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Challenges Faced by Family Caregivers of Relative's Post Amputation: A Pilot Study

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Abstract

Background: The common cause of disability is due to lower limb amputation (LLA), and the principal etiological factor is diabetes, an individual's functioning and disability is induced by LLA, causing physical, psychological and emotional dysfunction, requiring caregiver support for general healthcare. Caregivers play an important role in the life of an amputee. The aim of this study was to explore the experiences of caregivers of amputees. **Methods:** A qualitative, phenomenological approach was used to explore the experiences of caregivers of amputees within the Suva area in Fiji. This pilot study employed one-one interview after approval from the College Human Health Research Ethics Committee (CHHREC) and information about the amputee and their relatives were sought after approval from the DON CWM hospital. Researchers derived the addresses for the amputees and their relatives contacts who were contacted using the mobile phone contact given in the register. A relative of an amputee was interviewed for this pilot project. The interview was conducted in the Hindi Language and later translated to the English language. **Results:** Four themes were derived from the thematic analysis. The relative of the patient felt sad and frustrated about the change in responsibilities; she had neglected her self-care, had very little knowledge and lacked competence in caring for an amputee. **Discussion:** One interview was possible which highlighted the need for support in caregiving and relief financially and psychologically for the people who care for their relatives with an amputation.

Keywords

Amputee, Amputation, Discharge Planning, Pain Management, Patient and Family Education

1. Introduction

Permanent disabilities resulting from lower limb amputation (LLA) affect the functions of the person's life by significantly altering the physical, psychological, emotional and social functions. Lower limb amputation due to diabetes increases the individual's dependence on caregivers for support and care [1]. They are most likely to feel depressed and anxious, experience phantom limb sensation and loss of job due to the amputation [2] [3]. Depending on the cause of the amputation, individuals often have lifelong challenges affecting their daily activities of living, often depending on their family members providing wound care [4], the caregivers are usually lacking the knowledge and ability to care for the ones in need [5] [6].

Caregivers face challenges of caring for the increasingly dependent person with an amputation, filling in for their everyday needs, their wellbeing, and emotional recovery. LLA is a global health challenge which affects the well-being of the patient, families and societies equally also responsible for permanent disability [1]. The support provided to the individual with amputation negatively impacts the caregiver, leading to decreased patient outcomes and economic hardships, creating psychological and physical stress as well [1] [3] [7].

The transition within their roles of the caregiver often leads to social and mental health issues and financial burden upon the family [1] [3] [8], stress, burnout, depression and anxiety is usually the result of caring for people with amputations [9]. Caring for patients with amputation leads to caregiver fatigue, financial and social strain, and other adverse outcomes [7]. Caregivers usually have added responsibilities such as medication administration and management, taking the patient for the Doctor's appointment by arranging transport and managing the wound site [5].

Lower limb amputation may include a toe, foot or leg are increasing worldwide especially in the United States [7], leading to permanent disability. The prevalence of amputation is also high in Fiji. Dr. Qereqeretabua, 2021, mentioned that Indigenous men in Fiji Lose Limbs to diabetes. 2016 data revealed 71% of below-knee amputations in Fiji with an alarming rate of 69% of i-Taukei men with amputation who lived in the greater Suva area. Diabetes-related amputations were high in the Colonial War Memorial Hospital accounting for 40% - 50% of diabetes-related surgeries with a total of 578 amputation in the three major hospitals in Fiji [10].

Moreover, urbanization plays a lead role in changing lifestyle behaviors, contributing to the increase in the number of people suffering from diabetes, increasing the burden of diseases in the Pacific Island Countries [11]. The increase in the number of amputations usually leaves families burdened with the care for such patients, leading to caregiver burden, psychological and financial constraints on families. Various studies across the globe discuss caregiver burden for patients with amputee, but there is no research conducted in Fiji to relate the experiences of caregivers of amputation. This study research reports the experiences of a caregiver who participated in the pilot study conducted by the researchers in Fiji.

2. Aim

This study explored the experiences of caregivers of amputees within the Suva Urban Area in Fiji.

