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The experiences of older persons with disabilities in humanitarian crises in Eastern Ukraine and Western Tanzania

Phillip Sheppard

Thesis submitted in accordance with the requirements for the degree of Doctor of Public Health of the University of London

2024

Department of Population Health

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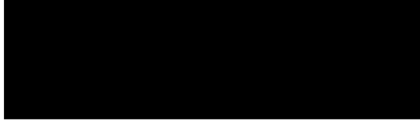
Declaration

I, Phillip Sheppard, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed:  Date: 4 February 2024

Phillip Sheppard

Abstract

BACKGROUND: Many older persons (≥ 60 years) with disabilities are affected by humanitarian crises, globally and this is likely to increase. Older persons with disabilities may be disproportionately affected in humanitarian crises because of factors at the intersection of age and disability however, there is limited research examining their experiences or access to daily and humanitarian support needs in these contexts. There is a need for a better understanding of the lived experiences of older persons with disabilities in humanitarian settings to inform humanitarian response.

AIMS: The overall aim of this DrPH research is to better understand the experiences of older persons with disabilities in humanitarian crises to inform evidence-based recommendations and strategies for humanitarian response.

METHODS: 1) A systematic review was conducted to examine the available evidence on older persons with disabilities; 2) Semi-structured qualitative interviews were conducted with 21 older persons with disabilities (11 Females; 10 Males) and 11 family members or caretakers living in Nduta and Mtendeli refugee camps in Tanzania and 31 older persons with disabilities (17 Females; 14 Males) and 5 family members or caretakers living in government-controlled areas (GCA) of Donetsk and Luhansk regions of Ukraine. A thematic analysis was used to analyze the data.

FINDINGS: The analysis identified a range of factors that shape the experiences of older persons with disabilities in the two contexts associated with environmental (physical and social), personal factors and agency.

CONCLUSIONS: Older persons with disabilities have unique experiences, barriers and facilitators in humanitarian crises which are shaped by their intersectionality. In addition to environmental factors, personal factors and agency; dominant humanitarian framing, structures and decision-making influence their experiences, challenges and dependency.

In memoriam

I would like to dedicate this Thesis to my brother, Stephen Sheppard (Steve), who passed away in June 2023.

Steve lived most of his life with mental illness and tragically succumbed to his silent struggles.

Being my older brother, I looked up to Steve when I was growing up. I sought advice from him and often referred to him as "*the athletic one*".

Steve demonstrated remarkable resilience as he dealt with mental illness and sought all treatments that were available to him. As his illness became more severe, it was difficult for him to connect and communicate with others, but he would seek my advice on things related to exercise, nutrition, mental health and navigating the healthcare system. He would also offer words of encouragement – The second last message I received from him was *"Congrats on submitting your thesis".*

May this dedication be a tribute to Steve's resilience and a reminder of the importance of mental health awareness and promoting open dialogue around mental illness and the challenges that we all face.

Let it also be a reminder of the importance of health research. Through research, we can develop effective treatments, improve access to healthcare services, and reduce stigma and discrimination. By working together, we can support and improve the lives of our brothers and sisters around the world.

Acknowledgements

I would like to express my deepest gratitude and appreciation to all those who have supported and guided me throughout this DrPH journey.

First, I would like to extend my gratitude to my primary supervisor Dr. Sarah Polack who provided a constant source of guidance throughout the entire DrPH. Thank you to my supervisors Dr. Jennifer Palmer, who encouraged me to dive deeper into the concepts and literature and to Dr. Jane Wilbur, who came on in my final year having just completed her PhD (as one of your first students, I can say with certainty that your future students are lucky to have you). I would also like to thank Dr. Karl Blanchet who helped with the early conceptualizations of this research. To all of you, thank you for sharing your expertise and for your patience and encouragement.

I would like to extend my sincerest thanks to the members of the advisory groups who allowed me to draw on their expertise to guide this research so that it can be of use to research and humanitarian practice.

I would also like to thank the staff at HelpAge International and the researchers in Ukraine and Tanzania who made this research possible. It was a pleasure working and learning from you.

I am immensely grateful to the participants of this research who shared their experiences for this research.

This DrPH research would not have been possible without the support of family and friends. First, to my parents and siblings who have supported me throughout all my crazy adventures. To my friends, thank you for putting up with me (or should I say without me) while I worked on my thesis.

Thank you to Patrick and Crystal Cayen and the team at Ottawa Valley Physiotherapy for your friendship and constant support.

A sincere thank you to Sarah King – who provided clarity and encouragement throughout this tumultuous journey.

Finally, to Jenny Dea – for everything (for your constant support and encouragement and being my constant adventure partner)

And Lu (a good dog) – for taking me for walks and runs in the forest when I needed them most.

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Thesis Structure

Chapter 1: Introduction – describes thesis rationale and provides a summary of the literature on older persons with disabilities and caregivers in humanitarian crises.

Chapter 2: Key concepts employed in this thesis – presents key concepts used throughout this thesis including an overview of the frameworks and conceptualisations of disability, ageing, humanitarian crises and intersectionality. The implications of these concepts are discussed.

Chapter 3: Research design and methodology – provides details on study conceptualization, the framework used throughout this thesis and methodology for the systematic review and qualitative research in Tanzania and Ukraine.

Chapter 4: Systematic review on the experiences of older persons with disabilities in humanitarian crises

Chapter 5: Setting the Scene: The humanitarian context in Tanzania and Ukraine – provides contextual information for study settings including the background of the humanitarian crises and the situation at time of research.

Chapter 6: Results from Tanzania – presents the results of the qualitative research with older people with disabilities and caregivers in refugee camps in Western Tanzania.

Chapter 7: Results from Ukraine – presents the results of the qualitative research with older people with disabilities and caregivers in conflict affected areas of Eastern Ukraine.

Chapter 8: Discussion – discusses and synthesizes the findings from Tanzania and Ukraine and draws on concepts throughout this thesis. This chapter also discusses the strengths and limitations, transferability and reflections. Recommendations are provided based on the findings of this research and considerations for future research are provided.

List of abbreviations

ADCAP	Age and Disability Capacity Building Programme
CBR	Community Based Rehabilitation
CCM	Camp Coordination and Camp Management
DPO	Disabled People's Organizations
HIC	High-income country
HRW	Human Rights Watch
IAG	International Advisory Group
IASC	Inter Agency Standing Committee
ICF	International Classification of Functioning, Disability & Health
LCP	Life course perspective
LPD	Life course perspective of disability
LMIC	Low-and middle-income country
NAG	National Advisory Group
NGO	Non-governmental Organization
OHCHR	United Nations Office of the High Commissioner for Human Rights
OPD	Organizations of People with Disabilities
RCM	Refugee Coordination Model
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNPRDP	United Nations Partnership on the Rights of Persons with Disabilities
UDHR	Universal Declaration of Human Rights
WG-SS	Washington Group Short Set
WHO	World Health Organization

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CHAPTER 1: INTRODUCTION

1.1 Rationale for this thesis

1.1.1 Older persons with disabilities - An overlooked population in humanitarian crises

Many older persons (60 years of age and older) with disabilities may be affected by humanitarian crises, globally. The United Nations (UN) estimate that 26 million older persons experience disasters each year (1). With an estimated 46% of people over 60 years of age living with a disability (2) more than 11.9 million older persons with disabilities may be affected by disasters, annually. This number is likely to increase with global demographic changes (the number of older persons is growing faster than any other age group) (3), the increased prevalence of disability in older age (because of the accumulation of health risks across their lifespan) (4) and the expected rise in the number of humanitarian crises and people in need of humanitarian assistance (1,3,5–8).

The increase in older persons with disabilities affected by humanitarian crises will likely be most pronounced in low- and middle- income countries (LMIC) because all three factors: disability (4,9) (Figure 1), ageing (3,7,10,11) (Figure 2), and humanitarian crises (1,5,6,12,13) are more prevalent and are expected to increase disproportionately in these settings. The World Report on Disability estimates that 80% of the one billion persons with disabilities live in LMIC (4). The prevalence of disability is higher in LMIC as compared to high-income countries (HIC), especially among older persons (Figure 1) (4) This is not surprising since there is strong evidence to support that disability and economic poverty are intrinsically linked (9). In terms of ageing, LMIC are projected to see the fastest increase in older populations, globally (3) and estimates suggest that by 2050, around 17% of the world's population will be over 65 years of age and that 80% of older people will live in resource poor areas and countries affected by climate change and conflict (3,7,11). Humanitarian crises show a similar trend. Currently, most humanitarian crises occur in LMIC. According to the UN's Global Humanitarian Overview (1), in 2019 most conflict induced displacements took place in Africa and the Middle East and most natural disaster induced displacements occurred in Asia. In the same year, 81% of refugees were hosted in LMIC (13). Humanitarian crises are expected to increase in LMIC due to a variety of factors, such as climate change which is expected to disproportionately impact those living in LMIC and result in increased rates of violence and displacement (14). In many cases, LMICs have less capacity to mitigate and manage the impacts of crises (14,15), causing them to be at even greater risk of adverse events.

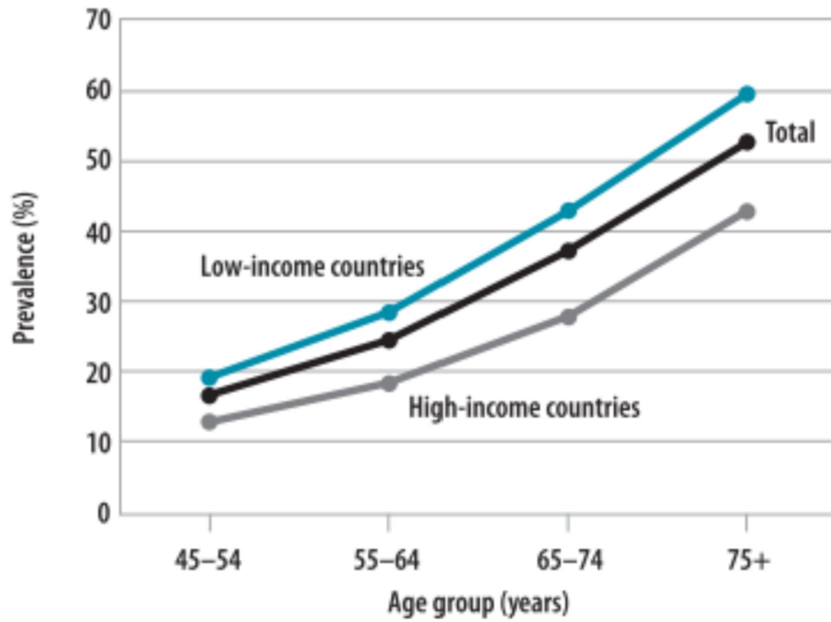


Figure 1. Age-specific disability prevalence by country income. Demonstrates how: (a) prevalence of disability increases with age, and (b) LMIC have higher prevalence of disability across all age groups (Source: WHO, 2011 (4))

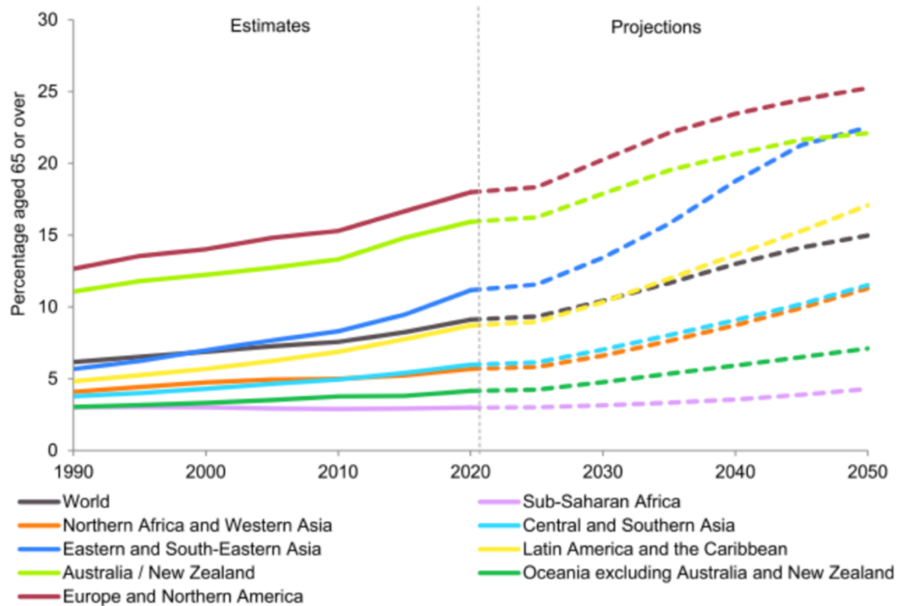


Figure 2. The proportion of the total population aged 65 years or over, by region, 1990-2050. Over the next three decades, the number of older persons worldwide is expected to more than double. The greatest increase will occur in LMIC (Source: WHO, 2019 (3))

There is some evidence that older persons with disabilities may be disproportionately affected in humanitarian crises. They may face additional challenges in these settings and difficulty accessing humanitarian assistance (8) because of factors and barriers (see Table 1) associated with both ageing and disability (2,16–18). In recent years, there has been an increasing focus among humanitarian actors on providing better support for older persons and persons with disabilities. For instance, the Age and Disability Capacity Building Programme (ADCAP) (17) and Inter Agency Standing Committee (IASC) Humanitarian Guidelines (19) highlight the disproportionate impact of humanitarian crises on older persons and persons with disabilities and provide guidelines for humanitarian actors on improving access and effectiveness of humanitarian response. It is widely acknowledged in humanitarian response and research that older persons with disabilities have unique experiences and challenges in humanitarian crises. Yet, research typically focuses either on older persons or persons with disabilities, separately. There have been a limited number of studies that have focused on the lived experiences of older persons with disabilities in humanitarian situations (Chapter 4). Particularly, little is known about their ability to access humanitarian services and how they meet their daily and humanitarian service needs.

Table 1. Common types of barriers faced by persons with disabilities in humanitarian crisis settings (Source: (20))

Type of Barrier	Description
Physical	Inaccessibility of the built or natural environment. e.g., rough terrain; stairs; lighting; ventilation; inaccessible facilities, buildings, evacuation routes, and equipment; etc.
Information or Communication	Inaccessible information or knowledge. e.g., information only delivered in one manner (text or sound), lack of sign-language or braille materials
Organizational or Institutional	Laws, policies, strategies or practices that discriminate against persons with disabilities. May not be intended but can indirectly exclude persons with disabilities by not taking needs into account.
Attitudinal	Attitudes of others (individual, society or group) can deny persons with disabilities their dignity and create disabling environments. e.g., stigma, discrimination, bullying, fear, low expectations, and the inability to see past impairment.

Most of the research on older persons and persons with disabilities has been conducted in singular humanitarian situations, but rarely examined through a comparison of settings. Comparing across settings can improve the understanding of how context shapes experiences, address the tendency to over-generalise and transfer (21,22) (e.g., Western dominated ideas of and responses to crises, disability, and older age in different settings), and may provide insight into context appropriate strategies in humanitarian response. This research will focus on two different humanitarian contexts – the conflict in Eastern Ukraine and refugee camps in Tanzania (More detail is provided in Chapter 5).

1.1.2 Humanitarian response

A humanitarian crisis is *"an event or series of events that represents a critical threat to the health, safety, security or wellbeing of a community or other large group of people, usually over a wide area"*, according to the Humanitarian Coalition (23)(p.1). The types of humanitarian crises include natural disasters (e.g., earthquakes, floods and cyclones), man-made (e.g., conflict) and complex (where there is considerable breakdown that goes beyond the capacity of a single agency (24)) (23). Humanitarian actors are the groups that respond to crises and include non-governmental organizations (NGOs), agencies (e.g., UN), inter-agency networks and governing bodies (25). The coordination of crisis is typically undertaken by the United Nations (UN) and is arranged according to the 'cluster approach' (Appendix 1) (26). Clusters are groups of humanitarian organizations (organized by the IASC) that collaborate and coordinate on items related to the main sectors of humanitarian action (e.g., health, protection, WASH). The cluster approach is shown in Figure 3 (26). This figure outlines the various clusters and (along the bottom) the response continuum (including prevention to reconstruction) (26).

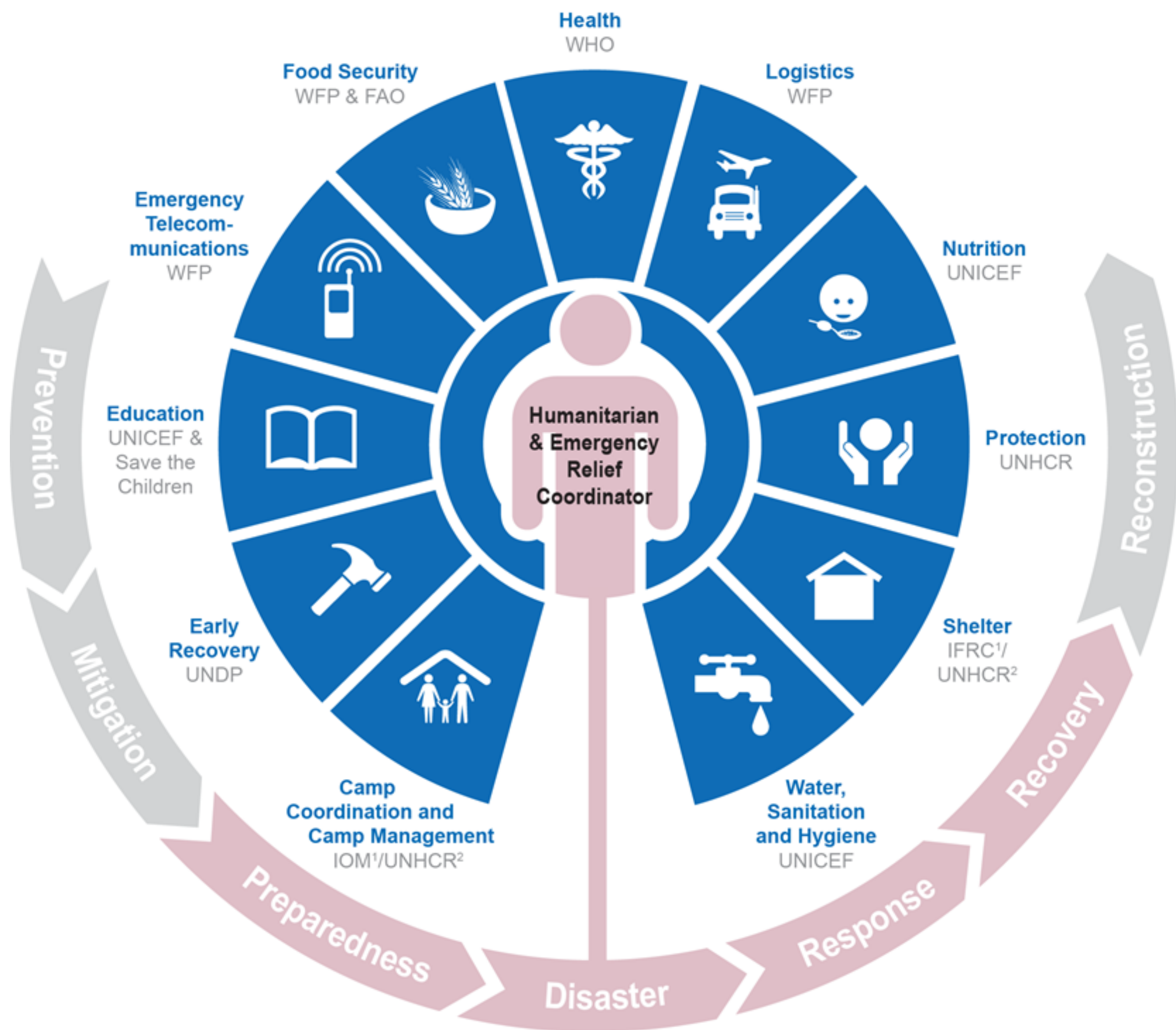


Figure 3. The United Nations cluster approach (Source: (26))

Age and disability inclusion are seen as cross-cutting considerations, meaning that they should be considered in all aspects of humanitarian coordination (8,19,27). There are also several guidelines and standards on age and disability inclusion in humanitarian crises (Table *2*) (Further description in Appendix 2). The twin-track approach (a combination of mainstreaming inclusion across all areas and targeted initiatives) is commonly advocated for age and disability inclusion in humanitarian action (19,28). There appears to be a growing understanding of the intersectionality of older persons with disabilities in humanitarian action but little evidence to guide recommendations and programs.

Table 2. Guidelines, conventions and standards on age and disability in humanitarian response

Guidelines, conventions and standards on age and disability in humanitarian response
- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (29) - Sphere Humanitarian Charter and Minimum Standards in Humanitarian Response (30) - Core Humanitarian Standard for Quality and Accountability (CHS) (31) - The Sendai Framework for Disaster Risk Reduction (SFDRR) (32) - The Sustainable Development Goals (SDGs) (33) - The Charter on Inclusion of Persons with Disabilities in Humanitarian Action (34,35) - The Inter Agency Standing Committee (IASC) 'Guidelines on the inclusion of persons with disabilities in humanitarian action'(19) - United Nations Disability Inclusion Strategy is a process that began in 2018 to strengthen disability inclusion across the entire UN system (36). - ADCAP - Minimum Standards for Age and Disability Inclusion in Humanitarian Action (17). - ADCAP - Humanitarian Inclusion Standards for Older People and People with Disabilities (8).

CHAPTER 2: KEY CONCEPTS EMPLOYED IN THIS THESIS

In this section, I introduce the key concepts relevant to this thesis, beginning with the concepts of 'disability', 'ageing' and 'intersectionality'. I then move on to discuss how 'emergency framing' is often used to frame decisions and practices in the field of humanitarian action, including for older people with disabilities, and how such normative framings can both help and hinder our understanding of the needs for this population and how assistance should and does happen. A common thread running through social science critiques of each of these concepts is the importance for both humanitarian crisis response and research of attending to peoples' holistic lived experiences within the social context.

2.1 Disability

Disability is complex and difficult to define. Various models have been developed to help explain the concept. The earlier models tend to focus on the physical body and impairments whereas the more recent ones incorporate social and environmental components and attempt to encapsulate the complex and multidimensional interactions involved.

The earliest conceptual model of disability is the moral or religious model (37). This model can be broken down into two distinct views. The first was that disability is a punishment for past behaviour (e.g., moral or ethical sin) from the individual, a family member or a relative (the greater the sin the more severe the disability) (37,38). The second saw disability as a test of faith where persons with disabilities and their families were seen to be chosen to gain patience and courage through suffering (37). Most disability advocates and researchers now reject the moral/religious model of disability (39,40). The same is true for organizations, policies and guidelines. However, this conceptualisation is still quite widespread around the world, especially in rural areas (37,39,40). In areas where the moral/religious model is predominant, persons with disabilities often face stigma and discrimination because it perpetuates the idea that persons with disabilities differ from 'able-bodied' norms (37,41). Stigma is the process of devaluing and dehumanising certain groups and involves labelling, negative stereotyping, linguistic separation and power asymmetry (42). Discrimination is exclusion based on difference (age, sex, identity, culture, religion, disability, etc.) (43–45). Stigma towards persons with disabilities can result in discrimination (46–48).

One of the earliest models, the charity model, views persons with disabilities as unfortunate and something to be pitied (37). This model often depicts persons with disabilities as helpless and dependent on others for care and protection (37). As such, this view holds that persons with disabilities cannot arrange for their own needs and have to rely on assistance and care from others (37,38). Persons with disabilities are expected to accept and be grateful for the assistance they receive (37). Interventions based on this model tend to have an assumption that persons with disabilities are dependent and require assistance and specialist services from 'experts' (49). Most in the disability community as well as research, advocacy and organizations view the charity model as negative as it perpetuates negative stereotypes and misconceptions of persons with disabilities. However, this type of framing arguably continues to pervade humanitarian action.

The medical model of disability came about in the late 1800s with the advancements in medical sciences, largely replacing the moral/religious model (37). The medical model views disability as a physical or pathological problem that needs to be solved and prioritizes medical and rehabilitative interventions (37,50). Disability is seen as something to be prevented and cured or minimized as much as possible (37). Therefore, (in contrast to the social model – discussed below), the medical model focuses on limitations associated with a person's impairment and adjusting the individual or physical body to the environment. This model disregards the role of society and the environment in exacerbating or causing disability (51). According to Retief and Letšosa (37), the medical model can endow medical professionals who diagnose persons with disabilities with tremendous power, because diagnosis (and treatment) is based on what is deemed 'normal' in society. Yet, those very experts are the ones who determine what is in fact 'normal'.

The social model of disability is generally described as developing in response to critiques of the medical model and more adequately reflects the lived experiences of persons with disabilities. Its development was led by disability advocates and Organisations of People with Disabilities (OPD) (also referred to as Disabled People's Organisations (DPOs)) (52). The social model has been the predominant view of disability since the 1980s and has had a profound impact on how we view disability today. The social model laid the groundwork for the development of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (53). In contrast to the medical model, the social model of disability states that the challenges faced by persons with disabilities are not in their physical bodies but due to the physical and social constructs in which they live (4,52,53). As described by Lawson and Beckett (53)(p.363) the social model, *"describes the process of disablement and defines disability as a form of social oppression".* This model provides an important distinction between 'impairment' and 'disability'. The

former, impairment, includes functional limitations caused by physical, mental, or sensory conditions (53,54). The latter, disability, refers to disadvantage and marginalisation as a result of the way the environment and society respond to that impairment (53,54). According to this view, since it is society that results in disability, solutions should involve changes to society rather than to the individual (37).

The social model has been subject to scrutiny, however. The main critique is that the social model does not acknowledge the realities of impairment as a disabling factor and that the distinction between impairment and disability is artificial (37). Some state that the model is too simple and does not adequately capture the experience of disability (53). However, some disability advocates (who developed the model) have stated that it is the "heuristic qualities" of the model that make it an effective tool which can be adapted to specific contexts to identify where policy reform is needed (53)(p.364). Another critique of the social model is that it tends to focus on physical impairments rather than all types of impairments (53,55).

The human rights model of disability was borne from the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and, as the name suggests, views disability as a human rights issue. The UNCRPD explains that *"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* (56)(p.4). This model recognizes disability as a social construct which is created when impairments interact with societal barriers (54). Some researchers and organizations have used the social model and human rights models interchangeably yet, most see them as distinct (37,54). Lawson and Beckett (53) state that the models have much in common yet should be seen as performing distinct functions and working together. The social model is a 'model of disability' – it describes the process of disablement and defines disability as a form of social oppression (53). As such it serves to identify where policy reform is needed. The human rights model on the other hand is a 'model of disability policy' – it provides guidance on policy responses to disability (53). With both the social and human rights model, disability has increasingly become understood as an interaction of factors including social and environmental barriers. Therefore, context is vital to understanding disability.

Perhaps the most widely used conceptual framework for disability, currently, is the World Health Organization (WHO)'s International Classification of Functioning, Disability and Health (ICF) (Figure 4) (50,57) which aims to encapsulate the multifaceted experience of disability including the 'medical' and 'social' factors. The ICF understands disability as a dynamic interaction between health conditions and contextual factors that are both personal (e.g., age, sex, education) and environmental (e.g., terrain,

building design, laws) (4,57). This is described as a "bio-psycho-social model" where disability is defined as *"the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)"*(4)(p.4). According to the ICF, impairments are problems in body function or alterations in body structure (e.g., paralysis or blindness). Limitations are defined as difficulties executing activities (e.g., walking or eating) and participation restrictions are problems with involvement in any area of life (e.g., due to discrimination) (4,57). However, these are not inevitable. Two individuals with the same impairment do not experience the same restrictions because they are mediated by personal and environmental factors. Personal factors *are "the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states" (e.g., age, gender, other health conditions, social background)* (57)(p.17). Environmental factors *"refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning."* (57)(p.214). This includes the individual level (immediate environment such as home, workplace or school) and the societal level (community, government, transportation, laws, attitudes, and ideologies) (57) *(*p.17*).* Defining disability in this way - as an interaction of factors rather than an aspect of an individual - means disability can be reduced by eliminating environmental and social barriers which hinder an individual's full and active participation in daily life (4).

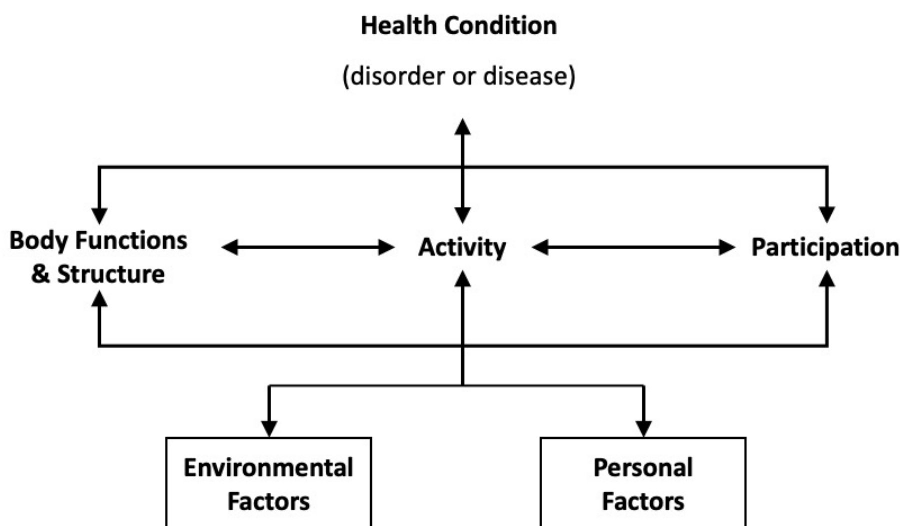


Figure 4. International classification of functioning, disability, and health (Source: (57))

2.2 Ageing

2.2.1 Ageing Frameworks

Across the globe, older people hold important roles in communities, including in humanitarian crises. They are often economically active and take on multiple social roles such as assisting with the care responsibilities of younger family members, providing wisdom and advice to younger generations (58) and helping to preserve culture and language (58). There have been several thoughts and frameworks on ageing and older age. I will discuss the most common ones in this section and follow it with how this compares with the common disability frameworks.

Many of the traditional perceptions of ageing in global and humanitarian health reflect the biomedical model, where ageing is viewed primarily as a physical process (59). For instance, international convention defines "older age" as 60 years of age and older (2,8). This age has been used because, as stated in the World Health Organization (WHO) World Report on Ageing and Health (2)(p.26), *"by age 60, the major burden of disability and death arise from age-related losses in hearing, seeing and moving, and non-communicable diseases, including heart disease, stroke, chronic respiratory disorders, cancer and dementia"*. The focus of this definition is self-evidently on physical and cognitive health as it relates to disability and death in older age. It also reflects another common conception of the biomedical model and of earlier models and theories on ageing from medical sociology and the sociology of ageing more broadly – that older age is a time of decline and withdrawal (both physical and social) (59). According to this traditional model, the main response to the problem of ageing should be to slow or stop the ageing process (59). Ageing from the biomedical point of view is considered something to fight against (59).

It is now more widely understood that ageing is more than a physical or cognitive process and that older age is not simply a time of decline and withdrawal. Research on ageing has progressed towards an acknowledgement of the multifaceted and complex interaction of factors, including social contributors (59). A report developed by the United Nations (UN), HelpAge International and AARP, explains that *"the concept of 'old age' is multidimensional, which includes chronological (based on birthdate), biological (related to human body ability), psychological (concerned with psycho-emotional functioning) and social age (related to social roles such as grandparents)"* (60)*(p.21)*. There has also been a conceptual shift from that of preserving life and preventing decline (physical and cognitive) and withdrawal (from social interactions and livelihood) to an active approach and one of prioritizing quality of life and participation (59,61). With this has come a focus on 'successful ageing'.

Researchers have paid particular attention to 'successful ageing' in the literature, however, there are many definitions and overlapping terms (such as healthy ageing, productive ageing, active ageing, and ageing well, among others) (62). One of the most common conceptualizations of successful ageing was developed by Rowe and Kahn (63)(p.433) who defined it as including: *"low probability of disease and disease-related disability; high cognitive and physical functional capacity; and engagement with life"* (63)(p.433) (most importantly interpersonal relations and productive activity (activities that create societal value) (Figure 5). They go on to explain that *"… successful ageing is more than the absence of disease… and more than the maintenance of functional capacities... Both are important components of successful ageing, but it is their combination with active engagement with life that represents the concept of successful ageing more fully"* (63)(p.443). There is a significant focus on activity and function (in contrast to the biomedical approach) and how to expand healthy and functional years in the life span (62,64). Along with this, there is an emphasis that the risk factors that can negatively influence ageing are largely modifiable (64).

The successful ageing approach promoted more positive views around ageing with an emphasis on policies and programmes that promote individual agency and healthy lifestyle changes, according to Stowe & Cooney (2014) (64). However, this model has been subject to much debate and is no longer believed to adequately represent ageing. The focus on personal agency and ageing outcomes as modifiable can lead to negative attitudes and stigma towards older people who are in poor health (64). In addition, according to Urtamo (62)(p.361), more recent research has suggested that *"the absence of disease and disability is not the most important element in the concept of successful ageing and that people with chronic disease can also age successfully"*. The primary critique of Rowe and Khan's model is that it does not take into account the developmental processes, earlier life events and how some factors can have an influence on ageing over time (64).

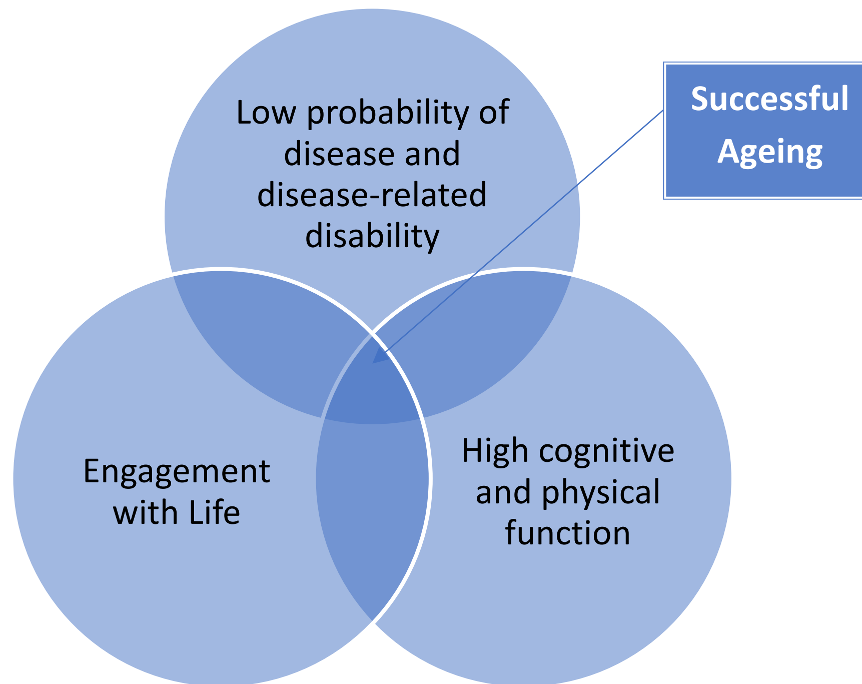


Figure 5. Model of Successful ageing (Adapted from Rowe & Khan, 1997 (63))

The "life course perspective" (LCP) addresses the critiques of Rowe and Khan's model of successful ageing. It views ageing as a lifelong process and acknowledges the effects of events earlier in life in shaping the experience and outcomes throughout one's life (including function and wellbeing) (64–70). It also acknowledges that factors prior to birth (such as genetics and family socioeconomic status) can have an influence on older age (64–70). The events and situations earlier in life (and prior to) can impact older age by (1) occurring at critical periods of development (principle of timing); (2) having a cumulative effect over time; or (3) influencing intermediate life situations, conditions and roles that can subsequently influence later-life outcomes (social trajectory model) (64). The life course perspective highlights how some factors are modifiable, while others are not. Context and life experience are critical in shaping older age (64–69). For instance, experiences during childhood and throughout life, (such as living in poverty, parental behaviours and abuse, health, and discrimination) can all have an influence on older age (64–70). Even individual and societal perceptions of ageing can influence outcomes in older age (59,61,71) (Appendix 3). It is important to note that positive life experiences and situations can also influence ageing (72). In addition, the life course perspective highlights the effect of social experience, relationships (with family and friends), and support structures on ageing (64–70). A visual representation of the life course perspective is presented in Figure 6 (65).

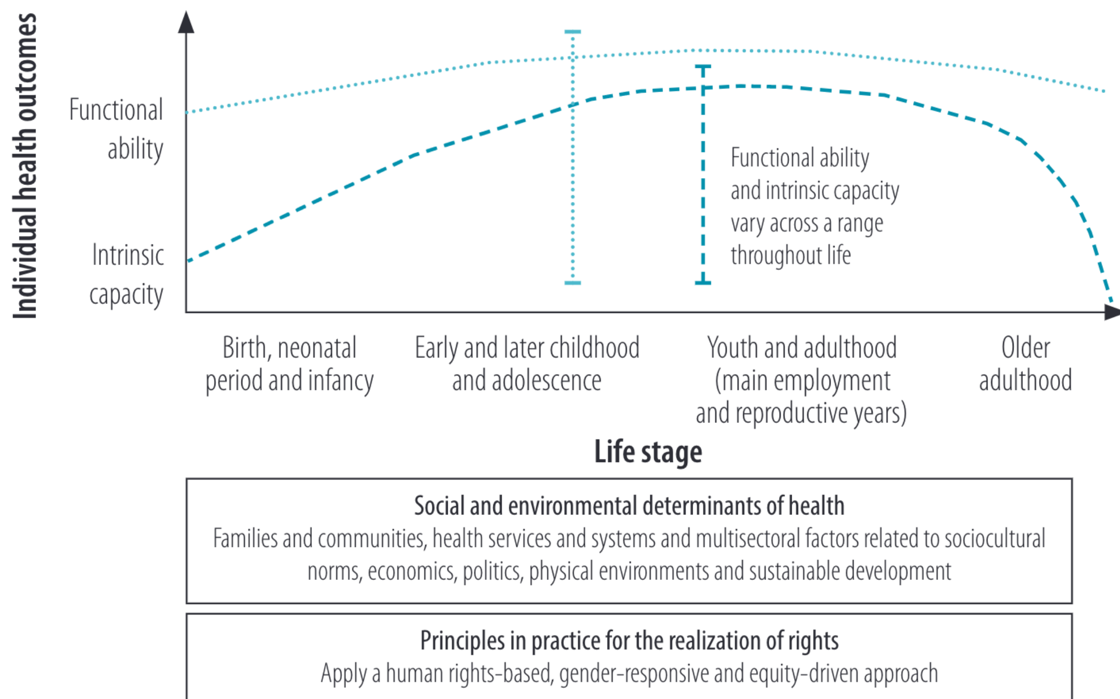


Figure 6. Visual representation of the life course perspective of ageing (Source: (65) (p.43))

Descriptions of the life course perspective (LCP) of ageing state that functional ability is the primary outcome of the life course perspective and is *"the sum of the individual and environmental attributes that enable a person to be or do what they have reason to value"* (65). They go on to explain that *"functional ability is determined by the individual's intrinsic capacity and physical and social environments and by the interaction between the individual and these environments"* (65). *"Functional ability also takes into account the interaction between, and the inter-dependence of, individual, social and environmental determinants of health and the individual agency and collective actions required to ensure health and well-being throughout life"* (65). Intrinsic capacity is the combination of physical and mental capacities (65). In Figure 6 (above), functional ability and intrinsic capacity are depicted as idealized arcs across the life course (65). Kuruvilla et al., (2018) (65) explain that *"intrinsic capacity follows a biologically determined trajectory of physical and mental capacities. In contrast, functional ability can be optimized throughout life by a supportive environment. The vertical bars in Fig. 1 indicate that functional ability and intrinsic capacity can vary across a range at all life stages. This variability depends on the individual's circumstances*

and on the critical events that influence health trajectories." (65)(p.43). For simplicity and clarity, I have created a visual representation of the LCP, specifically as it relates to functional ability Figure 7.

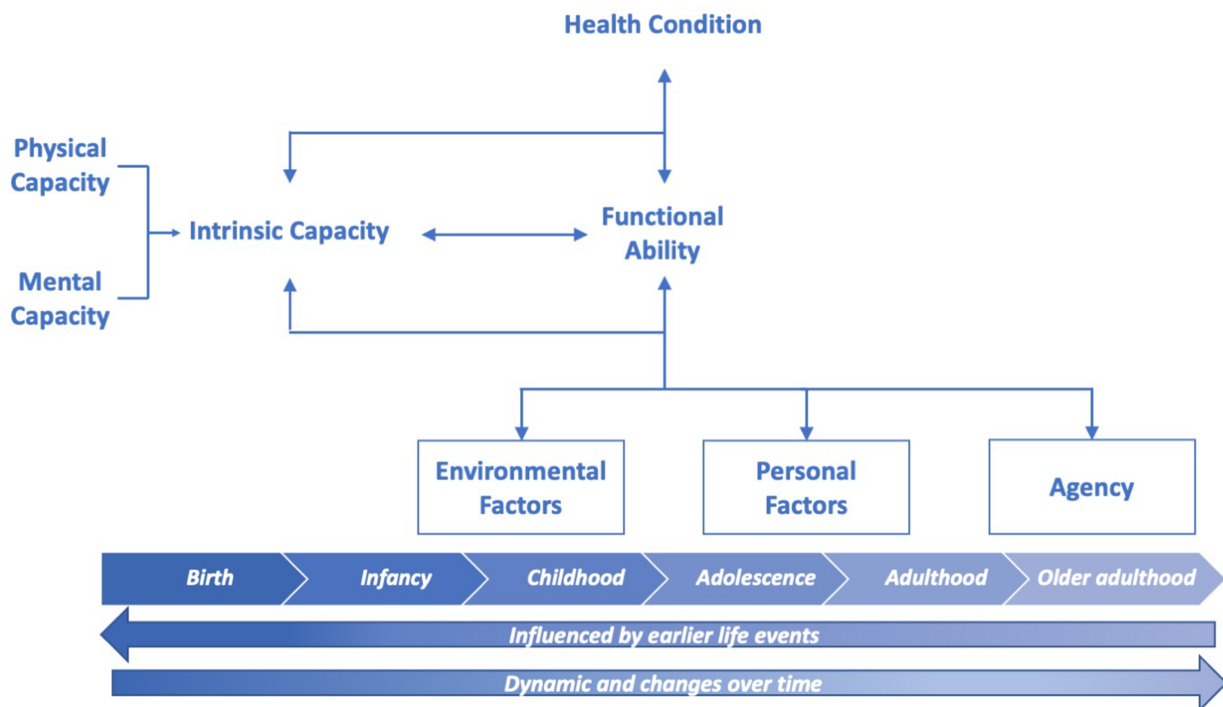


Figure 7. Visual representation of the life course perspective of ageing as it relates to functional ability (Created based on description of the LCP by Kuruvilla, 2018 (65)).

This perspective is the preferred understanding of ageing as it incorporates the multifaceted experience and contributors throughout the lifespan. Humanitarian actors, such as HelpAge International, highlight this approach and how the experience of ageing is unique to individuals. In describing the implications of the life course perspective, HelpAge explains: *"How policies and programmes are implemented affects our lives across the life course and influences our wellbeing in old age. In designing policies, we must look forward at their impact in our older age, but also look back and respond to older people's diverse past experiences…"* (72).

2.3 Comparing the ICF framework of disability and the life course perspective of ageing

The life course perspective has many similarities with the ICF framework of disability (65), which I have outlined in Table 3. Both frameworks acknowledge the influence of a range of factors in shaping ageing and disability, respectively. This includes biological, health conditions, and contextual factors that are personal and environmental. Both frameworks recognize that an individual's experiences are dynamic and change over time. The LCP acknowledges how earlier life events and events prior to birth impact ageing. The influence on earlier life events is included in the ICF, (50) however, not as explicitly. Also implicit in both the LCP and ICF is that positive experiences or factors have a positive influence on the individual (57,72).

There are also differences between the ICF and LCP frameworks (Table 3). The ICF is a conceptual framework for disability and is used as a classification system to describe health related conditions (73). The ICF is primarily concerned with how health conditions and contextual factors influence participation and functioning whereas the LCP focuses on how people experience ageing and transition through life stages. Although the label for the primary outcome of the LCP is "functional ability", which at a surface level seems to be simply a physical outcome, it focuses much more on the freedom that people have to live a life that they would like. Functional ability is defined as *"the sum of the individual and environmental attributes that enable a person to be or do what they have reason to value"* (65).

Another difference is that the LCP explicitly recognises the agency of the individual in shaping experience. Agency has been described as *"the feeling of control over actions and their consequences" (a sense of* "*being in the driving seat when it comes to our actions")* (74)(p.1). Therefore, it relates to an individual's sense and power to make decisions and act on what they have reason to value (73). The ICF framework does not include agency. This has been flagged as a limitation of the ICF and a reason why some advocates and scholars are calling for a revision of the framework (75). Another minor difference is that the LCP states the importance of collective actions to promote health and well-being throughout life. The ICF does not include this explicitly. However, the importance of policies, initiatives and so called "collective action" is included in external factors.

Table 3. Comparison of the International Classification of Functioning, Disability and Health and the Life Course Perspective of ageing.

	ICF Framework of Disability	Life Course Perspective of Ageing
Overview of framework	Disability is *"the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)"*(4)*(p.4).*	Views ageing a life-long process. Acknowledges the effects of events earlier in life in shaping the experience and outcomes throughout one's life. (64–70). Main outcome: functional ability (65)
Focus of Framework	How health conditions and contextual factors influence participation and functioning	How people experience ageing and transition through life stages
Dynamic Interaction between individual and contextual factors	√	√
Acknowledges importance of earlier life events	√ (Indirectly included – incorporated in personal factors)	√ (Main focus of framework – events prior to birth and throughout life)
Experiences are dynamic and change over time	√	√
Acknowledges effect of positive experiences	√	√
Acknowledges Agency as an influencing factor	X	√

2.4 Suffering and agency in humanitarian crises

Today, the humanitarian sector is a large, global industry with international collaboration and coordination, and involvement in virtually all aspects of global health and international politics (76–80). Multiple histories of humanitarianism have unfolded around the world and uniquely affect how humanitarianism is practiced globally (81). However, many contemporary global practices and philosophies of humanitarianism stem from the international humanitarian system's historical roots in European battlefields where medical actors were providing care to soldiers and civilians of their own and other countries and prisoners of war (76–80). Some of the most persistent ideas around vulnerability, suffering, expertise, and the ways decisions should be made in humanitarian settings (79,80) are described next (for a more thorough description of humanitarianism See Appendix 4)

Importantly, humanitarian agencies and NGOs tend to define themselves and frame their work in terms of 'emergency' relief and crisis response, even though most now maintain a long-term presence in many countries and incorporate long-term social development activities into their work (77,79,80). This section will explore how framing in terms of crisis or emergencies can: neglect an examination of the causes of suffering and crises; make the events seem extraordinary; prioritize life over dignity; and result in false representations of individuals. These factors can all influence humanitarian response and researchers must take special care to address them in order to inform humanitarian action and preserve the dignity and experiences of those caught up in crises.

2.4.1 Emergencies can neglect an examination of causes of suffering

Humanitarian "emergency" or "crisis" implies that the events require immediate action and decisive response (79,82). As described by Calhoun (80) *"'Emergency', is a way of grasping problematic events, a way of imagining them that emphasizes their apparent unpredictability, abnormality and brevity, and that carries the corollary that response – intervention – is necessary"* (80)(p.3). Humanitarianism thus frames events as sudden and unpredictable when in reality they often develop gradually and are at least somewhat predictable (80,82). To clarify, there are certain hazards and events that are sudden such as earthquakes, tsunamis, and floods (among others) that meet the classic definition of humanitarian crises (82). However, even these events are often (at least partially) predictable and the vulnerability that people and communities experience as a result of them is often exacerbated by a myriad of factors including (often to a large extent caused by) human activity and decision making (80,83).

This type of emergency or crisis framing can result in humanitarian actors responding to humanitarian needs without an examination or comprehensive understanding of the historical and contemporary context, the causes of the emergency and suffering, or who is most at risk (80,82). As a result, humanitarian intervention alone is often not a long-term or comprehensive solution to suffering because it does not address the underlying problems that led to it (79,80). The lack of contextual understanding and failure to engage with the individuals affected, local government, organisations (such as Organisations of People with Disabilities (OPD) and Older People's Associations (OPA) and local NGOs), and experts in the area (such as medical professionals) can lead to a response that is not context appropriate, relevant, or effective. In addition, groups and individuals who are most affected and marginalized in humanitarian crises (such as older persons and persons with disabilities) may be missed in the response. In short, a 'one-size-fits-all' response that humanitarians are forced into in the rush of needing to make decisions quickly can create problems. This is well understood, and humanitarian agencies do not claim to solve all short- and long-term issues.

