ORIGINAL RESEARCH

Transition from Hospital to Home-Based Care for Older Adults in Southwestern Uganda: Informal Caregiver's Experiences

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Background: The transition from hospital-based to home-based care is a complex and challenging process. In most developing countries, patients transfer directly from hospital to home immediately after stabilizing from acute illness. After discharge, all the patient's care needs are taken over by informal caregivers whose experiences and practices may directly or indirectly impact the quality of patient care as well as the outcomes. This study aimed at exploring the experiences of informal caregivers during the hospital to home transition process of older adults.

Methods: We conducted a qualitative exploratory study that used one-on-one interviews to describe individual experiences of care givers of older adults admitted in a clinical care setting. We interviewed caregivers of older adults with diabetes and of hypertension who were admitted at the inpatient department of internal medicine at Mbarara regional referral hospital (MRRH). All audio recorded interviews were transcribed verbatim by the research assistant in the local dialect and back translated into English the official language spoken in Uganda. The study utilized content analysis approach to analyze 23 interviews conducted.

Results: Of the 23 participants interviewed, majority were aged between 20 and 40 years and females. Three major themes emerged from the data: informal caregivers' experience during hospitalization, experience during preparation for discharge and experience after discharge. **Conclusion:** Caregiver experience during hospitalization influences their involvement and compliance with the discharge process which in turn affects their ability to deliver quality post discharge care to the patient. Healthcare systems need to put targeted effort and resources in the discharge process and home follow-up visits to improve home-based care by caregivers. Community-based geriatric care centers can bridge the care gap during transition from hospital to home-based care.

Keywords: Experience, discharge, caregiver, home-based care, older adults

Background

The transition from hospital-based to home-based care is a complex and challenging process. Studies in high-income countries show that transfer of patients from hospital to home-based care has become more common compared to institutional care centers. In developing countries where institutional care centers are scarce, every patient is transitioned to lower-level of care immediately after stabilizing from acute illness or even directly from hospital to home which is often times a common practice, this reduces healthcare costs. Commonly, informal caregivers take lead in caring for these older persons after discharge. An informal caregiver is an individual who provides unpaid care and support to a family member, friend, or neighbor who needs assistance due to a physical or mental disability, illness, or age- related condition.

There is still limited involvement of informal caregivers in care transition process.⁵ This interferes with effective care giving role uptake and performance by informal care givers. Informal caregivers need to be provided with adequate information during preparation their care giving role.⁶ Informal caregivers also take responsibility of managing medicines, and complex medical equipment used in patient care.⁷ Informal caregivers' contribution to patient care while in the hospital

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is underappreciated,⁸ yet if they are empowered can provide the necessary care to ensure optimal post-discharge recovery.^{1,9} Although it is clear that the role informal caregivers' impacts the quality of patient care transitions both directly and indirectly there is limited knowledge of their experiences and perspectives during the transition process.

Therefore, this study aimed at exploring the experiences of informal caregivers during the hospital to home transition process of older adults.

Methods

Study Design and Setting

We conducted a qualitative exploratory study that used one-on-one interviews to describe individual experiences of care givers of older people (defined as persons older than 50 years)¹⁰ admitted in a clinical care setting. Our aim was to explore the transition process of older adults from the hospital to home-based care from the informal caregiver's perspective. The study was conducted at Internal Medicine department of the Mbarara Regional Referral Hospital (MRRH), located in south western Uganda. MRRH is a public referral health facility and the main teaching hospital of Mbarara University of Science and Technology (MUST). Other health training institutions in south western Uganda also utilize MRRH for clinical placements. This hospital has a catchment area of over four million people. It is located 270 kilometres from Kampala, the capital city of Uganda. The Department of Internal Medicine receives patients with both communicable and non-communicable diseases. The department is run by a multi-disciplinary team of consultants, nurses, clinical officers, pharmacists, residents and other professionals like physiotherapists, nutritionists and social workers who are called upon whenever need arises.

Study Participants and Recruitment

We included primary caregivers of inpatient older adults with diabetes and/or hypertension who were admitted to the Internal Medicine ward MRRH. Also primary care givers were included if they stay with the older person for the entire admission period and stayed with the older person for at least seven days post discharge. The first author (JO) enrolled study participants through identifying the potential participants from the ward. Telephone contacts and home address of both the patient and primary caregivers were recorded. We first telephoned the potential participants to schedule inperson interviews after discharge from the hospital. The study purpose was introduced to the targeted participants and only those who provided written informed consent were included in the study. Participants were recruited until saturation was achieved at the 23rd participant when no new information was generated.

