Discover Public Health

RESEARCH Open Access

Understanding barriers and facilitators towards death notification and reporting in island districts of Uganda

Douglas Bulafu[1*], Steven Ndugwa Kabwama[3,4], Rawlance Ndejjo[1,2], Rose Nampeera[5], Chukwuma David Umeokonkwo[5], Christine Kihembo[5], Sheba Nakacubo Gitta[5,6], Carol Kyozira[7], Stephen Robert Kasumba[8], Jean-Edgard Nguessan[9] and Rhoda K. Wanyenze[1]

*Correspondence:
Douglas Bulafu
dbulafu@musph.ac.ug
[1]Department of Disease Control and Environmental Health, School of Public Health, Makerere University, Kampala, Uganda
[2]Department of Preventive Medicine, College of Medicine, Korea University, Seoul, South Korea
[3]Department of Community Health and Behavioral Sciences, School of Public Health, Makerere University, Kampala, Uganda
[4]Department of Global Public Health, Karolinska Institutet, Stockholm, Sweden
[5]African Field Epidemiology Network, Kampala, Uganda
[6]Department of Epidemiology and Biostatistics, School of Public Health, Makerere University, Kampala, Uganda
[7]Department of Integrated Epidemiology, Surveillance, and Public Health Emergencies, Ministry of Health, Kampala, Uganda
[8]National Identification and Registration Authority, Kampala, Uganda
[9]Centers for Disease Control and Prevention Foundation, Atlanta, GA, USA

Abstract

Introduction Death registration is a fundamental component of civil registration and vital statistics (CRVS) systems, providing essential data for public health monitoring and planning. However, many deaths remain unregistered, in low-resource settings such as island communities. Understanding the barriers and facilitators of death registration is critical for developing interventions and policies to improve compliance and improve CRVS systems.

Methods This study employed an exploratory qualitative approach, utilizing 8 focus group discussions with community health workers and leaders, 20 in-depth interviews with community members and 20 key informant interviews with officers involved in the death registration process. The study was conducted from February-August 2024 in Kalangala and Buvuma Districts, Uganda. Data were analyzed thematically, identifying barriers and facilitators.

Findings Key barriers included poverty, lack of awareness of death reporting and notification and fear of victimization, unknown identity of the deceased and privacy concerns regarding paternity and marital status. Additionally, religious and cultural beliefs, lack of skilled personnel to register deaths, shortage of supplies like registration forms, and an expensive unsynchronized system with many unofficial costs also hindered the process. However, family support, support from local authorities, and proximity to registration offices facilitated the death notification and reporting process.

Conclusion Addressing barriers to death registration necessitates a multifaceted approach, which includes ongoing community sensitization to raise understanding about the importance and process of death reporting and notification, as well as to eliminate fear of victimization. Community and religious leaders should be engaged during the sensitization process. Furthermore, NIRA and district health teams should procure more supplies while simultaneously hiring additional employees to bridge the human resource gap.

Keywords Death registration, Barriers, Facilitators, Civil registration, Island communities

1 Background

Registration of deaths and their causes is crucial for governments to effectively plan for their populations. Reporting facilitates the timely dissemination of information regarding mortality and its causes to the responsible authorities for appropriate action [1]. However, more than two-thirds of deaths occurring in communities worldwide go unregistered in Civil Registration and Vital Statistics (CRVS) systems [1]. In most African countries, cause-specific mortality trends are tracked using epidemiological models because there is a low coverage of the civil registration system, and unreliable national statistics on causes of death [2]. Similarly, the rate of death registration in Uganda remains considerably low, with only 24% of national deaths recorded, according to recent statistics from the Uganda National Bureau of Statistics (UBOS) [3].

Notably, data from the National Identification and Registrations Authority (NIRA), a body mandated to register deaths, shows an even lower registration rate of 1% [4]. The disparity is attributed to variations in data reporting criteria employed by both NIRA and UBOS. The registration process involves several administrative levels and differs on the place of death. In health facilities, death reporting involves health workers filling and issuing a Death Notification Record (HMIS 100) and Medical Certificate of Cause of Death, which is entered into the DHIS2 system by a records officer and linked to NIRA for formal registration. On the other hand, for deaths occurring in the community, the process starts with the Next of Kin (NoK) of the deceased reporting to the Local council (LC) 1 (village leader), notifying at the sub-county, to certifying the death at the NIRA head offices [5]. As a result, there is very low registration at sub-counties and health facilities and the underreporting is worse in rural areas, such as Uganda's island communities, where deaths frequently go unreported [6].

Island communities in Uganda encounter a number of deaths attributed to drowning, road traffic accidents, communicable and non-communicable diseases, maternal and neonatal deaths amongst other causes [6]. However, these deaths are hardly notified and registered with the health facilities and sub county authorities [6]. Even when deaths are registered, there is often insufficient evidence regarding the cause, hindering efforts to monitor mortality trends and implement appropriate interventions [7]. Improving mortality statistics and patterns in these island settings requires a succinct understanding of the barriers and facilitators regarding community death reporting and registration.

This paper presents community perspectives on barriers and facilitators for death notification and reporting in Kalangala and Buvuma Island districts. The study findings will inform interventions and national policy aimed at improving community-based death reporting and registration in the island communities and Uganda at large.