This certainly does not mean that humanitarian relief should, or could, be abandoned in lieu of long-term solutions (80). In fact, as Calhoun (80) explains, the very nature of these circumstances is often the result of problems that do not have quick and easy solutions. What is needed, however, is a system that addresses both. As stated by Redfield (79): "*Simply to denounce situations would achieve no immediate humanitarian ends and to endorse political agendas would potentially sacrifice the present needs of a population for the hope of future conditions…" (p.342)*. For humanitarian response and research, this means that an understanding of the context, historical aspects of the situation and the underlying causes of suffering are needed to effectively respond to the social protection needs of individuals and progress towards long-term solutions for society.

Another argument in the literature is that emergency or crisis framing makes it seem as though humanitarian emergencies are the exception to an otherwise peaceful order when in fact, they are quite common (80,82). Several researchers have used the following quote by Walter Benjamin to help explain the normality of humanitarian crises: *"the tradition of the oppressed teaches that the 'state of emergency' in which we live is not the exception but the rule"* (79) (p.340) (80)(p.15). These events are devastating and need attention and response but, they are not as unusual or unpredictable as conventionally described (80). By changing our perception of crises as "unusual" to "commonplace", we can improve the response to crises and develop plans for better dealing with them while also decreasing their frequency and addressing their root causes (80).

2.4.2 Emergencies can displace preservation of agency and dignity

Humanitarianism focuses on decreasing suffering and saving lives (79,82) and the response mechanisms of humanitarian organizations often reflect this (84). However, this focus on preserving life and decreasing suffering can displace the agency and dignity of those affected by crises. As Calhoun (80) explains: *"Thinking in terms of humanitarian emergencies draws on this sense of agency in promoting intervention to minimize the suffering. But it precisely denies agency to those who suffer" (p.18).* In this quote, Calhoun is pointing out the agency that humanitarian actors have to intervene and simultaneously the displacement of agency for those affected by crises. One of the most prominent examples of this is the concept of the refugee camp as intervention, which has been the subject of significant critical anthropological analysis.

Shortly after the development of the Universal Declaration of Human Rights (UDHR) in 1948, Hannah Arendt highlighted the challenges faced by "stateless people" including those who have been displaced, especially refugees (85)(p.119). Arendt noted that the UNDR declared the protection of rights irrespective of national affiliation, however, no political community could defend these rights for stateless people because the power to do so remained within nation-states (85). As a result, they were left with the rights of those who are "*nothing but human*" ((86)as cited in (85)(p.119). Italian philosopher Georgio Agamben made the connection between concentration camps and refugee camps and expanded on Arendt's use of *Zoë* and *Bios*, ancient Greek terms for life (79) with the former, *Zoë*, representing *"zoological life, the simple act of living"* and the latter, *Bios*, signifying *"biographical life, a life that is properly formed through events such that it can be narrated by story*" ((87)(p.8-9) as cited in (79)(p.340)). Agamben described the condition within the camps as "bare life" – where "*human subjects are reduced to a depoliticized state without status or political rights and freedoms"* (88,89). In other words, refugees are often reduced to *Zoë* at the expense of *Bios.* Redfield (79)(p.342) explains in discussing refugee camps: *"In this setting, human zoology exceeds biography: those whose dignity and citizenship is most in question find their crucial measurements taken in calories rather than in their ability to voice individual opinions or perform acts of civic virtue. The species body, individually varied but fundamentally interchangeable, grows visible and becomes the focus of attention"*. A critical component of bare life literature is that the focus on preserving life and the body (*Zoë*) displaces people's individual stories and experiences (their biographies – *Bios*), including their agency and efforts to manage their situation (82). In summarizing the work of Boltanski (90), Ticktin (82)(p.3) writes: *"humanitarianism requires innocent sufferers to be represented with the passivity of their suffering, not in the actions they take to confront and escape it"*.

Lisa Malkki (1995) (91) challenged the traditional notions of 'bare life' to argue that refugees are diverse individuals with unique personal histories and situations. In her 1995 article "Refugees and Exile" (91)(p.496) she explained: *"Forced population movements have extraordinarily diverse historical and political causes and involve people who, while all displaced, find themselves in qualitatively different situations and predicaments. Thus, it would seem that the term refugee has analytical usefulness not as a label for a special, generalizable "kind" or "type" of person or situation, but only as a broad legal or descriptive rubric that includes within it a world of different socioeconomic statuses, personal histories, and psychological or spiritual situations".* In her research with Hutu refugees who were displaced from Burundi in 1972, Malkki suggested that camps are both products and producers of national identities and politics (85). Her work explained how histories are important for understanding the complexities within a displaced population and for making it possible for displaced people to pursue their desired futures (92)*(p.560)*. Therefore, while humanitarian action tends to respond to refugees as a homogeneous group, and a *"problem"* that can be dealt with through management and response that is devoid of knowledge of the history and context that led to people being displaced (92)(p.560), refugee populations are in fact individuals with unique and personal histories and experiences that continue to evolve in relation to the political realities which shape life after crisis, including the politics and norms of humanitarian response.

Since Malkki's original work, researchers have developed similar critiques of the humanitarian system, including response mechanisms for displacement and refugees (92)*(*p.560*)*. Williams (2020) (92) explains that despite the continued critiques on displacement and refugees, most researchers continue to focus on the biological needs of refugees (92)(p.561). Few researchers have moved beyond looking at refugees as a collective, homogeneous group that are passive recipients of aid to explore their lived experiences and how they make choices about their lives and meet their needs (92).

The anthropological analyses of refugee camps help to highlight the experiences of people in all humanitarian crises, including IDPs, people who need shelter in place as well as people who have decided not to move. The individuals who find themselves in these situations are much more than uniform bodies that need to be saved. They are unique individuals with diverse stories, experiences, histories, and perspectives. Yet research in this area has historically responded by focusing on measuring suffering and death and biological needs, rather than individual experiences (79). This may have a particularly negative effect on individuals and groups who are more often marginalized and excluded from humanitarian response (such as older persons with disabilities) (93,94). It is important, therefore, that humanitarian

action and research that aims to inform it goes beyond thinking about the need to secure 'bare life' to provide solutions that reflect and elevate the voices and experiences of individuals affected by crises.

2.4.3 Emergencies create 'hierarchies of humanity'

Emergencies often create imaginary representations of people (80,82,95,96). One such representation, as described by Miriam Ticktin (82), is the portrayal of innocence. The 'classic' victims of emergencies and the subjects of humanitarianism are children, women, older persons and persons with disabilities – the innocent who faces disaster and bears no responsibility for their suffering (80,82). The portrayal of persons with disabilities has many similarities in these contexts. In fact, this innocence, passivity and need to be 'saved' is what Ticktin (82) suggests qualifies people for humanitarian compassion and assistance. There are several issues with the image of innocence. First, like the focus on bare life, it leaves no space for the experiences of life or individual biographies (82). Second, it creates "hierarchies of humanity" ((97) as cited by (82)) and separates people into those who are in need of help (the innocent sufferer) and those who can feel and act on compassion and have the power to protect and undertake rescue (the humanitarian) (82,96). Not only does this stifle the voices of people affected by crises but it can perpetuate the often essentialized view of certain populations and people as victims (95,98). Thus, emergency or crisis framing can lead to exclusions and marginalisation (95,96).

2.5 Intersectionality

Intersectionality was coined by Kimberlé Crenshaw who looked at the multi-dimensional experience of black women In the United States (99,100). Crenshaw used the term to describe the marginalization of black women in anti-discrimination law as well as feminist and antiracist movements and policies (99–101). Crenshaw argued that individuals possess multiple identities and that these identities intersect with one another to create unique experiences, marginalizations and discriminations policies (99–101). Since then, the concept of intersectionality has evolved to be used by academics and activists to cover a range of issues and social positions around the globe and cover many disciplines. In 2013, Crenshaw and colleagues described intersectionality as *"a method and a disposition, a heuristic and analytical tool"* (102)(p.1).

Intersectionality *"recognizes that people's lives are shaped by their identities, relationships, and social factors. These combine to create intersecting forms of privilege and oppression depending on a person's context and existing power structures such as patriarchy, ableism, colonialism, imperialism, homophobia and racism",* according to a report developed by the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) and UN Women (103)(p.8). They represent this using the "Intersectionality Wheel" (Figure 8). Intersectionality developed from the work and advocacy of Black feminist scholars who examined the complex and interconnected experiences of Black women in the United States in the 1980s (104)(p.15). The term *"intersectionality"* was introduced by Kimberlé Crenshaw in 1989 (99) to address the marginalization of Black women in the legal system and situations of domestic violence as well as social movements, theory and politics (101,102,104,105). Since that time, it has been used in various disciplines, locations and contexts areas around the globe from activism to academia to understand the complex web of social identities and discrimination and as a tool to address the inequities created by them (104). Crenshaw and colleagues explain that *"intersectionality is a method and a disposition, a heuristic and analytical tool"* (102)(p.303). In an interview in 2013, Crenshaw described intersectionality *"as a lens through which you can see where power comes and collides, where it interlocks and intersects…"* (106)*(p.1).*

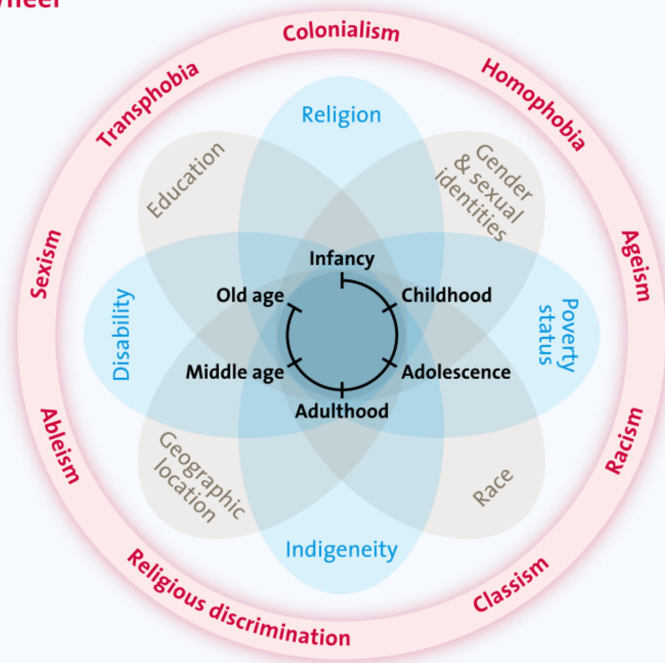


Figure 8. Intersectionality wheel demonstrating the various factors (identity, relationships, social) that combine to create intersecting forms of privilege and oppression depending on a person's context and existing power structures (note this figure does not include all intersecting identities) (Source: UNPRPD/UN WOMEN (103) (p.8)).

A report developed by Humanity and Inclusion (HI) and F3E explains that in humanitarian crises (and all contexts), intersectionality shapes a person's experiences, roles and responsibilities, access to and control over resources (such as basic services, healthcare, and education), experiences of power, and the capacity to respond to different barriers and opportunities (93)*(p.6).* An important aspect of intersectionality is that social characteristics such as age and gender are socially constructed identities and that these characteristics (or locations) are not only added, but multiplied and create distinct barriers, challenges, discriminations, and oppression (104)(p.17). Therefore, although this has not been well explored, the experiences of an older person with a disability in a humanitarian crisis are likely not to be simply the experiences of an older person or a person with a disability in the same context – their experiences are unique and complex. So too are the barriers they face.

Another important aspect of intersectionality is that inclusion efforts are often designed to meet the needs of people who fit within a particular socially constructed group and a singular identity (e.g., persons with disabilities, older persons, or children). As a result, it often excludes those who have multiple identities (93,94,104). As stated by Crenshaw, in her landmark piece in 1991: *"the problem with identity politics is not that it fails to transcend difference, as some critics charge, but rather the opposite – that it frequently conflates or ignores intra group differences"* (101)(p.8). The same is seen in humanitarian assistance – efforts towards inclusion are often geared towards particular groups, such as persons with disabilities or older people (94). As a result, the needs, barriers, and risks of people at the intersection of multiple identities, such as age, disability, or displacement status are often overlooked (94,103). So too is the value of these individuals in informing decisions and improving response mechanisms (as described in Chapter 1) (94,103).

2.6 Study Rationale

The preceding two chapters presented information regarding the current evidence on older persons with disabilities in humanitarian crises and examined various frameworks and concepts related to disability, ageing and humanitarian action. Many older persons with disabilities are affected by humanitarian crises, globally and this number is likely to increase, especially in LMIC. Older people with disabilities are likely to have unique experiences in humanitarian crises because of the intersectionality of age and disability. There are commonalities between the predominant frameworks of disability (ICF) and ageing (LCP). Each recognizes the complex and multifaceted nature of the social characteristic and highlights the influence of contextual and personal factors in shaping experience. The LCP additionally emphasizes the influence of earlier life events and agency in shaping the experience of ageing. At the intersection of multiple social characteristics. People have unique experiences and agency. Yet, initiatives often neglect people at the intersection of multiple marginalized identities. Therefore, older people with disabilities are particularly at risk of being neglected in humanitarian response. However, little is known about their experiences in humanitarian crises, the nature of the barriers and facilitators they face in accessing daily and humanitarian support needs and how these are shaped by contextual factors. This understanding is needed to inform evidence-based recommendations and strategies to ensure older people with disabilities are not left behind.

CHAPTER 3: AIMS & OBJECTIVES, DESIGN AND METHODOLOGY

In this chapter, I describe the aims and objectives of this thesis as well as the research design and methodology used to address them.

3.1 Project Background

3.3.1 'The Missing Millions' Project

This DrPH research was completed as part of a wider study conducted in collaboration with HelpAge International titled the *'Missing Millions'* Project which aimed to explore the experiences of older persons with disabilities in humanitarian crisis settings (Figure 9) (107). In this chapter, I will detail the project components that are included in this DrPH and the deeper analysis that took place after the publication of the report.

3.3.2 HelpAge International

HelpAge International is an International NGO that works with older people living in low- and middle-income countries to create better services and policies, and to change the behaviours and attitudes of individuals and societies towards old age (108). HelpAge has national and field offices in both Ukraine and Tanzania. At the time of data collection, HelpAge was working in Ukraine to deliver services to older people affected by the conflict (108). In Tanzania, they were delivering services to older people living in refugee camps as well as providing rehabilitation services for people of all ages (108). For this research, HelpAge assisted with logistics, safety and security, identification of study participants, and access to older persons with disabilities and their families.

Missing millions:

How older people with disabilities are excluded from humanitarian response

Funded by:

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Figure 9. Missing millions report cover page (Source: HelpAge, 2018 (107))

3.2 Research Aim:

The overall aim of this DrPH research was to understand the experiences of older persons with disabilities in humanitarian crises to inform evidence-based recommendations and strategies for humanitarian assistance.

3.3 Research Objectives

- To identify and describe the available evidence exploring the experiences of older persons with disabilities in humanitarian crises.
- To explore the lived experiences of older persons with disabilities in two diverse humanitarian crisis settings (conflict affected areas of Eastern Ukraine and refugee camps in Western Tanzania) including how they access daily and humanitarian support needs.

3.4 Research Overview, Design and Questions

This thesis used several methods to address the research objectives. Figure *10* summarizes the research objectives and corresponding thesis chapter where it is addressed. The methods are described in more detail in the sections that follow.

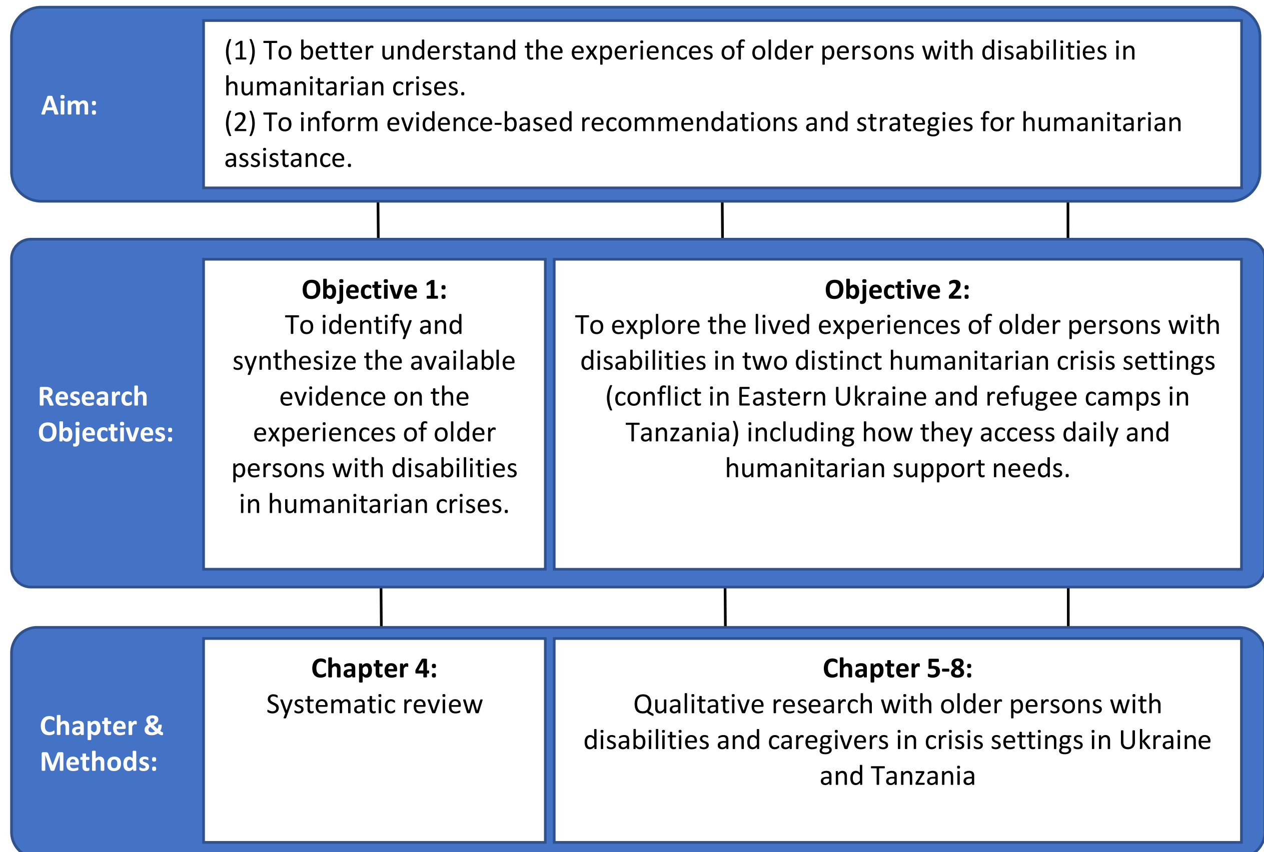


Figure 10. Thesis structure and overview of research aim, objectives and corresponding methods and chapter.

3.4.1 Research design, overview and questions related to objective 1

To address Objective 1, a systematic literature review was conducted to answer the research questions stated below. Further methodological details are provided in Section 3.7.

Research questions related to objective 1:

(1) *What* is the available evidence on the experiences of older persons with disabilities in humanitarian crises?
(2) *What* is the quality of the evidence?

3.4.2 Research design, overview and questions related to objective 2

Objectives 2 and 3 seek to explore the lived experiences of older persons with disabilities in two distinct humanitarian crisis settings – conflict affected areas of Ukraine and refugee camps in Tanzania (Figure *10*).

Phenomenological research methodology underpinned this research and influenced the data collection tools used (109). This type of research describes the lived experiences of individuals as they experience a certain phenomenon and focuses on the commonalities between them (109). Qualitative methods were used because they provide rich insights into how people experience the world and access services (e.g., humanitarian and healthcare) and the complex relationships between various elements that influence a person's experience (22)(p.2).

Green and Thorogood (21) describe that in qualitative studies *"aims are generally to seek answers to questions about the 'what', 'how' or 'why' of a phenomenon…"* (p.5). In objectives 2 and 3, I answered questions related to the *'what'* and the *'how'*. Research questions associated with each objective are as follows:

Research questions related to objective 2:

In conflict affected areas of Eastern Ukraine and refugee camps in Western Tanzania:

(1) *What* are the lived experiences of older persons with disabilities?
(2) *How* do older persons with disabilities meet their daily and humanitarian support needs?

(3) *What* factors (barriers and facilitators) influence their access to daily and humanitarian support needs?
(4) *How* do these experiences and strategies compare between the two settings?

3.5 Frameworks employed in this thesis

3.5.1 Overview of Frameworks

I will draw on the ICF Framework of Disability (50,57) and the Life Course Perspective of ageing (64–70) to examine the experiences of older persons with disabilities in humanitarian crises. These were selected through reviewing the literature and humanitarian guidelines and in consultation with my DrPH supervisory group and the international and national advisory groups. The ICF framework and life course perspective of ageing are the predominant frameworks used for disability and older age, respectively. They are also the frameworks most widely used by humanitarian organizations. As outlined in Chapter 2, there are similarities and differences between the two frameworks (101–105).

Intersectionality has been shown to be a useful framework in health studies research as it allows researchers to explore the complex experiences of individuals at the intersection of various identities, facilitates a greater understanding of their lived experience and assists in developing solutions to address inequities (100)(p.4). In this thesis, intersectionality is used to bring together concepts around ageing, disability, and humanitarian crises. The intersectionality wheel, as depicted in Figure 11 is a visual representation of the intersection of older age, disability and humanitarian crisis in shaping the experiences of older persons with disabilities in humanitarian crises.

Figure 11. Visual representation of intersectionality framework for older persons with disabilities in humanitarian crises and the contributing locations of older age, disability, and humanitarian crises (and respective frameworks).

Intersectionality is commonly presented using the intersectionality wheel such as in Figure 11. While this is a useful visual representation, it risks simplifying and framing the experience of older persons with disabilities in humanitarian crises as the sum of older persons, persons with disabilities and humanitarian crises. The issue with this is that, as described in Chapter 2, intersectionality is more than the sum of an individual's singular socially constructed identities (104)(p.17). For this thesis, a framework was needed that captures the unique experiences of older persons with disabilities that is not simply the addition of age and disability.

3.5.2 Life course Perspective of Disability– A framework on the intersectionality of ageing and disability

For this thesis, I have used a framework that combines the ICF framework of disability and the LCP of Ageing. I refer to this framework as the “Life Course Perspective of Disability” (LPD) throughout this thesis (Figure 12). This framework recognizes that disability is a complex and dynamic phenomenon that is influenced by multiple factors that change over time. It understands disability as a dynamic interaction between health conditions and contextual factors (personal and environmental) and highlights the importance of agency in shaping the experience of disability at all ages (including into older age). The LPD acknowledges the influence of earlier life events in shaping experiences and outcomes throughout one’s life. In Figure 12, I provide a visual representation of the Life course Perspective of Ageing and in Table 4 compare this framework with the ICF and LCP.

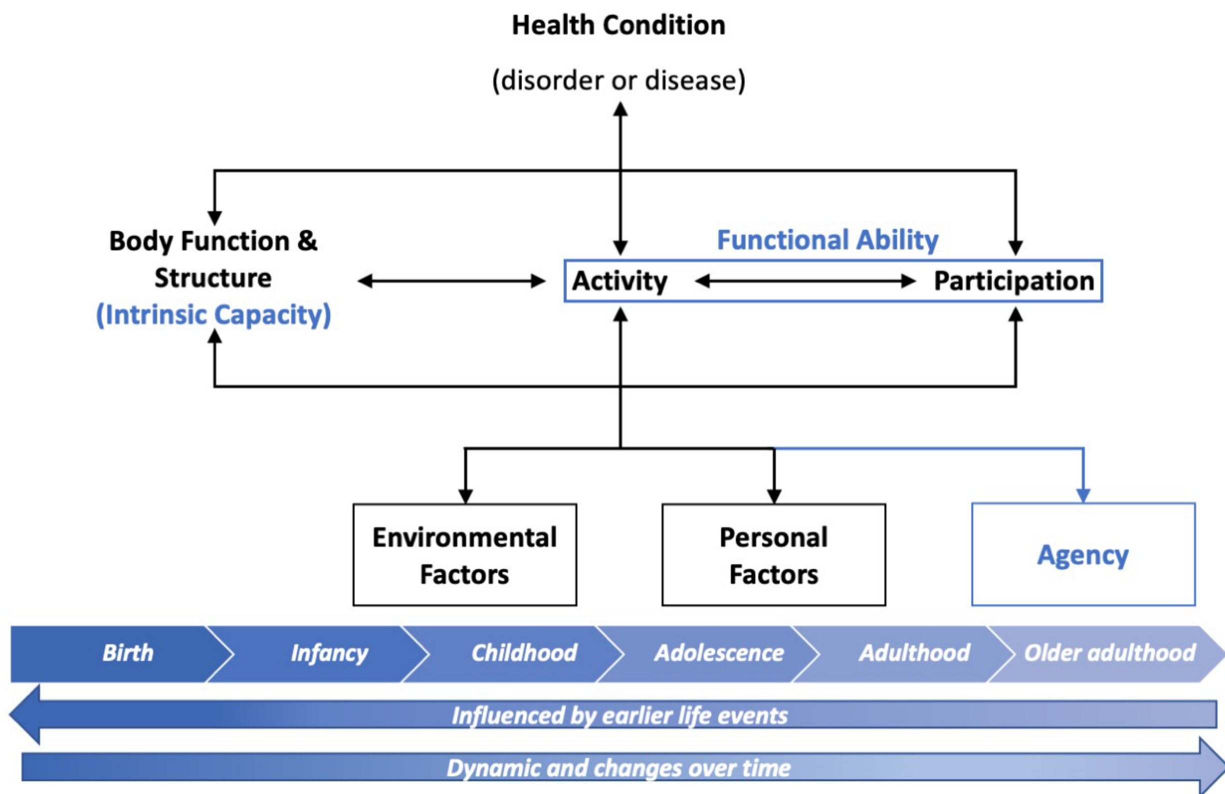


Figure 12. The Life Course Perspective of Disability - a combination of the International Classification of Functioning, Disability and Health (ICF) (in black) and the Life course Perspective of Ageing (LCP) (in blue)

Table 4. Comparison of the International Classification of Functioning, Disability and Health; the Life Course Perspective of ageing; and the Life Course Perspective of Disability.

	ICF Framework of Disability	Life Course Perspective of Ageing	Life course Perspective of Disability
Overview of framework	Disability is *"the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)"*(4)*(p.4).*	Views ageing a life-long process. Acknowledges the effects of events earlier in life in shaping the experience and outcomes throughout one's life. (64–70). Main outcome: functional ability (65)	Developed for this research. Recognizes disability as a: - Complex and dynamic phenomenon that is influenced by multiple factors that change over time. - Dynamic interaction between health conditions and contextual factors (personal and environmental) Highlights the importance of agency in shaping the experience
Focus of Framework	How health conditions and contextual factors influence participation and functioning	How people experience ageing and transition through life stages	How people experience disability and ageing throughout life
Dynamic Interaction between individual and contextual factors	√	√	√
Acknowledges importance of earlier life events	√ (Indirectly included - incorporated in personal factors)	√ (Main focus of framework – events prior to birth and throughout life)	√
Experiences are dynamic and change over time	√	√	√
Acknowledges effect of positive experiences	√	√	√
Acknowledges Agency as an influencing factor	X	√	√

3.6 Intersectionality to guide methodology

Intersectionality principles coincide with many qualitative research processes and methods. It can be used to strengthen qualitative research or as a standalone framework for research development, data collection and analysis (100,110). Abrams et al. (2020) (100) provide guidelines for incorporating intersectionality into qualitative research. The authors suggest that intersectionality can be used to guide the entire research process, or it can be as a framework for data analysis (100). They recommend that intersectionality be considered during study conceptualization and design because it can be useful for participant recruitment, data collection and knowledge translation (100). This research project was not explicitly framed and designed from the outset to adopt the intersectional approach presented by Abrams et al. (2020) (100) however, many of the methodological considerations they recommend were included in the research design and data collection processes. I summarize the guidelines offered by Abrams et al. (2020) (100) in Table *5* and outline if these methods were used in this thesis. They are described in more detail throughout this chapter.

Table 5. Methodological considerations to include intersectionality in qualitative research, as described by Abrams (2020)

Elements to incorporate intersectionality into research*	Incorporated in this DrPH?	Reasoning provided by Abrams (2020) (100) *
Study Conceptualization		
Consider the identities and influence of/on: • Participants • Researchers	 √ √	Important to recognize and account for the insider-outsider position Use to account for and minimize influence
When possible, include community members as part of research team	**Partially** Included local researchers but often not from community	Improves diversity, reflection and understanding. Promotes collaboration, leadership and knowledge translation
Collaborate with community stakeholders and/or use community advisory boards	√	Promotes shared agency, trust and rapport
Participant Recruitment		
Consider who are the individuals in the category of interest? • The role of inequality in their lives and commonalties	√	Assists with recognizing mechanisms of influence, development of research questions & design
Consider where to recruit	√	Marginalized groups may face barriers accessing traditional health sites
Consider how to recruit / sampling approaches	√	Facilitate identification of individuals and ensure representation
Data Collection		
Collaborate with communities in development of interview guides	**Partially** Collaborated with advisory groups and researchers.	Can reduce power imbalances, structural stigma and social injustice
Triangulation	**Partially** Interviews with caregivers	Can enhance understanding of a phenomenon

	No document review	
Pilot test interview guides	√	Ensures participants will understand questions and are appropriate
Collaborate with individuals from community about data collection	**Partially** Collaborated with HelpAge, advisory groups and interviewers.	Assists researchers in avoiding pitfalls that impede study or negatively influence quality Promotes agency
Ethical Concerns	√	Protects confidentiality Safeguards participants Ensures voices are heard in manner participants would like
Data Analysis		
Outline data analysis approaches, coding, framing used	√	Depends on research questions
Reflexivity		
Apply reflexivity to methodology	√	Acknowledge influence of identity and power embedded within the research

*Many of the aspects in these columns are direct quotes from Abrams (2020) (100).

3.7 Systematic review on the experiences of older persons with disabilities in humanitarian crises

The systematic review followed the process described by the Centre for Reviews and Dissemination at the University of York (111) and Butler et al (2016) (112). Butler defines three main stages of qualitative reviews – (1) developing a search strategy, (2) reviewing the literature and (3) data extraction and synthesis (112). Each of these steps is described below.

3.7.1 Stage 1: Developing a search strategy

Defining the question

For this review, I use the Population, Context, Outcome (PCO) framework, which is outlined in Table 6 to address the literature review question *"What are the experiences of older persons with disabilities in humanitarian crisis settings."*

Table 6. PCO framework used in this review.

Population	Older persons with disabilities
Context	Humanitarian crises or emergencies
'Outcomes'	Experiences: this was kept deliberately broad considering expected lack of literature but included risks, needs, capacities as well barriers and facilitators to accessing humanitarian protection and services

Keywords and search terms

Search terms related to "humanitarian" OR "crisis" OR "emergency" OR "emergencies" AND "disability" OR "disabilities" AND "older OR "elderly" OR "old" OR "ageing" were used. The search strategy used terms relevant to each topic, informed by previous literature, (disability, older persons (113,114) and humanitarian crises (115,116) to create a master search strategy (Appendix 5).

Inclusion and exclusion criteria

Several inclusion and exclusion criteria were used to set boundaries for the review and to mitigate personal bias (112). Table 7 and Table 8 outline the inclusion and exclusion criteria for this review, respectively.

Table 7. Inclusion criteria for this review and justification.

Inclusion Criteria	Justification
Qualitative, quantitative and mixed methods studies	It was anticipated that there would be little relevant literature on the experiences of older persons with disabilities in humanitarian crises, therefore, the search was kept broad to ensure all relevant studies were included in the review.
Peer reviewed articles	
Any country	
All humanitarian crises (including displacement, conflict and natural disasters)	
Older persons OR 60 years of age and older	No age limit was set because 'older' was defined differently in different studies. Therefore, if the study stated 'older people' it was included (i.e., the definition of 'older' used by the study was applied). In studies that did not state older, 60 years of age was the cut-off to define 'older people'.
Studies up to 2023	No restriction placed as no previous systematic review has been conducted on older persons with disabilities in humanitarian crises and it was expected that few articles would be identified.

Table 8. Exclusion criteria for this review and justification.

Exclusion Criteria	Justification
Resettled refugees in high-income countries	The aim of this review is to examine the experiences of older persons with disabilities living in humanitarian crises to inform humanitarian response.
Studies that presented findings only on older persons or only on persons with disabilities (i.e., not explicitly older persons with disabilities). (Note: studies that included younger people or older people without disabilities were included if the authors presented findings specifically on older persons with disabilities)	This review aims to examine the literature specifically on the experiences of older persons with disabilities.
Studies focused on populations with accidents and injuries that do not specifically discuss related long-term disabilities and chronic illness (heart disease, diabetes, etc.)	This review aims to look at long-term disabilities.
Studies published in languages other than English	Due to the scope and resources of this project, studies published in languages other than English were unable to be translated and included in the review.
Studies that present prevalence of disability only without other relevant descriptive information on experiences	This study aimed to look at the experiences of older persons with disabilities in humanitarian crises.
Studies conducted in long-term care facilities that did not provide information on disability	An argument could be made that older persons living in a long-term care facility have decreased participation because they require assistance with ADLs. However, this is not an accurate assumption. Persons without disabilities and younger people can live in long-term care facilities.
Studies related to the COVID-19 pandemic	Considered outside the scope of this review as COVID-19 is a distinct global pandemic with unique characteristics and impact (e.g., Global impact and concerted effort on curbing the spread of COVID-19 across all countries with differing health services).

Search Strategy

For peer reviewed journals, seven databases (CINHAL, Cochrane, EMBASE, Global Health, MEDLINE, PsychInfo, Social Policy and Practice) were searched for studies that met the inclusion criteria using search terms related to ageing, disability and humanitarian crises. Broad search terms such as 'elderly' and 'humanitarian' and 'disability' were also applied to the Source database (117) (an international online resource centre focusing on disability and inclusion) and the following literature sources: UNHCR, HelpAge International, Humanity & Inclusion and CBM websites and Google scholar (first 5 pages only). The same process was conducted in 2017 and 2023.

3.7.2 Stage 2: Reviewing the literature

Organizing the citations

All references from each database were imported to EndNote (Ver 20.5) (118). Duplicates were deleted using EndNote functions and checked by PS.

Reviewers

The review process involved three researchers – myself and my supervisors (SP and JW). As the primary investigator, I developed the search strategy based on previous literature reviews and support from LSHTM librarians, conducted the search, organized the articles and led the review process.

Stages involved in reviewing the literature

This systematic review was initially conducted in 2017 to inform the research project. It was updated in April 2023 to gain an understanding of new literature and assess the quality of the evidence.

All potential articles underwent a three-stage screening process based on the inclusion criteria (112,119).

Stage 1: All citations were screened based on title. Any uncertain citations were included in the next stage.

Stage 2: Included citations from stage 1 were screened based on abstract. Any uncertain citations were included in the next stage.

Stage 3: Review of full text article of each study screened in stage 2.

For the review conducted in 2017, each stage was independently conducted by PS and SP. After each stage, PS and SP met to discuss the findings. For the full text screen (stage 3), each study was read in full by PS and SP and assessed for inclusion. Prior to screening, it was agreed that in the event of a discrepancy, a third reviewer would be sought for a decision. This did not occur in this 2017 review. In 2023, PS completed all stages of the review. Any citations that PS was unsure about at any stage were automatically included in the next stage of analysis. Any uncertain citations in the final stage (full-text review) were flagged for revision by SP and JW who assessed them for inclusion.

3.7.3 Stage 3: Quality assessment

The critical appraisal tools provided by the Joanna Briggs Institute (JBI) were used to assess the risk of bias within each article included in this review. The JBI institute has several tools for appraising research with various study designs (such as cross sectional, case control, cohort, and qualitative, among others) (120–123). The JBI tools have been found to have the widest applicable range among risk of bias tools (as compared to the Critical Appraisal Skills Program (CASP), National Institute of Health (NIH) quality assessment tool and the Scottish Intercollegiate Guidelines Network (SIGN)) and is the preferred tool for assessing articles with cross sectional study designs (compared to NIH and the Appraisal tool for Cross Sectional Studies (AXIS) (122). The JBI tools are useful for this review because they are unique enough to be used with different study designs but similar enough to allow for comparison.

The citations were assessed by PS. Each study was rated as having a low, medium or high risk of bias, based on the following classifications used in a previous systematic review by Scherer et al. (2022) (124) (p.3):

- ***Low risk:*** *all or almost all of the criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions.*
- ***Medium risk:*** *some of the criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study.*
- ***High risk:*** *few or no checklist criteria were fulfilled, and the conclusions of the study were thought likely to alter if these had been met.*

3.7.4 Stage 4: Data extraction and synthesis

The following information was extracted from each article and organized using Excel: publication year, country where the study was conducted, country income classification (low, medium, and high income based on World Bank classification (125)), crisis context (e.g., conflict, displacement or sudden onset), study design, disability classification, disability or impairment type, age of participants, older age classification and number of older persons with a disability in the sample.

The main findings related to the experiences of older persons with disabilities were organized according to the LPD Framework. Data were organized in Excel (ver. 16.73) according to Environmental Factors, Personal Factors, Agency, Body Structure/Impairment, Influence of Earlier Life Events and Changes Over Time. Within these themes, a thematic analysis was used, allowing for the identification of themes from the data. Narrative synthesis was used because of the heterogeneity of study designs and the inclusion of qualitative studies.

3.8 Qualitative research exploring the experiences of older persons with disabilities in humanitarian crises in Ukraine and Tanzania

3.8.1 Project advisory groups

The research design, analysis and dissemination were guided by input from international advisory group (IAG) and national advisory groups (NAG). The groups consisted of stakeholders and representatives from disability, older persons and humanitarian organizations and associations. They were assembled by first reaching out to people who were known experts in the areas of disability and global health or humanitarian crises. A snowball approach was then used to recruit additional people for the advisory groups, whereby experts were asked who else could be included to inform the project. The IAG consisted of 11 representatives from different international organizations, humanitarian organizations and research institutions who are experts in the areas of disability, inclusion, and humanitarian response (Table 9). The NAG in Tanzania and Ukraine consisted of 13 and 8 individuals, respectively (Table 9).

Table 9. International and national advisory groups included representatives from the following organizations (NB, names not included as permission has not been sought for this).

International Advisory Group: • CBM – Emergency Response Unit • CBM – CBM International • HelpAge International – Global Disability Advisor • HelpAge International – Humanitarian Policy Manager • Humanity and Inclusion – Technical Advisor, Disability in humanitarian crises • Independent consultant – Disability in humanitarian crises • Independent consultant, research associate and policy advisor – author Minimum Standards for Age and Disability Inclusion in Humanitarian Action (Pilot Version) for the Age and Disability Capacity Building Programme (ADCAP) • Leonard Cheshire Disability • LSHTM researcher and policy advisor to iNGOs on rehabilitation and disability • LSHTM Researcher and Director of the International Centre for Evidence in Disability (ICED) • UNHCR – Disability Inclusion in Humanitarian Action
Tanzania Advisory Group: • ADD International Tanzania (2 Representatives) • Commission for Human Rights and Good Governance (CHRAGG) • Good Samaritan Social Service Trust (GSSST) (2 Representatives) • Government of Tanzania – Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDEEC) (2 Representatives) • HelpAge International Tanzania • Institute of Social Workers (ISW) (2 Representatives) • Prime Minister's Office (PMO) (2 Representatives) • Tanzania Data Lab (DLAB)
Ukraine Advisory Group: • Danish Refugee Council (DRC) • Education for Older People • HelpAge International, Ukraine – field office in Sloviansk • Sloviansk association of people with disabilities - Director • Sloviansk City Council (2 Representatives) • Ukraine NGO for persons with disabilities

International Advisory Group

Three meetings were held with the International Advisory Group (IAG): one at the beginning of this research (prior to the development of topic guides) to discuss the research approach, topic guide questions and study setting; one prior to data collection to review topic guides and research methods; and one after data collection to discuss emerging findings. A final workshop was held to present and discuss research findings after data analysis was completed. The IAG was included to ensure the research would be relevant to their programs and appropriate for the contexts. They were also included to facilitate knowledge translation. The IAG provided the following input:

- Include questions in the topic guides that align with the common humanitarian structure (e.g., WASH, healthcare, housing, food, etc.).
- Suggestions on where to look for previous information and relevant research.
    - E.g., UNHCR report on Age, Gender and Diversity (2015) (126).
- Strategies to ensure actionable outcomes from the research.
    - E.g., include questions focused on barriers and facilitators to accessing humanitarian services.
- The potential influence of conducting research in areas where HelpAge International was present and how this may influence the results.
- Include representatives from organizations of older persons and organizations of persons with disabilities on the advisory groups in each country.
- Use standardized tools to ascertain disability type and severity.
- The importance of family members and caregivers in the lives of persons with disabilities and older persons. Encouraged including them in the research.
- Develop strategies to influence government policy within each country.

All of the input mentioned above were incorporated into the research, with the exception of developing specific strategies to influence government policy as this was beyond the scope of this DrPH research. However, government representatives were included on the national advisory groups in each country and in the dissemination workshops. Many of the representatives from NGOs and associations were also working to influence government policy. The Washington Group Questions - Short Set was used to measure disability. This measure was used to ensure a standardized approach that is consistent with humanitarian practice and research, as this is the most used measure of disability (127–129). Family

members were included in the research based on the input from the advisory committee, and this helped provide a deeper understanding of the role of caregivers, the impact on the family and the lived experiences of older persons with disabilities.

National Advisory Groups

The national advisory groups (NAG) were consulted prior to the data collection in each country and helped: to ensure that the research and topic guides would be useful and relevant to their work; that the questions and language respected the culture, diversity and customs in each setting; and that the topic guides adequately captured the experiences of older persons with disabilities living in each setting. Additionally, members of the NAG provided information on the context and considerations for interacting with people in the crisis affected areas. They also supported the interpretation of the findings and dissemination. The NAGs provided the following input:

Ukraine

- Younger people often perceive older people as a burden.
- There is a lack of inclusion of persons with disabilities within the country.
- Many older people have low incomes.
- There are limited social supports for older persons with disabilities.
- There is limited coordination and referral systems between institutions and healthcare services.
- There is limited communication and collaboration between institutions (government and non-governmental) in Ukraine.
- There is a low quality and lack of healthcare services in conflict affected areas.
- Many organizations lack funding.
- Some people in Eastern Ukraine identify as Ukrainian while others identify as Russian. Special care should be taken during interviews to be impartial.
- Important to include the government in research.
- Accessibility is a major concern in the Eastern part of the country that should be explored.
- Important to look at various areas within Eastern Ukraine.

Tanzania

- Use participatory approaches - Include older persons and persons with disabilities in research development and dissemination.
- Having researchers who are from Burundi and have a disability.
  - (This was not possible given the research timeline and restrictions. The research team is presented below.)
- Hold a dissemination event at the conclusion of data collection.
- Complete a preliminary analysis with study participants and key actors to help guide further data analysis.
- Ensure research is of value to all parties, including participants, policymakers, organizations, NGOs and government.
- Collaborate with government and research ethics in Tanzania to have protocol validated. This will make it more applicable and accepted in Tanzania.
  - Research ethics and approval, and approval from camp management were completed prior to data collection. The research team also met with camp management and government in the areas surrounding the refugee camps to discuss the research prior to data collection.
- Try to capture the cultural and participatory aspects of disability.
- Interviewers should interview participants of the same sex.
- Older interviewers would be ideal to increase the chances of honest discussions.
- Be patient during interviews and communicate clearly.
- Interviews may uncover traumatic experiences and participants should be guided to appropriate services within the refugee camps.
- Share research findings in a variety of ways – meetings, reports and scientific articles.

3.8.2 Research team

The research team consisted of myself, local researchers in each setting, a HelpAge staff member and HelpAge drivers. My role involved leading the development and testing of the topic guides, training of the research teams, daily reviews of emerging data within the research team through data collection, presenting preliminary findings to advisory groups and the more in-depth analysis for this thesis.

There were 3 national researchers in Tanzania (Table *10*) and 2 in Ukraine (Table *11*). In Tanzania, the researchers were from Tanzania and were not refugees. One of the researchers (SS) lived in North-Western Tanzania whereas the other two did not live in the area surrounding the refugee camps. In Ukraine, one of the researchers (AK) lived in the conflict affected areas of Donbass, and the other (OS) lived in Kyiv. The research teams included males and females with a mix of experience and backgrounds including cultural and professional expertise (see Tables 10 and 11 for details). Due to the duration of the research, researchers with previous experience conducting interviews and/or working with crisis affected populations were sought. In each setting, the researchers spoke the local language spoken by participants as well as English. The national researchers conducted the interviews and transcribed their own interviews.

None of the researchers, including myself, have a disability and all were under the age of 50 years. Recognising this discrepancy between the researchers and participants, I implemented several strategies to ensure that the research development, data collection and analysis were informed by older persons and persons with disabilities. In each country, representatives from Organisations of People with Disabilities (OPWD) and Older People's Associations (OPA) were key members of the research advisory groups and were consulted prior to and during data analysis to inform the analysis of the data. Despite these steps, the research team characteristics are still likely to have influenced the data collection and interpretation, which will be reflected on in the discussion (Chapter 8).

Table 10. Research team for data collection in refugee camps in Tanzania.

Tanzanian Researcher	Age (at time of research), Sex & Residence	Languages	Background
AH	20-30 years Female Northern Tanzania	Swahili English	• Research assistant for several qualitative research projects in Tanzania related to health behaviour, access to healthcare, wellbeing and caregiver experiences. • University degree in Communication
SS	40-50 Male North-Western Tanzania	Swahili English Kinyarwanda Kirundi Hangaza	• Logistics and management with humanitarian organizations and private companies in Tanzania. • Survey enumerator and environmental manager with humanitarian organizations. • Trades & farming
FA	20-30 years Male	Swahili English	• Data collection in rural communities in Tanzania • Development of questionnaires • Dissemination of survey data • Degree in Database Programming
PS	30-40 years Male Canada	English French	• DrPH Candidate at LSHTM • Physiotherapist • Work in humanitarian / global health settings • MSc biomechanics and ergonomics

Table 11. Research team for data collection in refugee camps in Ukraine.

Ukrainian Researcher	Age (at time of research), Sex & Location	Languages	Background
AK	40-50 years Male Donbass, Ukraine	Ukrainian Russian English German	• Associate professor of Philosophy • Interpreter for Organization for Security and Co-operation in Europe (OSCE) Office for Democratic Institutions and Human Rights (ODIHR) and other humanitarian organizations and UN agencies
OS	20-30 years Female Kyiv	Ukrainian Russian English French Spanish	• Postgraduate studies in Business and Economics • Project coordinator and management for UN agencies and European Commission projects
PS	30-40 years Male Canada	English French	• DrPH Candidate at LSHTM • Physiotherapist • Work in humanitarian / global health settings • MSc biomechanics and ergonomics

3.8.3 Training and pilot testing

I led 4 days of training for the interviewers prior to data collection that included research protocols, qualitative interview techniques (including considerations for interviewing people with different impairment types), note taking and review of topic guides and ethical considerations in data collection. The topic guides were also discussed and revised to ensure relevance and suitability to the local language and culture. The interview guides were pilot tested with 1 interview per researcher (3 in Tanzania and 2 in Ukraine). This enabled the topic guides to be tested and adapted as well as to provide feedback on interview experience and techniques.

3.8.4 Study setting and timing

The qualitative interviews were conducted in Eastern Ukraine (May 2017) and Tanzania (October 2017). The two settings were selected because they are in geographically different areas, are distinct humanitarian situations (active conflict in Eastern Ukraine and displacement/refugee camps in Tanzania) and have contrasting population age structures (high proportion of older people in Ukraine, low in

Tanzania) (see Chapter 5). The feasibility of the study was also taken into consideration. At the time of the research, both settings were relatively stable humanitarian situations which allowed for safe access for researchers and adequate time to conduct the research. In addition, HelpAge International operates in each setting which assisted with logistics, access, and security.

In Tanzania, the interviews were conducted in Nduta and Mtendeli refugee camps in Kigoma Region, Western Tanzania (bordering Burundi). Civil conflict and political instability in Burundi have resulted in more than 249,000 Burundian refugees being displaced to Tanzania (130). The majority of the refugees have been accommodated in Mtendli, Nduta and Nyarugusu refugee camps (130). Around the time of this research, reports stated that there were 117,460 people living in Nduta camp, 50,789 people living in Mtendeli and 132,756 in Nyarugusu (131). Older people accounted for 2.27% of the population within the camps accounting for 5,349 people (2648 Males & 2,701 Females) (131). Nduta and Mtendeli are in the communities of Kibondo and Kakonko, respectively. A more detailed description of the context is provided in Chapter 5.

In Ukraine, the research was conducted in the Donetsk and Luhansk regions in Eastern Ukraine, along the border with Russia. These provinces have been affected by armed conflict since 2014. Between 2014 and the time that this research was conducted in 2017, the conflict had resulted in more than 9,940 deaths, 23,455 injuries, extensive suffering and significant displacement (132,133). At that time, it was estimated that there were 3.1 million people in need in Eastern Ukraine, 930,000 of whom were over the age of 60 years (134). Luhansk and Donetsk regions (collectively known as Donbas) were separated into Government and Non-Government Controlled Areas (NGC). Due to security concerns, the research was conducted only in government-controlled areas (GCA) and included people who have lived in the area throughout the conflict as well as internally displaced people (IDPs). A more detailed description of the context is provided in Chapter 5.