3. Methods

A qualitative, phenomenological, and descriptive design [12] was used to explore the experiences of caregivers of amputees in those who resided in the Suva Urban Area. A qualitative approach allows the researchers to explore the different individual experiences and to begin assumptions and use interpretive/theoretical frameworks that inform the study of research problems [13] [14]. Phenomenological studies were described by [15] as capturing and communicating with the participants' experiences using their own words through observation and interview and to understand the meaning of the lived experiences [16]. A purposeful sampling with rich experiences of the phenomena [17], was selected to gain the experiences of two (2) caregivers who took care of the patients with low limb amputation. According to [13] purposeful sampling involves selecting individuals who have knowledge and had experienced the phenomenon.

3.1. Participants

There was only one caregiver available for this case pilot project who was conveniently chosen as she took care of her husband when he was discharged from the hospital. The caregiver is a middle-aged woman who takes care of her husband living in a sub-urban area within the greater Suva Area. She takes care of her husband alone who has a limb amputation, a diabetic, has a history of past cardiac surgery, and complains of short breath. She lives with her husband and two grandchildren, one of whom is a disabled child attending the Hilton special school.

The caregiver has been caring for her husband for a year now, and since the amputation has taken place both her children have moved out to live on their own. They do not visit them or provide any form of support, they do not drive and they depend on public transport if they need to go places.

The second caregiver had opted out of the study due to personal reasons. The participant signed a voluntary consent form after a verbal explanation of the purpose of the research was highlighted to her in her own language.

3.2. Data Collection

Data collection took place at the participant's residence maintaining confidentiality and privacy during the interview. A structured interview guide was used during the interview in the Hindi language. The interview took about 60 minutes to complete as we needed to prompt the caregiver sometimes to completely understand the answers she had given. She would also stop as she would feel emotional while discussing the events of the amputation and the caregiving process. Data saturation was gained as the caregiver had no new information to give to all the questions in the interview guide.

The one-one interview was audiotaped and later transcribed from the participant's language to English by two members of the research team. Ethical approval was sought from the FNUCHHREC (127-22), a faculty approval was also gained from the Medical Superintendent and the Director of Nursing at the Colonial War Memorial Hospital (CWMH). This process allowed the researchers to gain access to CWMH to obtain participants' residential addresses and phone contacts of the participant's residence to collect data from caregivers of amputees.

3.3. Data Analysis

One participant agreed to take part in the pilot study and one-one interview was conducted, audiotaped and transcribed verbatim including all notes and observations taken during the interview. The transcriptions were read several times by two researchers, then the principal investigator and another member had read the analysis to ensure reliability and consistency of the transcriptions. The themes were then coded, highlighting the key concepts. The codes were then grouped into similar themes which were organized into categories, then into meaningful clusters. Data coding was done for the interview, and a unique number was given to the participant.

4. Results

This result will discuss four themes that emerged from the interview of the pilot study which is reflected in Table 1 below:

Table 1. Themes derived.

Themes	
Sad and frustrated	*Yes, I do get tired and angry about what has happened today. The sons are not with us.*
Change in responsibilities	"*he used to earn and feed us for so long but now he is sitting at home, and we must look after him*".
Neglected self-care	*Yes, I feel that. One of my legs is also bad and I can't walk very well but nobody is here, so I have to look after him.*
Little knowledge and lacked competence in caring for an amputee	*No training provided to take care of the amputation.*

The relative of the patient felt sad and frustrated about the change in responsibilities; she had neglected self-care and possessed little knowledge and competence while caring for an amputee.

4.1. Sad and Frustrated

The participant felt sad that there was no one else in the house to take care of her husband who had suffered a loss of the lower limb due to diabetes causing significant disabilities [18]. Her children had left the house to live on their own leaving their mother to be the sole caregiver for their father during these difficult times. Caregiver burden increases significantly when there are other comorbidities suffered by the amputee leading to more stress and increasing the caregiver's mental and physical health [1], relatives are always willing to support the amputee, never leaving them alone and ensuring all tasks are carried out efficiently [19].

