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Promoting the Autonomy and Well-Being of Older Adults in Informal Care in Canada: A Review of Self-Determination Theory

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Abstract

This review stems from an independent course as a PhD student in exploring knowledge on existing literature on the utilization of self-determination theory in informal care for older adults. Societal changes and trends in globalization is affecting informal caregiving the preferred form of care in Nigeria. Older adults who have reduced autonomy experience low quality of care and life. A secondary method of data collection was used to elicit information. Data relating to the use of self-determination in informal caregiving was sourced through databases such as Google Scholar, PubMed, and Science Direct using combination of keywords such as self-determination, informal caregiving, and older adults. From the reviewed literature, themes that emerged include caregivers' motivation, relationship with caregivers, and need for autonomy as part of the underpinnings of self-determination theory amongst older adult in care. The three basic tenets of self-determination theory; competence, autonomy, and relatedness are evident in studies concerned with older adults who practice self-determination. Older adults who practice self-determination have high self-esteem and better chances of quality of life. There is usually less incidence of depression and hopelessness amongst older adults who are allowed to exercise their autonomy and improved quality of life. Caregivers who encourage autonomy reported effective and efficient care services and have a positive disposition towards providing care. Policy makers can provide structures that support healthy ageing and policies should recognize autonomy as a fundamental ethical principle and actively address paternalistic attitudes.

Keywords: *Autonomy, informal care, self-determination, older adults*

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1.0 Introduction

The care needs of people continue to change as they age and must be met to address their environmental, social, physiological, and psychological needs (Dostalova, 2021). These care needs may range from personal care and support to their psychological health needs as well as practical support for social activities (Abdi et al., 2019). Due to the problems with the formal and informal care systems around the world, there are more older adults with unmet care and assistance needs (Abdi et al., 2019). This is due to the changing landscape of care in both formal and informal care systems (Abdi et al., 2019). Moreover, a study has shown that providing care to meet the needs of older people can be challenging for family caregivers (Ojifinni & Uchendu, 2022). Accordingly, Ramsey-Soroghayé et al., (2023), noted that when people advance in age, they encounter challenges and barriers which hinder them from maintaining physical and psychological health an aspect of aging that promotes healthier, more productive, and longer lives. Some older persons with cognitive problems also experience significant personality changes that comes with overwhelming feelings of hopelessness, purposelessness, and depression when left unattended, and some of them even become violent (Care International, 2019).

Some older people rely on their family members to manage their care by making decisions about their medications and treatment; coordinating services in the community to meet their needs; companionship and emotional support (Grossman & Webb, 2016). In Nigeria, we have traditionally relied on families to support one another emotionally and to help aging parents, grandparents, and other family members when they are unable to care for themselves (Tanyi et al., 2018). Concerning older people, in particular, a WHO report highlighted how pain is frequently underestimated for older people, especially for those with dementia, and highlighted a widespread failure to inform and involve patients in decision-making, lack of home care, lack of access to specialist services, and lack of palliative care within a residential home, sometimes against their will which is both demanding and expensive for family members and those who provide support for them (WHO, 2018).

There is no established care model for caregiving in Nigeria, apart from the traditional family care system where three-to-one family support is potentially accessible, with most older adults relying on their offspring, spouses, in-laws, and God (Okoye, 2014). This reliance on the traditional family care system indicates the significance of familial relationships and the cultural value placed on intergenerational support in Nigeria. Familial bonds and the expectation of family members to provide care for older adults could shape the understanding of caregiving and influences the roles and responsibilities assigned to family members. Older adults often live with relatives and are happy with the care they receive. Thus, implementing the person-centered approach (also referred to as self-determination) could make it easier for people to make decisions for themselves in daily life. With this strategy, the two parties' relationship is crucial to a good outcome (Okoye, 2014). The fundamental elements of this strategy are to generate a collaboration built on decentralized decision-making. If the older person is going to be as self-determined as feasible, then this shared decision-making process needs to pervade every step of the older people's care process (Ekman et al., 2011).