3.8.5 Study population and recruitment

Interviews were conducted with older people (60 years of age and older) with disabilities. Additionally, family members or caregivers were also interviewed to explore their perspectives and experiences in relation to living with or caring for an older person a with disability.

3.8.6 Participant sampling

Stratified purposeful sampling was used to capture variation in age, disability and location (109,135,136). Study participants (older people with disabilities) were selected through databases provided by HelpAge International, which included information on age, sex and disability. Details regarding the databases are provided in Table 12. The number and characteristics of participants included in each setting are provided in Chapters 6 and 7.

Participants were sampled to ensure representation of males and females, a range of age groups, impairment types and geographical locations. In addition, in Ukraine, consideration was also given to location (internally displaced and living in areas affected by conflict). Older age was defined as 60 years of age and older based on international convention (2,8). Participants were sampled in 10-year increments including: 60-69, 70-79, 80-89, and 90+ years. To ensure representation of these different characteristics, sampling was continually monitored throughout the data collection based on the age of the participant and the Washington group short set questions (Appendix 6). A sampling frame table was constructed to ensure representation across these groups was achieved. Family members were selected to ensure distribution across different zones of the refugee camps (Tanzania) and provinces (Ukraine).

Table 12. Information on databases used to identify and sample participants in Tanzania and Ukraine.

Setting	Database information	How disability was classified in the database	Participant sample selection
Refugee camps in Tanzania	UNHCR administered a questionnaire to all people upon arrival to the refugee camps. Database included all older people and people with disabilities identified within the camp. Information provided for this research included: - Demographic data (age, sex) - Location within camp - Impairment type (visual, hearing, mobility, mental) - Impairment severity (mild, moderate, severe)	UNHCR used their own standardized form to classify disability. This was based on difficulty among functional domains related to seeing, hearing, mobility/function, cognitive.	**Older persons with disabilities:** - Refugee camps were separated into zones. - In each zone, purposively selected participants from across different age range and type of functional limitation **Family members:** - Purposively selected
Eastern Ukraine	Database consisted of older people identified by various agencies and government bodies. Information in database: - Demographic data (age, sex) - Current location - Impairment type (visual, hearing, mobility, mental) - Impairment severity (mild, moderate, severe)	Disability based on government classification system. Note: Not all people with disabilities in Ukraine had a government disability classification. In these cases, impairment type was determined by through interactions and assessments from HelpAge Staff.	**Older persons with disabilities:** - Luhansk and Donetsk were separated into areas. - From each area, purposively selected participants from different age range and types of functional limitation. **Family members:** - Purposively selected

3.8.7 Data collection

Semi-structured interviews were used to explore the lived experiences of older persons with disabilities and their caregivers and to probe further into how they access daily and humanitarian support needs, the barriers they face, the strategies they use and the wider implications of older age and disability in humanitarian crises. This method also allowed the necessary structure to cover the same key topics across different contexts while providing the flexibility to adapt to unique cultures, languages and humanitarian crisis settings. It was also the most feasible approach in these humanitarian crises. According to Russell (2018)(137)(p.164.), semi structured interviews can be advantageous in situations where participants won't be interviewed more than once. In Tanzania, access to refugee camps and the amount of time for the research was strictly limited by camp management and government policies. The conflict in Eastern Ukraine was ongoing at the time of the research and there were often very limited windows of time to access certain areas, and the threat of further escalation. For these reasons, semi-structured interviews provided an optimal research method.

3.8.8 Interview topic guides

Interview topic guides were developed based on a literature review and input from international and national advisory groups. Two different topic guides were used to collect information from 1) older people with disabilities (Appendix 7) and 2) caregivers (Appendix 8). In line with the World Health Organization (WHO)'s International Classification of Functioning, Disability and Health (ICF) (4,57) and the 'life course perspective of ageing (64,72) which emphasise the multifaceted experiences of disability and ageing as well as the complex interactions that contribute to them, the topic guides collected information on personal, environmental, social and contextual factors associated with their lived experience, access to daily and humanitarian support needs and the impact of living in a humanitarian crisis context. Being aware of the ways peoples' needs can be exacerbated by intersecting vulnerabilities and how dominant frames in humanitarian practice can prioritize life over agency and dignity, the topic guides also asked about individual agency, views on available response mechanisms, the ability of individuals to participate in society, inform humanitarian decision making and take ownership over their lives. For family members and caretakers, the interviews also explored the experience and impact of living with an older person with a disability.

The Washington Group Short Set (WG-SS) was used to ascertain the type and severity of disability. The WG-SS was developed by the Washington Group on Disability Statistics in 2001 to assess self-reported functional limitations for use on national Censuses (17). These questions ask about level of difficulty ('none', 'some', 'a lot' or 'cannot do') with seeing, hearing, mobility, communication, cognition and self-care (128)). The questions were designed to be used across a variety of cultures, backgrounds, nationalities and socioeconomic status (17). The WG-SS have been tested and applied in a number of countries and contexts around the world (138–140).

Topic guides were translated into the local languages of participants and reviewed by the national advisory groups to test quality and ensure they were appropriate for the local context. The language was also evaluated during the pilot testing and re-evaluated throughout to ensure language was appropriate and clear.

3.8.9 Interviews

The majority of interviews took place in the participant's homes. However, in the refugee camps in Tanzania, some interviews took place at an agreed upon location just outside of the participant's home because of privacy issues related to the overcrowding in the camps. This primarily occurred if they lived with others in a shared house. There were two exceptions where interviews conducted in Ukraine that were conducted at the rehabilitation centre where the individuals were living. This was done to obtain the perspective of people living in different situations. The interviews were conducted in the preferred language of the participant (Ukraine: Ukrainian or Russian; Tanzania: Swahili or Kirundi) and lasted approximately 45 minutes to 1.5 hours. Because the interviews were conducted by the national researchers, the interviews did not require translation. I attended all interviews in Tanzania - For around half of the interviews, I was present before and during the interviews to monitor and support the quality of data collection. For the other half, I was present after the interview was conducted. As the research progressed, the interviewers required less assistance (e.g., with research logistics) and I would present myself afterwards to discuss the interview process and content. When I did interact with participants, the national researchers translated the dialogue. In Ukraine, I was present for approximately 50% of interviews because interviewers were often conducting interviews in different locations at the same time. The impact of my presence and how it may have influenced the interviews is reflected on in the discussion.

Each interview was audio-recorded with consent from the participant (more details in the ethics section) and notes were taken by researchers that covered observational components such as the context and participant reactions (reviewed at the end of each day). Given that many homes were small and crowded, it was often not possible to have complete privacy for one-on-one interviews. In some cases, interviews were conducted with other family members present (where possible in a different room). For adults with communication or intellectual impairments that severely limited their ability to understand or communicate, responses from the individual were sought wherever possible and appropriate during the interview, with a family member providing additional input or serving as a proxy, where needed. In these cases, the research and consent information were explained to the participant (where required, via a family member or caregiver) as well as the proxy. If both agreed, they were included.

3.8.10 Transcription and translation

The audio-recordings of the interviews were transcribed into the local language and then translated into English. In Tanzania, all the interviews were transcribed and translated by the national researchers who conducted the interviews. In Ukraine, around half of the interviews were transcribed and translated by the interviewers and the other half were completed by a translation company (due to time constraints). To assess the quality of these translations, the transcripts were compared with the translations by the national researchers as well as field notes.

3.8.11 Data management and analysis

The data analysis involved several stages to allow for input from stakeholders and advisory groups which informed the subsequent analysis. A preliminary data analysis was conducted shortly after data collection to enable timely dissemination of key findings in country and to contribute to the project report for the wider study (107). For this DrPH research, a deeper analysis of the data was undertaken, guided by concepts and frameworks presented in Chapter 2. Each analysis stage is described in this section.

Preliminary analysis and development of emergent themes

At the end of each day of fieldwork, the research team (including myself) met to review all the interviews conducted that day (verbally and by reviewing notes). During the daily review, we discussed and agreed

on emerging themes. We also sought to identify any gaps in the research that necessitated adding questions to future interviews or required further exploration which were then adapted accordingly. From these discussions, a list of themes and sub-themes was developed and updated throughout the fieldwork.

Upon completion of data collection, I held a preliminary analysis workshop with the interviewers in each country to further develop and generate a list of key themes and sub-themes. After the data collection in each setting, I held a meeting with the national advisory groups to share these preliminary findings and obtain their feedback.

Coding and thematic analysis

A preliminary rapid analysis using a thematic approach was conducted initially to allow for timely dissemination. The interviews were then coded using a thematic content analysis in NVivo (ver. 11.4, 2006; ver. 12, 2020) (141) whereby the content of the data was categorized into themes and subthemes (21). Subsequent analysis incorporated the themes and subthemes from the thematic coding analysis as well as those based on input from advisory groups provided during dissemination workshops (national and international).

Themes were based on common areas of focus and division of humanitarian response, such as the IASC cluster approach (142) (e.g., WASH, food, housing). This was a deliberate decision based on consultation with advisory groups to promote interaction and engagement from humanitarian actors and support knowledge translation. In addition, having well defined areas that are commonly accepted in the humanitarian literature and response facilitated analysis of the complex humanitarian contexts. Finally, consistency of themes between the two settings allowed for an examination of the lived experience of participants in each setting. These themes were broad enough to allow for flexibility between settings yet focused enough to allow for comparison. This facilitated the development of recommendations for humanitarian action (Chapter 8). Finally, my hope is that presenting the findings in a manner that is consistent with current humanitarian practice will facilitate knowledge translation and implementation and serve to inform humanitarian action and research.

Dissemination workshops were held in each country as well as with the international advisory group. The in-country dissemination workshops included the national advisory group members and key stakeholders. The dissemination workshop in Tanzania was held by my primary supervisor (SP) while the one in Ukraine

was held by a representative from HelpAge International. The purpose of these dissemination workshops was to share the key results of the study, validate findings and seek further feedback from stakeholders and advisors.

Secondary coding and thematic analysis

A secondary deeper coding analysis was completed using a thematic content analysis (21) in Nvivo (ver. 11.4, 2006; ver. 12, 2020) (141). During this analysis, content were categorized into themes and subthemes (21) according to the common humanitarian cluster areas. The analysis of the findings was shaped by deeper engagement with the ideas and frameworks presented in Chapter 2 (e.g., intersectionality, emergency framing, ageing and disability) and the LPD framework. My learning, immersion and thinking on this evolved over the process of this research, including how to tie together the different ideas to reflect on and compare the findings in the two settings, which I reflect on in the discussion.

3.9 Research Ethics

There is increasing literature on the ethical considerations of conducting research in humanitarian contexts. Bruno and Harr (2020) (143) completed a systematic review and meta-analysis in 2020 and identified fifty-two references covering the ethics of research in humanitarian crises (143). The findings stress that while research is extremely important to inform humanitarian response and public health initiatives in these settings, people affected by and living in humanitarian contexts can be at increased risk during the research process (143–145). The increased risk was suggested to be related to *"weak government protections, disrupted health systems, insecure living conditions, and unreliable food and unsafe water…"* (143). In addition, there is often a need for rapid data collection and implementation of research findings and are sometimes in areas with limited oversight or regulatory bodies (143)(p.2). Research in humanitarian crises therefore requires increased justification and robust ethical standards and protocols including risk identification, harm minimisation strategies and participant consent protocols that are appropriate for the participants and setting (143–145). These various ethical considerations are presented in this section.

3.9.1 Ethics approval

This research received ethical approval from the London School of Hygiene and Tropical Medicine, the Sociological Association of Ukraine, and the National Institute for Medical Research in Tanzania (Appendix 9-11).

3.9.3 Ethical considerations and harm minimisation

There are inherent risks to conducting research with people living in and affected by humanitarian contexts (143). In this section, I discuss some of the ethical considerations of the field research and the methods used to address them and minimize harm to participants and researchers.

Participant consent

Participant informed consent is an important aspect of research ethics (143). There are specific considerations for informed consent in humanitarian crises as well as for older persons with disabilities. For instance, Bruno and Haar (2020) (143) comment how Western norms of written consent may be difficult in certain populations if there are low literacy rates and how certain cultural norms can make it difficult to ensure the anonymity of participants. For example, in certain cultures, the head of the household must agree before family members can participate (143). There are also specific considerations in seeking consent when conducting research with persons with disabilities. People with visual impairments may require large print, visual or audio consent methods; sign language interpreters or visual information may be most appropriate for people with hearing impairments; and simplified material and consent information may be more appropriate for people with intellectual or cognitive impairments (146,147). Authors have suggested that a flexible approach may be needed when conducting research with persons with disabilities in humanitarian crises and that consent should be continually assessed (143,148). In working through the consent process involving a woman who used an informal sign language, Thompson and Wickenden (2023) (148) explain some of the complexities around the consent process. In the case presented, the authors wanted to ensure their research was inclusive and gained the perspective of an individual who used informal sign language but her family member (who typically communicated with the participant) was not present on the day of the interview (148). The authors provide three steps to how they managed this type of situation. First, was safeguarding and ensuring that

one of the central principles of research ethics, 'Do no harm' (nonmaleficence), guided their decision making (148). Second was working with local partners and third was having a flexible approach (148).

For this DrPH, various methods were used to ensure participants were appropriately informed in order to be able to make a choice whether or not to participate. Participants were contacted and visited by HelpAge International staff prior to the interviews to provide clear verbal and written information about the research and asked if they would be willing to be visited by interviewers for the study. When visited by researchers, participants were again provided with verbal and written information and given time to ask questions. If willing to take part they were then asked to provide their signed (or thumb-printed) consent. Information about the study and consent forms were translated and communicated in Ukrainian, Russian (Ukraine), Swahili or Kirundi (Tanzania) as appropriate. Consent from all study participants was observed by an independent witness. For adults with communication/intellectual impairments that limited their ability to understand/communicate, a simplified oral assent was sought. The researcher had responsibility for determining the capacity to consent (rather than a carer) and all participants were assumed to have capacity unless it was otherwise established by the researcher. Only if the researcher judged that the person was unable to fully understand the information or to communicate their wishes, then a proxy responder was consulted (e.g. family member). In these instances, responses from the individual were sought wherever possible and appropriate during the interview with a family member providing additional input where needed. Consent from both the proxy and participant were received in these cases. Throughout this process, participants were invited and encouraged to ask questions about the study and their answers were addressed by the research team. An additional consent form was completed for any photos that were taken. No participants needed a sign-language interpreter. Interviewers were trained on making interviews as inclusive as possible (e.g., facing the participant and speaking loudly, clearly and steadily). Interviews were conducted at people's homes so that people with mobility impairments were not excluded.

Participants may feel pressured to participate or respond in a certain manner

A particular challenge of conducting research in humanitarian contexts is that participants may feel pressured to participate in research (149). To limit this risk, participants were informed that their participation was voluntary, their willingness to participate and their responses would have no impact on the assistance they received, that they could stop the interview at any time and that their responses would

be kept anonymous. However, it is possible that the relationship with HelpAge International influenced the participant's choice to participate and the interview responses. For example, some participants might be less willing to be critical of an organization they had received support from in the past or may receive from in future. Others may feel that it is in their best interest to demonstrate a need to receive additional assistance. Further critical reflection on this, and how it may have influenced the findings, is included in Chapter 8.

Confidentiality

All data from this research were kept confidential to the researchers. Participants were provided with a unique code and no personal information was included in the reports; for example, we included the region or refugee camp, when presenting findings and quotes, rather than specifics about their location that could be used to identify them.

Participants may be perceived as receiving additional support

This DrPH research was focused on older persons with disabilities. There is a chance that others living within these settings could view the presence of the research team as the participants receiving additional support or assistance. To mitigate this, the interviews were conducted separately from any delivery of service.

Risks to researchers

There are risks to researchers that are inherent to working in humanitarian contexts (143,150) such as *"threats to physical safety; risk of psychological distress; potential for accusations of improper behaviour; and increased exposure to everyday risks such as infectious illnesses or accidents"* (150) (p.23). In Tanzania, the refugee camps were located around 1 hour's drive from the town where the research team was staying and there was a strict curfew for leaving the refugee camps because of armed robberies that targeted NGO vehicles that were quite active on the roads. In Ukraine, the data collection was conducted close to the contact line of the conflict. While the research was conducted in GCA to avoid areas of active conflict, the conflict was still quite close (bombing and shelling could often be heard in the distance).

Prior to the data collection, these risks were discussed among the research team and various strategies were adopted to minimise the risk to researchers. These included:

- Researchers undergoing security training
- Adhering to HelpAge security policies and procedures
- Having the security officers from HelpAge support logistics
- All research staff carrying a mobile telephone and informing the logistics and security team of movements
- Security briefings with HelpAge staff each morning
- A debrief at the end of each day
- All fieldwork being conducted during daylight hours
- Travelling in HelpAge vehicles and having a HelpAge staff member with easily identifiable logos
- Having approval from local authorities to conduct the research

Safeguarding

In the challenging context of humanitarian crises, people are often faced with increased risk of violence and trauma (149). Participants may therefore discuss traumatic experiences they have encountered over the course of their lives. This was discussed with the research team prior to the field research including how to identify if a participant was becoming distressed and what actions should be taken (including pausing or stopping the research process and directing them to sources of additional support). At the end of each day, the daily debriefs also included a discussion related to any challenging conversations that arose and strategies were developed about how best to handle them over the course of the research.

Local organizations and participants may not directly benefit from the research.

There is often a substantial gap between research and translation into practice. Therefore, direct benefit to the participants of this study as well as local and partner organizations could not be guaranteed. This was discussed with the participants as part of the consent process as well as with partner organizations. Advisory panels, dissemination workshops and partnerships with associations and organizations were three of the methods implemented in the research design to facilitate knowledge translation. Partnerships

between NGOs and researchers have been shown to improve knowledge translation in humanitarian settings (151), so too has community-engagement (152) and rapid dissemination of information (145). These were all incorporated into this research.

Using Proxies during interviews

Proxy-reports (responses provided by a respondent such as a family member or caregiver (147)) were used for participants with impairments that severely impacted their ability to communicate. In some cases, family members provided clarification or supported communication for the participant with a disability. In other cases, proxies provided their perspective of the situation of the participant. There are several ethical considerations when using proxies. First, the autonomy of participants may be limited because they are not providing answers directly (147). Second, participants may be reluctant to share information in the presence of a proxy, family member or caregiver. Third, the proxy could filter information provided by the participant or neglect to report negative findings. Yoon (2023) (153) and Santaro (2023) (147) state that careful consideration must be taken when deciding who can serve as proxies for persons with cognitive disabilities. Some of the primary considerations provided by Yoon (2023) (153) when using proxies for people with cognitive impairments include:

1. The proxy must have adequate knowledge of the individual and situation to be able to provide accurate information.
2. The closeness of the relationship.
3. Thinking of individuals with impairment rather than proxies' opinions or interests.
4. Previous experience of decision making for those individuals.

For this DrPH, proxies were primary caregivers and were informed to reflect the experience of the person with a disability, as best they could, rather than their own opinions or experience.

3.10 Positionality and motivation for this research

It is well understood that the researcher's background and positions influence all aspects of research (21,22,100,154). This includes the researcher's socio-economic background, previous experiences and nationality (21,22,100,154). There are also deeper elements that can have an impact on the research such

as personal beliefs, views about the world, assumptions about the research and thoughts on knowledge and theories (21,22,100,154). It is important for researchers to reflect on their own positionality (155)(p.2), which I do in this section.

I am a white, non-disabled male who grew up in a small rural town outside of Ottawa, Canada. My daily life and upbringing did not involve the effects of humanitarian crises, conflict, or displacement. Therefore, I am an “outsider”.

I am a physiotherapist by profession. In my final year as a physiotherapy student at Queen’s University in Canada, I completed an international clinical placement in Nepal where I studied and worked at a child development centre and paediatric hospital in Kathmandu. It was a positive experience but one that left me questioning the role of healthcare workers in global health. After I returned, I attended a lecture on Community Based Rehabilitation (CBR) from Dr. Malcolm Peat. He spoke about the inequities in healthcare and rehabilitation and the need for community-based evidence and research. These two events were the catalyst that led me to work in global health.

I began by working in development and CBR and through these experiences observed how poor access to healthcare has a negative and drastic impact on an individual’s life. I decided to pursue public health to address these inequities. I was accepted to LSHTM with the hope of conducting research on CBR. I then experienced an earthquake while I was in Nepal and decided to defer my start date to work with humanitarian NGOs to develop rehabilitation initiatives after the events. During these experiences, I saw how the earthquake further added to the challenges and inequities in accessing rehabilitation and healthcare, especially for persons with disabilities. I decided to shift the focus of my DrPH to examining the experiences of persons with disabilities in humanitarian crises with the overall goal of developing evidence-informed solutions to meet the needs of people affected by crises. Around the same time, HelpAge International was building upon their work to look at age and disability in humanitarian crises and I took the opportunity to conduct research in collaboration with them.

I approached this research as a healthcare professional and humanitarian worker wanting to inform practice. This DrPH journey has been accompanied by an evolution in thinking and a shift in views and epistemological position, which I will reflect on in the discussion (Chapter 8).

CHAPTER 4: SYSTEMATIC REVIEW ON THE EXPERIENCES OF OLDER PERSONS WITH DISABILITIES IN HUMANITARIAN CRISES

In this chapter, I present the results and discussion from a systematic review which serves to address objective 1 of this thesis - to identify and synthesize the available evidence on the experiences of older persons with disabilities in humanitarian crises (Methods in Chapter 3). A systematic literature review was conducted in 2017 to inform this research and the review was updated in 2023 to gain an understanding of the extent of the recent literature.

4.1 Results

4.1.1 Study Selection

In 2017, 2,668 records were identified through database searches. 449 duplicates were removed, and an additional 7 records were identified from additional sources. In total, 2,226 records were screened of which 1,893 were excluded by title and 236 were excluded by abstract. This left 97 articles for full-text review. 89 articles were excluded after full text review and four could not be found. The remaining 4 articles were included in this review (Figure 13)

In 2023, 2,207 records were identified through database searches and 4 others were identified from additional sources. 408 duplicates were removed which left a total of 1,803 articles for review. Of these, 1,357 and 318 were excluded by title and abstract, respectively. 128 full-text articles were reviewed of which 117 were excluded and 7 could not be found. Four articles were identified for inclusion. None of the articles identified by the author from 'additional sources' were included in the review. The total number of articles from 2015 and 2023 was 8. This process is outlined in Figure 14.

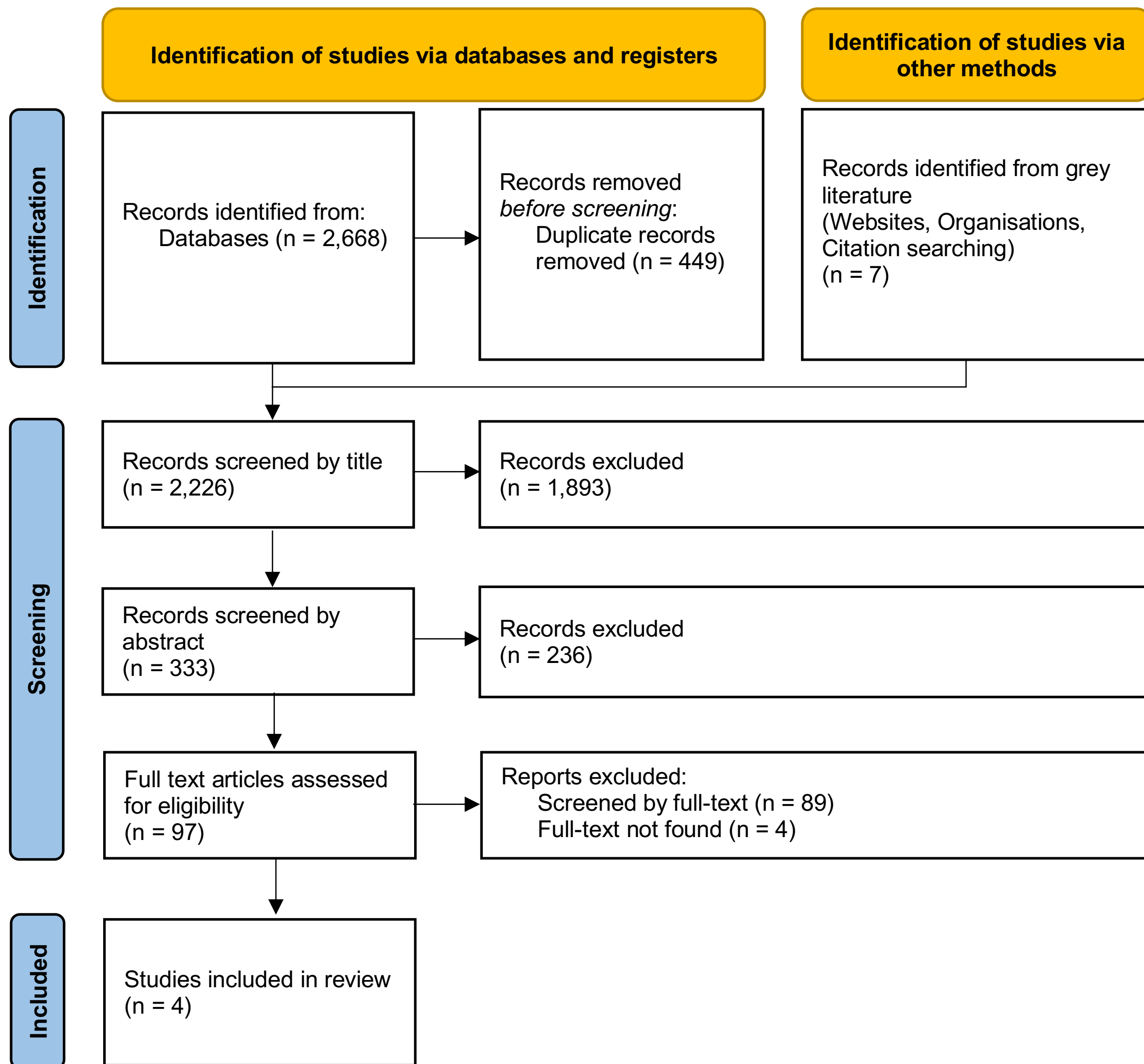


Figure 13. PRISMA Flow chart for article review completed in 2017

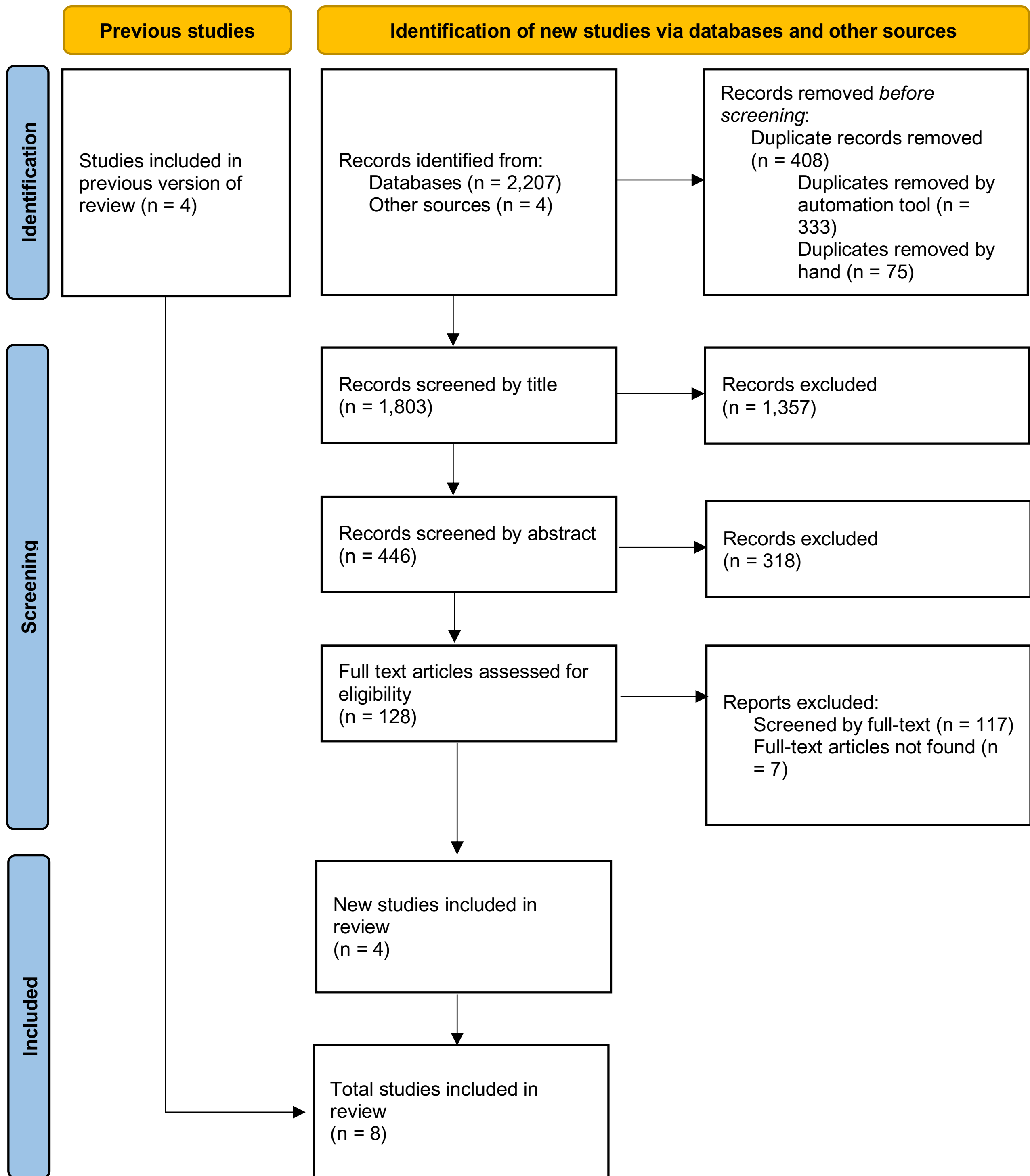


Figure 14. PRISMA flow chart for article review conducted in 2023

4.1.2 Study Characteristics

As shown in Table *13*, of the included articles in this review (n=8), four (50%) studied humanitarian crises in Asia (156–159), three (37.5%) of which focused on Japan (156,157,159). The remaining five (62.5%) articles were conducted in Lebanon (160), New Zealand (161), Sudan (162), Taiwan (158) and Ukraine (163). No articles were conducted in North or South America. Only one article (12.5%) was published prior to 2010 (162) and of the remaining seven articles, three (37.5%) were published between 2010-2019 (156,160,161), and four (50%) were published after 2020 (157–159,163). Of the eight articles, five (62.5%) were on studies conducted in high-income countries (156–159,161), two (23%) in lower-middle income (160,163) and one (12.5%) in a low-income country (162).

The crisis context varied, with only two (23%) of the articles researching the same event (the 2011 earthquake/tsunami in Japan) (156,157). Two articles (25%) focused on refugee situations (one in a refugee camp (162), one with refugees living in the host community (160). Only one article (12.5%) examined a conflict (163). The remaining five (62.5%) articles were conducted in situations of sudden onset disasters: three (37.5%) due to earthquakes with/without tsunami (156,157,161), one (12.5%) due to flooding (159), and one (12.5%) due to typhoon (158). Table *13* provides a summary of the study characteristics.

Different methods were used to ascertain disability and/or impairment. These are outlined in Table *13*. Two studies (23%) used the Katz Index (160,163), which assesses activities of daily living (ADL). Other than the Katz Index, no two studies used the same disability classification.

In terms of type of disability or impairment, four studies (50%) focused on mental health conditions (156–158,163) (including dementia or cognitive deficits (16) Post Traumatic Stress Disorder (PTSD) and/or depression (157), chronic mental illness (158) and psychological distress (163)). Two studies (23%) used Activities of Daily Living (ADLs) to classify disability (160,163), and one (12.5%) looked at persons with visual impairments (161). One article included individuals with multiple impairments (12.5%) (160). The definition of older age varied from 40 years or older (161), to 75 years and older (156) (Table *13*).

Three (37.5%) of the articles used a mixed methodology approach (156,160,162). Of these, two (25%) used a combination of prevalence surveys and qualitative research methods (160,162), and one (12.5%) used a combination of cross-sectional and qualitative methods (156). Of the remaining five (62.5%) articles, one (12.5%) used a qualitative method (161), three (37.5%) used a retrospective cohort approach

(157–159) and two (25%) used a cross-sectional approach (163) (Table *13*). A summary of the characteristics outlined in this section is provided in Table *14*.

Of the eight articles in this synthesis, six (75%) were considered to have a low risk of bias (156–160,163), one (12.5%) was considered medium risk (161), and one (12.5%) was considered high risk (162). Of the four articles published in 2020 or later, all had a low risk of bias (157–159,163).. Potential sources of bias in the medium and high risk of bias articles included (but were not limited to): unclear description of statistical analysis (162), unclear description of the validity of questionnaires being used (162), inadequate response rate (162), methodology not being clearly stated (161), and lacking statements on the researchers' biases/influence (161) (Table *13*) (Appendix 12).

Table 13. Study characteristics for articles included in the systematic review.

First author (year)	Country	Country income	Crisis context	Study design	Ctrol	Disability classification	Disability or impairment type	Age of participants in years (No. m/f)	Older age definition	No. of older PWD	Risk of bias
Godfrey (1989)	Sudan	Lower	Refugees living in refugee camps	Mixed (Prevalence and qualitative)	N	Self-report (according to degree of difficulty experienced on 10 functional activities)	**Difficulty with functional activities**	45-59 (33/57) 50-59 (89/99) ≥60 (62/43)	≥ 45 years	Not specified	High
Strong (2015)	Lebanon	Lower middle	Refugees living in community	Mixed (Prevalence and qualitative)	N	Katz index of independence in ADLs	**Multiple impairments** Physical impairment Visual impairment Hearing impairment **ADLs**	60-74 (92/82)	≥ 60 years	134	Low
Good (2016)	New Zealand	High	Sudden onset (earthquake)	Qualitative	N	Visual impairment diagnosis	**Visual impairment**	40-50 (2/2) 60-70 (0/2) 70-80 (1/4) 80-90 (0/1)	≥ 40 years	12	Medium
Akanuma (2016)	Japan	High	Sudden onset (earthquake and tsunami)	Cross sectional analytical	Y	Clinical Assessment, Clinical Dementia Rating (CDR), Diagnostic and Statistical Manual of Mental Disorders criteria	**Mental health impairment** Dementia	≥ 75 (n=180)**	≥ 75 years	180	Low
Kino (2020)	Japan	High	Sudden onset (earthquake and tsunami)	Retrospective Cohort	N	Screening Questionnaire for disaster mental health (PTSS), Geriatric Depression scale short form (depression)	**Mental Health impairment** Post-Traumatic Stress Disorder (PTSD), Depression	PTSS ≥ 65 (1,013/1262) DEP ≥ 65 (853/882)	≥ 65 years	1,735	Low
Shih (2020)	Taiwan	High	Sudden onset (typhoon)	Retrospective Cohort	Y	International Classification of Disease, 9th revision,	**Mental health impairment**	30-64 (289,507/372,422) ≥ 65 (104,614/130,627)	≥ 65 years	13,115	Low

						clinical modification (ICD-9-CM)					
Miyamori (2021)	Japan	High	Sudden onset (flood)	Retrospective Cohort	Y	Government classification (based on ability to perform ADLs and Care Needs	**Level of care need**	<65 (4,493)** 65-74 (25,390)** 75-84 (82,079)** 85-94 (124,602)** ≥65 (22,520)**	≥ 65 years	259,081	Low
Summers (2023)	Ukraine	Lower middle	Conflict	Cross sectional analytical	Y	Kessler K6 Psychological Distress Scale, Katz index of independence in ADLs	**Mental health impairment** **ADLs**	≥ 60 years (406/770)	≥ 60 years	166	Low

*Age not specified

**Number of participants by sex not specified for each age group

Table 14. Summary of article characteristics (n=8 articles)

Variable and category	*n*	%
Region		
- Africa	1	12.5
- Asia	4	50
- Europe	1	12.5
- Middle East	1	12.5
- Oceania	1	12.5
Country		
- Japan	3	37.5
- Lebanon	1	12.5
- New Zealand	1	12.5
- Sudan	1	12.5
- Taiwan	1	12.5
- Ukraine	1	12.5
Country income status		
- Low	1	12.5
- Lower middle	2	25
- High	5	62.5
Crisis Context		
- Refugees living in Refugee Camp	1	12.5
- Refugees Living in Community	1	12.5
- Sudden Onset Disaster	5	62.5
o Earthquake +/- Tsunami	3	37.5
o Flood	1	12.5
o Typhoon	1	12.5
- Conflict	1	12.5
Study design		
- Cross sectional analytical	2	25
- Mixed – Prevalence and Qualitative	2	25
- Qualitative	1	12.5
- Retrospective Cohort	3	37.5
Decade of publication		
- 1980	1	12.5
- 2010	3	37.5
- 2020	4	50
Disability or Impairment Type		
- Multiple impairments	1	12.5
- Visual impairment	1	12.5
- Mental Health impairment	4	50
o Dementia	1	12.5
o PTSD and Depression	1	12.5
o Psychological Distress	1	12.5
o Chronic Mental Illness	1	12.5
- Activities of Daily Living (ADLs)	2	25
- Difficulty with functional activities	1	12.5
- Level of care needed	1	12.5
Disability classification		
- Self-report on difficulty with functional activities	1	12.5
- Katz Index	2	25
- Kessler K6 Psychological Distress Scale	1	12.5
- Visual Impairment diagnosis	1	12.5
- Clinical Assessment, Clinical Dementia Rating (CDR), and Diagnostic and Statistical Manual of Mental Disorders Criteria	1	12.5
- Screening Questionnaire for Disaster Mental Health and Geriatric Depression Scale	1	12.5
	1	12.5
	1	12.5

- International Classification of Disease, 9th Revision, clinical modification (ICD-9-CM) - Government Classification (based on ADLs and Care Needs)		
Number of older persons with disability in sample		
- <15	1	12.5
- 100-200	3	37.5
- 1000-2000	1	12.5
- 10,000-14,000	1	12.5
- >200,000	1	12.5
- Not specified	1	12.5
Older age classification (years)		
- ≥ 40	1	12.5
- ≥ 45	1	12.5
- ≥ 60	2	25
- ≥ 65	3	37.5
- ≥ 75	1	12.5
Risk of Bias		
- Low	6	75
- Medium	1	12.5
- High	1	12.5

The number of articles that presented findings related to various elements of the Life course Perspective of Disability are presented in Table 15. Of the included articles, 6 (75%) presented findings on environmental factors, 2 (25%) presented findings related to personal factors, and 2 (25%) presented findings on agency. Three studies (37.5%) also looked at the influence of humanitarian crises on health condition or impairment. No studies looked at the influence of earlier life events or how disability changes over time as this was not a focus of this systematic review.

Table 15. Number of articles that presented findings on various elements of the Life course Perspective of Disability framework.

First author (year)	**Environmental Factors**	**Personal Factors**	**Agency**	**Health Condition / Impairments**
Godfrey et al (1989)	✓		✓	
Strong et al (2015)	✓			
Good et al (2016)	✓	✓	✓	
Akanuma et al (2016)	✓			
Kino (2020)				✓
Shih (2020)				✓
Miyamori (2021)	✓			
Summers (2023)	✓	✓		✓
Number of articles	**6**	**2**	**2**	**3**

4.1.3 Environmental Factors

Six of the 8 articles (75%) presented findings related to environmental factors (Table 14).

Difficulty escaping danger

Difficulty escaping danger for older persons with disabilities was reported in 3 (37.5%) of the articles (156,160,162). Two studies, with displaced populations (Sudan and Lebanon) (160,162), found that older persons were more likely to be left behind in humanitarian crises, which was often attributed to disability. Godfrey et al. (1989) (162) found that only 1-3% of adults in refugee camps in Sudan were 60 years and older and more than half of older family members had been left behind in Ethiopia, because of they could not complete the journey due to associated with disability and illness (162)(p.710). Similar results were reported by Strong et al. (2015) (160) where older refugees reported that the reason why family and friends were left behind in Syria included limitations due to physical disabilities (as well as lack of financial resources, safety, and the necessity to protect house or other assets) (p.4).

Two studies found that older persons with disabilities had increased difficulty leaving their homes in sudden onset disasters. Strong (2015) (160) found that 10% of older refugees in Lebanon were unable to leave their homes and 4% were bedridden (p.6). Akanuma et al. (2016) (156) reported that many older persons with Mild Cognitive Impairment (MCI) (n=18/89) displayed “inappropriate behaviour” (author’s terminology) (p.350) (such as repositioning objects, becoming confused and engaging in other activities) rather than staying in a safe location or escaping danger during the 2011 earthquake in Japan (130). One study presented findings related to evacuation centres (161) and found that older persons with visual impairments were hesitant to go to the facilities following an earthquake because of their need for assistance and the expected loss of independence (161).

Physical environment

Two articles (159,161) presented findings on physical barriers. Good et al. (2016) (161) found that older people who had a visual impairment faced a number of physical barriers following two large earthquakes (and hundreds of aftershocks) in New Zealand. Participants faced challenges due to physical damage to terrain (such as liquefaction), landmarks that had been destroyed, barriers on sidewalks, detours, and difficulty locating or using traffic signals. There were also barriers navigating around construction material (e.g., scaffolding) and security fences that had been erected after the earthquakes (161) (p.430). The barriers were particularly difficult for people with visual impairments who used canes or dog guides (161).

Challenges were also reported because of disruptions to water in their homes (161). Similarly, Miyamori et al. (2021) (159) suggested that the disruption of infrastructure was a possible reason why older persons with disabilities discontinued long term care (LTC) services after floods in Japan.

Structural factors

Transportation

Good et al (2016) (161) found that, in a post-earthquake context (New Zealand), temporary roadway, and changed public transportation schedules negatively impacted the ability of older persons with visual impairments from accessing services (such as healthcare, pharmacy, and supermarkets), visiting friends and family and navigating their surroundings (161).

Assistive technology

One study presented findings related to assistive technology. Good et al. (2016) found that post-earthquake challenges with the physical environment and transportation were further compounded by assistive technologies (AT) not functioning as intended in the context of the altered landscape and rapidly changing situation (161). For example, cellular telephones with Global Positioning Systems used to navigate walking routes and public transportation became unreliable because of physical barriers and altered schedules (161). Guide-dogs, used by some participants, often needed comforting during and after the earthquakes and many needed to be re-trained (161). They also experienced communication barriers because text messages were not reliable in the post-disaster context (161). The authors recommended that persons with visual impairment should access appropriate technology and learn to use text messages (such as voice to text) prior to a disaster and maintain their ability to use a cane for navigation (161).

Financial Barriers/Economic Factors

Economic factors were discussed in two articles (162,163). One discussed the influence of economic factors on psychological distress (163) and the other spoke about livelihood opportunities (162,163).

Summers et al. (2019) (163) examined psychological distress and disability among older persons living in conflict affected areas of Eastern Ukraine (163). The study found a high prevalence (75%, $P<0.0001$) of serious psychological distress among older persons who were moderately or severely dependent based

on the Katz Index of Dependency (163). The authors comment that in addition to other factors (such living in a conflict zone, living alone) economic challenges related to the conflict likely contributed to their distress (163). In their sample, they found that 85% of older persons (with and without disabilities) in GCA and 88% of those in NGCA were living on less than three dollars per day (163). Godfrey et al. (1989) (162) found that older persons living in refugee camps in Sudan were willing to work but employers discriminated against them in favour of younger people.

Inaccessible information about disasters

Two studies highlighted communication barriers (156,161). Following the Great East Japan earthquake in 2011, older persons with mild cognitive impairment and those with dementia had lower understanding of television news reports related to the earthquake as compared to older persons without mild cognitive impairment or dementia (described as *"healthy subjects"* in the study) (156)(p.352). The authors noted that even the healthy subjects did not fully understand the news reports and recommended that news broadcasts should use pictures and methods that were easier to understand (156). Good et al (2016). found that having a radio to listen to updates was where older people with visual impariments received their news following an earthquake (161). However, they still had challenges accessing the information that was useful for them, which included the condition of roadways and disruptions in public transportation (161). Receiving information following the earthquake was even more challenging for persons who were deaf and blind (161). Akanuma et al. (2016) recommended that in preparation for emergencies, it is important for people with visual impairments to acquire a radio and keep it in working condition with a good supply of batteries (161)(p.429).

Availability of services

Findings related to the availability of services were presented in two studies (159). Miyamori et al. (2021) (159), found that in Japan, older people who had high care needs that lived in flood affected areas had higher rates of "discontinuation" of long-term care (LTC) services (including home visits, day services, and residential services in nursing homes) compared to those who lived in non-flood affected communities. The authors explained that when an individual starts a long-term care program in Japan, they usually continue with it until the end of their life and that the discontinuation of that services usually means *"something catastrophic has happened" (either death, hospitalization, the inability of a provider to over a*

service because of disaster damage, and forced relocation) (159)(p.2). Interestingly, among older people, those who were younger (65-79 years of age) and had less severe disabilities discontinued care more often than those who were older and had more severe disabilities (159). They attributed this to the care being interrupted (by floods) in the community (home care and day services) - where people who are younger and with lower care needs tend to access services compared to those with higher care needs who tend to receive care in facilities (e.g., in long term care facilities) (159). The authors suggest that in disasters, scarce resources may be prioritized towards people with high care needs (vs. low care needs) and that in disaster settings, care should be distributed to not only those with high care needs (159). A study in conflict affected areas of Ukraine (163) highlighted high unmet need for mental health services for older people with disabilities experiencing psychological distress.

4.1.4 Personal Factors

Family, friends and caregivers

Only 2 of the 8 articles (25%) presented findings on older persons with disabilities related to personal factors (161,163). One was related to family and friends (161) following an earthquake and the other reported on the lack of assistance available to participants in conflict (163).

Every visually impaired older person interviewed by Good et al. (2016) (161) after the earthquakes in New Zealand (n=12), reported that contact with family or friends in the week following the earthquake was essential, especially given the limited support from organizations. Participants with less social networks felt isolated and *"panic-stricken"* (p.429). Similarly, they found that people with larger social networks recovered from the trauma of the events quicker than those who were more isolated (161). In conflict affected areas of Ukraine, Summers et al. (2019) found that in GCA 24.6% of older persons who needed assistance with ADLs did not have access to it (163). A similar trend was observed in NGCA where 16.7% of older persons who needed assistance did not have access to any (163).

4.1.5 Agency

Findings related to agency were more difficult to identify and analyze for the identified studies. None of the studies in this review specifically examined the agency of older persons with disabilities in

humanitarian crises as their primary aim. There were, however, two articles that looked at how participants perceived themselves during humanitarian crises (160,161).

Self-Perceptions

Self-perception appeared to be closely tied to the ability of older persons with disabilities to contribute to their families and communities and could change with ongoing crises. Older Syrian refugees who had disabilities and were living in Lebanon expressed feeling like a burden or guilty if they could not help with caring for younger family members or contribute to their families financially (160). In contrast, participants who could assist with those activities did not have the same feelings of guilt financially (160). Interestingly, this was not the same for Palestinian refugees where younger family members were expected to care for older family members (160). In post-earthquake New Zealand, people with visual impairments who were able to support others had improved self-perceptions (161). In the same study, the authors found that with ongoing aftershocks, people with visual impairments had an erosion of their sense of independence over time (161). Unfortunately, no other articles provided similar results in long-term protracted crises (such as conflicts).

Humanitarian assistance

A reliance on humanitarian assistance can lead to a reduction in choice and therefore decreased 'agency'. Only one study reported on findings related to humanitarian assistance and older persons with disabilities (161). They found that in the context of a post-earthquake setting in a high-income country (New Zealand), older persons with visual impairments received little assistance from organizations or government agencies. Older persons with disabilities were therefore left to manage mostly on their own (or with support from family/friends) (161). Two other studies reported older people had a high reliance on humanitarian assistance in refugee contexts but did not disaggregate between participants with and without disabilities (160,162).

4.1.6 Health condition / impairment

Three of the articles included in this review presented findings related to the influence of humanitarian crises on health condition or impairment and all were related to mental health (157,158,163). Kino et al.

(2020) (157) found that after an earthquake, 32.9% of people with depression prior to the event did not have depression 2 years after the event (157). They attributed this to some people becoming more socially active after disasters which can help to reduce depressive symptoms (157).

One study reported findings related to monthly visits for stress-associated illnesses (insomnia, anxiety, depression, PTSD, episodic mood disorder and adjustment reaction) following a Typhoon in Taiwan (158). They presented very few results that disaggregated older age and disability but what they did report is that the number of visits for people with pre-existing mental illness increased after the disaster and slowly decreased (158). Contrarily, for older people without pre-existing mental illness, the number of visits increased quickly after the disaster and continued to increase (158). They concluded that people (of all ages) who had mental health impairments prior to the disaster were able to manage the stressors if they continued to access mental health services (158).

