data were collected to aid our analysis. The data consist of prior and recent obstetric data of the mother, as well as demographic data.

The second interview took place one month following the neonatal loss, realized in the home of the patient or at an area designated by her. In this interview, guided questions were used to verify her perceptions of that moment, her perceptions about her adaptation to daily life following her loss, and her perceptions about mourning and the quality of her professional activities. The analysis of the interviews was conducted by careful listening to and reading of the transcripts, which were organized into nuclei of meaning and meaningful utterances.

To protect the privacy and anonymity of all the interviewees, codes are used: Mother 1 = M1, Mother 2 = M2, Father = F, etc.

3. Ethical Standards

This study was approved by the Committee of Ethics at the Fundação Hospitalar do Estado de Minas Gerais (Hospital Foundation of the State of Minas Gerais, Brazil), and by the Committee of Ethics in Research at the Universidade Federal de Minas Gerais (the Federal University of the State of Minas Gerais, Brazil), Research Approval Code: 2.727.563: 2.727.563.

4. Results

Initially, there were 34 mothers who submitted paperwork for inclusion in this study. All of them agreed to an interview 30 days following their neonatal loss. However, only 12 of the original 34 participants provided interviews. The demographic data of the 12 mothers that agreed to an interview are found in Table 1.

Table 1. Demographic data of 12 women who lost children, February-October 2019.

| Education level | Formal work | Pregnancies | Living children | Age of the baby at the time of loss (in weeks) | Presence of a companion | Presence of the father | Education level |
|----------------|-------------|-------------|-----------------|-----------------------------------------------|-------------------------|-----------------------|----------------|
| 27             | Incomplete High School | Yes | 2 | 1 | 9,1 | Yes | No |
| 36             | Graduate School | No | 2 | 0 | 16 | Yes | No |
| 27             | Incomplete High School | Yes | 2 | 0 | 8,5 | Yes | Yes |
| 37             | High School | Yes | 3 | 1 | 7 | No | No |
| 34             | Incomplete Middle School | No | 3 | 1 | 19,3 | Yes | Yes |
| 39             | School | No | 3 | 1 | 11,6 | Yes | Yes |
| 26             | University | No | 1 | 0 | 11 | No | No |
| 25             | High School | No | 1 | 0 | 12 | Yes | No |
| 40             | High School | No | 2 | 1 | 9,4 | Yes | No |
| 29             | Incomplete High School | Yes | 3 | 1 | 11,6 | No | No |
| 35             | Middle School | Yes | 2 | 1 | *285g | No | No |
| 20             | University | Yes | 1 | 0 | 12,1 | Yes | Yes |

5. Results and Discussion

The existence of paternal suffering, recognized by their partners, was one of the more significant discoveries in our study. From the women's accounts, the fathers’ pain was notable, and that they attempted to control their feelings as
a way to help the mothers cope with their losses. Regarding the question of gender, some studies on neonatal loss indicate that, as women are the ones who carry the baby, a greater sense of guilt can manifest in them in contrast to men. As for the men's part, according to Souza and Muza (2011), they usually offer more controlled responses to neonatal loss due to the need to present themselves as “strong”, and as a means to provide emotional support for women. Moreover, men typically have lower levels of depression in contrast to women, due to the type of meaning they assign to neonatal loss. However, there are symptoms like depression and anxiety in men following the neonatal loss, with specifics which warrant attention (Lewis & Azar, 2015; Obst et al., 2020).

Note the following women’s accounts from our interviews:

“The father suffers too as well. A man doesn’t show much, right? A man remains more restrained, [but] they suffer a lot.” (M7).

“Besides the concerns about the loss [of the child] and all that, there is the worry about me. Just like he said: ‘it was more devastating for me because I saw you suffering, you not feeling well.’ That’s the type of suffering he goes through. He said it was devastating for him because of that [loss]. So, he was worried: ‘Gosh, when is this going to end? Is she ok? Yes, he was anxious.” (M7).

“They say that the father doesn’t feel anything. He does. And for a man, it is even worse because he bottles it up. A woman talks a lot; she talks a lot. And I would stay in the room, I spoke with my girls, one supporting the other. But a man doesn’t do that. He stays quiet. So, he suffers more.” (M7).

