

Access to health care for people with disabilities in rural Malawi what are the barriers?

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Abstract

Introduction People with disabilities experience significant health inequalities. In Malawi, where most individuals live in low-income rural settings, many of these inequalities are exacerbated by restricted access to health care services. This qualitative study explores the barriers to health care access experienced by individuals with a mobility or sensory impairment, or both, living in rural villages in Dowa district, central Malawi. In addition, the impact of a chronic lung condition, alongside an impairment, on health care accessibility is explored. **Method** Using data from survey responses obtained through the Research for Equity And Community Health (REACH) Trust's randomised control trial in Malawi, 12 adult participants, with scores of either 3 or 4 in the Washington Group Questions, were recruited. People with cognitive impairments were excluded. Each of the selected participants underwent an individual in-depth interview and full recordings of these were then transcribed and translated. **Findings and discussion** Through thematic analysis of the transcripts, three main barriers to timely and adequate health care were identified: 1) Cost of transport, drugs and services, 2) Insufficient health care resources, and 3) Dependence on others. Other barriers identified were distance to a facility, which was most hindering for the participants with a chronic lung condition, and unfavourable health seeking behaviour, whilst 'time' was found to be a common underlying factor. Attitudinal factors were not found to influence health care accessibility for this cohort. **Conclusions** This study finds that health care access for people with disabilities in rural Malawi is hindered by closely interconnected financial, practical and social barriers. There is a clear requirement for policy makers to consider the challenges identified here, and in similar studies, and to address them through improved social security systems and health system infrastructure, including outreach services, in a drive for equitable health care access and provision.

Introduction

Equitable access to timely and adequate health care is an intrinsic component of overall equity in health and lack of it may be both an indicator and "contributory cause" [1](p16) of a population's health inequalities. An array of diverse barriers, occurring at various points along the pathways to care, restricts health care accessibility for many individuals and groups globally. Especially disproportionate though, is the extent and impact of the barriers encountered by the world's largest minority group: people with disabilities [2].

It is estimated that over one billion of the global population are disabled in some way and, with this figure on the rise, the World Health Organisation (WHO) has declared a need for more qualitative research in order to better understand the "lived experiences of people with disabilities" [2](p.46). A recent systematic review [3] highlights an especially "urgent" (p.2) requirement for research in low- and middle-income countries as it finds strong evidence for both cause and consequence associations between disability and poverty.

Malawi is a low-income country with a particularly poor health system, the performance of which is limited by the number of facilities, provision of drugs, medical personnel and amount of funding [4]. Given that 85 percent of the country's population live in rural communities [5], the impact of these challenges on the accessibility of health care, for many, is further restricted by lack of physical infrastructure and financial means. Among those living rurally, people with disabilities are especially vulnerable to health care access barriers [6].

Health care accessibility

The WHO describes 'accessibility' - encompassing physical, economic and information accessibility as well as non-discrimination - as one of the four elements of the right to health, along with availability, acceptability and quality (the AAAQ framework) [7].

The 'three delays model' [8], first put forward by Thaddeus and Maine in the context of maternal mortality yet applicable to all aspects of health, identifies three critical points of potential delay in accessing of health care: "(1) delay the decision to seek care; (2) delay arrival at a health facility; and (3) delay the provision of adequate care" [8](p.22). This model is universally relevant, but the extent of each delay varies between and within countries, communities and even families. Importantly, the interpretation of the model in this paper is such that the accountability of each delay is with the system and society, not the disabled person.

In a more recent paper exploring factors involved in reaching the health system interface, Levesque *et al.* [98] build upon the three delays model and define health care accessibility as the sum of five dimensions: "Approachability; Acceptability; Availability and accommodation; Affordability; Appropriateness" [98](p.8). In explanation of these, Levesque *et al.* present five accompanying abilities of the health service user: "Ability to perceive; Ability to seek; Ability to reach; Ability to pay; Ability to engage" [98](p.8). Their analysis, which includes an overview of various categorisations of the factors known to influence a person's access to suitable and timely health care, highlights the complex nature of health care accessibility and, in turn, its barriers.

It is important to consider the contextual variation of health care accessibility by exploring how the weight of certain dimensions and abilities may shift with respect to specific regions, societal contexts and health systems.

This paper will use correlations with Thaddeus and Maine's 'three delays' and Levesque *et al.*'s model as tools to support explanations of the financial, practical and social barriers faced by our participants in rural Malawi.

Health care accessibility for disabled people in Malawi

Findings from a large-scale household survey presented by Eide *et al.* [10] reveal that, like disability itself, barriers to health care access for disabled people are diverse. In Malawi and three other African countries, four main access barriers are identified: "lack of transport, availability of services, inadequate drugs or equipment, and costs" [10](p.11). These findings broadly align with the accessibility dimensions, 'availability and accommodation' (for the first two findings), 'appropriateness' and 'affordability' respectively. This suggests that health care accessibility for disabled people in Malawi is more likely to be restricted by the abilities to reach, pay for and engage with the services available than to perceive the need for and to seek health care.

In contrast, a study by Grut *et al.* [11], finds "lack of information and knowledge" (p.7) to be a barrier to tuberculosis services for disabled people in Malawi. Discussing the role that understanding disease plays in accessing timely and adequate health care, Grut *et al.* imply that the 'ability to perceive' the need for care is a limiting factor of accessibility in this setting.

There are disagreements in the literature about the role of community and health care workers' attitudes towards disability in providing a barrier to health care access. Most authors, including Eide *et al.*[10], conclude that attitudinal barriers exist. Meanwhile, Grut *et al.* [11], though they do not explore the role of community attitudes, find that people with disabilities are treated respectfully by medical personnel.

Research question

A review of the literature on the health inequities experienced by disabled people presents a clear problem: people with disabilities face restricted access to health care. Given this, identification of the barriers to health care for the world's largest minority group remains a "leading research priority" [12](p.1857). There has been a lack of in-depth exploration of the barriers to general health care access experienced by people with mobility or sensory impairments in rural low-income settings. It is this gap in the literature which the present study, conducted in Dowa district, central Malawi, is designed to address.