2 Materials and methods

2.1 Study design and setting

An exploratory qualitative study was conducted from February – August 2024 in Kalangala and Buvuma Island districts located on Lake Victoria. Service delivery in these island districts is complicated by multi-layered multi-dimensional factors that make the delivery of and access to health services difficult. Health service delivery is further affected by health system performance challenges such as poor reporting by community health workers, inadequate technical support to poorly performing districts, limited community participation and citizen empowerment in service delivery in the island districts. In

2020/2021 these districts scored lowest, in health care delivery including death reporting [8]. Kalangala, also known as the Ssese islands, is a group of 84 islands scattered throughout Lake Victoria, 65 of which are habitable with a population of 66,300. Only 15 health centers serve these 65 islands, with one Health Centre IV serving as a regional health center. Bugala is the largest island, covering an area of approximately 296 km2. Kalangala district is bordered by Mpigi district to the north, Mukono to the east, the United Republic of Tanzania to the south, and Masaka and Rakai districts to the west [9]. On the other hand, Buvuma district comprises a collection of 52 Islands in Lake Victoria, in Eastern Uganda with no territory on the mainland, with approximately 55,300 people [10]. Just like Kalangala, Buvuma district has no hospital, and has a Health center IV that serves the islands [10].

2.2 Study participants

Study participants were purposively selected (Table 1). We conducted a total of 20 key informant interviews (KIIs) among District Health Officers (DHOs), health workers, district NIRA officers, police officers, cultural leader, religious leader, Sub county chiefs, Ministry of Health (MOH) officials, National NIRA officials. We also conducted 8 Focus Group Discussions (FGDs) among community health workers (CHWs) and Village/Local Council leaders (LCs). Each FGD comprised of an average of 10 participants. Also, we conducted 20 in-depth interviews among community members who had ever participated in the process of death notification and reporting. These KIIs, IDIs, and FGDs were sufficient to reach data saturation.

2.3 Data collection

FGD and interview guides were used to guide the FGDs, KIIs, and IDI interviews. The guides were developed based on the constructs of the Social-ecological Model (SEM) [11]. The guides explored barriers and facilitators towards strengthening death notification and reporting in Buvuma and Kalangala districts. The discussions and interviews were conducted by experienced and trained interviewers and note takers who had a background in health sciences, and fluency in *Luganda*, the commonly spoken language in the study districts. The FGDs were conducted in central places which included the sub county headquarters, local leaders' residence, and at the health facility as determined

Table 1 Study Participants

District	Kalangala District		Buvuma District	
IDIs	6 notifiers	4 non-notifiers	6 notifiers	4 non-notifiers
FGDs	2 – LCs	2 – CHWs	2 – LCs	2 – CHWs
KIIs	1 District Health Officer 2 Health worker (in charges) 2 Health Assistants 1 Surveillance Focal Person 1 NIRA officer 1 police officer 1 cultural leader 1 Sub county chief		1 District Health Officer 2 Health worker (in charges) 2 Health Assistants 1 Surveillance Focal Person 1 NIRA officer 1 police officer 1 Religious leader 1 Sub county chief	
National KIIs	2 MOH officers 2 NIRA officers			

Notifiers were community members who have ever participated in the process of death notification and reporting

Non-notifiers were community members who had experienced a death of a close family member that was never notified and reported

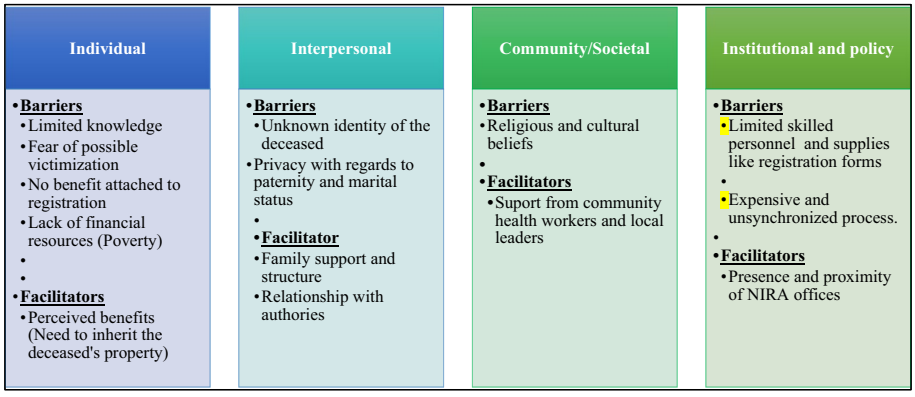

Fig. 1 Study findings presented on the constructs of SEM

by the field guides. The KIIs and IDIs were conducted in private places such as offices of key informants, and homes of In-depth interviewees. During the field data collection activities, the research assistants were supervised by SK and RN in Kalangala and DB in Buvuma. In addition, daily debriefing meetings were held to ensure data quality.

2.4 Data management and analysis

All the KIIs, IDIs and FGDs were audio recorded using audio recorders. Thereafter, the research assistants transcribed the data verbatim in the local languages and then translated them into English transcripts. All the IDI, FGD, and KII interview transcripts were imported into Atlas ti version 7.0 software (GmBH, Berlin), and coding was done by 5 data analysts following the semantic approach, with new codes appropriately added. During this process, words or related phrases from the transcripts were grouped together to form codes. At the end of the coding process, and guided by thematic analysis, related codes were then grouped to form sub-themes, and related sub-themes were grouped to form themes. Study themes are presented supported by participant quotations for illustration.