“How does a father not stay with his wife? The mother just lost a child. And the child is his too; it’s not just the mothers. Why can’t he stay home for a day? What about his feelings?” (M5).

“He didn’t cry at all; he wanted to be strong so that two weren’t there crying. Who was going to support us at that moment?” (M3).

“My husband has difficulty in expressing himself and speaking about what he feels inside, but I can see it in his attitudes, in the way he acts, that this situation impacted him deeply on a psychological level. I believe this must affect his work.” (M2).

“With me, he isn’t able to talk about it, because he is afraid that I will get hurt. And I am also not able to speak openly with him like I would like to, because he gets upset. So, he doesn’t show his feelings to support me. [It’s] like that, you understand?” (M1).

The father’s presence with the baby

The presence of family members plays a fundamental role in supporting women who have lost children; to be able to count on support from those closest to them is essential (Conway & Russell, 2000). The father of the baby has been shown to be an actual figure (Rodrigues & Hogo, 2005) to the mother following a neonatal loss. His presence is significant, and his absence can cause a sense of helplessness and sadness in women, as we have observed in our accounts of women who have lost babies. It is possible to hear in their speech, one which is full of emotion, that he does play an essential role in sharing this painful experience with her. This is evidenced in the following accounts:

“And there you are alone, and you have no one with you, no one to speak with about anything. Right? You are alone. To have someone there at least to give you a hand at that moment, to spend the night. I think that if a man had at least the day off from work would be interesting, for women.” (M4).

"My husband went back to work. And the day he told me about it I said, 'my God.' Then he went back to work, my God, what am I going to do? I didn't want to be alone." (M5).

“If he had not been there, it would have been… [she quickly continues]. It would have been worse; the suffering would have been greater for certain.” (M3).

“You can have your whole family present, but the only person that I want to talk to is the father. He wants to know what I’m going through, he can talk more openly about this topic because he is going
through the same thing as me, maybe not as intense as what I went through, but he is there and is seeing the same things that are going on. And that is why I think he should have some time off, and he had no such thing. He had to go back to work.” (M1).

“My husband, honestly, I would have liked to have had his companionship near me. But I didn’t get it. And I still don’t have it, because he had to go back to work as soon as I left the hospital.” (M2).

What men say

As observed above, the women affirm their feelings of suffering, the sadness of their losses, and the speech of men show a sense of commitment toward their wives, and to their jobs. The men tend to show a more traditional male social role, one which has been crystallized into social and familial norms, whereby their emotions are more reserved and private. Note the following accounts from men:

“So, I wasn’t there. I had to work, and that was bad. Yes, I wanted at least to spend one day with her. She wasn’t feeling well at home, and I had to work. But I was the only one who could support her. (…) I only work to keep up the house and pay the rent. I lost a child. But life must go on.” (F, M6).

"You remember everything, even more so in my case. I work here. I come here and see fathers carrying their children, mothers carrying their children, so at any moment you remember what happened, right? And when I come to work, and I go through the entrance, I remember everything that happened that day. So, I go up to the third floor to try to be by myself, but at lunchtime and everything else that goes on there, it sometimes gets complicated, you see?” (F, M12)

Men also express the importance of having official and legal recognition when they comment on the lack of worker protection laws for neonatal losses and the suffering caused by them. These were also articulated by women:

“I believe that fathers should have at least two days since not only a mother [but] a father takes a hard hit as well. For him, it is also a loss. To be there, he needs to be there to support his partner with everything; it’s necessary. That doesn’t mean that two days are enough…” (F, M12)

“It would be essential. But this law is going to change. We’re going to get there. If it’s not us, then other parents are going to do it. What we didn’t have others are going to have.” (F, M6).

In the speech of the women during these interviews, silence often follows light crying, as well as pauses that "stop" the speech, which also demonstrates the experience of these losses. Indeed, in examining the function of silence during the mourning process of a loved one Poli (2008) notes that it occurs on the margins of representation, that it is impossible to express in words the reality of death. Hence, the loss of a loved one can be expressed by a lack of words, by insufficient discourse, and by a disconnect between words and feelings. This was rather evident in all the interviews conducted for this research, and notable in both the women and men.