The findings from this qualitative study are being used to complement the data obtained in the Triage II Plus project [13] in which it is nested. Triage II Plus, which is being carried out by the Research for Equity And Community Health (REACH) Trust in Malawi, is a trial investigating the approaches to improve detection and management of chronic airways disease. For this reason, our study will also examine how the access barriers may differ for people who have a chronic lung condition in addition to their impairment.

The aim of this nested study was to explore the barriers to timely and adequate health care experienced by people with mobility or sensory impairments, or both, in rural Malawi and there are two objectives within this:

- 1) To make comparative observations about the barriers reported by participants of different gender, age and type of impairment (mobility, sensory, or both), as well as between those who have a chronic lung condition and those who do not.
- 2) To explore how the barriers may interact with each other and investigate the possibility of a common underlying factor.

The overall research question addressed in this paper is: what are the barriers to timely and adequate health care for people with a mobility or sensory impairment, or both, in rural Malawi?

Methods

Recruitment

The Triage II Plus Endline Survey provided the data for selection and recruitment of participants. In order to coordinate with local research assistants, and because the data collection for the current study was conducted at the same time as that of the Triage II Plus project, the first 12 survey respondents who were considered to meet the inclusion criteria and could be located using the household GPS coordinates provided, were recruited for the study. The inclusion criteria required participants to be over 18 years old and to have a mobility impairment, sensory impairment, or both, as identified through the short set of the WHO Washington Group Questions [14] within the survey. All respondents who were scored as 3 ('a lot of difficulty' carrying out a specified activity) or 4 ('cannot do' the specified activity at

all) for the questions concerning ability to move, see or hear were included in the study. Table 1 shows the total numbers of scores ≥ 3 and scores < 3 recorded in the Triage II Plus Endline Survey for each of these Washington Group Questions.

Table 1. Triage II Plus Endline Survey figures.

	PAL*	PAL+**	Control	TOTALS:
Number interviewed	4,447	4,145	4,365	12,957
Difficulty seeing ≥ 3	13 (0.29)***	16 (0.39)	16 (0.37)	45 (0.35)
Difficulty seeing < 3	4434 (99.71)	4129 (99.61)	4349 (99.63)	12912 (99.65)
Difficulty hearing ≥ 3	24 (0.54)	10 (0.24)	17 (0.39)	51 (0.39)
Difficulty hearing < 3	4423 (99.46)	4135 (99.76)	4348 (99.61)	12906 (99.61)
Difficulty walking ≥ 3	54 (1.21)	47 (1.13)	28 (0.64)	129 (1.00)
Difficulty walking < 3	4393 (98.79)	4098 (98.87)	4337 (99.36)	12828 (99.00)

A table showing the total number of people with scores ≥ 3 and number with scores < 3 in each of the Washington Group Questions asked within the Triage II Plus Endline Survey.

*PAL = Practical Approach to Lung health intervention. **PAL+ = PAL plus community outreach intervention.

***Figures in brackets refer to the percentage of total in that category.

Due to limitations in time, specialist experience and expertise, people with a cognitive impairment or mental illness, who were identified by the Triage II Plus interviewers using the information in respondents' health passports, were excluded. The 12 people recruited live across 11 different rural villages in the broad catchment area of Chinkwiri health centre in Dowa district, central Malawi. Participation in the study was voluntary and all people interviewed gave informed consent beforehand with a signature or stamp mark on the consent form. Blank copies of this form and other accompanying research documents, written in English and Chichewa, are included in an additional file (Additional File 1).

The Triage II Plus survey responses were also used to gather data about participants' baseline characteristics, specifically age, gender and type of impairment. This information, along with self-reported presence or absence of a chronic lung condition, allowed for comparisons between the barriers experienced by people of similar or differing profiles in the analysis phase of the study. By recruiting the first 12 locatable respondents who met the inclusion criteria, we had a random sample of adults with mobility impairments, sensory impairments, or both, and achieved considerable variation in participant profiles, as shown in Table 2. The separate category distributions are combined in Table 3 to give a complete picture of the profiles in the cohort interviewed.

Table 2. Participants per category.

men:	7
women:	5
TOTAL:	12
participants aged >18 & ≤29 years:	4
participants aged ≥30 years:	8
TOTAL:	12
participants with a mobility impairment:	7
participants with a sensory impairment:	3
participants with a mobility and sensory impairment:	2
TOTAL:	12
participants with a chronic lung condition:	4
participants without a chronic lung condition:	8
TOTAL:	12

A table showing the number of participants in each separate category for gender, age, type of impairment and presence or absence of a chronic lung condition.

Table 3. Summary of participant profiles.

	Men, aged >18 £29 years	Women, aged >18 £29 years	Men, aged £30 years	Women, aged £30 years	TOTALS:
MI*	0	1 (B)	3 (C, E, L)	0	4
SI**	1 (G)	0	0	1 (F)	2
MI + SI	0	0	0	2 (H, J)	2
MI + CLC***	1 (A)	1 (K)	1 (D)	0	3
SI + CLC	0	0	1 (I)	0	1
MI + SI + CLC	0	0	0	0	0
TOTALS:	2	2	5	3	12

A complete summary of participant profiles with reference to age, gender, type of impairment and presence or absence of a chronic lung condition. The corresponding participant reference letters are in brackets below the number in the box.

*MI = Mobility impairment **SI = Sensory impairment ***CLC = Chronic lung condition

Fieldwork process

This study has been designed to obtain high-quality and detailed accounts about participants' experiences as disabled people living in rural Malawi regarding their navigation of pathways to care and perceptions of barriers to health care access. In order to achieve this, the interviews used aspects of the 'McGill Illness Narrative Interview' [15] structure.