3 Results

The study findings were organized and presented based on four levels of the social ecological model (Fig. 1);

3.1 Barriers

a. Limited knowledge on death reporting and registration

The results showed that community members had limited knowledge and were not aware of death reporting and registration. Some had never heard about death notification and reporting and those who had, were unaware of how to initiate the process. Some participants felt that registration would lead to land insecurity, while others thought that the local leaders were the ones who benefited from death notification and reporting.

> *"Lack of knowledge really hinders us because we are not sensitized. People are not sensitized and don't know what to do. This is a very big problem of not knowing. We need to put in effort so that our community members get to know what to do. Truth*

is that we don't know that death reporting is really a very important issue", male respondent FGD 03 Kalangala.

In addition, community members were unaware that NIRA registered deaths. They believed that when a loved one passed away in a health facility, the facility would issue a report, but they did not know that NIRA registers deaths and provides death certificates to the families of the deceased.

"People don't know that NIRA does death reporting;…. people know that NIRA gives out national identity cards, isn't it? Now, with the health facility; people know that they give a death certificate if a person dies. Even those in their community also know that when the community loses someone, the facility should help them with burial. So, this reporting is technical and requires someone to take the responsibility or role as its key in his duties. Also if NIRA is supposed to do that, we would be hearing them announcing, even going to radios to make talk shows but we don't hear such things. So, you find that people are working in their institutions and they are doing well but you find they have not collaborated well", male respondent KII-02 Buvuma.

b. Fear of possible victimization

Community members were afraid of the legal implications of reporting deaths to the police. They feared being asked numerous questions about the cause of death or even being imprisoned. There was a belief that reporting a death, especially to the police, would imply they had detailed knowledge about the circumstances, even if they did not. People feared being treated as suspects and the potential for lengthy police delays and questioning. As a result, many chose to bury deceased villagers without reporting the death, to avoid prolonged investigations.

"People fear the police because the person died from the village not at the health facility. You can spend a day at police making a statement because of the endless and difficult questions asked of you concerning the deceased,… don't bury the dead person, let us first investigate what killed him/her etc. So, that makes some people fear and they decide to bury because they can't restore anything", male respondent FGD 02 kalangala.

c. No benefit attached to registration

Some community members emphasized that there was no benefit of registering deaths especially if it was a child or the person left no property behind. Relatives of the deceased often considered the burden they were left with after losing a loved one, especially the responsibility of caring for the deceased's children. As a result, they were reluctant to spend money on the registration process to obtain a certificate.
" The person sees no value for him/her in registering a death, it is not easy to get, their person has died; so, they don't see anything to gain. Imagine, somebody has lost a relative and the sub-county is far away, and that person is expected to incur in transport fees to go and register death yet they are now responsible for the orphaned children….need to provide for them sugar and school fees", female respondent KII 06 Kalangala.

d. Lack of financial resources to conduct the process

Some families lacked financial resources to transport the body of a deceased loved one to a health center for a post-mortem. Community members explained that reporting a death often meant the body would be taken to the mortuary for examination, requiring the family to later arrange and pay for its transportation back home. Many felt that this process was burdensome, especially since no assistance was provided for returning the body. As a result, families often chose to keep the body at home to avoid the hassle and costs. Additionally, the inability to afford transport, death certification fees, and mortuary charges discouraged families from pursuing death certificates, leading some to resort to smuggling bodies to bypass these challenges.

"Someone can die within the community and no one has the money for fuel to transport that body at that particular time when the person is pronounced dead. They will call someone at the facility and the phones are off, yet the family is very poor. The body will remain there until the next morning when they get fuel. Since there are no funds to take care of those who are dead, money for fuel is just even collected". female respondent KII 06 Kalangala.

e. Unknown identity of the deceased in the community

Many people in these fishing communities seasonally migrate to and from the island, without their families and some do not disclose to anyone where their ancestral homes are. In case such a person dies, it is difficult to register that death then because there is hardly any information about them. Indeed, migrants from neighboring countries like Rwanda, Tanzania, Burundi and Kenya, who come to fish intentionally refuse to mention that they are the relatives of the deceased because they have no burial sites. They therefore abandon the deceased to the police and public health officers to bury in the district burial grounds, and therefore no need for registration.

"Sometimes the relatives or friends of the deceased abandon the dead bodies. For example we have Tanzanians, Kenyans and Rwandans who live on the islands and came to fish. When it is announced that X has drowned, and the body was taken to the health facility for post mortem and now awaits to be picked up, but the relatives or the friends of the deceased, intentionally don't show up, yet the body can't be kept forever. We then have no choice but to and dispose it off. You can't give details about that person unless there is someone responsible for him/her. You will not know the names of the deceased, their age, where he/she came from since they found the body floating on water". Male respondent KII 10, Kalangala.

f. Privacy with regards to paternity and marital status

A participant mentioned that women are likely not to register the death of a child if they are not sure of the biological father. Some women do not want to expose the paternity of their children especially if they had multiple partners and not sure who the right father is.
Others were not interested in being referred to as widows, so they don't register the death of their spouses.
"The information has to stop there. At times it goes back to the mothers. A mother can have a child with 3 fathers, so when that dies, the truth is they will ask you who the correct father is, and the mother worries that this might bring her problems and

hence decides to avoid giving more information or being asked further. That's what I believe causes people not to care to register those who have died", female respondent FGD 06 Kalangala.

g. Religious and cultural beliefs

Death notification and registration often conflicted with certain religious practices. Islamic tradition recommends the immediate burial of the deceased, which meant that burial ceremonies often took place without obtaining a death notification. Participants emphasized that it was impractical to ask Muslims to delay burial until the necessary documentation was acquired, as their customs demanded swift burial. They also mentioned that the distance between burial sites and the locations for obtaining notification letters made the process even more challenging.