A study, by Summers et al. (2019) (163) found that older people in conflict affected areas of Ukraine who were moderately or severely dependent (used as a proxy for disability) were 5.2 (95% CI, 3.34-8,11) times more likely to experience serious psychological distress compared to those who were independent (p.4). They recommended that humanitarian decision makers should consider screening people with moderate/severe levels of dependency for psychological distress.

4.2 Discussion

4.2.1 Summary of evidence

The aim of this review was to identify and describe the available evidence on the experiences of older persons with disabilities in humanitarian crises. Eight articles were identified with nearly two-thirds being conducted on humanitarian crises contexts in high income countries (HIC) and two thirds on sudden onset disasters. Half of the included articles were published after 2020. A range of experiences were identified among older persons with disabilities, with a particular focus on the challenges and barriers they encounter during humanitarian crises.

More studies reported findings related to environmental factors than any other element of the LPD framework. Physical barriers were commonly reported, with studies highlighting the challenges older persons with disabilities faced during displacement, evacuating during a disaster and navigating the post-disaster environment. The focus on environmental factors is not surprising since physical access and

accessibility are among the most reported findings in studies on persons with disabilities and older persons in humanitarian crises (164). Physical barriers have been shown to hinder the ability of persons with disabilities (of all ages) to access services in humanitarian crises, including displacement and refugee camps (165–167), conflict and sudden onset disasters (168–170) and are often the focus of humanitarian guidelines (171,172). Physical barriers have also been shown to negatively influence access and the ability of older persons to escape danger and migrate in humanitarian crises (165,173,174). However, missing from the literature was the influence of the social environment and how that shaped the experiences of older persons with disabilities. Also missing is an examination of the social factors that influence their experience. A deeper understanding of the factors that lead to certain barriers for older persons with disabilities would also be valuable.

Two studies in this review found that older persons with disabilities had difficulty escaping danger due to physical and communication barriers. Previous literature has also found this and suggested that older people are more hesitant to flee their communities (175–178). One study highlighted that ATs commonly used by persons with visual impairments were found to be unreliable after sudden onset disasters (161). This included mobile telephone and GPS navigation tools (161) which are often disrupted in humanitarian crises where telecommunication infrastructure is damaged or overwhelmed (179). This could contribute to the challenges faced by older persons with disabilities, as mobile phone use has been shown to reduce fatalities in humanitarian crises (179). Previous literature suggests that AT can help improve access and inclusion (180). It is also important to note that simply providing AT and communication devices is not enough – adequate training and maintenance is needed (180).

The article in this review that presented findings on AT recommended that older persons with disabilities be able to use and have access to various technologies prior to a disaster (161). This finding is consistent with the literature that suggests that people should not rely on a single communication device (179). Assistive technology has been shown to positively influence the lives of persons with disabilities (all ages) in other humanitarian contexts, such as refugee camps (181,182). However, there is a lack of research on AT among persons with disabilities and older person in humanitarian crises (181,182) therefore, it is not surprising that few AT findings were reported for older persons with disabilities in this review. Strengthening AT access is a focus of the AT2030 initiative (183) (a global initiative aimed at improving access and research for AT), and the increased challenges faced by older persons with disabilities has been acknowledged in the Global Report on Assistive Technology (182). It is important to note that only one article discussed AT in this review.

Findings related to personal factors were scarce. These were only explored, in a limited way, in two articles. Family and friends were reported to be important after sudden onset disasters for immediate and long-term recovery. This is supported in previous literature on older persons and persons with disabilities which have found that family and caregiver support is important in humanitarian crises (184–187). In Syria, older refugees were found to be increasingly dependent on family members for financial support, survival and care, as well as navigating the healthcare system (177). In the present review, one study found that a quarter of older persons who needed assistance in Ukraine did not have any support (163). The authors did not speculate on the reasons. However, family and community support structures have been cited as being disrupted for older people and people with disabilities in humanitarian crises which (30,188). In addition to disruptions in family, previous literature from Syria has found that some people likely don't have the necessary skills to care for an older family member (177). These factors may contribute to the lack of care received.

Given the importance of family in supporting older persons and persons with disabilities in humanitarian crises and the role of older persons within them, humanitarian actors have stated that the needs of older people must be addressed in conjunction with the needs of the family and community (186). A gap analysis looking at the inclusion of older people and persons with disabilities in humanitarian response found that it was important for persons with disabilities to be kept with their carer and older people to remain with families. (189). It is important to note that the expected role of family, friends and caregivers varies between cultures and contexts (160,190).

The agency of older persons with disabilities was seldom discussed in the identified articles. What was uncovered was that the ability to complete expected roles within the family and community seemed to be related to improved sense of self-worth. Previous research has uncovered similar findings where older people experience a reduction in power and influence in displacement (174). This altered role in the community can exacerbate the psychological impact of the event (164,174) . The findings from this current review suggest that ongoing crises (such as ongoing aftershocks), eroded agency and independence of older persons with disabilities. No studies looked at protracted or long-term crises, which have been found to result in long-term physical and mental health effects for people of all ages (191).The decreased agency of older persons with disabilities can have impacts on the community, as older people have been found to be important in rebuilding their communities after disasters such as earthquakes (192).

The only study that reported on humanitarian assistance reported that the assistance provided to older persons with disabilities after an earthquake in New Zealand was inadequate (161). Two other studies in

this review reported that older people with and without disabilities had a high reliance on humanitarian assistance in refugee contexts (160,162). They did not disaggregate the findings by disability and were not included in the tally for Agency. However, they do offer some valuable information related to agency and assistance. Agency refers to individual choice (73) and, as explained by Godfrey et al (1989) (162), *"their [older refugees] dependence on relief was not one of choice"* (p.711).

It is widely agreed that the input and feedback of humanitarian aid recipients is vital to increase agency of individuals affected by crises so to create a more inclusive and effective response mechanism (17,19,164,174). However, no studies in this review looked at the ability of older persons with disabilities to inform or contribute to response initiatives. This may reflect findings that older people are seen as passive recipients of aid rather than individuals with agency over their daily and healthcare needs (177).

All the articles that presented findings related to body structure or impairment (around one third of all articles) were related to changes in mental health during crises. There were mixed results with two showing a negative influence of crises (158,163) and one finding a decrease in depressive symptoms following an earthquake (therefore a positive influence) (157). The findings are consistent with a systematic review that found most studies reported a detrimental effect of crises on mental health outcomes (PTSD, depression, psychological distress and adjustment disorder) (7). However, one study in their review found that older age was a protective factor against major depressive episodes following a tsunami in India (7,193). Importantly, the studies in the present review speculated that increased social connection and continued attendance to mental health services helped older persons with disabilities deal with the stressors associated with crises (158,163). These findings underscore the importance of providing access to mental health services and programs that foster participation and inclusion in humanitarian crises.

4.2.2 Evidence gap

The limited number of articles identified in this review (n=8), clearly highlights the lack of evidence on the experiences of older persons with disabilities in humanitarian crises. None of the studies explored barriers of facilitators to accessing humanitarian response or daily needs. There is particular concern around geographic and crisis context distribution, and the scope and quality of the evidence. With half of the studies being published since 2020, it is evident that research in this area is increasing. This aligns with

the increased focus of humanitarian NGOs and intergovernmental organizations on intersectionality (8,103,194–196). Initiatives such as the ADCAP consortium, have continually highlighted the need for research and programs focused on older persons with disabilities in humanitarian crises (8).

More than half of the included articles were conducted in crises from high income countries, with one third conducted in Japan. Only one (12.5%) was conducted in a low-income country and this study was conducted in 1989 (162). Only one study was conducted in the Middle East (160) and one in Eastern Europe (163). There are no articles that looked at humanitarian crises in South, Central or North America. It is evident that geographical spread of articles is quite limited. Given that the prevalence of older age (3,7,10,11), disability (4,9), and humanitarian crises (1,5,6,12,13) is highest in LMIC and that response mechanisms are often less robust in these areas, there is a clear need for increased research in these settings.

In terms of impairment type, half of the studies included mental health impairment. Only one included people with visual impairments. Half of the studies looked at ADLs, difficulty with functional activities or level of care needed. It is important to note that a wide variety of methods were used to ascertain impairment or disability type and no studies used the Washington Group Questions which is the most widely used in disability research and advocated for by humanitarian organizations (129,197). Given the range of impairments across the lifespan and into older age, future research should include a greater breadth of disability and more consistency between classification.

It is important to note that many articles were excluded from this review because they included older persons with disabilities within the sample but did not disaggregate data by age and/or disability. Research and humanitarian actors have highlighted the importance of disaggregated data on older persons with disabilities (8,19). This was even flagged in articles included in the present study going back to the 1980s (160,162). Unfortunately, this does not appear to be common practice within the literature. It is promising to note that if authors include a measure of disability (such as the WGQ) and disaggregate data, the body of evidence in this area will likely increase significantly. For future research on older age and disability, researchers should disaggregate their findings by age and disability. This will help with the usefulness of their data and increase the body of knowledge in an area with little research.

This review contained only eight studies demonstrating a clear lack of research in this area. In terms of quality, 6 (75%) were considered low risk of bias, 1 medium and 1 high. It is important to note that the study that reported most on experience and from which made up the majority of findings were from a

study of medium quality (161). Most studies only provided limited data on older persons with disabilities among a larger sample. Many of the low-risk studies were of retrospective cohort or prevalence design, which provided less insight into the lived experiences of their subjects than the medium and high risk articles (161,162) Improving the overall quality of future research would ensure that the lived experiences of older persons with disabilities in crises are considered when making policy decisions. Sources of bias that weakened the two articles (161,162) that were otherwise insightful and interesting included: not using high quality and validated questionnaires, poor methodology descriptions, researcher bias/influence and poor statistical analysis.

4.2.3 Strengths and limitations

There were several strengths and limitations to this literature review. A strength is that this is the first systematic literature review, to my knowledge, that looks specifically at the experiences of older persons with disabilities in humanitarian crises. The inclusion of persons who had a disability prior to crises is another strength as a previous systematic review on persons with disabilities and older people in humanitarian crises highlighted a bias in the literature towards people who are injured during a disaster (189). There were also several limitations to this review. Articles not in English language were excluded which may have resulted in missed evidence. This is important to note given the limited geographical spread of articles and may influence the generalizability of the findings to other contexts. Because of the limited number of articles, this review presented findings with older people as one group. By grouping all older people into one category there may be a lack of nuanced understanding on how experience differs across the age range. Seven articles could not be found despite significant effort. As such, some articles may have been missing from the review. Another limitation is that the article review conducted in 2023 was conducted by a single researcher. Several steps were taken to account for this. First, any article, title and abstract that I considered remotely possible for inclusion went to the next stage of article screening. Second, any full text articles that were questionable were reviewed with SP and JW to assess for inclusion/exclusion. Finally, a decision was made to exclude articles related to the COVID-19 pandemic because of its distinct global nature that was not the focus of this review from the outset in 2015. With the impact of COVID-19 on older people, a review that includes older persons with disabilities should be conducted in the future.

4.2.4 Implications

This review identified eight articles that examined the experiences of older persons with disabilities in humanitarian crises and no studies explored barriers or facilitators to accessing humanitarian response or daily needs. The limited geographic spread and focus on high income countries and sudden onset disasters may limit the applicability of the findings to conflict and displacement in LMIC and demonstrates the need for future research in this area to inform inclusive humanitarian response. The recommendations from this systematic review will be addressed in the discussion, while drawing on findings across from this DrPH.

CHAPTER 5: SETTING THE SCENE

5.1 Introduction

In this chapter, I provide an overview of the study contexts for the qualitative research in Tanzania and Ukraine including crisis background, humanitarian structure and what is known about the frameworks or perceptions of disability. The contexts were selected, in large part, to improve transferability of findings. Transferability refers to the generalizability or applicability of the findings to other contexts, settings or populations (198–200). Conducting research in different contexts has been suggested to help improve the transferability (201). A summary of the contexts is provided in Table 16 and transferability is further discussed in Chapter 8.

Table 16. Summary of contextual elements of humanitarian crisis in Ukraine and Tanzania (Sources provided throughout section)

	Tanzania	Ukraine
Income classification of country (125)	Low income	Lower-middle income
Type of crisis	Refugee camps	Conflict and internal displacement
Population	Refugees from Burundi	IPDs and people living in GCA
Duration of conflict (in 2017)	Current: 2 years recurring cycles of displacement > 20 years	Current: 3 years
Proportion of crisis affected population > 60 years of age	2%	30%
Proportion of crisis affected population with a disability	Not available	15%
Provision of services	Humanitarian agencies	Government social assistance and Humanitarian agencies
Healthcare	Mostly provided by NGOs	Universal coverage and high out of pocket costs
Movement restrictions	Prohibited from leaving refugee camps	No laws prohibiting movement. Safety inhibits travel.

5.2 Refugee camps in Tanzania

5.2.1 Crisis background

The current refugee crisis in Burundi began in 2015. However, Burundi has experienced repeated cycles of violence and displacement (202,203), meaning that some (mainly older people) likely experienced multiple conflicts, crises, and displacements throughout their lives. The longstanding political violence in Burundi have primarily been between the majority Hutu and minority Tutsi populations (203–205). In 1993, a conflict began that lasted almost 9 years (206,207) resulting in an estimated 300,000 deaths and displacement of more than 687,000 people (203,208). In 2000, the Arusha Peace and Reconciliation Agreement for Burundi was signed and has been credited as helping to end years of conflict in the country (203,208–210). Almost half a million Burundian refugees were repatriated from Tanzania with assistance from UNHCR following this agreement (208). However, those who returned to Burundi reportedly faced significant challenges associated with poverty, unemployment, loss of housing, lack of infrastructure, and difficulty returning home after spending a long time outside of the country (208). In 2015, there were political protests that resulted in more than 420,000 Burundians being displaced to neighbouring countries (130,211,212). The data collection for this DrPH research occurred 2 years later (in 2017). At that time, many Burundians were still living in the refugee camps. This was also the beginning of a large voluntary repatriation programme (212). Since then, from September 2017 to December 2021, almost 110,000 refugees were assisted in returning home to Burundi from Tanzania (212).

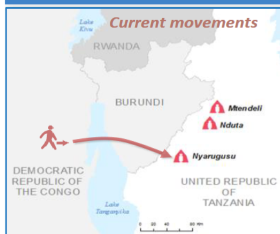
5.2.2 Age and disability in refugee camps in Tanzania

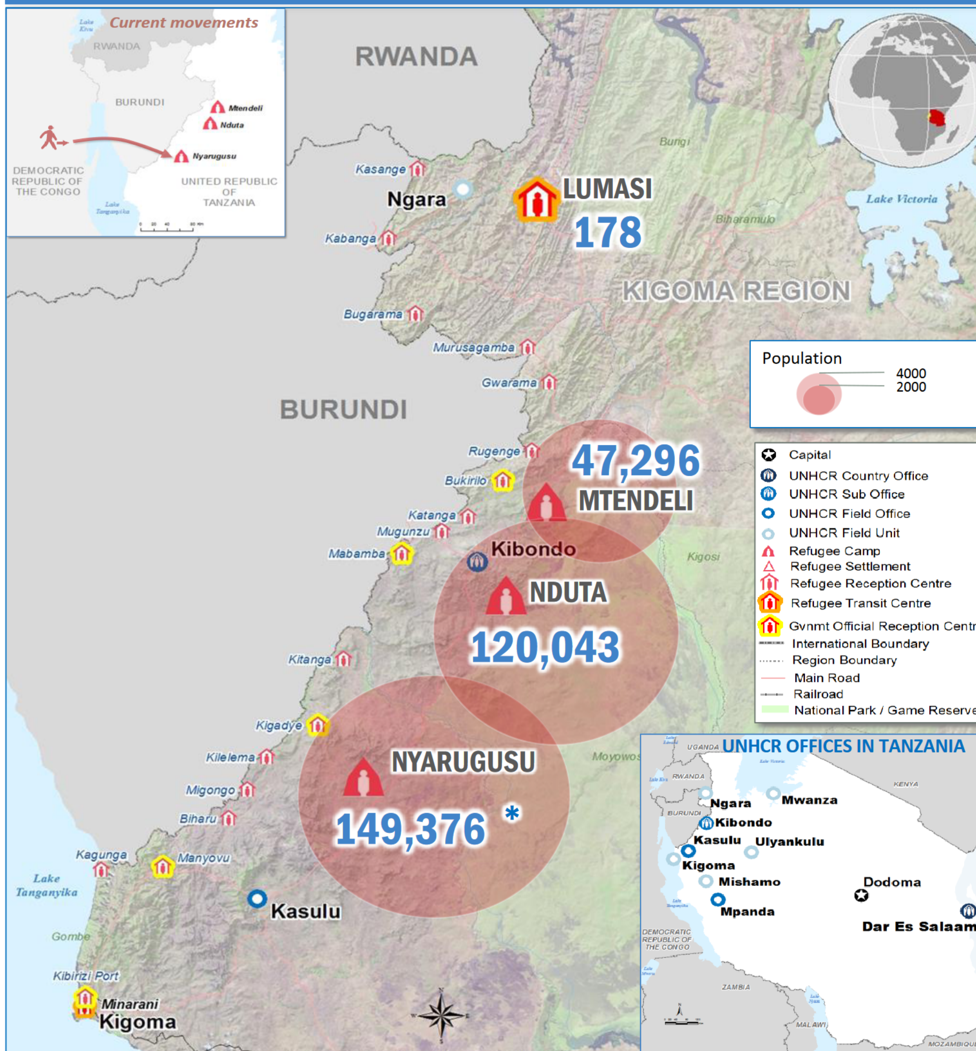
Tanzania hosts a large number of refugees due to the political instability and conflict in neighbouring countries. In 2017, there were over 273,000 refugees living in North-Western Tanzania. They primarily live in three refugee camps (Mtendeli, Nduta, Nyarugusu) located close to the Burundian border, where nearly 75% of refugees originate (Figure 15) (130,213). In contrast to Ukraine, the refugee crisis in Tanzania may be described as a *"crisis of younger people";* only 2% of people living in refugee camps are older persons (Figure 15) (131,213,214). Data on disability prevalence in the refugee camps in 2017 were not available.

Literature on the experiences of older people and people with disabilities in this setting is limited. A survey found that people with disabilities (all ages) who live in the refugee camps face increased rates of violence, discrimination, and access barriers as compared to the host community (215). They also found that most

persons with disabilities were not financially independent and could not engage in livelihoods (215). Only 14% of persons with disabilities (all ages) living in the camp were able to work (215). A different study looked at access to food and found that older people living within Nyarugusu refugee camp were found to face food insecurity due to access issues and the lack of availability (216)

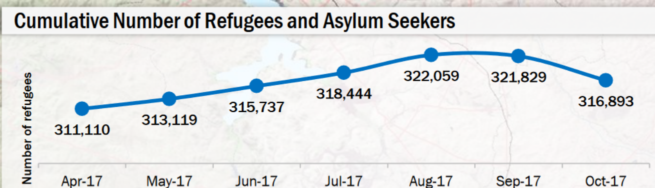
North-West Tanzania - REFUGEE CAMPS POPULATION UPDATE as of 31 October 2017



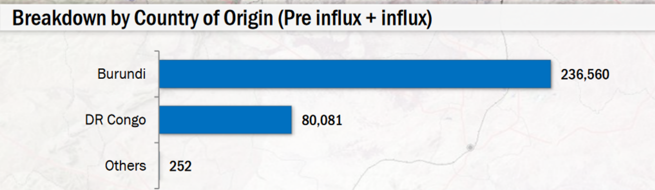


Total Number of Persons of Concern	316,893
Total Number of Refugees	273,812
Total Number of Asylum Seekers	43,081
Total Number of Households	89,648

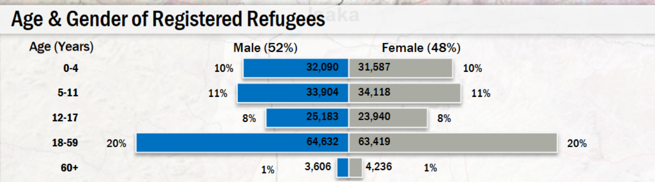
Cumulative Number of Refugees and Asylum Seekers



Breakdown by Country of Origin (Pre influx + influx)



Age & Gender of Registered Refugees



Background information

The current Burundi refugee situation in Tanzania began late April 2015. The months that followed saw a high number of persons of concern arriving in Tanzania. Prior to allocating new camp site by the Government of Tanzania, the population was temporarily hosted in Nyarugusu camp, which was already host to 65,000 other persons of concern, mainly DR Congolese. The camp quickly ran out of capacity to host the new population, prompting the opening of a new camp, Nduta, in Kibondo district on 05-Oct-2015. Nduta's capacity was put at 60,000. Another camp, Mtendeli in Kakonko district, was also opened and began officially receiving refugees from Burundi on 14-Jan-2016. By September 2016, Mtendeli reached its full capacity of 50,000. The next month Nduta camp was re-opened to receive newly arriving refugees from Burundi; while all other nationals entering Tanzania to seek asylum are hosted in Nyarugusu camp. The 2015 prima facie declaration for Burundian asylum seekers was revoked on 20-Jan-2017. Burundian asylum seekers arriving since then undergo status determination processes being conducted by an ad hoc committee of the National Eligibity Committee. Meanwhile, volontary rapatriation of burundian refugees as officially began in September 2017.

The boundaries and names shown and the designations used on this map do not imply official endorsement or acceptance by the United Nations. Sources: Boundaries: UNCS; Background: USGS; Data: UNHCR, IOM

* 65,167 persons of concern pre-Burundi crisis, 84,209 New Arrivals from mainly Burundi and DR Congo

For more information or suggestions please contact: tankbim@unhcr.org or visit: https://data2.unhcr.org/en/situations/burundi/location/2034 Creation Date : 06 Novemvber, 2017

This document is prepared by UNHCR

Figure 15. Population of refugees living in refugee camps and communities in Tanzania as of 31 October 2017 (Source: UNHCR, 2017 (213))

5.2.3 Refugee camp structure and management

At the time of the research, Camp Coordination and Camp Management (CCCM) in Nduta and Mtendeli refugee camps was undertaken by UNHCR (in partnership with Tanzania Ministry of Home Affairs (MHA) and the Danish Refugee Council (DRC)) (217,218). CCCM is the name given to the standardised coordination mechanism that organizations adhere to through the Refugee Coordination Model (RCM) (219). The function of the CCCM vary depending on the context and crises, however, the primary function remains the same – ensure the needs of displaced people are met (219)(p.2). The CCCM must adhere to rights-based protocols and standards.

There are specific UNHCR guidelines on older persons (220) and (separately) persons with disabilities (221) that acknowledge the double protection risk and challenges faced by older persons with disabilities (Appendix 13). However, there are no specific standards that address older persons with disabilities. UNHCR guidelines often referred to "persons at heightened risk" or "persons with specific needs" which includes persons with serious health conditions, older persons and persons with disabilities (as well as other groups) (220,222)**.** These standards highlight the need to identify and consult persons at heightened risk, collect disaggregated data, ensure access to humanitarian assistance and protection (222,223).

Table *17* provides an overview of services available in Nduta and Mtendeli refugee camps in 2017 (217,218). At the time of this research lack of funding was a major challenge for NGOs working within the camps. In 2017, UNHCR only 20% of the funding needed to meet the needs of people living within the camps (217,218). This influenced access to needs including core relief items (CRI) (e.g., blankets, buckets, tarpaulins, etc.), housing, infrastructure, WASH, food and livelihoods (217,218).

Table 17. Summary of services available in Nduta and Mtendeli refugee camps (Source: UNHCR (217,218))

Service	**Nduta** (217)	**Mtendeli** (218)
Hospital	1	1
Health posts	6	1
Community Based Rehabilitation	2	-
Women's centers	1	-
Food distribution centers	3	1
Police posts	3	2
Common market (outside camp border for commerce with community	1	1
Camp based market (inside camp)	2	1

5.2.4 Identification and assistance for older people and people with disabilities

In Nduta and Mtendeli refugee camps, UNHCR identifies *"People with specific needs"* when they arrive at the camps, including people with disabilities (based on UNHCR assessment, not Washington Group Questions) (224). As per global standards, UNHCR aims to mainstreaming services for 'People with Specific Needs' across all their projects and initiatives within the camps. It also partnered with organizations that have a particular focus on one or more of the population groups. In Nduta and Mtendeli refugee camps, UNHCR refers all older people and people with disabilities to HelpAge International.

5.2.5 Government involvement in refugee crisis in Tanzania

According to UNHCR, *"protecting refugees is primarily the responsibility of States"* (225) (p.7). Therefore, the laws, policies and decisions of governments can have a profound impact on refugee experiences. UNHCR generally assists States to establish procedures (225), which is the case in Tanzania (226) where the Government partnered with UNHCR to host refugee populations within Tanzania (226). The opinion and policies of the government can therefore have an important impact on the experiences of refugees.

Tanzania has generally been quite welcoming of refugees and is known to have an *'open door policy'* (226,227). However, the approach of the government has shifted in recent history, and they are no longer as welcoming (226). This has been attributed to the protracted nature and extent of the crisis (226).

Tanzania has agreed to a number of international, national and regional laws and policies that protect the human rights of refugees. For example, internationally, they have agreed to uphold 'The 1951 Convention Relating to the Status of Refugees' (and 1967 Protocol), which is grounded in the Universal Declaration of Human Rights (225,226,228,229). Their regional laws and policies reinforce and expand upon the international ones and help to promote collaboration between countries (226). The national laws within Tanzania are where the government restricts the movement of refugees (226).

At the time of the data collection, refugees were prohibited from leaving the refugee camps. These were enforced by the Refugee Act of 1998 (the Act) (230) (NRP) (226,231). According to these laws, no person could leave refugee camps without prior permission, and they could only undertake limited livelihoods within the refugee camps (226,232).

In 2017 the government of Tanzania began repatriating refugees. There have been concerns (raised by organizations such as Human Rights Watch (HRW), Amnesty International, and the UN) that Burundians have been forcibly repatriated (233–236). These actions contradicted many of the laws and policies that Tanzania has agreed to, including the UDHR, 1951 Convention Article 33 on non-refoulement, and many of the regional policies (226).

5.2.6 Perceptions and frameworks of disability

Research on the perceptions of disability among Burundians (within and outside of Burundi) could not be found. Even prevalence data on disability has not been well established in these areas (237,238). One report, published by UNICEF in 2023 (238), examined inclusive education in Eastern and Southern African countries and mapped various elements of disability within countries of the region. One factor they looked at was how countries define disability. They found that 14 of the 21 countries in the region have adopted the UNCPRD definition of disability (including Burundi and Tanzania) (238). However, even in countries that have adopted the UNCRPD, most countries (including Burundi) referenced both the social model and medical model within their legislations and laws (238). They also found that the definitions of disability were not consistent across all policies and government documents (238). The authors suggest that this highlights a lack of universal understanding of the social and rights-based frameworks of disability (238). Burundi was among the countries that used both frameworks within their documents, suggesting a lack of universal understanding. Tanzania consistently used the social model of disability in their policies and

documents which the authors state demonstrates a more widespread adoption and understanding of the framework compared to countries that use both (238).

5.3 Conflict in Eastern Ukraine

5.3.1 Crisis background

The crisis in Eastern Ukraine began in 2014. However, the cause of the conflict stems from the country's longstanding tumultuous history and pull between Europe (and the West) and Russia as well as factors related to the fallout at the end of the Cold War (239). At the time of this research in 2017, the conflict had resulted in extensive damage, suffering and displacement (240)(p.6). A nearly 500 Km 'contact line' divided Luhansk and Donetsk Regions into areas that are under Ukrainian government control (Government Controlled Areas (GCA)) and those outside of it (Non-Government Controlled Areas (NGCA)) (240–242). The NGCA of Luhansk and Donetsk are collectively known as Donbass Figure *16* (240–242). Since the start of the conflict in 2014 and November 2017, the United Nations Office of the High Commissioner for Human Rights (OHCHR) recorded 10,303 people killed and 24,778 people injured as a result of the conflict (243).

5.3.2 Age and disability in Eastern Ukraine

The conflict in Eastern Ukraine has been deemed "*one of the 'oldest' humanitarian crises in the world"* (242)*(p.11)* – not in terms of duration, but because 30% of 3.4 million people in need are over 60 years of age (134,242–244); a higher proportion than in any other humanitarian settings (242)(p.26). This age structure has been attributed to younger people leaving their homes because of safety, economic and access issues and older people staying because many are less mobile or willing to leave (242,245–250). Disability prevalence around the time of data collection for this research (2017) is limited but in 2020, UNOCHA estimated that 15% of people who lived close to the contact line of the conflict had a disability, compared to 6% in the rest of the country ((242) (p.28) (source data: (251)). Reports have indicated that older persons and persons with disabilities have difficulty accessing social assistance, pensions, humanitarian assistance, and healthcare (242,244,252).

Figure 16. Map of Ukraine demonstrating the contact line and non-government controlled areas (NGCA) (in orange) (Source: UNOCHA (2017)(240)

5.3.3 Humanitarian coordination

The humanitarian response in Ukraine is organized according to the United Nations Cluster approach and includes both UN and non-UN humanitarian organizations (26). In 2017, a common theme for Humanitarian Response Plan was a focus on protecting and improving access to services and social benefits for the most vulnerable (including older people and persons with disabilities) as well as protection mainstreaming (253). However, lack of funding was a major issue in Ukraine at the time of this research which led to gaps in service and organizations reducing or closing their programs (240,254). This meant bigger gaps in service delivery and reduced capacity of remaining organizations to deliver assistance (240). The government was involved in supporting affected people in Ukraine and mainly trying to link them with long term solutions and social assistance programs (255). There was a particular focus on IDPs however, they still faced additional challenges associated with verification procedures, housing, subsidies and stigma (256).

5.3.4 Access

Access to NGCAs was also a major challenge at the time of the research because of insecurity (240). In 2017 only four international organizations had permission to deliver services in NGCA of Luhansk and one in Donetsk (240). In addition, the Ukrainian government restricted movement of people and goods across the contact line (253)(p.12). The challenges in accessing NGCA restricted this research to GCA. People living in NGCA have even more difficulty accessing daily needs, government assistance and social supports (257).

5.3.5 Healthcare

Ukraine has a multi-tiered healthcare system with various levels of service providers (258,259). The system is organized so the physician is primarily responsible for coordinating medical care for the population in a catchment area (258). In 2015, The European Observatory on Health Systems and Policies reported that the healthcare system was largely inadequate to meet the needs of the population (259) *(p.47)*. Corruption has also been reported within the healthcare system which results in higher out of pocket costs for patients (258,260). The conflict had resulted in further degradation of infrastructure. There have been several health reforms since 2014, however the effects of these have not been seen until

recently (260). Therefore, the participants in this study faced the challenges of the previous models, before reform.

5.3.6 Perceptions and frameworks of disability

Ukraine ratified the UNCRPD and optional Protocols in 2010 (261,262) however, according to a UN Report (263), Ukraine predominantly applies a medical or charitable approach to persons with disabilities. The government has taken steps to advance the UNCPRD within the country and ensure the widespread use of ICF framework of disability (such as translating the ICF into Ukrainian and providing training programs) but, according to several reports, the adoption of both remains slow within policies and society (261–263). Ukraine has a number of legislations and laws relating to the protection and anti-discrimination of persons with disabilities but they are mainly focused on social protection and do not fully reflect the UNCRPD and are commonly not implemented (261,262). Updating these laws was flagged as an important step towards full adoption of the UNCRPD.

The most predominant framework within the medical system in Ukraine is the biomedical model (263) - where disability and ageing are seen as physical or pathological problems that need to be prevented or solved with medical and rehabilitative interventions (37,50). There have been efforts to move towards the ICF and a bio-psycho-social model (263) however, as reported by the Equal Rights Trust (262), the legacy of the Soviet era continues to influence healthcare, laws and legislation.

In terms of perceptions of disability in Ukraine, a report written by the Sociological Rating Group (an NGO and independent research group) found that Ukrainian society has a *"neutral attitude"* towards civilians with disabilities and a more positive attitude towards military personnel with disabilities (264). The majority of respondents stated that they believe persons with disabilities can live in a similar manner to those without disabilities (264). Most people also reported they feel comfortable communicating with persons with disabilities (264). While this is promising, the authors of the study comment that these responses were likely skewed *"in an attempt to present oneself in the best light"* (264) (p.1). Persons with disabilities felt that people in Ukraine mostly had feelings of pity towards them (264). The report stated that people who were injured as part of their role in the military were generally perceived more favourably, and people reportedly believed that they should receive additional assistance.

PREAMBLE TO CHAPTERS 6-8:
Qualitative Research Findings and Analysis

Introduction

In Chapters 6 and 7, I present the findings from the qualitative research conducted in refugee camps in Tanzania and conflict affected areas of Eastern Ukraine. I begin with findings from Tanzania because there was a greater humanitarian presence in the refugee camps as compared to Ukraine. As such, many aspects related to their experience, daily needs and access to services were provided or controlled by NGOs. By contrast, in Ukraine there were fewer NGOs and humanitarian agencies, pensions and social supports were provided by the government, and participants were responsible for managing how they met their daily needs. In many ways these factors introduced complexity. Thus, findings are presented with the more humanitarian actor intensive environment first, followed by a complex environment with fewer humanitarian actors.

Throughout the results in Chapters 6 and 7, the themes and subthemes follow common groupings of humanitarian management, such as the IASC cluster approach (142) (for more information see Chapter 1 and Appendix 1). Within these chapters, I focus on findings that highlight the experiences of older persons with disabilities and their access to daily and humanitarian support needs.

In the discussion chapter (Chapter 8), I discuss and synthesize the findings from Chapters 6 and 7 using the LPD Framework. In the discussion, I also compare the findings between contexts, draw on concepts presented in the introduction (Chapter 1) and key concept chapters (Chapter 2) and relate to the available evidence as presented in the systematic review (Chapter 4) and other relevant literature.

Participants

Details about the participants' age and disability from each context are provided in Table 18. Twenty-one interviews were conducted in Tanzania and thirty-one were conducted in Ukraine. Eleven caregivers were interviewed in Tanzania and five were interviewed in Ukraine. The most commonly reported disability domains in both Ukraine and Tanzania were difficulty with walking (97% and 90%, respectively) and seeing (94%, and 71%, respectively). The overwhelming majority of older persons with disabilities in both contexts had difficulty in multiple domains (100% in Ukraine and 90% in Tanzania), with only two subjects (10%, both Mtendeli camp in Tanzania) reporting difficulty in only one domain.

Background

Most participants in Tanzania stated they had left Burundi because of the risk of violence (politically or financially motivated). One participant left Burundi, in part, for the hope of receiving needed medical care in Tanzania that they could not access in Burundi. Many faced a variety of barriers (e.g., difficult terrain), lacked access to daily needs (e.g., not having enough food or water) and safety concerns (e.g., gunfire) during displacement. Once the participants arrived at the refugee camps, they had largely escaped the threat of violence from conflict. They did face other protection risks that will be explored in the coming chapters but, generally, the threat of violence from conflict was not reflected as a major contributor to participants' lived experiences or access to daily and humanitarian support needs. By contrast, in Ukraine the conflict was ongoing and security threats inherent in living in conflict affected areas pervaded many aspects of daily life and decision making. The threat of violence, difficulties and dangers in travelling, checkpoints and crossing the contact area made it difficult for participants to travel within and outside of cities. Participants thought about their security on a constant basis. It influenced their ability to access daily needs, interact with others, and access humanitarian assistance and healthcare. Security, therefore, influenced all other areas and is a common thread that runs through the findings from Ukraine.

In Ukraine, there were some who were internally displaced from the NGCA and others who lived and stayed in the conflict affected areas in GCA. In the following chapters, I have highlighted where their experiences differ. In Tanzania, all participants had been externally displaced and were living in refugee camps.

The exposure to previous crises varied between the participants in each context. In Tanzania, because of the history of violence and repeated cycles of displacement in the region, some had experienced multiple displacements throughout their lives. In Ukraine, participants had lived through the geopolitical tensions of the cold war, ongoing political tensions and some recounted experiences during World War II.

Table 18. Participant age and disability characteristics from Tanzania and Ukraine.

Characteristics	Older Persons with Disabilities, by region and age													
	Tanzania (n = 21)							Ukraine (n = 31)						
	Mtendeli			Nduta			Total	Donestk			Luhansk			Total
	60-69 n=2 No. (%)	70-79 n=2 No. (%)	80+ n=6 No. (%)	60-69 n=5 No. (%)	70-79 n=3 No. (%)	80+ n=3 No. (%)	**No. (%)**	60-69 n=5 No. (%)	70-79 n=6 No. (%)	80+ n=5 No. (%)	60-69 n=4 No. (%)	70-79 n=5 No. (%)	80+ n=6 No. (%)	**No. (%)**
Sex														
Male	0 (0)	1 (5)	3 (14)	3 (14)	2 (10)	1 (5)	**10 (48)**	3 (10)	3 (10)	2 (6)	2 (6)	1 (3)	3 (10)	**14 (45)**
Female	2 (10)	1 (5)	3 (14)	2 (10)	1 (5)	2 (10)	**11 (52)**	2 (6)	3 (10)	3 (10)	2 (6)	4 (13)	3 (10)	**17 (55)**
Severity of disability														
Some difficulty in less than 2 domains	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	**1 (5)**	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	**0 (0)**
Some difficulty in at least two domains	1 (5)	0 (0)	2 (10)	0 (0)	0 (0)	0 (0)	**3 (14)**	3 (10)	2 (6)	0 (0)	0 (0)	0 (0)	1 (3)	**6 (19)**
A lot of difficulty/cannot do in at least one domain	0 (0)	2 (10)	4 (19)	5 (24)	3 (14)	3 (14)	**17 (81)**	2 (6)	4 (13)	5 (16)	4 (13)	5 (16)	5 (16)	**25 (81)**
Disability Type (at least some difficulty)*														
Seeing	0 (0)	2 (10)	4 (19)	4 (19)	3 (14)	2 (10)	**15 (71)**	5 (16)	5 (16)	5 (16)	4 (13)	5 (16)	5 (16)	**29 (94)**
Hearing	1 (5)	0 (0)	0 (0)	1 (5)	1 (5)	2 (10)	**5 (24)**	2 (6)	4 (13)	4 (13)	1 (3)	3 (10)	6 (19)	**20 (65)**
Walking	2 (10)	2 (10)	6 (29)	3 (14)	3 (14)	3 (14)	**19 (90)**	4 (13)	6 (19)	5 (16)	4 (13)	5 (16)	6 (19)	**30 (97)**
Remebering	0 (0)	2 (10)	1 (5)	1 (5)	2 (10)	2 (10)	**8 (38)**	1 (3)	4 (13)	3 (10)	3 (10)	4 (13)	3 (10)	**18 (58)**
Self-care	0 (0)	1 (5)	1 (5)	3 (14)	2 (10)	1 (5)	**8 (38)**	1 (3)	3 (10)	5 (16)	3 (10)	5 (16)	3 (10)	**20 (65)**
Communicating	0 (0)	0 (0)	1 (5)	1 (5)	1 (5)	1 (5)	**4 (19)**	2 (6)	2 (6)	2 (6)	1 (3)	1 (3)	3 (10)	**11 (35)**
Multiple Domains	1 (5)	2 (10)	6 (29)	5 (24)	3 (14)	3 (14)	**19 (90)**	5 (16)	6 (19)	5 (16)	4 (13)	5 (16)	6 (19)	**31 (100)**
Only 1 domain	1 (5)	0 (0)	1 (5)	0 (0)	0 (0)	0 (0)	**2 (10)**	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	**0 (0)**

*Based on WG-SS (127)

CHAPTER 6: RESULTS FROM REFUGEE CAMPS IN TANZANIA

6.1 Livelihoods

ET sat against a tree in front of his home (made from tarpaulin) in Mtendeli refugee camp. ET was an 80-year-old man and he had severe difficulty with mobility and some difficulty seeing. He explained that he couldn't work and was supported by camp management and NGOs (what he refers to as "authorities").

> *"We are supported by the authorities here in the camp because as you can see, I am not able to go out and work like other people."*

The inability to engage in livelihoods was the norm for older persons with disabilities in Tanzania. Of the 21 participants, 20 had no livelihood despite approximately 40% (9/21) engaging in a livelihood before living in the refugee camps. Participants and caregivers uniformly reported that while younger people and people without a disability were able to work, older people with disabilities were unable to, despite the desire to do so. The primary reason provided by participants was that livelihood activities for refugees were mostly physical in nature and, because of physical decline associated with older age, the work available was not feasible for them. For instance, ET commented:

> "*I would like to work on farms in the host community, but I have no ability to do that because of my old age. I am here waiting for support from the authorities."*

A lack of livelihood activities had a cascade of effects on other areas of life, hindered the ability of participants to access daily needs within the refugee camps and caused decreased independence and participation (Figure 17). As depicted in Figure 17, the inability to engage in the livelihood activities available in this context, contributed to poverty. This resulted in difficulties supplementing the food and non-food items (NFI) provided by NGOs. Because of this, participants relied on family members and NGOs to meet their daily needs, resulting in decreased independence and agency.

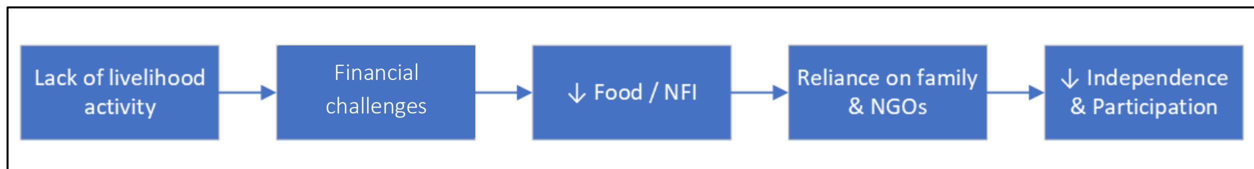


Figure 17. A lack of livelihood activity for participants caused a cascade of effects. It resulted in poverty which led to a lack of food and NFIs. This contributed to a reliance on family members and friends and ultimately decreased independence and participation.

In the absence of livelihood activities, participants primarily relied on younger family members in Tanzania for financial support. Family members who earned monetary income primarily engaged in agriculture (within and outside of the camps) or sold non-food items (NFI) they received from humanitarian agencies for money. In some rare cases, family members or caregivers of older persons with disabilities worked as 'incentive workers' for NGOs delivering community services within the camps. Often the money earned by a caregiver or family member, regardless of the type of work, was insufficient to support the entire family. One family member commented that he was considering returning to Burundi because he could not earn money in the camp. In addition, family members often needed to balance caregiving responsibilities with work, limiting the time they could engage in livelihood activities and amount of money they could earn.

An additional constraining factor related to livelihoods was the inability to access work in the communities outside of the camp. Government policy prohibited refugees from going into the community and some participants reported possible safety concern (violence or being arrested) when interacting with the host community.

The only exception in terms of livelihoods was the experience of 'BT' who managed to consistently cover his food expenses by selling tomatoes and other products. BT was a 65-year-old man who lived in Nduta refugee camp who had decreased function in his left arm and leg that caused him to have a lot of difficulty walking. He also had some difficulty with vision. BT previously engaged in agriculture in Burundi but was unable to return to it because of his impairments. When BT arrived at the camp, he (like others) was provided with a small sum of money. He used what he was provided and some money he brought with

him to buy items (mostly tomatoes and tobacco) and re-sold them at the common market located just outside of the camp border. He continued to do this for the year and a half that he lived in the camp.

The amount of money that he made selling tomatoes and other goods was likely small. However, it seemed to have a profound impact on his independence and agency. When asked what helped him take care of himself, B replied *"The only thing that helps me to take care of myself is money"*. The money he earned allowed him to access food, which helped him meet his nutritional needs. However, he still faced challenges obtaining his preferred food (see Section 6.3) and repairing his home (See Section 6.2).

The ability to have a business and engage in a livelihood activity had other wide-reaching implications, including socialization. BT stated that he was unable to participate in social activities within the camp however, as evident in the quote below, he was able to interact and socialize with others while selling items at the market. The same opportunities were not available to others, who often experienced loneliness and isolation (see Section 6.5).

> *"All the time that I am not in the market I am alone. But once I am in the market I am always with my friends.", he explained*.

This case demonstrates how the ability to engage in a livelihood activity can help to interrupt the cascade of effects that can result in decreased independence (Figure *17*). By having a livelihood activity, BT was able to supplement food and assist himself. Even the language he used was different than other participants. He referenced his own agency more often and how his income helped him to take care of himself. He still relied on NGOs for food and NFIs but was able to supplement it with his income. The livelihood activity assisted in increasing independence and social participation.

There are several factors that make BT an outlier. First, BT did not have any family members or children who relied on him (B and his wife had previously separated and his children lived on their own). Therefore, the money provided to him could be allocated to starting a livelihood rather than supporting himself and his family. Second, while BT had difficulty walking, he was able to ambulate using crutches which increased his mobility. Third, at 65-years-old, B was on the younger end of our sample which may have had an impact on his mobility.

6.2 Housing

V sat on a bench outside his home in Nduta refugee camp, his crutches leaning against the brick wall behind him. He explained the challenges maintaining his home:

> *"In order to get money to pay the brick makers, I sold a portion of the ration we are receiving. That caused us to have a shortage of food."*

V was 62 years old and before being displaced he was a casual labourer. When he arrived at the refugee camp two years earlier with his wife and their 7 children, he was allocated a small single room house made of bricks and a tin roof. Over time, his home needed repairs but V didn't have an income (neither did anyone in his family) and his impairment had progressed to the point where he could no longer complete repairs himself. He told us that camp management did not maintain or provide funding for repairs. So, V and his family sold food to pay for supplies and labour.

The experience of V was common for people living in the refugee camps. Houses were primarily small single or double room homes arranged in densely packed zones. In both camps, the older, more established zones were more orderly, with distinct plots of land for each household. The houses in these zones were mostly constructed of red locally made brick and a tin roof. In the newer zones the housing, plots of land, roads, and paths were more irregular (because they were hastily built to accommodate large influxes of refugees). There, houses were primarily made from tarpaulin (plastic sheets) with sticks, trees, mud, and other locally available materials. Between houses were rough paths and the roads were more difficult to navigate than in other parts of the camp. In all sections of the camp, people made additions and modifications to their homes using tarpaulin and locally available materials.

Like V, participants in both types of houses (especially tarpaulin) reported that houses were in poor condition, unstable, in need of repair and offered little protection from the elements. Many respondents pointed out holes in their walls or roofs that leaked when it rained, or how loose tarpaulins flapped in the wind, and were worried their houses would collapse. Many houses made of brick had a tarpaulin door.

While people of all ages lived in the same type of structures, older persons with disabilities faced additional factors that contributed to their poor living conditions. First - in many cases, participants were

unable to complete repairs on their own which they attributed to their impairment. Second - despite being derelict, organizations responsible for providing new residents with shelters reportedly neither repaired the houses nor provided building materials or tools for the inhabitants to maintain houses on their own. However, most did not have an income to pay for materials or labour themselves. Third - several people in our sample lived alone because they were either separated far from family and caregivers during displacement, did not have any family, were alone for periods of time while family members sought work outside of the camps, or were isolated from those around them. These individuals did not have support structure close by and, as a result, lived in houses (or sections) that were in a state of disrepair.

Other participants (such as V) had the opposite experience – they lived in overcrowded houses. V lived in a one room home with 9 inhabitants. He explained:

> *"[I have] no Privacy. At this age living in the same house with grown up children isn't good at all."*

Participants attributed crowding in houses this to the allocation process, the low supply of housing within the camps, and the small plots of land. A brief background on camp processes and implications will aid understanding how older persons with disabilities ended up living in crowded houses.

Upon arrival to the camps, individuals were offered a place to live, either a house or a room within a two-room house. According to participants, if people arrived with too many family members to live in one house, while attempts were made by NGOs to place family members close to each other, this was often not possible. As a result, some participants were allocated a house far from family members and caregivers. Participants often relied on caregivers and family members for assistance with activities of daily living (ADLs) (Section 6.7) and needed to live close to them. They were then faced with a decision to either live far away from their support (likely sharing a room in a house with others) or live in the same household as their family. All participants who were given the choice decided to live with family in an overcrowded house rather than live on their own without support. Participants requested solutions from NGOs such as expanding their homes or building a separate home on the same plot of land but were denied because of lack of space. As described below, V chose to stay with his family in an overcrowded home, rather than be separated from them.

"This house is very small. I have even contacted DRC [Danish Refugee Council] and have shown them the need to expand the house, but they didn't help. The reason being the smallness of the plot of land they have allocated and if they allocate a new house that means they will be separating our family members. To me expansion of my house is a real need…"

Because of the lack of privacy, V and his family fabricated rooms using clothes for walls to create some privacy and his eldest son informally found housing with a neighbour so they could all live close to each other.

6.3 Food and non-food items

Food insecurity was discussed by every participant in Tanzania. The rations were consistently reported to be insufficient to meet the needs of participants and this affected them physically and emotionally. The quotes that follow highlight the food shortages and impact on participants.

