

Examining the Information Practices of Caregivers of Elderly Family Members / Maya Shaked

Abstract

In recent years, global socio-demographic shifts, characterized by increased life expectancy and a rising prevalence of chronic illnesses, have led to a continuous growth in the elderly population requiring ongoing medical care and support. Consequently, the demand for informal caregivers has surged (Anderson & White, 2018; Brémault Phillips et al., 2016). Despite the increasing responsibilities placed on these caregivers, there remains a dearth of knowledge regarding the challenges faced by family members and friends in their caregiving roles and how they cope with these responsibilities. Informal caregivers often find themselves without adequate support to fulfill their roles optimally. Research indicates that informal caregiving is a multifaceted endeavor, with the burden often manifesting as fatigue, depression, stress, and difficulties in collaboration (Sholts et al., 2023). The growing elderly population has also led to a higher incidence of dementia, a condition now more prevalent and impactful than ever before, as recognized by the World Health Organization (WHO, 2021). The onset of dementia can be perplexing, making it challenging for both patients and their families to grasp the gravity of the situation, resulting in uncertainty. Early diagnosis of dementia enables the development of suitable treatment plans for both the caregiver and the patient (Pálsdóttir, 2017).

This thesis focuses on informal caregivers of elderly family members, exploring their caregiving experiences. It delves into the role of information in shaping the experiences of informal caregivers, examining how they strive to find new meaning amidst the chasm that emerges between the familiar reality they once knew and the frequent disruptions in their lives. It also investigates how they construct a sense of "new normalcy."

Informal caregivers constitute a crucial component of the healthcare system, accounting for approximately 70-90% of the care provided to children and adults with chronic conditions in the community. Despite their substantial contribution and increasing numbers, supporting informal

caregivers is not a priority within the healthcare system (Parmar et al., 2021). Informal caregivers are typically family members but can also include friends or neighbors who provide varying degrees of care to individuals requiring assistance with daily tasks and activities (del-Pino-Casado et al., 2021; Diviani et al., 2020). Over time, the demands of caregiving can take a toll on caregivers, often resulting in a deterioration of their physical and mental health (Ambugo et al., 2021; Litzelman et al., 2017).

This research examines the information practices of informal caregivers, drawing on Genuis and Bronstein's model (Genuis & Bronstein, 2017) for seeking normalcy in the face of health challenges. The study aims to shed light on the transient nature of the normalcy constructed by caregivers as they brace themselves for further changes in their family member's condition, which tends to deteriorate over time. The research uncovers the gap that emerges when there is a lack of information, followed by a defining event that signifies an irreversible shift from the previous state, prompting caregivers to engage in "information practices" to construct meaning and navigate their family member's health condition.

This study is underpinned by three theoretical frameworks that elucidate how individuals undergoing significant life changes construct their understanding of those changes: the "Normalcy Theory" (Myers, 2013), the "Sense Making Theory" (Dervin, 1998), and a conceptual framework proposed by Alzougool and colleagues (Alzougool et al., 2013) that examines the information needs of patients. Additionally, the concept of "Incognizance" plays a central role in understanding the initial stage of the information-seeking process. Incognizance refers to an ongoing lack of awareness regarding specific information needs (St Jean et al., 2018). It is characterized by a lack of recognition that one requires certain information, particularly during the pre-diagnosis phase. Consequently, individuals may unintentionally avoid seeking relevant information, even if they encounter it. The initial stages of dementia often make it difficult to assess the gravity of the situation, leaving both patients and their families unprepared and grappling with uncertainty. During this initial period, most caregivers manage their roles independently, deferring information-seeking until a later stage.

At the outset of this study, prior to the interview phase, it was hypothesized that family caregivers might be reluctant to seek information due to anxiety. However, the research revealed

that caregivers did not avoid information; instead, they often lacked awareness of the impending change. Months or even years could pass before family members recognized that their loved one was experiencing illness. Symptoms such as forgetfulness, irritability, and confusion were frequently attributed to aging rather than an underlying health issue, delaying the initiation of information-seeking processes. As the situation deteriorated, family members gradually realized that something was amiss but lacked clarity on the specifics, prompting them to embark on information searches, including consulting with family doctors, scouring the internet, and seeking guidance from close acquaintances. Typically, after a period of uncertainty, a significant crisis occurred, leading to an acknowledgment that reality had changed, necessitating action, and initiating a process of meaning-making. This social process often involved comparing experiences with other caregivers in similar situations, accepting the new reality, and adapting to it.

The study involved interviews with caregivers of elderly family members. The initial contact with participants was established through the researcher's personal network, including neighbors and acquaintances, as well as individuals participating in a support group for family caregivers of Alzheimer's and Parkinson's patients, which the researcher attended monthly to recruit interviewees. To address the research questions, 19 in-depth interviews were conducted with family caregivers responsible for elderly nursing home residents. These interviews sought to capture the caregiver's perspective on the events they encountered and their understanding of the resulting reality. Qualitative research methods were employed to illuminate the evolving roles of caregivers, their emotions and experiences, and their strategies for information-seeking, all aimed at enhancing the care they provide to their family members while safeguarding their own health and well-being.

