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THEY “DON’T CURE OLD AGE”

They “don’t cure old age”:

Older Ugandans’ delays to health care access

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Abstract

Purpose of study: Uganda’s population is ageing, which comes with increasing and varied burdens of disease and health care needs. At the same time, gerontological care remains neglected. This paper examines the factors that cause older Ugandans to delay health care access.

Design and methods: We conduct a thematic analysis of data drawn from nine focus groups held with rural Ugandans aged 60-plus. Our analysis highlights the factors that delay older persons’ access to health care, and how these align with the Three-Delay Model, which was developed to assess and improve obstetric care in low-resource settings.

Results: Our participants report delays in (I) deciding to seek care related to mobility and financial limitations, disease etiology, severity, and stigma; (II) reaching care because of poor roads and limited transportation options; and (III) receiving appropriate care because of ageism among health care workers, as well as poorly staffed and undersupplied facilities.

Implications: Delays to care are complex and impacted by factors at the individual, community and health system levels. We argue for the need for multipronged interventions that will address these delays, improve access to care, and ultimately enhance older Ugandans’ health and wellbeing.

Key words: Access to and utilisation of services, Focus Groups, Healthcare Policy, Sociology of ageing/social Gerontology

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Older Ugandans’ Delays to Health-Care Access

Purpose of Study

Despite the impact of disease and endemic poverty, the number and percentage of older persons in sub-Saharan Africa is growing (Mills, Bärnighausen, & Negin, 2012; Negin, Bärnighausen, Lundgren, & Mills, 2012). As with ageing populations around the globe, with increased age comes increasing and varied disease burdens (Murray et al., 2012). Older Africans suffer not only from diseases related to poverty, but also from HIV (Mahy, Autenrieth, Stanecki, & Wynd, 2014; Negin & Cumming, 2010) and non-communicable diseases (NCDs) such as hypertension, stroke, and diabetes (Ameh, Gómez-Olivé, Kahn, Tollman, & Klipstein-Grobusch, 2014). In the context of Ugandans’ living longer, and increasing morbidity from a range of illnesses and chronic conditions (Mathers, Fat, & Boerma, 2008; Mayosi et al., 2009), we explore the factors that cause older Ugandans to delay seeking, reaching and acquiring health care, despite their needs. We conduct a thematic analysis of focus groups with Ugandans aged 60-plus to outline factors that lead to older persons’ delaying health-care access.

In low- and middle-income countries, older persons’ health-care access is impacted by demographic, economic, and health-status factors (Peltzer et al., 2014). Across many contexts, health-care access has been found to be lower among those who are poor, younger, male, less educated, have better self-rated health, and have no chronic illnesses (Albanese et al., 2011; Peltzer et al., 2014; Vela et al., 2012). Importantly, the availability of “accessible, affordable and quality health care” is also a crucial factor (Lloyd-Sherlock, 2000; Peltzer et al., 2014). For example, out-of-pocket expenses can be a deterrent to seeking care and detrimental to individual

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and household finances if care is sought (Albanese et al., 2011; Brinda, Kowal, Attermann, & Enemark, 2015; Wong & Díaz, 2007).

Over the past 20 years, many African public health systems have expanded from their early focus on acute infectious disease and maternal and child health to include TB and HIV (chronic infectious disease) services (Cohen, Li, Giese, & Mancuso, 2013; Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). Despite a parallel emerging epidemic of NCDs in older adults, there has been less focus and expansion in the area of gerontological care (Mayosi et al., 2009; Negin, Rozea, & Martiniuk, 2014; Rabkin, Kruk, & El-Sadr, 2012), thus creating gaps in appropriate care options for older Africans. While there has been some work in Uganda on access to care by older Ugandans living with HIV (Kuteesa, Seeley, Cumming, & Negin, 2012; Negin, Nyirenda, Seeley, & Mutevedzi, 2013), we expand the focus here to build on work that explores the factors that delay older Ugandans with a variety of health concerns from seeking, reaching, and receiving the care they need (Droti, 2014).

Older Ugandans generally receive care at government-run Level III Health Centers. These health centers provide free and accessible care at the sub-county level for a population of about 20,000. Officially, these centers are equipped to provide “preventive, promotive and outpatient curative services, and emergency maternal deliveries,” as well as “inpatient, maternity and laboratory services” (Ministry of Health, Uganda). However, owing to a variety of factors at the individual, community, and health-system levels, older Ugandans delay accessing health services. Delays are caused by a limited willingness to seek care, restricted ability to reach care, and low expectations of receiving appropriate and adequate care (Droti, 2014; Nnko et al., 2015). These issues are similar to those outlined in Thaddeus and Maine’s “Three-Delay Model” (Thaddeus & Maine, 1994).