Data Collection Tool

We developed a semi-structured interview guide with questions tailored to the transition experience from hospital to home of older adults. Key guiding question included: Can you please tell me what it is like to be a caregiver?

Data Collection Procedure

Data were collected between July 2022 and February 2023. An experienced research assistant in conducting qualitative research interviews conducted the in-depth interviews. The participants were care givers of older adults, who were purposively selected. The participants were informed about the purpose of the study and were assured about confidentiality of their responses and that any publications would be de-identified with respect to quotations from the interviews. Informed consent was obtained, and interviews were conducted from their homes seven days post discharge. The period of seven days post discharge was considered to be sufficient for the participant to have settled home and fit for the interview. Written consent was obtained to audio record the interviews, supported with field notes.

During the interviews, open-ended questions were logically asked following the interview guide. Probes were used to either obtain more information or for further clarification. All interviews were conducted in-person, in the local language (Runyankore-Rukiga), and lasted for approximately 45 to 60 minutes. Saturation of information was reached at the 23rd person, where no more new information was obtained. No more interviews were conducted thereafter.

Data Management and Analysis

All audio recorded interviews were transcribed verbatim by the research assistant in the local dialect (Runyankore-Rukiga) and translated into English the official language spoken in Uganda. The transcripts were reviewed by JO for accuracy, ¹² inserting notations for pauses, clarification of information and punctuations. This study utilized thematic analysis to develop and interpret patterns within the data (Graneheim UHet al 2004) to ensure replicability and validity inferences from texts to the contexts of their use. During data analysis, all the transcripts were read and re-read by JO and PM together with two research assistants to familiarize with the data and the overall meaning. ¹³ Data were manually organized into codes, sub themes and then themes. ¹⁴ Coding was done by PM and research assistants independently, and reviewed by JO, and other coauthors for consistency checks to ensure rigor. ^{15,16} Where there was disagreement on content themes, there was discussion and responses switched to where they were most appropriate by consensus.

Results

In this study, we interviewed 23 care givers of older people, majority who were females in the age range of 20–40 years. All participants had either a biological or marital relationship with the recipient of their care. Alongside care giving, participants were involved in business, peasantry and housekeeping (Table 1).

We used manual thematic analysis to generate codes which we then grouped and renamed into sub-themes and themes. Three major themes that emerged were caregivers' experience during hospitalization, experience during preparation for discharge and experience after discharge emerged from data analysis. These themes were further divided into sub-themes as shown in Table 2.

Experience During Hospitalization

Acquiring Knowledge

Some caregivers used the time of hospital stay to ask healthcare providers question so as to gain more knowledge about their patients' condition and how to care for them after discharge. Caregivers interacted with fellow caregivers and healthcare providers thus enhancing their knowledge of the patient's condition.

Variable Frequency (N=23) **Education level** Age <20 01 Non 05 20-40 12 Primary 06 10 06 >40 Secondary 06 **Tertiary** Sex Relationship 20 Female Daughter 13 03 03 Male Son Wife 05 01 Husband Mother 01 Residence **Duration of caring** 09 П <I year Rural 12 04 Urban I-5 years >5 years 10 Marital status Occupation of care giver Married 18 Civil servant 03 02 09 Widowed Peasant 09 Single 02 **Business** 01 02 Divorced Housewife

Table I Participant Socio-Demographic Characteristics

Table 2 Themes and Sub-Themes

Themes	Sub-Themes
Experience during hospitalization	Acquiring knowledge Prolonged hospital stays Congestion and Lack of privacy
Discharge process	Discharge on short notice Premature discharge Discharge on request Escaping from hospital
Post discharge care	Care giving roles Assisting to perform ADLs Monitoring and medication management Caregiver burden Financial constraints Emotional distress Physical sickness Abandoning work Motivation for care giving Good previous relationship with the patient Cooperation from family members Prior knowledge and experience

The time I spent in the hospital with my mother, whenever a doctor would come to check on her, I would make sure that I ask her a lot of questions so that after I have gone back home then I don't get confused...whenever the doctors would come in whatever instructions they would give me I would make sure to perfection it. (F, 25 years)

Congestion and Lack of Privacy

During hospitalization, patients and caretakers sleep in one open general ward. Caregivers expressed concerns about lack of privacy in such a ward. This is further compounded by congestion on wards. Due to congestion and lack of privacy, caretakers reported that patients would demand to be discharged so that they go back to the comfort of their homes.

