Involving older people in the preparedness, response, and recovery phases in humanitarian emergencies: a theoretical framework on ageism, epistemic injustice, and participation

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Humanitarian emergencies disproportionally affect older people. Although defining an older person by an age range can help alert us to emerging or changing needs and potential vulnerabilities during humanitarian emergencies, ageing is not necessarily synonymous with increasing vulnerability, and individual variations exist due to the heterogeneity of older people. In general, reduced access to safety, health services, clean water, and appropriate food puts older people at increased risk of poor health outcomes during humanitarian emergencies, including disability, injury, malnutrition, and mental health issues. The theoretical framework presented in this Personal View explains how ageism, further compounded by intersecting oppression, leads to the exclusion of older people from the preparedness, response, and recovery phases of humanitarian emergencies. The exclusion of older people is discriminatory, violates core humanitarian and bioethical principles, and leads to an epistemic injustice. We suggest that humanitarian actors implement participatory approaches with older people in humanitarian contexts. Through these approaches, solutions will be identified by and together with older people, leading to community-driven and context-appropriate ways to include the needs and strengths of older people in the preparedness, response, and recovery phases of humanitarian emergencies.

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Introduction

Leaving no one behind is a foundational value of the UN's Sustainable Development Goals and a core principle for many humanitarian organisations.[1] Yet, older people are systematically left behind in humanitarian emergencies.[2] The relevance of Médecins Sans Frontières' 2015 warning remains clear: "leave no one behind: without action, it's just a slogan".[3]

Humanitarian emergencies affect the lives and wellbeing of people, and include acute and protracted emergencies caused by conflict, natural disasters, food insecurity or famine, and outbreaks.[4] These emergencies disproportionately affect older people, who could have pre-existing health issues, limited physical functioning, and reduced access to services.[5–8] Their typically higher dependency on social and financial support networks, compared with other demographics, could further increase the risk of adverse health outcomes.[6,9] During humanitarian emergencies, pre-existing conditions can be further exacerbated.[10] Older people, whether they relocate or stay behind, often have reduced access to safety, health services, clean water, and appropriate food in humanitarian emergencies, putting them at increased risk of poor health outcomes including disability, injury, malnutrition, and mental health issues.[11] In addition, older people might have visual and auditory constraints and cognitive deficits, which can create communication challenges.[12]

Defining an older person by age range has several limitations and does not consider context-specific, sociocultural definitions and perceptions of age.[13] In some cultures, being considered of older age is much more associated with agency, authority, and social status than numerical age,[14] and simple associations between age and vulnerability can be both discriminatory and culturally blind. Although the concept of defining an older person with an age range can help alert us to emerging or changing needs and potential vulnerabilities during humanitarian emergencies, ageing is not necessarily synonymous with increasing vulnerability, and individual variations exist.[15,16] The term older people includes people of different ages, gender, ethnicity, sexual orientation, socioeconomic status, and disability status. The lens of intersectionality acknowledges that individuals have different dimensions that interact and shape the person's experience with inequality, injustice, exploitation, and oppression.[17,18] Similarly, vulnerability can be conceived using the notion of layers, emphasising that older people might have different "layers of vulnerabilities" (ie, interacting aspects that can both increase or decrease vulnerabilities) in addition to their older age that are, at times, overlapping.[15]

The exclusion of people from preparedness, response, and recovery phases of humanitarian emergencies on account of age is both discriminatory and violates core humanitarian and bioethical principles. Age-related discrimination violates both the right of older people to appropriate, accessible, and inclusive humanitarian assistance and the fundamental humanitarian principles of humanity and impartiality.[19] Moreover, it violates the core bioethical principles of autonomy, beneficence, non-maleficence, and justice.[20] Exclusion undermines older people's ability to make effective decisions about how best to promote their wellbeing. Discrimination is a prima facie harm and violates obligations of beneficence and non-maleficence. Perhaps most obviously, it violates core obligations rooted in justice and fairness.

Over the past two decades, there have been multiple calls to include older people in the preparedness, response, and recovery phases of humanitarian emergencies with little to no uptake.[21,22] We aim to develop a theoretical framework to understand the continued exclusion of older people from participation in preparedness, response, and recovery phases in humanitarian emergencies and to provide practical guidance to translate the principle of leaving no one behind from a slogan into action.