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The Three-Delay Model

Thaddeus and Maine’s (1994) Three-Delay Model identified “obstacles to the provision and utilisation of high quality, timely obstetric care” in Africa by defining a chronology of barriers that result in delays to pregnant women’s health care access. The model has been adapted to emergency care (Calvello et al., 2015) and used to develop interventions that reduce maternal mortality (e.g., Lalonde, Okong, Mugasa, & Perron, 2003; McCarthy et al., 2015). However, to the best of our knowledge we are the first to adapt the model to analyse delays to accessing care among older Africans. As shown in Figure 1, the model outlines Three Delays: (I) deciding to seek care, (II) identifying and reaching medical facilities, and (III) receiving adequate and appropriate care. The length of delays and likelihood of a delay’s impact on service utilisation and outcomes are influenced by socio-economic and cultural characteristics, accessibility of facilities, and quality of care. In other words, our model posits that older Africans’ delay accessing health care not merely due to a lack of financial resources but also to a broader set of interconnected individual, community, and health-system factors and that these factors create feedback loops that influence future health care decisions. We view delays to seeking, reaching and acquiring care as crucial intervention points for older persons, for whom chronic disease management (whether HIV or NCD) is particularly important for their ability to remain self-sufficient. ‘Community’ factors are presented as an intermediary level between the patient and the health system—both a physical place with regard to available infrastructure (water, electricity, roads) and a social space, where social support and interpersonal relationships (or lack there of) impact older persons’ health and health decision-making.

<FIGURE 1 ABOUT HERE>

Design and Methods

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The data are drawn from a qualitative study conducted in 2015 in Kalungu district in rural south-west Uganda. The area is home to the Medical Research Council/Uganda Virus Research Institute [MRC/UVRI] General Population Cohort (GPC), established in 1989, initially to study the epidemiology of HIV, but in recent years has expanded to cover other conditions. A considerable amount of research on older persons has taken place at the site including the Study on global AGEing and adult health (SAGE)-Wellbeing of Older People Study (WOPS) survey and a number of qualitative studies (Asiki et al., 2013; Scholten, Seeley, Mugisha, Zalwango, & Wright, 2011). A clinic serves the GPC population and offers clinical services to over 70 patients daily from the 25 study villages that form the GPC, however, it should be noted that most of the population will first visit a government or private health clinic, closer to their home, rather than travel to the MRC/UVRI clinic. The MRC/UVRI clinic provides referrals to specialists and inpatient care, as needed, and very occasionally provides transportation to the clinic or sends health workers into the community. Given the presence of the MRC/UVRI Clinic, the delays outlined below are likely to be more severe in places where non-governmental organisations and research bodies do not offer subsidized care.

Two local facilitators conducted nine focus group discussions [FGDs] with older Ugandans living in the area. The authors used the MRC/UVRI GPC list as a sampling frame to draw participants aged 60-plus (Asiki et al., 2013). This list includes information on NCD diagnosis (as a result of recent surveys collecting information on these conditions) and HIV status. Table 1 shows the distribution of FGDs by gender and diagnosis. Each FGD had seven to eight participants and was held in a central and convenient location. Informed consent was obtained and each FGD participant received 10,000 Uganda shillings (\$3.70) as compensation. With assistance from the Project Manager (author), the FGD facilitators recorded and transcribed

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the FGDs. Transcripts omitted participants’ names and personal information. We also conducted nine Key Informant Interviews with health care workers and community leaders. In this paper, we focus on the perspective of older persons about their decisions to seek care, ability to reach care, and views of acquiring adequate care.

<TABLE 1 ABOUT HERE>

Analysis

In our thematic analysis, we searched across our dataset to find “repeated patterns of meaning” that reflect older Ugandans’ experiences, perceptions, and beliefs about health-care barriers (Braun & Clarke, 2006, 2013). We first carefully read every FGD transcript (Braun & Clarke, 2006). The lead author created memos on major themes that arose in each FGD and outlined the broader, focal themes related to participants’ financial, social, and physical wellbeing. The team reviewed these memos to develop the coding tree, build consensus around the major themes and assess their fit with the team’s contextual knowledge of the site. At this stage, barriers to care and the ways they delay older persons from seeking and accessing care emerged as a major issue, so the research team delineated the major themes and codes related to ‘delays to care’.

Next the lead author coded the FGD using the major themes, and developed additional lower-level codes using participants’ own language, noting outliers and areas of agreement and contestation among FGD participants. All of the codes related to barriers and delays to care, revealing themes clustered around timing and place, were collected in a separate document. The research team used this document to delineate Three-Delays to care and their related sub-themes. In discussion of the results, themes and sub-themes were combined, split, or dropped. Then, the research team defined the final model and mapped its alignment with the Three-Delay Model and

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the existing literature from Uganda, as well as where it extends current knowledge. Finally, we use the analysis to tell a fuller story of older persons’ perspectives of the complexities and challenges that they face in seeking, reaching and acquiring health care in rural Uganda. In the results section, focus groups are designated by number as well as whether with “M” for male or “F” for female, as well as diagnosis, “HIV” or “NCD”, or “Any” if no specified diagnosis.

