

Internal Facilitation by Health Assistants for the “WHO Lay Health Worker Dementia Care” in Rural Uganda: A Formative Evaluation

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Background: Dementia is characterized by cognitive symptoms like memory loss, difficulty with language, and impaired judgment, alongside behavioral and psychological symptoms such as depression, anxiety, and aggression. Early diagnosis and tailored care are essential for managing these symptoms, improving quality of life, and reducing caregiver burden. Dementia affects a substantial portion of older people globally, especially in low- and middle-income countries like Uganda, where rural healthcare systems face challenges in dementia care access. To address these needs, we gathered key stakeholders' perspectives on a culturally tailored model employing lay health workers, supported by health assistants as internal facilitators, to implement the World Health Organization dementia toolkit in rural communities.

Methods: We conducted a formative qualitative study, utilizing one-on-one interviews with health assistants, district health team members, and primary healthcare providers in rural Uganda. We solicited their perspectives on implementing the World Health Organization dementia toolkit at the village level. The integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework guided data collection and analysis, focusing on implementation support, process improvement, and practice sustainment.

Results: Strong support was found for health assistants' roles in facilitating lay health worker-led dementia care at the community level. Health assistants' familiarity with lay health workers and pre-established structures were considered facilitating factors. Key challenges included knowledge gaps in dementia care and limited resources. Participants emphasized the importance of training, mentorship, and standardized reporting tools to enhance the implementation of dementia care. They recommended providing the health assistants with job guides, updated reporting templates to collect dementia indicators, and orientation on what they should do during internal facilitation with the lay health workers using the dementia toolkit.

Conclusion: Health assistants' internal facilitation provides a promising strategy for scaling dementia care in rural Uganda by leveraging community-based lay health workers. Addressing identified knowledge gaps, communication needs, and resource constraints will be essential to sustaining dementia care interventions in these communities.

Keywords: dementia care, internal facilitation, lay health workers, Uganda, rural health, i-PARIHS framework

Background

Dementia is a global public health concern with potentially devastating consequences for people with dementia and their family caregivers.¹⁻³ It is characterized by cognitive symptoms like memory loss, difficulty with language, and impaired judgment, alongside behavioral and psychological symptoms such as depression, anxiety, and aggression.^{4,5} These symptoms disrupt daily functioning and significantly affect both patients and caregivers.^{6,7} Early diagnosis and tailored care are essential for managing these symptoms, improving quality of life, and reducing caregiver burden.^{8,9} Effective care strategies can help mitigate the impact of dementia, supporting both the individual and their family in managing the condition.

Nearly 60% of the global population with dementia lives in low- and middle-income countries (LMICs).^{10,11} In southwestern Uganda, the prevalence of dementia is estimated to be 20% in adults age ≥ 60 years.¹² Delivery of dementia care is challenging in rural regions in sub-Saharan Africa such as Uganda, where 80% of the population resides in the rural areas and at least 23% of households have one older adult living in the home.^{13,14} Prior research by our team in rural Uganda determined that dementia awareness and support services were virtually non-existent,^{15,16} and family caregivers were left to provide care on their own, resulting in high levels of emotional, social, and financial burden.^{7,17–19} These challenges underscore the need for innovative models of care tailored to rural settings in LMICs.^{10,20}

In response to the growing global burden, the World Health Organization (WHO) developed the dementia toolkit²⁰ consisting of evidence-based practices for detecting and managing dementia and caregiver support delivered by Lay Health Workers (LHWs) to create dementia-friendly communities. In prior work, we conducted a “pre” and “post” pilot study with LHWs in rural Uganda on the WHO dementia toolkit and demonstrated that training was feasible and resulted in improved knowledge and attitudes around dementia care.^{20,21} However, subsequent implementation and delivery of the WHO dementia care toolkit was minimal and highly variable. Discussions with primary healthcare providers identified the need for a practical, scalable, culturally tailored implementation strategy.

In the Ugandan healthcare system, Health Assistants (HAs) supervise LHWs to implement public health plans and services; however, dementia care is not currently included among their responsibilities.^{22,23} Uganda has a decentralized health delivery system that empowers communities to actively participate in the management of their local health services at the village level.^{22,24} The communities select LHWs through a popular vote as their first point of contact for healthcare.^{20,22} In Uganda, the functions of HAs align with the characteristics of effective internal facilitation, including local respect and a formal supervisory role, following a step-by-step process, frequent tracking of progress, understanding local contextual factors, and skills in improvement methods and local problem-solving.²⁵ The HAs supervise the LHWs, provide public health education, and implement and monitor public health plans.^{22,23}

This formative study aimed to gather the perspectives of the HAs, district health team (DHT), and primary health care providers to guide the co-designing of a culturally tailored implementation strategy consisting of the WHO dementia toolkit by LHWs to provide dementia care at the village level supported by internal facilitation from HAs as supervisors. We call this strategy WHO Lay Health Worker Dementia Care, with Internal Facilitation (WLDC+IF).

Methods

This study is informed by the integrated Promoting Action on Research Implementation in Health Services (i-PARIHS Framework), which views internal facilitation as an “active ingredient” within the local, organizational, and broader health system *context* to enable the successful adoption of interventions.²⁶ In this project, we conceptualize internal facilitation as a strategy that involves working with community members to support the implementation of WLDC+IF.²⁵ The components and functions of internal facilitation by the HAs include (1) implementation support, (2) process improvement, and (3) practice sustainment to facilitate the implementation of the who dementia toolkit by LHWs (Figure 1).