"We don't have food since yesterday because we are waiting for another ration in two weeks' time. Sometimes I cry and tighten a rope around my stomach, or sleep on my stomach due to being hungry. We are hungry and have no money to buy anything we may want… I'm just a human being who doesn't have anything." (M, a 62-year-old female living in Nduta refugee camp who had complete vision loss and difficulty with self-care and remembering)

"The food shortage here leads to insecurity. We get a small ration which can't be sustainable for a month…. We are all faced with famine here." (SP, the son and primary caregiver for his mother, P, who reported her age as 102 years old and had complete vision loss)

Food rations were provided every 28 days from central distribution points and were widely acknowledged to be insufficient. Although not by design, people living within the camps were required to supplement the food they received with what they could buy or grow themselves. However, both strategies were difficult for older persons with disabilities. Others living in the refugee camps could reportedly cultivate the small plot of land outside of their homes or, in some cases, a plot of land outside of the camps (contradicting camp policies which could lead to security risks). They used this food to supplement the rations directly (by consuming what they grew) or indirectly (by selling produce at the common market

and buying what they desired). As described in the following quote, older persons with disabilities did not have the same opportunities and were reliant on humanitarian support.

> *"We receive the same amount of food as other people but, it is not sufficient… They [younger people] can walk and do activities and they can do something to add to the rations they receive even though the rations cannot take them through the whole month."* (H, a 60-year-old woman who lived in Nduta and had a vision impairment and tuberculosis who was married to K, an 89-year-old man who had difficulty with mobility, vision, and remembering. They both had gastric ulcers.)

In addition to food shortage, participants had little choice over what they ate and their diets lacked variety. This was especially difficult for people who had difficulty eating the food provided (generally ugali, beans, flour).

Strategies used to manage the food insecurity included: borrowing food from family or friends and 'repaying' it when they received their next rations or selling NFIs for money to buy food. Others would sell food from a future ration for money to meet their immediate demand. Both strategies reduced the amount of food in future rations, creating a cycle of chronic food shortages that had the potential to compound with each ration.

Access to food and NFIs was difficult for older persons with disabilities because of the physical inaccessibility and challenges at distribution sites. Humanitarian organisations recognized the additional difficulties and provided rations two days earlier and had separate queue for older people and people with disabilities. However, participants suggested these strategies didn't completely overcome access barriers. Many had difficulty waiting in line for long periods of time, travelling to distribution sites and carrying items (such as heavy food) home. HelpAge International provided transportation via a 3 wheeled motorcycle, which helped, but this did not seem to be available to everyone. Participants attempted to overcome these access challenge by having a family member or friend collect rations for them. But, as explained by SP, this was often difficult because of the camp processes and the humanitarian authorities' overriding concern with food theft and abuse of the rationing system.

> *"The challenge when I go to the distribution site to receive my mother's portion is that they always tell me that am going to steal the food. They refuse to give me her portion."*

6.4 Water, sanitation, and hygiene (WASH)

Water was accessed from stations dispersed throughout the camps and was usually available, except during periods of drought in the summer months. During these times, everyone in the camps experienced difficulties accessing water and participants reported that some went up to three days without water. The most significant challenge faced by participants was described by Y, a 76-year-old man who lived in Nduta, when he said: *"We have water; it is a matter of fetching it".* Participants pointed to the combination of personal (health condition or impairment) and physical environmental factors (rough terrain, long distance and inaccessibility) that made it difficult for them to reach water stations and carry heavy buckets water.

Latrines were mostly small structures constructed out of wood frame with tarpaulin walls. They were dispersed throughout the camps and usually there were several latrines close to a cluster of houses that shared them. Outside of the latrines were handwashing stations. Some consisted of a large plastic bucket with a tap, while others consisted of a bottle of water with a string that individuals stepped on so they could wash their hands without having to touch taps or other surfaces (referred to as a 'tippy tap'). Most participants had latrines that were separate from their houses and shared with multiple households. In addition to the environmental and structural barriers described, participants noted that they had more difficulty accessing latrines at night, because there was no lighting and they had no torches or light source. People with visual impairments seemed to have additional challenges accessing latrines and required assistance from family members to access and use them.

Difficulties with toileting seemed to be a particular source of tension with families and between households that shared latrines, as illustrated by derogatory language in some interviews and older persons with disabilities being accused of leaving the latrine dirty. Below are several examples:

> *"We pull him like a goat using his walking stick". (F, the daughter of an 80-year-old man with an intellectual disability, Nduta)*

> *"This man sometimes he may want to go outside but he can't. It is impossible. He can't help himself and he can't go to the toilet. He just pisses on himself where he is." (OT, the son of an 83-year-old*

man who had a lot of difficulty with walking, self-care and communicating and some difficulty with remembering, Mtendeli)

"When the toilet is dirty, neighbours say that it is our mother who left the feces in the toilet because she is blind, so she is not able to use the toilet. That's why we have asked for adaptive toilet for our mother to minimize the conflict." (W, a 19-year-old woman who lived in Nduta and was the primary caregiver for her grandmother who had complete vision loss and difficulty with mobility)

In some cases, strategies to support WASH accessibility appeared to either not be available or accessed by a majority of people in our sample who needed it. This was described by W (19-year-old woman who lived in Nduta and was the primary caregiver for her grandmother who had complete vision loss and difficulty with mobility). W stated that her family requested to have a toilet close to their home that her mother could use and they planned to tie a rope from the house to the toilet to facilitate access. They had implemented this in Burundi and suggested that this approach would improve access and help the older persons with disability and caregiver be more independent.

"She can't go to the toilet without help or support. We ask you to follow up so that they [NGOs] can build an adaptive toilet near to the house and put a rope that will direct her to the toilet. This will help her in case there is nobody around to support her. We applied this in Burundi, and she was taking herself to the toilet. This can also make me free and engage in different activities to earn money for buying her medicine because if I do not get friends to help me, it becomes a problem."

6.5 Healthcare

'Z' sat outside of her tarpaulin home and recounted the harrowing experiences she encountered throughout her life during multiple wars in Rwanda and Burundi. In 1991, while living in Rwanda during the civil war, Z was 26 and having just given birth to her son, she was walking with sisters from the Catholic Church, her newborn in her arms, and they came across several soldiers. The soldiers beat and stabbed her several times, leaving her badly injured, including a dislocation in her leg. She received some initial

treatment for her injuries, including injections and medication and then moved to Burundi to escape the war and went almost 20 years without receiving any follow up medical care for her injuries. Z moved to Tanzania to escape the ongoing war and violence in Burundi. At the time of the interview, Z was 65 years old and lived in Nduta refugee camp. She had a lot of difficulty walking and seeing and some difficulty with self-care. There were more healthcare facilities available in the camp than what she had access to while living in Burundi however, she had difficulty physically reaching them, as described in the quote that follows:

> "*I have hard time getting there [the hospital]. I even stop on my way there several times to catch my breath, and if I can't find any transport, because of my disability, I just drag myself just so I can get there*."

The above account reveals many of the complexities around health and healthcare access for older persons with disabilities. Most participants had complex healthcare needs because of conditions associated with their impairments, older age, a lack of access to healthcare services throughout their life (which resulted in conditions and impairments going untreated for long periods of time or at all), and a myriad of other factors (such as lack of access to water, food, etc.). Once they reached the refugee camps, they may have escaped security threats associated with war but faced other insecurities (such as food, water, and shelter), all of which can negatively impact on health. Like Z, many had difficulty accessing healthcare facilities and services because of physical barriers (long distances, rough roads, and inaccessibility) within the camps.

Even when older persons with disabilities could access the facilities, treatment was often not available for them. Overwhelmingly, participants explained that treatment or medication they were told (by a health professional) that they needed were not available in the camps. Since they could not leave and did not have the funds to pay for it, these treatment options could not be accessed. For example, Z explained that at one point she was prescribed a medication that was no longer available within the camp. She was provided with pain medication to manage her symptoms but found them to be of little use.

Participants reported mixed attitudes from healthcare staff. Some participants felt that persons with disabilities were given higher priority at hospitals than others. For example, two people had been told to go ahead of others in line at healthcare facilities because of their impairment. However, this seemed to be mostly reported by those with impairments that could be seen by others. Most had challenges with long wait times at hospitals because healthcare was provided on a 'first-come first-served' basis. With this

people who arrive early have a better position in the queue. This was more difficult for older persons with disabilities because of the barriers faced reaching the facilities.

Several personal and organisational factors facilitated access to healthcare. Support from family, friends and neighbours was an important factor. In some cases, these individuals would physically assist older persons with disabilities or help them access transportation or NGO workers. Camp management attempted to offer housing to older persons and persons with disabilities that was close to these facilities, however, because of space constraints and high demand, this was often not possible. HelpAge provided transportation for older people within the refugee camps which was reported to be very beneficial for those who used it. However, this transportation was not used by all because some were unaware of the service, and others could not contact the incentive worker to request the service.

Homecare, for people who received it, was perceived as extremely valuable in improving access to healthcare and appropriate treatments/interventions. For instance, 'ND', a daughter and primary caregiver, explained that home visits helped to monitor her mother's condition, identify when she was sick, and bring her to the hospital. This was especially helpful for those older persons with cognitive or communication difficulties who were less able to voice their concerns or symptoms with caregivers. However, only four people mentioned that they received care at home, mainly in the form of rehabilitation and/or exercises delivered by HelpAge staff.

6.6 Participation and socialization

'C' left Burundi almost a year and a half before the interview because of active fighting where he lived. He described that he had nowhere to stay or sleep and left to find somewhere he could *"live peacefully".* His family remained in Burundi and at the time of the interview he lived alone in Mtendeli refugee camp. C was 80 years old and was the father of seven children. Since none of them lived close by and he had a lot of difficulty with walking he explained: *"I have no ability to go and visit them… it is too far."*

This was the situation faced by many participants in Tanzania – they faced challenges socializing and spending time with others, outside and within the camps. As a result, isolation was a pervasive problem especially for those who lived far from family. Like C, some individuals were displaced while their families

remained in Burundi. Others had family and friends who were displaced and living in different refugee camps in Tanzania or neighbouring countries. They attributed the inability to visit friends and family to their impairment and the long distances between them.

Within the camps, there were two primary factors that hindered social participation: (1) physical barriers and (2) barriers to meaningful inclusion. Even those who lived with others (such as family members) experienced isolation as, in many cases, household members were their only source of social interaction. Some described how their family members or caregivers were the only ones who communicated in a way that they could understand. The same two factors seemed to prevent participants from participating in decision-making processes within the refugee camps, as illustrated in the dialogue below, between C and the interviewer:

> *Interviewer:* *"What about meetings, are you able to attend when people are discussing issues related to the services being provided [within the camp]?"*
>
> *C:* *"When the meetings are far from here, I don't go because I don't have enough energy to walk."*
>
> *Interviewer:* *"What activities would you like to do?"*
>
> *C:* *"I don't feel like doing any activity because I have no ability to get involved."*

Here, C described how (1) physical inaccessibility and (2) barriers to meaningful inclusion prevented participants from being able to inform decisions. He later alluded to a third factor that contributed to this; the perception that their needs were not being addressed. Despite the desire to be involved in the decision making process, participants sometimes felt as though camp management and NGOs within the camps did not address the concerns of older persons with disabilities. As C explained:

> *"Yes, there are meetings we [older people with disabilities] are invited to attend but they [camp management and NGOs] don't work on the concerns that we are giving."*

Several factors helped participants to socialize including neighbours. Many had good relationships with the people who lived nearby and described them as "friends" and would sometimes visit each other. For those who could reach them, Community Safe Spaces (CSS) for older people were also important, offering valuable opportunities for interacting with others. CSS were developed by HelpAge where older people

could go to interact with others, play games and participate in various activities (like singing and playing music). One individual, ‘S’ (a 60-year-old woman who lived in Mtendeli refugee camp and had some difficulty with hearing and walking) described how going to CSS to talk with *“fellow Burundian people”* about the challenges of having a disability, sharing prayer, and singing with others helped to reduce stress. One participant, BT (introduced in Section 6.1 on livelihoods), interacted with people while selling items at the market.

6.7 Family and caregivers

Family and caregivers played an important role in the lives of older persons with disabilities. Many participants described how family members helped during displacement in the form of physical assistance (such as supporting to walk, carrying, and guiding); paying for transportation, travel expenses and border costs; and navigating procedures (e.g., border and refugee camps). Within the refugee camps, family and caregivers assisted with accessing health and humanitarian services (food, water, latrines and NFIs), supported with ADL’s, accessed firewood, repaired homes, and provided financial assistance. Caregiving roles were most commonly occupied by women; either daughters (around half of participants) (Table 19) or spouses (3/11). Less common was for a grandchild or neighbour to fulfill the role of primary caregiver. Neighbours were important for socialization, but only one served as a primary caregiver in our sample.

Table 19. Primary caregiver relation to older person with disability in refugee camps in Tanzania

Relationship to older person with a disability	Female	Male
Child	5	1
Grandchild	1	0
Spouse	3	0
Neighbour	1	0
TOTAL	**10**	**1**

Many younger family members who were caregivers (especially the adult children of older persons with disabilities) had mixed sentiments related to assisting a family member. They referred to it as their “duty”

or their expected role within the family and community and it was also a clear expression of dedication to their family member. The following quotes demonstrate the common sentiment of children:

> *"[Caring for our father] does not affects us because he is our father, we are happy to assist him"* (MF, 30 year old female and primary caregiver for her father, Mtendeli).

> *"It doesn't affect us in any way, we just live with him because he is our father, and we can't leave him and we can't do anything most off all we just love him and we give him what we are able to give him."* (OT, the son of an 83-year-old man who had a lot of difficulty with walking, self-care and communicating and some difficulty with remembering, Mtendeli)

Some spouses explained that living with a person with an impairment increased their caregiving requirements twofold - because of the additional caregiving needs of their partner and the reduced support at home and within the family. This was especially the case for people who also had dependents. Yet, this changed with age - as the children grew older, they often needed less care and support. If children lived with or close to the parents, they could support with caregiving activities. The interviews revealed that when a parent had a disability, children were expected to "*jump in"* (F) to help support the family, even at a young age. In some cases, both spouses had an impairment or health condition that made it more difficult for them to care for each other and meet daily needs, especially if they did not have children or were displaced far from them.

Several participants reported that family dynamics were altered by having a family member who had a disability. In Burundi and Tanzania, it is more common for men to be the head of household (265). However, in families where a child (female or male) supported the family financially and cared for a parent who had a disability, often they were considered the head of household, regardless of if they were younger or older than their siblings. Interestingly, when two married individuals lived together without children, the man was considered the head of household, regardless of if he had a disability or not.

Financial and livelihood implications on the family that were identified as well. There were extra costs associated with supporting an older family member with a disability and caregiving sometimes limited the ability to engage in livelihood and social activities. This exacerbated the challenges for older persons with disabilities and their families, as evidenced in the following quote:

> *"It's so limiting, as we use most of our time to take care [of my grandmother], as well we spend a lot of money for her, and we cannot engage ourselves in other activities."* (ND, a 25-year-old woman who cared for her grandmother N, a 68-year-old woman who had some difficulty with mobility)

Family members and caregivers suggested a variety of methods that would help support them and their families. The most common were capital to start a business, cash assistance, additional food, support with cost of services (e.g., healthcare), and caregiving support.

CHAPTER 7: RESULTS FROM CONFLICT AFFECTED AREAS IN EASTERN UKRAINE

7.1 Protection/Security

> *"The ATO [Anti Terrorist Operation] soldier's [Ukraine Special Forces] have a control point in our village. The Luhansk People's Republic armed forces were a few kilometers from us and there was constant fire in our village. They shoot from there, and the others answer back. They shoot day in and day out…"*

> *"They opened fire all the time. The fragments from missiles were everywhere. It influenced us very much."*

The quotes above are from HL, an 87-year-old man who recollected the events that he and his wife (70 years old) had endured during the conflict. Before being displaced in 2015, they lived in Popasno, Luhansk Region, an area of active fighting. They had sheltered in place and were forced to hide in their basement.

> *"The missiles exploded in our yard. The windows were broken. We were stressed. We lived like this for a month. I mean a month in the basement. At first, we were in the yard, when they started to shoot, they did not shoot too hard, then, when they started to shoot severely in both directions, we were very stressed."*

The experience of HL and his spouse highlights a common experience of participants in Ukraine – many sheltered in place during the conflict rather than leaving prior to it. There were several factors that contributed to this, including lack of financial resources, environmental barriers (long distances, rough terrain, inaccessibility), lack of accessible and affordable transportation and having nowhere else to go. Some participants did not want to leave their homes which led them to shelter in place.

During active violence, some participants were able to shelter in the basements of their homes or a local building (school, church or hall). For others, these shelters (or means of reaching them) were inaccessible, meaning they had to remain in their homes.

The tendency to stay in their homes resulted in security issues for people who stayed and for those who were displaced (Figure 18). Participants who remained in their homes continued to be exposed to direct and indirect risks of active conflict. For those who did relocate, this sometimes meant that they did so at times of greater risk and complexity (e.g., increased fighting, degradation of the environment, and military checkpoints)

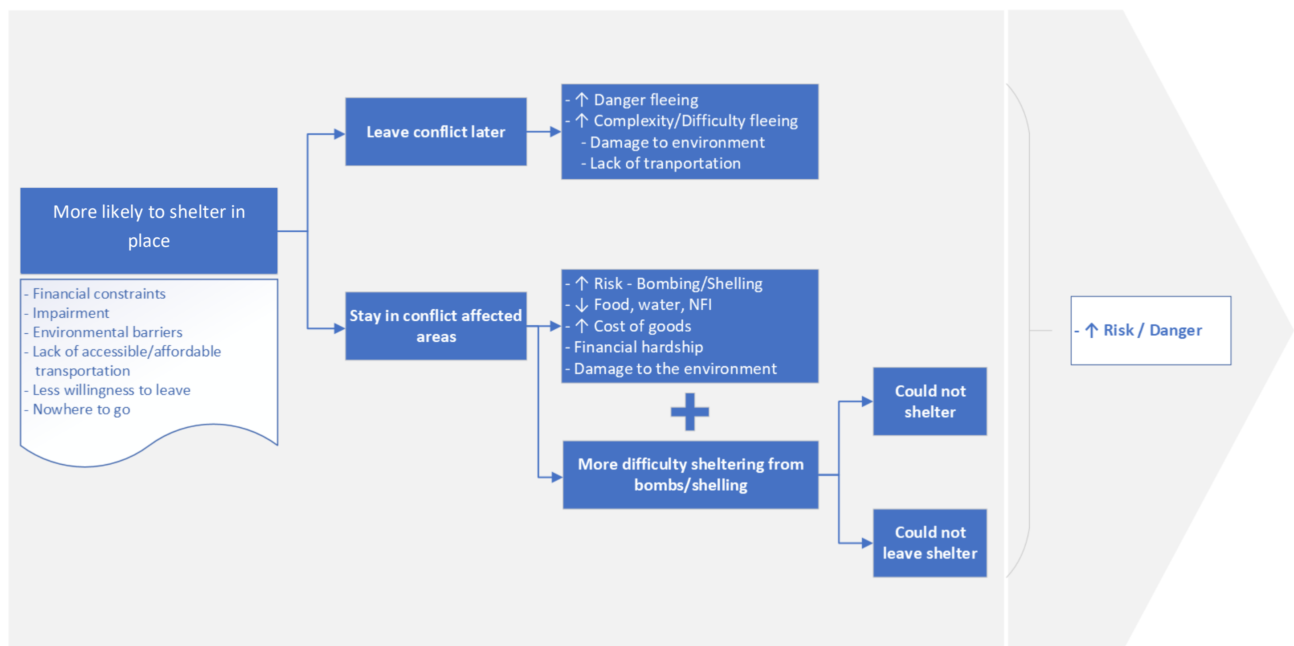


Figure 18. Participants had difficulty leaving conflict affected areas which caused them to either stay in the areas and/or flee later. This led to increased security risks.

The experience of HL and his wife highlight the profound and long-term impacts of remaining in areas of active fighting. The conditions in the basement they sheltered in were poor; damp, without electricity and with a collapsing ceiling. This contributed to significant and long-lasting deteriorations in their physical health and mental health (e.g., HL reported difficulty sleeping when it rained because it reminded them of shelling).

7.2 Livelihoods

CD sat on a chair in the living room of her 3 room flat in Kramatorsk, a city in Donetsk region. She was 71 years old, and had lot of difficulty with walking, self-care and seeing. She explained the impact of inflation that was caused by the conflict and the lack of additional supports.

> *"Prices rise immediately [with the conflict]. And so, the pension does not manage to catch up. Well, they promise [to increase my pensions]. All of them promise. Well, it's only in words."*

The financial challenges associated with inflation and inadequate social supports limited her ability to access needed medical care, food and other daily needs. She had recently incurred rib and shoulder injuries falling on the stairs while leaving her apartment complex and couldn't afford the medical expenses, so it went untreated. She used a credit card and went into debt to cover the cost of food and utilities.

Financial challenges were a common experience for all older persons with disabilities in Ukraine. Lack of money was a constant concern and poverty underpinned many of their daily challenges. Many reported pre-existing financial difficulties that were exacerbated by the conflict because of inflation and decreased value of the Ukrainian currency.

While inflation likely affected all people living in these areas, it was challenging for older persons with disabilities to manage it for several reasons. First, in Ukraine people over 60 years generally do not work and rely on retirement pensions and other forms of social protection (described in Table 20) provided by the government. Participants reported that pensions had not increased to offset inflation and participants could not work to supplement their income. Second, many participants had additional expenses related to healthcare (including medication and transportation).

Table 20. Social protection schemes mentioned by participants. (Name and description reflect common language used by participants. Reference serves as verification).

Pensions	
Retirement or "old age" pension	Available to men/women, 60/58 with years of age and older, with at least 35/30 years of contributions to the state in Ukraine. Partial pensions available for people who do not meet the above criteria (266).*
Disability pension	Available to individuals with a government classification of disability. The amount of money received was based on the severity of disability (266).* - Group I: Incapacity for any work and requires constant attendance (highest support). - Group II: Incapacity for any work and does not require constant attendance. - Group III: Incapacity for usual work (least support) (1 being the most severe and receiving the highest amount of support and 3 being the least severe and receiving the lowest amount (See Chapter 5).
Subsidies	
Housing subsidy	Additional funding for utilities and housing costs, based on government disability classification.
"Resettlement" subsidy	For IDPS to assist with additional costs associated with being displaced (e.g., accommodation)

*Taken directly from USA Social Security (2018) (266)

Participants also faced environmental, structural and attitudinal barriers to accessing social protection entitlements. Physical barriers compounded by lack of accessible to public transport or affordable alternatives, made it physically difficult for some participants to reach government offices and banks to apply for and/or collect their pensions and subsidies. In terms of structural barriers, the application processes were reportedly lengthy and forms difficult to complete, which prevented some from receiving social protections. Long wait times to receive a classification (because of lack of available appointments) resulted in delays in receiving financial supports. Because of this, some participants had to travel to other cities for assessments and applications which compounded the travel challenges and added extra costs (e.g., transportation and accommodation).

Some participants expressed frustration at what they felt like was an unfair or arbitrary allocation of disability classification and supports. One person was denied their pension from a government official for

"*unexplained reasons*". Others felt as though they should have received more funding than they were allocated given their impairment.

To cope with lack of financial resources, participants often relied on family or friends. For some, their children worked in other parts of the country and sent money back to them. Others borrowed from friends or neighbours, yet many of them were also living in poverty. The effects of living in poverty and a lack of financial support had widespread and profound influences on their lives and ability to meet daily needs.

Internally displaced persons

IDPs faced additional challenges accessing social protection. Some were unaware of the supports available to them and/or did not know how to apply for them. Others, who had been displaced from NGCA to GCA had difficulties registering because they lived in informal or temporary accommodation needed to have papers signed by the property owner. HL had had been displaced from a city in the NGCA to a temporary accommodation the GCA of Luhansk:

> *"I wanted to apply for it [housing subsidy]. But the owner has left somewhere… I went to the Social Services Department, but an employee told me the owner must sign the papers."*

A key structural barrier for some older people with disabilities was related to requirement for IDPs to present themselves for verification every three months to receive their pensions. This was explained by JL, a 65-year-old man who was displaced from Luhansk city in 2014 because of bombing and shelling close to his home. JL had both legs amputated and used a wheelchair and had difficulty with seeing, hearing, remembering and self-care. He explained attitudinal and structural barriers he faced receiving financial support as an IDP

> *"…There is such an attitude to the re-settlers, perhaps they want us to go to our homes. Every three months they need confirmation that we are alive… Every three months they need to bring me down from the fourth floor and to bring me up again… I tell them that it is better for me if a postman could bring my pension to the flat… They say that is not permitted for the re-settlers… This is how they make fun of the re-settlers, of the disabled persons."*

This quote also highlights the intersecting stigma and discrimination related both to being an IDP and having a disability. It demonstrates how participants with disabilities were being disadvantaged, humiliated and made more vulnerable by the verification system. The verification processes were designed and implemented in a way that decreases agency of the applicant and creates a power imbalance between those who can provide (and are the gatekeepers) of social assistance and those who receive leaving recipients with very little say in how or how much they receive.

Negative attitudes towards IDPs were also experienced from members of the community, as evident in the following quotes from participants who had not been displaced:

> "*It's more difficult to live now because of internally displaced people… The internally displaced people get everything. They have gas meters installed in the apartments they rent, they have discounts for rent payment, food packages, though they have bought the apartments here. They run their business and receive aid. We have nothing…"* (JH, a 75-year-old woman who lived in Luhansk)

> *"Be content with what you have. These people [IDPs] are sneaky, they lie."* (DD, an 81-year-old man who lived in Kramatorsk, Donetsk Region with his wife and had a lot of difficulty with hearing and some difficulty with seeing, walking and remembering)

7.3 Housing

DD sat in the kitchen of his two-room flat, which was located on the first floor of an apartment complex in Donetsk. He was 81-years old and lived with his wife. He pointed to the damaged walls and ceiling in his kitchen.

> *"We suffered from water leakages… [There was damage] in the toilet facilities, in the bathroom, in the kitchen and, in the corners. The plaster on the kitchen ceiling was completely destroyed", he explained.*

The couple had previously enjoyed having members of their church visit but were embarrassed because they couldn't afford the needed repairs to their home. Their income from pension and subsidies was barely enough to cover their expenses (less than 3000 UAH (112 USD) total per month). They cut costs by lowering their heating and not using much electricity. DD needed hearing aids but they decided to forgo buying these to save for house repairs. *"We don't have money for hearing aids. We want to do repair here"*, he explained.

The inability to repair homes or pay for maintenance and utilities was a common experience for older persons with disabilities. Most lived in poorly maintained homes, either large 4-6 storey, Soviet era apartment complexes or two storey houses outside the main cities. In the context of competing needs (e.g., health, transportation, assistance, etc.), participants were often left with difficult financial decisions. In contrast to the case of DD, most participants prioritized healthcare and medication over home repairs and many took similar cost saving measures (such as lowering their heating and utilities) which resulted in worsening of living conditions (e.g., being exposed to very cold conditions in the winter).

Physical barriers that prevented access to homes was another significant challenge. Most apartment complexes did not have a lift and in those that did, the lifts were often not large enough for a wheelchair, were poorly maintained or not functioning. Many complexes and homes had a set of stairs at the entrance with no accessible alternative, which prevented some participants from being able to leave independently. These barriers contributed to decreased independence, increased isolation, and increased cost (for assistance). This was explained in the following quote by AD, who lived on the nineth floor of an apartment complex in Donetsk region. She was 68-years old and had severe difficulty with mobility and seeing and some difficulty with hearing. She also supported her friend who was 83-years old and used a wheelchair. AD explained how the inaccessibility of their building prevented her friend from being able to go outside.

> *"The only thing that upsets us is – Will you make a note, please? Can you help us install wheelchair ramps to transport her from here?... She wants to go outside."*

Most participants lived alone or with a single family member or caregiver and experienced isolation. However, some lived in overcrowded houses, having moved in with family members or friends as a cost

saving measure or for additional support. Others were forced to live in crowded housing because of displacement – living in temporary accommodations or moving in with people they knew in a safer location.

Internally Displaced Persons

The challenges with housing and living conditions were more pronounced for IDPs. Many moved to temporary housing that was in poor condition. They expected to stay in these temporarily but as the conflict dragged on, many ended up living there for years. Some also repeatedly faced the threat of forced eviction from building owners and had nowhere else to go. This was explained by RA, a 65-year-old man who had been displaced several times. He had a lot of difficulty with seeing, walking, remembering and self-care and some difficulty communicating.

> *"We were put in buses…. we were brought to Odessa region… to a sanatorium. Then we lived there. Nobody wanted to pay the director [owner]… he made everybody leave… He himself is a private entrepreneur… it was terrible... he switched everything off including the water and elevators [lifts], to evict us… we lived on the 12th floor…"*

7.4. Food and non-food items

> *"We sometimes lack food. We are three here… We spend most of our money on medical products… We spend all our money for drugs. Rental payment. We lack money. That is why we sometimes have nothing to eat."*

This is how AD described the food insecurity she experienced in Krematorsk, Donetsk. She lived with her friend and her friend's son, who had moved in with her when they were displaced in 2015. AD was a 68-year-old woman who had a lot of difficulty with mobility and seeing and some difficulty hearing. Her friend used a wheelchair for mobility and needed support with self-care activities.

Lack of food was a major concern for all participants in Eastern Ukraine. The conflict had resulted in food shortages, which created increased demand and drove up food costs. While this likely affected all people in the area, older persons with disabilities faced particular challenges because of the issues related to lack of livelihoods, low pensions and inability to supplement income. When confronted with the decision whether to pay for food or healthcare/medication, the latter usually took precedence. Because of this, participants often went without enough food (insufficient quantity), could not choose what to eat (limited variety), and often focused on affordability of food over nutritional value (quality). Getting to the shops to buy food access was another common challenge due to physical barriers and lack of transportation.

Some participants attempted to alleviate food security issues through growing food. In rare cases, participants had a small plot of land where they could grow food and others grew vegetables in pots. For most, this did little to combat food insecurity. There was one outlier, who was able to supplement food through gardening.

BL, was a 68-year-old woman who lived in Luhansk with her husband. She had fractured her hip and suffered a stroke the year prior to the interview. BL had a lot of difficulty with walking and self-care and some difficulty with seeing. Combined, BL and her husband received 3,126 UAH (117 USD) per month in pensions and social supports and spent the majority on medication, leaving little for food. They had a seasonal home ("dacha") that was passed down by family that had 12 Hectares of land. BL's husband planted a vegetable garden which helped them meet food needs. BL explained:

> *"Well, I can tell you that we do not buy potato, beet, cabbage, tomatoes, cucumbers, fruits, vegetables, onion, or garlic. Well, we use our own. I also do preservations… I made preservations of vegetable paste and cooked lescho [stew] and sauces. For God's sake, we have everything. It is okay with us concerning this. We have a garden of sweet pepper and chili pepper."*

However, BL and her husband are outliers and were the only participants who were able to grow this much food. They were able to do this because they had a separate home with a plot of land that they could access using public transportation. In addition, BL had the support of her husband who was able to garden. These factors were not available to others.

A few participants reported that NGOs distributed food in conflict affected areas, however, this was reportedly infrequent and only for IDPs. Some participants received food from NGOs in the past but not recently. They attributed this to many organizations closing their programs due to lack of funding. Like in other areas, older persons with disabilities met their food needs with support of family and caregivers who provided food of money to buy food.

7.5 Water, Sanitation and Hygiene (WASH)

Apart from the periods where water was shut off, most participants had water in their homes. Some people only had access to cold water that they heated on a stove for cleaning and bathing. Most also had a bathroom with a toilet and shower or bath in their homes. Two older persons with disabilities in the sample (JS - an 81-year-old woman who reported some or a lot of difficulty in all WG-SS domains and CP a 78-year-old woman some or a lot of difficulty with seeing, hearing, walking, remembering and self-care) did not have a bathroom in their homes. In these cases, the bathroom was separate from their home, which made access difficult. They washed in a wash basin in the yard or in the kitchen and one (CP) occasionally used a bucket latrine to avoid having to leave their home.

The biggest WASH challenge for participants was when water was shut off, which happened occasionally. The following quote by ND highlights the challenges associated with this and how he (and members of the community) supported each other. Unlike ND, most people did not have wells close to their homes and had difficulty accessing water when it was disrupted.

> *"I have a well. Here, we were cut off water two times, and people queued to take water from my well. Half of micro district was there having arrived by cars… [it is] 4 meters deep. The water is near, of good quality…. All the neighbours have made paths to my well… We should help each other..."* (ND, 64-year-old man who lived in Donetsk Region with his wife and had some difficulty with walking, seeing and communicating - mainly due to a workplace injury when he was younger).

In a few cases, an older person with a disability reported receiving washing powders, detergents and soaps from an NGO. However, with the closure of many programs, these support mechanisms were no longer being offered.

> *"…Unfortunately, [the project], is closed… I wish they would open more projects like that one… They provided us with products, gave us a wheelchair for washing procedures, for her to go to the toilet…"* (AD, 68-year-old woman who lived in Donetsk and had severe difficulty with mobility and seeing and some difficulty hearing)

Water insecurity seemed to be particularly difficult for IDPs who lived in temporary accommodations; some participants described that building owners sometimes had their water shut off in an attempt to force eviction (As discussed in section 7.3).

7.6. Healthcare

HL, who sheltered in his basement with his spouse (described above), explained that he and his wife had several health conditions that required treatment (some caused by or worsened since being in the basement). They had both recently spent time in the hospital and HL describes the need to decide between conditions to treat or medications to buy because of financial challenges.

> *"We choose among the medical products. We do not treat everything.",* he explained. *"Sometimes we buy [medical products]. We pay for the problems that are most crucial. If we had received our internally displaced person money, it would have been easier for us."*

The above account reveals unique aspects of the experience of older persons with disabilities in Ukraine - Most had complex healthcare needs and in some cases their conditions were likely exacerbated by the conflict. There appeared to be direct (through exposure to difficult situations) or indirect causes because of various insecurities (lack of food, poor housing, and inadequate WASH).

Cost

The cost of healthcare was a prohibitive factor that hindered access to healthcare services and medication. Many had increased healthcare needs yet insufficient financial resources to pay for them. Participants were often left with difficult decisions about how to allocate limited financial resources such as whether to pay for food or medicine (medicine usually took priority), or which medical condition to treat over others (most urgent taking priority). Some opted to use home or herbal remedies as treatment because they were more affordable.

Availability

Needed healthcare services were often not available in Eastern Ukraine. Availability of even basic or routine healthcare services were reportedly very limited and specialist services (e.g., for hearing or vision) were even more scarce. There was a shortage of healthcare in these areas prior to the conflict but it has been exacerbated for 3 main reasons, according to participants. (A) Many healthcare workers (including qualified doctors and specialists) had relocated to other areas of the country; (B) healthcare facilities along the contact line had been damaged; and (C) previously, many people received specialist care in larger hospitals and cities that were now located in NGCA (such as Donetsk city), which would require crossing the contact line and increasing security risks.

Environmental barriers

Environmental barriers coupled with lack of affordable accessible transportation (as described previously) made accessing healthcare facilities difficult. This was described by many participants and so too was the inaccessibility of healthcare facilities in the regions. Participants reported that many hospitals did not have lifts, bathrooms were inaccessible, and there were often insufficient places for people to sit or lie down while they were waiting.

Structural barriers

There were long wait times at healthcare facilities because care was delivered on a ‘first-come first-served’ basis. With this structure, people who show up early in the morning have a better position in the queue which was more difficult for older persons with disabilities. Because of this they often arrived later and had to wait longer for care. This was explained by DD, an 81 year old man who lived in Donetsk region and had difficulty with mobility, hearing, seeing and remembering.

"To get the appointment at the doctor specializing in your problem, you have to be there at 6 a.m. If you don't, you get there, and there are no tickets left. I hurry, I don't wait for trolleybus, before sunrise… The situation with these tickets is really unpleasant..."

Experiences with healthcare professionals

Participant experiences of interacting with healthcare professionals were mixed (some positive and some negative). For instance, BR, a 66-year-old man who lived in Luhansk had requested a home visit from a doctor because a stroke had affected his mobility and speech and made it difficult for him to leave his home. The following quote highlights the doctor's response. It is important to note that healthcare is designed to be free of charge, but it appeared this was not the case for homecare.

"…I asked an employee from the Social Services Department to go to the clinic to ask the doctor to come [to my home]. When she [social services employee] returned, she told me that the doctor got angry and asked why she should come to my place. Doctors don't want to do that. If you give them money, they agree to come … I gave them some money. The doctor got angry again that she had to come to me."

One participant was denied long-term care because they had a family member whom the healthcare provider stated should be able to care for him. JL was a 65-year-old man who had been displaced and lived with his ex-wife. He had bilateral lower leg amputations and used a wheelchair for mobility. He also had some difficulty with seeing, hearing, remembering and self-care. JL wanted to be admitted to a long-term care facility but was denied because he had a daughter (who lived in Lviv approximately 700 Km away) who the facility deemed should be able to care for him. The situation is summarized in the quote that follows and demonstrates the lack of choice and agency that participants had in choosing their desired care.

"She [facility staff] came to my room and they told her [referring to his ex-wife]: "If he is alone we could register him, but he has daughter, let her take him." I told her that my daughter has 4 children, she is a re-settler herself. They say: "It does not concern us. She should take you to herself, to Lviv. If not, then let her pay for the care facility." The care facility is expensive."

Internally Displaced Persons

There were additional structural barriers faced by older persons with disabilities who had been internally displaced. Some IDPs could only receive healthcare services where they were registered (i.e., the areas they had previously fled). These participants were required to travel long distances to receive care and, in some cases had to cross the contact line and checkpoints to receive care in NGCA with active conflict. JG, a 66 -year-old woman who had diabetes (and reported a lot of difficulty seeing and some difficulty with mobility and remembering), explained how delays in registration led to her travelling to receive insulin.

> *"Now I get insulin here. Because earlier I needed to cross the border [and return to the area I was registered], as a matter of fact… I was traveling during the whole 2 years, until I got insulin here. I went every two months. And now they have registered me here. I get here."*

Facilitators

Several factors facilitated access to healthcare. The most effective was homecare health services, although few received this (mainly due to cost). Having someone to assist in reaching healthcare services and/or supporting with treatment at home (e.g., exercises or administering medication) was also helpful.

The value of homecare was evident in interview with QL (the primary caregiver for PL, a 79-year-old man who had diabetes and was unable to walk or complete self-care activities independently). QL assisted with all ADLs and administered insulin for PL five times per day. On two occasions, they paid a doctor to come to their home (for pneumonia and intravenous treatment). While this was helpful, they could not afford to do it regularly and instead prioritized it for when they needed it most.

> *"Yes [when L005 falls ill], we call our physician… A nurse from hospital [also] comes to give injections and feed him intravenously. We cannot do without them."*

Summary

In this section, the findings demonstrate how participants often had complex healthcare needs that were likely exacerbated by the conflict. Various factors inhibited access including cost, availability of services, and physical and structural barriers. The experience with healthcare professionals was mixed. IDPs experienced additional barriers associated with displacement and structural barriers. Facilitators included homecare and caregiver support.

7.7 Socialization and participation

Social participation

RS sat in her room at the rehabilitation center where she lived in Donetsk. She was 73 years old and lived with her daughter who was around 50 years old. They had been displaced because of shelling and bombing close to their home in the NGCA. RS had a lot of difficulty with walking and seeing and some difficulty with hearing and remembering. Her daughter had Multiple Sclerosis and required care. RS often felt isolated and lonely because she couldn't visit her friends who remained in her hometown. She explained the challenges.

> *"They [friends and family] have been living for two years under constant shelling. How will I go [to visit them]? There is no one to drive me. The only way is to go by bus, but I cannot go by bus, and I don't have money to rent a car…"*

Isolation and loneliness were common and pervasive issues for many participants. While there were many reasons for social isolation, they primarily can be summarized in two main areas: (1) the decrease or loss of existing social structures and (2) barriers to social participation outside of their homes (explained in Table 21).

Table 21. Factors that contributed to (1) loss/reduction of existing social structures and (2) barriers to social participation outside of the home for participants in Ukraine.

Loss of existing social structures	**Barriers to social participation outside of the home**
- Being separated from family or friends due to displacement (of self or others). - Family or friends (predominantly younger people) moving to other areas for economic and safety reasons. - Death of loved ones and friends (primarily due to older age). - Security and protection risks.	- Physical barriers (long distances, rough terrain and inaccessibility). - Lack of affordable accessible transportation. - Security and protection risks. - Challenges associated with health condition or impairment

Security threats created both a loss of existing social structure and prevented social participation outside of the home. Engaging in social activities with people that lived far away was made more challenging because violence, additional checkpoints and explosive remnants of war (as explained by AD).

> *"Before [the conflict] we could go to the cinema or the club…we could go to the forest in the open air. Today we can't go there, there are mines, artillery shells."* (D001, a 68-year-old woman who lived in Donetsk and had severe difficulty with mobility and seeing and some difficulty hearing)

Participants were sometimes reluctant to engage in social activities because of a health condition or impairment. One participant mentioned feeling like a burden or "inconvenient" to others. Others found it difficult to interact with others. For instance, HW (spouse and caregiver) noted that her husband (who was 85 years old, needed a lot of assistance with ADLs and used a wheelchair for mobility), found it difficult to interact with others.

> *"We do not invite friends [to our home]. He does not like it. He does not like people to come. That's why we do not meet with friends. Our children sometimes visit us. He even feels uncomfortable when his grandchildren come and stay for a long time. It's difficult for him. It's because of his disease. It's very difficult for him to see other people. He only says hello and he wants them to leave."*

For many, involvement in church was a valuable source of socialization. Not everyone wanted to or could participate, but it seemed to reduce isolation and loneliness for those who did. In a few cases, members of the church would visit those who had difficulty leaving their homes.

There were also community safe spaces (CSS) for older people in Eastern Ukraine that provided opportunities for social interaction. These were developed by HelpAge and designed to increase social opportunities for older people (267) (p.1). The CSS seemed to be valuable for people who could reach them, but most couldn't because of the physical and transport barriers described earlier.

JH was an outlier in that she was the only older person with a disability who appeared to be quite heavily involved with the community. She volunteered with an NGO focused on assisting older people and

people with disabilities in Eastern Ukraine since 2004. She was 75-years old and had some difficulty with hearing, walking, remembering and self-care and a lot of difficulty seeing. She faced similar barriers to isolation as others (lived far from family, difficulty with transportation out of the city, etc.). However, her role with the NGO provided an important source of relationships and social participation (as seen in the quote below). JH credited access to local transportation with helping her volunteer. Unlike other participants, she could access and use public transportation.

> *"No, I do not [feel sad]. I am a member of a society of people with disabilities. They are my second family."*

Inclusion in decision making

Participants generally did not feel they were able to inform decision about policies or programmes that affected them. There were no clear ways to inform the government. Some voiced their concerns with social protection providers, but this had little to no effect. A few people mentioned being aware of meetings to inform NGO processes but once again the physical barriers (long distances, rough terrain, lack of transportation) prevented them from being able to attend. For people who could attend, communication barriers limited their ability to participate. This was explained by DD, who was 81 years old and had a lot of difficulty with hearing:

> *"The main problem is that when people lower their voice at a meeting, I cannot hear them. I am not involved."*

7.8 Family and caregivers

Caregivers (which I refer to as family and friends who provided informal assistance) assisted older persons with disabilities in countless ways. They assisted with displacement, finding homes in new locations, assisted in accessing daily needs (food and NFIs) and healthcare and helped people overcome the common physical barriers. In some cases, caregivers helped with the delivery of healthcare at home (e.g., administering insulin, providing medication, and completing exercises) and assisting with ADLs.

Caregivers were most commonly spouses or children who lived in the same houses. Less commonly, caregivers were friends or neighbours. In all but two cases, the primary caregiver lived with the individual

they supported. In one of these cases, a son would go to the home of his father who had a disability to deliver food and assist with ADLs. In the other, two sons worked together to support their father. In some cases, children would provide financial support at a distance, while living and working in another area of Ukraine or Russia but did not support with caregiving duties.

Children and family members generally saw it as their role to take care of older family members. This was explained by KH, a 56-year-old man who was the grandson of CH (a 97-year-old man who had a lot of difficulty hearing and some difficulty with seeing, walking, remembering, self-care, and communicating). KH shared primary caregiving duties with his brother. They helped with activities of daily living (such as washing and shaving), buying food and supplies, and taking their grandfather to the doctor. When asked about this and how they manage the healthcare costs, KH responded: *"And what can we do? We will not leave him. He brought us up."*

Although the support provided by family and caregivers was generally provided without hesitation. Some caregivers (especially spouses) mentioned that assisting with self-care activities was difficult because it was physically demanding and they rarely had a reprieve. Others stated that it influenced their livelihoods, social life, and ability to travel and live in a different location. For younger caregivers, their role sometimes impacted their capacity to work. For example, KH explains how he took a leave from work to care for his grandfather. Similarly, JB, who cared for his 78-year-old father (who had Alzheimer's disease and stomach cancer) explained that he could not work as a driver.

> *"Me and my brother try to do it [take care of my grandfather] one by one… We do not leave him. Brother will be today in the second shift and today I obtained a leave from my job." (KH)*
>
> *I cannot go to work because of him. Do you understand? Now I receive only pension. Earlier I had a lot of them [jobs]. But now I cannot. (JB)*

CHAPTER 8: DISCUSSION

8.1 Overview

This chapter includes a discussion of research findings. I begin with a brief review of findings from the systematic review, (Objective 1) (Section 8.2). I then discuss the key findings on the experiences of older persons with disabilities and access to daily and humanitarian support in Tanzania and Ukraine (Objective 2) (Section 8.3). This is followed by a discussion around the strengths and limitations of this research, transferability and reflections. I then provide recommendations and discuss areas for future research.

8.2 Findings related to Objective 1: Review of the literature on the experiences of older persons with disabilities in humanitarian crises

The systematic review, presented in Chapter 4, identified only 8 articles that examined the experiences of older persons with disabilities in humanitarian crises, demonstrating a lack of evidence in this area. Studies were conducted in limited geographic locations and crisis settings. The quality of articles was mixed. None of the studies explored barriers or facilitators to accessing humanitarian response or daily needs.

8.3 Findings related to Objective 2: experiences of older persons with disabilities

This study sheds light on the experiences of older persons with disabilities in conflict affected areas of Eastern Ukraine and refugee camps in Western Tanzania. In this section, I discuss these experiences and the key findings of this thesis. I have structured it according to the Life course Perspective of Disability (LCD) (Figure *19*) and separated this section based on factors that influence disability and functional capacity in older age. These factors include Environmental Factors, Personal Factors and Agency. Based on the findings from Ukraine and Tanzania, Environmental Factors have been further sub-divided into Physical, Social and Economic Environments. I have chosen to discuss the physical and social environment

together because they are so closely linked and interdependent. In Figure *19*, I have marked these factors with a number to signify the sections that follow. I begin this section with a discussion on (1) Physical and Social Environmental Factors and (2) Personal Factors, followed by (3) Economic Environment and (4) Agency. The first 2 sections focus predominantly on the experiences of older persons with disabilities and their access to daily and humanitarian support needs, while the sections on Agency and the Economic Environment additionally discuss humanitarian programming. In this way, I begin by discussing the daily lives and lived experiences of older persons with disabilities and gradually broaden the focus to explore how their experiences are shaped by humanitarian structure, framing and decision making. I then provide recommendations for each setting as well as humanitarian response, globally, based on the findings of this research.

The findings within each section are primarily organized according to common humanitarian focus areas (e.g., protection, food and health). I have done this to facilitate knowledge translation and facilitate recommendations that are relevant to humanitarian response and practice. A summary of findings and how they compare across contexts is provided in Figure *19*.

