Forsaking treatment and enduring the status: Ageing into a disability

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Abstract. This article explores the process(es) through which people age into and experience disabilities. It focuses on acquired disabilities among older persons in rural areas of Wakiso district in Uganda. The cases presented reveal the complexities involved in seeking and accessing health care for older persons, and ultimately how it all contributes to the disablement process. It further highlights the fact that what characterizes the disablement process of older persons goes beyond diseases, and includes the decision-making process which affects the treatment seeking journey, especially on whether to seek treatment or not, and when this is to be ceased. The article draws from a qualitative study on ageing and disability in Uganda, in which 30 older persons were interviewed in their homes. The paper's original contribution and emphasis is that of what characterizes the disablement process of older persons, which goes beyond diseases and other environmental factors to include perceptions and decisions of older persons as well as their significant other(s) especially in seeking treatment.

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Introduction

Disability debates have pointed to the contribution of both the impairment and the social environment to the disablement of individuals (Oliver, 2013; Regler, 2018; Whyte & Ingstad, 1995). The treatment seeking process is part of the social environment that significantly contributes to the disablement of the older person. The two cases shown in this paper, seeks to delineate how the decision on whether and when to seek treatment for the older person is commonly a function of many actors within and outside the family. These decision-making processes are influenced by several factors including infrastructural challenges, available care arrangements, as well as availability or absence of financial resources (Ssengoba, 2010). It is evident that bio-medical causes account for old age disabilities, because of the general belief that old age brings about decline in health and functional ability (Kowal et al., 2010). However, this paper will go beyond the attribution of bio-medical causes to disabilities in old age, and analyze other social factors related to the decision to take or ignore treatment of bio-medical conditions, that underline this process and journey into a disability. It is argued that what characterizes the disablement process of older persons goes beyond diseases, but factor in the decisions made during events of injuries and the treatment seeking journey, especially on whether to seek treatment or not, and when to stop. Understanding the process that leads to disability among older persons is important in designing appropriate interventions. However, there is inadequate information on the profile of disability among the older persons.

In order to answer the key question of how older people age into and experience disability, this paper, presents two (2) cases: The first case is about how Nabanja was hit by a banana plant, from which she acquired a mobility impairment and how she maneuvered her treatment seeking process. The second story illustrates some of the participants whose journey was followed when seeking treatment. Besides the above two accounts, other statements and examples are explored revealing similar experiences from other respondents, to support the main arguments of this paper. The paper attempts to break down the journey that led to disability in the lives of the participants, older persons, between the age of 60 to 95 who formed part of this study. This shows how older persons maneuver the treatment seeking journey and how that shapes, their experiences of ageing into disability. Subsequently, this paper highlights the importance of understanding the events that characterize the transition from health to disability among older persons.

Case one: Nabanja and her treatment seeking journey

When you meet Nabanja for the first time, you cannot miss her sparkling grey hair and her dark glaring and humorless face. Nabanja has little recollection of the year she was born, but she estimates her age to be somewhere past 80. She lives in a well-built iron roofed 2-bedroom house in Sumbwe, a rural village in Wakiso. She claims to have built the house from her own income she got from the sale of part of her land where the house is now located. Nabanja lives alone at night in the house but during day, one of her great granddaughters aged 25 years old, comes around to help her with house chores such as washing clothes, cleaning the house and sometimes cooking.

Nabanja narrates that in the year 2015 while in her garden behind the house a banana stem that she was cutting hit her back, causing her to fall and broke her leg. *This is when my life started changing*," explains Nabanja. She was taken to Mulago, a National referral hospital in Kampala for treatment. She was told by the doctors, that she needed surgery that would cost her a minimum of 2.5 million Uganda Shillings (approximately 800 dollars). Unfortunately, Nabanja did not have that amount of money and decided to leave the hospital and went to her son`s home to be taken care of temporarily. Nabanja narrates that the pain increased, and her son contacted a traditional herbalist in that area who started treating Nabanja with herbs, rubbing them on her back, the broken leg and wherever she felt the pain. Although the treatment from the herbalist gave her some relief, Nabanja says she did not heal and could not walk. On realizing that she was not likely to get better soon, Nabanja asked her son to return her to her house in Sumbwe. In her home, Nabanja continued to use both the herbal medicine and painkillers bought from a nearby drug shop. By the time we met again in August 2017, Nabanja had stopped using the drugs from hospital because she felt her children were spending a lot of money and she did not realize much improvement in her health, but acknowledged that the pain had reduced to a great extent.

