Family Caregivers' Accounts of Their Understanding of Cancer and Its Effects on Patients

Felistus Ndamba
https://orcid.org/0000-0002-4440-4301
University of South Africa
fellykwany@gmail.com

Modjadji Linda Shirindi
https://orcid.org/0000-0002-3351-6519
University of South Africa
shiriml@unisa.ac.za

Mankwane Daisy Makofane
https://orcid.org/0000-0002-2382-8471
University of South Africa
nase.melale@gmail.com

Abstract

Effective caregiving centres on grasping the complexities of cancer. Family caregivers are essential to supporting patients, and their knowledge of the disease and its impact on the patient can significantly influence their well-being and care. Recognising these complexities will enable social workers to enhance support systems for patients and family caregivers. In this study, which was conducted in South Africa, a qualitative research approach, utilising exploratory, descriptive and contextual research designs, was adopted, and in-depth semi-structured interviews were conducted. Ecosystems theory was used to understand the participants' experiences. The findings revealed that family caregivers had limited knowledge of cancer, its causes and treatment. Recommendations to improve service delivery are presented.

Keywords: cancer; understanding; effects; family caregivers; patients

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Introduction

Cancer is the leading cause of death in economically developed countries and the second leading cause in low- and middle-income countries (Finestone and Wishnia 2022, 1; WHO 2022). In most African families, care for cancer patients is provided by family members who are classified as informal caregivers (Ngozwana 2019, 290). Family caregivers are often the primary source of support for cancer patients, providing social and emotional support (Glajchen 2011, 226). Family caregiving refers to "the provision of unpaid care to another individual in the family, household, or social network that has physical, psychological, or developmental need" (Revenson et al. 2016, 5). It involves providing emotional, physical and financial support to someone with limitations in their physical, mental or cognitive functioning (Schulz et al. 2020, 636). However, in some countries, such as South Africa, family caregivers receive a government care dependency grant to help them care for critically ill patients.

Family caregivers include parents, siblings, children, spouses, friends, neighbours and members of the extended support community (Molassiotis and Wang 2022, 495; Opsomer et al. 2022, 44). These people typically have a close relationship with the patient. There are many factors that influence caregiving, such as love, obligation, tradition and religious norms (Biliunaite 2022, 3). However, in certain situations, such a responsibility might be neither chosen nor anticipated (Revenson et al. 2016, 7; Rha et al. 2015b, 376). As a result, there is a need to investigate family caregivers' understanding of cancer and its effects on patients.

Family caregivers provide cancer patients with substantial emotional, physical, psychological and social support (Molassiotis and Wang 2022, 494). The essential unpaid support provided by family caregivers enables cancer patients to manage their illness and recover (Parra et al. 2019, 44; Rha et al., 2015a, 174). Caring for someone with advanced cancer is a demanding and stressful experience. Family caregivers must cope not only with the challenges of daily care, but also with anticipatory grief as they face the loss of their loved ones. Therefore, the research question is, how does a cancer diagnosis have an impact on family caregivers as they may have to spend most of their time caring for the patient?

Background and Rationale of the Study

The increase of cancer incidence, along with its high death rate and significant morbidity, is a growing national health and socio-economic concern (DoH 2017, 8). The WHO (2022, 1) notes that cancer accounts for one in every six global deaths or nearly 10 million annually. In 2018, 18.1 million cases of cancer were estimated per year worldwide and the number is expected to double in 20 years (WHO 2020). In South Africa, about one-quarter of the population is affected by cancer through diagnosis or personal connections (CANSA 2017, 1). The National Cancer Registry receives over 100 000 cancer reports annually, approximately 80 000 of which are new cases (Singh

et al. 2015, 107). Family caregivers therefore play a crucial role in offering support and care to cancer patients. Their ability to provide effective support may be compromised by limited knowledge of and skills in caregiving, coupled with insufficient resources.