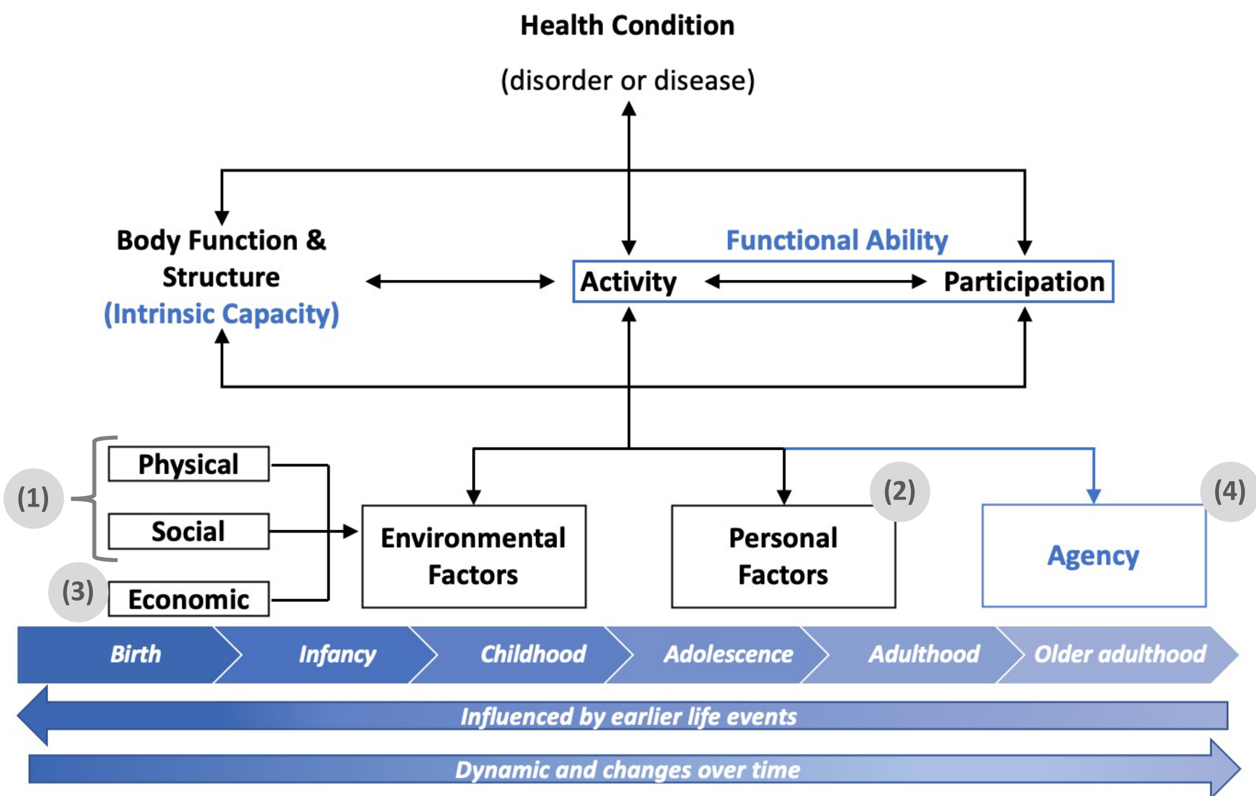


Figure 19. The Life course Perspective of Disability (a combination of the ICF Framework of Disability (50) and the Life course perspective of ageing (64,65,68), used for this thesis; see section Chapter 3 for more details).

A note on the discussion - Since Environmental Factors, Personal Factors and Agency are interconnected and combine to shape the dynamic and multidimensional experience of older persons with disabilities, many of the findings are cross-cutting and influence each other. For example, access to healthcare is influenced by all three. To reduce repetition, I discuss these findings under the domains that are the most relevant. However, there is some overlap. In addition, some findings apply to many areas. For example, as evidenced throughout this research, physical barriers (such as long distances, rough terrain, poor roads, and inaccessibility of buildings) and lack of access to transportation inhibited access to virtually all humanitarian and daily needs and contributed to decreased participation for participants in both settings. To cut down on repetition, I have chosen to present these findings only where they add relevant or unique

information rather than presenting the same findings throughout. Finally, for consistency and clarity, I have structured this section in a similar way to the results chapters. A summary of findings and how they compare between Tanzania and Ukraine is provided in Table 22.

Table 22. Summary of findings from research in Tanzania and Ukraine and recommendations.

	Burundian refugees in Tanzania	Ukrainians living in GCA of Eastern Ukraine	Recommendation	Tanzania	Ukraine
Physical and Social Environments					
Increased Protection Risks					
Difficulty Escaping Danger	- Challenges due to physical, financial and structural barriers and lack of transportation - Mostly during displacement	- Challenges due to physical, financial and structural barriers and lack of transportation - evacuating during shelling and during displacement	- Support individuals in escaping danger by assisting with transportation, improving accessibility, and providing necessary financial support - Ensure bomb shelters and areas to evacuate shelling are accessible and easily reached	√	√ √
Staying in homes		- More likely to stay in homes / hesitant to leave - Some leave areas late in progression of conflict causing increased challenges	- In addition to supporting with evacuation, provide supplies and assistance to people who choose to stay in their homes.		√
Security threats	- Largely escaped danger - Some theft and security concerns in camp (e.g., food & NFI stolen in one case)	- Security pervaded all aspects of daily life and decision making	- Provide smaller rations at a time (while addressing access barriers) - Ensure full provisions are met for all. - Focus on long-term and comprehensive solutions	√ √ √	√ √ √
Healthcare					
Physical Barriers	- Physical barriers (long distance, rough terrain), lack of transportation	- Physical barriers (long distance, rough terrain), lack of transportation	- Provide support with access to healthcare such as assistance with transportation. - Reduce physical barriers - Ensure accessibility of facilities. - Ensure adequate seating and rest areas available. - Offer homecare services to older persons with disabilities	√ √ √ √ √	√ √ √ √ √
Cost	- Financial barriers prevented access to services	- Financial barriers prevented access to services	- Provide additional financial support to people with high healthcare needs	√	√

		- Financial barriers prevented access to medication	- Reduce out of pocket costs (especially in areas with Universal healthcare such as Ukraine)		√
Structural	- First-come, first served		- Care should be based on need and availability of services with special care not to discriminate based on factors such as age or disability.	√	√
Stigma	- Mostly positive experience experienced	- Some faced stigma	- Training of healthcare staff on needs of older persons with disabilities and issues around inclusion and stigma.		√
Availability	- Limited availability of services		- Provide specialist services in (or near) affected areas where possible on a regular basis and/or assist with travel and accommodation to access them.	√	√
Housing					
Poor living conditions	- Houses inadequate to withstand elements	- houses in need of repairs IDPs - poor condition of temporary accommodation - services occasionally shut off	- Support in upkeep of homes, procuring needed equipment (e.g., provide equipment or funding), accessing and paying others to complete repairs. - Prevent shutting off utilities as a means of forced eviction	√	√ √
	- Exacerbated by inability to complete repairs on own, access supplies or pay for repairs				
Overcrowding or isolation	- lack of housing and allocation often led to overcrowding	- some experienced overcrowding others isolation	- Allocation processes should balance need for support and proximity to services while decreasing overcrowding - Government support for adequate accommodation for IDPS	√	 √
Livelihoods and financial challenges					
Primary source of income	- limited availability in camps - selling food and NFI	- Received pension from government (not enough to account for inflation)	- Ensure livelihood opportunities are available and accessible to older persons with disabilities - Pensions should increase in proportion to inflation - Improve access to financial support by providing in people's homes or accessible location and decrease barriers to access.	√	 √ √
Access	- Inability to engage in livelihoods because physical nature	- Barriers accessing pensions and social supports (physical, structural, attitudinal) - IDPs need to present at banks			
Livelihood expectations	- working into older age seemed to be the norm - many wanted to work	- People expected to be supported by government into older age.			
Influence	- Poverty underpinned many challenges (food, NFI, shelter, etc)				

Transportation					
Access barriers	- Physical barriers accessing transportation		- Ensure transportation is accessible and can be reached	√	√
Financial	- Transport provided free of charge but most did not use	- Transport suppose to be free for older people but often not	- Ensure policies for free transport are upheld		√
Food and NFI					
Physical barriers	- Difficult to access due to physical barriers and lack of transportation		- Facilitate access to transportation for individual and supplies	√	√
Not enough food	- what is provided is insufficient	- pensions insufficient for needs	- Increase pensions in proportion to inflation - provide sufficient food to meet daily needs - facilitate ability to supplement food (livelihoods, gardening).	 √ √	√ √
PERSONAL FACTORS					
Complex Healthcare Needs & Influence of earlier life events					
High healthcare needs	- Many had high healthcare needs, likely due to accumulation of health risks across life course yet decrease access to services.		- ensure adequate healthcare services and access for older persons with disabilities who often have high healthcare needs	√	√
Family/Caregivers					
Provided support	- Family and caregivers provided important support for participants - participants often relied on family for financial and other support (food and NFIs)		- Humanitarian and government should take into consideration the role of older persons with disabilities in the family and the importance of family support.	√	√
Impact on family	- caregiving occasionally influenced ability to engage in social and livelihood opportunities				
Isolation	- older persons with disabilities often felt isolated from family and friends.		- facilitate communication with family and friends - in displacement ensure family is kept together - allocate housing to facilitate family and caretaker support	√ √ √	√ √
ECONOMIC ENVIRONMENT					
Constraints to humanitarian programming					

Financial constraints	- Financial constraints influence older persons with disabilities since they are unable to supplement aid they receive		- Provide livelihood opportunities, consider cash based transfers and additional supplies for older persons with disabilities	√	√
Economic impact of disasters		- Inflation and decreased value of currency with no increase in pension	- increase pensions proportional to inflation		√
Increased costs	- Likely to experience increased costs associated with health conditions		- consider financial assistance and subsidised care	√	√
Agency					
No choice on assistance or daily needs					
Little choice over daily needs and assistance	- Services, food and NFIs provided by NGOs. Participants unable to supplement	- low pensions resulted in decreased choice	- Consider cash-based transfers to improve individual choice - Funding to support humanitarian agencies to provide complete daily needs	√	√
Informing decisions	- lack of communication channels to inform decisions - not included in decision making processes		- improve communication channels to inform inclusion and ownership - include older persons with disabilities in informing humanitarian action	√	√

8.3.1. Physical and Social Environment

Environmental factors *"refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning"* (57)(p.214). It includes the physical (e.g., roads, home, workplace, buildings) and social environments (transportation, laws, attitudes, community).

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The findings of this study clearly demonstrate how older persons with disabilities faced significant challenges living in humanitarian crises in Tanzania and Ukraine and how environmental factors influenced their access to daily needs, humanitarian assistance, and social support schemes. Humanitarian crises can influence both the physical and social environments and can cause or exacerbate pre-existing inequities (19,268–270). This research demonstrates how this influence on the physical and social environments negatively influences older persons with disabilities.

Note - There is a section later in the discussion where I present factors related to the economic environment (Section 8.3.3). While this is also an environmental factor, I have kept it separate because the focus of this section is on experiences and access to daily needs. The Economic section to come focuses on the findings that relate to the broader aspects of humanitarian programming and emergency framing.

Increased protection risks

Difficulty Escaping Danger

The findings of this thesis demonstrate how older persons with disabilities have difficulty escaping danger in humanitarian crises. This was a particularly evident in Ukraine where participants were still experiencing direct threats from the on-going conflict. Participants in Ukraine had difficulty leaving their communities, reaching bomb shelters, and sheltering in place because of physical (e.g., long distances, rough terrain and inaccessible infrastructure), financial (insufficient livelihoods) and structural barriers (e.g., need to pay for transport despite polices that say otherwise). In Tanzania, participants described previous difficulties during displacement from Burundi (prior to arriving at the refugee camps) but did not need to escape danger on a daily basis while living in the refugee camps. In addition to challenges during displacement, research has suggested that older persons have difficulty returning to their home countries. A study conducted by HelpAge International and Inter Agency Standing Committee (IASC) found that the majority of people who were unable to return home when camps were closed in Uganda and Pakistan were older people (185)(p.9). This could present challenges as Tanzania and UNHCR have supported voluntary repatriation of refugees beginning in 2017 (271).

The findings of this thesis related to difficulty escaping danger agree with the limited previous research on older persons with disabilities in situations of displacement and sudden onset disasters. A study that examined the experiences of older persons (60 years of age and older) who were displaced from Syria and Palestine to Lebanon from 2011-2013 found that older refugees had difficulty during displacement and crossing into Lebanon (160). They attributed the difficulties to physical disabilities as well as inadequate financial resources to leave, safety issues related to the fighting and the need protect a house or other assets (160). While the study did not explicitly focus on older persons with disabilities, the majority of study participants reported poor health (via a questionnaire) and were found to have functional impairments (via Katz Index of Independence in Activities of Daily Living (272)) (160). Similar findings were reported during displacement from Ethiopia to Sudan in 1984-85 where disability was a reason why older people were left behind while others fled (162). Research in sudden onset disasters in HIC have uncovered similar findings. Older people with impairments had difficulty evacuating following sudden onset disasters in Japan (earthquake) (273), USA (hurricane) (274), New Zealand (earthquake) (161). The reasons provided in the research and by humanitarian actors are primarily associated with lack of financial resources, health concerns, mobility impairments and isolation (275–277) which are like the findings of the present study. In terms of conflict, there appears to be a lack of empirical evidence on the ability of older people with

impairments in reaching bomb shelters. However, the challenges that older persons, persons with disabilities and older persons with disabilities face in escaping danger and reaching bomb shelters has been reported by several humanitarian agencies working in Ukraine (276–278).

Staying in their homes

In Ukraine older persons with disabilities tended to stay in their homes and shelter in place after others had left because of physical barriers and the desire to stay in their homes. This resulted in increased protection and security risks initially (because of direct risk of violence from the conflict and difficulty accessing daily needs) and when they did then leave (because leaving later in the progression of the conflict increased complexity and danger). Similarly, a needs assessment conducted in Ukraine in 2020 found that 99% of older people living in conflict affected areas did not want to be evacuated (178). Previous literature also suggests older people are more hesitant to flee their communities and they may be left behind while family members and other leave (175,176). Smith (2021) (176) explained that in addition to barriers that make it difficult to leave, older people may choose to stay while others leave because of their connection with their communities. Protection risks associated with leaving later were highlighted in a study from Syria where older people who left at later dates reportedly experienced more violence than those fleeing earlier (160).

Security threats pervaded many aspects of daily life and decision making

In Ukraine, security threats were a constant concern for participants and pervaded all aspects of daily life. Bombing and gunfire were ever-present in the lives of most participants and had a cascade of effects that led to further security risks and influenced all aspects of daily life, health, and ability to access daily and humanitarian support needs. In Tanzania, by contrast, direct security threats and violence were not as omnipresent. However, they were not completely absent; some participants in Tanzania reported security issues from which older people with disabilities seemed to be at risk (e.g., theft of food and NFIs). These findings are consistent with reports from Ethiopia that older people faced several protection concerns (psychological abuse, physical and sexual violence, theft) (174).

Healthcare

In this section, I discuss the findings of this thesis related to environmental factors associated with healthcare access including physical barriers, care delivery structures, cost of services and availability. This section includes aspects related to many different aspects of the LCD. For clarity, I have kept them together. An important aspect of healthcare is also the influence of life events on healthcare needs which is further discussed in Personal Factors.

Physical barriers to accessing healthcare

Access to healthcare was challenging for older persons with disabilities in Tanzania and Ukraine. A variety of physical and structural barriers (long wait times) and lack of transportation made it difficult for older persons with disabilities to access healthcare services in both settings. These findings are consistent with the limited previous research on older persons with disabilities in humanitarian crises in high (161) and low-income countries (160,279) including situations of conflict (280) and refugee camps (279). Health clinics in refugee camps in Nepal, Thailand, Yemen, Jordan, and Ecuador were reported to be physically inaccessible by persons with disabilities (279). Studies from New Zealand (161) and Japan (273) found that the destruction of infrastructure prevented older people with visual impairments from reaching health services, leading to worsening health following natural disasters (161). Previous literature, on older persons and persons with disabilities specifically in Eastern Ukraine found that lack of public transportation in Luhansk and Donetsk regions affected access to healthcare facilities, pharmacies, and markets (280). They also found that older persons with disabilities living closer to the 'contact line' had significantly lower access to healthcare services than those who lived a further distance from it (280), which agrees with the findings of this thesis. IDPs in Ukraine faced additional challenges accessing needed healthcare services, which is consistent with previous literature (281).

Healthcare delivery structure – 'first-come, first-served'

The findings of this research suggest that the care delivery structure based on a 'first-come, first-served' approach negatively influenced access to healthcare for older persons with disabilities in both Tanzania and Ukraine. A 'first-come, first-served' delivery structure is one where priority is given based on the order in which participants arrive at the healthcare facility. The challenges participants faced reaching healthcare facilities (as described above in physical barriers) combined with this 'first-come, first-served'

approach created particular challenges for older persons with disabilities. This was because people who reached the facilities earlier received priority care, which was difficult for participants in this study. They then faced long wait times. Previous research has found that long wait times hinder access to health care for older persons with disabilities (279).

The 'first-come first-served' approach is a prominent discussion in healthcare ethics (282) and the allocation of healthcare resources has become an even greater focus of attention during the COVID-19 pandemic (283). The 'first-come, first-served approach' is often used in crises in an attempt to treat people equally (283). However, according to Rawlings et al (2020) (283), there are several challenges. People with better access to information and resources (financial and social) tend to be prioritized and it is not an efficient use of limited healthcare resources (283). Several other service delivery approaches are available including priority treatment for (a) people important to responding to the crisis (e.g., healthcare professionals) or (b) the most affected. Another approach is to try and allocate resources to those who will benefit the most (283). However, in each of these cases, older persons with disabilities may be at risk of exclusion. For example, younger people may be prioritized over older people with disabilities (282,283). In a critique of the 'first-come, first-served' approach, Fleck and Murphy (2018) (282) discuss the challenges in ethical decision making in deciding who to admit to an ICU between an 85-year-old and 50-year-old given the difference in *"expected life years"* (p.4). They do go on to explain that other strategies must be used for allocating resources when they are limited. There is a risk that with any strategy that uses triage, age and/or disability could be used to inform decisions. This is an important discussion that deserves significant research and debate.

Experience with healthcare staff

Interestingly, experiences with healthcare professionals were found to be generally more positive in Tanzania compared to Ukraine where experiences were mixed. In Ukraine, some spoke positively of their experience and others had negative experiences. The experience in Ukraine is more common in the literature – older persons with disabilities have been shown to experience stigma and discrimination that prevent them from accessing healthcare (185). The findings from Tanzania where people with 'more visible' impairments were more likely to receive priority treatment (e.g., moved to the front of the line at healthcare facilities), also align with previous research that people with "invisible" or "hidden" impairments often have more difficulty accessing services (279).

Cost of healthcare services

Financial barriers were a significant barrier that prevented access to healthcare and medication in Ukraine. Health care is intended to be delivered free of charge in Ukraine (280) yet one of the most reported factors that hindered access was the high costs associated with healthcare services and medication. In the context of low pensions, many participants were faced difficult choices such as which conditions to treat or medications to buy. This finding is supported by a quantitative analysis of older people and persons with disabilities in Eastern Ukraine that found cost of healthcare for Ukrainians was among the highest in Europe (in 2015, out of pocket payments were 48%) (280). The authors attributed the high costs to the disruption of referral systems and transportation costs as well as high medication costs for older people (280). This was especially the case for those with less access to healthcare services (280). These findings are supported by the results of this thesis. Banks et al. (2021) (284) found that persons with disabilities faced high healthcare costs associated with direct (transportation, more frequent visits, assistive technology, care needs) and indirect (being excluded from livelihoods) costs. They also comment that older people with disabilities may have costs that are different from others in the population. These findings are similar to the findings of this research. While I did not compare the costs with the rest of the population, there are unique costs at the intersection of age and disability that hinder healthcare access. Previous studies have also found that households with an older person with disabilities had higher healthcare costs (285).

Interestingly, in Tanzania, financial barriers were found to influence access to healthcare and medication but were reported less than in Ukraine. This is surprising as it contradicts studies from humanitarian crises and refugee camps where cost is commonly identified as an important factor limiting access to healthcare and medication (160,285–287). A study of Syrian refugees living in Jordan found that 79% of older refugees stated financial difficulties were the primary reason they did not seek medical care and 85% reported they had difficulty affording medication (160). Similar results were observed in Lebanon, South Sudan, and Ukraine where a third of older people interviewed reported cost of care as the reason they did not go to health facilities regularly (286). These findings in Tanzania may be explained by the setting – the healthcare provided in the camps was provided free of charge by NGOs therefore, instead of talking about costs, participants mostly discussed access issues. The influence of cost on access to healthcare in refugee settings should be further explored in future research.

Lack of availability of healthcare services

Availability of healthcare services was limited in both study settings. In Tanzania, even basic healthcare services and medication were often not available within the refugee camps. In Ukraine, basic services were limited in the conflict affected areas and specialist services were often not available. Specialist services (e.g., eyecare) could be accessed in other areas of the country in Ukraine (at great distance and cost to the individual) whereas in refugee camps in Tanzania, if the services were not available in the camp, older persons with disabilities could not access them. Although the lack of availability and, in Ukraine, the high direct and indirect costs of health care is a general issue in these settings (185,284,288), it is likely to disproportionately affect older people with disabilities because they will, on average, have higher healthcare needs.

Poor living conditions

This research found that older persons with disabilities experience poor living conditions in Tanzania and Ukraine. Shelters were often inadequate to protect against the elements in Tanzania. In Ukraine, many participants reported that their houses and flats needed repair. These findings are not surprising since previous literature and NGO reports have documented the challenging living conditions faced by all people living in refugee camps (289–292), (including in Tanzania (232,293,294)) and conflict affected areas, (including Ukraine) (280,295). Poor living conditions may be particularly detrimental to older people with disabilities. For example, a report by HelpAge and Handicap International suggested that poor housing can have a negative impact on the health, independence and social lives of older people (165) (p.31). They also found that housing was the second highest concern (after income and livelihood) of households that included an older person with an impairment (165). The Global Protection Cluster Working Group explains that older persons and persons with disabilities should receive targeted support because of the additional challenges they face and negative implications and they must be included in informing decisions (296) (p.238).

The findings from this research support previous research and add to the literature by providing more information on the underlying cause of the challenges. In both Tanzania and Ukraine, the combination of the inability to complete repairs on their own, insufficient financial resources to pay for upkeep and lack of family support resulted in poorer housing conditions. In Ukraine, the findings revealed how participants tended to prioritise allocating their pensions toward healthcare costs and medicines over home repairs.

Participants in Ukraine who were internally displaced were particularly disadvantaged in terms of housing. Some IDPs who lived in temporary accommodations occasionally had their water and/or electricity shut off to force their eviction. This violates International Humanitarian Law (IHL) and Human Rights Law (296,297). Forced evictions have been noted in other humanitarian crises and violate IHL and human rights law (295,298,299).

Difficulty accessing livelihoods and financial challenges

The findings of this thesis highlight the profound financial challenges that older persons with disabilities faced in both humanitarian crisis settings and the detrimental impact this had on their lives. In Tanzania, the interviews highlighted the lack of income generating opportunities for older persons with disabilities because of the physical nature of the livelihood activities within the refugee camps. An economic evaluation of refugee camps in Tanzania conducted in 2018 found that the livelihoods available were mostly physically demanding and that older people and people with health conditions often could not participate (232).

In Ukraine, the main source of income for older persons with disabilities was from pensions and social protection schemes which were insufficient to meet their needs. They had faced challenges with low pensions prior to the conflict and these were further exacerbated by the economic impacts of the crisis. These findings are consistent with an analysis by the WHO that found 74% and 81% of older people living in Eastern Ukraine relied solely on pensions in 2018 and 2019, respectively (187,280). They too found that factors related to the conflict that distributed delivery inhibited access to pension (280). Findings from the research in this thesis highlighted that several barriers hindered access to pensions and social support schemes, including physical barriers, lack of transportation and structural barriers (lengthy and difficult application process). IDPs faced additional structural barriers (having to present for verification) and attitudinal (stigma and discrimination) barriers that made it more difficult for them to access pensions. These findings are also supported in the WHO report (280).

The findings from this DrPH thesis related to the lack of livelihoods in Ukraine and Tanzania agree with research conducted in many countries around the world. A study conducted in Kenya, Bangladesh and the Philippines found that older people with visual impairments were poorer and less likely to work than older people without visual impairments (300). In Cameroon, Guatemala, Haiti, India, Nepal, and the Maldives where older persons with disabilities were significantly less likely to be working than older people without

disabilities (285). Financial challenges are commonly reported for older persons and (separately) persons with disabilities in humanitarian crises (185), including refugee camps (160,165,279,301), natural disasters (302), and conflict (280). In Lebanon, older refugees reported financial challenges and 74% stated they relied on humanitarian assistance or financial support to meet daily needs (such as food, water, shelter or medicine) (160).

The inability to engage in livelihood activities in Tanzania and the insufficient pensions in Ukraine underpinned many of the difficulties that older persons with disabilities faced in daily life, including accessing food and NFIs, fixing their homes and accessing healthcare. It reduced their agency and increased reliance on humanitarian and social supports. This has been found in previous literature on older persons with impairments in humanitarian crises which suggests that financial difficulties can reduce access to basic services and daily needs such as nutrition and healthcare (165,185,302). Economic challenges were found to elevate the impact of the disaster on older people following the earthquake in Nepal (302). Access to livelihoods and economic supports have been found to increase the ability of people to withstand the negative implications of crises. For example, Masabo et al. (232) found that in refugee camps in Tanzania, people who engaged in livelihood activities were better able to manage their environment compared to those who did not.

The implications of a lack of livelihoods extend beyond the material as it can also impact mental health and wellbeing. A systematic review examining the health needs of older people affected by humanitarian crises in LMIC reported low income and loss of income were associated with higher rates of PTSD, depression and decreased quality of life (7). Humanitarian organizations often favour younger people for the positions available which according to Day et al. (2007) (185) can contribute to the exclusion of older people.

8.3.2 Personal Factors

Personal factors *are "the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states" (e.g., age, gender, other health conditions, social background)* (57)(p.17).

………..

Personal factors were not explicitly explored with great depth in the interviews and most of the relevant findings relate to complex healthcare needs and family, which will be discussed in this section. In this section, I explore some of the personal factors that influence the experience of older persons with disabilities in humanitarian crises. There is a need for further research exploring Personal factors in more depth, including intersectional aspects such as the influence of gender, ethnicity, religion, sexuality, and many other characteristics in shaping the experiences of older persons with disabilities in humanitarian crises.

Complex healthcare needs and influence of earlier life events

Many participants in this study had complex and high healthcare needs, as would be expected with this population (2,4,284,303). Although not specifically explored in this study, it is likely that many factors contributed to this including the accumulation of health risks, (in some cases) poor access to healthcare services and exposure to humanitarian crises across their lifespan. In both settings (especially in Tanzania), participants reported difficult circumstances associated with crises throughout their lives (2,4). The WHO states that the physical and social environments explain most of the variation in the health of older people (with some genetic contribution) (304). Research has shown that individual experiences, living conditions and physical and social environments throughout one's life have lasting influences on health (physical and mental) and mortality (2,65,305–308). This is a central component of the Life course Perspective of Ageing which is the predominant view of ageing (64–70). This is also a central tenant of the Life course Perspective of Disability which is used in this thesis. It is widely acknowledged that ageing is a lifelong process and that events earlier in life and prior to birth can have an influence on older age and functioning (64–70).

Exposure to humanitarian crises can influence health in older age. A study conducted in Vietnam with ageing individuals (military and non-military) who lived through the American War found that greater exposure to potentially traumatic experiences (death and injury, stressful living conditions, and fearing death and/or injury) earlier in life was associated with worse health in later-life (309). In contrast to most research, they also found little association between displacement and health in older age (309). What is more commonly reported in the literature are adverse physical and mental health effects of displacement, which has been documented in Sri Lanka (310) and Georgia (311) and among Palestinians in Israel (312). These findings are troubling, especially given the high number of displacements, globally. In addition, the participants in this DrPH research faced challenging humanitarian experiences prior to and during the data collection and were found to have difficulty accessing healthcare, all of which likely impacted their health.

Caregivers

Caregivers provided vital support to older persons with disabilities in both Ukraine and Tanzania. This assistance included: help accessing daily needs (e.g., food, NFIs), escaping from danger, and supporting access and delivery of healthcare (e.g., assisting with transportation and homecare, administering medications). Caregivers were also an important source of socialization for older persons with disabilities. One study from the systematic review (Chapter 4) found that family and friends were important in the immediate aftermath of an earthquake and social networks helped to recover from the event. No studies in this review were identified as specifically looking at caregivers of older persons with disabilities in humanitarian crises, however, the focus of this review was on the experiences of older persons with disabilities. A systematic review on the experiences of caregivers of older persons with disabilities should be conducted in the future. Family support has been reported to provide valuable support (e.g., physical, financial, emotional, access) for older persons and persons with disabilities (177,184–187), yet family and social ties are often disrupted in humanitarian crises (30,188). Considering the combined needs of older persons and persons with disabilities and their families and caregivers, as well as attempts to prevent separation, are advocated in humanitarian response (164,186).

In the present study, the duties performed by caregivers were found to hinder the ability of the caregiver to socialize and engage in livelihoods. Previous studies have also found that households that included an older person with a disability had higher healthcare costs (285), therefore the inability to engage in livelihoods can be additionally challenging. Some caregivers in the present research identified a need for additional assistance with caregiving duties (e.g., homecare and transportation needs) as well as financial support to assist with accessing daily needs or starting a business for livelihoods. Aldersey et al. (2016) (184) found that one of the greatest needs for caregivers of people with intellectual and developmental disabilities (IDD) was material. The authors suggested that when basic needs (e.g., food, shelter and healthcare) are not met, the specific caregiving duties involved when assisting a person with a disability is challenging (184). Several supports were found to assist in caregiving duties: information about disability and where to seek support, self-help groups and other families of persons with disabilities (184). Future research should examine the evidence and experiences of caregivers of older persons with disabilities in these contexts.

8.3.3. Economic Environment

The economic environment related to humanitarian crises negatively impacted older persons with disabilities in Tanzania and Ukraine. Specifically, the study findings show how (1) constraints to humanitarian and social support schemes and (2) the negative socioeconomic impact of humanitarian crises create gaps that particularly disadvantage older persons with disabilities which perpetuate their dependency and exacerbate exclusion. The influence of funding constraints on humanitarian agencies was apparent in both settings, whereas the socioeconomic impact of disasters was more clearly observed in Ukraine.

Constraints to humanitarian programming

Financial constraints to humanitarian programming had a detrimental impact on the experiences and ability of older persons with disabilities to access daily needs in Tanzania and Ukraine. In both settings, humanitarian agencies and NGOs experienced funding constraints which hindered their operations and ability to fully meet the needs (e.g., food, NFI, shelter and financial support) of people affected by crises (Tanzania (313–317) ; Ukraine (240,249,253,254,318)). This does not suggest that humanitarian agencies willingly omit or intentionally restrict aid or assistance to older persons with disabilities but rather that the constraints imposed on humanitarian agencies (primarily due to lack of funding) limit their ability to provide what is needed to uphold international humanitarian standards (such as the ADCAP humanitarian inclusion standards (8,17), the Sphere Humanitarian Charter and Minimum Standards (30), the Core Humanitarian Standards (31)) and the Humanitarian Principles (319,320)). As a result, they must operate and function to meet immediate needs and limit what they can provide to people affected by crises. While the lack of assistance affects people of all ages and abilities living in humanitarian crises (188,321), the findings of this DrPH thesis show how older persons with disabilities are disproportionately affected by these constraints because of the barriers that make it more difficult for them to supplement the aid and support they receive (through livelihoods or agriculture). This phenomenon occurred through a cascade of events. The lack of food in refugee camps in Tanzania is one example that highlights this.

In Tanzania, funding constraints meant that organizations were not able to provide enough food to meet people's individual daily needs. A report published around the time of this research stated that the food provided to people living within the camps met only 63% of daily caloric requirements (316). The findings of this present study clearly demonstrate the suffering and hardship this caused for older persons with

disabilities living within the refugee camp. It also shows how the insufficient quantity of food inadvertently created a system where people living in refugee camps in Tanzania needed to supplement what was provided to them. However, the older persons with disabilities interviewed were unable to supplement their daily needs because of a variety of barriers that hinder their ability to participate in livelihood activities or cultivate their own food. Participants used several strategies to deal with the food shortages such as borrowing against future rations and selling NFIs. This resulted in chronic food shortages, lack of supplies and contributed to poor living conditions. Participants also depended on others (family, friends and neighbours) to meet their daily needs. This created a cycle of chronic dependency for older persons with disabilities on humanitarian organizations as well as those around them.

The influence of funding constraints was also apparent in Ukraine as organizations were reportedly closing their programs because of lack of funding, according to the interviews. This has also been noted in previous reports (107). The funding constraints and resultant exit of NGOs have the potential to impact all older persons with disabilities however, since the findings of this study suggest that older persons with disabilities who are also IDPs were more often the recipients of assistance of food and NFIs, this potentially impacts IDPs to a greater extent. Particularly evident from the findings in Ukraine was how humanitarian crises influence the economic environment which has a negative impact on older persons with disabilities. This will be discussed in more detail below.

Previous literature and reports have noted the significant challenges associated with lack of funding and increasing need for humanitarian assistance which negatively impacts all aspects of humanitarian response from food, NFI, shelter, WASH, and healthcare, for all people affected by crises (188,321–326). Reports also acknowledge that people who are most at risk are the most negatively affected by these constraints and that older persons and persons with disabilities are among the most affected by inadequate funding for humanitarian assistance (6,244,289,327). There is limited research on how humanitarian constraints impact older persons with disabilities. A study with older Syrian refugees living in Lebanon found that older persons were increasingly dependent on relatives for survival because of a lack of independent income (177). The influence of lack of livelihoods in refugee camps (especially ones that restrict movement and opportunities) has been reported to result in high dependency on humanitarian assistance (6).

Unfortunately, funding constraints for humanitarian organizations are not unique to Tanzania and Ukraine. Lack of funding is a common barrier that prevents sufficient delivery of aid, globally (1,6,323,327).

Therefore, the implications may be similar in other humanitarian contexts. The influence of funding constraints on the lives of people affected by crises should be further explored. So too should the solutions to these challenges in the current landscape with increasing numbers of humanitarian crises and lack of funding.

Economic impact of disasters

Humanitarian crises can have wide-ranging and dramatic economic impacts, locally and globally (328,329). One of the most recent examples of economic disruption that has received widespread media attention globally is the economic impact of the current conflict in Ukraine which has disrupted the national, European, and global economies (330). While the impacts outside of Ukraine have only recently been felt with the escalation of the conflict in 2022, they were clearly apparent in Eastern Ukraine at the time of this research. The findings of this study demonstrate how disruptions to the economic environments caused by humanitarian crises negatively impact older persons with disabilities and perpetuate dependency and exclusion. This was most evident in the findings from Ukraine.

The conflict in Eastern Ukraine resulted in decreased employment, increased costs and inflation in the conflict affected areas which had a detrimental impact on people living in conflict affected areas (331). During the winter of 2016-2017, 23% of households in the conflict affected areas did not have enough food to meet their needs (254). The results of the present study reveal how older persons with disabilities are disproportionately impacted by these economic impacts of disasters and are less able to withstand the economic shock of crises. There are several factors that contributed to this. The main one was that the areas experienced inflation and pensions and social supports remained unchanged. This influenced the usefulness of these supports and participants were often unable to meet their daily needs. In addition, older persons with disabilities in this study could not supplement their income by other means (such as livelihoods or agriculture). As evidenced in previous literature older persons with disabilities experience additional costs (direct and indirect) (284) and are likely to experience additional financial challenges compared to older persons without disabilities.

Older persons with disabilities used several strategies to accommodate inflation such as borrowing from family members or going into debt. Like the impact of humanitarian underfunding, this created ongoing financial challenges and perpetuated dependency (on social support structures and family).

8.3.4 Agency

Agency refers to *"the feeling of control over [one's] actions and their consequences"* (74)(p.1). It relates to an individual's sense of power to make decisions and act on what they have reason to value (73).

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The findings of this study show how older persons with disabilities lack agency in humanitarian crises in Tanzania and Ukraine. This includes the sense of lack of choice over what they receive and the inability to inform decisions regarding their own assistance.

Lack of choice on assistance or daily needs

Study participants in both Tanzania and Ukraine had little choice over their daily needs and the assistance they received. In Tanzania, the quantity, type, and timing of food and NFIs that refugees received was highly managed by NGOs managing and working within the camps. Older persons with disabilities had little choice as to what they received and the way they received it. This is not surprising given the global shortage in funding for food and NFIs (322,332). The lack of food choice and restrictive policies in Tanzanian refugee camps have been noted in the literature (333). This DrPH research also demonstrated how, in some instances, participant ideas and suggestions to improve access to daily needs and independence (e.g., tying a rope between house and latrine, expanding homes and building houses on the same plot of land and having a family member collect food and NFIs) were either met with resistance or there was no communication path for them to share these ideas and suggestions.

In Ukraine, the humanitarian context was highly complex and mostly unmanaged. At first glance, older persons with disabilities appeared to have some agency in this setting, as they received a government pension that allowed them to choose where to allocate their funds. However, by exploring further, the results reveal how their low pensions, the lack of services in the area and the barriers they faced accessing daily needs (as described previously) drastically limited their choice and agency. IDPs were impacted by the same challenges in addition to most having limited choice when it came to decisions around where to live (in contradiction to the UN Guiding Principles on Internal Displacement (334)). In each setting older persons with disabilities had very little choice over their daily needs and decreased agency.

It is important to look at strategies to improve personal choice in humanitarian crises. As found in the systematic review (Chapter 4), no research was found that specifically examined personal choice and

agency for older persons with disabilities in humanitarian crises. There are several strategies that have been used by humanitarian organizations to improve choice for the general population affected by humanitarian crises, such as cash based transfers (CBT) which are increasingly being used in humanitarian crises (especially refugee contexts) (333). With CBT, people affected by crises receive money instead of (or in addition to) food and NFIs (335). According to the World Food Program (WFP), this allows people to buy the supplies and food they need (increasing agency) and has a positive effect on the host communities (335). The WFP states CBT has been effective in humanitarian crises around the globe including sudden onset disasters in Ecuador (earthquake 2016) and Fiji (cyclone 2016) as well as longer term crises in Syria and neighbouring countries (conflict), Turkey (to Syrian refugees), and Somalia (335). CBT is best suited for areas where food is available to purchase (335).

While the CBT strategy does seem promising, there could be some challenges for older persons with disabilities, evident in the present research such as the physical and structural barriers in accessing local markets, accessing, and carrying food and NFIs in refugee camps and challenges accessing banks and stores in Ukraine. Special care needs to ensure that CBT are delivered in a way that older persons with disabilities can access, and future research should explore this. CBT has shown promise for this population as it has been implemented in Eastern Ukraine, and ODI stated that delivery methods (e.g., postal service) could be leveraged to meet the needs of older people who could not leave their homes (336). A qualitative study in Nyarugusu Refugee camp and the host community in Tanzania explored the effectiveness of a pilot CBT program and found that people (of all ages) preferred it over the typical food distributions because it allowed them choice and diversity of food (333). Future research should examine CBT for older persons with disabilities in humanitarian crises.

Informing decisions and humanitarian action

Collaboration with and meaningful participation of older persons and persons with disabilities in humanitarian decision making is widely cited by humanitarian organizations as an important element in improving services and inclusion in the response (17,19,171,175). Yet, there was little evidence of participants informing humanitarian decision making in either study context. In both settings, participants were largely unaware of opportunities to inform response activities. In Tanzania, there was also the perception that even if they could attend meetings, the needs of older persons with disabilities were not being addressed. In Ukraine, communication barriers (i.e., not being able to hear meeting discussions)

limited participation in meetings. In terms of informing government processes, the common view was that government supports could not be changed (18,20,161,167). These findings align with a recent systematic review that found the increased attention towards inclusion of older persons and persons with disabilities was not reflected in the literature (164)(p.34).

The lack of agency and inability to contribute positively to decisions, planning and implementation of response could contribute to creating what Ticktin referred to as *"hierarchies of humanity"* (Didier, 2010 (97) as cited by Ticktin, 2015 (82)) described in Chapter 2. Translating this concept to the current study, by not being able to inform decisions about their lives, older persons with disabilities are at risk of being reduced to simply 'the recipients of aid' and NGOs and governments are the providers and have the power to make decisions (82,96). This can lead to further exclusion and marginalization (95,96). Humanitarian action should ensure they are valuing the perspectives and contributions of older people.

8.3.5 The problem with emergency framing

The findings from Tanzania and Ukraine highlight some of the constraints associated with emergency framing and the short-term nature of humanitarian response.

Lack of comprehensive understanding

Emergency framing (i.e., humanitarian response that tends to focus on immediate action and decisive response) can neglect a comprehensive understanding of the causes of suffering (66,68)). This research demonstrates how in Tanzania and Ukraine the often generalized approach (e.g., to food delivery or pensions) did not address the specific attitudinal, physical and structural barriers of older persons with disabilities and therefore denied them dignity, autonomy and accessibility. Researchers have highlighted how people affected by crises are not passive recipients of aid (337–340). This applies to both the efforts older persons with disabilities take to manage their situations and that they are people with important contributions, stories and experiences and should be treated with dignity and respect.

In the present research, participants made efforts to meet their daily needs, (especially where humanitarian response and social protection fell short (such as food). However, because of the challenges they faced and the restrictive policies, this often led to a reliance on others. Researchers have found that

humanitarian assistance makes up only part of what people use to meet their daily needs and humanitarian assistance alone is often not enough to meet people's needs (340)(p.8). Harvey and Lind (2005) explain that we should try to understand how humanitarian assistance is part of a "*complex web of interdependencies*" (340) (p.11).

The findings of this research highlight some of the complex interdependencies and how older persons with disabilities are often excluded in humanitarian assistance. While most people affected by crises generally use humanitarian assistance and social supports as one method to meet daily needs (340), older persons with disabilities in Tanzania and Ukraine were often denied other opportunities. In the refugee camps in Tanzania people were not allowed to leave the camps (a common practice in some refugee camps (333,340)(p.11)) and livelihood opportunities were scarce and often physically demanding. Participants were therefore mostly reliant on humanitarian and social assistance. Any shortcomings in assistance (e.g., partial provisions of food or pensions that do not meet daily needs) can have a detrimental effect on their lives, force them to rely on others and deny them agency.

Short-term nature of humanitarian response

The historical roots of humanitarian assistance have resulted in a tendency towards short-term assistance (76–80,341). Contrarily, the crises of today are often complex and long lasting (341). In response, humanitarian have trended towards including longer term projects that would typically be thought of as development (77,79,80,341). This discrepancy and framing in terms of emergencies has led to several challenges, including the tendency for organizations to focus on short-term solutions (79,80,82,341). This research highlighted how older persons with disabilities are affected by this structure and suggest that the lack of long-term solutions contributed to a system of dependency that they had no way of escaping.

The issues surrounding the short-term nature of humanitarian response have been the subject of much discussion in the academic, humanitarian and development communities and there is general consensus that both immediate needs and long-term solutions must be addressed in humanitarian response (76–80,341). Harvey and Lind (2005) (340) point out how the criticisms are commonly directed at humanitarian organizations and not development. Both contexts studied in this research would benefit from both a focus on meeting full daily needs and longer-term solutions (whether that be from humanitarian agencies, development or both) which may help to break the cycles of dependency observed in this research.

8.4. Strengths and Limitations

This was the first study to my knowledge to explore the in depth the experiences of older persons with disabilities in two contrasting humanitarian contexts. As seen in the systematic review, there is a lack of research in this area with none of the identified articles exploring the barriers of facilitators to accessing humanitarian response or daily needs. This DrPH thesis has several strengths and weaknesses that are outlined in this section.

8.4.1 Systematic Review

The strengths and limitations of the systematic review are described in Chapter 4. A brief review is provided in Table *23*.

Table 23. Systematic review strengths and limitations

Strengths	Limitations
- First review to examine experiences of older persons with disabilities in humanitarian crises. - Included people who had a disability prior to crisis. - Broad focus	- Language bias towards English articles. - Older age examined as one category rather than examining differences within age group. - Seven articles not found. - 2023 article review conducted by single review (with questionable articles verified by SP/JW).

8.4.2 Breadth of research

Given the lack of research on the experiences of older persons with disabilities in humanitarian crises, I approached this research with a broad focus. This was decided based on the previous literature and stakeholder input. This is a strength because it explores and presents findings on a wide variety of topics. Moreover, it addresses a clear gap in the literature while fostering an understanding of the multifaced aspects of the experiences of older persons with disabilities in two contrasting humanitarian crises. However, there is a trade-off – it does so at the expense of exploring specific topic areas in great depth. My hope is that this study can set the stage for future research in this area.

8.4.3 Partnership with HelpAge International

Data collection for this DrPH was conducted as part of a research project in collaboration with HelpAge International, an international Non-Governmental Organization (iNGO) focused on promoting the wellbeing and inclusion of older people (342). This collaboration with HelpAge was facilitated by their desire to conduct research on older persons with disabilities in humanitarian crises. It was forward thinking members of the organization who sought researchers to collaborate with, which was ideal and facilitated the entire process. Partnerships between NGOs and academic researchers are increasing in global health research, which offers many benefits that improve research and practice (151,343). These collaborations, if managed well, help to improve research, programs and practice, thus benefiting those affected by crises and the humanitarian and global health practitioners and researchers. Despite the benefits, there can be challenges that must be addressed in these collaborations (151,343).

For this research, there were several notable strengths to the partnership with HelpAge. In addition to the staff who were a delight to work with and learn from, HelpAge provided invaluable knowledge of the context and logistical support in accessing and travelling within the crisis affected areas. They also facilitated access to experts, stakeholders (international, national, and local) and research participants. As a practitioner and healthcare professional, I am drawn to research that informs practice and improves the lives of those affected by global health challenges. HelpAge supported the dissemination of this research and knowledge translation within their organization and with partners and stakeholders at local, national and international levels. Collaborations between NGOs and researchers have been shown to enhance knowledge translation (151) and this was facilitated through the dissemination of the preliminary findings of this research in the "Missing Millions" Report (107) and dissemination workshops in each study country as well as in the UK. The findings were disseminated nationally and internationally with the assistance of HelpAge international and their networks.

A limitation of the collaboration with HelpAge was that participants were recruited from HelpAge databases and were known to the organization which may have impacted the study in several ways. First, most participants were aware of HelpAge and the role of the organization in the response. Some were also beneficiaries of their services. This could have influenced participants' responses. For instance, they could have felt pressured to demonstrate their need for assistance or may have been less willing to be critical of the organization. To limit this, the research was kept separate from HelpAge programs as much as possible. The interviews were conducted in private by trained independent local researchers (with no affiliation to HelpAge). While local NGO staff were involved in the process of guiding logistics, the selection

of participants was independent. Before the interviews, each participant was informed that their responses would remain confidential and would not influence the assistance they received.

The partnership with HelpAge International promoted research that blended academic rigor with humanitarian response initiatives. Working closely with HelpAge and working on the "Missing Millions" Project meant that I needed to balance the academic research objectives of this DrPH thesis with the objectives of this project. The staff at HelpAge International were aware that this research would be used for my DrPH thesis. To balance the need for immediate findings to inform programs with a deeper analysis, the "Missing Millions" Report was published that looked at the barriers and facilitators that participants experienced in Ukraine and Tanzania, and this was followed by a deeper analysis of the data and immersing myself with concepts related to intersectionality, disability, older age and humanitarian crises.

The partnership with HelpAge International also influences the transferability of the findings. This research was conducted in humanitarian crises where humanitarian organizations were working with participants who were known to (or beneficiaries) of HelpAge's programs. The experiences of older persons with disabilities who are living in humanitarian crises with less assistance from organizations or where HelpAge does not operate are likely quite different. While this study did include two diverse humanitarian crises with varying levels of humanitarian involvement, future research should focus on conducting research in contexts that have different degrees of humanitarian assistance.

8.4.4 Research tools

Qualitative Interviews

I used semi-structured interviews as the primary means of gathering qualitative data. Topic guides were developed before data collection and the open questions enabled participants to answer in the way that best fit their experiences. Therefore, the information provided, and its relative importance, was dictated by participants (21). I chose this method of data collection because it:

- allowed for input from stakeholders throughout the entire process.
- produced rich data on pre-determined topics from the advisory groups and allowed for deeper exploration of topics that came up in the interviews.
- facilitated gathering information on experiences and stories.

- was structured and flexible enough to provide rich data on participants' experiences in humanitarian crises.

As with any method, there are strengths and weaknesses. The topic guides were developed with input from stakeholders with extensive humanitarian expertise and knowledge which is a strength. The topic guides generally used common humanitarian focus areas (e.g., food, WASH, shelter, etc.). This assists with knowledge translation and applicability to humanitarian response. However, there is a risk that the discussions would be limited to these areas alone. To mitigate this, interviewers were trained how to use the topic guides as a prompt for discussion, whilst probing into important points raised by the participant.

Washington Group Questions

The Washington Group Questions Short Set (WG-SS) was used to classify disability for this thesis for several reasons. First, it is widely used a variety of cultures, backgrounds, nationalities, and economic statuses (129,138,344,345). Second, it was developed based on the principles of the WHO ICF framework and therefore fits with the LPD frameworks. Third, the questions in the WG-SS are non-technical and do not require expertise in disability. They minimize assumptions about the experiences of persons with disabilities, are simple to translate, and can be used by national researchers who do not have a background in disability research (344). Fourth, the tool allowed for data that were consistent across settings and populations that were studied in this DrPH thesis. Fifth, it facilitated sampling in a non-stigmatising way of describing functional limitations rather than directly asking about disability. Finally, the WG-SS is the main promoted tool to be used by NGOs in humanitarian and development settings (129,138,344,345), which will promote consistency and transferability of results.

A limitation is that the WG-SS do not explore the extent to which people self-identify as having a disability and how this may have influenced their experiences. A common critique is that the WG-SS does not capture mental health impairments and is not intended for children younger than 5 years of age (129). For this study, the experiences of participants were further explored in qualitative interviews and the tools were validated for use with adults, making it suitable for this study.

