

Tanner's Story: A Phenomenologic Stance towards Newborn Death

Helen J. Brown

Un point de vue phénoménologique sera exploré ici comme perspective de développement d'une connaissance personnelle de la pratique des soins infirmiers offerts aux familles vivant la perte d'un nouveau-né. L'expérience de l'auteure vis-à-vis de la mort du nouveau-né est analysée à l'aide des thèmes existentiels de van Manen. La validation de la maternité est le thème essentiel qui émerge d'une analyse fondée sur les thèmes existentiels du monde vécu de van Manen. La pensée phénoménologique est présentée comme une voie vers la compréhension de soi et la réflexion pouvant informer la connaissance personnelle de la pratique des soins infirmiers et les relations que nous entretenons avec les familles.

A phenomenologic stance is explored as a perspective from which to develop personal knowledge for nursing with families experiencing perinatal loss. The author's experience of newborn death is analyzed using van Manen's existential themes. An essential theme — validating motherhood — emerges from an analysis based on van Manen's lifeworld existential themes. Phenomenologic reflection is presented as a path to self-understanding and reflection, which may inform personal knowledge for nursing practice and the relationships nurses nurture with families.

It was a long, quiet journey home with my sister. My numbness momentarily gave way to the shock and reality that I was going home without my newborn son. As this day ended I knew that it would be permanently composed in my memory along with a number of other powerful experiences. Of these experiences some were positive, such as giving birth to my beautiful boy, and some were devastating, such as when I generated the courage to say goodbye as Tanner took his last breath snuggled between my husband and me, in our ever so brief "family bed."

It is a challenge to see into another person's life with real clarity and understanding, yet in nursing we accompany people through their health and healing experiences and seek to understand and create knowledge related to the meaning of those experiences. As professionals grounded in humanistic philosophy (Parse, 1987; Paterson & Zderad, 1988; Watson, 1985), nurses care for people who have suffered

Helen J. Brown is a faculty member specializing in perinatal, pediatric, and neonatal nursing, British Columbia Institute of Technology, Burnaby, British Columbia.

perinatal loss, an experience that is unique to childbearing women and their families. A true understanding of perinatal loss supports what Lauterbach and Becker (1996) describe as the ultimate aim of nursing, to be "a human caring art and science to assist persons and society in becoming more fully human" (p. 57). The search for meaning in newborn death is inseparable from the experiences of life and death that are woven seamlessly into our lives.

Purpose

There has been considerable discourse, in the development of nursing knowledge, on appropriate ways of knowing (Gortner, 1990; Schultz & Meleis, 1988; White, 1995). A postpositivistic philosophy of knowledge development in nursing supports interpretive understandings of personal experience and introspective analyses of subjective realities. In this context, both self-understanding and reflection have the potential to inform nursing knowledge and the relationships with families that the profession nurtures.

The purpose of this paper is to provide a way of thinking about the contribution of personal knowledge to nursing practice, one that emerges from an existential analysis of the newborn-death experience. I will propose that reflection and self-understanding from a phenomenologic stance can provide insights and understandings for nurses caring for families experiencing perinatal loss. My personal experience of newborn death is the lens through which I will interpret van Manen's (1990) existential themes.

Perspective: A Phenomenologic Stance

The primary thesis of this paper is that a phenomenologic stance, as a particular perspective from which to explore the meaning of loss, can inform personal knowledge for nursing practice through self-understanding and reflection on lived experiences. A phenomenologic way of being, or a process of phenomenologic reflection, has the potential to sensitize nurses to the relationship between personhood, self-understanding, personal experience — as a way of knowing, or knowledge in experience — and nursing practice. In particular, a phenomenologic stance combined with narrative as the primary scheme by which human existence is rendered meaningful (Polkinghorne, 1988) can be a lens through which to view the development of nursing knowledge.

As a method of human science research, phenomenology calls into question how we live as human beings (van Manen, 1990). In nursing,

this form of inquiry focuses most frequently on the research method, to generate knowledge for practice. I believe that approaches to inquiry can be broadened to include analysis of and reflection on personal experience, to help human beings understand the unique nature of human thoughts, behaviours, and ways of being in the world. Rather than attempt to understand what it is like to live within the respondent's world, we might seek opportunities for self-understanding, using phenomenologic reflection as a way of acquiring personal knowledge.