> I didn't see any reason why my children should spend that much! They have young children to take care of! Me I am aged now! I decided to come back to my house and die from here.

Desirous to walk again, Nabanja sent her granddaughter to ask a nearby carpenter to make for her a pair of walking sticks, but she was unfortunately unable to use the walking sticks. The sticks did not provide enough support that she needed. She then asked the carpenter to instead make under arm crutches. Sadly, Nabanja realized that she might not be able to use the crutches either, as she could hardly support herself to stand and walk with them. This is when she resorted to crawling as the best option. Ever since the accident, Nabanja never regained her full functioning and performance of everyday chores and she narrates:

> When I realized that I might not be able to do my work the way I used to, I called my granddaughter with her husband, and I asked the husband if he could allow my granddaughter to come and help me at home sometimes. Her husband agreed. Now my granddaughter comes here almost daily and helps me with house chores. She helps me particularly to wash clothes, clean the house and other chores. Most times I cook for myself if she can bring the food near here. The good thing, as soon as I built this house, I planted gasiya, (a type of tree) from which I get firewood to cook. After buying for me food, it would be too much asking my children to buy firewood as well. So, I had to find an alternative source (conversation with Nabanja, November 2016).

Ten months later, Nabanja was visited again by the research team and found her in a frailer state. She could not do any work by herself anymore. She could not even see clearly. In her own words, the only thing she did was to, *sit and eat*.

Looking at this story, Nabanja acquired her impairment from an accident of a falling banana plant during her everyday work. When the attempts to seek treatment turned out to be futile, coupled with her perception about her ageing body, the views of the significant others, the

impairment became a permanent state of her body, and ultimately qualifies her to a state of disability.

Case two: Mutumba, Mariam and Namusoke; Manoeuvring the treatment seeking journey

As a moral ethic, the research team made some efforts to support some of the participants to access health care during the study period. Overwhelmed by the appalling health situation, the pain, unpleasant odour in some of the houses, (as the majority of older people with disabilities could not take themselves to the latrine anymore), left the research team distraught and sometimes saddened. This aspect of the research process many at times proved challenging to continue the fieldwork. One of the study team members, an orthopaedic surgeon, offered to give treatment at no cost to some of the old people that we thought were in dire need of urgent health care. With gratitude, the research team reflected through our participants and approached three of them: Mutumba, Mariam (Mutumba's wife), and Namusoke, whom we thought most needed urgent health care.

Mutumba`s two lower limbs were both broken when a cyclist knocked him down. In our first interaction, Mutumba informed us that he was taken to hospital and the doctor recommended a surgery whose financial cost was unaffordable for them as a family. Mutumba's wife, Mariam disclosed how the doctors had also advised that he was too old for such a major surgery. Mariam had a stroke that paralyzed her right-hand side. Namusoke had suffered from a swollen leg that was quite painful and to what cause she had not established yet, but was suspicious that her neighbours were not happy with her progress as she had one of her children working in UK, so this could have caused this problem to her by bewitching her.

Thinking of how to bring them to the health facility was quite a challenge. All of them ideally needed a caretaker to come along with and could not easily use public transport, given the pain and their immobility. So, the research team had to organize private means of transport. Mutumba needed to be lifted in and out of the car. The physical distances between the two homes was also quite long. Namusoke lived completely in a different sub-county from Mutumba and his wife. Moreover, it was preferred to take the three of them at once, at least for the first visit, to the orthopedic surgeon.

Namusoke lived close to the road and was agreed, that Namusoke`s caretaker should bring her to the hospital. Mutumba and his wife were to be picked up by the research team from their home, this was done with support from their grandson and our research assistants who lifted him into the car.

To the research team surprise, Namusoke did not show up, although money for transportation was provided to her caretaker. When Namusoke's neighbor was called to find out what had happened, she explained that they failed to walk up to the taxi stage (about 300 meters from the home). On the other hand, Mutumba and his wife was so pleased to visit a doctor. Mariam was recommended for physiotherapy, which ideally is supposed to be a free service provided at this government referral hospital. However, such services could hardly be reached free of charge. The research team often had to part with some small amount of money every week

for her to get the physiotherapy treatment. After about two months, Mariam registered a tremendous improvement in her mobility. She was able to move slightly faster and a few times without a walking stick, which was an exciting moment for her and the research team.