8.4.5 Field-Based data collection

All attempts were made to hold interviews in a private setting during data collection and participants were informed of confidentiality of their responses. In some situations (especially in refugee camps or in Ukraine when people lived with others) privacy could not be fully guaranteed. In these situations, where possible participants were brought into a separate room or outside, or others were asked to leave for the interview. In the lack of complete privacy, participants may have self-censored their responses to report socially acceptable behaviours, or through fear of judgement or retribution. Another limitation is the small number of caregiver interviews and that the research did not include data from staff and policy makers working in humanitarian crises. To accommodate this, stakeholders and representatives from organizations for persons with disabilities and older people were included in guiding the research.

People with different types and severity of disability were included in this study. However, for participants with communication or intellectual impairments that severely limited their ability to understand or communicate, responses from the individual were sought wherever possible and appropriate during the interview, with a family member providing additional input or serving as a proxy, where needed. This may have influenced the research because the participant may have been more hesitant to share certain information (due to the connection with the caregiver) and their experiences may have been filtered through the voice of the caregiver. Future research should use strategies that allow for rich data from all people.

8.4.6 Analysis

Data were analysed iteratively. This offered many strengths. Firstly, the analysis incorporated knowledge and expertise of the research team, stakeholders and representatives in each setting and at the national and international levels. The initial analysis allowed for rapid and timely dissemination of key findings writing of the “Missing Millions” report (107). This was followed by a more in-depth analysis drawing upon a comprehensive and broad exploration of the literature on humanitarian crises to establish meaningful connections and insights. Through this deeper analysis, connections were made between various aspects of the lived experience of older persons with disabilities and the wider humanitarian response system and mechanisms and the development of the LPD Framework that is used throughout this thesis. Having these multiple stages of analysis allowed feedback from relevant stakeholders from the early stage (including DPO/OPD representatives) and enabled me to explore the data with greater depth to understand and

articulate the complexities of age, disability and crisis more fully. I included stakeholders at all stages of data analysis which allowed for continual input, refinement and cross checking of themes and analysis. The goal was to reflect backgrounds accurately, produce research that was beneficial for humanitarian actors and improve knowledge translation.

8.4.7 Participants

This study was designed to include participants with a range of impairments (type and severity) and age (within people >60 years). This was done to capture the experiences with a variety of individuals, which helps to increase transferability. Participants also included people who had a disability since childhood or adulthood as well as those who had a disability beginning in older age. A systematic review found that most articles on disability in humanitarian crises look at people who are injured in the disaster and few are conducted with people who have a pre-existing disability (164). This study included both, which is a strength. However, the experiences of older age may vary depending on if a person is disabled earlier in life or if they develop a disability in older age (284). Future research should further explore the experiences of both groups. Another limitation is that study participants were living in areas with NGO involvement and included in the HelpAge database. The experience of people in areas without any NGO involvement may differ.

8.4.8 Intersectionality

Throughout this thesis, intersectionality was used to guide the thinking around older age and disability in humanitarian crises. As described in Chapter 3, many of the methodological considerations outlined by previous authors (e.g. Abrams et al. (2020) (100)) were included throughout this thesis and the primary framework (the LPD) was informed by intersectionality to capture the unique experiences of older persons with disabilities in these settings. While intersectionality has taken on many forms, the common assumptions around the concept include that (a) all people interact with the world through multiple socially constructed categories, (b) these categories interact with one another to create unique experiences, and (c) these interactions are embedded within a field of power dynamics (110). Another common thread (which stems from Crenshaw's original work) is that social movements, programs and

policies designed to meet the needs of people with singular identities often neglect those at the intersection of multiple identities (93,94,104).

This thesis explored the unique experiences of older persons with disabilities and the findings revealed how common humanitarian response structures and efforts towards inclusion are often focused on providing services and protection mechanisms for people with singular identities and often neglect older persons with disabilities. A limitation of this DrPH thesis is that intersectionality was not deeply woven throughout. This reflects my evolution as a social scientist over the course of this work. At the outset, I approached this research as a healthcare and humanitarian professional and primarily sought to identify barriers and facilitators to guide humanitarian action and programmes. As I immersed myself in the research, I came to realize that there are many complex and interconnected factors that influence a person's experience. Therefore, the concepts of intersectionality were incorporated more fully into the final chapters of this thesis, which I wrote in my final years of the DrPH. By drawing on literature from older age, disability, humanitarian crises and social science, my hope is that this research can be used to address the cause of many of the challenges faced by older persons with disabilities in these settings and improve transferability to other settings. On reflection, given this knowledge, engaging more deeply with intersectionality from the outset would have enabled greater exploration during the in-depth interviews and this is key learning for my future research.

This was one of the first studies to explore the situation for older persons with disabilities in humanitarian crises and I focussed primarily on characteristics older age and disability. However, it is important to note that there are many other characteristics that intersect to shape experiences that could have been explored (e.g. gender, type of impairment, displacement status, ethnicity, religion, socioeconomic status, citizenship, education level, occupation, political beliefs, language, family structure, social class, community involvement, social network, cultural background, and many others) (110). Theriault and Daniel (110) explains that each of us possess a virtually infinite number of social characteristics that can be examined. Future studies would add to the literature by examining additional social characteristics and how they intersect to shape experiences. To reduce bias and uncover which of the many characteristics influence an individual's lived experience, future studies can approach research in a more open ended, empirical way. As described by Theriault and Daniel (110), rather starting with assumptions that certain characteristics (i.e., age and disability) have the greatest influence on a person's lived experience, the researchers could allow the most influential characteristics to be discovered throughout the research. For example, Theriault (110) explored out of school programs for LGBTQ youth and after several months of

research found that sexuality was not an important characteristic for many of the participants (as initially assumed). He found instead that ethnicity, disability and socioeconomic status were more important characteristics (110). Approaching intersectionality research with assumptions can therefore diminish the research (110).

8.5 Transferability

Transferability generally refers to the generalizability or applicability of the findings to other contexts, settings or populations (198–200). Transferability was an important consideration for this research from the outset. Many of the components built into this research to promote transferability are elaborated on throughout this discussion. To promote transferability, this research was conducted in two contrasting humanitarian contexts, in different geographical locations and with diverse populations and demographics; with a high proportion of older people affected in Ukraine and a low proportion in Tanzania. A description of the context and participant sample are provided to assist others in determining whether the findings of this study are appropriate for use in their own setting, which has been highlighted as an important component to improve transferability (200). The participant sample (with a range or ages and disabilities) was also designed to improve transferability however this comes at the expense of targeted research on any age group.

Research in different geographical locations (e.g., Middle East, Central and South America, Oceania) and humanitarian crises (e.g., sudden onset, longer term) would be a valuable contribution to the literature. Since the data collection was completed over a relatively short period this research provides a snapshot of time and crisis. It does not look at participants' experiences over time. Future research should examine the experience of persons with disabilities in humanitarian crises longitudinally, including transitions from adulthood to older age.

8.6. Reflections

8.6.1 Intersectionality as an approach

This study used intersectionality framing to guide the research. Intersectionality has gained increased attention in qualitative research and with humanitarian actors. Abrams (2020) (100) offers guidelines for

incorporating intersectionality into qualitative research (outlined in Chapter 3). These components were built into this research. There were some areas that were partially incorporated, including collaboration with people from the community. While national advisory groups (including representatives from Organizations of Persons with Disabilities and Older persons) and researchers helped to inform the research, older persons with disabilities from the refugee camps were not included in the development stage due to restrictions (e.g., movement and time in camps controlled, refugees not being allowed to leave, and travel restrictions in Ukraine) and study time constraints. This was managed by having people who worked within the camps as part of the advisory groups and by pilot testing the interview guides. The main sources of data were from interviews. The data were supplemented by holding advisory group meetings in country to check for accuracy of the information. Abrams (2020) (100) also talks about the importance of various levels of analysis. In this research, an iterative analysis process allowed for an initial examination of findings and a deeper analysis and understanding to better understand the connections between various components of the participants' lived experiences.

Intersectionality describes that social characteristics (such as age, disability and displacement or crisis status) are multiplied to create distinct experiences, barriers, challenges, discriminations and oppressions (104)(p17). Therefore, the experience of an older person with a disability is not simply the experience of an older person or a person with a disability in the same context, their experiences are unique (104). This research does not compare all groups, but the findings shed light on the experiences of older persons with disabilities. Future research should look at comparing the experiences across groups.

There are several challenges with intersectionality framing. A common limitation is that intersectionality research tends to focus on participants at the intersection of *"marginalized identities"* rather than *"privileged identities"* (346). The use of semi-structured interviews, in theory should alleviate this assumption since participants can answer in the way that best represents their experience. Nevertheless, the findings mostly uncovered barriers and vulnerabilities. The positive experiences, abilities and contributions associated with age and disability in crisis settings should be a focus of future research. There are also critiques that intersectionality creates representations of people that can only be applied to that context (346). However, I believe that a strength of this study is that the unique settings (i.e., contrasting settings and demographics) improves transferability. Another common criticism, relevant to this research, is that everyone has endless identities and social positions, requiring careful consideration for research (346). The consultation and collaboration with advisory groups assisted in deciding to focus on older age and disability in crisis settings since it is an under-studied group that is disproportionately

affected. However, there is a need for future research examining the intersection of multiple identities (e.g., older women with disabilities in humanitarian crisis settings).

8.6.2 The life course perspective of disability framework

A strength of this study is that the research was guided by a conceptual framework that I developed that builds upon dominant framing of disability (ICF) (50,57) and ageing (LCP) (64–70). While intersectionality is commonly depicted as a wheel with the identities around the outside and the combination of that identity in the centre, the LPD integrates the interconnected aspects of a person's lived experience. As such, it does not simply add the singular identities, it is a representation of the unique, multifaceted, and dynamic experiences of older persons with disabilities. Throughout this research, I have identified gaps related to older persons with disabilities in the current frameworks and built upon. For instance, including agency as a contributing factor fills a recognized gap in the ICF framework (75) and uncovered important information surrounding emergency framing and the humanitarian system.

Many findings of this research were related to Environmental Factors and Agency of the LPD and limited findings related to Personal Factors. The influence of earlier life events and the dynamic and changing nature of disability was not explored in this study. Further exploration of various elements of the LPD could be developed in future research.

8.6.3 Participant expectations:

Participants were informed that their responses would have no impact on the assistance they received from HelpAge or other organizations. Despite this, some of their interview responses demonstrated a certain level of expectation from taking part in the research. Despite clear communication that their responses would not impact the support or resources received, some participants requested assistance or that their wishes be communicated to HelpAge or other organizations. For instance, in Tanzania W (a 19-year-old woman who lived in Nduta and was the primary caregiver for her grandmother) asked the researcher to follow up with the NGO to have an adaptive toilet built for her grandmother.

> *"She can't go to the toilet without help or support. We ask you to follow up so that they [NGOs] can build an adaptive toilet near to the house and put a rope that will direct her to the toilet…"*

Similarly, in Ukraine AD (a 68-year-old woman and had severe difficulty with mobility and seeing and some difficulty with hearing who supported her friend who was 83-years old and used a wheelchair) asked the interviewer for help installing a wheelchair ramp.

> *"The only thing that upsets us is – Will you make a note, please? Can you help us install wheelchair ramps to transport her from here?... She wants to go outside."*

These responses demonstrate that despite efforts to convey that there was no association between the research and care received, in some cases this did not translate into practice. The reason for this is likely partially related to the association with HelpAge as well as the presence of HelpAge staff and logos during the interview process. These finding reflect the complexities of conducting research and communication in humanitarian crisis setting. Participant expectations should be added to the list of considerations as presented by Bruno and Haar (2020) (143) which includes: the ethics review process, community engagement, the dual imperative (research that is academically sound and policy driven), informed consent and cultural considerations. While there are several benefits to researcher-NGO collaborations (as previously discussed), research in these settings must aim to address the research expectations and communication while maintaining high ethical standards and access to people living in these contexts.

8.6.4 Ethical considerations

Participant consent

To ensure participant consent during this DrPH research, written consent was obtained, as described in Chapter 3. Participants were provided with and read information and consent forms and encouraged to ask questions as part of deciding whether to take part. However, these approaches have their limitations in terms of accessibility and inclusion. Future research with older persons with disabilities should consider additional methods during the consent process such as: providing varied means of communication for research participants (e.g. visual, large print and easy to read materials; audio tape; and sign language interpretation) (146). Falb et al. (2019) (149), highlight that if any technical language is used, participant comprehension should be assessed (such as asking the participants to repeat the concepts back in their own words).

Using proxies

This study used proxies for people with impairments that severely influenced their ability to communicate. Proxy-reports may limit the autonomy of persons with disabilities and have several ethical considerations as discussed in Chapter 3. Yoon (2023) (153) explains that there are no clear guidelines on how to include people with cognitive impairments in research and the appropriate research tools. In addition, people who have cognitive impairments are diverse and include people with a wide range of impairments and levels of cognitive function. This is an important area of research methodology that must be developed to ensure active participation of all people in research and promote the voices and agency of persons with disabilities. Yoon (2023) (153), suggests identifying the “capacities” of persons with disabilities and aligning this with the best way to gain their insight for the research.

Future research should consider other methods that facilitate active participation of persons with disabilities, including people with cognitive impairments. These may include participatory methods, observation, arts-based research approaches (visual, performative or collaborative (153), communication boards sign language or photography or photovoice. It's essential that the voices of people with cognitive disabilities are heard in research, and to create a supportive approach to make the research experience enjoyable for them too (153).

8.6.5 Disability frameworks and participant responses

Tanzania

Tanzania and Burundi have both adopted the UNCRPD (238) which defines disability in terms of the ICF framework (relating to the interaction between impairment and environmental factors that influence participation (50,56)). Within the context of education legislation and laws, it has been found that Tanzania is more consistent in using the social model than Burundi (where the social and medical model are often used) (238). This may have influenced the responses because some may have the perception that disability refers to inclusion and environmental factors (ICF framework), whereas others may think in terms of the medical model (and focus on the need for medical or rehabilitative interventions). In the context of refugee camps, the charity model may also influence people to refer to disability and the need for assistance.

From my observations in Tanzania, it appeared as though representatives from NGOs (international and local) as well as government officials referred to disability in terms of participation in society and inclusion

within programs and initiatives. This likely reflects the influence of international standards and norms in the humanitarian landscape. Older persons with disabilities often referred to their desire to participate and engage in various aspects of society as well as the need for additional assistance, which reflects the ICF or social models and the charity models. Caregivers also focused on participation but more often spoke about the need for additional assistance and medical interventions (medical model). The lens through which an individual views disability seems to influence the responses and there may be limitations to thinking in terms of international frameworks that were predominantly developed in the Global North.

African researchers and disability advocates have suggested an alternative conceptualization of disability which reflects the notion of *ubuntu* which is an ethical world view and *"a philosophy of shared collective humanness and responsibility"* (347) (p.2) (*"I am because we are"* (348)(p.2)). *Ubuntu* emphasizes the interconnectedness of all people and focuses on belonging. It also encompasses spiritual and ecological aspects of a person's experience. It does not put blame on the individual who has a disability but instead attempts to uncover why a community or state is failing to respect human diversity and develop solutions to address this (347). A model of disability that incorporates ubuntu has been suggested to represent the experience of Africans with disabilities more accurately and help to address colonial and postcolonial oppressions and disablement (347). I will incorporate this into future research.

Ukraine

In Ukraine, representatives from NGOs spoke of disability in terms of the ICF framework however, there appeared to be more of a focus on medical interventions. This is reflected in the research which has found that the medical and charity models of disability are most common in Ukraine (263). This may have influenced responses as individuals may be more focused on medical interventions than factors to promote participation or social inclusion. This may explain the focus on medication and medical care and how many participants prioritized medication over other aspects of daily life.

8.6.6 Positionality - 'Insider'/'Outsider' Status

As expected, my status as an "outsider" was obvious in Tanzania. Because of my pale skin, my presence often attracted much attention in the refugee camps. Most of the time, people seemed to expect that I was a humanitarian worker. This was understandable since we travelled with HelpAge staff as a research team in the HelpAge vehicles.

I expected that my status as an outsider would be less obvious in Ukraine because the population is predominantly white. While this was true in some respects, a conversation with a colleague clarified that I was mistaken. A couple of weeks into the data collection, a colleague from Ukraine asked: *"Why do you dress like that? You look like you're going for a hike?".* Clearly, my plaid button-up shirt (inspired by my Canadian roots) and Blundstone boots (inspired by my affinity for practicality) gave me away as an outsider. I was also an outsider in terms of culture, background and language. As a 30-year-old male without a disability, I was an 'outsider' to participants who were older persons who had a disability.

Both 'insider' and 'outsider' researcher positions have limitations and strengths and require unique considerations (100,349). The 'insider' perspective is said to promote empathy and rapport building and can facilitate discussion (100). However, insider researchers may face potential bias because of their position (350). For example, in Ukraine an insider's thoughts on the conflict may influence how they interact with people who support a certain side and in Tanzania someone who lives in a refugee camp and is competing for scarce resources may have biases towards older persons with disabilities.

The outsider has been described as a neutral, objective and detached observer which can facilitate or hinder discussions (21,350). For instance, some might be more willing to talk about taboo subjects since the outsider doesn't understand cultural norms whereas others might feel uncomfortable (100). However, gaining trust can be difficult for the outsider (350). Some researchers suggest that outsiders cannot fully understand a culture or situation they have not experienced (350) while others say they bring a perspective (349). Most view the insider/outsider positions on opposite ends of a continuum and that the researcher occupies some positions as an insider and others as an outsider (100,350).

I was aware that I was an 'outsider' during this research and took action to mitigate the negative aspects and leverage the beneficial aspects of that position. I continually consulted with experts and local staff to try and understand the insider perspective. The extensive consultation with advisory groups and sharing of key findings were also an attempt to accomplish this. The local researchers were trained on this, and I only presented myself when necessary during interviews so as not to influence participant responses.

However, my presence may have influenced participant responses. Some may have been nervous about sharing certain details or, since many viewed me as a humanitarian worker, they may have been motivated in a manner that they perceived could influence the assistance they received. This was mitigated by me not being present unless necessary and informing the participants of my role and that their answers would be kept confidential and have no implication on the assistance they received.

My background and experience as a healthcare professional, humanitarian and in development settings influenced the study. In addition, having collaborated with HelpAge at the International level may have influence how staff, researchers and participants perceived and interacted with me. Within the organization, people may have perceived me as coming to evaluate their programs or performance. This could have influenced participant selection and logistics. To account for this, I was part of the participant selection process to ensure that it was completed randomly. Participants may have altered their responses to either filter what they said to not speak negatively about the organization or attempt to demonstrate need in hopes of receiving additional assistance. To mitigate this, I did not present myself until after the interviews were conducted unless the national researchers required assistance.

I needed to be conscious of my role and position in the development of topic guides and training of the interviewers as well. As a healthcare professional, I am frequently completing subjective assessments that, on a superficial level, resemble qualitative interviews. However, there is a critical difference - when assessing a patient and health condition, my role is to guide the patient to become specific about their symptoms to discover what that health condition might be and to guide my objective physical examination. This typically involves going from broad (e.g. a patient might start by stating “I have back pain”) to the specific with little exploration of other topics (e.g. “I have sharp pain on the right side of my back that radiates down my leg when I bend forward”). For the qualitative research in this DrPH, the focus of the interviews was about guiding people to speak about their experience in various areas of life and helping them to open up about that experience and explore wide ranging ideas that may or may not seem connected. In other words, going from specific (e.g., a participant might say “we often lack food…”) to broad (e.g., guiding a participant to uncover the reasons why they lack food such as “the distributions don’t last us a full month.”).

The analysis was another area that may have been influenced by my background. As someone who is commonly working with individuals in delivering services or projects, my focus initially was on informing

program delivery. I had to develop and learn on a professional and personal level how to engage with deeper concepts and theories and be more data driven. This is reflected throughout this thesis.

8.6.7 Positionality of the research team

I sought to work with local researchers in each setting who shared aspects of background and culture. However, not all the local researchers were true 'insiders' from the population. In Tanzania, refugees were not allowed to leave the camps and the amount of time I could spend in the camps was extremely limited and controlled. This reduced who could be researchers. In addition, because of the different populations and locations of the camps and the requirements to support the consultation with stakeholders, development and knowledge translation, the researchers were required to speak Swahili and English. In Ukraine, there were fewer limitations on location, but the researchers were required to speak Ukrainian, Russian and English. Few researchers who lived in conflict affected areas were found in Eastern Ukraine.

In Tanzania, the researchers were national Tanzanians but were not Burundian or living in the refugee camps. This resulted in the researchers being outsiders in terms of the refugee and Burundian experience. There are benefits and challenges to this (as described above). As Falb et al. (2019) (149) explain, employing data collectors who are from refugee camps may pose risks to confidentiality. In Tanzania, one of the researchers lived in the area surrounding the refugee camps and had a lot of experience working with NGOs within the refugee camps. Another was a researcher with experience in qualitative methods and one had experience in qualitative research projects in Tanzania related to healthcare. In Ukraine, one of the researchers was from the conflict affected areas and a professor of philosophy, the other had experience in research and global health. The research team complimented each other very well and I ensured continual knowledge sharing, and reflexivity was built into the research process. Throughout the research, I had discussions with the researchers to discuss emerging themes and the impact of our presence. While their insider perspective offered great insight into the experience and depth of the findings, the outsider position also effectively encouraged participants to share their experiences. In most cases, participants were eager to share their experiences. For instance, one participant shared with a family member: *"They came all the way from London to talk with us… it is quite exciting*". Our affiliation with HelpAge International was also evident throughout the interviews and the research team informed participants of the confidentiality and that their responses would in no way impact the assistance they received in the moment.

Attempts to match participants with interviewers of similar age, gender and backgrounds are often encouraged in qualitative research (21). In this research, local researchers completed the interviews and in most cases, participants and researchers were matched for sex. However, the interviewers were all under the age of 60 years and none had a disability. This may have impacted the willingness of participants to share information with the researchers. This was addressed in the training and throughout the research. It was also discussed with national advisory groups and staff.

8.6.8 Evolution of thought

Epistemology

My evolution as a researcher and global health professional over the course of this research has been profound. I am a physiotherapist by profession with a primarily quantitative research background. Prior to this research, my position was rooted in positivism (assumes the world is objective and can be represented by facts and concepts (351). Over the course of this research and having explored concepts related to ageing, disability and humanitarian crises, my views are more aligned toward interpretivism (people interpret the world based on their social reality) (351). I still believe that there are objective facts in the world. However, it is clear to me that the way that we interpret the world influences our experience. This is especially the case when it comes to characteristics such as age and disability. My evolution of thought can clearly be seen in the outputs of this research. The "Missing Millions" Report is a reflection of my positivist view with a focus on barriers and facilitators. This research and the components that explore connections and experiences of older persons with disabilities as it relates to wider concepts and framing reflect my transition interpretivism.

Humanitarianism

Through this research, I reflected on my own positions and views of the world, especially global health and humanitarian response. As a physiotherapist and humanitarian worker, my view of humanitarian action prior to this research aligned with classical humanitarianism where humanitarian crises are the exception to the 'normal' (352). Now I see that this view is rooted in 'emergency framing' and the historical roots of humanitarianism. Another view is resilience humanitarianism which emphasizes the importance of local communities in responding to crises (352). Given my background in community-based

rehabilitation, my views of global health have always been based on community involvement however when it came to crises, I saw them as one of exception. Now, I see the value and importance of both. There are many cases where humanitarian crises require immediate response from external actors. However, these should be rooted in local capacity and communities. The local, global, and humanitarian communities should work together to create long-term and comprehensive solutions and resiliency.

8.7 Conclusion

The aim of this DrPH research was to understand the experiences of older persons with disabilities in humanitarian crises to inform evidence-based recommendations and strategies for humanitarian response. The systematic review identified a clear gap in the literature; however, it is promising to see growing interest and quality of evidence in this area. The unique experiences of older persons with disabilities were explored as well as the complex, multifaceted and interconnected factors that influence their access to daily and humanitarian support needs. This research also discusses how dominant humanitarian framing and structure can contribute to the challenges faced by older persons with disabilities. The work presented has theoretical and practical implications on the experiences of older persons with disabilities, with the development and use of the LPD. This research can be used to inform recommendations for humanitarian action.

8.8 Recommendations

In this section, I provide recommendations to inform humanitarian, based on the results of this research. A summary of findings and recommendations specific to Ukraine and Tanzania are provided in Table 22. In this section, I focus on crosscutting recommendations to inform humanitarian response more broadly. It is important to consider the factors related to transferability when implementing these in other contexts. As discussed throughout this discussion, these recommendations should be used as building blocks to inform humanitarian practice and research and future research should focus on building the knowledge on the experiences of older persons with disabilities in humanitarian crises and specific strategies to meet their needs. The following recommendations are for humanitarian actors.

1. **Create programs and coordination mechanisms focused on older persons with disabilities.**
    a. This research demonstrates how the humanitarian response system does not meet the needs of older persons with disabilities and how inclusion efforts that are aimed at older people and persons with disability (separately) occasionally do not meet the needs of older persons with disabilities.
    b. Using a 'twin-track approach' the inclusion of older persons with disabilities should be mainstreamed across all programs and initiatives and targeted approaches should be used to create specific inclusion initiatives for older persons with disabilities.
    c. Considered intersectionality of older persons with disabilities across all humanitarian clusters.
    d. Strengthen collaboration between organizations that are targeted towards older people and persons with disabilities and more generalized organizations.

2. **Collaborate to build long term strategies into humanitarian action.**
    a. From the results of this research, it is evident that older people with disabilities are negatively affected by emergency framing and the short-term nature of humanitarian response.
    b. Collaborate with communities, older people's associations, and organizations of persons with disabilities to build longer term solutions to humanitarian crises.
    c. Collaborate with development focused organizations and incorporate development initiatives and programs into the response.

3. **Collect and disaggregate data by disability and age.**
    a. This research demonstrates how older persons with disabilities have unique experiences and needs and face specific barriers (or combinations) in humanitarian crises.
    b. Routinely collect and analyze data on age and disability to locate older persons with disabilities and understand their needs, capabilities and the barriers they face in accessing humanitarian assistance.
    c. Collect standardized information on age and disability (such as the WG-SS)
    d. Disaggregate data on age and disability to better identify older persons with disabilities and inform programs.

4. **Include older persons with disabilities in the humanitarian response planning stage and identification of support mechanisms.**
    a. Older persons with disabilities were unable to inform decision making processes and efforts toward inclusion in Tanzania and Ukraine.
    b. Include older persons with disabilities in informing decisions to support inclusion efforts and promote agency and dignity (they are best positioned to provide a nuanced understanding of their own experience).

5. **Consider older persons with disability in conjunction with family and caregivers.**
    a. Family and caregivers were found to provide vital support to older persons with disabilities in humanitarian crises and helped with accessing daily needs.
    b. Caregiving was found to hinder participation in livelihood activities.
    c. Consider the role of older persons with disabilities within their families and communities.
    d. Consider who supports and assists the individual and how they could be impacted by caregiving duties.
    e. Provide support to caregivers to assist with caregiving roles and other daily needs.

6. **Advocate for sufficient funding and support for older persons with disabilities**
    a. Older persons with disabilities were found to be disadvantaged by the partial provision of aid and insufficient social supports which led to chronic dependency (because of the inability to supplement what they received).

b. Advocate with funders to provide enough funding to meet the full provision of assistance.
c. Work with older persons with disabilities, older persons associations and organizations of persons with disabilities to advocate for sufficient social supports that meet the needs of people affected by crises (e.g., increase in proportion to inflation).

8.9 Future Research

Over the course of this research, many areas for future exploration were identified. These include (but are not limited to):

- The influence of earlier life events on shaping the experience of older persons with disabilities in humanitarian crises.
- A deeper exploration of how agency and personal factors influence their experiences.
- Research conducted with older persons with disabilities in different geographical locations and contexts.
- The intersectionality of age, disability, and gender in humanitarian crises.
- How the experience of older persons who have had a disability since childhood or adulthood compares to older people who have a disability in later life.
- The experiences of caregivers of older persons with disabilities in humanitarian crises.
- The contributions of older persons with disabilities to family and community in humanitarian crisis settings.

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APPENDICES

APPENDIX 1: The United Nations Humanitarian Cluster System

According to the United Nations Office for the Coordination of Humanitarian affairs, clusters are groups of humanitarian organizations, both UN and non-UN, in each of the main sectors of humanitarian action such as health, protection and food security (26). They are designated by the Inter-Agency Standing Committee (IASC) and have clear responsibilities for coordination. Figure 3, in Chapter 1 depicts the UN cluster system and components.

The aim of the cluster system is to "strengthen system-wide preparedness and technical capacity to respond to humanitarian emergencies and provide clear leadership and accountability in the main areas of humanitarian response" (26). At the country level, the cluster system aims to strengthen partnerships, and the predictability and accountability of international humanitarian action, by improving prioritization and clearly defining the roles and responsibilities of humanitarian organizations. According to UNOCHA (26), the clusters achieve this aim by:

1. Supporting service delivery by providing a platform for agreement on approaches and elimination of duplication
2. Informing strategic decision-making of the HC/HCT for the humanitarian response through coordination of needs assessment, gap analysis and prioritization
3. Planning and strategy development including sectoral plans, adherence to standards and funding needs
4. Advocacy to address identified concerns on behalf of cluster participants and the affected population.
5. Monitoring and reporting on the cluster strategy and results; recommending corrective action where necessary
6. Contingency planning/preparedness/national capacity building where needed and where capacity exists within the cluster.

APPENDIX **2:** Disability and age guidelines and policies in humanitarian action

Disability inclusion in humanitarian action has seen increased attention in recent years. Many reports, guidelines and standards on humanitarian action now state the importance of inclusive response and mainstreaming of disability across all humanitarian sectors. The Sphere Handbook (30) (one of the most widely referenced humanitarian resources, globally) highlights the importance of inclusion of people with disabilities across all sectors of humanitarian action as well as in the design, implementation and monitoring of programs. The handbook also references standards specific to disability inclusion, such as the Age and Disability Capacity Building Programme (ADCAP) Humanitarian Inclusion Standards for Older People and People with Disabilities (8). The United Nations Office for the Coordination of Humanitarian Affairs (UNOCHA) Global Humanitarian Overview, 2021, dedicates a section to the impact of humanitarian crises on persons with disabilities ((1), p.52) and recommends continued work to *"mainstreaming the inclusion of persons with disabilities into strategies, policies and programming"* ((1), p. 54). The report also comments on the importance of data collection and sharing on disability in humanitarian settings (1).

The increased focus on disability in humanitarian response was also evident in the response to the COVID-19 pandemic. The World Health Organization (WHO) and the Pan American Health Organization (PAHO) were quick to develop reports highlighting various considerations for persons with disability. These reports included guidelines on inclusion for family members, households, healthcare workers, governments and humanitarian actors (353,354). The extent to which these guidelines are implemented in humanitarian action is a separate issue. However, disability inclusion has come a long way in humanitarian action to the point where it is now mainstream in guidelines and reports across a wide variety of sectors. The following section will examine some of the key legislation and documents that have led to disability mainstreaming.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is a legally binding human rights treaty aimed at promoting and protecting the human rights and fundamental freedoms of all persons with disabilities (56). The Convention was adopted in 2006 and has 182 signatories. Article 11 of the UNCRPD specifically addresses situations of humanitarian emergencies and states that parties shall

take *"all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters"* (56) (pg. 10). Other articles address factors directly related to humanitarian settings such as: equality and non-discrimination (Article 5), accessibility (Article 9), the right to life on an equal basis with others (Article 10), security (Article 14), freedom from violence and abuse (Article 16), liberty of movement and nationality (Article 18), access to information (Article 21), access to health (Article 25) and rehabilitation (Article 26), access to employment (Article 27), participation in political and public life (Article 29), and cultural life (Article 30). There is also an emphasis within the UNCRPD on data collection that informs and protects human rights (Article 31) (56). The guiding principles of the convention include: respect for human dignity, individual autonomy (including the freedom to make one's own choices), and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (355).

The UNCRPD resulted in a shift in attitudes and behaviours towards persons with disabilities which had dramatic influence globally (19). Following the entry of the UNCRPD, disability was understood as a human rights issue (4,56). The humanitarian community began to change their approach from a charity and medical model to a rights-based approach that promoted the participation and inclusion of persons with disabilities (19,356).

The Sphere Movement

Sphere is a movement that aims at improving the quality of humanitarian action and was started in 1997 by a group of humanitarian professionals from non-governmental organisations (NGOs), Red Cross and Red Crescent Movement (357). The Sphere Humanitarian Charter (223) was drafted in 1997 and outlines the rights of all people affected by disaster and conflict including: the right to life with dignity, the right to receive humanitarian assistance, and the right to protection and security (223). The Charter highlights the rights of all people and explicitly states that no one should be discriminated against for any reason, including disability and age, among others (223) (pg. 4).

The Sphere movement has since developed the Sphere Handbook - Humanitarian Charter and Minimum Standards in Humanitarian Response - which released it's 4th edition in 2018 (30) in consultation with hundreds of humanitarian organizations and thousands of people worldwide. The handbook aims to inform humanitarian action and ensure accountability across all sectors. Sphere's main belief is that *"all individuals have a right to a life with dignity and therefore a right to assistance"* (70, p.10). They refer to "people" as *"including women, men, boys and girls, regardless of their age, disability, nationality, race, ethnicity, health status, political affiliation, sexual orientation, gender identity or any other characteristic that they may use to define themselves"* (30) *(p.10).* The handbook highlights that factors such as disability, age or health status can limit access to assistance. It also explicitly states that having a disability or to be of older age *"does not in itself make an individual universally vulnerable. Rather, it is the interplay of factors in a given context that can strengthen capacities, build resilience or undermine access to assistance for any individual group*" (30) (p. 12). In the section on persons with disabilities, the handbook highlights the unique obstacles faced by persons with disabilities in humanitarian contexts and the importance of removing physical, communication and attitudinal barriers in these contexts (30) (p.14). The group also emphasizes the importance of collecting disaggregated data by sex, age and disability (30) (p.11).

Core Humanitarian Standards

The Core Humanitarian Standards for Quality and Accountability (CHS) were developed in 2014 by the Sphere group and sets out nine Commitments that organisations and individuals can use to improve humanitarian response quality and effectiveness (30,357). The CHS and Commitments are shown in Figure 20. The CHS places an emphasis on understanding the needs, capacities, barriers, and vulnerabilities of all people who may be disproportionately affected in humanitarian crises, including persons with disabilities. It explains how social and contextual factors contribute to increased vulnerability, which is consistent with widely accepted definitions of disability (such as the ICF – covered in detail below) (57). There is also a focus on strengthening the inclusion of persons with disabilities in all aspects of society and in humanitarian response, including the development, implementation and monitoring of humanitarian programming as well as staffing of humanitarian actors. Like other documents and guidelines, the CHS highlights the importance of collecting disaggregated data on age, sex, and disability (at a minimum) to gain a better understanding of the impact of humanitarian crises on persons with disabilities (30).

Figure 20. The Core Humanitarian Standard

Sendai Framework for Disaster Risk Reduction (SFDRR)

The Sendai Framework for Disaster Risk Reduction (SFDRR) 2015-2030 was adopted in 2015 at the Third United Nations World Conference on Disaster Risk Reduction (32) with the overall expected outcome of reducing disaster risk and losses of lives, health and assets (32). To accomplish this, the framework states the importance of inclusive and integrated measures to prevent and reduce exposure and vulnerability to disaster (32) (p.11). The framework lays out four primary objectives: understanding disaster risk; strengthening disaster risk governance to manage disaster risk; investing in disaster risk reduction for resilience; and enhancing disaster preparedness for effective response, and to “build back better” in recovery, rehabilitation and reconstruction (32) (p. 35). Through collaboration and engagement with all

stakeholders, including persons with disabilities and older persons in all aspects of disaster risk reduction, the SFDRR improved inclusion of people with disabilities in humanitarian response focusing on a "people centred approach" (32) (p.5). According to Stough and Kang (2015) in their in-depth article examining the SFDRR and persons with disabilities, *"the SFDRR has firmly established people with disabilities and their advocacy organizations as legitimate stakeholders and actors in the design and implementation of international disaster risk reduction policies"* (358) (p.1).

Sustainable Development Goals (SDGs)

The Sustainable Development Goals (SDGs) 2015-2030 was adopted in 2015 by all United Nations Member States. The SDGs are a set of 17 goals with the aim of providing *"a shared blueprint for peace and prosperity for people and the planet, now and into the future"* (33). The SDGs built upon the Millennium Development Goals (MDG) 2000-2015 by focusing on a global approach including environmental sustainability. Throughout the document, there is an overarching theme of *"no one will be left behind"* and a focus *"to realize the human rights of all"* (359) (p.1). Several targets are relevant to humanitarian crises and persons with disabilities (Table *24*) A primary focus of the SDGs is upholding human rights and promoting non-discrimination. As such, disability is viewed as a cross-cutting issue within the SDGs, rather than specifically being mentioned in goals and targets. Hashemi et al. (2015) (303) note that since people with disabilities make up a very large minority group, globally, including disability is imperative to achieving the SDGs. Their article examines Goal 3 – health, throughout which they argue that "*the goal is unlikely to be achieved without specific strategies focusing on the one billion people with disabilities…"* (303)*(p.1106).* Given that there is a higher prevalence of disability in low-and middle-income countries (which is where humanitarian crises are more likely to occur) the same argument may be applicable to humanitarian crises – without a focus on reducing barriers and vulnerability associated with disability, it may be unlikely that the goals and targets related to humanitarian crises will be met.'

Table 24. Sustainable Development Goals (SDGs) goals and targets related to disability in humanitarian crises.

Sustainable Development Goals – Goals and targets related to disability in humanitarian crises
Target 1.5 - By 2030, build the resilience of the poor and those in vulnerable situations and reduce their exposure and vulnerability to climate-related extreme events and other economic, social and environmental shocks and disasters
Goal 3 - Ensure healthy lives and promote well-being for all at all ages
Goal 9 - Build resilient infrastructure, promote inclusive and sustainable industrialization and foster innovation
Target 10.2 - By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status
Target 11.5 - By 2030, significantly reduce the number of deaths and the number of people affected and substantially decrease the direct economic losses relative to global gross domestic product caused by disasters, including water-related disasters, with a focus on protecting the poor and people in vulnerable situations
Target 11.b - By 2020, substantially increase the number of cities and human settlements adopting and implementing integrated policies and plans towards inclusion, resource efficiency, mitigation and adaptation to climate change, resilience to disasters, and develop and implement, in line with the Sendai Framework for Disaster Risk Reduction 2015–2030, holistic disaster risk management at all levels
Target 13.1 - Strengthen resilience and adaptive capacity to climate-related hazards and natural disasters in all countries

World Humanitarian Summit

The first World Humanitarian Summit (WHS) was held in May 2016 with 9,000 participants from Member States, NGOs, UN and non-UN agencies (360). The WHS, through core responsibility two: *"Uphold the norms that safeguard humanity*", urged all state parties to commit to upholding laws and human rights conventions such as the UNCRPD (361). Core responsibility three: "*Leave no one behind*", recognized that persons with disabilities and older people are among the most marginalized in humanitarian contexts and need a targeted approach to decrease the barriers they face in accessing services such as education, healthcare and livelihoods (361) (22/62). The WHS pledged to increase the inclusion and voices of marginalized groups, such as people with disabilities in humanitarian action (362) (p.19/62) and concluded with a commitment to develop a globally endorsed system-wide set of guidelines to improve inclusion of persons with disabilities in humanitarian action. This resulted in the adoption of The Charter on Inclusion of Persons with Disabilities in Humanitarian Action (19,35).

Charter on Inclusion of Persons with Disabilities in Humanitarian Action

The Charter on Inclusion of Persons with Disabilities in Humanitarian Action was developed leading up to the World Humanitarian Summit in 2016 by over 70 stakeholders from governments, UN agencies, NGOs, and organisations of persons with disabilities (34,35,363). The Charter represents five commitments which the endorsers agree to uphold: non-discrimination; participation; inclusive policies; inclusive responses and services; and cooperation and coordination (19). The Charter pledges to make humanitarian action inclusive of persons with disabilities (1.1 p. 1) (35), to ensure access to humanitarian response without discrimination (1.2), to place persons with disabilities at the centre of all stages of humanitarian response (1.2; 1.6; 1.10; 2.2; 2.3), and to uphold international conventions (such as the UNCRPD) and laws (1.5). The Charter affirms its commitment to the 2030 Agenda for Sustainable Development (SDGs) and the goal of "*leaving no one behind*" (35) (1.6, p. 1), and the Sendai Framework on Disaster Risk Reduction (SFDRR) (35) (1.6, p.2). The Charter recognizes the disproportionate impact of disasters (1.7) on persons with disabilities. This is due to the increased barriers and vulnerabilities persons with disabilities face in humanitarian contexts, as well as the potential of these crises to cause or exacerbate disability disabling impact of these crises that can cause or exacerbate disability (1.8). As with other reports and standards on disability in humanitarian crises, the Charter also emphasizes the need for disaggregated data on age, sex and disability (35)(1.9, p.2) (2.3.c p.3).

According to a report prepared by the International Disability Alliance, Humanity and Inclusion, and CBM (34), the Charter is a useful tool to increase understanding of how inclusive humanitarian action can be achieved. The authors of this report state that it is an important document because *"It demonstrates the collective willingness to enhance the full and meaningful inclusion and participation of persons with disabilities and their respective organisations across the humanitarian system, in line with the UN Convention on the Rights of Persons with Disabilities"* (UNCRPD) (34)(p.1). The report noted that a year after its adoption, the Charter had already led to changes in practice and an increased focus on inclusion in humanitarian action: stakeholders were focusing on strengthening capacity, policies and practices began to include disability, and the Charter served to inform and progress global resources on inclusive response (34). It also progressed the development of the Inter Agency Standing Committee Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action (19,34).

Inter-Agency Standing Committee (IASC) - Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action

The Inter Agency Standing Committee (IASC) 'Guidelines on the inclusion of persons with disabilities in humanitarian action' was spurred from the World Humanitarian Summit in 2016 and the Charter on the Inclusion of Persons with Disabilities in Humanitarian Action (19). According to the IASC, the system-wide guidelines set out actions to improve identification and response for persons with disabilities in humanitarian crises (19). They are the first humanitarian guidelines to be developed with and by persons with disabilities along with mainstream humanitarian organizations and stakeholders (19). The four primary objectives of the guidelines are: provide guidance on inclusion of persons with disabilities in humanitarian programming and coordination; increase capacity; ensure accountability; and increase participation of persons with disabilities across all phases of humanitarian programming (19) (p.8). The IASC advocates for a '*twin-track approach*' that incorporates inclusive mainstream programmes in combination with targeted interventions for persons with disabilities (19) (p.17). The guidelines adhere to the CRPD and are intended to be applicable and implemented across all settings and humanitarian crises, as well as designed to be adapted to the specific context and situation (19).

United Nations Disability Inclusion Strategy

The United Nations Disability Inclusion Strategy is a process that began in 2018 in order to strengthen disability inclusion across the entire UN system (36). The focus of the strategy is to create a framework for implementation of the CRPD, SDGs, SFDRR, as well as other international human rights instruments (36). The Disability Inclusion Strategy follows three key approaches: a twin track approach; intersectionality; and coordination. Intersectionality acknowledges that various factors such as age, gender and location can impact a person's experience. Coordination refers to the fact that multi-level collaboration is essential in achieving disability inclusion. The UN Disability Inclusion Strategy is a culmination of many other reports and efforts and demonstrates the current landscape of disability inclusion in humanitarian response.

ADCAP Humanitarian Inclusion Standards for Older People and persons with disabilities

There has been increasing attention among the humanitarian sector to address the issues faced by older people with disabilities in recent years. For example, the Age and Disability Capacity Building Programme (ADCAP) is an international program designed by a consortium and led by HelpAge International. Its goal is to ensure that older people and those with disabilities can access emergency support in times of disaster through supporting relief organizations to better respond to their needs (17,364). The aim of ADCAP was to *"improve humanitarian actors' understanding of the needs and capacities of older people with disabilities*" (364) (p.1). To meet this aim, HelpAge International's approach was three-fold: to develop resources/guidelines; to strengthen capacity of humanitarian actors; and to collect evidence on age and disability (364).

The ADCAP consortium developed the 'Minimum Standards for Age and Disability Inclusion in Humanitarian Action' in 2015 (17). The standards include a set of key inclusion criteria for age and disability based on the Core Humanitarian Standards and provide general recommendations as well as information for specific sectors and clusters (e.g., WASH, nutrition, health) (17). These standards evolved into the 'Humanitarian Inclusion Standards for Older People and People with Disabilities' (8). This evolved version consists of nine Key Inclusion Standards (as shown in Table *25*) in addition to sector-specific inclusion standards for protection, WASH, food security and livelihoods; nutrition; shelter; health; and education (8) (p.10). These Key Inclusion Standards are designed to strengthen inclusion of older people

and persons with disabilities in humanitarian response and can be used as guidance for programming and a resource for training or advocacy (8).

Table 25. Humanitarian Inclusion Standards for Age and Disability Inclusion in Humanitarian Action - Key Standards (directly from (8) (p.10).)

Humanitarian Inclusion Standards for Age and Disability Inclusion in Humanitarian Action – Key Standards

1. Identification
Older people and people with disabilities are identified to ensure they access humanitarian assistance and protection that is participative, appropriate and relevant to their needs.

2. Safe and equitable access
Older people and people with disabilities have safe and equitable access to humanitarian assistance.

3. Resilience
Older people and people with disabilities are not negatively affected, are more prepared and resilient, and are less at risk as a result of humanitarian action.

4. Knowledge and Participation
Older people and people with disabilities know their rights and entitlements, and participate in decisions that affect their lives.

5. Feedback and complaints
Older people and people with disabilities have access to safe and responsive feedback and complaints mechanisms.

6. Coordination
Older people and people with disabilities access and participate in humanitarian assistance that is coordinated and complementary.

7. Learning
Organisations collect and apply learning to deliver more inclusive assistance.

8. Human resources
Staff and volunteers have the appropriate skills and attitudes to implement inclusive humanitarian action, and older people and people with disabilities have equal opportunities for employment and volunteering in humanitarian organisations.

9. Resource management
Older people and people with disabilities can expect that humanitarian organisations are managing resources in a way that promotes inclusion.

Summary

There has been increased attention in recent years on promoting humanitarian action that is inclusive of older people with disabilities. Humanitarian actors and consortiums have developed useful tools, guidelines, and recommendations to promote humanitarian response that is participatory, inclusive, and accessible for older people with disabilities. There is limited research on older people with disabilities in humanitarian crises. As such, the guidelines are primarily based on research on disability and (separately) older people in humanitarian crises, in addition to field reports, surveys and stakeholder knowledge. What is lacking is research on the lived experiences of older people with disabilities in humanitarian crises, the barriers and facilitators they face in accessing to humanitarian services, and how those factors inform policy, guidelines and decision making in humanitarian action.

APPENDIX 3: Influence of perceptions and thoughts around ageing

Individual and societal thoughts and perceptions of ageing can also have an influence on older age, which can be influenced by context and life experiences. Research has shown that the perceptions of ageing and what it means to 'age successfully' varies by culture and individual (59,61). Perceptions and thoughts of ageing are shaped by a myriad of interacting factors, including societal discourse (59), cultural and personal opinions and values, social expectations, traditions, and religious beliefs (61). Societal views on ageing can consequently influence an individuals' perspective on ageing which can impact physical and psychological health and wellbeing (59). Research has shown that stereotyping and stigma in society can lead people to internalize the stigma, embody it and perpetuate it (59). Negative stereotypes around ageing are reinforced during a lifetime and can influence people as they age (59). Ageism, the prejudice against older people and ageing is a significant issue from both an individual and population-based perspective (59,71). A recent systematic review examining ageism and health, found that ageism was observed in all 45 countries and across all continents where studies took place (71). The study also found that in 95.5% of the 422 studies identified, ageism adversely affected a broad range of health outcomes, including: exclusion from health research, devalued lives of older persons, lack of work opportunities, denied access to healthcare and treatments, reduced longevity, poor quality of life and wellbeing, risky health behaviours, poor social relationships, physical illness, mental illness, and cognitive impairment (71).

APPENDIX 4: History of humanitarianism

History of Humanitarianism

The meaning of humanitarianism can vary depending on the person, culture or context (77) (p.1). However, Davies (2012) explains that underlying meaning of 'humanitarian' generally refer to *"a concern for the welfare of the whole of mankind and a desire to effect change in this regard"* (77)(p.2). The understanding and action of humanitarianism has evolved since its inception.

The Western origins of humanitarianism are generally linked to the role of humanitarian intervention in military settings, especially the European experience of war and natural disaster (77,78). The history of humanitarianism is not solely Western as multiple histories have unfolded around the world. However, many of the origins of the formal international humanitarian system have developed according to the Western history which has shaped the broader humanitarian landscape (78).

In the nineteenth century, the term 'humanitarian' shifted from a moral concern to focus on operations for social and political change (77). Initially, there was a shift in thinking from religious based explanations of the world to scientific ones (77). Disasters started to be seen as preventable rather than being *"the judgments of God"* (77)(p.3). By the mid nineteenth century, technological advancements led to increased human cost of conflict and increased communication about conflicts (78). Governments, therefore, had a greater incentive to minimise the impact of conflict (78) (p.5). There were also improvements in military medicine (triage, evacuation and evidence informed medicine) (78) (p.5)). At this time, humanitarianism was mainly focused on providing care to soldiers (of the same nationality) who were fighting abroad (78).

