

Research Experience with a Person Going through the Process of Dying and Death

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AS A POSTGRADUATE RESEARCHER IN NURSING studying the process of dying and death in individuals and their families, I met and cared for a 34-year-old woman named Beth who had terminal breast cancer. My experience with Beth and her family was part of a larger research project that sought to learn the best way to care for such families.

For many health care professionals, death is viewed as something contrary to life instead of a part of it. Indeed, most therapeutic efforts have the sole objective of cure.¹ When a patient's condition becomes terminal, many health care professionals view their efforts as a failure and have difficulty accompanying and supporting their patient, leading to a sense of psychological and social abandonment in the person who is dying, as well as their family.

The design of this research project included the ability to change focus in response to the dying individual and her family. The study group collaborated at key moments to make decisions regarding the execution of the study. My experience with Beth was therefore both individual and shared, making it enriching for all those involved. With my research goals in preliminary outline form, and facing fear, distress, and uncertainties, I placed myself in a challenging research position.

My motivation was the desire to enter the intimate world of the person who is dying, get to know them at a human level, and to be able to implement forms of care based on their needs and requests, placing them at the center of this care. I began to form a relationship with Beth and her family, particularly her two teenage daughters and mother, based on the pillars of attentive listening, care, and availability to spend time together. Over the nine meetings, during seven months I had with the family, I learned the story of Beth's life, narrated to me in a very personal way, but with a certain distancing of one who seems to be telling a story that they are not a part of. During these meetings, the affirmation of death was ever present, yet at the same time, denied: "*I told the doctor I'm already healed, I believe. In the name of Jesus I am healed...because I put God in my life and if I die, I will die. No use crying.*" As her needs increased, family conflicts intensified, but so did acts of kindness and care. The process of deteriorating health does not occur in parallel with people's lives, but amalgamates with life itself, modifying routines, relationships, and lifestyles.²

Beth was eventually hospitalized to better relieve her respiratory distress and severe pain. During her last stay in hospital, one of her children called to say that Beth was asking for me. I arrived to find her in a state of great anxiety and she asked the question I had most feared, the one I had agonized over how to answer: "What's happening to me?"

While I soothed and supported her, I told her that she was dying. At that critical moment, I was fully present as a researcher, nurse, and human being, in conversation and in silence with Beth. The restful sleep that followed showed me how effective my care-presence was. Beth died the following day and I attended her wake, seeking to comfort her family, particularly her children.

In this experience of researching and understanding Beth's process of dying and death, the originally proposed format of study gained hues, highlights, and definitions during the process, obliging the research group to change focus and make decisions, sometimes in the spur of the moment, because the initial objective was to investigate a person in the process of dying, but soon the health status of Beth worsened. We did not know if we would have time to collect the data and whether we should change the subject of study, but we decided to continue the research with Beth. The experience of caring for Beth and her family was simultaneously a process of studying, learning, and caring.

The aesthetic dimension became present in substantive form in the research as 'creation' or, metaphorically, as a 'work of art,' conceived and elaborated over time. This view arose out of the understanding that the research was an open-ended experience based on different positions and perspectives, assuming modes of development based on experimentation, composition, relationship, and movement.

Ethics is also a theme that runs through the entire research, through respect for the human dimension of the person who died and her family, and also in my own experience as researcher and human being, deeply affected by this way of seeing life, death, and care.

As I expressed in my research diary, "The greatest difficulty I faced was talking about death to the person who was dying." This was the first time as a nurse when I had felt really close to the dying person and her family. I had been to her home, knew her day-to-day life, and was aware of her feelings and experiences. As both a researcher and human being, I was fully present, not restricted to merely recording what was said

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like a stenographer, but reacting to every laugh and every sob, and sharing in her fears, anguish, and anxieties.

In my opinion, it is this sharing of feelings that enables the life story to be condensed, and increased depth and involvement to be achieved between the researcher and his or her subject, so that the telling of one's story and the listening by the other become a mutual relationship of care and human growth. Thus, listening to and caring for Beth enabled me to understand that my professional responsibility to the human being who is living with his or her final moments is an 'attitude-willingness' to be together with the patient, in fact and in full, caring during life, of life, and for life.

In caring for Beth, I was at the same time a nurse, a researcher, and a human being. With the support of my research group, I realized that research can become a form of artistic creation, as it requires initial outlines but is modified and elaborated upon over the course of the project. My experience was enhanced by my sensitivity to learning from the many dimensions of living with the dying, with all its peculiar nuances, hues, movement, and highlights.

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mediadores na efetivação do direito pátrio em saúde: Análise de itinerários terapêuticos de pessoas/famílias no SUS/MT" (Health institutions and the judiciary power as mediators in the establishment of Brazilian health law: Analysis of therapeutic itineraries of people/families in the SUS/MT developed within the scope of the Nursing, Health and Citizenship Research Group (GPESC) of the faculty of nursing of the Universidade Federal de Mato Grosso (FAEN/UFMT), and financed by the Bolsa de Iniciação Científica e de Mestrado (Grant for Academic and Master's Degree Research). Approved by the Ethics Committee for Research involving Human Beings of the Hospital Universitário Julio Muller, under protocol 671/CEP-HUJM/09, and addendum No. 036/CEP-HUJM/2011, which authorizes interviews with subjects aged between 5 and 18 years.

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