"Each person adheres to their own religious beliefs and practices. Some individuals may be deeply religious and may express their disagreement with registration by stating that they have already buried their loved one and secured their belongings according to their customs. Those who follow traditional beliefs might explain that their practices align with their cultural or spiritual traditions", male notifier 01, Buvuma.

"For the Muslims you cannot say do not bury until you get the letter, yet they have to bury instantly, they cannot wait. Sometimes even the long distance between the burial site and is to where they get the letter from makes it hard," male KII 10 Buvuma.

In addition, some perceived death registration as counting the dead which was against the Buganda cultural norms. Counting the dead is only done by the clan leaders and cultural leaders and this belief could have hindered people from death reporting.

"Because people don't know as the Baganda tribe say "Omuffu tebbamubala" meaning "the dead cannot be counted". So, they take registration of deaths as "counting the dead" people will be like why you register a dead person. Why do you make a death notification? Deceased are only registered in the clan records not government records", female KII 9 Buvuma.

h. Limited skilled personnel and supplies

There is limited access to skilled staff to support death notification and registration. The responsible officers are not always available at their offices when needed. The respondents emphasized that these workers report to work on Tuesdays and leave on Thursdays, making it hard for the community to report deaths.

"The first barriers are at sub county level. Today is Saturday, but you will find the employees of this place only work on Tuesday and then they go on Thursday. So, suppose there is a person who dies today, or you need to bury today. Then you tell the person to go the sub county to get permission they might reach when there is no one. There are also many barriers related to lack of knowledge because right now if you tell a person to go get a card and go to NIRA, they don't know where to begin from. The biggest barriers are lack of knowledge and constant absence of the responsible government officials," female respondent FGD 08 Buvuma.

i. Expensive and unsynchronized process

Registering death involves engaging different stakeholders at the different administrative levels right from the village local council chairperson to the health facility up to NIRA. This process, has a lot of associated expenses which include high transport costs from one island to another, making telephone calls and at times paying unintended fees (bribe) to the officers to receive services, yet some of the relatives of the deceased are too poor to afford such costs.

" They are asked for money beyond a million which makes people to ignore the process on grounds that they can't afford that money to enable them get a death certificate because from the health facility, it requires you to go to the judge for him/her to confirm that you are going to get letters of administration for the deceased's property " female respondent FGD 03 Kalangala.

3.2 Facilitators

a. Need to inherit the deceased's property

Many individuals believe that deaths are primarily registered when the deceased owned assets requiring administration. Participants noted that registration is typically pursued by those with financial means and those expecting to inherit property.

"People who register are the people who have money and hope to get other property but for those whose deceased had no property, after burial, it is over and even forget about that name. Not all who lose people come to register their people but those who have need or when the deceased had some property. In most cases, if they have not called us to join their meetings, that person comes with a family letter confirming that he/she was selected to work on the deceased's property," female respondent, FGD 04, Kalangala.

Similarly, participants also emphasized that registration was often pursued to manage potential disputes over inheritance. Therefore, the urgency to secure administrative letters ensured clarity regarding ownership and inheritance.

"The only people whose registrations are done are people who have had properties and or were wealthy, which can bring misunderstandings/conflicts between family members. So they quickly to register the deceased with relevant authorities because they want administrative letters." Male respondent KII 11, Buvuma

b. Family support and structure

Participants highlighted that family support and structure significantly influenced the ease of processing a death certificate. In nuclear family settings, the process was typically more straightforward because close family members, such as children and spouses, were readily available to manage the documentation. For instance, when the deceased had only one child, disputes over assets were minimized, simplifying the process.

"If it's a husband who died, the wife will follow up with the relatives and kinsmen. They will need access to his bank account. If it's the husband who has died, the wife will follow up with the relatives, kinsmen, the brothers, the uncles, the closest people in that home." female respondent, KII 09 Buvuma.

Another participant emphasized the role of family meetings in facilitating the process. During these gatherings, responsibilities were assigned among family members, and collective support was provided to navigate procedural hurdles.

> *"We had a family meeting. There was me, our other uncle, my siblings, we were like 10, but since I was still in a state of mourning after losing dad, I did not understand it well but were a reasonable number. In the meeting, they wrote minutes and elected an heir who was going to take on the responsibility of father's property. We moved together with him because I didn't have a national ID we helped each other because I was also elected to be part of the process." Male notifier 03, Buvuma.*

c. Family relationships with authorities

Families that had good relationships with the authorities were offered assistance during the death reporting process ensuring that required documents are presented harmoniously to the relevant offices. Participants emphasized that such support made the process easier for them.

> *"I have a sister who works at the district who is helping me process this registration faster. She has advised me on lots of things. My brother is the chairman, and also my sister works at the district, they helped me ease life for me. Because the person who would ask many questions was my in-law." female notifier 04, Kalangala.*

d. Support from community health workers and local leaders

Participants mentioned that local leaders and community health workers supported the community members during the process of death notification, reporting and registration. They usually notified the community about death and helped the bereaved family in organizing burial and collecting contributions to support during the funeral. Furthermore, local leaders also supported families of the deceased by giving them letters to commence the process of death registration. In addition, some local leaders also advised community members on how to register death.