A Phenomenologic Stance: A Narrative of Newborn Death

The purpose of phenomenologic reflection is to capture essential meaning (van Manen, 1990). My interpretation of the experience of newborn death will be based on four lifeworld existential themes, as guides to phenomenologic reflection: *lived space*, *lived body*, *lived time*, and *lived human relation* (van Manen). These world-of-lived-experience existential themes probably pervade the lifeworld of all human beings, regardless of their historical, cultural, or social situatedness. In order to come to an understanding of the meaning of my son's death, I will address fundamental insights related to these four themes.

Lived Space

Lived space is felt space (van Manen, 1990). The theme of lived space, as the way in which I experience the world, encourages me to reflect on the special care nursery (SCN), the ocean, my home, and the places of my day-to-day existence. My lived space became the setting for the events surrounding Tanner's birth and those surrounding his inexplicable severe hypoxic insult. The delivery room became a place where words described and framed Tanner's precarious existence. My being thrust into the SCN lived space, as a care receiver rather than as a care provider, contributed to my existing internal chaos and confusion about accepting Tanner's short life. This space eventually shifted to the beach, where we had chosen to take Tanner for his last few moments of life. After we left the health-care setting behind, our house became the lived space, where the evidence of our hopes and dreams was visible and tangible in the room we had prepared for Tanner. I have hesitated to change the lived space of Tanner's room, since it validates his existence in our life and is full of treasures and the gifts that were given to us.

My day-to-day space is "safe" places where I nestle with family and friends as life continues in a new, unanticipated direction. My lived space (that is, my day-to-day life) feels empty. I find my most profound

comfort in the shared space of healing with my husband. We describe our felt space — our day-to-day experience of grief following our son's death — as similar to sailing in a storm: the waves wash over you and startle you, and just when you are beginning to recover from the assault another wave comes. There is no pattern. One is never sure when that rogue wave is going to come and leave your boat a crumpled mass of debris. It has been a continual challenge to find the calm seas between the storms that leave us a crumpled mass of emotional debris.

My day-to-day space offers me limited opportunity to refer to my son, since he is not physically present. My journey of healing has been a continual search for a space where I can find validation for my pregnancy, labour, and birth, and for Tanner's short life. The search for this space shaped the weeks following his death and is integral to the experience of suspended time.

Lived Time

Lived time is subjective time, as opposed to clock time, which is objective time (van Manen, 1990). Our experience of time is not often the subject of reflection, but when we are awaiting vacation it seems to pass slowly and when we are on vacation it seems to pass quickly. I experienced time as a whole new dimension following Tanner's death. Time was suspended, as if the familiar measures of morning, afternoon, evening, and night-time were intangible and incomprehensible. The hours and minutes of watching Tanner's final struggle for breath, and the moment of passing his body to his grandparents to take to the funeral home, where they would part with his physical being, seem timeless. The time spent with family forms a comforting image in my memory, yet I cannot discern how we actually passed those days.

For me, questions have arisen related to the experience of lived time: Must one live 80 years in order to have a meaningful life? Can the value of life be measured based on our limited understanding of time? This dimension of our experience inspired us to create memories in a limited amount of time, by taking pictures, visiting the ocean, saving a lock of hair, making plaster moulds of our son's hands and feet. These memories will enable us to share Tanner's spirit with others for an unlimited amount of time.

Pregnancy represented my journey through time from conception to delivery: 37 weeks of intense attachment and fear. My nursing practice made me fully aware that this journey can be hazardous and that healthy babyhood cannot always be expected. Despite my fear, our son

was, in the words of my mother, "incorporated into every dimension of his parents' lives and was celebrated, as Chinese babies are, from the time of conception." This celebration of my pregnancy has enriched Tanner's short life by helping me to value the cherished moments we shared and will continue to share as a family.

Lived Body

Lived body refers to the phenomenological fact that we are always bodily in the world (van Manen, 1990). The embodied experiences of pregnancy and the postpartum period caused me to reflect, as I sought to understand the healing of my body following emergency forceps delivery and the ensuing bodily changes that signified both motherhood and nonmotherhood. The changes that my body underwent as it returned to its nonpregnant state seemed to me almost a betrayal — I wanted to stay within a mother's world to validate Tanner's existence. I constantly searched for meaning in the irony of a changing body. I had a strong desire to return to my pregnant body, Tanner nestled safely inside. I still proudly display my linea nigra — the embodiment of his existence. The chant "no belly, no baby; no belly, no baby" rang in my head those first few weeks at home. I believe this was my way of understanding the reality of being suspended between two worlds, motherhood and nonmotherhood. I belonged in neither world at that point; I had lived through pregnancy and birth but my mothering experience was suspended, because my baby was not with me in body.