...there was no privacy and remember we were there in the medical ward; no privacy and she could be demanding that they discharge her and she goes home into her bed. (F, 59 years)

Because of the conditions on the ward with patients full, I would say if we could go home, even you see there was no space to do exercises from,...Even the hospital was congested with patients, so you would need a place that is calm. (F, 38 years)

Prolonged Hospital Stays

Some caregivers were concerned about staying in the hospital for long. This prompted them to request for discharge so that they could continue to care for the patient from home.

I was tired of staying in the hospital. And for her I first asked the doctor; can you allow us to go home? I felt bad because I was not working but only there in the hospital. So, I asked him if he could discharge us from the hospital so that when I reach home, I can see how to take care of him. (F, 25 years)

Some participants described their stay in the hospital as physically and emotionally exhausting. This was particularly mentioned as falling sick and staying awake throughout the night.

When I fell sick, because of staying awake for nights and I couldn't sleep well, I failed and I asked them [relatives] to stay in the hospital.(F, 59 years)

I feel tired but an elephant can't get tired of its trunk. I feel chest pain because I was lifting; I also feel of course spending sleepless nights. but in those short days I would first raise him to go and urinate, urinate, because of drinking a lot he was urinating frequently, even this affected my life, coldness exposure, was about to cause allergy, waking up in the night every minute every minute without sleeping but I persevered in all that. (F, 47 years)

Discharge Process

Pre-Discharge Health Education

Some participants reported being health educated about how to care for the patient after leaving the hospital. One of the participants mentioned that she was taught how to exercise, feed and give medicine to the patient.

We were taught how we are supposed to care for the patient, how to do exercises, because she had stroke, we were told to buy medicine, then they told us after a few days to we were told to go back...They helped us because the advice they gave us was that we kept exercising her do massage, we give what to eat and drink and medicine, and we did that and she improved. (F, 40 years)

Gaps in the Discharge Process

Caregivers identified and described several gaps in the discharge process. These included inadequate preparation for discharge and discharge on short notice. One of the caregivers stated that they were informed about being discharged that very day. They were not informed early enough to get ready to go home.

I saw them (health workers), bring to us papers, they first came and measured him, they said the sugar levels have reduced, said they will discharge us to go home. (F, 38 years)

Another caregiver explained that they were never given any prior preparation before discharge, adding that they even did not have transport to take them home and had to improvise.

I was never prepared that on that very day they would discharge us. But when they informed us that we have been discharged, we became responsible and looked for means of transport...We were not prepared to know that on such a day they would be discharging us or the next day; we knew nothing about that. (F, 40 years)

Premature Discharge

Caregivers also described instances of premature discharge in regard to the patients' condition. One of the care givers reported feelings of discontentment when the patient was discharged before she could barely stand up. Due to the fact that the wards are often times congested, health workers are compelled to prematurely discharge patients who have stabilized in order to create more space for new and more critical patients.

For sure, when I was discharged, I was not happy. Because they discharged a person who could not stand up, when I was still lifting, so I asked myself, they have discharged me when she is still bedridden, what will I do...?. (F, 48 years)

When we're going to be discharged, I was not aware and I was not prepared because I was seeing when she was still badly off and my heart told me that may be is it because we are going in festival season...(M, 38 years)

Discharge Against Medical Advice

Caregivers shared that sometimes the patient demanded to be discharged for non-medical reasons. One of the reasons reported was running short of funds to sustain their stay in the hospital. This financial constraint is compounded by the prolonged stay in the hospital during which all the financial resources leaving the patient and the care givers with no alternative but to request for discharge before they are medically fit to go home.

Sincerely speaking, you never wanted him to be discharged...But because of his little understanding and pressing you that "I want to go home", I want to go home claiming that he has run short of funds. (F, 73 years)

Another caregiver narrated that she requested for the patient to be discharged because her own health was also deteriorating. She therefore decided to request for discharge before the due time.

...because of the fact that I fell sick and had poor health I had no; I couldn't manage staying in the hospital and I requested for a discharge and the rest we shall treat her at home. (F, 59 years)

Escaping from Hospital

One of the caregivers reported that the patient escaped from the hospital without going through any official discharge process. The participant explained the patient claimed that he would deteriorate when he remained admitted in the hospital and so decided to escape.