> *"My father was a resident of that area for some time but when he fell sick, they took him to Namisindwa but since he was a resident the leaders helped me and my family to get that letter because they knew about his land that BIDCO had taken". Male notifier 02 Kalangala.*
>
> *" It wasn't easy for me because chairman is my relative, when he heard and reached the scene and he saw someone familiar has died. He mobilized people and requested them to collect some funds that will bring the police and check the dead body. So, I believe they collected some money and they later called the police and helped me to register". female notifier 02 Buvuma.*

e. Presence and proximity of National Identification and Registration Authority (NIRA) Offices

The establishment of NIRA offices closer to communities has significantly improved access to vital registration services. Previously, individuals had to travel long distances, often to Kampala, to obtain essential documents such as death certificates. For many, navigating the city was a challenge. However, with NIRA offices now available at the subcounty level, the registration process has become more convenient and accessible.

"They helped us by the way because those days you had to first go to Kampala to get the death certificate. Some of us don't even know our way around Kampala. The process has been made easy because we now register deaths from the sub county and NIRA is near us. So, I don't find hard going to NIRA because of its proximity in case I have to go there", female notifier 3 Buvuma.

4 Discussion

This study explored barriers and facilitators to death notification and reporting in Uganda's island communities of Kalangala and Buvuma districts, revealing critical gaps and opportunities for improving civil registration and vital statistics (CRVS) systems in these unique settings. Participants highlighted a range of barriers hindering effective death reporting and notification which included limited knowledge, fear of possible victimization, lack of financial resources, unknown identity of the deceased, cultural and religious beliefs, limited skilled personnel and supplies, and the process being expensive. Nonetheless, the support from community health workers (CHWs) and local leaders, family support, family relations with those in authority and registration being a mandate for inheritance and administration of the deceased's property emerged as a facilitating factor for death notification and reporting.

A significant barrier identified was the lack of knowledge among community members about the processes, importance of death notification and registration and the role of the National Identification and Registration Authority (NIRA). These findings align with findings in other low-resource settings [12, 13]. For example, findings from a studies conducted in Guinea-Bissau and Kenya showed that lack of knowledge and a limited understanding of the benefits of death registration were attributes to low death notification and reporting [12, 13]. Improving awareness through targeted community engagement, media campaigns, and stakeholder involvement could help bridge this knowledge gap.

Just like other studies in Guinea Bissau [12], Ghana [14] and Kenya [15], lack of benefits attached to death reporting and notification was a barrier to the process. According to some participants in this study, there was no advantage to reporting deaths, particularly if the deceased was a child or left no property behind. They were hesitant to pay for the registration process to receive a certificate as a result. This finding highlights ignorance about the importance of death reporting and therefore the need for continuous sensitization and health education among the population about the importance of death reporting and notification [14].

This study highlighted that some people feared to notify and report community deaths to authorities due to possible victimization. Community members were concerned about the legal ramifications of reporting deaths to the police because they believed that reporting a death, particularly to the police, implied detailed knowledge of the circumstances, which they did not. According to the Criminal Procedure Code Act (Cap 116) of Uganda the authorities investigate the person who reports the incident as part of due diligence [16], but that doesn't make them criminals. Yet, studies have shown that fear of victimization undermines reporting of health events, including death, because it causes feelings of insecurity and anxiety [17, 18].

Poverty emerged as a significant barrier to death reporting, as many families lacked the financial resources needed for essential procedures such as transporting bodies for

post-mortem examinations. The process itself was not only costly but also complex and unsynchronized, requiring multiple steps that added to the financial burden. The costs involved, coupled with logistical challenges including high transport costs discouraged families from following through with the death notification and reporting process. The island communities' reliance on water transport and the scarcity of health facilities meant that families faced significant logistical hurdles when attempting to notify and report deaths. These findings are similar to a study conducted in Indonesia which revealed that limitations in access to registration services such as long distances to registration offices and high costs in the process, hindered death notification and reporting [19]. Therefore, establishing mobile registration units and utilizing digital tools could help overcome these access issues, bringing services closer to communities in remote locations.

In this study, there was a challenge of registering deaths for individuals with unknown identities due to seasonal migration. Similar findings have been documented in studies on transient populations, where individuals move frequently for work and lack strong social ties within host communities [20, 21]. Research on migrant workers on shores of water bodies in many regions of Africa like Uganda has also shown that many transient workers do not disclose personal details, making death notification and reporting difficult [21, 22]. In line with our findings, evidence from the World Bank shows that unregistered civil events like deaths were prevalent among undocumented migrant workers, as they often had no immediate relatives present to facilitate formal registration [23]. This implies that many deaths remain unreported, leading to gaps in vital statistics, which are crucial for public health planning and resource allocation [24]. Without accurate death registration, policymakers may underestimate mortality rates and misallocate resources, particularly for health services.

Privacy concerns regarding paternity and marital status also emerged as a significant factor affecting death notification and reporting. Women who are uncertain about the biological fathers of their children may hesitate to report a child's death, fearing potential social or legal repercussions. Similar findings were observed in studies conducted in Uganda and Kenya, where stigma surrounding multiple paternity led to reluctance in disclosing parental details in official documentation [25, 26]. Likewise, a study in India found that women who remarried after widowhood sometimes refrained from registering the deaths of their previous spouses due to cultural taboos associated with widowhood [27]. This reluctance to register deaths has critical legal and social implications. Unregistered deaths can hinder access to inheritance rights, particularly for widows and children, as legal documentation of the deceased is often required for property succession. Moreover, the lack of official records affects demographic data accuracy, which is essential for planning social welfare programs and policies supporting vulnerable populations.

