__Original Research Article__

"I don't even know what is wrong with my aunt; I don't know if it is stroke or what": Support for family caregivers of patients with spinal cord injury in a resource-limited setting in Ghana

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ABSTRACT

Introduction: The global incidence of spinal cord injury (SCI) is on the rise. Family caregivers of patients with SCI play a significant role assisting with care at home, to help them integrate into the community. The caregiving role requires support to cope with the physical, psychosocial and financial challenges experienced.

Aim: This study explores the support system of family caregivers of patients with SCI in Ghana.

Materials and methods: A qualitative exploratory design was used and ten family caregivers of patients with SCI were sampled purposively. Data was collected through individual face-to-face interviews using a semi structured interview guide. Interviews were audio-recorded, transcribed verbatim, coded to identify themes and subthemes, and content analysis done.

Findings: Two main themes and six subthemes emerged. Family caregivers received physical, financial and emotional support from significant others, though many continued to have unaddressed financial and physical support needs. There were significant gaps in healthcare system support as most family caregivers had little knowledge and skills about SCI and its management, and outpatient clinic timing was not favourable.

Conclusion: Family caregivers should be involved actively in management of patients with SCI, and assisted to explore and utilize few support resources available.

Keywords: Spinal cord injury, social support, family caregivers, healthcare system, palliative care, low- and middle-income countries

1. INTRODUCTION

Globally, 250,000 to 500,000 people suffer a spinal cord injury (SCI) each year [1]. The majority of these individuals tend to be young, active males between the ages of 16 and 30 years [2]. The prevalence of SCI is expected to increase due to improved access to quality health care [3]. Injuries of the spinal cord can cause devastating and remarkable dysfunction and disability, resulting in paralysis of the arms or legs, loss ofbladder and bowel control, and loss of sexual function [4].

Managing SCI requires important health care resources and can place significant financial demands on patients, their families and the entire community [5, 6]. The majority of individuals withSCI discharged from health facilities return to their own residences [7] and usually require support with personal care [8]. Often, kinfolks provide informal care even though they do not receive financial remuneration for their services [9].

The services provided by family caregivers are indispensable for maintaining the health, wellbeing and community integration of individuals with SCI [4]. Heightened emotional stress, burnout, fatigue, anger, resentment, mental weariness and isolation have been reported among family caregivers of individuals with SCI as the result of assuming this role [10]. In addition, solving problems and performing roles related to relationships and employment are among the difficulties informal caregivers experience [11].

Because of the significant caregiver burden, support systems must be available for these family caregivers. Such support may come from healthcare professionals through training on how to handle patients and strategies to help them cope better [3, 12]. The availability of home care services, respite care centres, day care centres, support groups, rehabilitation centres and other family members to provide any form of assistance required is important for helping family caregivers cope with the stress of caring for a patient with SCI. In Ghana, most of these resources are not accessible because of unavailability or high cost.

The increasing incidence of SCI globally and locally implies that an increasing number of people assume caregiver roles [1]. It is therefore critical to explore the support systems available to family caregivers in resource-limited settings such as Ghana. The aim of this study was to explore support systems available to family caregivers of patients with SCI in Ghana and to identify other avenues for supporting family caregivers to cope with the caregiving role.

2. MATERIALS AND METHODS

2.1 Study design and setting

The study employed a qualitative approach with an exploratory descriptive design to understand the experiences of family caregivers of patients with SCI and the support systems available to them [13].

In Ghana, patients with SCI undergo imaging studies via computed tomography (CT) or magnetic resonance imaging, but the cost of these investigations must first be considered. Patients who can pay will undergo surgery and are discharged home when their general condition is stable. Those who cannot pay are discharged home on palliative care. Neurosurgery services are available in four of the sixteen regions of the country [14]. The country has no designated rehabilitation centres for patients with SCI; rehabilitation occurs in the patient’s home setting.

The study was conducted at the Komfo Anokye Teaching Hospital, a referral centre with more than 1000 beds. It has 11 clinical directorates, one of which is the General Surgery Directorate. Patients with traumatic SCI were seen by the Neurosurgery Unit, which conducts outpatient visits twice a week between 12 hrs and 18 hrs of gestation. Although the hospital does not have a dedicated neurosurgery ward, 15 beds have been dedicated to neurosurgery patients in the various wards of the General Surgery Directorate. According to hospital records, 408 patients with SCI were admitted to the hospital between January 2019 and December 2022.

2.2 Study population and sampling

The study population comprised family caregivers of patients with SCI receiving care at the neurosurgical unit of KATH. Those included were older than or equal to 18 years and had been providing care to their relative at home or in the hospital for at least two months since the onset of SCI. Family caregivers who could not communicate in English or Twi (a Ghanaian language) were excluded from the study.

