

Research Article

The Cultural Elements in the Experience of Caregiving for Family Members with Alzheimer's Disease

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Abstract

With the increasing life expectancy, the world is facing population aging and related diseases. In this context, Alzheimer's disease is one of the main neurodegenerative diseases that occur during the aging process. It compels family members of affected individuals to dedicate themselves to their care. Consequently, those who provide care are called family caregivers. They are engaged in a demanding caregiving relationship. The experience of caregiving is influenced by the cultural background of the caregivers.

This article aims to understand the cultural factors at play in the lived experience of caregiving among family caregivers. To achieve this, a clinical method, primarily case study, was employed, and data were collected through semi-structured interviews with caregivers in facilities dedicated to elderly care. Thematic content analysis revealed that Alzheimer's disease is not universally perceived by all caregivers as a rupture. Some view their role as legitimate and rewarding (feeling useful, responsible, and competent). Cultural factors such as intergenerational solidarity and the desire not to contradict ancestors dominate their representation of the caregiving relationship.

Therefore, these cultural factors play an undeniable role in the caregiving relationship with close relatives who are experiencing illness. Taking these factors into account could be beneficial for the assistance provided to family caregivers.

Keywords: Alzheimer's disease, Family caregiver, Lived experience, Caregiving relationship

Introduction

According to the World Health Organization (WHO) in 2022 [1], the proportion of people aged 60 and over in the global population will nearly double from 12% to 22% between 2015 and 2050. This rapid aging of the population necessitates significant efforts by all countries to prepare their social and health systems for this demographic shift. By 2050, the median age of the global population is expected to increase by 10 years, reaching 36 years.

As the world's population ages, the incidence of Alzheimer's disease and other types of dementia continues to rise. Alzheimer's is a degenerative disease that causes brain lesions and is not a normal part of aging. Globally, approximately 46.8 million individuals are affected by dementia, with 58% residing in low-income countries. The frequency of new dementia cases is estimated at one every 3.2 seconds, totaling 9.9 million new cases annually. The WHO report from 2023 [2] projected a new dementia case every 4 seconds, equivalent to 10 million cases per year.

The impact of Alzheimer's disease extends beyond individual patients, affecting families, caregivers, and communities. Understanding the cultural factors involved in caregiving for Alzheimer's patients is crucial for providing effective support and

improving the quality of life for both patients and their families.

In Africa, as in most southern countries, population aging poses numerous challenges, including the care of elderly individuals with reduced autonomy (Golaz, 2013). The current proportion of elderly individuals stands at 5.5% and is expected to more than triple by 2050 (Sajoux, Golaz, & Lefèvre, 2015), leading to increased demands for social protection and healthcare. Research indicates that elderly individuals in Africa face a significant burden of morbidity and disability, often due to chronic conditions that are frequently overlooked or untreated [3].

Within the context of large extended families in Africa, it becomes the duty of children to provide daily support and care for their parents, preserving the dignity and integrity of their ailing and dependent parents. African family dynamics consistently demonstrate this sense of duty toward parents, whether in North, West, South, or Central Africa.

In this context, caregiving for parents takes on an exclusive dimension, reversing traditional parent-child roles. In the eyes of children, parents are recognized for having provided unwavering attention, protection, and care, even during times of empowerment and strong family bonds.

Many informal caregivers actively engage in caring for sick individuals. In this study, we will use the term “caregiver” to define someone who primarily assists a dependent person within their immediate environment with daily activities [4]. Natural caregivers, family caregivers, or close caregivers encompass anyone who provides care or support.

Natural Caregivers: Understanding Their Role and Challenges

A natural caregiver, also known as a family caregiver or informal caregiver, refers to anyone who provides care and support to a family member, friend, or neighbor with physical or mental disabilities, chronic illness, or precarious health. These caregivers may be of any age and come from diverse backgrounds. Their profiles vary due to individual circumstances (such as age, gender, and cultural identity) and the specific needs of the person they assist (such as age and the nature of their disability).