Results

Our older Ugandan respondents could articulate the factors that impact their decisions to seek care and ability to do so, thus outlining the delays they face. Most decisions about seeking health care in this community occurred only after symptoms appeared and individuals began feeling unwell. Our respondents reported ailments ranging from “old age” aches and pains to symptoms of sexually transmitted infections (STIs) and formally diagnosed illnesses like ulcers, hypertension, and HIV. As men in one FGD said, “Lack of necessities in life and sicknesses such as malaria and pneumonia affect old people. Other sicknesses ... include back ache, painful legs and poor eye sight” (FGD9-MAny). Even though Level III health facilities aim to provide preventive care, our respondents rarely mentioned preventive care. Also, our respondents reported seeking informal medical care, such as collecting and boiling herbs, visiting traditional healers, and buying over-the-counter medicines at local shops. When asked where older persons go for treatment when they are ill, the majority named local and some more distant formal health-care facilities including village clinics, the MRC/UVRI clinic, government dispensaries, Level III Health Centers, private clinics, and hospitals. The results summarised in Figure 2 outline what delayed our respondents from seeking, reaching, and obtaining health services.

<FIGURE 2 ABOUT HERE>

Delay I: Deciding to seek care

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Deciding to seek care depends on individual conceptions about when it is appropriate to seek care, including ideas about illness such as severity, etiology, and stigma, and individual-level barriers such as mobility and financial limitations. In sub-Saharan Africa, some older persons seek informal care or traditional medicine because they believe an illness is not severe or its cause is not biological (Clausen, Sandberg, Ingstad, & Hjortdahl, 2000; Mulumba et al., 2014; Wandera, Kwagala, & Ntozi, 2015). Even when older persons consider an illness to be severe, they often report not seeking care because of poor access to health facilities (e.g., distance or cost), or poor quality of care (Ameh et al., 2014; Bovet et al., 2008; Mulumba et al., 2014; Wandera et al., 2015). In this way, decisions at Delay I are interrelated with factors related to Delays II and III, such as anticipated ability to reach services and quality of care.

Illness factors: Etiology, severity, and stigma. Etiology sometimes determined where and when participants sought care. Men in particular reported that an illness caused by witchcraft, usually as a result of jealousy among neighbors, was a reason to seek “local medicine” (FGD2-MNCD) rather than formal care at government or private health clinics (Nnko et al., 2015). In general, however, participants’ responses suggested that seeking informal or traditional medicine did not lead to good outcomes. One woman said, “there are some who think they have been bewitched (*amayembe*) then seek traditional healing and by the time they turn to health units, given tablets and injections, their lives are already wasted” (FGD6-FHIV).

Older persons also reported delaying care until an illness was considered severe. One man in the FGD of participants with NCDs explained, “By the time you see an old person is sick it means he had been sick for some long period. You can tell after observing that he spent days inside his house with the door to his house closed” (FGD2-MNCD). Aches and pains, dizziness,

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shortness of breath may not be deemed severe enough for older persons to seek care, and yet may portend the onset of NCDs.

Some illnesses have a stigma that led older persons to delay seeking care. Respondents reported “shyness” about having HIV or STI symptoms (e.g., gonorrhoea), which are perceived as “inappropriate” diseases for older people. In this context, participants seemed to use gonorrhoea and syphilis as catch-all terms for those diseases as well as some other, similar conditions. As one male FGD participant said, “Some old people are lazy to go for treatment, like those who would get gonorrhoea and remain with the sickness without reporting at the health center for treatment” (FGD7-MAny). Others in the group concurred, “Some old people hide to mention that they have AIDS and this is caused by shyness... They feel shy because of their age and think that people will laugh at them” (FGD7-MAny). Some respondents worried about fellow residents, whereas others worried about treatment by health workers. One older woman said sadly, “We even develop a habit of keeping silent about some illnesses... You say to yourself, ‘How shall I disclose such an illness to such a young health worker!’” (FGD8-FAny). Other respondents highlighted that other symptoms may carry the stigma of ‘old age’, one male respondent with an NCD said, “When you go to the health facility and explain to *basawo* [health worker] the way you are feeling, it could be painful joints, they just inform you that please *muzeyi* [old man/elder] you are suffering from old age. You get miserable and return home annoyed. If they give you drugs you can’t trust that the drugs they have given you will help to cure the problem you have presented to them because of the comment they made” (FDG2-MNCD).