The choice of questions and accompanying prompts in the topic guide was partially informed by Thaddeus and Maine's 'three delays' model [8] and the accessibility dimensions and abilities described by Levesque *et al.* [9]. In order to minimise restrictive interview structure and maximise depth of discussion and insight, the open questions were simply used to guide the illness narrative described by the participant [16].

The semi-structured interviews were carried out by the principal researcher and an experienced interpreter, who translated between English and Chichewa. In this paper, the interviewees have been referred to alphabetically, as Participants A-L. Three of the four participants with hearing impairments used a combination of lip-reading and interpretation by a family member to understand the questions and were usually able to respond autonomously. When communication with the interviewer became difficult, however, the family member responded on the participant's behalf.

There were also two cases where the entire interview was carried out by proxy. One was a participant with a hearing impairment, Participant G, whose mother was his proxy. The other was a woman, Participant B, whose grandmother acted as her proxy because Participant B's mobility impairment rendered her unable to speak. It has been made clear in the findings when a quote is directly from a participant and when it is from a participant's proxy. It is acknowledged that interview answers obtained in this way, particularly when the proxies are family members, are less reliable than those which are given directly by the respondent themselves and this is recognised as a limitation of the study. In light of this, none of the conclusions drawn are based solely on findings given by proxies, rather they are each primarily supported by direct respondent answers.

In a similar way, the language barrier and use of a translator might be considered a limitation. Research shows, however, that allowing a local translator to lead the interview, as was the case in this study, is of great benefit to the quality of the information obtained. This is because conducting the interview in the participant's own language not only allows the interview data to be captured in its natural form, but also allows a strong rapport to be built with the participant, who generally feels more relaxed speaking to someone of the same nationality and tongue [17]. The literature on the impact of translations in qualitative research favours the approach used in the current study, which is to transcribe the interview recordings then translate the transcripts into English [18, 19].

Analysis

After carrying out the 12 interviews, full audio recordings were translated into English and transcribed by the same interpreter who had assisted with the interviews. The transcriptions were then manually coded to identify recurring themes. The open coding approach adopted allowed for all new and perhaps unexpected themes to be identified as well as those anticipated in advance based on the literature review [20]. NVivo qualitative data analysis software was used to label and visualise relationships between themes [21].

Findings And Discussion

The findings of this study are presented in four sections: the first three sections are dedicated to the three key findings (each of which is subdivided into three components) and the fourth section, 'Other Findings', presents further potential barriers, a possible common underlying factor and an interpretation of the relationships between all the barriers. Discussion of the findings, with reference to the relevant literature, follows the presentation of each one.

Key Finding 1: Cost as a barrier

Malawi has a predominantly agricultural economy, including a lot of subsistence agriculture, hence most rural citizens earn a living by farming. Participant H, a 77-year-old woman with vision and mobility impairments who is unable to farm as she once did, described challenges with regard to finding work:

"I try to go for piecework in other people's fields; but that doesn't work because they can't allow me because of my disability".

The intense physical labour involved in farming is frequently unmanageable (or at least perceived to be) for people with sensory and, especially, mobility impairments, often rendering them unemployed and unable to earn money [22].

Another interviewee, Participant K, a 21-year-old woman who has impaired mobility associated with a chronic lung condition, did not work in farming but ran a small business. Talking about why she had to close her shop, she said,

"It has everything to do with my illness, because now I am not able to be as productive as I used to be and also we used most of the money in the business to pay for the transport to the [health care] facility".

When income is limited, as described here, costs may become barriers. Even though the closest health care facility to most participants is a public community health centre, where services are free at the point of delivery, almost all the people interviewed described cost - be it of transport, a 'health passport' or pharmacy drugs - as a significant barrier to timely and adequate health care.

Cost of transport

A few participants, unable to walk to the health centre due to their impairment and with no outreach services to attend to their medical needs, described the need for transport in order to access health care. One man, Participant C, a 47-year-old with severe mobility impairments following a recent stroke, revealed the financial difficulties he now faces in trying to reach the health centre to receive care when he needs it:

"I travel on a bicycle which we borrow from some people in the community, and we pay for it, but sometimes it happens that we don't have the money for hiring the bicycle, so instead I just stay here at home because there is nothing else we can do about it".

No longer able to walk due to his stroke, Participant C cannot work on the farm to earn a living anymore. Given this, the next question enquired about where he found the money to pay to travel by bicycle last time he went to the health centre:

“My sister is the one who provided the money [...] She had been asking for piecework from other people in the community, and when she worked, they paid her and she took part of the money and we used it for my transport”.

The themes of reliance on others and family support, which surface clearly here, are expanded upon later as another finding.

Participant A is a 25-year-old man with impaired mobility and a chronic lung condition who, though able to travel to the local health centre for free, explained the financial considerations involved in reaching facilities which are further away:

“I have a bicycle which I use whenever I want to go to [the community health centre], which is closer, but one time I went to [the mission hospital], for that I sold my tobacco and I used the money for transport”.

Participant A went on to explain how this hospital is often the more appropriate facility for the health care he requires and highlighted the impact of his inability to pay to access it:

“It’s difficult, because it always involves money in order to travel because I have to use public transport, so money for me is an issue here, and I cannot do anything about that aspect, and that is why I resort to just going to [the community health centre] nearby for treatment”.

In this way, cost has the potential not only to provide a barrier to the receipt of timely health care, as experienced by Participant C, but also to hinder access to appropriate and adequate care as revealed here by Participant A. The financial barriers associated with distance to a suitable health care facility provide a clear example of Thaddeus and Maine’s ‘2nd delay’ [8] to health care access as well as the hampered ‘ability to reach’ and ‘ability to pay’ (as described by Levesque *et al.*) [9] to access facilities.

Cost of a health passport

In Malawi, all users of public health facilities are required to own, and take care of, a personal ‘health passport’ in which, given the absence of an established online system, their complete medical record is kept. In some discussions, the challenge of this responsibility was revealed, with Participant A saying, “my mother had even lost my initial health passport because it was not constantly needed” and Participant D, a 77-year-old man with a mobility impairment and a chronic lung condition, telling us his document was “destroyed in the rains”. For a patient to replace their lost or damaged health passport costs 200 Malawian Kwacha (the equivalent of US \$0.28), which is approximately one third of the Minimum Daily Wage in Malawi [23].