Cancer is historically associated with pain, suffering and, ultimately, death (Budziareck das Neves et al. 2017, 593). Encountering a cancer diagnosis is shocking (Maree et al. 2018, 6), leaving family caregivers in denial and experiencing stress and stigma, as it is challenging for families to accept their loved one's condition. Family caregivers therefore require sufficient information about the patient's condition, disease progression, potential adverse reactions and treatment guidance (Given and Reinhard 2017, 51). During hospital visits, healthcare professionals update family caregivers on the patient's progress to ease their fears and uncertainties. A lack of information and poor understanding of cancer and its treatment can confuse caregivers (Nemati et al. 2018, 311). It is against this backdrop that the researchers sought to explore and describe family caregivers' understanding of cancer and its effects on patients, given the stressful nature of the disease.

The problem statement for this study is: There is limited information on family caregivers' understanding of cancer and the effects of the disease on the patients.

It was anticipated that this research would provide healthcare social workers with a comprehensive understanding of family caregivers' accounts regarding their understanding of cancer and its effects on patients, to aid their intervention efforts. It was envisaged that the research findings would inform social workers in developing intervention strategies to enhance the social functioning of cancer patients and their caregivers. In addition, this study will serve as a baseline for future in-depth studies on this topic and contribute to the body of knowledge in the social work profession.

Theoretical Framework

Ecosystems theory was used to explore the family caregivers' understanding of cancer and its effects on patients at micro, meso, exo, chrono and macro levels. The theory underscores the interconnectedness of individuals, groups and communities (Miley et al. 2013, 31), emphasising family caregivers' interaction with the patients, family, community and broader society (Deacon and Macdonald 2017, 82). Family caregivers can be understood within their family and environmental contexts.

Microsystems

This level includes immediate people such as the family, friends, neighbours and colleagues (Deacon and Macdonald 2017, 88; Langer and Lietz 2015, 33). In this study, this level showed how direct social, emotional and physical support shaped family caregivers' daily coping. Their presence provides a supportive environment essential for effective caregiving.

Mesosystem

This system entails direct interactions and relationships among family caregivers and their close social network such as neighbours, friends and colleagues (Deacon and Macdonald 2017, 88; Langer and Lietz 2015, 33). In this study, it highlighted collaborative support networks which enhance family caregivers' ability to execute their duties effectively.

Exosystem

This system refers to the social settings that influence individuals without direct participation (Deacon and Macdonald 2017, 89; Haight and Taylor 2013, 33). This includes the community resources, educational opportunities and access to healthcare. Lack of knowledge on palliative care and treatment may lead to poor health outcomes. In this study, this level helped to strengthen the identification and analysis of unmet caregiving needs without direct involvement.

Chronosystem

This system represents the historical events and transitions that shape and influence family caregivers' experiences (Haight and Taylor 2013, 34). This approach helped patients and family caregivers to identify and use their inner strengths to cope with the demands of cancer treatment and caregiving. Understanding these dynamics provided insights into adaptive coping strategies.

Macrosystem

This is a larger system that encompasses cultural patterns, societal values, institutions, economic structures and policies (Langer and Lietz 2015, 33; Pask et al. 2018, 1082). The macrosystem looks at the availability and accessibility of services to the patient and caregiver. In this case, service delivery was shaped by government policies and legislation. In addition, culture and religious beliefs influenced how family caregivers and patients managed their illnesses, with some fearing stigma if they did not perform certain expected rituals. Some family caregivers attributed the illness to ancestral spirits or witchcraft; the patients, therefore, had to appease their ancestors and/or take traditional herbs for healing.

These five interrelated subsystems are essential for caregivers to understand cancer and its effects. The exploration of these systems revealed their influence on family caregivers' understanding of cancer, its treatment and side effects, and adjustment as the cancer progresses.

Research Methodology

A qualitative approach was used for this study. Creswell and Poth (2018, 44) state that qualitative research is interested in the meaning participants ascribe to the problem

under investigation, rather than the meaning given in the literature consulted. This approach afforded the participants an opportunity to deeply express their personal knowledge and understanding of cancer and its treatment.