Self-determination is regarded as the ability of older people to make decisions and choices about the support and care they receive. Studies like that of Ryan & Deci, (2012), Breitholtz et al., (2013), and Dombestein, et al., (2019) have established that autonomy with feelings of being volitional, having a choice, and demonstrating responsibility; competence with feelings of empowerment and the capacity to achieve goals; and relatedness with feelings of being understood, cared for, and

valued by significant others are three innate psychological needs for growth and personal well-being that influence self-determination of older adults. Also, Leeuwen et al., (2019) opined that there is a strong connection between the quality of life of older people and autonomy. Care in later life is an area of great concern due to the increasing number of older people across the globe with unmet care, health, and support needs in both formal and informal care systems (Abdi et al., 2019; Ikeorji et al., 2023). Informal caregivers refer to individuals within one's social circle, such as family members, friends, or neighbors, who assume the responsibility of providing unpaid care to someone in need. This care is typically extended to individuals facing challenges due to disabilities, illnesses, or other difficulties. Often, informal caregivers, predominantly women, fulfil this role for prolonged periods of time (Ebimbo & Okoye, 2021).

1.1 Statement of the Problem

According to recent figures, people in the UK who are 65 and older may expect to spend over 50% of their remaining lives dealing with a chronic physical or mental health problem, which will increase their need for care and support. In fact, in this age range, 30% of women and 20% of men already require assistance with at least one ADL (Assisted Daily Living) (UK, National Statistics, 2017). The absolute number of older persons with low or high reliance is expected to rise by about a third by the year 2035, according to current projections, creating a considerable challenge to satisfy their care and support needs (Age UK, 2019). In some homes, family caregivers do not empower older adults and enable them to become involved in decisions that shape the outcome of their care (Shin et al., 2014). This may shift the burden of decision-making to family caregivers, who end up making decisions about care and support on behalf of care recipients.

Due to the burden of ongoing infectious diseases, alongside a rise in risk factors associated with chronic illnesses since 2010 in sub-Saharan Africa, the elderly population was estimated to be 43 million, and it is projected to reach 67 million by 2025 and 163 million by 2050 (WHO, 2021). As individuals grow older, there is a growing likelihood of experiencing physical or cognitive challenges that hinder their ability to live independently. These limitations in physical health, mental well-being, and cognitive functioning are the main factors that necessitate assistance from others among older adults (Adams et al., 2013). As noted in the study of He et al., (2020), Nigeria, known as the most populous country in Africa and the seventh most populous globally, is home to 10.9 million elderly individuals. With this large population of older people residing in their homes, there is a need for caregivers. The strain on caregivers caused by economic, psychological, social, and physical burdens, along with limited resources, can lead to inconsistent care quality (Ebimbo & Okoye, 2021). This can adversely affect the health of caregivers, who often struggle to prioritize their own well-being. In such circumstances, it raises concerns about whether the autonomy and well-being of older adult recipients would be adequately safeguarded (Mudiare, 2013; Ramsey-Soroghaye et al., 2023).

1.2 Objectives of the Study

- i. To examine the perception of older adults towards being involved in their care.
- ii. To investigate the factors that mitigate against the relationship between older adults and their care givers.
- iii. To explore the challenges faced by informal caregivers and evaluate the impact of caregiver strain on the quality of care provided to older adults.