Participant I is 56 years old, has a hearing impairment and requires treatment for his symptoms of a chronic lung condition but lost his health passport long ago. He described his need to pay for a replacement as the primary reason for not seeking health care:

“I don’t have money to go and buy a health passport to use so I didn’t go to the facility, because you are required to have a health passport in order to be able to be attended to at the facility”

“The money that we find from the piecework is not even enough, so how can I take K200 from it in order to buy a health passport? We only aim at buying food”.

This account highlights how poverty, which may be both a consequence and cause of disability [24], alongside system-level administrative barriers, can prevent access to even the most basic public health centre in this setting.

Cost of drugs

A consequence of poorly resourced public health centres - another barrier to adequate health care which will be presented as a finding in the next section - is the financial burden that frequent drug stock-outs places on patients. Users of the health care facility are required to purchase, from a private pharmacy, their prescribed medication which would have been provided for free at the health centre had it not run out of stock. Participants often drew attention to this problem and its impact in the interviews:

“The issue is the shortage of drugs [...] we are told that the drugs have run out, so we are told to buy the drugs instead. We from the villages who do not have money, [...] where will we get the money from? So we end up getting back home without any assistance” (Participant J, a 51-year-old woman with vision and mobility impairments)

“It hurts to see that they are telling you to go and buy the drugs at the pharmacy because they don’t have the drugs, when we have gone there for such treatment [...]. So when you get back home you can’t buy the drugs and you end up continuing to suffer as if you had not gone to the facility in the first place. (Participant H, 77).

Despite these two quotes being from women with the same types of impairments, similar experiences were also described by other participants of the full range of profiles, suggesting that the challenge of the 'affordability' dimension of accessibility cuts across gender, age, type of impairment and lung health status.

Summary and Discussion of Key Finding 1

Consistent with what has been repeatedly shown in other studies in rural Malawi and similar contexts, these findings highlight the significance of financial barriers to health care access for people with disabilities living in such settings, with 'ability to pay' proving an aspect of accessibility that is not only relevant for people using private services but also for those who attend public facilities.

Key Finding 2: Insufficient health care resources as a barrier

Almost all the interviews revealed that the health care provision available for this group of people was frequently inadequate to meet their medical needs, mostly due to functional, practical and systemic problems. Notably, however, in contrast with much of the literature [2, 6, 10] but in agreement with findings by Grut *et al.* [11], poor treatment of disabled people by health care practitioners was seldom mentioned and, in fact, the opposite was usually described. The following quotes are responses to the question, 'how are you treated by doctors and nurses when you receive care, compared to other people or compared to before you became disabled?':

"We don't have any problem, we are assisted properly" (Grandmother of Participant B, a 20-year-old woman with a mobility impairment, speaking as her proxy)

"They treat me well [...] the way [all the patients] are treated is the same" (Participant H, 77)

"There is no difference; the way they do now is just the same as they used to do it before" (Participant J, 51).

Instead, the main reasons for dissatisfaction with health care provision identified among our participants were unreliable drug supply, a shortage of doctors, and a lack of diagnostic testing and specialised treatment.

Not enough drugs

As alluded to in the comments about personal financial consequences of drug stock-outs, the health care facilities attended by our participants, and in many other parts of Malawi [25], frequently run out of drugs. The participants of this study frequently expressed frustration with the shortage of medicines:

"Here in our health facilities we have very big problems, because drugs are rarely found in the hospitals" (Participant F, a 45-year-old woman with a hearing impairment)

"There are cases where drugs run out due to the number of people who come to the facility to seek treatment" (Mother of Participant G, a 25-year-old man with a hearing impairment, speaking as his proxy)

"The drugs are in short supply; it only takes a few days and then we hear that the drugs have run out" (Participant K, 21).

When asked how their access to health care could be improved, some participants explained that a constant supply of medication would make a considerable difference, emphasising the significance of the '3rd delay' in their pathways to care.

Not enough medical personnel

It became clear over the series of interviews that the inefficiency and under-staffing of the health care facilities provides a direct barrier to accessing timely health care by causing long queues and significant waiting times:

"We might wait even up to 1 o'clock in the afternoon [having arrived at 9 o'clock] before we even have the chance to meet with the doctor" (Grandmother of Participant B, 20, speaking as her proxy)

"There is a problem because we go there when we are not feeling well and, because of the number of people there at the facility who need to be assisted [...], it takes too long and for a patient it also becomes very uncomfortable" (Mother of Participant G, 25, speaking as his proxy).

Not only is it possible for patients' conditions to deteriorate over the period of time they are waiting, but it also may take up to a whole day away from potential work for themselves and whoever might be accompanying them, which suggests a close link with financial barriers.

Discussions with participants revealed that there are insufficient trained medical personnel, and particularly few doctors, at the health care facilities which our participants are able to reach:

“At the moment we only have one doctor, and he has to treat over 300 patients in a day; that is a lot of work” (Participant H, 77)

“There are times where those hospital attendants who sweep the facility are the ones who dispense the drugs, because the medical personnel are tied up and because there are too many people” (Husband of Participant F, 45, speaking as her proxy).

Another participant, Participant D, 77, who went on to express his fear that “someone might die right at the facility” as a consequence of the extreme waiting times, highlights his doctor’s tardiness as a contributing factor:

“Another problem for us is the time the doctor reports for duty to open the clinic, most of the time he is very late to open the clinic and start providing services to people”.

In addition to health care provision inefficiency increasing the ‘3rd delay’ to attaining adequate health care, the interviews revealed that knowledge of the amount of time taken up by a visit to the health centre negatively influences participants’ health seeking behaviour. This observation, which more often appeared to be the case among men than women, points towards an increase in the ‘1st delay’. In this way, the serious mismatch between supply and demand has been found to provide both a direct and indirect barrier to accessing timely health care for our participants.