After living with a lot of pain and on pain killers for a long time (when he got them), Mutumba too was so pleased to meet the Orthopedic Surgeon. Mutumba is generally a very happy man, and he was over delighted when he entered the doctor`s room. We were touched by his expressions; *Who am I to see a big doctor, a real doctor, one so kind to touch a person like me*. He asked the doctor to close his eyes for a prayer that he himself made. In his prayer, Mutumba thanked God for such a kind doctor who even remembered and cared for old people. Based on the results of the x-rays which Mutumba did that same day, the doctor recommended surgery for both Mutumba's limbs, one at a time. Although the doctor was willing to offer the surgery for free there were other medical supplies requirements that needed to be bought, which was agreed to be provided by the research team. When this news was communicated with Mutumba's daughter (who lives in a distant district), she was hesitant to the surgery. Her concern was that no one would be available to take care of him while in hospital (In Uganda, normally when one is hospitalized, they will need a caretaker to stay with them in hospital to attend to them). She explained that she lived far from them, had a big family to take care of at home and there would be no one to care for Mutumba if he was to receive surgery. Mutumba seemed disappointed but accepted her decision.

Context and methods

This paper is part of a bigger study on disability and technology by a group of researchers who focused on the complex interaction of people experiencing disability and assistive technologies in Uganda and Switzerland. This component of the study was conducted in Wakiso District in the Central region of Uganda. The field work was done for a period of 10 months, in two phases; the first phase was in August 2016 to January 2017 and the second in August 2017 to December 2017.

Wakiso is a predominantly rural area. We worked with Village Health Teams as entry points, to identify old people who had mobility impairments in the villages in Wakiso district. VHTs are locally trained health volunteers in Uganda, that were introduced in Uganda's healthcare system by the Ministry of Health through the National Health Policy and Health Sector Strategic Plan in the year 2003 and are managed at the village level, to help increase the uptake of health services in communities (Nakigudde, 2011a). Since then, VHTs are being used to support several community-based health initiatives in the country and are thus familiar with residents in their areas. The paper may not give a comprehensive picture of the life of all older people in Uganda, neither does it portray a full picture of life with a disability in Uganda, but it describes the local situation lived by some older persons who have acquired impairments especially along their life journey or during old age.

There is an upward trend of older persons with disabilities in Uganda, in 2006, the Uganda National Household Survey estimated that, over 40% of people above 60 years have had at least some difficulty in functional areas such as hearing, seeing and other physical

disabilities(Uganda Bureau of Statistics (UBOS), 2006). In 2012, the Demographic and Health Survey estimated the number to have increased to 66.8% (Uganda Bureau of Statistics (UBOS), 2012). More people are living longer due to reduction in mortality rates, advancement in technology and health care (World Health Organization (WHO), 2015)

Wakiso district population was estimated to be over 2 million people during the 2012 population census, accounting for about 6% of the total national population (Uganda Bureau of Statistics (UBOS), 2013). Of the district population, 2.3% are older persons (60 years and above), while 53% of these have disabilities (Uganda Bureau of Statistics (UBOS), 2017). In terms of administrative structures, Wakiso has 17 sub counties, 153 parishes and 188 villages. The study was specifically conducted in 2 sub counties of Makindye Ssabagabo and Wakiso sub counties. While the biggest part of the district is semi-urban, with characteristics of urban, densely populated areas, suburbs, and with petty trading, it also has rural areas with small and scattered settlements that are predominantly agricultural with less or absence of developed infrastructure such as public means of transport and other social services.

In this paper, materials have been obtained from the qualitative part of the study, which involved 30 older people, comprising of 11 males and 19 females. We conducted at least two visits to each of the 30 respondents in their homes and some were visited more than 3 times within a period of 10 months. In-depth interviews, observations and informal conversations were held during these visits. All respondents were in the age range of 60 to 95 years and data was collected in their home settings. It is important to note that older people in Uganda predominantly age at home.

Ethical clearance was obtained from the Makerere University School of Medicine Institutional Review Board (IRB), and approval was secured from the Uganda National Council of Science and Technology (UNCST). Prior to interviews and observations, consent was obtained from participants. For purpose of protecting the identity of participants, pseudo names were assigned.

All interviews were audio recorded, and later transcribed and analyzed using the thematic content analysis (Graneheim & Lundman, 2004). Themes from each section are highlighted to form some of the arguments and then used to describe the meaning and significance of experiences in ageing and the use of assistive technologies.