To examine the experiences of informal caregivers dealing with the care of their family members, the following research questions were asked:

1. How do the caregivers describe the process of creating meaning in dealing with caring for the elderly family member?

2. How do the caregivers describe the process of creating a "new normal" in dealing with caring for the elderly family member?
3. What are the information practices of informal caregivers?
4. Which sources of information do the caregivers use when searching for information?
5. What are the information needs of the caregivers according to the model of Alzougool and his colleagues (Alzougool et al., 2013)

The analysis of the findings includes several layers based on the three theories and the concept of Incognizance. The first layer refers to the normalization process that serves as a framework for analyzing the data and understanding the entire process.

The process of creating the new normal can be divided into four stages:

1. A state without disease and is the original normal
2. Breaking the existing conventions of the known normality
3. Building a new social normality
4. "New Normal"

The results demonstrate how caregivers, confronted with the intricate condition of their beloved family member, are in search of a "fresh sense of normalcy." In this medical crisis, the need for normality emerges as a crucial component in the process of constructing meaning.

The second layer within the category framework incorporates a conceptual model developed by Alzougool and Chang (Alzougool & Chang, 2013), which encompasses four distinct types of information needs:

Recognized Demanded Need - Information needs that are both recognized and required.

Need Recognized Undemanded - Information needs that are recognized but not actively sought.

Unrecognized Demanded Need - Information needs that are required but not yet recognized.

Unrecognized Undemanded Need - Information needs that neither recognized nor required.

Another concept within this layer of the category scheme is the notion of "Incognizance," which is integral to the conceptual framework of information needs.

By integrating Genuis and Bronstein's model (Genuis & Bronstein, 2017) with Alzougool and Chang's conceptual framework (Alzougool & Chang, 2013) that delineates four types of information needs and incorporating Saint-Jean's concept of "Incognizance" (St. Jean, 2017), this research offers a profound exploration of its findings, fostering a comprehensive understanding of their implications.

The analysis of qualitative interviews conducted with family caregivers revealed five key thematic areas that characterize the experiences of the interviewed family caregivers:

First Theme - The Period Preceding Diagnosis: No-Illness Normal Unrecognized Undemanded Need This theme encompasses the concept of "Incognizance." During this phase, caregivers lack awareness of impending change. Initial signs of change are often disregarded, delaying the onset of the information-seeking process. It typically takes an initial event to trigger caregivers' awareness of the change.

Second Theme - The Disruption of Normalcy: Breakdown of Normal The phase of normalcy breakdown is divided into two sub-categories: 2.1 - Initial Signs of Change: Unrecognized Demanded Need Caregivers notice behavioral changes but are unable to attribute them to any specific cause, often assuming them to be part of the aging process. 2.2 - An Initial Defining Event: Unrecognized Demanded Need A significant event occurs, making it evident to family members that something has changed, compelling them to take action to address the situation.

Third Theme - Creating a New Reality: New Normal Recognized Demanded Need This theme delves into the process of constructing a new sense of normalcy through information practices. Caregivers compare their experiences with others, derive meaning from their situation, and come to terms with the existence of a new reality. They gain clarity about their family member's behavior, prompting them to initiate the information-seeking process.

Fourth Theme - Utilization of Information Practices and Sources for Meaning-Making Recognized Demanded Need This category illustrates the information practices employed by

caregivers to access formal and informal information sources during the process of creating a "new normal."

Fifth Theme - Challenges in Dealing with Information Throughout the process of establishing this new reality, a lack of information can hinder caregivers from ascribing meaning to their current situation.

Initially, the research began with the hypothesis that caregivers might refrain from seeking information to avoid confronting the consequences of their family member's health condition and to sidestep anxiety. However, data collection revealed a different scenario. Caregivers displayed a keen interest in obtaining relevant information to expand their understanding and knowledge. They sought to comprehend the purpose and processes of treatment and their own contributions in caring for their family members. They required support and information to identify challenges and coping strategies, all with the aim of addressing the situation in the most effective manner.

Upon receiving a formal diagnosis of the disease (usually following a significant event that unmistakably signaled a change in reality), caregivers initiated "information practices." These practices involved gathering information from diverse sources to navigate the situation and derive meaning from it, ultimately leading to the establishment of a "new normal." The period preceding the diagnosis, during which caregivers sometimes experienced vague premonitions or were unaware of seemingly insignificant events linked to old age, can be characterized as a state of "incognizance" (St. Jean, 2017). This phase emerged as crucial for caregivers, as a lack of awareness could strain the caregiver-patient relationship, delay treatment, and create a sense of helplessness. This phenomenon was a recurring theme throughout the interviews. It was only after caregivers recognized the change in their family member's condition and the necessity of addressing it that they embarked on the information-seeking journey, seeking knowledge that would imbue meaning into the creation of a "new normal." Sharing experiences and receiving support from family, friends, and especially other informal caregivers facing similar situations played a pivotal role in deciphering the family member's perplexing behavior and fostering acceptance of the new reality that demanded adaptation.

MMS Number: 9926929713105776