Not enough diagnostic testing or specialised treatment

Being unable to regularly travel to better-equipped facilities, due to both practical and financial reasons mostly resulting from their impairments, some participants expressed disappointment at the quality and responsiveness of services accessible to them:

“I would really be very grateful if [...] there was a provision for running tests in my chest so that they would be able to find out what really is my problem, and then they tell me what is really wrong with me; so that I would be given proper medication, instead of working on assumptions” (Participant K, 21)

“I would really like if there was a way of finding out what is causing all these problems that I have, and then be given proper medication for it so that my life will get back to normal” (Participant D, 77)

“The treatment that I receive is not up to my desired expectations. I really would appreciate it if they would give me an injection, because I know that injections are very effective; but I have never received any” (Participant L a 67-year-old man with impaired mobility due to arthritis).

These accounts highlight a further increase in the ‘3rd delay’ [8] and the issue of ‘appropriateness’ [9] as a limiting factor of accessibility, stressing how even if and when health care facilities are reached, receipt of ‘proper’ health care may not be guaranteed. It is important to acknowledge, however, that the dissatisfaction with health care described by participants may result not only from the underperformance of health care facilities but also, sometimes, from unrealistic patient expectations.

In a study by Saleh et al. [26], high expectations about the availability of diagnostic tests and curative treatment are reported to influence patients’ perceptions of health care service quality in Malawi, with patients especially attracted to the idea of receiving treatment in the form of an injection. In the current study, some participants alluded to a presumption that health care providers can cure their condition and hence, they expressed frustration about the fact that this has not been achieved. Saleh et al. find that these expectations are held, in particular, by users of private health care facilities [26].

Summary and Discussion of Key Finding 2

This section has proposed that insufficiencies in health care provision, which may be viewed as flaws in the ‘availability and accommodation’ and ‘appropriateness’ dimensions of accessibility [9], provide a major barrier to the attainment of timely and adequate health care for participants of this study. It is important to note however, that the issues the participants described affect all users of health care services, rather than only those with impairments. Nevertheless, it is possible that such barriers might be experienced more frequently by disabled people due to their statistically increased need for health care [2], together with a likely reduced ability to afford drugs elsewhere, to pay for private and less understaffed health care and to access distant and better-equipped facilities.

Meanwhile, it is likely that the reported positive attitudes of Malawian health care workers towards disability can be largely attributed to recent campaigns to improve their attentiveness towards disabled people’s needs, as described by Grut et al. [11].

Key finding 3: Dependence on others as a barrier

A recurring theme throughout all the interviews was that of dependence and needing support. Though given little emphasis in the surrounding literature, it is clear from this study that reliance on family, friends and the community may give rise to a social barrier to timely and adequate health care, with some participants losing their source of support, and others at the mercy of their care-giver's availability, financial situation and, ultimately, compassion. The notion of dependence as a barrier is intrinsically linked with other barriers and, among our participants, dependence mostly presented itself as a theme in discussions about financial support, transport and distance to a health facility and, in one case, communication. In discussing how dependency may hinder health care accessibility, it is also essential to acknowledge the ways in which support from others acts as a facilitator for health care access among people with disabilities.

Dependence on others for financial support

In response to the question 'how do you currently earn a living?', participants often revealed that their inability to make enough money renders them reliant on others:

"This is a very big challenge because I am incapacitated, and I cannot do any work here at all, and now I am solely dependent on the people who are looking after me" (Participant C, 47)

"I am not able to do a lot of piecework anymore; this affects my family in terms of basic necessities; so much so that we live with little and depend on getting support from other people surrounding us here" (Participant I, 56).

Notably, discussions about the need for family or community financial support, such as these above, did not appear to be restricted to a particular age group, gender or type of impairment. One woman, Participant H, 77, stressed the role that charitable donations play for her:

"There are also some well-wishers in the village who sometimes give me some money which I eventually use to buy the most day-to-day needs".

Meanwhile, Participant E, a 70-year-old man with a mobility impairment who lives alone and describes his financial situation as "a limiting factor", has lost his source of support:

"Now there is nothing that I do that can really fetch me the help that I need; the one whom I depended on for financial support lives very far now".

This highlights the inconsistency and instability that often accompany charity, demonstrating how the need to depend on others' generosity may act as a barrier.

Dependence on others for transport to health care facility

The other limiting factor that Participant E, 70, discussed was the reduced availability and accessibility of transport now that his relative no longer takes him to the health facility by bicycle. Similar accounts linking dependence on others with restricted ability to travel were given by other participants, mostly those with mobility impairments:

"[The reason why I have not gone to the health facility recently] is because of the one who takes me; he is usually not around to take me that much" (Participant C, 47)

"No I can't [ride a bicycle anymore], but if there is someone to take me, then that can work, otherwise it will be impossible for me to do that now" (Participant D, 77).

Other interviews revealed how the need to be accompanied when walking to the health centre may also limit when one can go and may extend the '1st' and '2nd' delays [8]. The grandmother of 20-year-old Participant B described these kinds of challenges in her explanation about how her granddaughter reaches health care:

"We walk very slowly till we reach the health facility [...] because I also have a walking difficulty because my legs are no longer able to support me due to old age"

"I feel that she needs to be under constant monitoring, and that is impossible because I cannot manage to take her all the time, due to both of our mobility challenges".

Highlighted here is the way in which the health status of the supporter may also be a factor contributing to the ability of the dependant to access health care.

Dependence on others for assistance with communication

One interviewee, Participant F, 45, revealed the difficulty she sometimes faces, as someone with a hearing impairment, when trying to converse with and understand her doctor. The notion of dependence on others for effective communication with health care practitioners, extension of the '3rd delay', was presented by Participant F's husband when he spoke as her proxy for part of the interview:

"I write something and then give it to her to take to the doctor; so they in turn write back to me when they have not managed to communicate with her properly. [...] because she is my wife, I am able to sit her down and explain to her one by one, everything which the doctor has found out and said" (Husband of Participant F, 45, speaking as her proxy).