Exploratory and descriptive designs were used. The exploratory mode of inquiry seeks to develop knowledge and facts about the situation based on research questions that guide the process (Shokane and Masoga 2021, 65). The descriptive design is used when the researcher has to observe participants' situations to accurately and precisely describe what is observed (Fouché 2021, 65). These research designs helped gather rich, detailed and textured participants' experiences (Creswell 2014, 14; McNarry et al. 2019, 43).

Non-probability sampling methods, that is, purposive and snowball, were used to select participants who met the selection criteria (Vehovar et al. 2016, 330). The inclusion criteria were that participants had to be family caregivers who had executed caregiving tasks for a cancer patient for six months or more. Home-based care organisations and hospices in the Gauteng province in South Africa were identified for inclusion in the study. An official letter of permission was obtained from these home-based care organisations and hospices to conduct the study with their clients. Social workers helped to recruit participants who were receiving counselling and group support from their organisations. Once the participants indicated their willingness to participate in the study, social workers provided the researchers with the prospective participants' contact details. The researchers then contacted them to schedule an interview date and obtain their consent. The participants recommended other family caregivers who fit the inclusion criteria and were willing to participate in the study. Interviews were conducted confidentially, and all data were stored safely. Seventeen participants took part in the study.

To collect the required data, semi-structured interviews were conducted and recorded in an environment in which the participants felt safe and comfortable. Interviews were audio-recorded with the participants' permission and subsequently transcribed. The data were analysed and categorised into themes and subthemes using Tesch's eight steps, as described by Creswell (2016, 158–162). Data saturation (Fusch and Ness 2015, 1409) was reached after the seventeenth interview.

All family caregivers recruited were from Gauteng, predominantly women aged between 26 and 70 years. Nine were married, two were living with life partners, five were single and one was divorced. Fourteen family caregivers had provided care for 6 months to 5 years, and 3 had cared for their family members for 6 to 9 years. Training backgrounds varied: two participants had nursing and medicine training, one had a caregiving certificate and the remaining 14 caregivers had no formal training. Data credibility, transferability, dependability and confirmability were ensured. To enhance transferability, data triangulation was employed, utilising multiple sources of data, and the theoretical approach was integrated into the study's data collection and analysis. In addition, thick descriptions were employed throughout data collection, which included

probing techniques, an audio tape recorder and note-taking, until data saturation was reached. Dependability was ensured through an audit trail, which confirmed that data were stored safely and that all steps of data collection and analysis were documented, should an audit be required. Through low-inference descriptors, the participants' direct quotations were used to interpret and analyse the data. To enhance the study's confirmability, the literature was consulted after data analysis to either confirm or contradict the study's findings, thereby eliminating personal or inherent biases. Theory triangulation was done by using many different literature sources to interpret and explain the experiences of family caregivers caring for patients with cancer.

Participation was voluntary, and the participants were informed they could withdraw from the study at any time without facing any consequences. Debriefing was necessary since the interviews may have evoked unpleasant feelings resulting from their lived experiences. The researchers considered withdrawing participants who were likely to experience secondary trauma. Arrangements were also made in advance with the debriefer to refer participants for counselling if needed, to minimise potential harm. A code was allotted to each participant to protect their identity. The researchers followed ethical principles of informed consent, avoidance of harm, violation of privacy, anonymity, confidentiality, deception of participants and publication of findings. Ethical clearance for this medium-risk study was obtained from the University of South Africa, reference number 2019-SWREC-58533559, dated 1 February 2019.

Research Findings

This article presents themes focusing on family caregivers' understanding of cancer and their perceptions of the effects of the illness on patients' health. The following four themes were derived from the data and are discussed below:

Theme 1 – Family caregivers' understanding of cancer and sources of information
Theme 2 – Family caregivers' reactions and feelings following a cancer diagnosis
Theme 3 – Health practitioners' failure to explain the illness to family caregivers
Theme 4 – Family caregivers' perceptions of the effects of the illness on patients' health

Theme 1: Family Caregivers' Understanding of Cancer and Sources of Information

It is essential to ensure that family caregivers possess adequate knowledge and understanding of cancer, which will enable them to provide comprehensive care and support to patients. The responses of 11 family caregivers indicated that they did not know what cancer was or what the implications of the disease were, which created fear, uncertainty and confusion. The participants' accounts are recorded below.