Discussion

A step by step in the disablement process

Deciding to seek treatment and manoeuvring the treatment seeking journey

The accounts presented reveal the common difficulties older people find in accessing treatment. Manoeuvring the public transport system, getting attention when they visit health facilities, and meeting the financial needs that come with seeking treatment are almost impossible for many older persons especially in rural areas of Uganda.

Observations reveal that older people acquired the impairment either due to sickness or accidents. In many cases, episodes of sickness and accidents followed by seeking treatment over a series of steps over a given period. The treatment seeking process that many participants went through and continue to go through, is a nonlinear process, but one characterized by alternations in treatment options and making decisions time and time again. The decision by the older person to seek treatment often involves significant others such as children, grandchildren, neighbours and other community members. What Janzen refers to as therapy management group, a common practice in many African societies (Janzen, 1987). When and where to go and how long to stay on treatment or when to stop, are always the issues at stake, with multiple challenges including the difficulties of manoeuvring the infrastructure at the health centres, long queues and having to wait at the health centre as well as the uncertainty of one's ability to afford health care.

As shown in the case of treatment seeking for Mutumba, Miriam and Namusoke, treatment seeking decisions are made complex by general infrastructure challenges including poor roads and unreliable mode of transport. In rural areas of Uganda in particular, accessing health care is a challenge for everyone but is much more difficult for older persons. The Uganda National Household Survey of 2012/13 indicates an average distance to a government hospital in rural areas as being 7.6 km and 3.4 km for lower government health facilities (Uganda Bureau of Statistics (UBOS), 2014). Older people with impairments and mobility difficulties, and without private means of transport can hardly manoeuvre to find their way to these distant health facilities. Moreover, as in the case for Mutumba, most older persons either live alone or with a spouse who is most often also of old age and frail or have grandchildren that are often young. They often need support from an adult, for instance a son or daughter who would be living in another area or district, especially when requiring assistance in visiting a health facility. During this study alone, different people had to be mobilized for support, where the research team had to make use of a private vehicle to take Mutumba and his wife for medical treatment. It thus must be a responsibility of either their son or daughter to arrange and take their old parent to a health facility. Given the mobility problems faced by older persons, seeking care sometimes also entails hiring or borrowing a private car, making the process rather expensive.

It is not only challenging for older persons to reach the health care facilities, but it is also an intricate process to receive services. Most health facilities in Uganda are characterized by congestion and a long waiting process. Standing in long queues for hours completely disadvantages older persons. Moreover, at some facilities the infrastructure is inadequate, such as absence of ramps or rails, a matter which reportedly renders accessing the facility difficult for the older person (Ssengooba, 2010). On the other hand, inadequacy in staffing usually means that people literally must struggle to get enough attention from a health worker in public health centres. According to Africa Health, there was a very low doctor to patient ratio: for every 24,725 patients, there was 1 doctor, and for every 11,000 patients there was 1 nurse (AfricaHealth, 2017). Moreover, the World Health Organization recommends one physician per 1,000 people (World Health Organisation (WHO), n.d). With this situation, the quality of care, particularly in terms of time spent regarding health personnel-patient interaction is often poor. It is perhaps for this reason and his experience that Mutumba was

surprised when he received close and warm attention from the orthopaedic surgeon when we took him to the hospital.

Affordability of treatment is another issue at stake. Old age has been reported to be one of the leading causes of individual poverty in Uganda and chronic poverty among older persons in Uganda has been attributed to unemployment, and persistent ill health. 88% of Uganda's population live in rural areas (UBOS, 2014) with older persons and other vulnerable groups constituting a significant fraction of this figure (Wandera, Ddumba, Akinyemi, Adedini, & Odimegwu, 2017). This means that their access to services, including quality medical services even with the capacity to pay, is technically limited (Ssengoba, 2010). The health budgets do not specifically spell out health-related needs for older persons and there is no health insurance schemes for such vulnerable categories of people (ibid.). Mutumba, his wife and Namusoke could evidently not afford to pay for the costly healthcare services if private transport to the health center was a challenge itself. There were instances when the children of older persons could raise the required amount of money, but some older people themselves did not want their children to incur such a cost for the surgery. They instead opt out as was the case of Nabanja who opted out of the surgery plans that was to cost her 2.5 million Uganda shillings.

