

Opening Life's Gifts: Facing Death for a Second Time

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Prior to the development of effective antiretroviral therapy, persons diagnosed with HIV thought they were going to die. Now, long-term survivors are contemplating death again as they age and develop other chronic diseases. The purpose of our study was to understand the experiences of adults living with HIV for 20 or more years as they faced death for a second time. Hermeneutic phenomenology guided the research as participants shared their lived experience through storytelling. Each person's story was audiotaped and transcribed verbatim. Transcript analysis occurred as data were collected. Three common themes from the narratives were identified: Making Choices, Transformation of Fear, and Meaning of Death. Positive and negative pathways influenced each participants' decision-making. Over time, fear of dying was transformed and energy was directed toward living. Even though the participants in this study were facing death again, they recognized it as a natural part of life.

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For many individuals, the most identifiable point in facing mortality occurs when they receive a terminal illness diagnosis. For these persons, death is on the horizon and no longer a remote possibility (Kuhl, 2011; Wrubel, Acree, Goodman, & Folkman, 2009). However, not all individuals who are diagnosed with a terminal illness face imminent

death. There are instances when someone is diagnosed, but medical treatment intervenes to stabilize physical health. A perfect example of this is the person who has been living with HIV infection (PLWH) for more than 20 years.

When the HIV epidemic started in the early 1980s, AIDS emerged as a leading cause of death among young adults in the United States (Buehler, Devine, Berkelman, & Chevarley, 1990). These individuals, along with family and friends, planned for death and not life. However, the introduction of effective antiretroviral therapy (ART) in the mid 1990s changed the landscape of the disease. The medications transitioned HIV from a death sentence to a chronic disease (Samji et al., 2013). To put this in perspective, life expectancy for a 20-year-old diagnosed with HIV in 1996 was about 39 years. But in 2011, with treatment and a healthy lifestyle, life expectancy had increased to almost 70 years (Marcus et al., 2016).

Because of successful treatment, it is estimated that one quarter of the 1.2 million PLWH in the United States are 55 years of age or older (Centers

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for Disease Control and Prevention, 2016). Many individuals in this segment of the population once faced death but survived, and are now contemplating death again as they grow old. Ironically, it is likely that these persons will develop other chronic illnesses such as cardiovascular disease, diabetes, or cancer, that might be the ultimate cause of death rather than HIV (Cima et al., 2016; Ingle et al., 2014).

As research is conducted about end-of-life care, it is important to understand that perceptions about death and dying vary widely due to influential factors such as age, culture, education, socioeconomic status, and personal experiences with death (Fang, Sixsmith, Sinclair, & Horst, 2016; Frost, Cook, Heyland, & Fowler, 2011). In an Institute of Medicine (2014) report on dying in the United States, committee members recommended that improving the health care delivery system for persons who were dying should be a national priority. They described the optimal delivery system as being person centered, family oriented, and evidence based.

Studies about HIV and aging predominantly focus on the physical aspects of aging and comorbidities associated with long-term HIV infection and ART use (Chambers et al., 2014). We found only one study that explored how individuals coped over time with the personal challenges of living with HIV. However, the study included individuals who were diagnosed with HIV after the advent of effective ART (Siomka, Lim, Gripshover, & Daly, 2013). We found no studies that explored how long-term HIV survivors lived through what was considered a death sentence prior to the development of effective pharmacologic treatment. Hence, the purpose of our study was to understand the experiences of adults living with HIV for 20 or more years as they aged and faced death for a second time.

Methods

Hermeneutic phenomenology, rooted in philosophy, was the research design that guided the study. Hermeneutical inquiry is the process of seeking understanding and interpretation to better comprehend a complex phenomenon as experienced by individuals through storytelling (Allen & Jensen, 1990;

Polit & Beck, 2017). This approach was chosen because it aligned with the study's purpose.

Institutional review board approval for the study was obtained from Kennesaw State University prior to data collection. The confidentiality of participants was maintained as all personal identifiers were removed and pseudonyms utilized. A consent letter was read out loud and questions answered before beginning each interview. All data were stored in a locked room and password-protected computer.

Sampling

Purposive sampling was used to recruit individuals from a large city in the southeastern United States who had been diagnosed with HIV for 20 or more years. Local AIDS Service Organizations and an individual living with HIV distributed flyers that described the study to potential participants. Interested participants telephoned the primary investigator for eligibility screening and additional information.

Sample size in qualitative research is controversial. The ideal standard is to interview until no new information is found, which is referred to as saturation (Walker, 2012). In phenomenology, 3 to 10 participants are acceptable if redundancy has occurred (Creswell, 2014). Therefore, collecting and analyzing data while continuing to recruit informants was necessary.

Data Collection and Analysis

Data were collected through one-on-one interviews that were conducted by the primary researcher in a mutually agreed-upon location. Interviews were based on the overarching question: *How do older adults living with HIV for at least 20 years approach the idea of dying for a second time?* Based on participant responses, open-ended questions were used as probes to guide the interview. Each interview lasted approximately 1 hour. At the end of the interview, each participant completed a demographic form and received a \$35 USD gift card to a local department store. Data about HIV status were gathered through self-report. All interviews were audiotaped and transcribed verbatim by an external paid transcriptionist.

The interpretative research team included members from diverse backgrounds who provided

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