> I feel like I don't have a clear understanding of what it [cancer] is and how it affects her and what her future looks like. I don't understand it. (P17, female, 26 years)

> I don't understand anything about cancer. (P9, female, 51 years)

The findings support the study of Nemati et al. (2017, 311), which shows that most family caregivers have a poor understanding of the information received about the disease and its treatment, creating confusion about caregiving. The findings above are a clear indication that many family caregivers were taking care of cancer patients without a clear understanding of the condition.

Five family caregivers reported using information they had read on social media and by hearsay from others, as well as from relatives who once had the disease.

> I know you get brain cancer and bone cancer and lung cancer which he has. That was caused because he smoked earlier in his life, so he smoked a lot and that triggered the cancer in his lungs. (P16, male, 29 years)

> At that moment I did not understand really, I know what cancer is but I can't really explain. There are different types of cancer, that's what I learnt through the cancer with my sister (lymph), the cancer (lymphoma) with my daughter. (P5, female, 63 years)

The findings above indicate that many family caregivers had personal experiences with cancer through a family member, but they had little knowledge of the disease. This suggests a need for social media to distribute information on cancer and to expand outreach for cancer awareness campaigns (Houlihan 2015). Such initiatives would help to address fears regarding the disease and enhance family caregivers' coping mechanisms, as the information would be easily accessible.

Three family caregivers who had studied palliative care and nursing reported using the knowledge they gained during their studies.

> I just had to follow my instinct, I did medicine in palliative care and worked in the palliative care unit where I had to work with terminally ill patients, but overall its different with working with your mother. (P11, female, 44 years)

> . . . it's like an instinct, and I have the nursing background, and I work in hospitals . . . I have been in the primary healthcare clinics also for many years . . . but I have a bit of background in the nursing theory about cancer. (P10, female, 50 years)

The quality of care provided to cancer patients may be greatly influenced by family caregivers' educational level, as they will have a better understanding of medical information and use available resources and support systems. A research study revealed that family caregivers with college education were associated with elevated caregiving and a lower caregiver burden (Hosseinpoor et al. 2013, 336). The findings indicated that it is heartbreaking to provide care to loved ones, even if the person has prior knowledge of and experience in caregiving.

Theme 2: Family Caregivers' Reactions and Feelings Following a Cancer Diagnosis

Cancer diagnosis marks a new journey for many couples and families. Family caregivers reported that it was an unpleasant experience to know that their loved ones had been diagnosed with cancer. They reported being shocked by the patients' diagnosis.

> It was a bit of a shock and the doctor said he will live for about two years. (P16, male, 29 years)

> At first it was a big shock to realise she was sick, there was emotional breakdown because I had to make sure she sleeps and eat well. We were also surprised because we have always been a healthy family, so when we got the news everyone was shocked . . . It was quite a big shock. (P6, female, 63 years)

The excerpts reveal that it is difficult for family members to receive the news of a cancer diagnosis. The disease is viewed as frightening and complicated (Frank 2013, xvii). Family caregivers' reactions align with Budziareck das Neves et al.'s (2017, 594) view that a cancer diagnosis is a dramatic, unexpected and shocking experience.

The accounts of two caregivers revealed that they were worried and unsure of how to inform others.

> It wasn't nice, definitely not, it was painful [pause] . . . it was difficult because you know you talk to people but well I didn't know what to tell people and what to ask them or whatever. (P5, female, 63 years)

> For nights, I did not sleep, I was worried that I would wake up and see him not breathing anymore. (P1, female, 70 years)

The quotes above support Li et al.'s view (2013, 179) that the diagnosis prompts couples and families to undergo readjustment and adaptation, including breaking the "bad news" to other family members and renegotiating changes in family and occupational roles. Family caregivers and family members must adapt to the new circumstances. The study by Budziareck das Neves et al. (2017, 595) highlights that family caregivers are afraid to disclose patients' diagnoses to relatives owing to uncertainty about relatives' reactions to the disclosure.