From our interaction with older persons in this study, several of them would get fatigued with having to look for money to pay for medicines at drug stores, while others, their children often living far would take very long to come to pay for the drug debts. When the debts accumulate it makes the older person uncomfortable and they tend to give up, and they instead opt to endure the pain and discomfort of their illness or disability. Other older people just get frustrated when symptoms do not seem to reduce despite taking lots of medicines for a long time. While for others it is the difficulties involved in their mobility for the regular refill when the medicines run-out. Mutumba`s grandchildren for example, would pick drugs from the drug seller near their home who was supplying the cream painkiller that Mutumba used. Later, his daughter who lives about 120km away would come after some months and pay for the medicine. However, when the debt accumulated, he stopped. Mutumba however, often requested the research team to buy pain killer cream for him, which he said gave him great relief whenever he had it. Considering all the above challenges, often, giving up was almost the easiest option for many of the older people.

After going through a series of treatment seeking options together with their related challenges, it was noticed that many older people often abandoned or stopped using any kind of treatment for their illness, sickness or impairment. Sometimes it is the older person and other times, like the case of Mutumba, it is the members of the treatment group who take the decision. For example, Mutumba did not undergo the recommended surgery because of the decision made by his daughter. From our observation, older people are often kept on painkillers or antibiotics or sometimes both. And to sustain these, those responsible for the treatment also opt for local sources of these medicines in the treatment circle. Drug sellers also try and make sure that they stock such drugs for clients. Most importantly, many a times they also provide on credit when the family has no money but need the drugs. Therefore, befriending this new partner in treatment was often important for these families.

Among our participants, abandoning was especially common for medicines and treatment from hospitals due to costs and distance. This is followed by medicine from drug shops due to financial costs and sometimes-traditional herbal medicines would be resorted to. Often older persons combined the use of both traditional and western medicine and would retain the former after abandoning western medicine.

Perception of self and by others: Too old to treat?

For many of the participants, if one had fallen and broken their limb(s), they were sometimes informed that they needed surgery, but were too old for the procedure, and would take a very long time to heal. 16 of the 30 participants had been informed that they had fractures and needed surgery. Only 2 of them had been operated whilst the other 14 could not, either because the financial cost that was too high, or they were advised that due to their age recovery would take a long course. The common medication given to this category was painkillers and antibiotics. Apart from being told by health workers that they were too old to be operated on, the story of Mutumba also reveals that this perception of being too old for a surgery was equally a result of a negotiation process that both the older person and their caretakers went through.

The *othering* of people with disabilities (Reid-Cunningham, 2009) seems to apply to older people too, specifically older people with disabilities, this is experienced especially when it comes to treatment decisions. In the case of older people in this study however, they do not seem to only be *othered* by other people, but by themselves as well. During this study, it was not uncommon for an older person to decide to quit treatment because they thought it was too expensive for their caretakers compared to what they considered to be their own value given their age! This kind of stigma and *othering* of the older person on themselves and by their significant others greatly influenced the treatment decisions and their life thereafter.

Another part of the negotiation process was the question of whether to treat the condition as either old age, sickness or disability. The answer to this question is seen to have informed or influenced the treatment decision. During the interaction with the participants, it became apparent that there was a negotiation on whether one perceived or should perceive their condition as old age or disability. Whereas the World Health Organisation argues that old age is the leading cause of disabilities(World Health Organization (WHO), 2011), participants seemed to have differing opinions. Some thought that disabilities made them seem older than they actually were, while others argued that the two were quite distinct. One of our respondents, Nsereko said: *Old age does not bring disabilities. However, by having this disability, you cannot do anything for yourself, you just sit, day after day, and year after year, so you become elderly* (Interview with Nsereko, September 2017).

Another participant Ms. Kiwanuka, narrated the following:

> My daughter now let me teach you this; old age is old age, and disability is disability. People who are like me in age, what they have is not a disability, but they are simply old.

> People who got accidents when they are young, or people who are born crippled or with a serious impairment are the disabled, and these two are different (Interview with Kiwanuka's wife, October 2017)

Self-perception as either disabled, old or sick greatly influenced the responses of the participants, on whether one continued treatment or tried to use mobility aids to support their movement or did nothing about their situation. Self-perception and the perceptions by significant others involved in the treatment seeking process greatly influenced the decisions to seek treatment and adhere to it or not. It further influenced the nature of treatment sought for and provided, for example, whether one went for and received surgery, or had to survive on painkillers or even completely give up treatment, all of which shaping the day to day realities and experiences of older persons. Certainly, other practicalities such as the availability of caretakers also mattered. Many older persons also expected their energy levels to reduce as they age, and therefore their ambitions to restore their mobility and become active again greatly diminished. This means that disability was kind of expected in the *ageing culture*! Cultural relativity of disability has had a profound influence on the treatment of people with disabilities over time (Reid-Cunningham, 2009), but it's now important to note how this cultural relativity also has a profound influence on how older persons themselves deal with their condition and outcomes.