After I arrived home, midst the warmth of my family, my physical healing became a tangible focus for the challenge of providing immediate remedies: food, water, exercise, sleep, the warmth of the sun, the beauty around us. The inevitable emotional pain, which was at times impossible, was embodied in restlessness, inertia, loss of appetite, and a feeling of overwhelming heaviness. My instinct and drive for health have been my guides through this dense fog of sadness and loss. For me, my mother's words, "Thank you for letting me care for your body," embody grief as experienced within my family relationship.

Three weeks after Tanner died I found myself attending a postnatal fitness class that, reflection and understanding tell me, validated my motherhood. All the mothers had their babies with them as they moved through the exercise routines. The reaction of many people was that seeing all those new mothers and babies must have been "pure torture" for me. When my family expressed a desire to protect me from this potentially hurtful experience, my response was: "I am a mother. I just don't have Tanner here with me. He is embodied by my memories of

him." Attending this class as a postpartum mother allowed me to validate motherhood by acknowledging the physical experience and bodily changes that surrounded Tanner's entry into our lives.

Lived Human Relation

Lived human relation is the relationships we maintain in the interpersonal space we share with others (van Manen, 1990). For me there is no more profound emptiness than that of the shared parenthood that emerged as suspended time and lived human relation; I was suspended between the world of parenthood and the world of nonparenthood. My husband and I feel emptiness when we try to understand our experiencing two of life's most powerful events, birth and death, in the same moment. All the anticipation and preparation for the change from couple to family of three ended abruptly — death 24 hours after birth. Our lives are forever changed because we are parents, the world looks different to us because we are parents, and we are vulnerable simply by being in the world as parents.

The central presence of my older sister, her husband, and their four-month-old son during Tanner's life is forever etched in my heart and soul. They shared tears, hard decisions, cuddles on the beach, and, most of all, their spirit, guiding us along the path we most feared to tread. Their own loss experience is integrally linked to ours, since we shared many hopes and dreams for Tanner's presence in our collective lives. This shared pain and vulnerability helped to lift the heavy weight of grief. My younger sister appeared almost instantly to spend time holding, admiring, and making memories of her own. She slept beside us the only night my husband, Tanner, and I would share as a family. I felt stronger as she lay beside me, ready in a moment to cry with us and admire our little boy as he lay so very still.

My understanding of Tanner's life and death is informed in significant part by my relationships with my family and the meaning that family members take from the experience. In the words of my sister:

I hope your souls, individual and collective, are finding some warmth somewhere too. Little Tanner is everywhere, inside each of us, in different ways, all the time. What an intense influence for one so little and pure. I couldn't love you more than I do — and yet each day I love you more.

If experience can be reflected upon through lived space, lived body, lived time, and lived human relation, then I find the most profound meaning in my lived human relation with my partner in parenthood.

If to love someone is to feel their pain so intensely that your whole body groans in anguish when they are hurting, then I have truly found my soulmate. My pain is almost tolerable, but his is unbearable, and my healing is intimately connected to our shared comfort, inner peace, and life ahead.

An Essential Theme: Validating Motherhood

According to van Manen (1990), to determine the universal or essential quality of a theme is to discover aspects or qualities of a phenomenon without which it could not exist. It is my belief that without the essential theme of validating motherhood, the phenomenon of life and death of my newborn son has no fundamental meaning. Van Manen describes an essential theme, such as validating motherhood, as "knots in the web of our experiences, around which certain lived experiences are spun and thus lived through as a meaningful whole" (p. 90).

Further illumination on the theme of validating motherhood is offered by its location in the literature on perinatal loss: categories that emerge in the literature help one interpret the theme — the categories are integral to one another because they are associated with a search for meaning in newborn death.