Comments by two family caregivers revealed that it was hard, overwhelming and emotionally draining to witness the patients' suffering.

> There is lot more of emotional draining and its different when comparing it to when I worked with terminally ill patients in hospice and hospital. At times I found myself getting overwhelmed, sad, you know, scared; I kept on having an anticipated grief and trying to figure out how I can sort out everything and at the same time be there for her

> in terms of medication. I can say I have gone through anger, anxiety, overwhelmed, numbness, shutting off and frustration. (P11, female, 44 years)

> It is difficult seeing him in that situation, and I can't do anything; there is nothing I can actually do to help him. It is hard to see him go down, knowing it is basically the end. I would say it is mainly emotional, emotional challenges. I have questions and depression. (P16, male, 29 years)

The findings are in line with the explanation given by Alptekin et al. (2010, 607) that primary caregivers experience a considerable amount of stress, depression and anxiety, which develops at every stage of the diagnosis. Caregivers in this study revealed the wide range of intense emotions and feelings they experienced following diagnosis and during the caregiving process, such as anger, frustration, anxiety, sadness, hurt, loss and grief. Family caregivers provide between 70% and 80% of the care to their loved ones (Given et al. 2012, 205).

Theme 3: Health Practitioners' Failure to Explain the Illness to Family Caregivers

Family caregivers found communicating with providers, physicians, nurses, social workers, pharmacists and speciality pharmacies to be problematic (Given et al. 2012, 206). They reported that some healthcare workers responded to the questions but did not explain the patients' condition in detail.

> You know at XZ Hospital they don't have much time to sit down and explain to you. It's things you figure out along the way. I told you I did some research of the cancer and what to do. Some people say it's not a good thing to rely on internet but at least I get to know how to treat him and care for him and what to look out for and end-of-time symptoms. (P1, female, 70 years)

> Not really, they just said it's just breast cancer and it has progressed quite a lot, so, he did not explain much. So, when my brother called to ask questions like the life expectancy, they said they only respond to questions asked and with the treatment the patient can live for up to three years. Most of the time we get to be addressed by the nurses and even if there is a problem, we phone them, and they get to explain in relation to your question. (P6, female, 63 years)

The storylines above suggest that most family caregivers received limited information about the disease from healthcare workers. Some family caregivers were prompted to search for information online and in books, because they received insufficient information from healthcare providers. As much as there is plenty of information on the internet on cancer and its causes, some information is not validated empirically and might cause unnecessary fear or panic in the caregivers. A research study on the experiences of caregivers of pancreatic cancer patients revealed that the lack of clear information and support from healthcare professionals is often a source of distress (Sherwood et al. 2014, 389). The failure of healthcare professionals to communicate the

patient's progress left family caregivers feeling that they did not receive sufficient support from the healthcare system.

Some family caregivers commended the healthcare providers. Two family caregivers reported receiving good cooperation and valuable information regarding their patients' conditions from the healthcare providers.

> Cancer healthcare people has helped me a lot, they provide me with all the information that I need, and I really appreciate that. It's lymphatic leukaemia. They did give me all the information and what to expect, everything was explained to me. They say it will get worse and worse but after going to the doctor they said he is getting better. There is a nurse who also comes to check up on him. I must phone them when he is not well. (P12, female, 42 years)

> He [husband] is the one that told me that he was diagnosed with cancer then I accepted. So the doctor did not tell me at all. The only person who explained is Sr ML from the hospice. She told me the condition of my husband, she explained everything. (P9, female, 51 years).

The quotes above highlight the importance of effective communication from healthcare providers, as it helps to alleviate some anxieties and stress related to caregiving and the patient's prognosis. From the research study conducted in Australia by Shahid et al. (2013, 467) on identifying barriers and improving communication between cancer service providers and families, the findings revealed that, in any healthcare system, it is of great importance to respect and consider people from different cultures who are not fluent in English. A good and trusting working relationship between family caregivers and healthcare providers enables family caregivers to ask any questions at any given time without holding back their feelings.