It need be further noted that neonatal losses occur unexpectedly and unforeseen in the majority of instances, frequently occurring in the context of normal pregnancy (Brownlee &Oikonen, 2004; Fonseca et al., 2010). Such characteristics increase the shock of the parents, and moreover increase the difficulty in accepting it, and, given its sudden nature, impede family members in mobilizing resources and coping strategies to prepare emotionally for the loss (Callister, 2006). Furthermore, it cannot go unmentioned that many lost babies already had tentative names.

Despite the frequency of neonatal losses, which spontaneously occur in 15-20% of pregnancies of up to 22 weeks, the subsequent implications are underestimated or ignored by the political class, by the media, by society, and even by healthcare systems. It should be recognized that this type of mourning, which carries with it a considerable emotional impact, but is one whose effects are not fully appreciated by healthcare professionals, nor by society generally. However, it is one which should be more closely examined and considered.

This type of loss constitutes a particularly grave one, in the sense that it involves the parents and closest family members, and is one where a void is created – a void not only in relation to past memories but also future ones...
(Fonseca et al., 2010). Many times, such a loss is the parents’ first experience with mourning, and in the case of younger parents, it simultaneously affects both members of the couple, which compromises their ability for mutual support (Kavanaugh & Wheeler, 2003; Lang, Goulet & Amsel, 2004). In instances of multiple losses, the uncertainty of having a successful pregnancy can become ambivalent, for both mother and father. The subsequent lack of social rituals associated with neonatal loss (funerals, for example), disinformation within social networks in regard to how to offer support to a couple, and the overall social devaluing of such an event – considered by society as something less significant in comparison to the loss of an older child or an adult –, accentuate the lack of resources available to a couple going through this type of loss and therefore affect how they cope with it (Brownlee & Oikonen, 2004; Fonseca et al., 2010; Roli & Canavarro, 2001).

The organization of healthcare services for couples coping with neonatal loss, along with training of healthcare professionals who are involved with the families, is an important characteristic in the overall performance of a healthcare system, one which can contribute to the resilience of parents during their period of mourning (Homer, Malata & Ten Hoope-Bender, 2016).

Soubieux (2014) notes that neonatal loss in the psychology of the parents is not uniform. The period of mourning is related to the conceptualization of a life that existed and then ceased to exist. The elaboration of mourning for a neonatal loss is possible, but it can be filled with significant anguish. When such elaboration is possible, it can allow for a surprising psychological reconstruction. According to the author, mourning for neonatal loss is paradigmatic, as it revives and continues in future pregnancies (for the couple as well as for the close relationships). Moreover, a lack of its recognition on behalf of the support network, and a lack of understanding of the inherent suffering associated with the loss, can transmit a message that mourning is unnecessary, and therefore can create other difficulties (Public Health Agency of Canada, 2000).

A couple needs to make adjustments at multiple levels following neonatal loss: external (i.e. the functions of day-to-day life), internal (i.e. the roles one assumes, namely of mother and father, and, in the absence of other children, one may or may not know what one’s role is now), and spiritual (i.e. one’s belief systems, values, and assumptions). The mourning process reaches a conclusion when one is capable of emotionally integrating the loss of the child, and, therefore, is able to continue with life. This does not imply renouncing the relationship with the lost child but learning to manage the loss in a way that allows the parents to continue with their lives following their loss.

Symptoms are more intense in the first months following the loss, though widely vary in their diversity and intensity (Fonseca et al., 2010; Kavanaugh & Wheeler, 2003). In the relational domain, symptoms are noteworthy in the relationship between mother and father and include factors such as the desire to have a child, the duration of the pregnancy, and lack of previous neonatal losses. Family and social support systems, the nature of relations in the extended family, and the attitude of healthcare professionals involved are also factors with the greatest relevancy for the social network.