Financial concerns and quality of care. Perceptions about the quality of care and financial concerns are important factors in Delay II and III, but respondents also identified both

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as key to their decision whether to seek care at all (Delay I). Respondents reported that although local government health centers provide free care, they sometimes decide not to seek care there because these centers can be hard to get to, the quality of care they deliver is uneven, or they often do not have the necessary drugs.

Most older participants said cost affected their decision to seek care. As one respondent said, “Poverty sometimes results in poor treatment seeking. You are poor to the extent that you don’t have what [you need] to pay at the health facility for treatment” (FGD5-FAny). Another respondent said, “The distance I [go on] foot is long and I cannot afford it! However, I force myself and come!” (FGD6-FHIV). The other participants in her FGD echoed this challenge. Even if initial care at a government health center is free, the possibility of additional follow-up costs affected participants’ decisions. One participant said, “Someone might fall sick with a disease that can be treated and when he goes to hospital they tell him to go and buy the medicine, yet he does not have money. He just forgets all about seeking care” (FGD3-MHIV). A number of participants complained about being asked to pay for treatment at government health centers. As men in one FGD related, “Even when you have gone to the government health facility where the services are free of charge, in actual sense when you reach in the examination room the nurse asks for money to attend to your problem... Failure to pay and s/he invites another patient and leaves you there or tells you to go away” (FGD3-MHIV). While many of our respondents reported that they eventually seek care when their illness is sufficiently severe, factors related to costs and expectations of quality impact their willingness to seek care earlier or as a preventive measure.

Delay II: Identifying and reaching medical facilities

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In our model, Delay II encompasses the ability to reach a health facility, which includes distance and travel time, the availability of transport, how weather might affect road conditions and travel, as well as community-level health and social services, and infrastructure. In a number of sub-Saharan African contexts, a key factor contributing to poor health-care access is individual and community poverty, specifically food insecurity, poor hygiene, poor sanitation, and lack of safe water (Mulumba et al., 2014; Wandera et al., 2015). These factors are clearly connected to health itself, but also can impact decisions about where, when and how to expend financial and physical resources. In addition, at older ages, physical disabilities, particularly those that restrict walking, lower one’s likelihood of accessing health care (Gómez-Olivé, Thorogood, Clark, Kahn, & Tollman, 2013; Wandera et al., 2015). Delay II factors capture how even once a decision is made that one *should* seek care, community-level factors, or the absence of community services, may impede reaching the right health facility.

Distance and transport. Despite being intentionally located close to the population they serve, the distance to government health centers is not always walkable, particularly for older persons with decreased mobility, strength, and energy. Lack of motorised transportation is an even more salient concern; participants said that, “older persons fail to seek treatment because of [not having money for transport]” (FGD4-MAny). Although men and women spoke differently about transportation challenges, both related it as a concern. Women were more likely than men to report difficulty walking the distance to the health center; one older woman said “[my] problem was to walk all the distance from home to the facility [about 2 miles] to access treatment” (FGD5-FAny). Another complained about the difficulty to “just move with that [leg] pain” even within the village to visit friends, so she “do[es] not seek treatment from any health unit” (FGD8-FAny). Even when older persons knew they needed to return to the health center

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for care for chronic conditions, they emphasized this issue, as one man with an NCD said, “Lack of transport to the health facility. The nurse might have told you to go back for a review but you can’t go back because you might be suffering from painful legs and not able to foot to the health facility” (FDG2-MNCD).

When the distance to a health center is too far for an older person to walk, they must take a motorbike or minivan taxi, and the cost of those options complicated reaching care. The average cost from someone’s home to the clinic is about 1000/-Uganda shillings (~USD 0.30). Given the endemic poverty in the area, this is a significant cost, a consideration when deciding to seek care, and potentially delays one from reaching care. In a FGD with older men living with HIV, the facilitator asked about challenges to accessing care. The group responded, “Transport.” The facilitator probed, “How is it a challenge?” One group member said, “I might not have either a bicycle or motorcycle to carry me to the health unit.” Another added, “The biggest challenge is lack of money, once you have money, you can access the best treatment” (FGD3-MHIV).

Men were more likely than women to mention using neighbors or children to facilitate a trip to the health center. One man said, “You might fall sick but when cooperating with your neighbor. He comes to you and says; ‘Mr. S you are sick but why do you not go to the health facility? You then tell him, do I have means to reach there? That is when he asks his son to collaborate with your son to get a bicycle and take you to the health unit” (FGD3-MHIV3). Another man said, “[If an older person's health deteriorates] friends come for rescue and take him to the health facility” (FGD9-MAny). However, not all men were able to request this type of assistance. As one man noted “Some [older persons] say we shall take *omululuuza* [herbs] for the time being. This is because they do not even happen to have money to transport them to the health facility” (FGD3-MHIV).