Theme 4: Family Caregivers' Perceptions of the Effects of the Illness on Patients' Health

Cancer affects patients' health differently depending on the type of cancer, treatment modalities and individual circumstances. Family caregivers reported that their ill parents often experienced feelings of discomfort and shame for not being able to take care of themselves. They also reported that the changes were so sudden that some patients struggled to accept them.

> It is hard, the loss of dignity I have to wash her [pause], that's what I feel is that she lost her dignity and my mother was quite a proud clean woman and now she is dirty and her child has to clean her and that is hard for both of us really. It is hard for my mother; she used to cry a lot she was embarrassed you know . . . because of this frozen shoulder she could not wash her hair or get to funny places, I try to stand outside the shower and clean her. So, she never really gets used to the fact of me having to shower her . . . my mother is one who has been wanting to die for a long time, she says she is on her way and she

> is a burden and then a nuisance and we can't have a quality of life because she doesn't have quality of life. She just wants to go away and die. (P2, female, 66 years)

> Last week she walked from the bedroom to the bathroom, and she screamed, she can't put the leg after the other, she is getting weaker too quickly for me. (P3, male, 64 years)

The findings reveal that loss of independence is one of the effects of cancer and patients find it difficult to accept it to the extent that they often wish to die. Cancer patients become more stressed about the changes that the illness brings, such as restricted functional capacity, medical uncertainty and impaired sense of control (Vehling and Mehnert 2013, 189). As the disease progresses, patients' physical strength continues to deteriorate to such an extent that they have to rely on family caregivers for support. Another effect of cancer on the patient's health is weight loss.

> She is not feeling well. To make sure she eats because her appetite has decreased like now, she has lost almost 12 kg so that is one problem because she has to eat 30 minutes after taking her meds so I have to set an alarm so that she can have food 30 minutes after having her meds. (P6, female, 63 years)

> The first time when he was sick, he was tired, he lost weight. (P7, female, 59 years)

> . . . now he is even skinny. (P4, female, 64 years)

The illness and its treatments may lead to malnutrition, loss of muscle mass, weight loss and cachexia, a condition characterised by the loss of skeletal muscle and fat (Ladas and Kelly 2012, 126). This worsens the patients' condition, resulting in poor prognosis and lack of strength, and some of them may end up being hopeless and helpless. Not eating properly causes patients to lose weight, resulting in weakness, fatigue and even depression (Ramani et al. 2017, 45). Malnutrition in cancer patients leads to longer hospital stays, poor tolerance of treatments and lower survival rates (Planas et al. 2016, 431).

The participants reported memory loss as another effect of the illness on the patients' health. Patients find it difficult to remember events or information, and this varies in severity.

> She asks you again and again. It's like new information; she has a problem. It does hurt a little bit sometimes when she asks you who you are . . . it's like she is not here anymore even if she is here because her personality has changed . . . The problem is short term memory also like you tell her new information (P17, female, 26 years).

> Yeah, she lost memory, she cannot even recognise me, but at this moment she is now getting better and eat well so I can say I am coping well it's better than before. (P13, female, 39 years)

Ramani et al.'s (2017, 53) study found that cancer patients experience chemo brain, in which the ability to draw on semantic, episodic and procedural memory banks becomes impaired or slowed, leading to lapses in cognitive and motor activities. The change in cognitive functioning affects patients' memory, attention, processing speed, day-to-day activities and quality of life significantly. Hypersensitivity, irritation of the veins, anaemia, hair loss, alopecia, fatigue, dysuria, nausea and vomiting are some of the acute side effects of chemotherapy and radiation (Fleishman and Messner 2015, 5; Kelly 2014, 86; Miller 2018, 34). However, family caregivers' unwavering support, stoicism, hardiness and determination to fight the disease enable some patients to be cancer survivors.

