

Existential care to older patients with acquired deafblindness

A qualitative study exploring patients', nurses' and chaplains' experiences

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Abstract

Introduction:

Deafblindness is a mostly unknown and often misunderstood condition as the disability's nature is characterized by a combination of hearing and sight impairment and not only completely deaf- and blindness. The person concerned perceives the world as fragmented, which generates severe functional limitations in communication, access to information, mobility, and orientation. Older persons with acquired deafblindness are the largest group within the Deafblind population, and researchers expect their number to increase rapidly during the next decade. Research shows that becoming deafblind is related to vital existential challenges, such as social isolation, loneliness, depression, harm and abuse, and a lack of self-value. Older persons are considered particularly vulnerable due to dual sensory loss increasingly appearing in combination with age-related processes such as frailty. Thus, they need competent healthcare services addressing their existential needs. To secure forward-looking quality care, the Norwegian government requires focusing on patients' existential health. Nurses and chaplains are essential contributors to existential care, but research shows that caregivers struggle to identify and respond professionally to their patients' existential needs. Although research indicates that older persons with acquired deafblindness are exposed to existential suffering, there is a gap in the research literature about their experiences with receiving existential care and how caregivers experience providing it.

Aim:

The overall aim of this PhD thesis is to explore the lived experiences of older patients with acquired deafblindness when receiving existential care and of caregivers (nurses and chaplains) providing existential care to older patients with acquired deafblindness. The aims of paper I, II, and III were as follows:

- Paper I: To explore the lived experiences of older patients with acquired deafblindness when receiving existential care.
- Paper II: To explore nurses' lived experiences with providing existential care to older patients with acquired deafblindness.
- Paper III: To explore chaplains' lived experiences with providing existential care to older persons with acquired deafblindness.

Method:

This is a qualitative study and consists of individual open narrative interviews with four older patients with acquired deafblindness (paper I), as well as six registered nurses (paper II) and five chaplains for the Deaf (paper III) with experience in working with the patient group. The transcribed interviews were analyzed using Lindseth and Norberg's phenomenological hermeneutical analysis method for researching lived experience. To gain an overall understanding of the main findings, they were synthesized in the *comprehensive understanding and discussion* chapter in line with the analysis method used.

Main findings:

Existential care was about patients' and caregivers' mutual connectedness at an interpersonal level and caregivers' ability to guide their patients through periods of existential suffering. Encountering caregivers, the older patients experienced existential care when they felt acknowledged as normal human beings with the vulnerability deafblindness left in their lives. Feeling understood with one's needs caused by deafblindness could generate existential well-being and a sense of empowerment. Caregivers' adaptation to the patients' communicational needs and self-determination was a crucial concern. Connecting with their patients, the caregivers could sense their loneliness and aimed to build bridges to fellowships and give their patients new perspectives to reorient their lives. The caregivers facilitated this by being a link between the patients and their access to society and faith through individual adapted communication, caring acts, and church services. The caregivers experienced that trusting them was a vital prerequisite for their patients to experience existential care. Previous negative experiences demonstrated that trust in caregivers could be shattered and challenging to regain. Being misunderstood, the patients felt rejected, which could entail social withdrawal and loneliness. The patients expressed a sense of power imbalance between them and their caregivers and felt that their abilities and capabilities were easily over- or underestimated.

Concluding remarks:

The way caregivers meet older patients with acquired deafblindness appears essential for an experience of existential care. When the patients feel fellowship and being acknowledged, they can experience interconnectedness with their caregivers. This can help overcome burdens related to deafblindness. The caregivers' way of using and adapting tactile sign language, and haptic signals, can contribute to an experience of existential care. When caregivers are not ready to engage in relational care, patients can feel rejected, and experience loneliness and distrust. Healthcare growing from human relationships is essential to guide patients through their struggles, alleviate their burdens, and support them to find meaning. This must be considered regarding the increasing number of older patients with acquired deafblindness and other disabilities being exposed to a healthcare system that is steering away from a holistic to a technical philosophy.

Keywords: aging, connectedness, deafblindness, existential care, fellowship, phenomenological hermeneutical analysis, trust, vulnerability