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In sum, out of nine focus groups, only one (7-MAny) did not mention transport or distance to health services as a major obstacle. When discussing transportation, study participants frequently cited MRC/UVRI’s assistance in the past with transport as a key reason for seeking care at that clinic (which is at the center of the 25 villages that make up the GPC, and therefore not in easy reach for many). However, respondents also said this was a reason that older people are less likely to seek care currently, “The challenge that when one does not have money or anyone to give him support and moreover the MRC clinic never gives us transport like it used to do” (FGD4-MAny).

Delay III: Receiving adequate and appropriate care

Delay III encompasses impediments to accessing quality and appropriate care that occur once an individual has reached a facility. These issues include facility waiting times, the response and care given by health workers, and the availability and cost of appropriate equipment and medication. Older Ugandans and older persons elsewhere in sub-Saharan Africa commonly complain about health workers’ ageism; they report that health workers “devalue” and neglect them because of their age (Ameh et al., 2014; Mulumba et al., 2014). In one study, older Ugandans reported “not being informed of their condition or not being provided with a diagnosis” (Mulumba et al., 2014). In addition, although public health facilities in Uganda are required to stock and supply medicines free of charge to patients, supplies are often deficient and patients lack funds to purchase the medications elsewhere (Mulumba et al., 2014).

Ageism. Health workers’ perceived ageism and their general mistreatment of older persons contributed to older Ugandans’ mistrust of health facilities. “When a sick old person reaches the health facility he gets excited hoping *musawo* [health worker] is going to attend to his problem but he gets depressed when *musawo* looks at him with a bad face” (FGD2-MNCD).

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In nearly every FGD, poor treatment was one of the most common issues raised. Respondents said health workers shouted, were rude, accused older people of wasting their time and taking medicine that should go to younger persons, and criticised older people for not hearing, understanding, or acting “properly.”

Although the FGD respondents said that health workers did not “abuse” them, stories about backbiting and shouting seem to refute this. For example, several respondents said that health workers were reluctant to treat older adults because their complaints were considered illegitimate. A woman who was sickly and unable to walk reported “being rebuked and blamed for old age by the health worker, that the pain I was feeling was due to that!” (FGD6-FHIV). In men’s FGDs, there were similar claims. One said a health worker asked him, “Shall we also attend and give care for old age? That is not sickness but old age!” (FGD4-MAny). He further explained that this made him think that health workers “do not regard the elderly as important and just want to give care only to young people!” (FGD4-MAny). A participant from another FGD, “went back very depressed and angry” after a health worker scolded, ““The number of times you have reported here, don’t you get tired of walking?! We don’t cure old age!””(FGD7-MAny). These data do not reveal what presentations health workers called ‘old age’, but it is very likely that at least some of the symptoms and complaints are connected to NCDs.

A further complaint was that health workers accused older people of not being worthwhile recipients of free medication. In one FGD, the men talked about health workers’ responses to them, saying ““You are just finishing/wasting our medicine! Your period (of survival) is over!”” (FGD3-MHIV). They explained that a comment like this “worries [older people] very much, they lose hope. The older person then begins to wonder if the medical staff believes that he is no longer fit to live anymore!” (FGD3-MHIV).

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Older people also spoke about being disrespected as elders and devalued as either uncooperative or unintelligent. Both men and women said that older people sometimes get scolded when they do not properly hear or follow protocol. “Dealing with patients is very complicated, they may call a patient’s name to enter the room. Because the old person never heard so well he comes nearer and the nurse shouts at him please go away and wait for your turn. The old person gets embarrassed and neglected. That makes him hate the facility and the nurse” (FGD9-MAny). In one FGD, a participant was asked if she ever got up to ask the health worker for help understanding what to do or when she would be called, with a frightened look she said, “I feared to do so!” (FDG8-FAny).

Confidentiality and stigma. Older persons’ ability to access care was also affected by perceived stigma and fears about confidentiality, both of which interfered with the relationship between older persons and health workers. Older persons reported being reluctant to communicate their use of traditional medicine, and they often kept silent about “embarrassing” symptoms. Older persons in several FGDs said they “do not inform the *basawo* [health workers] about using both western and herbal medicine fearing that they may refuse to give them medicines or ask several questions or quarrel” (FGD9-MAny). Some older adults living with HIV reported concerns about what information health workers would disclose to others. One group was asked, “Are there health workers that publicise one’s sickness?” They responded, “Yes they happen to be there, he [the health worker] says; ‘I have examined him and he has several illnesses!’ Even the person who would not have been aware of what you suffer from gets to know about it then he spreads the rumor about you!” (FGD3-MHIV).

Perhaps owing to stigma and the related fear of disclosure or being accused of seeking care for ‘old age’, older adults sometimes hide their symptoms and illnesses from health workers.