We used a purposive sampling technique to identify family caregivers of patients with SCI who met the inclusion criteria. Ten (10) participants were recruited for this study. The sample size was determined by data saturation—the point at which no new analytical information emerged.

2.3 Data collection and analysis

The data were collected using a semi structured interview guide with probes. The interview guide had three sections: demographic information (age, sex, occupation, highest level of education, relationship to patient), interview questions (appendix 1), and conclusions. In-depth individual interviews were conducted with a face-to-face approach to allow flexibility of time and place in meeting each of the participants and to enable an exploration of their individual experiences and support systems [15].

The interview guide was piloted with three family caregivers of patients with SCI on admission, and adjustments were made. Participants signed or thumb-printed a consent form to indicate their willingness to voluntarily participate. The use of pseudonyms to represent the participants throughout the study was agreed upon. In-depth interviews took place at the location of choice of each of the participants to ensure their comfort and provide necessary privacy and confidentiality.

Individual face-to-face interviews were conducted over a period of one month, each lasting 18 to 40 minutes. All interviews were conducted in English or ‘Twi’ (a Ghanaian language), according to the choice of each participant. Interviews were audio-recorded, and field notes were taken to depict aspects of participants’ nonverbal communication relevant to the study objectives.

The audio-recorded interviews were transcribed verbatim, thematic content analysis was performed, and themes and subthemes were developed. Field notes taken were analysed to depict relevant observations made and have been placed in square brackets in the illustrative quotes.

2.4 Ethics statement

Permission to conduct the study was given by the Research and Development Unit of KATH. Ethical approval (with Ref: CHRPE/AP/512/18) was granted by the Committee on Human Research Publications and Ethics of the Kwame Nkrumah University of Science and Technology.

2.5 Methodological Rigor

To ensure the credibility of the study, transcripts and findings of the study were reviewed with participants individually through face-to-face discussion. However, none of them made changes to the data. Transferability of the findings was ensured by using data saturation as the standard for determination of sample size. The sample comprised participants of different ages, sexes and educational and occupational backgrounds. The demographic information is detailed in Table 1 below. The procedures employed throughout the study have been comprehensively described to ensure dependability and allow for external auditing. Confirmability was ensured by reviewing audio recordings of interviews, transcripts and inferences drawn from the interviews with colleagues.

3. RESULTS AND DISCUSSION

Table 1 illustrates the sociodemographic characteristics of the participants, and Table 2 illustrates the themes and subthemes identified in the study.

Table 1. Sociodemographic characteristics

Pseudonym	Age	Sex	Marital Status	Religion	Education	Occupation	Relationship to patient	Period of caregiving
Kofi	31	M	Married	Christian	Basic	Driver (sand truck)	Husband	3 months
Abdul	25	M	Single	Muslim	Basic	Farmer, artisan apprentice	Brother	8 months
Kojo	45	M	Married	Christian	Basic	Pastor	Husband	5 months
Abena	47	F	Married	Christian	Basic	Farmer	Mother	2 months
Akos	50	F	Widow	Christian	Basic	Cleaner	Mother	10 months
Adwoa	23	F	Single	Christian	Senior high	Unemployed	Niece	8 months
Ama	20	F	Single	Christian	Tertiary (nursing)	Student	Daughter	3 months
Akua	18	F	Single	Christian	Basic	Unemployed	Family friend	6 months
Yaa	38	F	Married	Christian	Basic	Unemployed	Wife	3 months
Esi	35	F	Single	Christian	Senior high	Trader	Mother	2 months

Table 2. Themes and subthemes

Theme	Subtheme
Support from social circle	Practical support
	Emotional support
	Financial support
	Recommending facilities for cure
Support from healthcare system	Knowledge and skills support
	Process and organization of care

3.1 Sociodemographic characteristics

As shown in Table 1, the majority of participants were female (7), employed (7) or Christian (9). Participants were aged between 18 and 50 years and had been providing care for 2 to 10 months.

3.2 Support from the Social Circle

3.2.1 Practical Support

The majority of participants did not receive any practical support in caring for their loved ones with SCI.A family caregiver relied to a large extent on practical support from another relative in performing the caregiving role and continuing to fulfil other social responsibilities, such as work. One male participant (a truck driver) who received this kind of support from his mother-in-law stated:

> My mother in-law comes around to assist with the laundry and meal preparation. She stays by her side while I go to work. This has helped to relieve some of the burden, as I could not go to work for two months at the onset of the condition because there was no one then to assist with her care. (Kofi)

However, the majority of the participants had not received any hands-on support from another relative to enable them to obtain some respite to attend to their work or rest for some hours in a day. Adwoa, an unemployed senior high school graduate who had been providing direct care to her aunt for 8 months, said:

> I don't work because of her. Since I assumed this responsibility, I am not able to go anywhere because I am the only person taking care of her and doing everything for her. Thus, I am not able to participate in any social activity.