Cultural and religious beliefs also posed substantial barriers to death notification and registration. In this study, the Baganda culture, for instance, viewed death registration as "counting the dead," thus contradicting traditional norms. Similarly, Islamic practices that emphasize immediate burial often conflict with the administrative requirements of death notification and reporting. These study findings are in tandem with those in a study conducted by Habaasa et al., which revealed that cultural beliefs such as burying suicide deaths, registration being considered a taboo, and catholic church registration

of the dead being mistaken for official death registration [5]. This study also further revealed that it was a cultural taboo against announcing death for infants, neonates, twins and even suicides have hindered death notification and reporting [5]. Another study conducted in Nigeria in which low death registration was reported among newborns also reported the same [28]. These insights underscore the importance of culturally sensitive approaches when designing interventions to improve death notification and registration [5]. Therefore, engaging cultural and religious leaders as champions for these processes could facilitate better community acceptance.

Limited skilled personnel significantly hindered death reporting and notification. Having limited personnel is attributed to inefficiency, reduced productivity, delayed service delivery, damaged the NIRA's reputation, and stress, frustration, and hopelessness [29] among clients which could have deterred them from registering deaths. In addition to limited skilled personnel, supplies were also limited. Limited supplies such as registration forms and equipment such as laptops affects productivity of staff which could in turn affects service delivery to individuals undertaking notification and registration. These findings are similar to findings in a study conducted in Kenya which reported that the death registration system faces various challenges including shortage of registration supplies which affected optimal performance of the process [13].

Despite these challenges, several facilitators to death notification and reporting were identified. CHWs and local leaders played a pivotal role in supporting bereaved families in death notification processes. Their involvement in organizing burials, raising community awareness, and guiding families through notification and registration processes was particularly notable. This is similar to a study conducted in South Africa which showed that CHWs could conduct verbal and social autopsy and registration for maternal and infant deaths to complement formal vital registration systems [13]. Indeed, studies suggest that CHWs are instrumental in collecting complete and high-quality vital events data like death registration data [30–32]. However, this should be accompanied with resources to support locally-defined incentive structures and levels of supervision and monitoring [31]. Therefore, strengthening their capacity through training and incentivization could further enhance their contributions to death reporting systems.

Family structures and support also emerged as facilitators to death reporting and notification. Nuclear family structures, strong intra-family relationships, and collaborative practices like family meetings emerged as key facilitators in overcoming procedural hurdles. Members of nuclear families have close relationships with each other including household heads [33], unlike extended family structures. Atuhaire et al., reveals that deceased persons who are not closely related to household heads are unlikely to have death certificates [4], or sometimes even the process commenced. This could be attributed to lack motivation to register such deaths since he or she may not be a direct beneficiary or next of kin for the deceased persons [4]. Furthermore, families' relationships with people in influential positions often navigated the process more efficiently, leveraging their networks and collective efforts to address challenges such as document preparation and succession planning. Such individuals supported through family meetings ensured task distribution and documentation readiness, reducing delays. It is plausible that people in influential positions have higher educational statuses and socio-economic statuses, hence are knowledgeable [13] and have resources to pay for the associated costs (such as transport) in the death registration process [4].

One of the facilitators for death notification and reporting was the legal requirement for inheritance and administration of the deceased's property. In this study, deaths were primarily registered when the deceased owned assets requiring administration and it was typically pursued by those who wanted to inherit property. This is consistent with other studies, conducted elsewhere, where death registration is highly driven by legal requirement to obtain a death certificate, to obtain burial permits, remarriage rights, welfare payment, inheritance and administration of the deceased's property [13, 34, 35]. The most likely explanation is that the death certificate is a crucial document required by the deceased's family to process claims like insurance, National Service Security funds, bank deposits, and permission to re-marry. This therefore, indicates that improving death notification and registration, requires appropriate enforcement measures and incentives that will stimulate demand [36, 37].

In this study, the presence and proximity of NIRA offices motivated people to notify and register deaths. These findings are consistent with other studies which highlight proximity of registration offices as a motivator for death reporting [4, 13, 35]. The extension of birth and death registration services to district and sub-county levels by opening registration offices reduces the distance people have to travel to access registration services, thereby reducing the cost of transportation and associated expenses and time away from daily work [13].

4.1 Limitations

The study had some limitations as it was conducted in the island districts of Kalangala and Buvuma, which may limit the transferability of the findings to other hard to reach communities in Uganda. However, the contextual issues highlighted in the study are likely to be similar to those in other island or rural areas across the country. Additionally, the study relied on self-reported data, which could be subject to recall bias or social desirability bias, as participants may have provided responses that they perceived as more acceptable or appropriate. However, participants were assured of confidentiality and were encouraged to honestly share their experiences. None the less, the findings offer great insights into the barriers and facilitators towards death reporting and notification in island communities.