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Those with NCDs, as well as those with HIV, were reluctant to share information about their ailments, as one man suffering from an NCD shared, “Old people are not open about the sickness they are suffering from. Even when they report at the health center they hide the sickness disturbing them at the time, instead [they] talk about minor sickness and [do] not mention the serious one” (FGD2-MNCD). While this man may have been talking about NCD symptoms, other older adults reported being uncomfortable sharing information about sexuality and STIs with young health workers, particularly those of the opposite sex. One male FGD participant explained, “What made me unhappy was to ask me how many sexual partners I have had in life. It was a young woman who asked me that. Why not a man to ask me such?” (FGD7-MAny). Women made similar claims, “There is being asked sensitive questions and the health worker is younger when you already abstained or you are a widow! For us the elderly you feel shy to address such issues” (FGD8-FAny). Participants also reported receiving rude responses when they did reveal such symptoms.

Staffing, equipment, and drug supply. Many individuals said long waiting times at health centers deter them from accessing care. Many participants complained of waiting all day: “I recently went to [name] clinic and got card number 16 having arrived early at 6:00 am. The card was issued to me at 9:00 am but the most challenging experience was that I got the medicine at 4:00 pm” (FGD8-FAny). Although the MRC/UVRI clinic is technically free, participants identified time as a costly trade-off. One woman said, “I fear going to MRC clinic because you go there feeling so bad, they make you wait on the line so long and by the time the *musawo* [health worker] attends to you, you are already in a bad condition.” She went on to say if one has money, they choose another facility, “You go there, spend less time and return home” (FGD1-FNCD).

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Participants also identified lack of necessary drugs as a major obstacle to care at government clinics, which is a common complaint throughout sub-Saharan Africa. One male respondent said, “My friend was annoyed at receiving [only] two tablets, but for me I sat at the government for a day and when they reached my number they informed me that there were no drugs” (FGD7-MAny). For poor patients, the drug supply shortage at public health facilities compounds health-care costs. A man living with HIV outlined his frustration to his FGD, “Personally what annoys me is prescribing for you three types of drugs but then they issue to you one type and tell you that go and buy the other two types from a drug shop. The health workers have that habit yet you might not have money to buy it!” (FGD3-MHIV). Several other participants said high drug costs prevent them from receiving good care; a man with an NCD said: “Another problem old people face in accessing treatment is that of money. Possibly you went to the health facility with 1000/= hoping it will be enough, after examination had been done *musawo* [health worker] tells you that treatment requires 5000/= but you only have 1/5 of the required payments. Instead of a full dose they give you a quarter of the dose that will not help to cure the sickness. You go home and wait until you will die” (FGD2-MNCD).

Indeed, for many older adults, beliefs about the availability of subsidised drugs seemed to drive their choice of a health care facility. In one of the men’s FGDs a long discussion ensued that framed long waiting times as a trade-off for free medication; there was a general consensus that this was true: “[The] majority of the older persons turn to MRC clinic because of their [older persons’] low income since here medication is free of charge. The clinic sometimes becomes full of patients then one wishes he falls sick when he has money so as to have another alternative such as going to a private health unit!” (FGD4-MAny). The MRC/UVRI has a relatively consistent drug supply and staff members are more knowledgeable of NCDs. The clinic is one among

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a limited number of non-governmental/research clinics supported by foreign donors and thus able to provide free care, in Uganda and elsewhere in sub-Saharan Africa.

Implications

Although the Three-Delay Model has been primarily used to analyse the health profile of pregnant women and emergency medicine, the delays affecting older Ugandans’ decisions to seek care, ability to reach care, and acquiring quality care mirror those outlined in the model and make it useful as an analytic tool for this population. As in the original model, our Three Delays capture the temporal order of potential delays to older adults’ accessing care. Extensive interplay exists between delays, and past experiences influence future decisions. When deciding whether to seek care (Delay I), older Ugandans consider difficulty in reaching care (Delay II) or prior experience of inadequate treatment (Delay III). Older Ugandans’ own words and experiences reveal both concrete factors that lead to delays in seeking, reaching, and obtaining care, and these feedback loops. Delays to care are complex and impacted by factors at the individual, community and health system levels, thus interventions that address them must come at each of these levels.

The limited existing literature on older persons in sub-Saharan Africa suggests this group has limited access to health-care services and thus has poorer outcomes from NCDs, disability, and HIV (Bovet et al., 2008; Clausen et al., 2000; Droti, 2014; Gómez-Olivé et al., 2013; Mulumba et al., 2014; Scholten, Mugisha, et al., 2011; Wandera et al., 2015). Indeed, large percentages of older adults with chronic illnesses (43%-67%) have not received any health care in the past year (Bovet et al., 2008; Gómez-Olivé et al., 2013). As rates of both NCDs and HIV increase among older adults, we must understand better what delays older persons from accessing care in order to promote better access, diagnosis, and treatment adherence (Negin &

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Cumming, 2010). Using the results, we develop a model that identifies factors that contribute to these delays at multiple levels. This model provides the foundation for contemplating potential interventions that must address issues at the individual, community and health-system level.