Another participant, who was a tertiary student and had been playing the caregiving role for 3 months, similarly recounted how she had to be absent from school to take care of her mom, as there was no other person to support her.

> Absenting myself from school affected me academically, as I missed many lectures. That particular semester, I had one referral after writing exams. If I had been to school earlier, this might not have happened. (Ama)

3.2.2 Financial Support

All participants received some financial support from their significant others (family friends, church members and relatives) towards meeting the healthcare needs of the patient as well as their dependents. One participant who worked as a cleaner before assuming the fulltime role as a family caregiver for her son said:

> My church members came to my aid as well as several individuals in the community. I say to the glory of God that lots of people gave me gifts in the form of money, and this gave me so much joy. (Akos)

Another 18-year-old participant who was a family friend of the patient and had been providing care for 6 months, disclosing how the patient was supported through the earnings of the patient's children outside the country, said:

> Her older children outside the country have been sending money for her management. Therefore, we have never had any financial challenges. There is always money to take care of her. (Akua)

One patient was financially supported by her personal savings and by her siblings outside the country. Her daughter, who had been caring for her for 3 months, related,

> My mother used to save and has some of her siblings outside the country who are supporting her with money. They send us money for her hospital and home management. Therefore, we have never encountered any financial difficulties. (Ama)

Most (7/10) of the participants, however, continued to experience severe financial difficulties despite the financial support they had been receiving because they always needed to be met, such as paying for imaging studies. One participant, a 31-year-old man who was caring for his wife, noted the following:

> At a point in time, I had spent all my savings. My pastor, uncle and other church members had to come to my aid to help me take care of my family. As I'm talking, I don't have much on me. When the doctor requested an MRI (magnetic resonance imaging), we were wept in our room because there was no money, as I had used contributions from my uncle and pastor to take care of the school fees of our children, feeding, clothing and other needs. (Kofi)

Another participant, a 25-year-old farmer, revealed in tears:

> It has been extremely difficult to raise money to take care of him because I have to abandon my farming activities from which I earn some amount of money. I have been depending on donations from family, mosques and friends. We were discharged because we could not pay for the recommended surgery. (Abdul)

3.2.3 Emotional Support

Another form of support received from the social circle of family caregivers is emotional support through words of encouragement. The majority of participants received emotional support from their family and friends. One participant shared her experience as follows:

> A few of her relatives come to pay her a visit, and when they come, they encourage me to be patient and not to get fed up, and this truly helps me to get faith in God.I get fed up sometimes and feel like quitting, but the encouragement I receive from my elder sisters about God's blessings and a better future keeps me going." (Akua)

Similarly, another participant said,

> "The words of encouragement received from other family members and friends give me the strength to continue with my brother's management" (Abdul).

3.2.4 Recommending Facilities for Cure

Another form of support offered to most family caregivers by their social circle was suggesting herbal, homeopathic or allopathic facilities where a cure may be obtained. One participant said:

> From the onset of her ill health, many people suggested places where help could be offered for her to have her healed, that is,to regain her ability to walk. Thus, I kept taking her from one place to another as I wanted her to recover quickly, but this was not happening. (Kojo)

Another participant (Kofi) mentioned that "upon the suggestion of my uncle, …took her [patient] to an herbal clinic." Another participant similarly said that "after his[patient's] discharge, some people recommended an herbalist at Obuasi who is noted for treating conditions like that of my son." (Abena)

3.3 Support from the Healthcare System

Family caregivers also identified various forms of support from the healthcare system that strongly affect the experience of caregiving as significant. These included knowledge and skills, attitudes of health professionals, and schedules of outpatient clinics.

3.3.1 Knowledge and Skills Support

Two (2) of the participants had received some education from healthcare professionals about how to care for the patient at home during admission. One of them, a tertiary student in a nursing school, said:

> I was taught how to manage her, so there was no need for me to search for additional information on her management. The only challenge we had was her wound becoming infected when I left for school. She did not comply with the wound management schedules. (Ama)

The other participant, a form four leaver, said she was given some amount of information on her new role at the hospital.