5 Conclusion

In conclusion, death registration is influenced by multiple barriers and facilitators across individual, interpersonal, community, and institutional levels. Death notification and reporting is hindered by financial constraints, limited knowledge, fear of victimization, and privacy concerns regarding paternity and marital status. Community-level barriers include religious beliefs, while institutional challenges involve limited personnel, supply shortages, and high costs. However, facilitators such as perceived benefits like inheritance rights, strong family support, relationships with authorities, community health worker assistance, and the presence and proximity of NIRA offices help improve registration. Addressing these barriers requires a multi-level approach, including community sensitization, financial support mechanisms, privacy protections, and policy reforms to streamline processes, ultimately strengthening civil registration and vital statistics systems.

Abbreviations

AFENET	African Field Epidemiology Network
CDC	Centers for Disease Control
CHWs	Community Health Workers
CRVS	Civil Registration and Vital Statistics
FGD	Focus Group Discussions
IDI	In-depth Interview
KII	Key Informant Interview
LCs	Village/Local Council leaders
MOH	Ministry of Health
NIRA	National Identification and Registration Authority
UBOS	Uganda Bureau of Statistics
WHO	World Health Organization

Acknowledgements
The authors extend their gratitude to the entire research team, the Ministry of Health, National Identification and Registration Authority, and Buvuma and Kalangala District Local governments.

Author contributions
DB, SNK, RN and RKW conceived and spearheaded the study. DB, SNK, and RN supported all data collection, analysis, and manuscript writing from the initiation of the project to the end. RN, JEN, CK, SNG, SRK, RNa and RKW provided technical support and supervised the work. All authors participated in drafting and reviewing the manuscript. All authors read and approved the final manuscript.

Funding
This work was supported by the Data for Health Initiative, a joint project of the CDC Foundation and Bloomberg Philanthropies through the African Field Epidemiology Network (AFENET) - Mortality Surveillance Grant Award 826. The views expressed herein are those of the authors and not necessarily those of CDC Foundation and AFENET.

Data availability
The datasets used and analyzed during the current study are available from the corresponding author upon reasonable request. All secondary data indicated in the manuscript are referenced.

Declarations

Ethics approval and consent to participate
We obtained ethical approval to conduct the study from Makerere University School of Public Health Research and Ethics Committee (SPH-2024-553) and the Uganda National Council for Science and Technology (HS2502ES). This study was performed in line with the principles of the Declaration of Helsinki. Administrative clearance was obtained from the respective district leadership before commencement of the study. Names of participants were not collected to ensure anonymity. Informed consent was obtained from participants before conducting interviews.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Received: 27 July 2025 / Accepted: 16 February 2026
Published online: 22 February 2026

References

1. Adair T, Rajasekhar M, Bo KS, Hart J, Kwa V, Mukut MAA, et al. Where there is no hospital: improving the notification of community deaths. BMC Med. 2020;18(1):1–8.
2. Masquelier B, Pison G, Rakotonirina J, Rasoanomenjanahary A. Estimating cause-specific mortality in Madagascar: an evaluation of death notification data from the capital city. Popul health metrics. 2019;17:1–12.
3. UBOS. Uganda Demographic and Health Survey. 2016. https://www.dhsprogram.com/pubs/pdf/FR333/FR333.pdf.
4. Atuhaire LK, Nansubuga E, Nankinga O, Nviiri HN, Odur B. Prevalence and determinants of death registration and certification uptake in Uganda. PLoS ONE. 2022;17(3):e0264742.
5. Habaasa G. The contribution of social norms and religious practices towards low death registration in 3 HDSS sites of Uganda. BMC Health Serv Res. 2022;22(1):1219. https://doi.org/10.1186/s12913-022-08589-9.
6. Kikule E, Mukooza EK, Mugarura E, Semujju S, Kusiima M, Ubomba-Jaswa P, Kanyesigye E. The health and socio-economic status of the Buvuma Main Island Community in Buvuma District, Uganda. 2014.
7. Kung S, Doppen M, Black M, Braithwaite I, Kearns C, Weatherall M, Beasley R, Kearns N. Underestimation of COVID-19 mortality during the pandemic. ERJ Open Res. 2021 Feb 15;7(1):00766-2020. doi: 10.1183/23120541.00766-2020. PMID: 33614772; PMCID: PMC7734715.
8. MOH. Uganda Ministry of Health, Annual Health Sector Performance Report 2020/2021. 2022.
9. Kwiringira JN, Mugisha J, Akugizibwe M, Ariho P. When will the doctor be around so that I come by?!' Geo-socio effects on health care supply, access and utilisation: experiences from Kalangala Islands, Uganda. BMC Health Serv Res. 2021;21(1):1163. https://doi.org/10.1186/s12913-021-07204-7.
10. Nguna J. Estimating the Costs of Responding to a Measles Outbreak: Buvuma Islands, Lake Victoria, Uganda, February-May 2017. J Interval Epidemiol Public Health. 2022;5(1):1.