Loss of the World of Motherhood

In the weeks and months following Tanner's death, the existential feeling of being abandoned in a world between motherhood and non-motherhood was the overarching theme in my day-to-day existence. Losing the world of motherhood drives my journey towards healing. I want to reclaim this world despite the irony of being in it without a baby. In my day-to-day world I so often want to say to the people I encounter, "I am a mother; please ask me about my baby." In addition, the thought of having another child helps me to gravitate back to the world of motherhood.

Lauterbach's (1993) phenomenological study explored the essences of the meanings in mothers' experiences of perinatal death of a wished-for baby. I find comfort in Lauterbach's work because I recognize my search to validate motherhood in the mothers' descriptions of existential abandonment by their baby. They describe "a profound feeling of isolation, of Being-a-mother in another world, and the loss of the world of mothering that follows death of a particular, wished-for baby" (p. 157). The women tell of their loss of both motherhood and its accompanying personal and social role. By reviewing the essential themes and

narratives in this study, I was able to verify and support my theme of validating motherhood. Extending this work, through further analysis of my narrative of newborn death based on Lauterbach's results, may provide opportunities to reflect with greater understanding of the experience of perinatal loss as an essential theme.

Symbolic Meaning of Loss

Theorists and researchers suggest that the meaning ascribed to the reality of loss, more than anything else, indicates how people feel about their loss. Toder's (1986) research with grieving parents examined the symbolic meaning of the loss of a child. My thematic approach could be considered a way of understanding the symbolic meaning of experiencing newborn death. In describing the symbolic meanings of the loss of a child, Toder alludes to a loss of identity: "...a sudden realization that the way you have been perceiving and defining yourself is no longer available or functional. It suggests that the old way no longer fits but that it has been stripped away before a new way of being has been developed" (p. 65). Women have expressed the need for caregivers who know what pregnancy means to them as individuals (Swanson-Kauffman, 1986). It is in this sense that my loss of identity as a mother, and the symbolic meaning of that loss, underlie my efforts to reclaim the world of motherhood.

It is my belief that the present work, because it focuses on the death of a first baby, introduces another dimension to the theme of loss of identity. Since Tanner was my first baby, my awareness of his existence represented a journey *towards* motherhood. Lederman (1984) describes such a journey in primigravid women as a progressive shift in their thinking away from the self-unit towards the mother-infant unit. During pregnancy we prepare for motherhood by imagining ourselves as a mother and contemplating our life as a woman with a child (Rubin, 1984). Motherhood was an "imagined identity" during my pregnancy. I believe the theme of validating motherhood following Tanner's death is bound to the notion that maternal identity is not completely formed until the infant is born and has an identity (Colman, 1983; Rubin). The moments for confirming Tanner's identity and my identity as his mother were finite, and it is a difficult process to grieve for an identity that existed so briefly and that was primarily an imagined one. My husband describes this imagined identity as a motion picture playing over and over in his mind prior to Tanner's birth and after his death. The journey to reclaim the world of motherhood is also a quest to capture what could have been and our identity as parents.

Birth and Death: Disorientation to Orientation

Davidson (1977) describes women's movement, following neonatal death, from disorientation to orientation. This process, which is inextricably linked to the woman's perceptual confirmation of her loss, is crucial to her reorientation after the death of her baby. I found disorientation to be pervasive, as my body returned to its pre-pregnant state even while I wanted to remain pregnant: orientation to the reality of newborn death was tangible in the suppression of breast-milk production, physical healing following emergency forceps delivery, and living with the experience of acute grief overlaid with an array of postpartum hormonal fluctuations. The movements between birth and death, disorientation and orientation, as described by Davidson, are another dimension of the experience of newborn death, a dimension that transcends time, space, body, and lived relations.

A Context of Personal Meaning

The theme of validating motherhood, in the present study, must be seen in a context of personal meaning. Swanson-Kauffman (1986) and Lemmer (1991) suggest, based on their studies with bereaved parents, that loss must be seen in a context of personal meaning that emerges through empathetic, caring, personal interactions with caregivers. Lemmer found that mothers' perceptions of noncaring following perinatal loss focused on nurses' failure to acknowledge the loss and the unique contexts of personal meaning associated with their experience of loss. An essential theme of validating motherhood is located within a particular context of personal meaning that recognizes the uniqueness of each experience of grief and loss.