> Before our discharge, the health professionals taught me how to manage him at home. I was told to be raising or exercising his limbs from time to time so that he could hold items and to assist him in a few steps. I was also told not to shout at him but to exercise a lot of patience in his care. (Akos)

She, however, added that:

> At the hospital, I was not taught how I could protect myself from assuming the wrong posture… At the onset, I was not told how I could prevent sores on my son's skin as he was confined to bed. However, I had experience taking care of my sick mother some time ago, so I remembered that I used powder on the skin. I therefore repeated this practice until a nurse told me to buy Vaseline for that purpose. (Akos)

Most of the participants expressed the need for information on the condition and training on caregiving activities. A female caregiver and senior high school graduate stated:

> I don't even know what is wrong with my aunt. …I don't know if it is stroke or what. …I have not been told how to manage her at home. I do everything based on our home knowledge. I think if we are given education on how to manage her at home, it will be very useful, as health workers know what is wrong with her. Teaching us the dos and don'ts in her home management might help her recover. (Adwoa)

The majority of participants (8/10) in this study emphasized that they had not been given any form of education on the condition or their role as health professionals. One participant, a 31-year-old truck driver, said:

> No health professional has ever taught me how to manage my wife at home, so whatever I do for her comes from my own 'home knowledge'. (Kofi)

Another participant, a 47-year-old woman who is the mother of a patient, said:

> I was not given any information on his care, how to bathe him in bed, how to turn him, how to manage his wound or how to care for his catheter. All I was told was to go home till I get money for the surgery. It is a nurse [engaged by family to dress patient's wounds at home] and the herbalist who has been teaching me what to do for him. (Abena)

Another participant, a 25-year-old man who is a brother to the patient, similarly reiterated:

> I was not given any information at all on his management. All I was told was to take him to Bechem Government Hospital for surgical wound management. However, I feel that if I had been educated on how to take care of my brother, it would have helped me. My brother always wants me to be around him lifting his legs, but I don't know if it is good for his condition or not. (Abdul)

3.3.2 Process and Organization of Care

Most participants expressed no concern about the attitudes of healthcare professionals toward them. However, one participant felt that the attitude of healthcare professionals was important as a support system because it contributed to his coping. He highlighted the need for nurses to have good attitudes by listening to them and treating them with respect to the following:

> I would like to talk about the nurses. Some of their attitudes were very disturbing. Sometimes, we would call for their assistance, and they would ask us to wait. We would see them sitting down idle, but they would not respond to our call. Sometimes, the way they would look at us made it difficult for us to approach them as we were afraid to. Additionally, sometimes, they would shout at us. In fact, if they could do something about it, we would be grateful. This made the caregiving role stressful. When you call them, they would act as if they had not heard. Aaah! It was difficult. In fact, they are proud, very proud. However, some of them have better attitudes. (Abdul)

Another issue identified by one family caregiver was the timing of outpatient consultation. Outpatient clinics are held in the afternoons, and this schedule was reported to be unfavorable to patients and family caregivers from outside the city. The participant revealed the following challenges he and the patient faced when they had to report for an outpatient clinic:

> Mostly, we spend hours waiting to be seen by the doctors at the OPD [Outpatient's Department]. The earliest we have been seen is at 6pm, and we live outside Kumasi. We usually have to spend the night at the OPD and get bitten by mosquitoes before we can leave the next day. This usually happens to those who come for afternoon clinic. I would plead that we are all seen in the mornings. (Abdul)

4. Discussion

4.1 Sociodemographic characteristics

The majority (7/10) of the family caregivers were females, an observation congruent with the findings of a previous study by Ae-Ngibise et al. [16] in which the majority of caregivers were females who were spouses, mothers or siblings of the care recipient. This could be attributed to the fact that females are traditionally considered to be caregivers [17].

Furthermore, the majority (6/10) of the caregivers were employed but were low-income earners; three (3/10) were unemployed, and one was a student. Oldenkamp et al. [18] also reported that 70% of informal caregivers were employed, which affirms the findings of this study. However, due to the demanding nature of the caregiving role, some participants had quit working at the initial phase of the injury, and one combined the caregiving role with his employment when he had adjusted to the new role. This finding is similar to findings from a study by Rattanasuk et al. [19] in Thailand, which showed that almost half of family caregivers combined their caregiving role with their jobs.

4.2 Support from the Social Circle

African countries such as Ghana often have wide networks of families made up of religious groups and extended family members who offer assistance to people or groups ploughed with disasters or deaths [16]. In this study, family caregivers received assistance from other relatives, friends, religious organizations and members of society, mostly through financial assistance and emotional support. Some participants depended solely on this kind of support, as they could no longer work to support themselves or their loved one. Participants recounted how support from religious bodies had made it possible for their loved ones to undergo successful surgeries. The majority of the family caregivers were appreciative of this support and acknowledged its positive impact on them and the patient. Baker et al. [19] similarly observed that social support helps mediate the burden associated with family caregiving, thereby promoting positive outcomes.