For him when he reached there [hospital], he said for him when he's admitted, he deteriorates further. He said that he should not remain in the hospital to die from there...that he can't stand to remain admitted in the hospital and he had to escape (F, 73 years)

Post Discharge Care

Care Giving Roles

Assisting to Perform Activities of Daily Living (ADLs)

After being discharged from the hospital, caregivers identified various roles which they had to perform on behalf of the patients. These included ADLs like feeding, bathing and exercising the patient.

I wake the patient up, bathe him, measure his blood sugar, give him what to eat, walk a bit; after getting tired I bring him back, because he doesn't see well.(F, 38 years)

Monitoring and Medication Management

Caregivers discussed that they take over the role of monitoring patients' disease parameters like blood sugar and blood pressure after being discharged from the hospital.

I have been with the patient since her discharge, I have been monitoring her conditions, I have been looking at her progress and if she keeps it up... (F, 50 years)

One caregiver shared how she with difficulty tries to use a glucometer to measure the patients' blood sugar even after being taught by a health worker.

Even the machine (glucometer) was first difficult to use...but later I got a health worker who showed me how to use it, but sometimes I go to measure and the machine refuses. (F, 38 years)

Another caregiver described how she was taught how to give insulin injection by a health worker while still in the hospital. She added that she was doing it however it was not easy for her.

I inject him but it's not easy for me...The health worker showed me when we were still in the hospital, I was shown that you hold it (insulin syringe) like this, fill it (insulin syringe) like this. (F, 38 years)

Psychosocial and Emotional Support

Caregivers also mentioned offering psychosocial support like counseling to the patient under their care as one of their important roles.

...keep counseling her; whenever she gets a problem you keep advising her but not in a rude way. I think that being a caregiver means taking care of her and giving her comfort as well as counseling her. (F, 40 years)

Care Giving Burden

While performing their care giving roles, caregivers reported meeting some challenges ranging from financial, physical, emotional, and socioeconomic as described below:

Financial Constraints

One of the caregivers narrated that they lacked money to run the family. This was compounded by the fact that they had borrowed a lot of money from financial groups which they could not pay back. This adds debt burden onto a family that is already struggling to meet the care needs of the patient. She added that they had even failed to pay school fees for their children.

We went into debts, because we did not have money of our own; we borrowed from here and there; we would be with loans, so we failed to get money [to pay back]. (F, 47 years)

Emotional Distress

As a result of financial constraints like failure to pay debts and other financial needs of the family, informal caregivers as well as patients become emotionally distressed. One of the participants reported feeling stressed because the family had no money to pay school fees for children. She added that the patient was equally stressed.

So, we got stressed; even the patient got stressed after improving; he saw that we were stressed. He had debts, children are at school needed money, we hadn't completed (paying) the fees...so we have been stressed. (F, 47 years)

Abandoning Work

Being a caregiver is a fulltime responsibility that compromises other responsibilities like jobs. One of the caregivers shared that she left her job to go and care for the old woman. She added that even when she wants to go to the garden, she has to first prepare for her what to eat.

I have stayed with her, we have spent 2 years but previously I spent 5 years before the stroke, after she developed stroke, I stayed with her again, I left my job, went to care for the old woman.(F, 56 years)

Motivation for Care Giving

Social Support

Most caregivers were motivated to carry on with their role because they had strong social support from family members and friends. One of the caregivers explained that she remained strong because the relatives regularly visited counseled and encouraged her.

Relatives have been coming, they also counsel us...they have been checking on us, the relatives counseled us and if they did not support us, myself alone I could not manage...They did not abandon me.... (F, 47 years)

Prior Knowledge and Experience

Some caregivers with prior knowledge and experience in care giving reported to be confident and motivated to perform their role. One caregiver who was a Village Health Team (VHT) volunteer claimed that she has experience of caring and showed desire to get even more knowledge of care giving if she could get a chance to train.

I give it(medicine) very well and because I am a VHT, that has also helped me, I have got experience, in fact if I had time and money, I would go to train on how to care for the elderly.(F, 39 years)

Spiritual Coping

Most participants turned to God in search for spiritual intervention. Some participants narrated that they get their strength and courage to keep caring from constant prayer. One participant said care giving is a God given responsibility and therefore God enables her to carry on victoriously.