Implications

Phenomenologic reflection is, consistent with van Manen's (1990) existential lifeworld themes, a way of developing personal knowledge for nursing with families experiencing the death of a newborn. Reflecting on an essential theme can help to interpret perinatal loss in a meaningful way, and thus inform the personal knowledge that is required in nursing. In other words, the *process* of phenomenologic reflection might inform nursing practice with families experiencing loss, in addition to the specific theme of validating motherhood. Furthermore, a process of reflection and self-understanding can serve to facilitate an understanding of broader contexts of human experience in caring for families experiencing perinatal loss.

However, families' experiences of newborn death can and do vary. Personal experience and reflection cannot be applied to the experience of all families, regardless of social context. For example, to assume that all women need to validate motherhood following newborn death would indicate a blindness to the diversity of women's experience; to do so would direct nursing action towards outcomes that might not represent the realities of individual women.

The following passage demonstrates the power of story-telling and the search for meaning in newborn death, while also speaking to the lived human relation of one family:

Tanner began in love and lived and died surrounded by love. In the time since his death we have felt the pervasive presence of love in all its diversity. Love has been shown by those determined to walk with us, when we are not very good company, and in their eager, gentle listening to the story even when they already know it. Love is felt in the words of comfort humbly offered, chosen, and spoken in love, and in the willingness to see and hear the pictures of Tanner's beauty.

All of these form a part of learning that says "life is fragile and precious. Children, grandchildren, lovers, partners, spouses, brothers-and sisters-in-law, and friends near and far are to be treasured and told that they are loved and valued." Tanner's immediate family is woven closer than ever. Perhaps all of us, because of Tanner, will love more extravagantly, cherish more fully, snuggle more closely, celebrate life and love more abundantly. We cherish him; he will be with us always.

References

- Colman, L.L. (1983). Psychology of pregnancy. In L. Sonstegard et al. (Eds.), *Women's health II: Childbearing* (pp. 3-16). New York: Grune & Stratton.
- Davidson, G.W. (1977). Death of a wished for child: A case study. *Death Education*, 1, 265-275.
- Gortner, S.R. (1990). Nursing values and science: Toward a science philosophy. *Image: Journal of Nursing Scholarship*, 7, 134-137.
- Lauterbach, S.S. (1993). In another world: A phenomenological perspective and discovery of meaning in mothers' experience with death of a wished-for baby: Doing phenomenology. In P.L. Munhall & C. Oiler Boyd (Eds.), *Nursing research: A qualitative perspective* (pp. 133-179). New York: National League for Nursing Press.
- Lauterbach, S.S., & Becker, P.H. (1996). Caring for self: Becoming a self-reflective nurse. *Holistic Nursing Practice*, 10, 57-68.
- Lederman, R.P. (1984). *Psychosocial adaptations in pregnancy* (2nd ed). New York: Springer.

- Lemmer, S.M. (1991). Parental perceptions of caring following perinatal bereavement. *Western Journal of Nursing Research*, 13(4), 475–493.
- Parse, R.R. (1987). Man-living-health theory of nursing. In R.R. Parse (Ed.), *Nursing science: Major paradigms, theories, and critiques* (pp. 159–180). Philadelphia: Saunders.
- Paterson, J., & Zderad, L. (1988). *Humanistic Nursing*. New York: National League for Nursing.
- Polkinghorne, D.E. (1988). *Narrative knowing and the human sciences*. Albany: State University of New York Press.
- Rubin, R. (1984). *Maternal identity and the maternal experience*. New York: Springer.
- Schultz, P.R., & Meleis, A.I. (1988). Nursing epistemology: Traditions, insights, questions. *Image: Journal of Nursing Scholarship*, 20, 217–221.
- Swanson-Kauffman, K. (1986). Caring in the instance of unexpected early pregnancy loss. *Topics in Clinical Nursing*, 8, 37–46.
- Toder, F. (1986). *When your child is gone: Learning to live again*. Sacramento: Capitol Publishing.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: Althouse Press.
- Watson, J. (1985). *Nursing: The philosophy and science of caring*. Boulder: Colorado Associated University Press.
- White, J. (1995). Patterns of knowing: Review, critique, and update. *Advances in Nursing Science*, 17(4), 73–76.

Acknowledgements

This work could not have been completed without the vision and creative energy of my mother, Dr. Pamela Brown. Her spirit and courage are distinctively woven throughout the narrative portions of this paper and throughout our lives as a family — a community of kinship, caring, love, and laughter.