The finding in this study that only one family caregiver had been receiving assistance with the physical care of the patient to attend to his work for some hours during the day to earn some money for her upkeep is worth noting. Although support from extended family members is thought to be an important characteristic of Ghanaian culture, there appears to be a progressive shift toward a more nuclear family orientation [21, 22]. For instance, the tertiary student who was providing care to her mother could have had another extended family relation take charge of direct caregiving roles while she continues her education. This progressive shift in family orientation may be challenging to avoid, but steps can be taken to develop other strategies to ensure that individuals requiring the assistance of informal caregivers are supported by their communities through compassionate neighbourhoods, an insurance package, or a residential institution such as a care home, day care center, or purpose-built rehabilitation center [23, 24].

The financial challenge was the most pressing need because the majority were low-income earners who had also quit their jobs on account of their new role as caregivers. Similarly, Ae-Ngibise et al. [16] emphasized that caregivers of people living with mental diseases in rural Ghana experience poverty due to their inability to engage in full-time work.

However, some caregivers who had close relatives living outside the country did not experience any financial challenges. These caregivers were unemployed and thus were potential candidates for financial exhaustion. However, because the funds they received from their well-to-do relatives were enormous, they never had any financial challenges. Nevertheless, these participants admitted that managing SCI was very expensive and that without financial support, it would have been difficult to care for the patients.

4.3 Support from the Healthcare System

One of the needs of family caregivers of patients with SCI observed in this study was the knowledge and skills needed to care for the patient. To mitigate this burden, information on the injury and the role of the caregiver should be made accessible to family caregivers [25, 26]. However, the findings of the current study revealed that information on SCI and the role of family caregivers was not readily accessible to most participants. For instance, a family caregiver who had been providing direct care for 8 months was not informed by healthcare professionals what condition or disease patient was suffering from. Ofosu-Poku [27] noted the need for healthcare professionals to have discussions with patients and family caregivers about their condition and management plans, corroborating the findings of this study. Another factor that may contribute to these findings is that healthcare professionals in limited-resource settings may lack awareness and knowledge about SCI and its management [28], further affecting not only their care but also their ability to educate patients and their family caregivers appropriately.

Family caregivers should be recognized as partners in healthcare, assessed for their health fitness and knowledge level required to undertake the role, and provided the needed training and counselling. This strategy has been shown to build confidence in family caregivers and enable them to deal with challenges associated with daily management of patients [29].

Nurses’ poor attitudes further increase the stress and anxiety of family caregivers. Rude verbal and nonverbal expressions and the absence of attention given to the obvious needs of patients, such as feeding and personal hygiene, were some manifestations of the poor attitudes of nurses cited by the participants. These findings corroborate the findings of Asenso-Okyere et al. [30] and Adofo [31] that some nurses in Ghana seem to have serious attitudinal challenges in their relationships with patients and their families.

The afternoon schedule for outpatient department clinics posed challenges, particularly for one participant and his brother, who normally travelled from a distant region. Patients normally had to spend the night at the waiting area of the outpatient department after their review before returning home the next day. Patients with SCI need to have their review appointment scheduled while keeping their peculiar challenges in mind. Hospital management must also explore the option of making arrangements fordecent accommodations for family caregivers, who may need to spend the night around the hospital.

Alternatively, the option of moving outpatient clinics to the morning could be explored. The role of neuroscience nurse specialists should be explored because it can potentially increase the percentage of patients seen at the clinic while ensuring that patients receive the best possible care [32].

5. CONCLUSION

Family caregivers of patients with SCI assume this responsibility without any prior preparation, a situation that is in itself quite stressful. This is further complicated by the enormous financial burden associated with SCI management and the lack of information and training support from healthcare professionals. The social support received by family caregivers helps them cope with the caregiving role.

It is imperative that healthcare professionals help family caregivers cope well with their role by first considering them indispensable parts of the healthcare team and providing them with all the necessary information and training on caring for their loved ones with SCI from the time of admission until they are discharged home.

CONSENT

All the authors declare that written informed consent was obtained from the patients for the conduct of this study and its publication.

ETHICAL APPROVAL

All the authors hereby declare that the protocol for this study was reviewed and approved by the appropriate ethics committee and was therefore performed in accordance with the ethical standards established in the 1964 Declaration of Helsinki.

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