Ageism: a cause of exclusion of older people

Humanitarian emergencies put strain on societies and systems, which contributes to a stronger surfacing of ageism, sexism, racism, and other forms of discrimination and oppression.[23,24] Ageism refers to the stereotypes, prejudice, and discrimination directed towards people on the basis of their age.[25] Ageism can operate consciously and unconsciously at macro (ie, institutional), meso (ie, interpersonal), and micro (ie, individual) levels, and can be directed towards other individuals or towards oneself (ie, self-directed ageism).[26] Ageism manifests differently in different societies, depending on the proportion of older people in the population, the value society places on older people, and other cultural values.[27] Many older people experience compounded or intersectional disadvantages due to membership in multiple stigmatised groups.[28–30] Intersectionality is increasingly considered as an important framework for health-systems research in low-income and middle-income countries to understand and respond to health inequities.[31] Similarly, research on intersectionality and health inequities in humanitarian emergencies is still scarce and does not specifically focus on ageism.[32,33] Despite the heterogeneity of older people, there are commonalities in their health needs on account of ageing and of being older in a humanitarian emergency.

Studies have shown that ageism can have severe consequences for a person's health, wellbeing, and human rights.[13] Ageism is associated with a shorter lifespan, poorer physical and mental health, slower recovery from disability, greater risk of cognitive decline, a reduced quality of life, and increased social isolation and loneliness.[34,35] Ageism cuts across interconnected levels, namely the institutional, interpersonal, and self-directed levels. An analysis of the mechanisms of ageism at each level allows for a better understanding of why older people are left behind in humanitarian emergencies.

Institutional-level ageism in humanitarian emergencies

At the institutional level, barriers and structural challenges often emerge for older people due to ageist attitudes translated into discriminatory laws, policies, and priorities, underfunding of health services for older people, and scarce accessible and affordable health services.[36]

Discriminatory laws, policies, and priorities

There is a range of international laws, policies, and standards explicitly safeguarding the rights of older people in humanitarian emergencies, such as equal access to food, shelter, medical care, and other services.[37–43] Although these policies might seem to be age-inclusive, their implementation is often lacking.[44] Furthermore, older people are often excluded from research and efforts for data collection on needs and access to services in humanitarian emergencies. In 2019, only one in three aid agencies collected data disaggregated by age group in their emergency response, and only one in four needs assessment reports mentioned older people.[21] This absence of visibility of older people and their health needs most likely reduces the support available to them during humanitarian emergencies. In addition, humanitarian organisations have policies and strategies which prioritise the needs of women of childbearing age and children, inevitably deprioritising the needs of older people.[45] At the health-facility level, this exclusion translates into triage algorithms that prioritise children, women of childbearing age, and younger adults.

Underfunding

The deprioritisation of older people in policies and strategic decision making is tightly linked to the lack of funding for services for older people.[12] A study in 2012 showed that less than 1% of humanitarian funding was allocated to projects involving at least one activity targeting older people.[46] A potential explanation for the limited funding for older people is the assumption that their needs are addressed through general interventions, such as health services and social protection programmes. However, older people have specific needs that are not typically included in general interventions and must therefore be addressed in tailored interventions, such as treatment for age-related chronic diseases, for visual and auditory impairments, and for incontinence, as well as nutritional support that takes into account specific age-related needs (eg, hard grains can be challenging to eat due to dental problems and older people often need more protein and micronutrients than other age groups).[46]

Accessibility and affordability

Older people often face challenges when seeking health care, including reduced physical access to health facilities, inappropriate medical services that do not meet the needs of older people, insufficient supply of medications and treatments, and unaffordable medical costs.[47,48] In many contexts there is little, if any, assistive technology, a shortage of incontinence products, and little sustained treatment of non-communicable diseases.[49–51] Additionally, insufficient expertise in ageing and geriatric health care in humanitarian organisations could be an indicator of ageist organisational decisions fuelled by underfunding age-appropriate services and programmes, social beliefs about older people, and attitudes towards older people.[48,52]