Study Design and Setting

One-on-one interviews were conducted to gather participants’ perceptions on a proposed implementation strategy involving LHWs providing community-based dementia care, guided by the WHO dementia toolkit, with internal facilitation (implementation support, process improvement, and practice sustainment) from HAs as supervisors.

Uganda’s health delivery system is decentralized and managed at the district level by the DHT under the District Health Officer (DHO), who oversee care within counties (comprised of sub-counties with parishes). Parishes are made up of villages consisting of 50–200 households. We conducted formative interviews in the largest county in the Lira district.²⁷ Each parish has one health assistant and approximately two LHWs per village.²⁸ Lira District is approximately 380 kilometers (236 miles) north of Kampala City, the capital city of Uganda.²⁹ It was purposefully chosen because of our ongoing research work in the area.³⁰

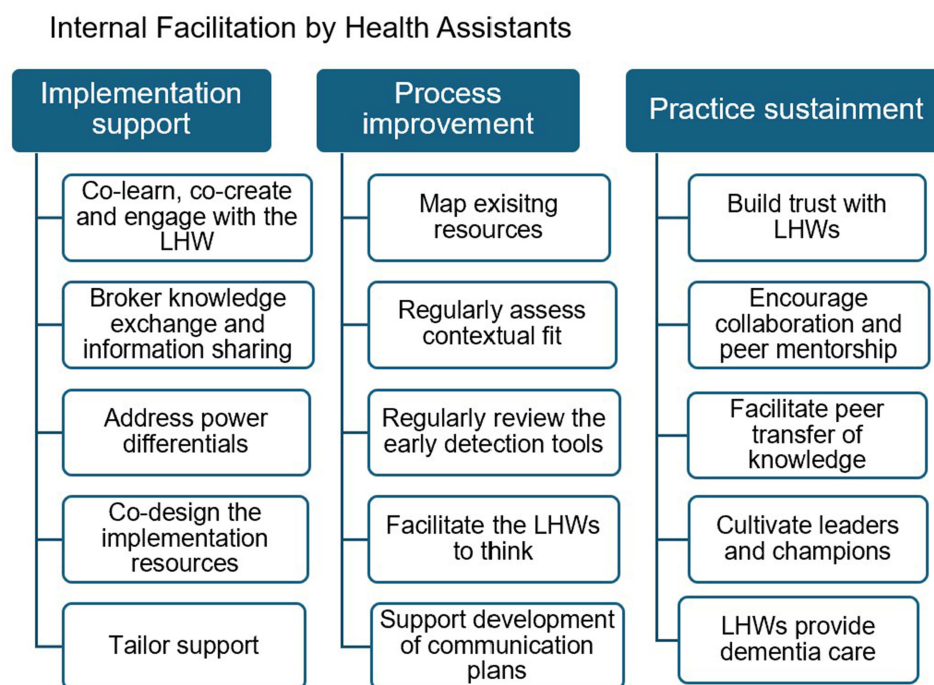


Figure 1 Internal Facilitation by Health Assistants.

Study Participants and Research Team

The study participants were HAs at two parishes, DHT members, and primary healthcare (PHC) providers at the health facilities to which the LHWs are attached. The HAs are health environmentalists, while the DHT are public health specialists who oversee all health-related activities at the district level on behalf of the Uganda Ministry of Health. The lead researcher (EKW) recruited study participants by phone to schedule in-person interviews. The target participants were informed of the purpose of the study, namely, to gain their perceptions about developing and evaluating the feasibility of a culturally tailored implementation strategy of the WHO dementia toolkit by LHWs to provide dementia care at the village level supported by internal facilitation from HAs as supervisors (ie, WLDC+IF). All participants were 18 or older and provided written informed consent to participate in the study. We purposefully recruited key people who directly engaged with the LHWs at the parish (2 hAs and 6 PHC providers [medical, clinical, and nursing officers]) and district (2 DHTs) levels. We aimed to obtain preliminary, guiding feedback rather than to achieve thematic saturation.

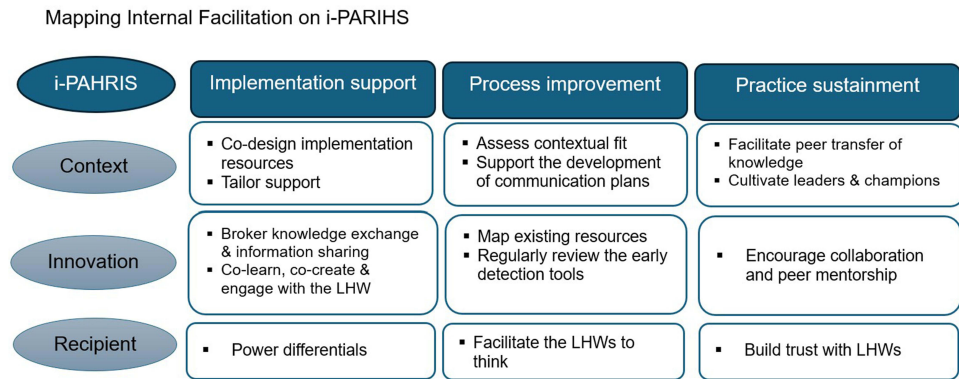
The research team had expertise in qualitative research methods, implementation research methods, community-based participatory research (EKW, ZMT, JEH, SJB), and health systems research (CO, JEH, SJB). The research assistants (VA and CKK) are trained qualitative research interviewers with social science backgrounds. CKK is a PhD implementation science student.