According to the Quebec Institute of Statistics, 21.1% of the Quebec population aged 15 and older are natural caregivers. Their contributions are exceptional, but they may also require specific support and services. Many natural caregivers may not even realize they fall into this role, especially if the support they provide is occasional or if they have no direct family connection to the person they assist. However, the government adopts an inclusive definition of natural caregivers.

Definition of Natural Caregivers

A natural caregiver is defined by the Law Recognizing and Supporting Natural Caregivers as someone who provides support to one or more individuals in their close circle—regardless of age or life circumstances—who experience temporary or permanent physical, psychological, psychosocial, or other forms of disability. This support can be continuous or occasional, short-term or long-term, and is offered on a non-professional basis. It is provided freely, knowingly, and revocably with the goal of promoting the recovery of the person being cared for and maintaining or improving their quality of life at home or in other living environments. The support can take various forms, including transportation, assistance with personal care and household tasks, emotional support, and coordination of care and services. It may also have financial implications for the caregiver or impact their ability to care for their own physical and mental health or fulfill other social and family responsibilities.

Understanding the cognitive evaluation that natural caregivers make of their situation is crucial for adapting to the evolving circumstances and preventing feelings of burden. While natural caregivers share similar situations, their experiences can vary significantly. Adaptation skills and coping strategies play an essential role in managing the caregiving burden.

Indeed, natural caregivers constantly face what is known as “stressful situations,” defined as “a situation that an individual perceives as significantly impactful to their well-being and potentially exceeding their resources” [5].

Within this context, culture—understood as the collective characteristics of a specific group of people—becomes one of the factors influencing the caregiving experience among family caregivers of individuals with Alzheimer's disease. According to Abou [6], culture encompasses the ways of thinking, acting, and feeling within a community, relating to nature, humanity, and the absolute. Group culture functions as a system that ensures coherence, facilitates organization, and symbolically regulates social life. It serves as a container where both implicit and explicit beliefs and convictions of the group reside. Culture thus acts as a knowledge system that organizes individuals within a given group around symbols, explicit and implicit concepts, and functions as a collective entity.

In line with this perspective, this article aims to explore the cultural elements at play in the caregiving experience among family caregivers.

Methodology of the Study

In line with the study's objective, we employed the clinical method, which is fundamentally qualitative and relies on case study analysis. This choice is justified by its focus on the uniqueness of each case, allowing for in-depth understanding. Specifically, we prioritized studying the functioning and lived experience of family caregivers in their caregiving situation.

The case study approach aims to capture the singularity of each case. We conducted the study within Wellbeing associations in Yaoundé, APAC in Douala (Cameroon), and the Geronto-Geriatric Center in Melen-Libreville (Gabon). Participants were selected based on the following inclusion criteria: being a parent of the affected individual, being of legal age, serving as the primary caregiver for at least 6 months, not having a history of psychiatric illness, and obtaining a negative score on the Mini Zarit test.

After obtaining their consent, we emphasized confidentiality and anonymity. Subsequently, we proceeded with data collection.

In this study, we employed the clinical method, which is fundamentally qualitative and relies on case study analysis. This choice allows us to delve deeply into the psychological functioning of participants and comprehensively explore their experiences. Specifically, we focused on understanding the functioning and lived experience of family caregivers in their caregiving situation.

To collect data, we conducted semi-structured interviews. These interviews allowed participants to express themselves freely, providing valuable insights. We transcribed the spoken data to facilitate analysis. Our approach involved thematic content analysis, identifying essential themes or units of meaning. We selected key passages to empirically ground our analysis.

Results

Case Presentation

Case KM

KM is a 55-year-old widow, Catholic, and of Bamiléké ethnicity. She completed her education up to the first year of high school (1ère D). KM describes herself as an active woman in society, occupied

by her profession as a “bayam-sellam.” This occupation involves purchasing staple food products in bulk from farms and selling them at retail prices in city markets. KM is the third of five siblings. For the past 10 months, she has been caring for her sick father. During the interview, she appeared relaxed and generously shared a wealth of information with us.