Consulting, asking and seeking for spiritual explanations

From our observations, older persons do not simply resign and accept their conditions, but try to make sense of their situations, the new mobility and health status and bodily changes. Many of the participants sought explanations for their situation and resorted to spiritual issues like God's plan for their lives or witchcraft. Receiving explanations from the health workers on the condition or illness were not always enough. Many continued to seek explanations for their conditions from other sources including diviners. This does not mean that they were seeking for a cure to these conditions but simply seeking for an explanation of what and why it happened - what Susan Whyte refers to it as "*asking*", while writing about the Nyole in Eastern Uganda in their response to adversity when they doubted why (Whyte, 1997). While several of our participants at this stage of their disablement process doubted if they will ever get a cure, they kept trying to understand their condition.

Older people like Nabanja would consult traditional herbalists or healers from whom they often got explanations like a neighbor or someone in the family might have caused their condition, because they were jealousy of something in the older person's life. Common grounds for jealousy reported were for example, if the older person had a child or children abroad, then one of the family members or a neighbor would feel jealousy and had done something to harm and cause unceasing pain to the older person.

God's will. This was often resorted to by some of our participants when there seemed to be no cure coming forth. Therefore, the individual referred to it as God`s will upon their lives and that God destined that this would happen and he (God) knows what is to come next. Although some of participants looked at it as simply God`s will that they would be in such a

situation, others still held on to the hopes that God would one day do something to rectify the situation. While others simply said they waited upon God to do whatever he deemed best for them. Nsereko, one of the participants, saw nothing outside God. This is depicted in his perception and belief in father Ngobya, a Catholic priest who died. Nsereko believes that father Ngobya protected him every day. Jaaja Mulokole *(*her nick name given by members of her community, literally meaning old grandmother*)* 60 years, who could neither walk nor stand but instead crawls in her house, still holds on to the hope that one-day God will decide that she should walk again and she believes that once this day comes, she will surely walk. Cherishing that hope, she always endeavors to tell her neighbors and everyone about God and asks them to believe in God. Because she cannot walk to go and talk to the people, she writes a scripture on her door every morning to tell her neighbors and by-passers about her God. The lack of knowledge on what old age will or might bring, leaves a lot of unanswered questions and a quest for answers on the changing bodies as well as health status of older persons.

Transiting from sickness, to old age and to disability

The social model of disability looks at disability as an interaction between the individual having the impairment and their environment, not the impairment itself. The model tries to explain that beyond disease and impairment, there are other environmental factors that do influence and cause disability (Oliver, 2013). Although this is also evident from this study, findings further reveal that individuals negotiated the environment and made significant decisions that ultimately contributed to their disablement.

After the point of seeking for treatment, often discussions among them or their neighbors and friends turned from asking them about how they are "feeling with the illness" (*oli otya obulwadde?* as often asked in Luganda) to how they are "with the weakness-that results from illness" (*oli otya obugonvu?*). *Obulwadde* is illness, sickness or disease in Luganda (language spoken in central Uganda), and *obugonvu* can be described as the body weakness that results from sickness. In this state, an individual is not yet perfectly healthy, but recovering from the sickness. The term is commonly used for and by older people in reference to their ill health. It was common for instance to greet an older person and in response he or she would say "*gyetuli tuli bagonvu*" literary meaning, *we are there, and we are weak (bagonvu)* and this could continue until the point when no more treatment is sought and "disability" as a category is claimed and taken on by the individual.

It is important to note that the above process does not reflect a linear model through which disability is acquired by the older person as presented by the disablement model by the International Classification of Impairments, Disabilities and Handicaps ICIDH (World Health Organization (WHO), 1980). The disabling conditions do not take place in a sequential manner neither do the people`s responses to it. Older persons went on treating one symptom after another, from one treatment method to another, until a cure could not be found or perceived as difficult or impossible, and then at this point, individuals resorted to God`s will, which in their view could not be changed by a human being but only God.