It is clear from this, that for some patients in similar situations but without the personal support Participant F has, communication difficulties may provide a significant barrier to the successful receipt of adequate health care.

Summary and Discussion of Key Finding 3

This section highlights the instability and uncertainty that reliance on other people may cause for disabled people in this setting and explains how this may provide a barrier to timely and adequate health care, by its potential to contribute to all three 'delays' and its impact on the patient's abilities to 'seek', 'reach' and 'engage (with)' health care [8, 9]. Nevertheless, the account given by Participant F's husband draws attention to the enabling benefits of appropriate support, when available, especially that provided by family members. Despite many participants expressing gratitude towards those who supported them, some also showed signs of frustration at the lack of independence as captured in the following quotes:

"If only this pain in my back would go; I would stop being so dependent on them and would start to do things in the way I used to do before" (Participant D, 77)

"Things have completely changed, I have become helpless because I can't do anything by myself the way I used to do in the past" (Participant L, 67).

In our study, feelings such as these were more apparent among men, particularly those who had developed their impairment later in life and had since experienced a change in their ability to exercise their fundamental right to health [7]. Recognition of the adjustment challenges and mental health difficulties which may be experienced by many such people with disabilities further stresses the necessity of equitable health care accessibility [27].

Other findings

The barriers presented in this section - distance from a health care facility and unfavourable health seeking behaviour - were less frequently described and considered to be less significant barriers to the access of timely and adequate health care compared with the three key findings but their roles in contributing to many participants' experiences of pathways to care remain important. Participants' reports of community attitudes towards disability are also discussed here and there is exploration of the possibility of 'time' as an underlying theme feeding into many of the identified barriers. Finally, this section presents the apparent relationships and interconnections between the barriers the participants face.

Distance as a barrier

The distance from a health facility was a common complaint but the main issues apparently associated with distance as a barrier were the cost and availability of transport and the quality of health care provision at the nearest facility, hence participants' comments on this tend to overlap with the key findings.

Still, some participants, especially those with a chronic lung condition, made comments specifically about the distance:

"I would like to find out how I could be assisted so that I could receive proper treatment since the health facilities are very far" (Participant A, 25)

"Even to go to [the community health facility], I must sit down [to rest] several times before reaching there" (Participant D, 77).

Interestingly, however, when asked what they thought would improve the accessibility of health care, none of the participants responded with ideas about having a closer facility available. This perhaps reflects assumptions that an increase and improvement in number and

distribution of facilities are improbable prospects.

It is also important to consider the role that age may play in determining the extent to which distance from a health care facility acts as an access barrier. Munthali *et al.* [25] find that old age is an independent barrier to health care access and describe how the long distances to facilities and poor transport options has a negative impact on the health seeking behaviour of elderly people, especially those with age-related impairments, like some of the participants of this study.

Unfavourable health seeking behaviour as a barrier

When asked why they decide to seek health care, participants generally responded with variations of: “so that I would feel better” (Participant A, 25).

Some participants, most men and one woman, exhibited what might be considered unfavourable health seeking behaviour [28]. There were a few comments about a lack of need and a lack of motivation to seek health care as well as occasional references to the use of traditional medicine in the place of conventional health care:

“I saw that I was better off than most of them who were there [at the health care facility], so I said to myself, why am I bothering to come here for treatment when I am better than most of them? [...] So I just left and got back home, and never went back” (Participant E, 70)

“The problem started again [...] and I had to go to the traditional doctor again” (Participant L, 67)

[In response to: ‘what is stopping you from going to the health centre about your eyesight problems?'] “Nothing, I am just lazy when it concerns that” (Participant J, 51).

Based upon these accounts, social and cultural factors may be considered to contribute to unfavourable health seeking behaviour [28]. It is also possible that the perceived barriers to health care access, including understandings of the quality of care provision, can become manifest in the health seeking behaviour of disabled people in this setting.

Attitudes towards disability

In contrast to findings of other studies in Malawi [29, 30], participants generally gave very positive responses when asked how they were treated by people in their community:

“They associate with me without any problem, and they also don’t treat me differently from everybody else, they just know to speak loudly so that I will be able understand” (Participant I, 56)

“They have accepted that I have this problem and they help me in any way they can so that I don’t have to be uncomfortable” (Participant K, 21)

“I am grateful that the people in the community accepted me following my disability, [...] I could be a laughing stock [...] but it is not such in this case. People here they come to chat with me, they come to see me, nobody has ever spoken badly about my illness” (Participant C, 47).

Exceptions to these assurances of acceptance of disability, came in the interviews with Participants D and E, both of whom are elderly men, in which references to social isolation within their rural communities were identified:

“I don’t get treated the way I am supposed to; because sometimes people can say hurtful words to me because of one reason or another, and I am not very free when I live here” (Participant D, 77).

“Sometimes I just see the way that they are reacting around me, I just know that I am not needed amongst them, so I just leave and come back home and sit here by myself” (Participant E, 70)

It might be inferred that feelings of exclusion and restricted freedom could increase the ‘1st delay’ to receipt of proper health care but this was not reported to be the case for these participants. As such, attitudes towards disability are not found to provide a barrier to health care access in this study.

Time as an underlying factor

Regardless of the specific barriers each participant described, a recurring theme was ‘time’. Whether the issue is lack of it, use of it, waiting or delays, time pressures may facilitate or exacerbate the impact of health care access barriers for disabled people in this setting, especially those of the three key findings.

Some participants drew attention to the role of time within financial barriers:

“It takes a long time for the crops to reach the stage where we could be able to sell” (Participant K, 21)

“Fortunately, [...] she may take several months before she goes [to the clinic] again; so we have some time to build up [money] again” (Husband of Participant F, 45, speaking as her proxy).