Delay I concerns reveal important barriers that simply expanding health services will not address, such as the need to expand knowledge about symptoms and possible treatment, reduce stigma around particular illnesses and aging, and increase social support so that older persons can ask for assistance when they need it. Most older persons no longer work, often owing to illness. The lack of a social welfare program for older persons in this region of Uganda (Stewart et al., 2014) means they lack funds to pay for private health services, necessary drugs, or transportation to health facilities. Older persons report under-utilising formal care because they use informal care instead, or because they did not consider their illness or symptoms severe enough to seek care (Ameh et al., 2014; Bovet et al., 2008; Wandera et al., 2015). Thus, poor infrastructure and lack of affordable transportation not only make reaching health facilities difficult, they also affect the decision to seek care, that is, older persons may delay seeking care until an illness is sufficiently severe to spend the money or social capital for transportation to the health center.

Multiple studies show that older Africans’ beliefs about the etiology of the illness, which include socio-cultural beliefs, influence their decisions about when and where to seek treatment (Clausen et al., 2000; Nnko et al., 2015). In many African settings, the symptoms of HIV are seen as similar to the effects of breaking taboos or witchcraft (Ashforth, 2002; Buregyeya et al., 2011). In these communities, addressing beliefs about witchcraft and HIV stigma is necessary to improve older persons’ health-care access and treatment adherence (Kuteesa et al., 2012). Until recently, NCDs were not likely to be tested for or diagnosed, nor were their symptoms known to

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have biomedical etiology beyond ‘old age’. In this way suffering from NCDs, perhaps even more than HIV, may be associated with ‘suffering from old age’, which was seen as untreatable, an idea reinforced by health care workers, and thus older persons are reluctant to seek care for such ailments.

The issues raised under Delay II suggest the importance of community infrastructure interventions to improve older adults’ health, such as better roads, and perhaps more community social services to provide information about NCD risk factors, as well as linking older persons with health facilities on a more regular basis. Investing in infrastructure would improve older persons’ access to health services without reducing their financial and social capital, and additional services in rural areas, where most older adults live, would eliminate the need for long travel to urban areas (Stewart et al., 2014). For older Ugandans, among whom disability and restricted mobility are likely to be higher than in the general population, poor roads, long travel times, and unavailable or costly transport are particularly important delays to accessing health care (Wandera et al., 2015). Older persons with chronic conditions (e.g. arthritis, high blood pressure, and diabetes), which may both impact mobility and increase the need for regular medical care, might not be capable of traveling by foot even relatively short distances due to shortness of breath, swollen joints, or tiredness. In addition, older persons are much less likely than children to be able to be carried by their carers. Thus, the distance to health services, compounded by the need to make regular trips for chronic care treatment, may exacerbate the importance of transportation to delays to accessing care. There may be an additional gender component, as women in our study highlighted the lack of social networks on which to draw for assistance with reaching health facilities.

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Delay III factors draw attention to health-system interventions needed to improve older persons’ access to quality care. Increasing health workers’ knowledge of older persons’ experiences, needs, and common illnesses might decrease conflicts between health workers and patients and increase older persons’ desire to seek care when they need it. Also, many of our respondents complained about the costs at government health centers and hospitals, particularly for drugs they had to purchase elsewhere. The MRC/UVRI Clinic compared to government clinics has a consistent, free drug supply (Asiki et al., 2013). However, the MRC/UVRI clinic does not reach the majority of people in the GPC, for the reasons set out above. However, because of its existence the findings from our FGDs may underestimate the impact of the factors related to Delay II and III. To improve older Ugandans’ health, the government health system must improve staff training and create more efficient supply systems.

Because we capture a number of issues at the health-system level, there are other conceptual frameworks related to access that may be relevant, e.g. Obrist et al.’s (2007) 5A’s (5 dimensions of Access) model among them. The delays—particularly the issues raised under Delay I—seem to provide a better framework for understanding not just the Availability, Accessibility, Affordability, Adequacy and Acceptability of access, but also the socio-cultural aspects of personal considerations around the decision to seek care at all, and the ways that the community may facilitate or hamper care.

As, Level III government health centers available to older adults have historically focused on maternal and child health, with a more recent focus on HIV services, they may need to be retooled to appreciate and address older adults’ health concerns. This focus might exacerbate older persons’ difficulty reporting symptoms of “young person’s diseases” (Moreira et al., 2005) or accessing care for what is viewed as symptoms of “old age”. Our research

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confirms that older persons see some of their inability to access quality care as connected to the lack of health care workers with geriatric specialty training, and that government health facilities do not necessarily provide the types of services, drug supply, or staff trained to treat older persons’ needs (Mulumba et al., 2014; Wandera et al., 2015).