Interpersonal-level ageism in humanitarian emergencies

Within the unstable and critical circumstances of humanitarian scenarios, a culture of ageism might exacerbate power dynamics, intergenerational conflicts, and discrimination, which in turn can increase the risk of violence and abuse against older people.[53,54] In such critical situations, older people's needs and capacities might be discounted and they might be actively excluded from care and support if they are considered less worthy of care and support.[55] Many older people are physically less able to travel and queue for food and water at distribution points.[56]

The pressure imposed by a humanitarian crisis might marginalise older people in favour of age groups perceived as stronger and abler. For instance, in disaster scenarios and relief responses, older people might be categorised as unproductive, dependent, helpless, weak, forgetful, and a poor investment for skills and credit programmes because they are unable or unwilling to learn or because they could die with their debt.[57] In addition, older people face age discrimination by health-care providers when seeking care.[58]

On the contrary, in an inclusive culture that values their roles, older people can be perceived in the key supportive roles they can have in humanitarian emergencies.[9,56,59] Older people often take on great responsibilities in the care of grandchildren, some of whom might have been orphaned, and in domestic chores and income-generating activities. However, during emergencies, communities can be placed under enormous stress, and traditional, positive attitudes about older people can resultantly be undermined.[60]

Self-directed ageism in humanitarian emergencies

Self-directed age discrimination is the result of the internalisation of the stigma and marginalisation experienced at the institutional and interpersonal levels. When society sees older people as a burden, older people may internalise this view, identify themselves as burdens, and act accordingly.[47,61] Stereotype embodiment theory suggests that when negative stereotypes are internalised, they can detrimentally impact health.[62]

In humanitarian emergencies, displacement might be needed for safety or to ensure access to services.[44] Since the Russian invasion of Ukraine on Feb 24, 2022, older people have constituted a disproportionate number of civilians remaining in areas of active hostilities, facing greater likelihood of being injured or killed.[63] Self-directed ageism can be a driver behind decision making around displacement or health-seeking behaviours. For example, older people might decide not to flee or seek health care because they do not want to be a burden to their family, use scarce resources, or slow their family down.[47] Older people might also make autonomous choices to prioritise the health of younger generations without internalising age-related stigma or marginalisation. Even if older people do not face physical and mobility constraints, they could decide to stay behind for different reasons: they might be reluctant to leave their house, land, and livestock; they might have resisted previous disaster evacuations without experiencing adverse outcomes; the prospect of moving and starting over elsewhere might be too overwhelming; or they, or their family, might decide that it is important for someone to stay behind to secure family assets.[10]

Ageism at all interconnected levels contributes to the continued exclusion of older people from the preparedness, response, and recovery phases of humanitarian emergencies. The exclusion of older people leads to less visibility of the needs of older people in humanitarian emergencies and less consideration of the knowledge, experience, and roles of older people.

Epistemic injustice: a consequence of exclusion of older people

In many societies, older people have an important role as community connectors, teachers of traditional practices, and historical witnesses of previous emergency events within the community.[55] Because of these roles and the knowledge they hold (eg, regarding previous emergencies in the area, the community, the local environment, and life experience in general), older people can be fundamental in emergency preparedness, response, and recovery phases. However, if they are excluded from participation in these phases, they lose the opportunity to use their knowledge, which can be considered an epistemic disadvantage.

Epistemic wrongs or disadvantages are moral wrongs that occur in processes related to knowledge production, use, or circulation.[64] The exclusion of older people can lead to an epistemic disadvantage if older people are unable to produce, use, or circulate their knowledge because knowledge is produced, used, or circulated in isolation from them, or their knowledge is disavowed. This process of exclusion deprives older people of their agency, autonomy, and independence, with decisions being made on their behalf. It also harms the community because valuable knowledge (eg, about the community and local environment) and life experience is not made available to decision makers. To decide whether cases of epistemic disadvantage are unjust, and therefore should be labelled as an epistemic injustice, five conditions must be fulfilled: (1) disadvantage condition, (2) prejudice condition, (3) stakeholder condition, (4) epistemic condition, and (5) social justice condition.[65]