Various studies carried out in African settings suggest that traditional medical treatment is common especially at the onset of the disability, and moreover disabilities are treated as illness (Shuttleworth & Kasnitz, 2006). Helander (1995) argued that there is lack of clarity on the bio-medical view where a disability is presented as a disease, but this is understandable as many of the disabling conditions start as disease. However, as seen earlier, even when treatment is sought, sometimes it not received or received but abandoned along the way.

The decision not to give the deserving treatment such as surgery to an older person was a complex one, and presented difficult ethical dilemmas, not only for the family, older person themselves but for health workers as well. Health workers often had to make difficult decisions on whether and how to treat the older person within a context of stiff competition for the inadequate medical resources as well as contemplating the health complications associated with the patients' age. Such decisions were almost a compromise unconsciously reached by the various parties involved in these scenarios, including: the state that has not provided sufficient access to health care for the older person; the health worker who is weighing the available resources on one hand and the likelihood of the healing process taking longer for the older patient on the other hand. Sometimes it is the relatives and children of the older person who could not afford to pay for health care or provide the physical care. As noted by Eeuwijk (2014) growing old and old age are significantly shaped by the provision or lack of care. In some countries in Africa such as Ghana, existing practices of adolescent fosterage, in which more extended and poverty-stricken relatives whose children would otherwise not continue their schooling, are called up to help provide care for older persons in exchange of school fees, or promise an apprenticeship after some years of service (Coe, 2018). Such arrangements although do exist in several homes of elderly people in Uganda, are still unreliable for several reasons primarily that many older people reside in rural areas where there are no schools nearby, and informal care providers might not stay long and these keep changing since the relationships are not based on any formal arrangements making it slippery.

The older person, considering all the above, weighs between what they consider a huge cost for their health care on one hand, and how many more years they anticipate living as well as the inconveniences of the healing process on the other. Studies in palliative care in various parts of Africa have revealed that often times the expectations, perception and attitudes of people towards death and dying do have multiple implications for care (Buhl, 2019). Behind every abandonment of treatment therefore, there was an aspect of frustration with the treatment seemingly not being effective, or treatment seeking being of inconvenience either due to cost, distance of absence of caretakers. Such treatment seeking process further complicates the experience and can propel the older person's disabling condition.

Because the perception of several older persons was that neighbours and other people's jealousy accounted for these accidents, falls, diseases and ultimately the impairments that they experienced, *consulting* and *asking* was a common phenomenon. As noted earlier, consulting and going to ask was not so much of seeking cure for the impairment or disability but rather helping them to understand the cause of the impairment. Scholars have written about the cultural understanding of disability in an African society, and highlight that African societies were more concerned with explaining what caused these disabilities (Shuttleworth & Kasnitz,

2006). Although a lot of efforts too are invested in seeking for a cure where possible, the desire to seek for a cause could subsequently justify such moves as consulting.

There came a point therefore when one 'accepted' their bodily situation, especially when one stopped the search for a cure and abandoned treatment. This is when the person started to think of their situation as either a disability, old age or both. Ultimately, if one stopped seeking for treatment, he or she would make several conscious and unconscious adjustments in his or her day-to-day life. This would enable him or her to accommodate the new identity and level of strength. When the impairment was significant and could not allow the older person to physically move from one place to another, often this would be accepted as disability. Whereas, when minor mobility impairments were sustained, often they would not be regarded as disability but simply old age. It was practically difficult to tell the difference or to precisely categorize the condition.

Some scholars have described disability in these similar situations. For instance, Helander (1995), noted that disability is what lies at the end of the line when all attempts to get back the normal body have failed. Some scholars have also shown the indistinctness that exists between the process of ageing and the acquisition of disability in later stages of the life course (Painter, 2010; Weeks, 2005). This is probably because older persons expect their bodies to function less and less as they age. In fact, a study of older adults' definitions of successful ageing in Bangladesh revealed that Bangladeshis see disease and disability as a normal part of ageing and do not emphasize freedom from disease or longevity as much as North Americans and the US-focused successful ageing discourses do (Amin, 2017).