Our study adds new information about older adults’ fear about disclosing symptoms and illnesses to community members and health workers delayed them from seeking care. Hiding pertinent information can delay access to adequate care and reduce the quality of care older people receive (Moreira et al., 2005); this can have important negative implications for both HIV and NCD care. According to our participants, being treated badly or feeling devalued by health workers leads to older people isolating themselves, becoming discouraged and depressed, and being less likely to return for future care.

Older persons need consistent, high-quality health care so they can monitor changes in their health, learn about preventive measures, and access the medicine and treatment they need. For those with chronic conditions, particularly NCDs like hypertension and diabetes, as well as HIV and TB, retaining patients in care is key to managing their condition. When multi-morbidity exists, it is extremely important to integrate services across diseases, and ensure chronic care and supervision. If older persons delay seeking care, have challenges reaching care, or are dissatisfied with care, they are less likely to be seen regularly. Without regular, high-quality care, older adults may be more likely to develop disabilities or be in a severe phase of an illness when they do reach care. At the severe stages of illness, illness management becomes more difficult and treatment less beneficial (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004; Goudge, Gilson, Russell, Gumede, & Mills, 2009). Effectively combating the delays preventing older persons from receiving care requires integrated interventions at the individual/family level, the

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community level, and health-system level. Looking ahead, the authors will move this work forward by using the research discussed here as the basis for a locally sustainable, multipronged intervention to reduce the delays in older Ugandans’ decisions to seek, reach, or acquire quality care, with the ultimate aim of improving their health and wellbeing.

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Table 1. FGDs by sex and diagnosis (HIV/NCD)

	Living with HIV	Diagnosed NCD	No specific diagnosis	Total by sex
Men 60-plus	1	1	3	5
Women 60-plus	1	1	2	4
Total by diagnosis	2	2	5	9

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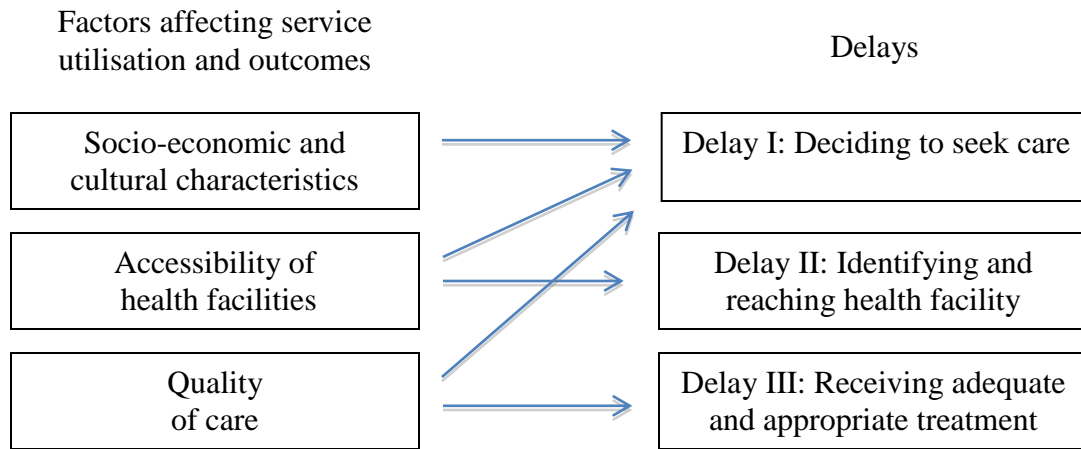


Figure 1. Three-delay model in gerontological care

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	Delay I: Seeking Care	Delay II: Reaching care	Delay III: Receiving appropriate & adequate care
Patient Factors	<ul style="list-style-type: none"> • Stigma of particular types of illnesses • Belief about etiology • Perceived severity of illness 	<ul style="list-style-type: none"> • Mobility • Access to transportation • Family/social support & networks 	<ul style="list-style-type: none"> • Stigma/embarrassed to share symptoms • Cost of care, drugs
Community factors	<ul style="list-style-type: none"> • Stigma/ageism within community • Transportation 	<ul style="list-style-type: none"> • Distance to services • Community transportation infrastructure • Weather and seasonal considerations 	<ul style="list-style-type: none"> • Fear of lack of confidentiality
Health system factors	<ul style="list-style-type: none"> • Beliefs about treatment costs & quality of care • Stigma/ageism by health care staff 	<ul style="list-style-type: none"> • Quality/ specialization of nearby services 	<ul style="list-style-type: none"> • Ageism/abuse by staff • Staff availability, competency • Lack of equipment • Poor drug supply

Figure 2. Three-delay model for older Ugandans’ barriers to health care