Similarly, ‘time’ presented as a common underlying theme behind complaints about health care provision. The amount of the day a visit to the health centre requires was repeatedly posed as a factor contributing to dissatisfaction with health care. Time was mentioned both in reference to travelling to the facility and waiting on arrival:

“it takes me a very long time to go and come back since I walk with a lot of difficulties” (Participant L, 67)

“A person may leave their home as early as possible to reach the facility in good time, but will have to wait a long time before the doctor reports for duties” (Participant D, 77)

“We usually wait a longer time since there are many people who go there since it is a public health facility” (Participant F, 45).

Notably, when the problems associated with the amount of time taken to visit the health centre were described, loss of potential working hours was not mentioned. It is likely that this is because some participants were unable to work at all but also because there were other, more direct consequences. Some, for example, described how the long waiting times mean patients’ conditions often decline considerably before they receive any medical attention. Participant L, 67, gave a different, practical, reason for time being an important consideration:

“we want to be there early so that we become one of the first people to be attended to, so that I [...] beat the scorching sun on my way back”.

Finally, participants who discussed the reliance on others that results from their disability made some comments which indicated how the lack of time or availability of the person who assists them is what makes dependency on others a barrier to access, as described by Participant C and his sister:

“Whenever I asked him to take me, he only postpone to the other day, and in that way, days go past” (Participant C, 47) [...] “We are waiting for the cousin who takes him to find time so that he can take him back [to the health care facility]” (Participant C’s sister, who is his main care-giver).

Interactions between barriers

The relationships between different barriers identified in this study to accessing timely and adequate health care are complex and dynamic. The associative, potentially causal and positive connections detected through the interviews have been summarised using analysis tools in NVivo to create and visualise relationships between themes (see Fig 1) [18]. The different types of link between barriers are labelled “may be associated with”, “may influence” (both bidirectional relationships) and “may cause” (a unidirectional relationship). In the visual model, barriers to health care access are displayed in bubbles, with the three key findings of the study in the large bubbles at the top. In examining this model, it is important to consider the role of ‘time’ as a factor feeding into the barriers and relationships.

Fig 1. Thematic map. An NVivo model showing the relationships between the barriers to health care access identified in the study.

This model illustrates the complexity of pathways to care and their accompanying barriers for people with disabilities. Reports of financial barriers, for example, may be associated with the distance to the health care facility, restricted transport availability and insufficient health care resources, both because cost may influence the choice of facility and because it might restrict the quality of care provision. Furthermore, financial difficulties may influence the degree to which the disabled person depends on others and vice versa which, in turn, may cause and exacerbate restrictions in availability of transport. It is thus clear that the barriers cannot be considered in isolation and, subsequently, strategies to address them demand combined implementation.

Conclusions

Barriers to accessing timely and adequate health care in rural Malawi may be encountered at various points along a pathway to care and our findings suggest that people with mobility impairments, sensory impairments, or both, face many of these barriers. The three main barriers identified in this study are: 1) cost of a visit to a health care facility, 2) insufficient health care resources, and 3) dependence on

others. Underlying these, and other barriers, there is a general theme of ‘time’. Table 4 shows how the main barriers identified in this study correlate with Thaddeus and Maine’s ‘three delays’ and Levesque et al.’s dimensions and abilities of accessibility.

Barrier to health care access (Key Findings of this study)	Delays (as described in Thaddeus & Maine’s ‘three delays model’ [8]) extended by this barrier	Dimensions and abilities of accessibility (as described by Levesque <i>et al.</i> [9]) hindered by this barrier
Key Finding 1: Cost as a barrier	2 nd delay (arrival at a health facility)	Affordability Ability to reach Ability to pay
Key Finding 2: Insufficient health care resources as a barrier	1 st delay (the decision to seek care) 3 rd delay (the provision of adequate care)	Availability and Accommodation Appropriateness
Key Finding 3: Dependence on others as a barrier	1 st delay (the decision to seek care) 2 nd delay (arrival at a health facility) 3 rd delay (the provision of adequate care)	Ability to reach Ability to pay Ability to engage

Table 4. Correlations with Thaddeus and Maine's and Levesque's models. A table showing the correlations between the barriers identified in this study, Thaddeus and Maine’s ‘delays’ and Levesque *et al.*’s ‘dimensions and abilities’.

Whilst it is recognised that financial barriers (especially costs of drugs) and experiences of inadequate health care (doctor shortages in particular) are likely to apply to the population at large, we maintain that for people with impairments the challenges may often have a “greater negative impact” [11](p.7). Dependence on family, friends and the community is presented as a central yet frequently under-acknowledged barrier to health care access which is especially pertinent for people with disabilities.

The limitations of the study include the use of proxies, the exclusion of people with a cognitive impairment or mental illness, and the relatively small geographical area in which the 12 participants live, meaning that they mostly attend the same health care facilities. Another limitation is the fact that it was not possible to obtain any interviews with health care workers, which might have provided a useful alternative perspective. The sample size may be considered a strength of this study for it is small enough to allow in-depth data collection yet large enough for there to be considerable variation in participant profiles.

Most of the different types of access barrier were experienced by participants of diverse profiles, suggesting that these challenges were significant enough to override any differences between gender, age or type of impairment. For people with a chronic lung condition in addition to mobility or sensory impairment, the main barriers were the same as for the other participants. Distance, however, was more often mentioned as a stand-alone barrier by the participants with chronic lung conditions, perhaps indicating that there may be a particular benefit to scaling-up lung health care through outreach services.

The execution of this study has met a crucial need for more in-depth exploration of the health care access barriers faced by people with mobility, sensory, or both, impairments in rural low-income settings. The study’s findings shed light on the significance and relevance of access barriers identified in the surrounding literature for people with these impairments in rural Malawi. In this way, the findings have the potential to inform local policy by giving an indication of which systems demand improvement or intervention.