I tell God give me strength and courage I tolerate what I am in, I become victorious because if you don't have God, you can't be victorious...when I go into my bed room, I say God help me to do this work because it's you who gave it to me no one called me to come and care for our mother.(F, 56 years)

The thing we first did was to surrender all to God, because we said if we don't surrender to God, we will be anxious, we will not manage, so more effort was put in prayer, we kept on praying, we have even born-again Christians who kept praying with us, even us we would pray for ourselves...after joining prayer and when people keep counseling you, you feel strengthened.(F, 47 years)

Discussion

This study aimed to explore caregiver experience in hospital, discharge process and post-discharge care. Our results show that care giving during hospitalization, discharge and after discharge is a continuous process. Caregivers ought to be directly involved in patient care at all levels of care because this influences the quality of care they offer.

Caregivers and their patients were uncomfortable with the congestion and lack of privacy on ward. Consistently, congestion and lack of privacy has been reported in public hospitals.¹⁷ A previous study has shown that lack of privacy hinders free interaction between the patient and healthcare providers as well as family members and this makes their hospital stay uncomfortable.¹⁸ In our study, patients resorted to seeking early discharge so as to regain the privacy and comfort of their homes. Relatedly, Dolu et al point out that patients returning to their own home allows them greatest independence and comfort.³ This perceived comfort by older patients when they return to their communities can be leveraged to put up community-based geriatric care centers which can bridge the care gap during transition from hospital to home.

During hospitalization, caregivers gain knowledge about the patients' condition and how to care for the patient after returning home. Caregivers in our study acquired this knowledge through asking healthcare providers questions. It has been found that care givers ask questions and seek clarity most especially during discharge. Divergent from our finding, previous studies have reported that caregivers get shy and ashamed hence hesitant to ask questions about patient's care. According to Topham et al, 2022, caregivers often have gaps in their knowledge of how to care for the patient after reaching at home. In our findings, caregivers had knowledge gaps about using medical equipment like glucometer and blood pressure machines. Also, caregivers may not be able to translate the knowledge they have learned into the home-based care without ongoing support from healthcare providers. Caregivers need to be adequately trained about home-based care including administering medicines, exercising the patient, use of blood pressure machine and glucometer before discharge.

Discharge Process

Studies have revealed that long hospital stays or delayed discharge are associated with poor patient outcomes, increased healthcare cost and stress among family caregivers.^{22,23} In the same line, our study showed that due to long stay in the hospital, caregivers became physically and/or emotionally exhausted. Others ran out of funds and all these compelled them to request for discharge against medical advice. Such forms of discharge against medical advice have been shown to be a global challenge though more frequent in developing countries. To address the emotional distress that result from prolonged hospital stay, patients and care givers should be given adequate and accurate information about the discharge process and an estimated discharge date.^{24,25} This will enable them to plan for the resources available to sustain them during hospital stay.

A previous study in Uganda reported that discharge planning often does not begin until immediately prior to discharge and generally does not include caregiver input despite the major role they play in patient care after discharge. This has remained consistent in our findings whereby caregivers described receiving a brief discharge preparation just on the same day they are being discharged. Inappropriate discharge and follow-up plan after arrival at home resulted in stress among the caregivers.³

Post Discharge Care

After hospitalization, older adults tend lose their ability to function and live independently thus requiring assistance from the caregiver to perform certain roles on their behalf.²⁷ In our findings, the common roles of caregivers assisted patients to perform were ADLs like feeding and bathing, monitoring patients' blood pressure and sugars, medication management as well as offering psychosocial and emotional support. Similar caregiver roles like emotional support, administration of

medications and meal preparation have been previously reported.²⁸ However, some caregivers were not comfortable using glucometer and insulin syringes even after being guided by a healthcare provider. This can explain the previous findings that inadequate information and preparedness of caregivers for hospital discharge increases the risk of readmission and poorer post discharge outcomes.²³ There is a need for continued information support for caregivers even after the patient has been discharged from the hospital.