11. Kilanowski PhD RNACFJF. Breadth of the Socio-Ecological Model. J Agromed. 2017;22(4):295–7. https://doi.org/10.1080/1059924X.2017.1358971.
12. Fisker AB, Rodrigues A, Helleringer S. Differences in barriers to birth and death registration in Guinea-Bissau: implications for monitoring national and global health objectives. Trop Med Int Health. 2019;24(2):166–74.
13. Wakibi S, Ngure E. An Assessment of Knowledge, Attitude, and Practices of Birth and Death Registration in Kilifi County in the Coastal Region in Kenya. Biomed Res Int. 2021;2021:9963703. https://doi.org/10.1155/2021/9963703. Epub 20211001.
14. Agyekum MW, Kyei-Arthur F, Bosompem SK. Do we register our deaths? Motivations and barriers to death registration in Ghana. PLoS ONE. 2024;19(10):e0312353. https://doi.org/10.1371/journal.pone.0312353.
15. Mathenge G, Lehohla P, Makokha A, Wanzala P. Factors associated with low levels of birth & death registration in Kieni East District of the Central Province of Kenya. Afr J Health Sci. 2013;26(4):272–90.
16. ULII. Criminal Procedure Code Act2023 2023/12/31/.
17. Cossman JS, Rader NE, FEAR OF CRIME, AND PERSONAL VULNERABILITY: EXAMINING SELF-REPORTED HEALTH. Sociol Spectr. 2011;31(2):141–62. https://doi.org/10.1080/02732173.2011.541339.
18. Yaghuoti E. The Relationship between Fear of Crime and Prevention of Secondary Victimization of Children from the Perspective of Health Rights. Health Law J. 2024;2(2):1–12.
19. Duff P, Kusumaningrum S, Stark L. Barriers to birth registration in Indonesia. Lancet Global Health. 2016;4(4):e234–5.
20. Arfaoui A. Mixed Migration Centre. 2025 2025/03/31/T11:41:41 + 00:00. https://mixedmigration.org/uncounted-unknown-migrant-deaths-disappearances-atlantic/.
21. Web R. 2023 2023/02/27/. [2025/04/02/06:40:51]. https://reliefweb.int/report/world/social-cohesion-and-forced-displacement-synthesis-new-research-enar.
22. Buyinza Mugeere A, Oporia F, Kobusingye O. A qualitative study of the causes and circumstances of drowning in Uganda. BMC Public Health. 2022;22(1):2024. https://doi.org/10.1186/s12889-022-14461-6.
23. Bronwen M. Identification in the context of forced displacement. https://documents1.worldbank.org/curated/en/375811469772770030/pdf/Identification-in-the-Context-of-Forced-Displacement-Identification-for-Development-ID4D.pdf
24. Musarandega R, Cresswell J, Magwali T, Makosa D, Machekano R, Ngwenya S, et al. Maternal mortality decline in Zimbabwe, 2007/2008 to 2018/2019: findings from mortality surveys using civil registration, vital statistics and health system data. BMJ Global Health. 2022;7(8):e009465. https://doi.org/10.1136/bmjgh-2022-009465.
25. Mbonye M, Siu G, Seeley J. The meaning of fatherhood to men in relationships with female sex workers in Kampala, Uganda: The struggle to model the traditional parameters of fatherhood and masculinity. PLoS ONE. 2022;17(8):e0273298. https://doi.org/10.1371/journal.pone.0273298.
26. Marsh V, Kombe F, Fitzpatrick R, Molyneux S, Parker M. Managing misaligned paternity findings in research including sickle cell disease screening in Kenya: 'consulting communities' to inform policy. Soc Sci Med. 2013;96:192–9. https://doi.org/10.1016/j.socscimed.2013.07.028.
27. Reed MN. The labor force participation of Indian women before and after widowhood. Demogr Res. 2020;43:673–706. https://doi.org/10.4054/demres.2020.43.24.
28. Tobin EA, Obi AI, Isah EC. Status of birth and death registration and associated factors in the South-south region of Nigeria. Annals Nigerian Med. 2013;7(1):3–7.
29. Lishomwa JM. Employee Absenteeism and Service Delivery at a Zambian Government Agency. Walden University; 2019.
30. Silva R, Amouzou A, Munos M, Marsh A, Hazel E, Victora C, et al. Can Community Health Workers Report Accurately on Births and Deaths? Results of Field Assessments in Ethiopia, Malawi and Mali. PLoS ONE. 2016;11(1):e0144662. https://doi.org/10.1371/journal.pone.0144662.
31. Munos MK, Koffi AK, Sangho H, Traoré MG, Diakité M, Silva R, Group MRW. Strengthening community networks for vital event reporting: community-based reporting of vital events in rural Mali. PLoS ONE. 2015;10(11):e0132164.
32. Nabukalu D, Ntaro M, Seviiri M, Reyes R, Wiens M, Sundararajan R, et al. Community health workers trained to conduct verbal autopsies provide better mortality measures than existing surveillance: Results from a cross-sectional study in rural western Uganda. PLoS ONE. 2019;14(2):e0211482. https://doi.org/10.1371/journal.pone.0211482.
33. Golubović M. Characteristics of children's family practices in nuclear families. Sociol Annual/Годишњак за социологију. 2022;18(28):51–63.
34. Jewkes R, Wood K. Competing discourses of vital registration and personhood: perspectives from rural South Africa. Soc Sci Med. 1998;46(8):1043–56. https://doi.org/10.1016/S0277-9536(97)10036-3.
35. Fall A, Masquelier B, Niang K, Ndiaye S, Ndonky A. Motivations and barriers to death registration in Dakar. Senegal Genus. 2021;77(1):21. https://doi.org/10.1186/s41118-021-00133-7.
36. Chisumpa VH, Odimegwu CO, De Wet N. Adult mortality in sub-saharan Africa, Zambia: Where do adults die? SSM-population health. 2017;3:227–35.
37. Joseph G, Da Silva ICM, Wehrmeister FC, Barros AJ, Victora CG. Inequalities in the coverage of place of delivery and skilled birth attendance: analyses of cross-sectional surveys in 80 low and middle-income countries. Reproductive health. 2016;13:1–13.

Publisher's note