Case ED

ED is a 55-year-old woman from the Sanaga Maritime region, and she follows the Protestant faith. Despite her limited elementary education (CEPE – Certificate of Primary and Elementary Studies) obtained in Edéa, she expresses herself quite well in French. Her general knowledge surpasses her educational level, particularly regarding Alzheimer's disease and societal matters. ED is a homemaker, married, and proud mother of five children.

Case LA

LA is a 35-year-old Cameroonian woman from the West region, specifically from the Bangangté tribe. She completed the equivalent of the third grade and works as a Community-Based Rehabilitation (CBR) agent. Her focus is on children and adolescents with disabilities.

Case P

P is a 30-year-old young military officer whom we met at the Geronto-Geriatric Hospital in Melen, Libreville, Gabon. He belongs to the Fang ethnic group, follows the Catholic faith, and holds a BEPC (Certificate of Basic Education). He is the second of three siblings, with the third sibling having passed away. As a single individual without children, he plays the primary caregiving role for his mother, who has been suffering from Alzheimer's disease for several years.

In the relationship between KM and her parent, in addition to these moral values, we can see the influence of tradition that she upholds. She bases her motivation for fully playing her role as a caregiver on recognizing the bonds of kinship and a sense of moral obligation due to the care her parents provided in the past. She states, “I take care of my parent because I love them, and especially because they are my father.” Furthermore, she attributes to tradition a role akin to the superego, dictating the moral principles she follows. According to her, “If I were to abandon my parent during this illness, the ancestors and even God would be against me.” She adds, “According to tradition, a child should never abandon their parent.” For KM, caring for her parent is both a moral duty and a traditional obligation.

KM's altruism means that she doesn't concern herself with absent siblings in the caregiving relationship with their father. She is willing to give herself entirely for her brothers and sisters.

As for ED, her motivations in the caregiving relationship with her parent are evident in how promptly she mobilizes when her older brother expresses any concern about their mother's health. She doesn't hesitate to drop everything and rush to the village to assess the situation. She recounts, “When my mother fell ill, my older brother called me, saying that Mom wanted me, that she constantly mentioned my name, and that maybe she had something to tell me. So I went to the village... I asked her if I could take her with me to Douala, and she

agreed. Then I sought my brother's approval, and he gave his consent.” Beyond this dedication and constant concern, ED stands out with the certainty that she can take better care of her sick parent than anyone else: “But I want to stay by her side to make sure she gets better. I am convinced that no one can care for her like I can because I love my mother so much!”

In her altruistic spirit, ED acknowledges the sacrifices her mother made for her since childhood. This brings to mind authors such as Piaget, Wallon, Winnicott, and ethologists who emphasize the attachment bond between mother and child from early years, with lasting effects on the child's personality. For ED, being close to her ailing mother evokes pleasant moments of affection, motivating her: “I have an opportunity to be close to her and repay what she has done for me since my childhood. I genuinely enjoy taking care of her because she's my mother.”

According to her, it's when parents are elderly that they become more valuable, contrary to modern notions of aging as a depleted, tired phase with nothing left to offer the younger generation: “Yes, even our village mothers become more endearing as they age because they have so much wisdom to share.”

In LA's verbatim, we can discern her love not only for her grandmother but also for her own mother, who has always been caring toward her and her siblings. It's as if through this assistance, she is also serving her own mother. Additionally, LA has experienced two divorces that affected her. Following the second divorce, she decides to live in the village and dedicate herself to caring for her grandmother. As the mother of her own mother, she believes her grandmother deserves her full devotion. It's not only her duty to help but also a blessing to have a grandmother: “It's normal; she's my grandmother. I'm happy to take care of her, and I don't complain even when it's tough. It's my duty as a granddaughter. Isn't having a grandmother a blessing?”