Participant mentioned "*I stay home and look after him, for nearly one year now, after the amputation, he is very sickly*"

"*We do not have any transport, we must do everything by ourselves, as our sons are not with us anymore, and we have to take care of two grandchildren*"

"*Yes, I do get tired and angry for what has happened, my sons are not with us, when we need to go for checking we have to call a taxi then the driver takes us*"

"*Relationship is broken now after amputation, feels like if you do not have a leg, you don't have anything, we were dependent on him, we are also looking after the other two kids*"

Continuous support from the health professionals is greatly needed that will reduce the burden of the caregiver who has to travel to the health center to attend clinics and get wound dressing changed, relieving caregiver burden while caring for the person with amputee. Health professionals should also ensure that a proper supply of dressing materials is available for the caregiver in case of emergencies.

4.2. Change in Responsibilities

The caregiver faced changes in her responsibilities that she had to take care of the husband who was once the breadwinner for the family. She felt responsible in caring for him, mostly left alone to do all the required activities for the husband adding to the physical stress incurred by the caregiver [19]. The role of caregivers is intensified when they must support their relatives with multiple disabilities, and the chronic illness they suffer from, spending substantial amount of time [20]. The patient's medical needs and the various visits to health care increase the burden of the caregiver [9]. Caregivers usually encounter a range of positive and negative experiences and differences in roles they play when they care for their relative's following amputation, often unpaid and untrained to take up the job of a caregiver [21]. They have various activities to carry out such as administrating medications including the hassles of medication administration to a patient who resists the medication, likewise, bathing a patient who is resisting a bath.

The quality of life of an amputee is altered resulting in negative somatic and functional impact and psychological functioning following amputation [8] [22], leading to increased dependence with physical limitations and significant alterations in the individual's performances [1] [8], doubling the need for caregiver assistance in the activities carried out for the amputee. The caregivers' responsibilities are various, including the complexity of events which lead to stress. When they must serve a reluctant patient their meals, or medication, for instance having to crush the tablet or giving an injection which the caregiver is not familiar with can cause enormous amounts of frustration and stress to the caregiver.

As eluded by the caregiver that "*he used to earn and feed us for so long but now he is sitting at home, and we must look after him*".

"*I stay at home and look after him for nearly one year now, after the amputation he has been very sickly, he has had heart surgery, has water in the lungs, has shortness of breath*"

"*Sometimes it happens, and we have to take him to the hospital, but we have to do everything ourselves*"

Upon discharge, the caregivers need to be trained sufficiently to be able to provide the care needed by the amputee. Respite care could also be planned for such patients who have commodities such as lung and cardiac diseases. Therefore, it is recommended that continuous support and teaching is provided to the caregivers during the home visits by health professionals.

She has a granddaughter and grandson who live with them. One of them is a disabled child and attends the special school in Suva. Making critical decisions for the patient can also be stressful [23], when the patient experiences negative perceptions about the amputation, leading him to feel burdened on the caregiver [24].

"*Now I put him on wheelchair, and he can go to the washroom by himself, before he could not go alone, I had to take him*"

"*He has crutches, but is difficult to use it, because of the steps in the kitchen. Now his leg is getting better so it's a bit better.*" She continues to speak: "*In the morning, he brushes himself, I have to put the coffee table in the bathroom for him to shower, I wash his clothes, and I dress him as well*"

Proper training needs to be provided to caregivers on how new equipment is used, this can support the patient better, relieving them of extra pain and frustration.

4.3. Neglected Self-Care and Social Life

The participant mentioned feeling weak and tired herself when caring for her husband, neglecting to care about herself, unable to devote enough time to rest in between the work she does. Participants in a study reported not having time to join events which lead them to acquire emotional stress [25]. Economic status, social lives and relationships are usually affected when someone cares for people with chronic disabilities [9]. The need for mental health and psychological support for caregivers was mentioned by [1]. [8] also mentioned that above knee amputation placed huge burdens on caregivers leading them to depression when they take care of these individuals for a longer period incurring huge caregiver burden. Caregivers often face emotional, physical and financial burden when they care for patients with amputation or chronically ill relatives [7].

The participant mentioned that she was unable to visit her relatives and friends due to the illness her husband has suffered, and caring for him has distanced her from most of her relatives and friends. Informal caregivers usually are the sole provider for the amputee in terms of physical and emotional support, leading the caregiver to stress, fatigue and social isolation [1].