2.1 Literature Review

Deci and Ryan initially used the word "self-determination" in their 1985 book, "Self-determination and Intrinsic Motivation in Human Behavior", where they defined self-determination as the ability to take care of oneself, make self-assured decisions, and think for oneself (Deci, 1971). The theory addresses two major things: people's innate growth tendencies and their innate psychological requirements. The concept of self-determination is crucial to an individual's general well-being as well as their psychological health, given how it can aid in obtaining independence. Self-determination places a person in control, which makes them accountable, and may be at fault for whatever transpires (Lopez-Garrido, 2021). This theory holds that one's fundamental demands for autonomy, competence, and relatedness are critical for both internalizing and externalizing oneself and for social development (Ryan & Deci, 2000). This is the process of integrating aspects of one's thoughts, feelings, and behaviours both within oneself (internalizing) and expressing them outwardly in social interactions (externalizing); for older adults, internalizing is incorporating and understanding social norms, values, and emotional experiences within oneself such as developing self-awareness, empathy, and a sense of morality. While externalizing, on the other hand, involves expressing one's thoughts, emotions, and behaviours in social contexts (Lopez-Garrido, 2021). SDT is an empirical theory of motivation, development, and well-being focused on the social contexts that support healthy psychological growth and natural processes of self-motivation (Deci & Ryan, 2012).

The first assumption of self-determination theory is that the need for growth drives human behavior and secondly, autonomous motivation is important. The first assumption holds that people are actively directed toward growth. This implies that, in developing a sense of help, it is important to gain mastery over challenges and take in new experiences. When people age and are becoming dependent on family or caregivers, they still desire to take charge of their life by involving in activities that concern their well-being. According to Breitholtz et al., (2013) where older people expressed their love for independence as being dependent makes them worried and uncertain about the future which leads to loss of identity, powerlessness, and depression. The second assumption of self-determination theory holds that autonomous motivation is important. This means that self-determination theory places a greater emphasis on internal sources of motivation, such as a desire to learn or independence than on external sources of incentive, such as money, prizes, or praise (known as extrinsic motivation) (intrinsic motivation).

According to Ryan & Deci, (2017) people who engage in activities with a complete sense of willingness, volition, and choice are said to be motivated autonomously as activities that are autonomously regulated are frequently intrinsically motivated. They believe that extrinsically motivated actions can also be autonomously motivated, that is, carried out with authenticity and vigor, given the correct conditions. Older people are more likely to perform better, learn better, and be more appropriately adjusted when they recognize the value and purpose of what they do. This makes them feel ownership and autonomy in carrying it out and receiving the needed support.

Several studies have utilized self-determination theory as their theoretical underpinning to explain the purpose of their study and explored how self-determination theory drives motivation for the autonomy of family caregivers. According to Barry et al., (2019), balancing personal costs of caregiving with caregivers' wants or obligations to provide care, is vital to promote the well-being of these individuals and their care recipients. Also, Ferrand et al. (2014) affirmed in their study to examine psychological need satisfaction and well-being in adults aged 80 years and over living in residential homes using the self-determination theory that, purpose in life and personal growth in

old age have a positive relationship with autonomy and relatedness which is important for the wellbeing of older adults. According to the self-determination theory (SDT), caregivers should be more autonomously motivated to provide care if their care recipient and their healthcare providers satisfy their psychological requirements for relatedness, autonomy, and competence.

Given how self-determination can aid in gaining independence, this idea is crucial to an individual's overall psychological health as well as their general well-being. Self-determination places the individual in control, which makes them responsible and possibly guilty for whatever transpires. People that engage in self-determined behaviors feel that their actions will affect outcomes because they have an internal locus of control. When presented with a challenging situation, those who believe in themselves feel that they can succeed in anything they set their minds to through perseverance, wise decisions, and hard effort. However, for someone to begin believing in their abilities, they must first believe in themselves (Lopez-Garrido, 2021). The SDT has been applied to family caregivers, particularly in exploring their motivation for caregiving, however, this study takes on a different approach to self-determination as it relates to the care recipients and how they are motivated to receive care guided by them.

Commendably, self-determination theory, when it comes to understanding human motivation and behavior, it has a high explanatory power since it takes into account both internal (like motives and goals) and external (like social ties, context) elements. Thus, for any theory to be evident in daily activities, Laski (2017) posits that practical inferences should reflect social theory. This means that theories when applied to real-life situations, should be able to help people understand the true nature of events. The self-determination theory brings to bear the true nature of the experiences of self-determination of older people when applied in caregiving for older people who have attained dependence.