To block a mother's thinking and to try to make her forget what happened after being discharged from the hospital creates a "conspiracy of silence". Neonatal loss during pregnancy or following birth should instead create a space for mothers, and for her family, to address this topic openly, to talk about their frustrations, their sense of guilt and powerlessness – not to confront the sadness but to help them reorient their lives. A family holistically needs healthcare attention, including the thoughts and feelings of the patients.

This leads us to assess the importance of comprehending the emotional experience of these mothers and their partners in the face of neonatal loss at its various stages: during pregnancy, during premature birth, or the following birth. Men can be affected by an unintentional indifference on the part of healthcare professionals, who tend to focus on the biological symptoms occurring in the mothers (Williams et al., 2020). However, fathers must have avenues available to them to express their feelings and pain at these moments. The interviews in this study show evidence that men need to be tended to as well at the time of neonatal loss.
This study also offers evidence that there is a need for healthcare intervention and a network of resources that can be made available for parents at the time of neonatal loss. Training and organization within the healthcare systems that work in this area are essential. A type of multidisciplinary training would be desirable to handle the problems associated with neonatal losses and the prevention of its harmful effects. It is also important to deepen the knowledge of this topic and to discover the specifics and subtleties involved in the mourning process, to offer better support systems for it, adjusted for individual cases and long-term support for the period of mourning.

It is furthermore important to construct and develop a support network and collaborative partnerships, intending to improve patient care services, to handle problems related to psychosomatic, emotional, psychological, or spiritual distresses caused by neonatal losses. That is, a new perspective for healthcare systems needs to consider fetal and neonatal losses as part of its service to patients. Such losses and a contextualized medical history of the family involved would result in positive and humanizing changes for healthcare systems. What is needed are carefully-planned actions both in the areas of healthcare and in law, the updating of policies, oversight, and research into best practices for patients who have suffered neonatal losses (Aguiar & Zornig, 2016).

As shown herein, women expressed the suffering of their companions and demonstrated how they wished to share their pain with them during their period of mourning. That is, mothers, provide evidence that they feel the need of their partners during their time at the hospital, as well as during the first days at home following the loss of a child.

The study also leads us to question current Brazilian worker rights regarding paternity, which has a great disparity between what is afforded to mothers and fathers. At the time of this writing, Brazilian law permits that women who suffer neonatal losses occurring up to and after 22 weeks of gestation are entitled to 15 days of mourning, while fathers have none (Article 395 of the Brazilian workers’ code).

Much work remains to attain a better comprehension of this issue and the creation of strategies which can offer adequate, healthy space for mothers and fathers who must deal with neonatal losses. Dedicating more research on this topic will undoubtedly be an important resource to inspire and inform meaningful changes in this area.

6. Conclusions

Paternal suffering following neonatal loss is very often ignored and forgotten about. Societal norms commonly do not allow paternal feelings to be seen or heard, as men are expected to be “the stronger sex”. Compassion, in this case, is considered exclusive for mothers. However, this type of pain is shared by the couple. And the lack of worker rights for men in Brazil shows that paternal mourning is invisible and ignored. Furthermore, there is an invisibility of the lost child by society generally.

But we need to give a voice to this pain, a legitimate one, independent of how long the child was here. Further research and directives of support, including supporting neonatal loss as part of the healthcare system, and meaningful steps to ensure quality treatment, are essential for making progress in this overlooked area.

References

Aguiar, H., & Zornig, S. (2016). Luto fetal: a interrupção de uma promessa. Estilos da Clínica, 21(2), 264-81. http://dx.doi.org/0.11606/issn.1981-1624.v21i2p264-281

Brownlee, K., & Oikonen, J. (2004). Toward a theoretical framework for perinatal bereavement. British Journal of Social Work, 34(4), 517-529. https://doi.org/10.1093/bjsw/bch063

Callister L. C. (2006). Perinatal loss: a family perspective. The Journal of Perinatal & Neonatal Nursing, 20(3), 227-236. https://doi.org/10.1097/0005237-200607000-00009

Conway, K., & Russell, G. (2000). Couples’ grief and experience of support in the aftermath of miscarriage. The British Journal of Medical Psychology, 73 Pt 4, 531–545. https://doi.org/10.1348/000711200160714
Departamento de Ações Programáticas Estratégicas da Secretaria de Atenção à Saúde do Ministério da Saúde. (2017). *Atenção humanizada ao recém-nascido - Método Canguru: manual técnico*. Brasília: Ministério da Saúde.