Care Giving Burden

In our study, caregivers encountered financial, physical, emotional, and economic forms of burden. Caregivers incurred debts to meet care giving costs; some abandoned their work while others were weak and sickly. All these resulted in emotional upset which in turn progress to burnout that has been previously reported.²⁹ Our findings align with those of a similar study which care giving affected informal caregivers' work life, health, and social life.³⁰ Financial burden is predominantly reported especially by studies done in developing countries. Studies have particularly shown out-of-pocket (OOP) expenses incurred during hospitalization and discharge, such as buying basic necessities like food or transport are financially straining to caregivers, and adversely affected the overall financial well-being of families.^{31,32} In Uganda, OOP is the main approach to purchasing health care services, yet OOP is associated with inequity in access, catastrophic expenditure and impoverishment. The financial challenge is worsened due to lack of working time by caregivers because they have to be with the patient most of the time.³³ Scholars have described care giving as a difficult task, requiring a lot of time, effort, attention, and devotion³⁴ and our findings paint a similar picture. To relieve caregivers from the financial burden due to increased costs of care that is compounded by loss of working time to earn an income, there should be other health financing approaches like health insurance schemes for older adults with such chronic illnesses.

Motivation for Care Giving

Besides the challenges, caregivers in our study found motivation to carry on from family members and friends who visited, counseled and encouraged them. Relatedly, Mamatsharaga et al, 2022 discussed that caregivers felt relief when relatives and friends visited them and assisted in the caring for the older people.³³ Although a number of studies have reported that caregivers seek support from other family members as the elderly person becomes more dependent and/or the demands for care increase,³⁵ some studies have reported lack of coordination, unbalanced caring roles and conflict among family members.³⁶

Caregivers with prior knowledge and experience in care giving were more confident and motivated to perform the role. A study among caregivers of older people with diabetes mellitus found a strong link between caregivers' knowledge of DM and patients' quality of life.³⁷ On the other hand, caregivers who lack knowledge in the care of older people may cause unintentional harm to the recipients of their care and tend to experience stress due to inadequate knowledge.³⁸ Intervention aimed at increasing caregiver knowledge can benefit the patient in terms of quality of care received and yet improve the caregivers' emotional wellbeing and satisfaction with their role.

Spiritual devotion and prayer was another common source of motivation for caregivers in our study. This is in agreement with previous findings which have reported that caregivers accept their situation and pray to God for positive outcomes.³³

Strength and Limitations

We collected data from care givers of older adults with diabetes mellitus or hypertension; we did not collect opinions of caregivers of older adults with other chronic illnesses. These may have had different experiences regarding the transition process. We also appreciate that experiences are individualistic; however, the knowledge gained through the study has given insights of the importance for future improvements of transition care for older adults.

Conclusion

Informal caregivers are at the center of the entire continuum of care for old people with chronic illnesses like Diabetes Mellitus and hypertension. They are at the forefront of care during hospitalization, discharge and home stay for these patients. Key roles performed by informal caregivers included but not limited to assisting in ADLs, medicine administration and monitoring disease parameters. Despite their vital input of informal caregivers in patient care, they encounter

various forms of undesirable experiences which included physical, emotional and financial strain. This study highlights a support gap for informal caregivers by health care system. This in turn compromises the quality of care offered. Informal caregivers need adequate support from multidisciplinary health care team in form of clear discharge instructions, emotional support, training and follow-up visits to enable them deliver holistic and quality care. A health-related policy should be formulated to help informal caregivers receive more professional assistance. Training opportunities should be provided for family caregivers to reduce the impact of care giving on the delivery of effective care.

Abbreviations

MRRH, Mbarara Regional Referral Hospital; MUST, Mbarara University of Science and Technology; DM, Diabetes mellitus; HTN, Hypertension; NCD, Non-communicable diseases; LMIC, Low- and middle-income countries; ADL, Activities of Daily Living.

Ethics Statement

This study was reviewed and approved by Mbarara University of Science and Technology Research Ethics Committee (MUST-2022-357) and the Uganda National Council of Science and Technology (HS2304ES). Administrative clearance was obtained from MRRH. The participants provided written informed consent to participate in this study and publication of anonymized responses in the manuscript. The study complied with the Declaration of Helsinki.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, and in all these areas; took part in drafting, revising, critically reviewed the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare no conflicts of interest in this work.