As per the verbatim below:

"*No, I can't go anywhere as I do not have time to go to the neighbors. Even we do not go to my family's house anymore. Even if someone passes, we cannot go as we do not have any transportation*"

Amputation results in greater dependence on others resulting in the duty of care significantly increased whereby caregivers are restricted to social life losing contact with relatives and friends [1]. Moreover, the caregiver reported that relatives did not visit her due to the increased responsibility she has been placed on.

She also mentioned that: "*I always tell my kids that now we do not have anyone around*"

"*One of my legs is also bad, and I can't walk very well, but nobody is here so I must look after him*"

"*I don't go anywhere, I have no time to go to my neighbors and to my families and when someone dies, I can't even go their funeral*"

"*It's a bit difficult to look after my husband, like I must be working the whole day then I need to cook and feel him and give the food on time, and give his medications on time*"

It is vital that respite care is provided for the caregiver as health care professional could plan care for the amputee out the house, bring them to the rehabilitation center, teaching them basics techniques such as new equipment, and encouraging them to be independent.

4.4. Lack of Knowledge and Competence in Caring for an Amputee

Lack of knowledge results in poor care and prognosis, caregivers should be trained to take care of their loved ones upon amputation. The caregiver mentioned that she did not receive any help that could improve the care she provided for her husband. Providing psychological support to the amputee affects them positively [8] which the caregiver could not provide due to lack of knowledge and expertise. Caregivers need to be empowered by the health care team to support them during the process to ensure patient safety and adherence to medical treatment [1].

As the participant mentioned that "*now when nobody is here, I have to look after him*"

"*I do what I can do for him* (*Husband*) *I work hard and do everything on time*"

"*Diabetes center informed me about his food, how to control, to give the medications and the injection of time*"

Proper training needs to be provided to caregivers prior to discharging the patient home, ensuring that the caregivers are competent in the care they must provide for the patient.

4.5. Not Training Provided to Care

The participant mentioned not having enough training that would enable her to care for her husband efficiently. Proper training is essential for the caregivers as they have never done this type of care, they need to be taught about how to carry out certain activities such as lifting from the wheelchair and transferring the patient around. Inadequate knowledge and skills in providing care for the amputee can lead to wrongly administered medication for instance. Proper training should also be provided in terms of where the family caregiver could look for more resources, and how to best utilize the available resources. Sufficient resources play an important role for the caregiver to provide care to the patient [9].

When the patient is discharged from the hospital, the caregiver should be able to interact with the health care professionals in the hospital setting or the nearest health center to coordinate with health professionals to reduce the caregiver's burden [4]. Moreover, effective discharge planning will assist the caregiver to get back to the health care professionals with any information they need regarding the care of the amputee.

"*When it's his clinic, then they do counseling at the diabetic center*"

"*The training is not enough*"

Continuous support and training will assist the caregiver with the different activities they need to provide for the patient. Caregivers need to be continuously

5. Discussion

This study qualitatively examined the experiences of a caregiver who provided caregiving support to her husband with an amputation. Our findings add to the current literature of presenting new findings on the subjective experiences of caregivers of amputees. This study is unique to the context of Fiji as there has never been any literature on the current results and the experiences of caregivers of amputees in Fiji. The findings of the current pilot study provide novel insight on the struggles of how a spouse takes care of her disabled husband alone with limited resources and training experiences.

Caregiving is challenging due to the enormous tasks a caregiver must carry out for the amputated client, sacrificing their time, effort, rest and sleep during this phase. The social lives, relationships and financial status of caregivers are affected when caring for patients with chronic disabilities such as diabetic amputations [9]. The caregiver had to deal with the patient's inability to carry out tasks himself, and the feelings of dependence he posed during this time. Having limited knowledge and competence added more stress and frustration to the caregiver. There was no support provided by the children and the relatives, adding to significant effects on the caregiver. However, the caregiver persevered to provide care, devoting time and energy unconditionally to her husband. There were moments when she neglected her personal care, devoting less time to sleep and rest. This also reduced her interactions with her family and friends, having no time to spend on funerals and visiting sick relatives.