Fonseca, A., Nazaré, B., Araújo Pedrosa, A., Canavarro, M. C. (2010). *Especificidades da perda perinatal: implicações para os agentes de intervenção*. In *Anais da 1ª Jornadas Peritia: Psicologia e Perda Gestacional*. Oliveira do Bairro: Peritia.

Frøen, J. F., Friberg, I. K., Lawn, J. E., Bhutta, Z. A., Pattinson, R. C., Allanson, E. R. … & Lancet Ending Preventable Stillbirths Series study group (2016). *Stillbirths: progress and unfinished business*. *Lancet* (London, England), 387(10018), 574-586. https://doi.org/10.1016/S0140-6736(15)00818-1

Heazell, A., Siassakos, D., Blencowe, H., Burden, C., Bhutta, Z. A., Cacciare, J., … & Lancet Ending Preventable Stillbirths investigator group (2016). *Stillbirths: economic and psychosocial consequences*. *Lancet* (London, England), 387(10018), 604-616. https://doi.org/10.1016/S0140-6736(15)00836-3

Heustis, J., Jenkins, M., & Wolfelt, A. D. (2005). *Companioning at a time of perinatal loss: a guide for nurses, physicians, social workers, chaplains and other bedside caregivers*. Fort Collins: Companion Press.

Homer, C., Malata, A., & Ten Hoope-Bender, P. (2016). *Supporting women, families, and care providers after stillbirths*. *Lancet* (London, England), 387(10018), 516-517. https://doi.org/10.1016/S0140-6736(15)01278-7

Horton, R., & Samarasekera, U. (2016). *Stillbirths: ending an epidemic of grief*. *Lancet* (London, England), 387(10018), 515-516. https://doi.org/10.1016/S0140-6736(15)01276-3

Kavanaugh, K., & Wheeler, S. R. (2003). *Depressive symptoms in men post-miscarriage*. *World Journal of Men's Health*, 11(5), 8-13.

Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). *Men’s grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model*. *BMC Pregnancy and Childbirth*, 20(1), 11. https://doi.org/10.1186/s12884-019-2677-9

Poli, M. C. (2008). *O psicanalista como crítico cultural: o campo da linguagem e a função do silêncio*. *Revista Mal Estar e Subjetividade*, 8(2), 365-378.

Public Health Agency of Canada. (2000). *Family-centred maternity and newborn care: national guidelines*. Ottawa: PHAC.

Rodrigues, M. M. L., & Hoga, L. A. K. (2005). *Homens e abortamento espontâneo: narrativas das experiências compartilhadas*. *Revista da Escola de Enfermagem da USP*, 39(3), 258-267. https://doi.org/10.1590/S0080-62342005000300003

Rolim, L. & Canavarro, M. C. (2001). *Perdas e luto durante a gravidez e puerpério*. In: M. C. Canavarro (Ed.) *Psicologia da gravidez e da maternidade*. Coimbra: Quarteto.

Soubieux, M. J. (2014). *Le deuil perinatal, un impensable à penser*. *Le Carnet PSY*, 185(9), 22-24.

Sousa, E. M. & Muza, J. C. (2011). *Quando a morte visita a maternidade: papel do psicólogo hospitalar no atendimento ao luto perinatal*. Monografia de Especialização em Psicologia Hospitalar e da Saúde. Universidade Católica de Brasília.

Williams, H. M., Topping, A., Coomarasamy, A., & Jones, L. L. (2020). *Men and miscarriage: a systematic review and thematic synthesis*. *Qualitative Health Research*, 30(1), 133-145. https://doi.org/10.1177/1049732319870270

**Copyrights**

Copyright for this article is retained by the author(s), with first publication rights granted to the journal. This is an open-access article distributed under the terms and conditions of the Creative Commons Attribution license (http://creativecommons.org/licenses/by/4.0/).