Data Collection

i-PARIHS domains guided data collection and analyses,²⁶ mapped onto internal facilitation constructs [ie, implementation support, process improvement, and practice sustainment]²⁵ see [Figure 2](#).

A semi-structured interview guide was developed, adapted to the internal facilitation constructs, and pre-tested with participants in another district to ensure comprehension and optimize the clarity of the questions ([Additional Files 1–3](#)). The research assistants used a conversational style with the participants during the interview,³¹ probing and encouraging them to provide accurate information. Data collection occurred in June 2024 and was conducted in person by CKK and VA.

CKK and VA introduced the components of the WHO dementia toolkit to the participants, including a community resource checklist, screening and detection tools, tools for dementia management and care, a list of dementia prevention and promotion activities, monitoring and evaluation tools, and internal facilitation, as illustrated in [Figure 1](#). All



Adapted from Harvey Kiston (2016) and Connolly Sullivan (2020)

Figure 2 Mapping Internal Facilitation on i-PARIHS.

participants were assured about the confidentiality of their responses and that any publications with quotations from the interviews would be de-identified.³² The interviews were conducted in private and quiet spaces where the different categories of participants were located at the time of the interviews. Verbal consent was provided for the audio recording of the interviews, supported with field notes. All interviews were conducted in person, in English, the official language in Uganda. The interviews lasted approximately 30 to 60 minutes, with an average time of 45 minutes. Before data collection, IRB approval was obtained (*refer to the declaration section, ethics approval, and consent to participate*).

Data Management and Analysis

All audio-recorded interviews were transcribed verbatim by CA, PK, RAK, and reviewed by EKW for accuracy and consistency.³³ All the transcripts (deidentified) were read and re-read by the research team members to familiarize themselves with the data.³⁴ EKW developed the coding framework matrix guided by the i-PARIHS domains.²⁶ Data were manually organized using a framework matrix³⁵ mapped onto internal facilitation constructs [implementation support, process improvement, and practice sustainment]²⁵ as *a priori* themes. The transcripts were manually coded because of the small sample size. The rows were used for sub-themes generated from the research questions, while the columns represented the subgroups (from probes and field notes) and responses from the participants.^{35,36} The content in the cells of the raw matrix was analyzed based on the research questions and the internal facilitation constructs to check that the responses were correctly placed under each category.^{35–37} The research team analyzed the results, agreeing on the quotes to include in the report and the key results to summarize. The research team provided in-person feedback was provided to the study participants.

The research team used different strategies to ensure the reliability of the findings. The audio interviews were transcribed by research staff who did not conduct the interviews (PK, RAK, and CA) to check the data quality collected. The transcribers peer-reviewed each other's transcripts before sharing them with EKW to review against the audio recordings. CO and ZMT reviewed the coded transcripts for consistency checks to ensure rigor.^{35,38} Four investigators (GZR, SJB, JEH, and CO) were not part of the data collection process, which allowed for objectivity and stimulated discussions that produced a more thorough and complete analysis. All the interview transcripts, audio recordings, and write-ups related to this study are securely stored on a password-protected computer.

Results

Participant Demographics

All the eligible participants¹⁰ recruited for the study were interviewed. The youngest was 28 years old, and the oldest was 50. The academic qualifications ranged from certificate level to master's degrees, and the years of professional work experience ranged from 3 to 17 (Table 1).

Table 1 Participant Demographics

Category	Sex	Age	Education	Years of Experience
DHT 1	Male	47	Masters	7
DHT 2	Male	53	Masters	10
HA 1	Male	36	Certificate	10
HA 2	Male	28	Diploma	9
PHC 1	Male	37	Diploma	8
PHC 2	Female	50	Diploma	17
PHC 3	Female	41	Certificate	17
PHC 4	Male	32	Bachelors	5
PHC 5	Female	39	Diploma	11
PHC 6	Female	39	Diploma	3

Below, we summarize our findings guided by the i-PARHIS implementation framework for internal facilitation by the HAs concerning (1) implementation support, (2) process improvement, and (3) practice sustainment to facilitate the implementation of the WHO dementia toolkit by LHWs (Figure 1).

Internal Facilitation Construct: Implementation Support

Perceptions About HAs as Internal Facilitators

All participants thought HAs' role as internal facilitators supporting LHWs in implementing the WHO dementia tools was appropriate. However, they added that the HAs needed to be trained in dementia care to ably support the LHWs.

...give them more knowledge on dementia. Secondly, supervise them to ensure they do the right work in the community. Then, monitor the work they are doing with the LHWs and evaluate what we have done (HA 2, Male)

I think they are the best to use because the health assistants work directly with the LHWs, even in other activities being implemented. So, first, there's already a relationship, and then two, the experience they have of working with them will be very supportive. (PHC provider 4, Male)

It is a good choice because these LHWs report to the health assistants. So, being the structure that already exists, it becomes very easy for them to interact at a routine level and for them to consult whenever there is a need. They interact daily with these people. So, I think it is a highly well-thought-out idea for these LHWs and health assistants to work together. (DHT 1, Male)

Perceptions About Lay Health Workers in Community Dementia Care

All participants indicated that the LHWs were the most appropriate people to implement the WHO Dementia Toolkit because they typically worked with the community and had established trust.