References

- 1. Allen J, Woolford M, Livingston PM, Lobchuk M, Muldowney A, Hutchinson AM. Informal carer support needs, facilitators and barriers in transitional care for older adults from hospital to home: a scoping review. *J Clin Nurs*. 2023;32(19–20):6773–6795. doi:10.1111/jocn.16767
- 2. Li J, Qi M, Werner RM. Assessment of receipt of the first home health care visit after hospital discharge among older adults. *JAMA Network Open*. 2020;3(9):e2015470–e. doi:10.1001/jamanetworkopen.2020.15470
- 3. Dolu İ, Naharcı Mİ, Logan PA, Paal P, Vaismoradi M. A qualitative study of older patients' and family caregivers' perspectives of transitional care from hospital to home. *Res Theory Nurs Pract.* 2021;RTNP-D-20-00067. doi:10.1891/RTNP-D-20-00067
- 4. Berglund E, Lytsy P, Westerling R. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish general population. *Health Qual Life Outcomes*. 2015;13:1–11. doi:10.1186/s12955-015-0309-2
- 5. Liebzeit D, Jaboob S, Bjornson S, et al. A scoping review of unpaid caregivers' experiences during older adults' hospital-to-home transitions. *Geriatric Nurs*. 2023;53:218–226. doi:10.1016/j.gerinurse.2023.08.010
- Mohammadi S, Zabolypour S, Ghaffari F, Arazi T. The effect of family-oriented discharge program on the level of preparedness for care-giving and stress experienced by the family of stroke survivors. *Iranian Rehab J.* 2019;17(2):113–120. doi:10.32598/irj.17.2.113
- 7. Rodakowski J, Rocco PB, Ortiz M, et al. Caregiver integration during discharge planning for older adults to reduce resource use: a metaanalysis. *J Ame Geriatrics Soc.* 2017;65(8):1748–1755. doi:10.1111/jgs.14873