3.0 Methodology

This study used a secondary method of data collection to elicit information on the topic. Data relating to the use of self-determination in informal caregiving was sourced using electronic search engines. The author searched databases with combinations of keywords related to the eligibility criteria using self-determination, informal caregiving, and older people. The databases searched are for social sciences which include GOOGLE SCHOLAR, SocIndex, PUBMED, Science Direct, and Web of Science. I limited my search to English language studies from the year 2012 to 2022. I did not include articles that had information on formal caregiving. The total search was 1,380 articles in all. I narrowed down my search using abstracts to delete articles not relating to the keyword. I sorted out the articles with headings and saved them in folders for easy access during the review. Out of 353 articles with similarity index, 261 and 42 from two databases were expunged because of their literature coverage. Only 15 of the studies that used self-determination theory were included. The data retrieved from the literature is discussed under three themes.

4.0 Results

Caregiver's motivation

Studies reveal that caregivers who develop a more autonomous (and less controlled) motivation to care for their recipient, help to improve their mental health, if their psychological needs are met in social relationships related to caregiving, such as their relationship with the care recipient or healthcare professionals (Ryan & Deci, 2000; 2017). When provided with the needed resources and support, older persons are more independently driven to take care of themselves. Compared

to individuals whose caregiving is less autonomously motivated, older adults believe that they have more freedom to choose to provide care and make decisions that improve their mental health (Dombestein et al., 2019). It has also been proven that caregivers are often concerned with the result of their caring role (Ferrandi et al., 2014). This could be a contributing factor for caregivers to provide quality care.

According to Greenwood and Smith (2019), separating accounts of reasons for starting to care from reasons for continuing to care proved to be challenging for carers because a significant portion of continuation motives for caring resembled initiation motives, such as love for the care recipient, a sense of obligation to provide care, companionship and job satisfaction, and the conviction that no one else was available. Studies such as that of Zarzycki and Morrison (2021), Dombestein et al., (2019) have shown that the services of caregivers are on the increase because the foundation of a society's care system is informal caregiving, and with an aging population, this demand is increasing. Informal caregivers had motivations for providing care but the most common is autonomous motivation which led to less exhaustion from caring and better personal functioning. This could infer that when caregivers are motivated by their own choice and internal commitment such as rather than external pressures, they are more likely to manage the challenges of caregiving more effectively, leading to improved well-being and functioning in their personal lives.

Relationship with caregivers

Caregiving for older people approaching dependence could be rendered by family members, spouses, or paid workers. The nature of care given is important and could be based on the level of relationship with caregivers (Ebimngbo & Okoye, 2021). This is important because having close, supportive relationships is a central component of older people's quality of life, regardless of whether older people fit the traditional criteria of a caregiver or care recipient (Hoppmann et al., 2016). Furthermore, healthy aging is rooted in relationships because close relationship partners interact in ways to maximize rewards and minimize costs to maintain relational harmony, members' thoughts, feelings, behaviours, and health. These are highly effective for interdependence (WHO, 2018; Monin et al., 2014a).

When people are in fulfilling relationships, they are either shielded from stress in the first place or are better able to handle stress when it arises, which is closely tied to physical health results. Studies that are particularly concerned with caregiver outcomes for spousal caregivers reveal that those who report higher pre-illness and present relationship satisfaction are more burdened, exhibit depressive symptoms, and engage in potentially harmful actions toward their care recipient (Notari et al., 2016). Also, research has indicated that caregivers experience less stress and more rewarding elements of caregiving when they and their patients share a greater sense of compassion and love for one another (Monin et al., 2014).

Similarly, some older people relate more with their paid carers compared with their biological children due to the level of relationships they build. According to the study by Moe et al., (2013) positive relationships may inspire the older person to disclose information about personal difficulties and wishes, as well as be described as relevant in permitting engagement in daily care and its planning. Also, Fjordside et al., (2016) posit that carers must be adaptable in their daily care delivery whenever an issue arises and work to build meaningful relationships between the older person and co-workers to further foster self-determination and a sense of respect among older persons. According to a review by Gregory et al. (2017) healthy interactions between senior

citizens, workers, and healthcare professionals are essential for maintaining power and independence. Therefore, for older persons to maintain mental and physical abilities as well as their quality of life, it depends on social connections.