They are the people who stay down in the community; they are the people who know the problem in the community. I know they will support them because some people with such conditions are their fathers or relatives, so they can help them much more. (HA 2, Male)

I think it is the best idea because there are the right people. You can't get the health worker to go and start from there [the community]. They are the best, and that is where it is supposed to start. I agree that the best option is LHWs. (PHC provider 5 Female)

...they are known as the village doctors, the foot doctors of the village. So, being the people who are known and trusted, I believe that the community would be open and be able to ask for support from them. ...I think it's a very good choice to use that approach. Because we don't have any other lower kind of health cadre that mixes with the community other than the LHWs. (DHT 2, Male)

Specific Support LHWs Would Require During the Implementation Process

Most participant responses revolved around the importance of training, training materials, and mentorship in response to the question of the specific types of support that LHWs would require during the implementation process.

Training them [LHW] to get knowledge because this is a new activity. ...supporting them with the package that guides them in doing such activity. Most of their activities have manuals that remind them of such conditions. (HA 2, Male)

They require continuous mentorship and follow-up. The LHWs need to be given ample time... The health assistants should have regular meetings with the LHWs for updates. They must be equipped with the necessary materials like data collection tools, guidelines, and practice. (PHC provider 5, Female)

A hand guide that gives them the signs and symptoms of various levels of dementia such that they can keep referring to them whenever they get those cases. Then, they also need a guided tool to record their cases, a community register to track their cases, their progress, and the kind of support they've got from wherever they have guided them. (DHT 1, Male)

Regarding how internal facilitation could help address the potential challenges when LHWs implement dementia care tools, the participants indicated that it would improve the knowledge gap on dementia, help in effective communication between the LHWs and the HAs, and tailor capacity building to the difficulties experienced.

Once we train them, we shall address the problem of inadequate knowledge of dementia. Support supervision will also address the challenges they may face in the field. Also, improving on their knowledge gap when we do support supervision. (HA 2, Male)

It will help in effective communication. The health assistants mentoring them will offer them support. This will help them to identify cases correctly, not doing guesswork. It will also help them to communicate as quickly as possible in case of anything. An effective referral will occur; hence, the person will be handled, and the condition will improve. (PHC provider 5, Female)

Working with the health assistants, their key supervisors, I believe if the LHWs encounter any problem with implementing their activities, they will ask for support. ...it's a matter of working with their supervisors and being open about their problems. Then, they'll be supported; if it is technical, they can get a knowledge backup from their key supervisors. (DHT 1, Male)

Participants recommended communication platforms, like SMS and WhatsApp, for effective internal facilitation between HAs and LHWs:

They can use text messages or phone calls because the LHWs are not yet so advanced in communication. I don't think other things like emails and WhatsApp will be effective, but mostly phone calls and text messages. (PHC provider 4 Male)

...we are going digitalization, and we have seen where we put up WhatsApp forum, especially a media forum where all our issues are channeled there; I'm happy that we already have one for community health extension workers... So, social media platforms may also help. So, if we have mobile phones, it will also enhance digital reporting; we are already piloting with several LHWs; we bought phones and are reporting on other indicators. They are moving on very well; we can borrow that leaf and then make sure we go digital. (DHT 2 Male)

Participants believed that tools such as copies of the WHO dementia toolkit, tablets for data collection and reporting, and standard reporting tools would help internal facilitators support the implementation process.

I know these days people have smartphones, and they can access soft copies of those handouts if given to them, which they can easily refer to in case of any challenge or anything like that. I mean, the information they can easily refer to before they can deliver the information. I think it could be better. (PHC provider 6 Female)

They have to have a uniform reporting template so that what is being reported in Village A Parish A by this health assistant is the same as what is being captured from the other side. So, there must be a standardized reporting tool. (DHT 2, Male)

Internal Facilitation Construct: Process Improvement

Understanding of Dementia

Most participants reported being unfamiliar with the WHO dementia toolkit and were hearing about it for the first time, except one primary healthcare provider reported hearing about it but did not know how it worked.

...so far, I am participating in this for the first time. (HA 1, Male)

I heard of it [the toolkit] but am not fully well-versed with it. How to manage the old people with dementia. (PHC provider 1, Male)

Regarding the village-level dementia care needs requiring the attention of HAs and LHWs, the participants had various responses, including nutritional, physical, mental, and financial support, case identification and referral, and awareness creation within the community.