In P's case, we cannot overlook the positive influence of family harmony on lightening the burden of caring for their sick mother. Mr. P emphasizes that unlike families where discord prevails and individuals tend to shirk their responsibilities, in their family, a spirit of mutual aid ensures that no one feels “abandoned” in their caregiving duties. He highlights the importance of consultation in their relationship with their mother: “We consult on everything related to our mother's health. Since her illness, we discuss her care more frequently.” It's also worth noting that common sense prevails among the members of this family. While the older brother's wife could have borne the responsibility of caring for their mother according to certain traditions, the brothers, especially our participant, come to her aid because she already has other significant family duties. This exemplifies practical wisdom within the family, contributing to lightening the burden. As our participant puts it, “The responsibility was too great to place solely on the wife, who already had a family to feed, care for, and children to educate. It was our duty as Mama T's sons.”

He expresses gratitude for all the effort his mother put into raising them, especially their late sister. “Contrary to any hardship, I feel good because she has always been there for us, especially our late sister, whose passing deeply affected her. I'm content to take care of her”.

KM's verbal expressions clearly reveal that cultural factors significantly influence her experience of caregiving for her father. She places great importance on the older generation, and her fear of ancestral retribution due to neglect is evident in her words: "According to tradition, a child should never abandon their sick father... If I even said he was wicked, may God forgive me..." Additionally, feelings of guilt and penance are present. KM believes that any wrongdoing toward parents is punished by God and ancestors. Out of fear of potential curses resulting from past misdeeds, she views caring for her parent as a form of penance.

Furthermore, KM emphasizes that her father deserves respect and honor in their culture: "He means everything to me. Besides, don't you know that among the Bamiléké, parents are more cherished by children than anything else? If someone neglects their sick father, they don't understand what they're seeking, and they may even face curses!"

According to KM, there is a belief that a curse awaits those who dare to neglect their sick or elderly parents. This starkly contrasts the treatment of older individuals in Western civilization versus African culture. While the former often involves retirement homes for the elderly, the latter keeps the elderly among their own, where they are cherished by their offspring. Like gathering around a fire, children find joy in surrounding their ailing father each evening, listening to stories, riddles, and advice. Even when ill, KM's father remains a central figure around whom the children love to gather. This desire to be close to her sick father is particularly pronounced because other siblings envy KM. They believe she alone receives all the blessings from their father, while they must wait for holidays and vacations to share in them: "If any of them could leave their work to replace me, I'm sure they wouldn't hesitate. During celebrations, the whole family gathers around Dad, and we celebrate together."

Another testament to KM's unwavering dedication to her father is her indignant response when asked about potential challenges in the caregiving relationship: "What problem could he cause me? I've been here since I understood he was ill. I'm proud to be his daughter, and I cannot neglect his illness!"

ED's family embodies the harmony characteristic of African families at large. This is evident in her older brother's desire to have the sick mother sent to his home. Failing that, he sends one of his wives to assist our participant, ED, who insists on staying with the patient: "The family takes great care. My older brother even sent one of his wives to lend me a hand. He even asked me to send Mom to the village because there's more family there. But I want to stay by her side to ensure she gets better."

Despite knowing that tradition demands unwavering devotion from every child toward their parents, ED doesn't need reminders. For her, it would be strange to act otherwise. Hence, she criticizes and feels indignant toward children who neglect their parents during illness: "We all know that even if tradition doesn't explicitly require it, caring for parents is non-negotiable. If someone feels unable to do so, either they have a problem, or they're not truly a child. I have no issues. Instead, I see it as an opportunity to be close to her and repay what

she has done for me since my childhood. Taking care of her brings me genuine pleasure because she's my mother".

For LA, the notion of ancestral respect is sacred. She neglects her own needs in favor of those of her patient, and by extension, her own mother and other elders in the family. Even the patient's numerous whims don't cause her to lose her composure. She manages everything as best as she can. When necessary, she ensures she follows the patient during her wanderings to keep her in sight and avoid upsetting her. "Her biggest whims include eating everything and sometimes doing things her own way. But knowing it's due to her illness, I endure and manage... It used to bother me a lot, but over time, I've grown accustomed to it. When she wants to leave, I let her and follow from a distance or send the children, as she can no longer cover long distances quickly."