Chaskes (2010) highlighted using his personal experience that one's identity as a person with a disability is always in a state of evolution and not a stable and fixed state. Additionally, some scholars have emphasized disability as an umbrella term that denotes different things in different places at different times and that is partially negotiated (Livingston, 2005)

Disability is also a fluid concept and is contextual. Currently, disability is seen as a constructed category and not a static state of the body. Social scientists generally believe that individuals are impaired if they experience, or are perceived by others to experience physiological or behavioural statuses or processes which are socially identified as problems, illnesses and other negatively valued differences (Shuttleworth & Kasnitz, 2006). Disability therefore exists when people experience discrimination on the basis of perceived functional limitations (Reid-Cunningham, 2009). This means, that in a society, culture, or place, certain impairments may not result into disabling conditions if they are not perceived as so. If this is the case, it probably explains why some of the older people in this study specifically did not perceive themselves as having a disability, while others would at some point mention that they have a disability and deny the same at another time. This is in agreement with Deegan's argument that ''Feeling normal or disabled,'' then, is a fluid condition, one that can change quickly and at any time (Jo Deegan, 2010). Many of the older people in this study expected their energy levels to reduce, they did not expect themselves to run up and down in household chores especially those that involve moving some distances such as fetching water, firewood, or even running

errands at home by themselves. This perception greatly influenced their morale to seek health care, once they did not have any more pain, there was a tendency to accept the status quo.

Further still, disability is seen as a limitation inability to perform parts or the whole of a desired social role, such as working, being a parent, attending church among others (Altman & Barnartt, 2001). In this view of disability, then the category of "disabled" is socially, rather than medically constructed, in part by the demands and limitations of the social and physical environments in which an individual lives, and in part by cultural values, expectations and definitions. Kohrman (1995) in the book Disability & Culture argues that many persons with disability do not accept the liminal identity ascribed to them by society and may create their own 'culture of disability' to support and inform their experiences. Older people often argued on whether or what they have should be a disability or simply old age. They therefore created their own culture of old age that is independent of disability! The debate about the definition of a 'disabled culture' or 'culture of people with disabilities' continues to rage, among researchers. Some researchers assert that the community of people with disabilities may be considered a culture or subculture, or that certain groups of disabled people may have their own culture (such as Deaf Culture) (Reid-Cunningham, 2009).

There was no standard definition of what it means to be an older person among the people that took part in this study. There was equally no standard definition of disability. Both these terms were used depending on what the person felt and experienced from one time to another. In Uganda, an older person is defined as anyone above the age of 60 (Government of Uganda (GOU), 1995). This definition, however, did not seem to be part of the lives of the people who took part in this study, partly because they probably were not in the formal sector where they need to retire from work. The markers of old age among our respondents were things like reduced strength, stopping to have sex, having grandchildren among others.

The International Classification of Functioning, Disability and Health (ICF) further defines disability as a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (World Health Organization (WHO), 2007). Based on the ICF definition of disability, 19% of the Ugandan population is estimated to have some form of disability (Uganda Bureau of Statistics (UBOS), 2016; World Health Organization (WHO), 2011) and globally, the prevalence of disability is likely to increase due to ageing populations and an increase in chronic health conditions (World Health Organization (WHO), 2015). Uganda has a somewhat vibrant disability movement, as well as a promising disability legal and policy framework. Furthermore, the country has been praised to be a champion in sub-Saharan Africa for advocating for the rights of persons with disabilities (Abimanyi-Ochom & Mannan, 2014). Despite such positive stance, older persons are often not included in disability initiatives in the country and rarely targeted by NGOs and other actors.

Conclusion

This paper brought to light the challenges that older persons must go through when accessing health care. These include: maneuvering the public transport system; the infrastructure at the health centers; the congestion; having to wait in long queues; and having to pay for treatment at the health center. Both the impairment and the physical environment do contribute to disability among older persons. The social environment too plays a significant role and most especially the treatment decisions that are made either by the older person themselves or their caretakers. This is further shaped by their perception of who an older person should be, and their expectations on the functionality of their age. Individual decisions play an important role in this process and are not only acted upon by the impairment and the environment.

Self-perception as either disabled, old or sick greatly influenced the responses of participants on whether one continued treatment or tried to use mobility aids to support their movement or did nothing about their situation. Although self-perception and the perceptions by significant others involved in the treatment of the older person, (including health workers, children care takers and relatives), might not have had anything to do with the reality of the bodily state, it greatly influenced the decisions of the older person and those around them, whether to seek treatment and adhere to it or not. It was observed that, disease would translate into disability, not only when there was a gap created between an individual having the impairment and their environment, but rather when treatment seeking options could not avail much and when the condition is perceived as incurable by either the individual or the significant others and finally a decision is reached to quit treatment.

It could be concluded that older person's perception and response during the process of seeking for treatment has a significant influence on their disability experiences. It is therefore important to understand the events that characterize the transition from health to disability among older persons if effective measures are to be sought.

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