Discussion

This study sought to understand family caregivers' understanding of cancer and its effects on patients. It highlights family caregivers' limited understanding of the disease and its treatment, as many of the participants relied on hearsay information. However, a few caregivers benefitted from nursing training, which improved their ability to care for their loved ones. Their support helps patients to accept their illness and potentially improve their prognosis.

Four themes surfaced from the data analysis. The first theme is family caregivers' understanding of cancer and sources of information. Many caregivers assumed their roles without a good understanding of the disease, relying on speculation, which created fear, anxiety and confusion. The second theme is family caregivers' reactions and feelings following a cancer diagnosis. A cancer diagnosis often shocked many family caregivers and they expressed concerns about disclosing it to other people. The third theme is health practitioners' failure to explain the illness to family caregivers. The lack of explanation from healthcare practitioners exacerbates the challenge. This may result in patient neglect and treatment default as the family caregivers do not understand the nature of the illness, how to administer medication timeously, or the diet to be given to the patient. The lack of knowledge of cancer among family caregivers underscores the need for healthcare professionals, such as nurses, to provide comprehensive education and training on cancer and caregiving to family caregivers. Involving patients and caregivers in multidisciplinary meetings can equip them with information about cancer, the patient's progress and available treatment options (Sklenarova et al. 2015, 1518). Research from the University Hospital of Clermont-Ferrand in France (Belgacem et al. 2013, 875) indicates that an educational programme for family caregivers that considers the needs of both patients and caregivers enhances their quality of life and alleviates the burden on family caregivers. When family caregivers are knowledgeable about the disease, they can manage medications more accurately, reducing the risk of errors.

The fourth theme reveals family caregivers' perceptions of the effects of the illness on patients' health. From the accounts of family caregivers, the side effects of treatment are hard to bear for patients as they lead to memory loss, fatigue, loss of appetite, lack

of strength and weight loss. Family caregivers observe some patients experiencing anxiety, severe stress, depression, feelings of helplessness and hopelessness. They have to spend more time providing care because some patients cannot do things such as going to work, attending events or visiting family and friends. Most cancer patients have to rely on family caregivers to do things for them and they become angry and frustrated. When caregiving demands supersede the available resources and support, patients become concerned about caregivers and other family members. Support from family and friends is crucial for patients to fight the cancer trajectory (Parrish 2014, 259). As a result of the cancer effect on patients, caregivers often feel overwhelmed, stressed and fatigued, may neglect their own health and experience social isolation. Respite care, support groups, counselling, education and training enhance their ability to cope with caregiving demands.

Conclusion and Recommendations

Family members often care for an ill person without receiving training. Lack of detailed information about the patient's condition affects care routines. Providing education, resources and support is essential for both patients and their caregivers. Healthcare professionals, such as social workers, nurses, doctors and oncologists, should educate family caregivers on treatment side effects and patient care. Training workshops can be organised for family caregivers and should cover topics such as cancer types, treatment methods, side effects, assistance with daily activities such as feeding, bathing or carrying the patient, managing medications and emergency procedures. This training can be done in hospitals or communities to reach more family caregivers.

Providing adequate psychosocial support is crucial to enhancing the well-being of patients and family caregivers. To move with the Fourth Industrial Revolution, digital and online counselling and workshops can support family caregivers who cannot leave their patients alone or cannot travel because of distance and/or financial constraints. Online videos can be made accessible to patients and family caregivers to learn about handling treatment side effects and various aspects of caregiving at their convenience. In addition, regular webinars can be organised with healthcare professionals to answer specific questions from patients and caregivers. A manual should be developed to cover post-discharge supervision and the importance of treatment adherence. There is a need to address the myths and misconceptions about cancer and its treatment.

Healthcare professionals should partner with CANSA to empower individuals, families and communities through awareness campaigns about cancer, the importance of cancer screening and available help. Information can be disseminated through social media and outreach initiatives. This will have a great influence on the coping mechanisms of patients and caregivers as the information will be readily accessible.

The limitation of this study is that it focused only on the advanced stages of cancer rather than the early or medium-term stages, where there is less likelihood of dependence on caregivers.

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