In P's case, cultural factors influencing their experience primarily revolve around communal living. This manifests as harmony and cooperation among family members, where nobody shirks tasks but instead contributes willingly. Additionally, in this family, elders are revered, as Mr. P points out. This reverence for elders is a typical trait in African culture: "Elders are sacred beings among us".

Discussion of Results

In Africa, old age is perceived not only as a time of rest but also as a sacred period for "reconnecting with the divine" (Tabboni, 2006, cited by Sadio-Ba Gning, 2015). Bourdieu previously noted that the entire relationship with the future is motivated by a desire to collaborate with God [7]. Consequently, old age is meant to involve contemplation and even asceticism for the elderly. Perceptions of old age, primarily shaped by implicit contracts, remind descendants of the intergenerational debt they must repay throughout their lives to their ancestors. In this context, participation in mosque or church discussions, visits to the sick, and pilgrimages to Islamic and Christian holy sites are highly valued. This assistance, which adheres to social norms, underscores the commitment children make to caregiving when their parents need assistance.

Old age represents a time of relinquishing personal plans, consolidated piety, strengthened moral authority, and the transfer of decision-making and economic power from the elderly to their descendants—the ones capable of maintaining family hierarchy and ensuring both material and moral survival.

Indeed, the care of elderly individuals in Africa follows a differentiation that favors male descendants with good socioeconomic status, often at the expense of women and younger siblings (Gning & Antoine, 2015). Descendants view old age as a "social retreat," allowing parents to reap the fruits of their investments, sacrifices, and deprivations in peace and comfort. The elderly maintain precedence, arbitrate conflicts, and serve as guarantors of family cohesion (Golaz, 2007). Old age symbolizes a golden era, conferring respect, power, and social recognition. It becomes a means to revitalize the "social contract" of lineage.

In Africa, the need for assistance extends beyond professional care. Considering the trajectory of illness and care as developed by Corbin

and Strauss [8], we recognize the significance of the family framework in dynamically rethinking the involvement of family members in providing necessary care for their loved ones. Communication, dialogue, and family solidarity play crucial roles in caregiving, whether rooted in blood ties, traditional values, or religious pillars. Each subject demonstrates that the family is the essential support system for bearing the burden of care.: Gning, S., & Antoine, P. (2015).

In *Vieillir en Afrique* (pp. 15-30). L'Harmattan. "Boquet and colleagues [9] drew attention to the cultural values of social groups and the social change that affects families, as the meaning attributed to assistance largely depends on it. It appears that intergenerational solidarity within the culture and the sense of gratification experienced in the caregiver-care recipient dyadic relationship are the cultural factors involved in the experience of caregiving among family caregivers of individuals with Alzheimer's disease [10-21].

Conclusion

The objective of this article was to understand the cultural factors at play in the caregiving experience among family caregivers of individuals with Alzheimer's disease. To achieve this, we used a clinical method, specifically case studies. Data were collected through semi-structured interviews with four caregivers from Wellbeing associations in Yaoundé, APAC in Douala (Cameroon), and the Geronto-Geriatric Center in Melen-Libreville (Gabon)."

Following a thematic content analysis, the obtained results reveal that Alzheimer's disease is not necessarily perceived as a rupture by all caregivers. Some view their role as legitimate and rewarding (feeling useful, responsible, and competent). Cultural factors such as intergenerational solidarity and the desire not to upset ancestors dominate their representation of the relationship with their close relative. Consequently, these cultural factors play an undeniable role in providing assistance to close family members in situations of illness.

Taking these factors into account could be beneficial for the support offered to family caregivers. Beyond the daily care of individuals with Alzheimer's disease, family caregivers also require psychological support to provide them with additional resources for coping with the situation. This, in turn, contributes to improving their quality of life.

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