The burden of caring is real, as seen in this pilot study, affecting the caregiver in numerous ways, reducing the visitation from relatives and friends due to her busy schedule. She felt that caring was her duty of care as he cared for them when he was well. The burden could be reduced with some support provided by various people around her, the healthcare professionals, relatives and friends, and their children by sharing the load of caring. Healthcare professionals could also visit the amputee occasionally to check on their progress, helping them understand the care needed, wound care and emotional support which are essential during these difficult times.

Proper discharge planning which connects essential services to the person with amputation and their relatives is greatly needed. Information about wound management, dressing, and supplies should be addressed during the discharge of the patient, connecting them to social welfare for support and other non-governmental organizations will be helpful.

The reliance on women who are not in the workforce to provide care to the disable in the homes was considered in the past. However, the trend for the need to have other members of the household is changing in this century where males are also seen as caregivers, who need to also to earn a living for themselves and their families, juggling between caregiving, work and other responsibilities [26].

The current pilot study was based on a woman and her sacrifices she endued whilst looking after disabled husband. Studies have reported that the caregiver faces multidimensional experiences which may have positive and negative consequences to the caregiver [7]. Making the amputee feel comfortable in his own home environment, places the caregiver to carry out extra duties, increasing the physical burden of caregiving [19]. This study is a true reflection of how caregivers work tirelessly, day and night to care for the amputee within their home environment. The struggle for caregiving is challenging in many ways, specifically when dealing with dependent relatives who rely on others for the activities essential for well-being, health, and maintaining life without assistance from others [1].

Support is essential for the caregiver in terms of financial, from relatives and friends to give space to the caregiver, psychological and social support should be prioritized [8] so that the caregiver could take breaks in between, rest and acquire adequate sleep. The caregiver in this study reported no assistance from her own children who had left their parents' home to live away on their own. Leaving the mother to be the sole carer for their father, who experienced stress, frustration and felt sad at times. Having problems of her own such as painful lower limbs, not resting adequately and depriving her of sleep. Caregivers are also required to be empathetic towards the patient who is undergoing huge emotional and psychological stress, having a limb removed is a traumatic event.

6. Implications for Practice

This pilot reports the result of only one interview may pose limitations for generalizing the results. However, this study has reported many challenges that individual caregivers face. It would have been more interesting to get more views for other caregivers. The result of this pilot study sets as a reminder to the health professionals who are in direct contact with caregivers and patients with amputation. Continuous support, counselling, training and ensuring that appropriate supply of essential items is available for the caregivers of amputees.

7. Conclusions

This study reports insightful information about the challenges faced by the caregiver whilst taking care of the family member at home after amputation. The participant felt challenged, sad, and frustrated, having to change her roles and responsibilities without proper guidance and support from authorities, family members and friends. Caregivers need to be trained adequately and be supplied with ample resources to enable efficient caring for the amputated patient. Healthcare professionals may also need to have constant supervision; check on the patients and their caregiver's progress on the care they provide to their clients. Constant upgrade of knowledge and skills for the caregiver will assist in providing sufficient support to the amputee reducing the caregiver burden. The burden of caring for the relatives must be shared with other people around, especially relatives and friends, to provide respite care to the caregiver, who needs to get sufficient rest and sleep.

Caregivers face various challenges while they care for the individual with an amputation, they need support, training and a proper discharge plan prior to sending the patient home. Continuous support from health professionals will enhance a better outcome for patient recovery and satisfaction.

8. Recommendations

This study results recommend that there should be proper support provided to caregivers of amputees in the home, ongoing training and supervision of the caregiver, supplies of material resources such as bandages and aids need to be provided for the care of the amputee.

The caregiver faces huge psychological challenges during caregiving, thus proficient support must accompany discharge planning from the hospital and having continuous support rendered through home visits, or via telecommunication services for the caregiver.

The family could also be connected to the counselor who could visit the family randomly to provide emotional support. Counsellors could provide emotional support to the patient and the caregiver. The church leaders also play an important role in providing support to the family who take care of patients with amputations.

Limitations

The only limitation that could be derived from this study is that there was only one participant for this pilot study.

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Conflicts of Interest

The authors declare no conflict of interest.

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