The creation of the Red Cross has been described as a pivotal factor in influencing humanitarian activities in this period (77,78). The Red Cross was born from the ideas of Swiss philanthropist, Henry Dunant, who helped wounded soldiers at the battle of Solferino (365). In 1862, Dunant developed ideas for a treaty that would require armies to care for all wounded soldiers and for the creation of national societies that would help the military medical services (365). A working group was formed in Geneva in 1863, with Dunant as a member (365). These initial ideas became the basis for international humanitarian law, the Geneva Convention (1864) and the Red Cross Movement (365). The Red Cross movement pioneered approaches for the provision of humanitarian medicine in war zones based on the principles of neutrality,

and impartiality (365). ‘Neutrality’ states that humanitarian actors must not take sides in hostilities and ‘impartiality’ signifies that humanitarian assistance must be provided solely according to need (366). The creation of the Red Cross has been described as *“the tipping point in breaking down borders for ‘humanitarian action’ and directing efforts specifically towards ‘distant strangers’”* (Barnett, 2011 (367) – as cited in Davies (2012) (77) (p.5)).

In the late nineteenth century to the early twentieth century, the National Red Cross Societies began to extend their role and operations beyond caring for those injured in war. During the First World War, the Red Cross/Red Crescent movement assisted prisoners of war (POWs) by assisting communications with family members, campaigning for repatriation of wounded and ill soldiers and helping to unite families (78). They also became a watchdog for observance of the Geneva Convention and laws of war, despite never officially adopting this role (78). Following the First World War, the Red Cross-National Societies were officially sanctioned to undertake peacetime “humanitarian” activities, by the Covenant of the League of Nations. These initiatives involved improving health, preventing disease, intervention in natural disasters and mitigating suffering throughout the world (77). What started as assisting national soldiers who were wounded on the battlefield transitioned to assisting civilians and POWs from other countries to humanitarian activities outside of militarized settings.

The years between World War I and World War II resulted in greater international collaboration and development of institutions to promote health and(77,78). The Treaty of Versailles in 1919, regulated the end of WWI and led to the creation of international humanitarian organizations. The League of Nations, (the predecessor to the United Nations) was established from this treaty with a mission to maintain world peace and prevent war through collective security (78,368). Other international organizations and institutions were also created at this time (e.g., Save the Children). The Red Cross Movement became more coordinated internationally and as a result the League of the Red Cross Societies was developed in 1919 (eventually becoming the International Federation of the Red Cross and Red Crescent (IFRC) (78). Humanitarian activities also became more international and started to be directed outside of Europe (78).

The evolution of humanitarianism continued during the Second World War (WWII) and was seen as something permanent and institutional (78). During WWII, the Red Cross was able to access conflicts and navigate difficult state politics because of their principles of impartiality and neutrality (e.g., access to concentration camps) (78).

After the Second World War there were several major developments in the humanitarian system. The United Nations was officially created in 1945 along with the United Nations Declaration of Human Rights (78). A number of specialized UN agencies were created (e.g., the World Health Organization (WHO) and United Nations International Children's Emergency Fund (UNICEF)). Other agencies were developed to act in certain situations to address crises with short timelines and targeted approaches. During the Cold War, is when governments became more involved in humanitarian activities to try and further their own agendas (Barnett, 2011 (367) – as cited in Davies (2012) (77) (p.9)). The humanitarian system also saw improved coordination and an increase in the number of non-governmental organizations (NGOs). The main beneficiaries of humanitarian assistance began to reside outside of Europe, which sparked a transition towards development efforts, especially in the 'global south'.

The Biafran War in Nigeria in 1967 was another pivotal moment in the evolution of modern humanitarianism (77,78,369). After the second world war, NGOs and the Red Cross commonly operated under the UN system. The position of the UN was that the Biafran war a national issue for the Nigerian government. The Nigerian government blocked an airlift of food and supplies to Biafara and as a result, NGOs including Oxfam, CARE and JointChurchAid began their own airlifts (369). In 1968, the ICRC also began airlifting supplies to the region despite Nigerian government opposition but in June 1969, one of their airplanes was shot down a Nigerian government fighter. This led the ICRC to stop airlift and others to complete airlifts at night. This is important for several reasons: it was the first time that NGOs acted against the approval of a government, and it showed the ability of NGOs to respond where the UN system could not (77,78,369). It is for these reasons the Biafara war is seen as a turning point that has led to modern humanitarian action (78).

Médecins Sans Frontières (MSF) was formed in 1971 by a group Red Cross personnel in response to the Nigerian civil war who felt it was their duty to act in a way that was not influenced by governments (79). MSF was formed with a core principle to speak out and bear witness (*témoignage*) and to condemn human suffering (78,79,370). They initially focused on responding to emergencies and gradually grew to spending longer periods in humanitarian crises to maintain a presence in certain parts of the world (79). They also began to address more chronic health conditions and diseases (e.g., HIV/AIDS) (79).

Since the end of the Cold War, humanitarianism has further transformed. The number of NGOs has grown and the sector has become more professional and coordinated (80). In addition, states have become more involved in humanitarian response. In some cases, they have used the term "humanitarian" to justify and legitimize military intervention. An example provided by Davies (2012) (77) is UK Prime Minister Tony Blair who made the case to act in Kosovo under *"humanitarian reasons"* ((77) p. 19). At the same time, humanitarian action has come to supplement state response. In situations where states cannot garner enough support or come to a consensus to respond in certain areas, humanitarian agencies fill the void (77)(p. 19). As stated by Calhoun (2004) (80)(p.1) *"Emergencies and humanitarian assistance now represent 'normal' components of a global society in which organizations from national governments to multilateral agencies and NGOs act to save lives, minimize suffering, and "do good"". "Emergency relief and intervention is a huge industry" (*(80) *Calhoun p.2).*

Humanitarianism has seen quite a significant evolution since the nineteenth century. What began as providing care to wounded national soldiers on the battlefield has progressed to address virtually all instances of human suffering with longer term commitments and a focus on human rights and development. However, the roots in militarized zones remain, with actors still framing their work in terms of emergency response.

APPENDIX 5: Search terms for systematic review on older people with disabilities in humanitarian crises

# ▲	Searches	Results
1	(person* with disabilit* or people with disabilit* or ((disable* or Disabilit* or Handicap*) adj5 (person* or people))).sh,ti,ab.	
2	(Physical* adj5 (impair* or deficienc* or disable* or disabili* or handicap*)).sh,ti,ab.	
3	((Hearing or Acoustic or Ear$3) adj5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*)).sh,ti,ab.	
4	((Visual* or Vision or Eye$3) adj5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*)).sh,ti,ab.	
5	exp Hearing impairment/ or exp vision disorders/ or exp Deafness/ or exp Blindness/	
6	(Schizophreni* or Psychosis or Psychoses or Psychotic Disorder* or Schizoaffective Disorder* or Schizophreniform Disorder* or Dementia* or Alzheimer*).sh,ti,ab.	
7	exp "schizophrenia and disorders with psychotic features"/ or exp Dementia/ or exp Alzheimer disease/	
8	((Intellectual* or Mental* or Psychological* or Developmental) adj5 (impair* or retard* or deficienc* or disable* or disabili* or handicap* or ill?6)).sh,ti,ab.	
9	(deaf* or blindness).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9	
11	Aged/	
12	((old* or aged or elder* or geriatric* or senior*) adj2 (people or adult* or person* or citizen* or population* or men or males or women or females)).mp. [mp=title, abstract, original title,	

		name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	13	(retired or retirement or frail or geriatric* or senior*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	14	("Abstract = 60 years" or "65 years" or "70 years" or "75 years" or "80 years").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	15	11 or 12 or 13 or 14
☐	16	(humanitarian or human right*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	17	(((((((catastrophe* or disaster* or drought* or earthquake* or evacuation* or famine* or flood or floods or hurricane or cyclone* or landslide* or land) adj1 slide*) or mass) adj1 casualt*) or tsunami* or tidal) adj1 wave*) or volcano*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	18	((((genocide or armed ajd1 conflict* or mass) adj1 execution*) or mass) adj1 violence).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	19	((war or conflict) adj3 (affect* or effect* or expos* or related or victim* or survivor*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	20	(displac* adj1 (internal or forced or mass or person* or people* or population*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword

		heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	21	((forced adj1 migration) or refugee*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	22	(politic* adj1 (persecut* or prison* or imprison* or violen*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	23	(emergency adj1 (service or setting or response or acute)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	24	(((critical adj1 incident) or crisis) adj1 intervention).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	25	acute onset disaster.mp.
☐	26	(humanitarian adj1 (aid or relief or rescue or peace*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	27	((conflict or war) adj3 (persecut* or rape or torture or violen* or victim* or survivor*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	28	(humanitarian adj3 (aid or relief or rescue or peace* or emergenc*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	29	16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28

☐	30	10 and 15 and 29
☐	31	(emergency not department).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
☐	32	29 and 31
☐	33	10 and 15 and 32

APPENDIX 6: Washington Group Short Set Questions (WG-SS)

Participant Code: **Location** **Date:**

<u>The Washington Group Short Set of Questions on Disability</u>

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
   a. No - no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?
   a. No- no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

3. Do you have difficulty walking or climbing steps?
   a. No- no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

4. Do you have difficulty remembering or concentrating?
   a. No – no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing?
   a. No – no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
   a. No – no difficulty
   b. Yes – some difficulty
   c. Yes – a lot of difficulty
   d. Cannot do at all

APPENDIX 7: Interview topic guides for older persons with disabilities

Qualitative topic guides for older persons

These questions should be used to guide discussion but do not have to be used in the sequence listed below. Not all questions will be relevant to all people. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above.
NB: Questions reflecting on their experience compared to others: compare to younger people and/or people without disabilities

1) Background on the household, person and family and daily life of the participant

a) Please tell me about your house
- Rooms, amenities, structure, permanence, toilet facilities
- Who lives with you in this dwelling?
- How long have you lived here?
- How do you feel about living here? (Safety)

b) Can you tell me about a typical day for you?
- What do you spend your time doing?
- Media (Radio/TV)?
- Where? With whom?
- Time spent with others or alone?
- How?

c) Tell me about your family and friends.
- Number or family members
- Where they live?
- Friends/family location (close to home, far away?)
- Do they visit often?
- Do you visit them?

2) Background on the person and her or his impairment or disability

a) Complete Washington Group Short Set Questionnaire.

b) For all aspects with at least some difficulty probe with the following:
- When did you first notice difficulties? (how long has it been?)
- What happened when you first noticed this?

- What (if any) medical / rehab / other services / assistive devices have you sought because of this condition?
    i. Are you still receiving these services if you need them?
    ii. If not, why?

c) How does this condition impact on your daily life (at home/in community)?
- Prompts: Activities, mental health (sad/lonely), accessing services, relationships (friends/family/volunteers), communications.
- Is there anything that is more difficult for you because of your age and/or disability?

d) What would help you look after yourself?

e) Do you feel you are treated differently because of your age, your disability, or political views?

f) Do you ever feel confused or disoriented?
- Is it difficult to manage taking the right pill at the right time?
- Do you ever misplace your keys?

g) Do you feel you have the choice or control over your life as compared to others? Do you see this as positive or negative?

- Who decides what you eat for breakfast?
- If you want something sweet to eat what do you do?
- Probe: do you buy, borrow money, who goes to store?

3) Experience of the humanitarian crisis, requirements, challenges

a) Can you tell us about what happened when you had to leave your home? Prompts: able to leave with others, journey. Was your experience similar or different to others? How? Why? (impact of age/disability)?

b) Mental Health:
- o In the last month have you felt anxious or depressed because of the things you have been through?
- o Difficulties sleeping? (How often?)
- o What do you think are the causes of these feelings?
- o Have you sought help for these feelings?

If not already mentioned – explore specific areas:

c) Shelter and WASH:
- o Please can you describe your dwelling (rooms, amenities, structure, permanence, toilet facilities).

- Do you feel as though you have the level of privacy that you would like?

d) Primary health care: (Ask for Before & After the crises)
   - If you get sick and need health care, what do you do?
   - Prompts: where do you go for treatment?
   - Do you face any challenges seeking health care (transport, physical access, attitudes of staff)?
   - What helps you to access health care (family, finances, proximity, assistive device).
   - How do your experiences compare to other younger members of your household?

e) Community/social support:
   - Do you take part in any community or social activities? If yes, what?
   - What activities would you like to do?
   - Is this different than before the conflict?

f) Income:
   - Can you tell us about any sources of income?
   - Probes: pension, disability allowances, relatives, work.
   - How do you access this?
   - Challenges in receiving?
   - How far this cover your basic requirements (heat, water, food, mobility aids, etc.)?
   - What do you do if this is not enough?
   - Has your level of income changed before/after the conflict?

g) Livelihoods:
   - Who in the house works/engages in income generating activities? Do you?
   - If yes, can you tell us more about this.
   - Are there any difficulties?
   - Does age/disability impact on your ability to work in any way?

h) Unpaid Activities:
   - Do you engage in any unpaid or volunteer activities?
   - Has this changed since the conflict?

i) Food:
   - Can you tell us about the main sources of food for this family?
   - What are the main challenges you face in accessing food –currently and before conflict?

Available response mechanisms

j) Can you tell us about any formal help (government, NGO, pension,etc.) that you are receiving currently or have received in the past? What is your experience of this? Prompts: accessibility, attitudes of staff, impact (positive and negative), challenges compared to others?
k) Are there other aids of services you are aware of that you could benefit from? If yes, what are the reasons you are not receiving this? Is this different for you compared to others?
l) Are you aware of any health or rehabilitation services are available to you?
m) What other services or support do you feel you need?
n) How do you access information about aid/relief/services/activities? Is this information equally available to everyone who needs it?
o) Have you been consulted about your requirements in humanitarian response/aid activities? Would you like to be? What suggestions would you make for people in your situation?

Services and Recommendations

p) What would be of most help to your family? And to you specifically? (prompts: health, rehabilitation, nutrition, shelter, protection, food, livelihoods)

q) What information would be helpful to you in this situation?

r) How should the information be communicated?

- Services available
- Information on disaster

Is there anything else we haven't covered about your experiences of this [humanitarian crises] you would like to tell me about today?

Additional Questions or Discussion Points:

APPENDIX 8: Topic guides for caregiver interview

Qualitative Topic Guide: family members/caregivers

NB: Questions reflecting on their experience compared to others: compare to younger people and/or people without disabilities

Background on the household, person and their impairment;

a) Can you tell me about your family? Prompts: Who lives in the house, who goes out to work, who is the head of the household.

b) Can you tell me what you know about [Name's] disability/impairment/difficulty? What do you think caused this condition? Are they accessing any medical or rehabilitation services? How has it helped? If not, why ?

c) How do you think this condition or their age impacts on their daily life? What things do they find more difficult or unable to do that other people in the household do?

d) How does this impact on the lives of other people in the family? Prompts: additional caring required, impact on livelihoods, resources, financial, shelter, communication, relationships, well-being, inclusion in the community (social inclusion).

e) Who within the family provides support?

Experience of the humanitarian crisis, requirements, challenges

f) Can you tell us about what happened when you had to leave your home? Did all members of the family leave together? What happens to older people with disabilities when they have to leave?

g) What are the major challenges you think [Name] faces in their everyday life? How do these compare to other younger people and people without a disability? What are the things that help them to cope?

h) What do you think are the specific requirements [Name] has that are different to other people in the household/family?

i) What are the barriers and challenges that [Name] faces in accessing needed services or external support? How do these differ from other people in the household?

j) Can you tell us about any aid programmes your family are currently receiving or have received in the past (give context specific examples)? Are all people in the household able to access these equally? Is [Name] able to access them in the same way? If not, why not?

k) Are there other aid programmes you are aware of that [Name] could benefit from but is not receiving (give context specific examples)? If yes, what are the reasons you they are not receiving this? Is this different compared to others in the household?

If not already mentioned – explore specific areas:

l) Primary health care: If people in your household get sick and need health care, what do you do? Is this the same or different for [Name]?. Why?

m) Livelihoods: Who in the house works/engages in income generating activities? Do you? If yes, can you tell us more about this? What do you like? What are the difficulties? Does [Name] age/disability impact on the labour activities for the family in any way?

n) Income: What are the sources of income for your family? And for [Name] specifically? To what extent do these cover the basic requirements for [Name]?

o) What would be of most help to your family? What about to [Name] specifically? Prompts: health, rehabilitation, nutrition, shelter, protection, food, livelihoods

p) Is there anything else you would like to tell me about today?

APPENDIX 9: Ethics approval LSHTM

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT
United Kingdom
Switchboard: +44 (0)20 7636 8636
www.lshtm.ac.uk

Observational / Interventions Research Ethics Committee

Mr Phillip Sheppard
LSHTM

1 June 2017

Dear Phillip,

Study Title: Examination of how HelpAge Ukraine is influencing disability policy nationally.

LSHTM Ethics Ref: 13636

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	Sheppard, P. - CV, Feb 2017	01/02/2017	1
Protocol / Proposal	Study Protocol - v1 - March 23, 2017	23/03/2017	1
Protocol / Proposal	Topic Guide - HelpAge Int - Policy Development - March 14, 2017	23/03/2017	1
Protocol / Proposal	Topic Guide - HelpAge Country Level	23/03/2017	1
Protocol / Proposal	Topic Guide - Partner Organisations	23/03/2017	1
Information Sheet	Interviews Record and Consent Sheet - v1 - March 23, 2017	23/03/2017	1
Information Sheet	stakeholder information sheet - Ukraine	23/03/2017	1
Covering Letter	OPA Ethics Re-submission - Sheppard, P.	19/05/2017	1
Protocol / Proposal	stakeholder information sheet - Ukraine	19/05/2017	2
Protocol / Proposal	Interviews Record and Consent Sheet - v1 - March 23, 2017	19/05/2017	2

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

Professor John DH Porter
Chair

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

Improving health worldwide

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Observational / Interventions Research Ethics Committee

Dr Sarah Polack
Associate Professor
Department of Clinical Research (CRD)
Infectious and Tropical Diseases (ITD)
LSHTM

1 February 2017

Dear Sarah

Study Title: Older age and disability in humanitarian crises

LSHTM Ethics Ref: 12017

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Protocol / Proposal	Protocol	29/11/2016	1
Protocol / Proposal	Topic guides families	29/11/2016	1
Protocol / Proposal	Topic guides Global Stakeholders	29/11/2016	1
Protocol / Proposal	Topic Guides key Stakeholders	29/11/2016	1
Protocol / Proposal	Topic guides older disabled people	29/11/2016	1
Investigator CV	CV Sarah Polack	29/11/2016	1
Investigator CV	CV Hannah Kuper 2016_1	29/11/2016	1
Information Sheet	Persons with Disabilities information sheet	29/11/2016	1
Information Sheet	Local stakeholder information sheet	29/11/2016	1
Information Sheet	Global stakeholder information sheet	29/11/2016	1
Information Sheet	Familes information sheet	29/11/2016	1
Information Sheet	Interviews Record and Consent Sheet (Global and local stakeholders)	29/11/2016	1
Information Sheet	Interviews Record and Consent Sheet (Persons with disabilities and family)	29/11/2016	1
Covering Letter	Response to reviewers	11/01/2017	2
Protocol / Proposal	Protocol v2	11/01/2017	2
Information Sheet	Familes information sheet v2	11/01/2017	2
Information Sheet	Local stakeholder information sheet v2	11/01/2017	2
Information Sheet	Persons with Disabilities information sheet v2	11/01/2017	2

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

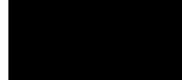
The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,



Professor John DH Porter
Chair

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

Improving health worldwide

APPENDIX 10: Ethics approval Tanzania

THE UNITED REPUBLIC OF TANZANIA

National Institute for Medical Research
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Fax: 255 22 2121360
E-mail: headquarters@nimr.or.tz

Ministry of Health, Community Development, Gender, Elderly & Children
6 Samora Machel Avenue
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11478 Dar es Salaam
Tel: 255 22 2120262-7
Fax: 255 22 2110986

NIMR/HQ/R.8a/Vol. IX/2588

02nd September 2017

Mr. Smart Daniel
Help Age International
C/o Josephine Lyegi
Prime Minister's Office
Ministry of Labour, Youth, Employment and Persons with Disabilities
P. O. Box 9846
Dar es salaam

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: Assessing the experience of older people with disabilities in humanitarian crises (Daniel S. *et al*) whose local investigator is Josephine Lyegi of the Ministry of Labour, Youth, Employment and Persons with Disabilities has been granted ethical clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Site: Nduta and Mtendeli

Approval is valid for one year: 02nd October 2017 to 03rd October 2018.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Muhammad Bakari Kambi

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY &CHILDREN

CC: RMO of Kigoma
DMO/ DED of selected districts

THE UNITED REPUBLIC OF TANZANIA
MINISTRY OF HOME AFFAIRS

Tel: +255-22-2112035/40
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Website: www.moha.go.tz

9 Ohio Street,
P. O. Box 9223,
11483 **DAR ES SALAAM**

In reply please quote:

Ref. No.KA 419/511/02C/24

29th September, 2017

Zonal Co-ordinator,
Refugee Services Department,
KIGOMA

RE: PERMISSION TO ENTER NDUTA AND MTENDELI REFUGEE CAMPS

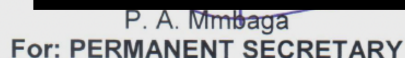
In accordance with Section 20 (1) of the Refugee Act No. 9 of 1998, permission is hereby granted for an official from International Centre for Evidence in Disability at the London School of Hygiene and Tropical Medicine to enter the above mentioned designated areas from **02nd – 31st October, 2017**. He will be under direct responsibility of HelpAge International Tanzania.

Full names and details of the person/ s are;

Full name	Title	Nationality
Mr Phillip Sampson Sheppard	Physiotherapist and Global Health Professional	Canadian

The purpose of his visit is to provide technical support to HelpAge International in conducting a a study to generate on the experiences, needs and inclusion of older persons with disabilities at the camps for possible future interventions.

Please accord him with all necessary co-operations.



P. A. Mmbaga
For: PERMANENT SECRETARY

134 Migombani Street,
Regent Estate Mikocheni
P.O. Box 9846
Dar es Salaam, Tanzania

Tel: (+255) 22 2700169, 22 2774796
Mob: (+255) 785 436 673
Fax: (+255) 22 2775894
E-mail: tanzania.office@helpage.org
Website: www.helpage.org

27th September 2017

Phil Sheppard

Physiotherapist Global Health Professional

London WC1E 7HT,

UK

Dear Phil,

Re: Invitation to visit HelpAge International Tanzania country office

HelpAge International is part of a global network that helps older people claim their rights, challenge discrimination and overcome poverty. We are working in over 65 countries across the globe in the areas of health, social protection, rights and emergency response.

With funds from UNHCR, BPRM and ECHO we are providing assorted protection services and access to life saving solutions to persons with specific needs (PSNs) – older people and people with disabilities – in Nduta and Mtendeli refugee camps in Kibondo district.

One of the activities that we plan to do in the next quarter is to conduct a study to generate evidence on the experiences, needs and inclusion of older persons with disabilities in the two camps in order to draw recommendations that will inform future interventions of other humanitarian programmes on better ways to integrate the specific needs of this group.

It is therefore in this regard that HelpAge International is pleased to invite you to visit the country office to provide technical support and share your expertise and professionalism in health and disability with our local team carrying out this exercise.

The study will take place between 08th and 31st October 2017 and will include meetings with older refugees with disabilities as well as stakeholders working in the two refugee camps.

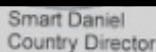
This letter is therefore written to support your request for an entry permit to the United Republic of Tanzania.

HelpAge has organized for your accommodation at the Amariah Hotel, Mikocheni in Dar es Salaam on your arrival and Kibondo district during field work.

Should you require any additional information, please do not hesitate to contact us.

Looking forward to welcoming you to Tanzania

Yours sincerely,



Smart Daniel
Country Director

HelpAge International is a global network supporting older people claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives

Certificate of Registration SO. No 7902
Certificate of Compliance No. 1771

Eastern, West and Central Africa Regional Development Centre
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Off Shanzu Road, Nairobi, Kenya
Tel: +254 20 2637854
Mob: +254 721 361608/733 33246

HelpAge International Secretariat
P. O. box 70156
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Fax: +44(0)20 7713 7993
Email: info@helpage.org
Website: www.helpage.org

APPENDIX 11: Ethics approval Ukraine

Соціологічна асоціація України

61022, м. Харків, пл. Свободи, 6
Харківський національний університет імені В.Н. Каразіна
Соціологічний факультет, ауд. 350а, 351а, тел.: +38 057 7075490, 7075651
E-mail: rektor@univer.kharkov.ua, sokur@univer.kharkov.ua, sau@univer.kharkov.ua

№ 03-24/03 від «23» березня 2017 року

ВИСНОВОК

стосовно методології та інструментарію дослідження «Похилий вік та інвалідність в гуманітарних кризах» («Older age and disability in humanitarian crises»).

Комісія з професійної етики соціолога САУ розглянула поданий протокол та інструментарій дослідження **Похилий вік та інвалідність в гуманітарних кризах (Older age and disability in humanitarian crises)**, яке реалізовується *Лондонською школою тропічної медицини* / London School of Hygiene & Tropical Medicine (LSHTM) та *HelpAge International в Україні.*

Дослідження спрямоване на вивчення ситуації щодо пережитого досвіду та потреб осіб похилого віку з інвалідністю в умовах гуманітарної кризи, на розуміння того, в якій мірі вони включені в діяльність з надання гуманітарного реагування та які специфічні фактори дозволяють або обмежують їх доступ до послуг та допомоги в даному контексті.

Протокол дослідження відповідає вимогам до програми наукового дослідження соціальних проблем, містить необхідний опис вибіркової сукупності та методології дослідження. Рекомендовано додати інформацію про етичні засади проведення дослідження, обов'язковість інформування респондентів щодо правил проведення дослідження, їх добровільної участі, права відмовитися від відповіді на будь-яке запитання або перервати участь у дослідженні. Протоколом передбачено отримання поінформованої згоди респондентів, забезпечення конфіденційності, залучення місцевих громад, дотримання умов безпеки для респондентів та осіб, які будуть проводити інтерв'ю.

Наданий інструментарій для якісних інтерв'ю з цільовим и групами дослідження, інформаційні матеріали для потенційних учасників, форми поінформованої згоди відповідають завдання дослідницького проекту, надають достатньо інформації респондентам. Зміст і стиль методології та інструментарію дослідження є коректними та гарантує дотримання прав, людської гідності та морально-етичних норм у відповідності до положень Гельсінської декларації прав людини, Конвенції Ради Європи про права людини та відповідних законів України.

Голова Комісії
з професійної етики соціолога
Соціологічної асоціації України **д-р філос. н. Головаха Є. І.**

APPENDIX 12: Quality review for articles identified in systematic review on older persons with disabilities in humanitarian crises.

First Author (year): Godfrey (1989) (162)
Type of study: Prevalence

JBI Prevalence Checklist	**Godfrey et al. (1989)**	Yes, No, Unclear, N/A
1. Was the sample frame appropriate to address the target population	Target population = Older adults displaced by war in Ethiopia living in receptions centres in Sudan between 1984-85 Sample frame = older adults living in 2 of the relief centres in Sudan (December 1985)	YES
2. Were study participants recruited in an appropriate way?	Subjects recruited slightly differently in the 2 relief centres (same for individuals & families) -Safawa I: Consisted of 17 villages. Two clusters of 12 shelters were randomly selected from each area. -Safawa II: Shelters were in well-defined rows which allowed for stratified sampling. A number between 1 and 6 was randomly selected and this number designated the first shelter to be surveyed, and then every 6th shelter was surveyed	YES
3. Was the sample size adequate?	Total population of camps at time of interviews were: - Safawa I: 11,672 - Safawa II: 11,856 In the two centres, 502 heads of family were surveyed. **n = 383** adult who reported themselves to be 45 years of age or older participated in the study. Calculated required sample size = **327.6** Sample size equation based on JBI Manual for Evidence Synthesis (121) and Naing et al. (2006) (371). $n = \frac{Z^2 P(1-P)}{d^2}$	UNCLEAR

	Where: n = sample size Z = Z statistic for level of confidence P = expected prevalence of proportion d = precision For this calculation: n = sample size Z = 1.96 (based on 95% confidence) as suggested by Naing (2006) (371) P = 0.21 (based on United Nations estimates for Ethiopia and Sudan as cited in (160) (p.709)). d = 0.05 (based on recommendation by Niang for articles with a prevalence between 10% and 90% (2006) (371) (p.10)).	
4. Were the subjects and setting described in detail?	**Subjects:** description included general background of reasons for displacement. Participants described by age, sex, disability and health status throughout. **Setting**: description included background of displacement, refugee camps, communities, and "villages" (specific centres named)	YES
5. Was data analysis conducted with sufficient coverage of the identified sample?	Response rate seems to be appropriate however, there was no mention of response biases (e.g., who agreed to be interviewed, number of older vs. younger who agreed, how many individuals or households refused). The authors did comment on biases related to questionnaire.	UNCLEAR
6. Were valid methods used for the identification of the condition?	Identification of disability based on questionnaire developed by researchers according to self-reported degree of difficulty with 10 functional activities. It is unclear if this questionnaire was validated prior to the study. Therefore, the answer to this question is: "NO". However, it is important to note that this study was conducted in 1989, prior to the development of standardized disability measurements such as the WGQ, which was developed after 2001 (128).	NO
7. Was the condition measured in a standard, reliable way for all participants?	The same questionnaires were used for (a) individuals and (b) households. There is no mention of the training of enumerators and the consistency between teams of interviewers.	UNCLEAR

8. Was there appropriate statistical analysis?	Statistical analysis not described. Authors mainly provide prevalence data however they do compare results across camps and against UN prevalence data and do not describe methods.	UNCLEAR
9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	No mention of response rate, no mention of dropout rates, no mention of not founds, no mention of barriers to participation or other biases	NO
OVERALL RATING: FOR RISK OF BIAS		**HIGH**

First Author (year): Strong (2015) (160)
Type of study: Prevalence

JBI Prevalence Checklist	**Strong et al. (2015)**	**Rating** (Yes, No, Unclear, N/A)
1. Was the sample frame appropriate to address the target population	Sample included older persons (60+ years) who were Syrian and Palestinian refugees in Lebanon. Selected participants were receiving assistance from Caritas Lebanon Migrant Centre (CLMC) or Palestinian Women's Humanitarian Organization (PALWHO) Limitations: - only refugees receiving assistance from CLMC/PALWHO were included (not all refugees). However, this is quite standard for studies on refugee populations. - PALWHO list - biased towards women (17% male vs 51% male from CLMC) Target population = Older refugees arriving in Lebanon between March 2011 – March 2013	YES
2. Were study participants recruited in an appropriate way?	Participants recruited as a systematic sample from CLMC and PALWHO databased (included 1,100 older Syrian refugees and 700 Palestinian refugees) Recruitment: systematic sampling and replacement sampling	YES
3. Was the sample size adequate?	*"These sample sizes allowed for the measurement of population characteristics within a margin of error of ±7.6%among older Syrian refugees and ±15% among older Palestinian refugees. The calculation of margin of error assumes the most conservative prevalence rate of 50%, a survey response rate of 95%, a study design effect of 1.0, and a 95% confidence interval."* Sample: - Syrians: n = 167 - Palestinians: n = 43 - Total: **n=210** Calculated required sample size (see below): **n = 249.6** Sample size equation based on JBI Manual for Evidence Synthesis (121) and Naing et al. (2006) (371).	YES

	$$n = \frac{Z^2 P(1-P)}{d^2}$$ Where: n = sample size Z = Z statistic for level of confidence P = expected prevalence of proportion d = precision For this calculation: n = sample size Z = 1.96 (based on 95% confidence) as suggested by Naing (2006) (371) P = .058 (based on prevalence data provided in by Strong et al. (2015) (160) (p.2)). *d* = 0.05 (based on recommendation by Niang (2006) (371)). Niang (2006) recommends that if the prevalence is below 10% or higher than 90%, *d* should be half of P. "*we recommend d as half of P if P is below 0.1 (10%) and if P is above 0.9 (90%), d can be (0.5(1-P))*"	
4. Were the subjects and setting described in detail?	Yes – subjects and setting described in detail. However, Syrian age categories were provided clearly whereas Palestinian age demographics were provided as a percentage of Syrian data. A more clear and standardized reporting of participant characteristics would improve the study.	YES
5. Was data analysis conducted with sufficient coverage of the identified sample?	Yes, the authors predicted a survey response rate of 95% and they had a response rate of 95.4% (Syrians) and 95.5% (Palestinians).	YES
6. Were valid methods used for the identification of the condition?	Functional status: Katz Index of Independence in Activity Medical diagnoses: self-reported All other data: qualitative	YES
7. Was the condition measured in a standard, reliable way for all participants?	Interviews conducted in Arabic by social CLMC and PALWHO social workers who received 5 days training.	YES

8. Was there appropriate statistical analysis?	Percentages & confidence intervals & p-values? - Yes	YES
9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Response rate = 95.4% (Syrians) and 95.5% (Palestinians)	YES
OVERALL RATING: FOR RISK OF BIAS		**LOW**

First Author (year): Good (2016) (161)
Type of study: Qualitative

Qualitative	**Good et al. (2016)**	Rating (Y, N, Unclear, N/A)
1. Congruity between the stated philosophical perspective and the research methodology?	**Philosophical perspective:** not stated. **Research methodology:** not clearly stated. Semi-structured interviews and thematic analysis	NO
2. Congruity between the research methodology and the research question or objectives?	**Research methodology:** Semi-structured interviews. Thematic analysis used to analyse data. Not clearly stated. **Research question/objective:** Question not stated clearly. Below is from abstract: *"This research explores the experience of 12 visually impaired Christchurch residents who lived through more than 12,000 aftershocks throughout 2010 and 2011."* [REF = GOOD] (p.1)	YES
3. Congruity between the research methodology and the methods used to collect data?	**Research methodology:** Semi-structured interviews. Thematic analysis used to analyse data. Not clearly stated. **Methods to collect data:** face to face semi-structured interviews in home. No details on interview questions or structure.	UNCLEAR
4. Congruity between the research methodology and the representation and analysis of data	**Research methodology:** Semi-structured interviews. Thematic analysis used to analyse data. Not clearly stated. **Analysis of data:** thematic analysis, open coding, analysis in relation to literature. No specifics on thematic analysis including who completed it, how it was done.	UNCLEAR
5. There is congruence between the research methodology and the interpretation of results	**Research methodology:** Semi-structured interviews. Thematic analysis used to analyse data. Not clearly stated (research approach not stated). **Interpretation of results:** recommendations for VI adults to improve lived experience with earthquake	UNCLEAR
6. Locating the researcher culturally or theoretically	No statement regarding the potential influence of researcher	NO
7. Influence of the researcher on the research, and vice-versa, is addressed	Statement regarding "volunteer bias" (subjects volunteered, they were not randomly selected). No statement regarding researchers.	NO
8. Representation of participants and their voices	Quotes included throughout.	YES
9. Ethical approval by an appropriate body	Approved by Massey University Human Ethics Committee (MUHEC)	YES
10. Relationship of conclusions to analysis, or interpretation of data	Very low sample size, participants volunteered, 5 subjects were not re-interviewed (out of 12), so interpretation is congruent with results, but perhaps not entirely transferrable/robust?	YES
OVERALL RATING FOR RISK OF BIAS		**MEDIUM**

First Author (year): Akanuma (2016) (156)
Type of study: Cross Sectional Analytical

Cross Sectional - Analytical	**Akanuma et al (2016)**	Rating (Y, N, Unclear, N/A)
1. Were the criteria for inclusion in the sample clearly defined?	Inclusion: Residents ≥75 years of age from Miyagi Prefecture in Northern Japan. Randomly selected from 6 communities. Exclusion: Not specified. However, not very applicable.	YES
2. Were the study subjects and the setting described in detail?	**Subjects:** 180 randomly selected individuals from 6 randomly selected communities within Miyagi Prefecture where previous study had taken place (Tome Project) 36.2% = "healthy" (control); 47.9% = MCI; 16% = dementia based on CDR. **Setting:** Yes	YES
3. Was the exposure measured in a valid and reliable way?	**Exposure:** Earthquake	YES
4. Were objective, standard criteria used for measurement of the condition?	Yes – measurement of dementia was ascertained by from the Clinical Dementia Rating (CDR) based on diagnostic and Statistical Manual of Mental Disorders, 4th edition, criteria. Conducted by trained physicians (neurologists and psychiatrists).	YES
5. Were confounding factors identified?	No	NO
6. Were strategies to deal with confounding factors stated?	UNCLEAR	UNCLEAR
7. Were the outcomes measured in a valid and reliable way?	Description for each measure quite detailed. The following were used in the study (1) Understanding NKS news: Showed video followed by structured interviews. Validated or pilot tested? = Unsure. But, they do have a control group to compare results. (2) Visual risk cognition task: used "picture description" is a test developed based off of the "picture description" which according to the study is one of the most sensitive tests for detecting language disorders in patients with Alzheimer's disease. (3) inappropriate behaviour during disaster: interviewed subject's families using standardized questionnaire.	YES
8. Was appropriate statistical analysis used?		YES
OVERALL RATING FOR RISK OF BIAS		**LOW**

First Author (year): Kino (2020) (157)
Type of study: Cohort

JBI – Cohort	**Kino et al. (2020)**	Yes, No, Unclear, N/A
Were the two groups similar and recruited from the same population?	Yes – the baseline data were obtained from a sample of 4957 people in 2010 and two different times post disaster (2013-2014 and 2016) within the same group. Same questionnaire for all surveys.	YES
Were the exposures measured similarly to assign people to both exposed and unexposed groups?	Exposure = earthquake and tsunami No control group	N/A
Was the exposure measured in a valid and reliable way?	Exposure = earthquake. Authors did not state the extent to which participants were effected .	YES
Were confounding factors identified?	The authors looked at the same group Pre and post therefore this is not applicable. Authors do discuss that they did not have immediate post-disaster data and potential attrition of people who were depressed pre-disaster.	N/A
Were strategies to deal with confounding factors stated?	N/A	N/A
Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	The study looked at depression pre and at 2 time points post disaster. Some scored as having depression prior to the event. I am marking this as N/A because the study aimed to examine changes in depression scores pre and post-disaster.	N/A
Were the outcomes measured in a valid and reliable way?	PTSS measured using Screening Questionnaire for Disaster Mental Health Depressive Symptoms were measured by the Geriatric Depression Scale Short Form	YES
Was the follow up time reported and sufficient to be long enough for outcomes to occur?	Study occurred from 2010-2016, with 5.5 year lapsing form exposure to last wave of study (2016) Pre: (2010), Event (2011), Post 1 (2013-14), Post 2 (2016). Yes – but authors note that with the outcomes, they may have been higher immediately post-disaster.	YES
Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	4957 respondents in first survey (PRE disaster) 3594 respondents in second survey (post) – **17.9% dropout rate** 2810 respondents in third survey (post) – **15.4% dropout rate** JBI Tool (121) provides the following: <5% = insignificant >20% = impact on validity Some respondents excluded for invalid consent, invalid ID)	YES

Were strategies to address incomplete follow up utilized?	Yes (e.g., death from earthquake, death from other, moved, unknown address)	YES
Was appropriate statistical analysis used?	Yes – paired t-tests, Markov chain Monte Carlo methods	YES
OVERALL RATING FOR RISK OF BIAS		**LOW**

First Author (year): Shih (2020) (158)
Type of study: Cohort

JBI – Cohort	**Shih et al (2020)**	Rating (Y, N, Unclear, N/A)
Were the two groups similar and recruited from the same population?	Yes – groups were taken from the same national health insurance database from the National Health Research Institute.	YES
Were the exposures measured similarly to assign people to both exposed and unexposed groups?	How was exposure measured? “Affected area” defined by the National Health Insurance Bureau? Both groups (elderly + non-elderly) exposed	YES
Was the exposure measured in a valid and reliable way?	Exposure: typhoon	N/A
Were confounding factors identified?	Confounding factors identified? - Yes Comorbidities were recorded using ICD classification and the Charlson Comorbidity Index was used. Socioeconomic status was listed, residence location listed, Suicide attempt hisory listed Several inclusion criteria were used to define “pre-existing chronic mental illness”. Other confounding factors (smoking, alcohol consumption, substance use, loss of family members, current work status were not collected)	YES
Were strategies to deal with confounding factors stated?	Yes – authors stratified by confounding variables identified. No multivariate regression	YES
Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	Some were, some were not. This was documented	YES
Were the outcomes measured in a valid and reliable way?	YES – detailed description of tools used to identify prevalence and incidence before and after disaster	YES
Was the follow up time reported and sufficient to be long enough for outcomes to occur?	Initial data = 2008 Crisis event = 2009 Follow up study = 2011	YES
Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	No	No
Were strategies to address incomplete follow up utilized?	No	No
Was appropriate statistical analysis used?	Yes	YES
OVERALL RATING: FOR RISK OF BIAS		**LOW**

First Author (year): Miyamori et al. (2022) (159)

Type of study: Cohort

JBI – Cohort	**Miyamori et al (2022)**	Rating (Y, N, Unclear, N/A)
Were the two groups similar and recruited from the same population?	Yes, patients were recruited from the same database and were classified as affected or not affected based on government data (Long Term Care Insurance Comprehensive Database)	YES
Were the exposures measured similarly to assign people to both exposed and unexposed groups?	Exposure: Flood	YES
Was the exposure measured in a valid and reliable way?	Exposure to flood certified by government.	N/A
Were confounding factors identified?	Yes. They collected information on individual, facility, and regional factors Age divided into 8 categories (less than 65, every 5 years to 95 years old, above 95). Level of care determined by local government based on opinions issued by family physician and care experts and objective data. Confounding factors clearly indicated.	YES
Were strategies to deal with confounding factors stated?	Yes	YES
Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	Yes	YES
Were the outcomes measured in a valid and reliable way?	Yes	YES
Was the follow up time reported and sufficient to be long enough for outcomes to occur?	May 1, 2018 – December 31, 2018 (flood = July 2018) - 2 months pre, 5 months post This shows drop out rates 5 months after but unsure whether or not this is sustained. I would say this does provide enough information for this time period but does not provide information about long term drop out rates (not the focus of the study – a limitation)	YES
Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	Study looked at discontinuation of services. Therefore, study used dropout rates as outcome	N/A
Were strategies to address incomplete follow up utilized?	N/A	N/A
Was appropriate statistical analysis used?	YES	YES
OVERALL RATING: FOR RISK OF BIAS	**Low**	**LOW**

First Author (year): Summers et al. (2022) (163)
Type of study: Cohort

JBI - Cross-sectional	**A Summers et al (2023)**	Rating (Y, N, Unclear, N/A)
Were the criteria for inclusion in the sample clearly defined?	Inclusion criteria: Current resident in a randomly selected cluster and consented to participate AND over the age of 60. Based on GCA vs. NGCA	YES
Were the study subjects and the setting described in detail?	Demographics, location and time frame all described	YES
Was the exposure measured in a valid and reliable way?	Exposure: Exposure to conflict.	N/A
Were objective, standard criteria used for measurement of the condition?	Dependency: Katz Index of Independence (163) Psychological Distress: KesslerK6 Psychological Distress Scale, which according to Summers et al. (2022) "*was previously validated in Ukraine and includes six questions about depressive and anxiety symptoms*" (163) (p.3).	YES
Were confounding factors identified?	Some were listed in the demographics table (gender, education level, housing situation, living situation and household income). Limitations were identified (self-reported data, inaccessible areas due to insecurity, no control, no pre-conflict data, no inclusion of institutionalized persons,	YES
Were strategies to deal with confounding factors stated?	Authors looked at economic hardship, education, housing situation, living situation and disaggregated data based on those factors.	YES
Were the outcomes measured in a valid and reliable way?	Yes	Yes
Was appropriate statistical analysis used?	Yes	Yes
OVERALL RATING: FOR RISK OF BIAS		**LOW**

Appendix 13: Principles and Standards related to older age and disability that CCCM must adhere to.

Underlying Principles	Description
Humanitarian Principles	The principles of humanity, neutrality, impartiality and independence must guide all interventions.
Do no harm	Interventions should be monitored and evaluated to ensure that they do not cause harm to displaced populations or host communities.
Key Standards	
Sector Specific Standards	For shelter, education, WASH, distribution, etc.), as set out in UNHCR's Emergency Handbook (372)
UNHCR Emergency Handbook	**Persons with Disabilities** (221) - Identify persons with disabilities proactively, including those with psychosocial and intellectual disabilities - Consult persons with disabilities and their families to identify their needs and capacities and understand what barriers impede the effectiveness of protection and assistance programmes - Ensure language respects the dignity and humanity of persons with disabilities. - Consult persons with disabilities when you decide the content of food and NFI assistance packages, to ensure distribution arrangements are accessible - Older individuals who have a disability are doubly exposed to protection risks. **Older Persons** (220) - Actively identify older persons - Consult older persons to identify their needs and capacities as well as short comings in protection and assistance programs - Ensure that older persons do not suffer discrimination and are able to fully participate in decisions that affect them and their communities - Ensure protection and assistance programmes are inclusive of older persons and that services are accessible to them. - Recognize and build on the capacities, skills and resources of older persons **Persons at heightened risk (or 'Persons with specific needs')** - Includes persons with serious health conditions, older persons, and persons with disabilities (among others) -

UNHCR' Emergency Handbook Age, Gender, and Diversity (AGD) (126) **&** **UNHCR's Policy on Age, Gender and Diversity (AGD)** (222) **(both documents cover the same information)**	"The purpose of this Policy is to reinforce UNHCR's longstanding commitment to ensuring that people are at the centre of all that we do. This requires that we apply an age, gender, and diversity (AGD) approach to all aspects of our work. Through this Policy, we aim to ensure that persons of concern can enjoy their rights on an equal footing and participate meaningfully in the decisions that affect their lives, families, and communities." (p.4) "**Age** denotes the different stages in a person's life cycle. It is important to know where people are in their life cycle, because their capacities and needs change over time. Age influences and can enhance or diminish people's capacity to exercise their rights, and must be considered in all protection, assistance and solutions programmes." **1. Age inclusive programming** "For purposes of analysis and programming, all data collected by UNHCR will be disaggregated, by age and sex at minimum, and by other elements of diversity where contextually appropriate and possible." **2. Participation and Inclusion** "At a minimum, country operations will employ participatory methodologies at each stage of an operation's management cycle, and will incorporate the capacities and priorities of women, men, girls, and boys of diverse backgrounds into protection, assistance, and solutions programmes." **3. Communication and Transparency** "At a minimum, all country-level protection and solutions strategies will detail the operation's approach to communicating with women, men, girls, and boys of diverse backgrounds, using means that are appropriate and accessible to all groups in a community." **4. Feedback and Response** At a minimum, all UNHCR operations will establish and operate feedback and response systems, including for confidential complaints. **5. Organizational learning and Adaptation** At a minimum, UNHCR operations will adapt programmes and strategies in response to input from persons of concern, and document this in country operation plans and annual reporting. "**Include persons of concern meaningfully in operational planning"**
UNHCR, Policy on Older Refugees (373)	Older refugees make up a large portion of UNHCR caseload (8.5% of overall population of concern) 3 Major challenges faced by refugees, in particular older refugees 1. Social disintegration

	2. Negative social selection 3. Chronic dependency Needs of older refugees must be mainstreamed Strengthen capacity of families and communities to meet their own needs and incorporate older people within them UNHCR's Goal: "Older male and female refugees, and other older persons of concern to the Office, live their latter years in dignity and security, contributing actively to their families and communities for as long as it remains possible for them to do so, and are offered care and support if they become physically or mentally frail." (373) (p.3).
UNHCR Integration Handbook on Older Refugees (374)	Recognizes that older people face particular risks during displacement and additional barriers to access protection and assistance, including resettlement and integration. Outlines most common obstacles faced by older people and strategies to overcome (income, language, housing, employment, health and mental health).
Sphere Standards	Set out in The Sphere Project, Humanitarian Charter and Minimum Standards in Humanitarian Response. Outlines the rights of all people affected by disaster and conflict including: the right to life with dignity, the right to receive humanitarian assistance, and the right to protection and security (223).
Minimum Standards for Camp Management	The **Minimum Standards for Camp Management,** 2021 Edition.
Inter Agency Standing Committee (IASC) Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action	System wide guidelines set out to improve identification and response for persons with disabilities in humanitarian crises (19).
UNCRPD	Article 11 – refers to the safety and protection of persons with disabilities in conflict and emergency situations
United Nations Principles on Older Persons (375)	Encourages governments to incorporate the following principles **Independence** 1. Older persons should have access to adequate food, water, shelter, clothing and health care through the provision of income, family and community support and self-help. 2. Older persons should have the opportunity to work or to have access to other income- generating opportunities. 5. Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities **Participation** 7. Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.

	Care 11. Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness. 13. Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment 14. Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives **Self-Fulfilment** 16. Older persons should have access to the educational, cultural, spiritual and recreational resources of society. **Dignity** 17. Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse. 18. Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.