Needs of autonomy

One of the fundamental ethical tenets of healthcare has been defined as autonomy, which is a human right that is safeguarded by international agreements and declarations (Moilalen et al., 2020). For older persons, perceived autonomy is essential because, when they enter residential care and must rely on others, their capacity to express their autonomy may be diminished. They are exposed to many risks due to this (Brownie et al., 2014). According to research, paternalism, and a lack of opportunities for older persons to participate in decisions about themselves have been problems for them (Gordon, 2018). Paternalistic attitudes may involve well-intentioned actions, but they can lead to a lack of respect for the autonomy and independence of older individuals as well as not giving older adults sufficient chances or avenues to actively engage in decisions that affect their lives (Chang, 2018). For older people to obtain subjective well-being, the needs for autonomy, relatedness, and competence must be met and create platforms for older adults to actively contribute to decisions that impact their well-being (Gordon, 2018).

Within the context of SDT, Tang et al., (2019) carried out a systematic review and meta-analysis of the literature on older people's well-being. Majority of the reviewed studies generally supported the notion that basic psychological need, fulfilment, and motivation (autonomous types) are favourable and correlated with well-being indicators (life satisfaction, positive affect, self-esteem, and subjective vitality) and unfavorably correlated with ill-being indicators (depressive symptoms, apathy, etc.). According to the authors, older adult's predisposition to be either proactive or passive is greatly impacted by the social circumstances of their upbringing. Thus, social support is important to enable people have the power to promote or obstruct well-being and personal development through interactions and connections with others. This assumption corroborates the finding of Dostálová et al., (2021) which affirmed that older persons reported a willingness to participate in care decisions and plans, despite how challenging it may seem, to maintain self-sufficiency and cooperation.

Older people would love to be treated as humans no matter their level of dependence as this has proven to improve their mental health. As affirmed by Cobo, (2014) in addition to being more active and content with the activities offered by their caregivers, older people felt more satisfied with exercising their autonomy. When older people remember how they oversaw their lives at a younger age, it makes them want to still take charge of their life in later years. According to Help Age International (2018), the findings from a comprehensive review involving over 450 older individuals revealed a stark contrast in the autonomy they experienced throughout their lives and in old age. The majority expressed an inability to make independent choices regarding crucial aspects such as finances, property, voting rights, place of residence, relationships, healthcare decisions, and participation in civic, charitable, or social activities. This means older people want to feel free in old age because they have a right to autonomy and independence. Self-determination theory proposes that for people to achieve psychological growth, there is a need for autonomy, competence, and connection (Ryan & Deci, 2020). That is why the theory places a greater emphasis on internal sources (intrinsic motivation) of motivation, such as a desire to learn or independence than on external sources (extrinsic motivation) of incentives, such as money, prizes, or praise (Cherry, 2022).

5.0 Discussion

When people become dependent, they need support from both caregivers and family members. The well-being of older people during this later phase of life is very important as it reduces further health complications. Findings from this review of literature shows that the three basic tenets of self-determination theory; competence, autonomy, and relatedness are evident in studies concerned with older people who practice self-determination. With these variables in mind, older people who practice self-determination have high self-esteem and better chances of quality of life (Hoppman et al., 2016). Furthermore, Bolenius et al., (2019) opined that older people who perceive a higher level of self-determination enjoy more quality of life than those who do not. This shows a positive relationship between self-determination and the quality of life of older people.