The implications of the findings include a requirement for better implementation of social security systems in Malawi to reduce the financial barriers to health care so commonly experienced by disabled people, frequently resulting from limited work opportunities. In addition, the study highlights a pressing need for improved drug supply to health care facilities, especially in rural areas, as well as improved numbers and distribution of trained medical personnel. Finally, it is possible that outreach schemes and community engagement in a ‘buddying’ system involving volunteers and health care workers may overcome some of the precariousness and vulnerability associated with dependence on others and so improve disabled people’s access to health care.

Importantly, given the close interconnections and intrinsic relationships between the barriers, the proposed strategies may have limited effectiveness in isolation. Instead, a multi-dimensional approach which facilitates integrated employment of interventions is needed. In this way, striving for equity in health care accessibility, Malawi may work to reduce health inequalities.

Declarations

Ethical approval

This study received ethical approval from the College Of Medicine Research and Ethics Committee (COMREC) in Malawi (reference number: P.07/13/1424), and the Liverpool School of Tropical Medicine (LSTM) Ethics Committee (reference number:14.040).

Ethics, consent and permissions

Written consent to participate was obtained from all interviewees prior to their interviews.

Consent to publish

All participants gave their consent for the publication of material obtained in the interviews.

Data Availability

Due to the level of detail in the qualitative transcripts from this study, even with direct personal identifiers removed, the stories and descriptions of participants within the transcripts makes them potentially identifiable, as well as containing sensitive and confidential patient information. We do not have ethical approval for the sharing of raw data sets from our institutional ethics committee and we have therefore deemed these raw data unsuitable for sharing publicly. We have tried to share as much data as possible through quotes within the text. The dataset is available on reasonable request from Julie Irving (Julie.irving@lstmed.ac.uk) who is an institutional representative and will hold a copy of the data and respond to external access requests. To ensure long-term data storage and availability it will be held by two of the authors, Josephine Harrison and Rachael Thomson, as well as Ms Julie Irving.

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Competing Interests

We have the following interests: Berthe Stenberg is employed by LHL International, a registered NGO. This author provided some technical contribution to the manuscript only and did not play a role in the study design, data collection or analysis. There are no patents, products in development or marketed products to declare.

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Figures

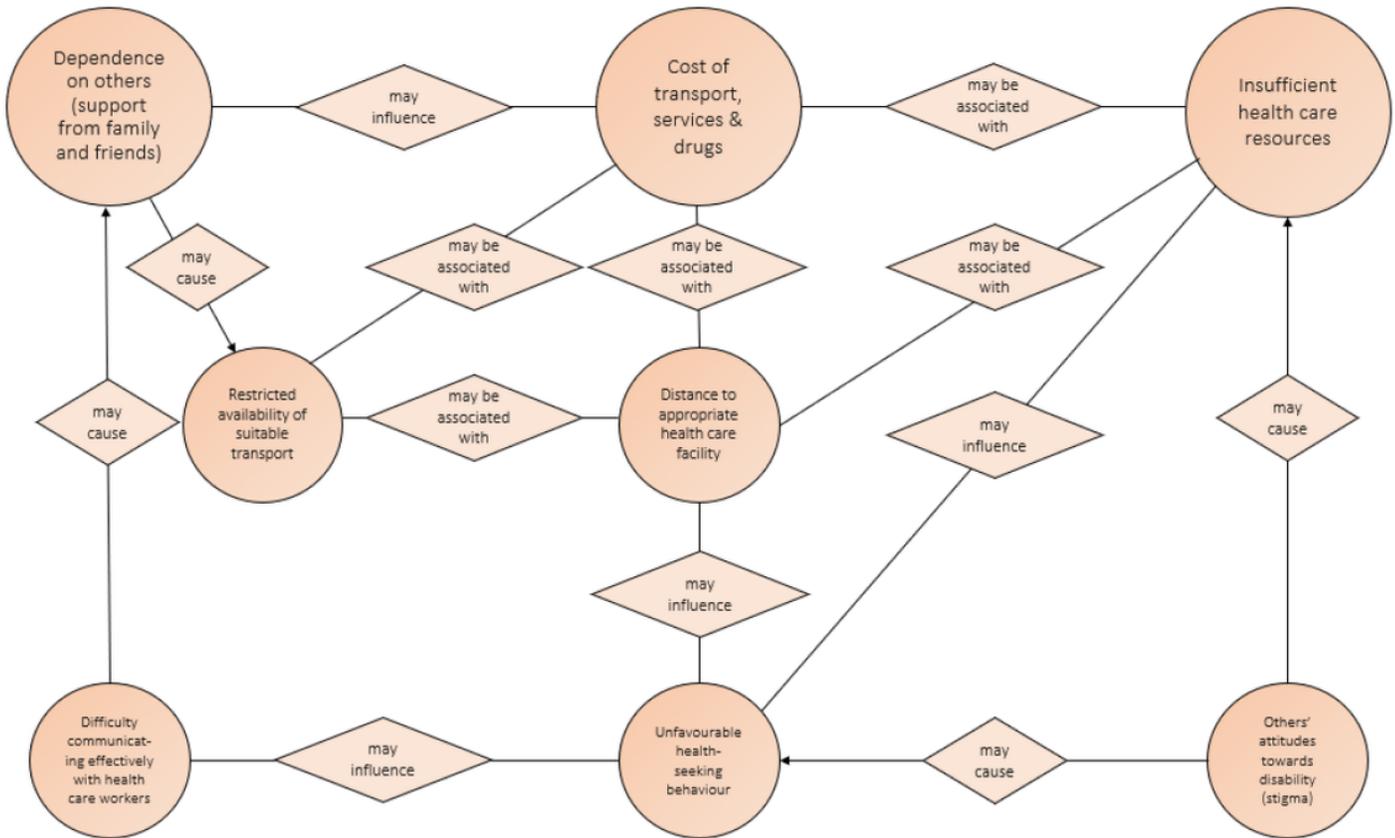


Figure 1

Thematic map. A NVivo model showing the relationships between the barriers to health care access identified in the study.

Supplementary Files

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- [supplement1.pdf](#)