These people need to be taken care of, you know, at the community level such conditions like dementia, those guys are being neglected... And we need to train the VHTs [lay health workers] on managing such cases. We need to handle the caretakers of the people with dementia so that those guys are taken care of. (HA 2, Male)

I think case identification, referral, and understanding of the community about the disease. (PHC provider 4, Male)

...identification of these cases. Yes, there could be many of them, and they are not being identified—awareness creation within the community. ...there is a need for a referral or medical attention. The community must know that such a case should not be left unattended because they can still be supported. (DHT 2, Male)

Regarding existing resources for dementia care services and how they could be utilized, the findings showed no specific resources for dementia care. However, the participants highlighted the role that health care has and how people with dementia could utilize the available services:

...when I look at the community, I don't see much, only that these people, once they have such kind of condition, it is when they come to this health facility. That's when they can be attended to, but any services down there are not there. (HA 2, Male)

We have a psychiatric clinic where if they come to the health center, they'll be attended to. Assessment is done, diagnosis, and treatment. Where need be, psychotherapy is given to them. At the community level, probably if we are to go outreaches. If they are identified and can come to where the outreaches will be, we can attend to them from there, or sometimes we have home visits. (PHC provider 6, Female)

...at least every family has a caregiver; we have extended family. So, you find an old person or somebody with dementia, having people around them. Another resource is that we have some community support organizations; unfortunately, they work in silence and have not been brought on board to align their roles and responsibilities concerning dementia management. So, we can still harness that. Fortunately, at the health facility level, we have psychiatric nurses, especially at Health Center 4; they can still be a very good resource in supporting the management of dementia at a community level. (DHT 2, Male)

When asked what their idea of process improvement was, especially when health assistants are providing support to the LHWs, the participants had varying opinions:

...[LHW] need to be trained and well-equipped with knowledge of dementia. We also need to identify areas of weakness where we have not understood, and we also need to conduct refresher training to ensure we are equipped with more knowledge of dementia. (HA 2, Male)

...we need to have some meetings with both the LHWs and our health assistant and sometimes also some community dialogue about dementia, and we can, as the health service providers. We can have some dialogue or health education in the community about dementia and how to go about it. (PHC provider 1, Male)

One of them is through reviewing performance and realigning roles and responsibilities. So, as they carry on their duties, they [health assistants] will identify areas of weakness and then realign their [LHW] responsibilities. They [health assistants and LHW] can also sit and share best practices so that parish A will also interface with parish B to learn and improve. At the health

facility level, they [LHW] should give feedback to their supervisors in charge of health facilities so that they can also improve their nursing and pharmacological care. (DHT 2, Male)

The participants indicated that HAs should constantly supervise and effectively communicate with the LHWs to respond to their experiences, engage in community dialogues, review reports, and provide feedback to the LHWs when identifying challenges and sharing best practices.

We always have quarterly meetings. We call all the VHTs [lay health workers] and try to do an assessment per village; each of the VHTs [lay health workers] gives a report, so whatever the challenge of a community per village, we look for ways of addressing it. Sometimes, we go to the ground where there is a need. I usually move because much of my work is not at the facility. (HA 1, Male)

Fortunately, the health assistants within this health sub-district are also community-based. So, I believe that closeness with the community will help them identify those challenges and best practices, and then regular interaction with the LHW through meetings will support and guide them. (PHC provider 4, Male)

Listen to the LHWs and the community members regarding dementia cases and management. Another one is through performance review meetings. While they reach the communities and the dialogues along the way, the LHWs should be able to submit monthly or quarterly reports and then sit and review them. Then, they can realign their priorities and intervention strategies. (DHT 2, Male)

Internal Facilitation Construct: Practice Sustainment

Most participants indicated the need for training or capacity-building measures for HAs to effectively support LHWs in implementing the WHO tools for community-based dementia care. These included training on dementia assessment and management and the provision of guiding materials or documents for reference.

They should be provided with the necessary key materials in that condition. So, as they meet the LHWs there, they will focus on the key materials given to them to identify the problems. When they're not given what to use, it will not be easy. ...you know, you will believe when you see things with your physical eyes. But when you are told and have not seen, you don't believe. (PHC provider 3, Female)

They need to understand what dementia is, but they also need to know the high-risk population, what can be done to identify the cases of dementia, how to identify the dementia cases, and the non-pharmacological support that can be offered. This will empower them to reach out to their LHW counterparts to provide effective mentorship and support in identifying cases. (DHT 2, Male)

Participants appreciated the idea of growing leaders and champions within LHWs through role-model leadership behaviors. They indicated that when someone is empowered with knowledge, they, in turn, empower others, manage challenges on their own without needing external support, create an environment where people are free with them, and that it is motivating to be recognized for excellent performance.

When we nurture leaders between them, they can manage certain things by themselves. They will be able to manage certain other things down there, and they will be able to come up with any problem or challenge they are facing down there and address them as real concerns. (HA 2, Male)

It will trigger these people to pull up their socks because they will see that if this person was among us, and now he's doing ABCD, I think I can also do it. So, it's only a matter of me putting more interest in getting to that level, which I think is the best solution. (PHC provider 5, Female)

It is a motivator for those who have been put in leadership. You will find that, much more like the LHWs champions or leaders, they feel very motivated, and others will want to become champions. People see when you're given open praise because of your group performance; they feel like they should perform better to be praised. (DHT 2, Male)

The participants highlighted analyzing the reports, developing a standard reporting tool to collect data on dementia care, regular meetings, and designing a support supervision tool as strategies that could be employed to assess and monitor the progress of the LHWs in implementing the dementia toolkit and how internal facilitation could support this process.

According to the work plan... they should put periods at which the progress will be assessed. It is from that we shall be able to identify the challenges and then deduce means of bridging the challenge. (PHC provider 4 Male)

I think one thing we need to develop is a support supervision tool that these health assistants can use such that they see how many dementia patients the LHW has identified within their area of operation, how many they have referred, how many they have handled at the community level, how many have recovered? So, we need a tool they regularly use to assess these LHWs when doing their work. (DHT 1, Male)

Lastly, on how LHWs could be supported in including dementia care activities within their daily workflow, all the participants proposed embedding dementia activities within the routine activities. Some suggested a meeting to explain to the LHWs the importance of including dementia care in their program so they do not feel like it is an extra activity.