Also, as affirmed in the study of Notari et al., (2016), there is usually less incidence of depression and hopelessness amongst older people who are allowed to practice self-determination as this gives them a sense of belonging. This gives credit to self-determination theory for its ability to address various topics of life in many situations ranging from health to education which gives it a wide scope. It also has a high heuristic value as a lot of studies have been conducted using it as a framework. This implies that, considering the development of SDT in 1980 and its subsequent extensive study and expansion, its cumulative impact is substantial (Ryan & Deci, 2019). The theory has also been addressed in terms of its ties to other theories, such as the Big Five personality traits (Openness, Conscientiousness, Extraversion, Agreeableness, and Neuroticism (often remembered by the acronym OCEAN) and their neuropsychological correlates of Fiske (Ryan et al., 2019). The abundance of measurements for SDT constructs that were created, such as the Intrinsic Motivation Inventory (Monteiro et al., 2015), the Revised Sport Motivation Scale (Pelletier et al., 2013), or the Self-Regulation Questionnaires for various contexts, such as health behavior, proves the testability of SDT aided by these tools using validated and tried questionnaire as the theory's major variables.

Findings from this review suggest that autonomy is highly correlated with good self-rated health, prevention of depression, and cognitive decline in older adults, which plays a significant role in active aging. The idea of autonomy is crucial since it directly ties to dignity, regardless of one's health. Indeed, the cumulative impact of numerous exposures and frequently unfavorable psychological, physical, and social factors raises the likelihood of getting sick, even though aging is not always a condition connected with sickness. Therefore, older persons may exhibit diminished cognitive capacities and suffer from various diseases that impair the ability to make independent decisions. This corroborates the study of Brownie et al., (2014) that older people will be at a high risk of health challenges if autonomy is reduced. Also, older people are better able to freely explore treatment alternatives with caregivers since they are more aware and concerned about their health nowadays if they have autonomy.

6.0 Conclusion

With improvements in technology and health care, people can expect to live 15 to 20 years longer than they did in the past. This longer life expectancy may lengthen the amount of time spent with functional reliance, raising the demand for carers that also retain autonomy and independence about functional characteristics. The self-determination theory is an important theory regarding the caregiving of older people because it helps to explain the real world and connects how older people amidst the complexities of modern-era society strive to feel in charge and autonomous. This study explored SDT using different literature reviews which helped to describe, understand,

and clarify activities regarding the caregiving of older people because, for older individuals to feel in charge and autonomous, solid connections between them and their care givers are essential which is also crucial for their mental and physical health. In exploring the caregiving needs of older people in Nigeria, SDT can be a resourceful tool in examining why older people may be motivated to be part of their care or make decisions about their care. Self-determination is exercised in a formal care system for older people, and the theory has been used to explain the motivations behind older people receiving care in the formal care system over the years. I am convinced its application could provide and enrich knowledge, informing care practice in informal caregiving in Nigeria.

7.0 Recommendations

Having explored these reviews, it is worthy to note that, there are numerous stereotypes about older people being helpless, ill, or dependent. Some older people continue to participate in social activities well into their 90s. It is not unusual for older people to resist these stereotypes. The need for long-term care arises from the fact that many individuals must deal with increasing frailty as a natural by-product of aging, sometimes in conjunction with cognitive impairment. This reduces people's desire for independence and increases their need for care when it comes to daily activities like shopping, cooking, eating, cleaning, or bathing. It is recommended that;

- Caregivers and family members build long-lasting relationships with older adults receiving care, showering them with love, empathy, and respect during caregiving.
- A transformation in the way health systems is designed to enable affordable access to integrated services that are focused on the needs and rights of older people and aligning health systems with the requirements of older populations.
- In line with the United Nations Declarations for Healthy Ageing (2021-2030), there is a need to emphasize the human right to autonomy, ensuring that older people are treated with dignity and have the freedom to shape their lives, regardless of their level of dependence.
- Policies should recognize autonomy as a fundamental ethical principle and actively address paternalistic attitudes. This will create opportunities for older persons to actively participate in decisions about their lives.
- Policymakers should prioritize the establishment of platforms that enable older adults to contribute to decisions affecting their well-being, ensuring that their needs for autonomy, relatedness, and competence are met. This is a way of fostering social support structures that empower older individuals to maintain self-worth and cooperative make independent choices in these crucial aspects of their lives.

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