- 8. Hogan U, Bingley A, Morbey H, Walshe C. The experience of informal caregivers in providing patient care in hospitals in low- and middle-income countries: a qualitative meta-synthesis. *J Health Serv Res Policy*. 2022;27(4):321–329. doi:10.1177/13558196221101968
- 9. Topham EW, Bristol A, Luther B, Elmore CE, Johnson E, Wallace AS. Caregiver inclusion in IDEAL discharge teaching: implications for transitions from hospital to home. *Prof Case Manag.* 2022;27(4):181–193. doi:10.1097/NCM.0000000000000563
- Kowal P, Dowd JE. Definition of an older person. Proposed working definition of an older person in Africa for the MDS project. World Health Organization Geneva. 2001;10(2.1):5188.9286.
- 11. Orb A, Eisenhauer L, Wynaden D. Ethics in qualitative research. J Nurs Scholarship. 2001;33(1):93–96. doi:10.1111/j.1547-5069.2001.00093.x
- 12. Sutton J, Austin Z. Qualitative research: data collection, analysis, and management. *Canadian J Hospital Pharm*. 2015;68(3):226. doi:10.4212/cjhp. v68i3.1456
- 13. Ruona WE. Analyzing qualitative data. Research in organizations: foundations and methods of inquiry. Foundations Methods Inquiry. 2005;223 (263):233–263.
- 14. Groenland E. Employing the matrix method as a tool for the analysis of qualitative research data in the business domain. *Int J Business Globalisation*. 2018;21(1):119–134. doi:10.1504/IJBG.2018.094106
- 15. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. Int J Qualitative Methods. 2006;5(1):80–92. doi:10.1177/160940690600500107
- 16. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277–1288. doi:10.1177/1049732305276687
- 17. Kazuma-Matululu T, Nyondo-Mipando AL. "Men are scared that others will know and will discriminate against them so they would rather not start treatment". perceptions of heterosexual men on HIV-related stigma in HIV services in Blantyre, Malawi. J Int Assoc Providers AIDS Care. 2021;20:23259582211059921. doi:10.1177/23259582211059921
- 18. Van Den Heuvel J, Teunis C, Franx A, Crombag N, Bekker M. Home-based telemonitoring versus hospital admission in high risk pregnancies: a qualitative study on women's experiences. *BMC Preg Childbirth*. 2020;20(1):1–9. doi:10.1186/s12884-020-2779-4
- 19. Mallette JK, Almond L, Leonard H. Fostering healthy families: an exploration of the informal and formal support needs of foster caregivers. *Children Youth Services Rev.* 2020;110:104760. doi:10.1016/j.childyouth.2020.104760
- 20. Scholes-Robertson NJ, Howell M, Gutman T, et al. Patients' and caregivers' perspectives on access to kidney replacement therapy in rural communities: systematic review of qualitative studies. *BMJ Open*. 2020;10(9):e037529. doi:10.1136/bmjopen-2020-037529
- 21. Chen L, Xiao LD, Chamberlain D. An integrative review: challenges and opportunities for stroke survivors and caregivers in hospital to home transition care. *J Adv Nurs*. 2020;76(9):2253–2265. doi:10.1111/jan.14446
- 22. Gonçalves-Bradley DC, Lannin NA, Clemson L, Cameron ID, Shepperd S. Discharge planning from hospital. *Cochrane Database Syst Rev.* 2022;2 (2):Cd000313. doi:10.1002/14651858.CD000313.pub6
- 23. Rameli PM, Rajendran N. Outcomes of complex discharge planning in older adults with complex needs: a scoping review. J Int Med Res. 2022;50 (7):3000605221110511. doi:10.1177/03000605221110511
- 24. Bayor S, Kojo Korsah A. Discharge against medical advice at a teaching hospital in Ghana. Nurs Res Pract. 2023;2023:4789176.
- 25. Cadel L, Guilcher SJT, Kokorelias KM, et al. Initiatives for improving delayed discharge from a hospital setting: a scoping review. *BMJ Open*. 2021;11(2):e044291. doi:10.1136/bmjopen-2020-044291
- 26. Kabajaasi O, Trawin J, Derksen B, et al. Transitions from hospital to home: a mixed methods study to evaluate pediatric discharges in Uganda. PLOS Global Public Health. 2023;3(9):e0002173. doi:10.1371/journal.pgph.0002173
- 27. van Dijk M, Vreven J, Deschodt M, Verheyden G, Tournoy J, Flamaing J. Can in-hospital or post discharge caregiver involvement increase functional performance of older patients? A systematic review. *BMC Geriatrics*. 2020;20(1):1–12.
- 28. Hahn-Goldberg S, Jeffs L, Troup A, Kubba R, Okrainec K. "We are doing it together"; the integral role of caregivers in a patients' transition home from the medicine unit. *PLoS One*. 2018;13(5):e0197831. doi:10.1371/journal.pone.0197831
- 29. Barber B, Weeks L, Steeves-Dorey L, et al. Hospital to home: supporting the transition from hospital to home for older adults. *Can J Nurs Res*. 2022;54(4):483–496. doi:10.1177/08445621211044333
- 30. Slatyer S, Aoun SM, Hill KD, Walsh D, Whitty D, Toye C. Caregivers' experiences of a home support program after the hospital discharge of an older family member: a qualitative analysis. *BMC Health Services Research*. 2019;19(1):1–10. doi:10.1186/s12913-019-4042-0
- 31. Nemetchek B, Khowaja A, Kavuma A, et al. Exploring healthcare providers' perspectives of the paediatric discharge process in Uganda: a qualitative exploratory study. *BMJ Open.* 2019;9(9):e029526. doi:10.1136/bmjopen-2019-029526
- 32. Krepiakevich A, Khowaja A, Kabajaasi O, et al. Out of pocket costs and time/productivity losses for pediatric sepsis in Uganda: a mixed-methods study. *BMC Health Services Res.* 2021;21:1–9. doi:10.1186/s12913-021-07272-9
- 33. Mamatsharaga IP, Mashau NS, Damian JU. I lack'me-time': the experiences of family caregivers of elders with diabetes mellitus in a selected village in South Africa. *Health SA Gesondheid*. 2022;27:1–7.
- 34. Agyapomah R, Boateng EA, Amankwaa I, Dzomeku VM, Peprah LO. "She is my work": caregiving for older adults with hypertension and diabetes mellitus. Clin Nurs Res. 2023;32(5):886–894. doi:10.1177/10547738231165886
- 35. Silva RAE, CdN S, Braga PP, DBdC F, Cavalcante RB, EABd C. Management of home care by family caregivers to elderly after hospital discharge. Revista brasileira de enfermagem. 2020;73:e20200474.
- 36. Gutierrez FJ, Ochoa SF, editors. It takes at least two to tango: understanding the cooperative nature of elderly caregiving in Latin America. Proceedings of the 2017 ACM Conference on computer supported cooperative work and social computing; 2017.
- 37. Thongduang K, Boonchieng W, Chautrakarn S, Ong-Artborirak P. The Influence of family caregiver knowledge and behavior on elderly diabetic patients' quality of life in Northern Thailand. *Int J Envir Res Public Health*. 2022;19(16):10216. doi:10.3390/ijerph191610216
- 38. Ab Ghani NN, Makhtar A, Elias SMS, Ahmad N, Knowledge LSM. Practice and needs of caregiver in the care of older people: a review. *Int J Care Scholars*. 2022;5(3):70–78. doi:10.31436/ijcs.v5i3.269

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