Let it be integrated into what they are doing so that when they go for the programs they have been doing, they include dementia into their work. (PHC provider 1, Male)

When we integrate the data-capturing tool into our real LHW tools, dementia community-level support will not be a stand-alone program. And so, while LHWs carry on with their health promotion and disease prevention initiatives, dementia should be part of the packages they give to the communities. I think that one will not overburden them. Dementia care must be integrated so that whenever they are carrying out health promotion, they carry it alongside dementia. (DHT 2, Male)

Discussion

This formative evaluation study provides insights from key stakeholders on barriers and potential facilitators implementing the WHO dementia toolkit through LHWs and supported by HAs as internal facilitators in rural Uganda. Findings underscore the feasibility and potential of this model for delivering dementia care in low-resource settings. HAs, with their community-based roles and supervisory responsibilities, were perceived as suitable internal facilitators due to their familiarity with the community and existing supervisory structures.^{1,10} This approach aligns with prior research that identifies local engagement and community-based facilitation as critical components of successful health interventions in LMICs.^{15,39}

A major strength of our approach is the alignment with the i-PARIHS framework, which highlights the value of tailored facilitation strategies to address contextual and cultural barriers to implementation. We confirmed that HAs may serve as liaisons, bridging the gap between formal healthcare systems and village-level care to facilitate dementia care. However, not many countries are using the health assistant's model. The closest study we found was in Zambia, where the community HAs conducted identical roles to the Uganda HAs, including public health awareness campaigns as well as testing for and treating minor illnesses.⁴⁰ Like Uganda, the Zambia community HAs did not include dementia care in their activities. From our findings, the HAs model could improve dementia care engagement within communities, leveraging the trust that HAs and LHWs hold among residents.^{20,21} Promoting the utilization of community health workers like the HAs and LHWs for dementia care at the community level could be a successful mechanism to prevent, screen, and manage dementia.^{41,42}

Challenges to successfully implementing and operating the HA approach as internal facilitators to the LHWs were identified, including knowledge gaps in dementia care among HAs and limited resources (job guides, reporting templates), highlighting the need for improved communication between HAs and LHWs. Addressing these issues will require targeted training and ongoing mentorship, as participants suggested, which are vital for fostering the confidence and competence of HAs.⁴³ In a scoping review by Alam, Ashrafi,⁴² engaging the community health workers in wide-ranging programs, eg, diabetes, hypertension, and infectious diseases, unfolded a variety of roles, barriers, and directions to establish disease-specific training guidelines. Community health workers are identified as LHWs who have little to no training and can establish a link between the community and the health care facility through health education and other support interventions.^{44,45} It is possible to systematically train them to ensure the productivity of these programs.^{21,46} Community health workers, when trained, could improve dementia care through educational and community awareness, screening for dementia, utilization of healthcare systems and dementia-related resources, and services for dementia caregivers.⁴² Additionally, as recommended by study participants, standardized reporting tools would facilitate consistent

tracking of dementia cases and support supervision.^{19,25} While digital reporting tools offer potential, the reliance on mobile technology may be constrained by resource availability in rural settings.⁴⁷

Our study also highlights systemic barriers within the district health management structure that may affect the sustainability of dementia care initiatives. These barriers include limited training and support for DHTs, whose roles are crucial for overseeing health programs. These results resonate with our previous study that involved the district health management team as external facilitators to the primary healthcare providers in the integration of mental health services into primary healthcare.³⁰ Strengthening the capacity of DHTs to prioritize mental health and dementia care could enhance the overall quality of health services and program sustainability.¹³

A primary strength of this study is its focus on a culturally appropriate, community-based model leveraging existing healthcare structures in Uganda. This model offers a potentially feasible and practical approach to addressing dementia care in rural LMICs. By engaging HAs as internal facilitators, the model aligns with community expectations and the established healthcare framework, which may help to promote program acceptance and sustainability.

However, this study has several limitations. First, the sample size is small and drawn from a single district, limiting the generalizability of findings. Additionally, the formative nature of the study does not aim for thematic saturation, potentially missing some key perspectives. Lastly, while qualitative methods provide valuable insights into participants' experiences and perceptions, mixed methods data on the implementation outcomes are necessary for a comprehensive assessment.

Conclusion

This study demonstrates the potential of using internal facilitation by HAs to support LHW-led dementia care interventions in rural Uganda. Engaging HAs in this role leverages existing community relationships and health structures, offering a scalable and culturally sensitive model for dementia care. However, successful implementation will require targeted training, adequate resources, and the development of standardized tools for monitoring and reporting. Addressing these needs can enhance the capacity of rural health systems in Uganda and similar LMICs to provide sustainable community-based dementia care.

Abbreviations

DHT, District Health Team; Has, Health Assistants; LHWs, Lay Health Workers; LMICs, Low- and Middle-Income Country; WHO, World Health Organization; WLDC+IF, WHO Lay Health Worker Dementia Care with Internal Facilitation.

Data Sharing Statement

The transcripts generated and/or analyzed during the current study are not publicly available because the study is in its preliminary stage and ongoing. However, they are available from the corresponding author upon reasonable request.

Ethics Approval and Consent to Participate

The Mbarara University Research Ethics Committee provided ethical approval under application number MUST-2024-1532. The study was registered with the Uganda National Science and Technology (HS5150ES), a regulatory body granting permission for research studies to be conducted there. The researchers upheld the rules and regulations provided by the MUST REC ethical framework for research involving human participants. Permission to conduct this study in the Lira district was obtained from the DHO. All the study participants provided written informed consent before each in-depth interview. Participants' privacy was ensured by using codes on the transcripts and conducting the interviews in private spaces. This study complies 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, or in all these areas; took part in drafting, revising, or critically reviewing 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.

Consent for Publication

All participants consented to the publication of their responses anonymized.

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Disclosure

The authors declare that they have no competing interests.

References

- Adler G, Lawrence BM, Ounpraseuth ST, Asghar-Ali AA. A survey on dementia training needs among staff at community-based outpatient clinics. *Educ Gerontol*. 2015;41(12):903–915. doi:10.1080/03601277.2015.1071549
- Wimo A, Guerchet M, Ali G-C, et al. The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimers Dement*. 2017;13(1):1–7. doi:10.1016/j.jalz.2016.07.150
- Giebel C. A new model to understand the complexity of inequalities in dementia. *Int J Equity Health*. 2024;23(1):160. doi:10.1186/s12939-024-02245-w
- Sharifi F, Ghandali R, Alimohammadi M, Ahmadipour P. Symptoms and diagnosis of dementia. In: *Nutrition in Brain Aging*. and Dementia: Springer; 2024:59–91.
- Onyike CU. Psychiatric aspects of dementia. *Continuum*. 2016;22(2):600–614.
- Isik AT, Soysal P, Solmi M, Veronese N. Bidirectional relationship between caregiver burden and neuropsychiatric symptoms in patients with Alzheimer's disease: a narrative review. *Int J Geriatr Psychiatry*. 2019;34(9):1326–1334. doi:10.1002/gps.4965
- Ainamani HE, Alele PE, Rukundo GZ, et al. Caregiving burden and mental health problems among family caregivers of people with dementia in rural Uganda. *Global Mental Health*. 2020;7. doi:10.1017/gmh.2020.7
- Possin KL, Merrilees JJ, Dulaney S, et al. Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use: the care ecosystem randomized clinical trial. *JAMA Intern Med*. 2019;179(12):1658–1667. doi:10.1001/jamainternmed.2019.4101
- Zwingmann I, Hoffmann W, Michalowsky B, et al. Supporting family dementia caregivers: testing the efficacy of dementia care management on multifaceted caregivers' burden. *Aging Mental Health*. 2018;22(7):889–896. doi:10.1080/13607863.2017.1399341
- Ferri CP, Jacob K. Dementia in low-income and middle-income countries: different realities mandate tailored solutions. *PLoS Med*. 2017;14(3):e1002271. doi:10.1371/journal.pmed.1002271
- World Health Organization. *Global Action Plan on the Public Health Response to Dementia 2017–2025*; 2017.
- Mubangizi V, Maling S, Obua C, Tsai AC. Prevalence and correlates of Alzheimer's disease and related dementias in rural Uganda: cross-sectional, population-based study. *BMC Geriatr*. 2020;20(1):48. doi:10.1186/s12877-020-1461-z
- Uganda Bureau of Statistics. The national population and housing census 2014-main report. Kampala: Uganda Bureau of Statistics. 2016.
- Uganda Bureau of Statistics. *Uganda National Household Survey 2019-2020*. Kampala Uganda; 2021.
- Owokuhausa J, Rukundo GZ, Wakida E, Obua C, Buss SS. Community perceptions about dementia in southwestern Uganda. *BMC Geriatr*. 2020;20:1–12. doi:10.1186/s12877-020-01543-6
- Kakongi N, Rukundo GZ, Gelaye B, Wakida EK, Obua C, Okello ES. Exploring pathways to hospital care for patients with alzheimer's disease and related dementias in rural South Western Uganda. *BMC Health Serv Res*. 2020;20:1–12. doi:10.1186/s12913-020-05365-5
- Abaasa C, Obua C, Wakida EK, Rukundo GZ. A qualitative investigation of the psychosocial services utilised by care-givers of patients with Alzheimer's disease and related dementias in southwestern Uganda. *Ageing Soc*. 2021; 43:1–14.
- Ainamani HE, Alele PE, Rukundo GZ, et al. Caring for people with dementia in rural Uganda: qualitative study of caregiving burden experienced by informal and formal caregivers. *J. Glob. Health*. 2019.
- Nankanga PN, Maling Z, Wakida EK, Obua C, Okello ES. Informal support for people with Alzheimer's disease and related dementias in rural Uganda: a qualitative study. *Int J Ment Health Syst*. 2020;14(1):1–11. doi:10.1186/s13033-020-00364-9
- World Health Organization. *Dementia Toolkit for Community Workers in Low-and Middle-Income Countries: Guide for Community-Based Management and Care of People With Dementia*. Manila: WHO Regional Office for the Western Pacific; 2018.
- Karungi CK, Wakida EK, Rukundo GZ, Talib ZM, Haberer JE, Obua C. Lay health workers in community-based care and management of dementia: a qualitative 'pre' and 'post' intervention study in Southwestern Uganda. *Biomed Res Int*. 2022;2022:9443229. doi:10.1155/2022/9443229

22. Village Health Team Strategy and Operational Guidelines. 2010. Available from: <http://library.health.go.ug/publications/health-education/village-health-team-strategy-and-operational-guidelines>, Accessed August 13, 2022.
23. World Health Organization. Primary health care systems (primasys): case study from Uganda. *World Health Organization*. 2017.
24. Government of Uganda. *Implementation Guidelines for Parish Development Model*. Kampala: Ministry of Local Government; 2021.
25. Connolly SL, Sullivan JL, Ritchie MJ, Kim B, Miller CJ, Bauer MS. External facilitators' perceptions of internal facilitation skills during implementation of collaborative care for mental health teams: a qualitative analysis informed by the i-PARIHS framework. *BMC Health Serv Res*. 2020;20(1):165. doi:10.1186/s12913-020-5011-3
26. Harvey G, Kitson A. PARIHS revisited: from heuristic to integrated framework for the successful implementation of knowledge into practice. *Implement Sci*. 2016;11:33. doi:10.1186/s13012-016-0398-2
27. Uganda Bureau of Statistics. *The National Population and Housing Census 2014 – Area Specific Profile Series*. Kampala: Government of Uganda; 2017.
28. Ministry of Health. National Health Facility Master List. *A Complete List of All Health Facilities in Uganda*; 2018.
29. Google. Distance between Kampala City Center, Kampala Uganda and Lira City, Lira, Uganda 2024. Available from: https://www.bing.com/search?q=Google.+Distance+between+Kampala+City+Center%2C+Kampala+Uganda+and+Lira+City%2C+Lira%2C+Uganda&cvid=091f39693f3749ac83b7c28bdacbcf39&gs_lcrp=EgRIZGdlKgYIABBFgDkyBggAEEUYOTIGCAEQRRhAMgYIAhBFGDwyCagDEOkHGPxV0gEIMjQ4N2owajmoAgSwAgE&FORM=ANAB01&PC=U531. Accessed February 4, 2025.
30. Wakida EK, Obua C, Haberer JE, Bartels SJ. Enhancing the capacity of providers in mental health integration (ECaP-MHI) in rural Uganda: the adaptation process. *J Multidiscip Healthc*. 2023;16:387–396. doi:10.2147/JMDH.S401495
31. Garbarski D, Schaeffer NC, Dykema J. Interviewing practices, conversational practices, and rapport: responsiveness and engagement in the standardized survey interview. *Sociol Methodol*. 2016;46(1):1–38. doi:10.1177/0081175016637890
32. Ryen A. Ethics and qualitative research. *Qual Res*. 2011;3.
33. Sutton J, Austin Z. Qualitative research: data collection, analysis, and management. *Can J Hosp Pharm*. 2015;68(3):226. doi:10.4212/cjhp.v68i3.1456
34. Ruona W. *Analyzing Qualitative Data. Chap. 14 in Research in Organizations: Foundations and Methods of Inquiry*. Richard AS, Elwood FH, edited by. San Francisco, CA: Berrett-Koehler; 2005:233–263.
35. Groenland E. Employing the matrix method as a tool for the analysis of qualitative research data in the business domain. *Int J Bus Glob*. 2018;21(1):119–134. doi:10.1504/IJBG.2018.094106
36. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *Int J Qual Methods*. 2006;5(1):80–92. doi:10.1177/160940690600500107
37. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107–115. doi:10.1111/j.1365-2648.2007.04569.x
38. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–1288. doi:10.1177/1049732305276687
39. Wimo A, Guerchet M, Ali GC, et al. The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimers Dement*. 2017;13(1):1–7.
40. Zulu JM, Kinsman J, Michelo C, Hurtig A-K. Hope and despair: community health assistants' experiences of working in a rural district in Zambia. *Hum Resour Health*. 2014;12:1–14. doi:10.1186/1478-4491-12-30
41. Alam RB. *Role of Community Health Workers in Addressing Dementia: A Global Perspective*. University of Illinois at Urbana-Champaign; 2020.
42. Alam RB, Ashrafi SA, Pionke J, Schwingel A. Role of community health workers in addressing dementia: a scoping review and global perspective. *J Appl Gerontol*. 2021;40(12):1881–1892. doi:10.1177/07334648211001190
43. Harvey G, Kitson A. PARIHS revisited: from heuristic to integrated framework for the successful implementation of knowledge into practice. *Implement Sci*. 2015;11:1–13.
44. Olaniran A, Smith H, Unkels R, Bar-Zeev S, van den Broek N. Who is a community health worker?—a systematic review of definitions. *Global Health Action*. 2017;10(1):1272223. doi:10.1080/16549716.2017.1272223
45. Organization WH. WHO guideline on health policy and system support to optimize community health worker programmes. *World Health Organization*. 2018.
46. Khetan A, Patel T, Hejjaji V, et al. Role development of community health workers for cardiovascular disease prevention in India. *Evaluat Prog Plann*. 2018;67:177–183. doi:10.1016/j.evalproplan.2018.01.006
47. Dhakal K. NVivo. *J Med Lib Assoc*. 2022;110(2):270. doi:10.5195/jmla.2022.1271