With regard to the exclusion of older people from preparedness, response, and recovery phases of humanitarian emergencies, all five conditions are fulfilled (figure 1). Firstly, the disadvantage condition states that older people must suffer epistemic or socioeconomic disadvantages, or both, and inequalities stemming from discrimination, such as having little access to health services and social protection due to the absence of

visibility of their needs and the disavowal of their knowledge and experiences. Secondly, the prejudice condition states that the discrimination must involve prejudiced sentiments, such as prejudice related to people based exclusively on their age, leading to the dismissal of their knowledge. Thirdly, the stakeholder condition sets out that older people must be affected by the decisions that they are excluded from influencing. The exclusion of older people from participation in the design, implementation, and evaluation of health services has a direct effect on the services made available to them, including accessibility. Fourthly, the epistemic condition states that older people must possess knowledge that is relevant to the decision that they are excluded from. Studies from different geographical regions have shown that older people are custodians of knowledge and community connectors in many contexts, which gives them knowledge relevant to decision making about their inclusion in preparedness, response, and recovery in humanitarian emergencies.[9,45,52,57] Finally, the social justice condition states that older people must concurrently suffer from other social injustices. This condition is supported by intersectionality, because older people in humanitarian emergencies will almost always face overlapping oppressions. Although there is some literature around epistemic injustice in general health care, literature on epistemic injustice in global health and in humanitarian emergencies specifically is more scarce.[66,67]

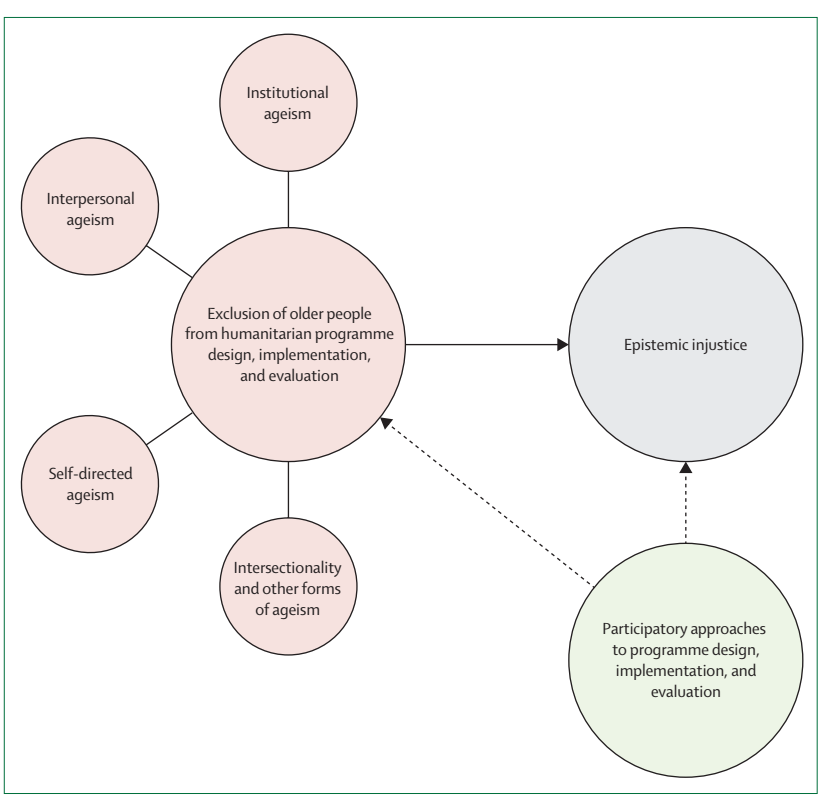

Figure 1: **Theoretical framework of how exclusion of older people from preparedness, response, and recovery in humanitarian emergencies leads to epistemic injustice**

Participatory approaches: a solution to include older people

To prevent and remedy this epistemic injustice caused by the exclusion of older people, participatory approaches in programme and intervention design, implementation, and evaluation could be used. Participatory approaches are used in different fields to ensure meaningful collaboration and engagement of different stakeholders in the design and development of products, services, or systems so that solutions are more appropriate and relevant.[68] For example, in health and social care, a person-centred approach includes patient participation, collaboration, and engagement, and contributes to appropriate and compassionate care. Autonomy, agency, and independence are at the core of person-centred approaches.[69] Examples of participation of older people in the design of health services, research, and innovation processes in Europe and the USA show that participation contributes to successful strategies for ensuring age-friendly health services.[70] Similarly, including older people in emergency preparedness, response, and recovery phases will lead to interventions that are context-appropriate and are owned and supported by communities. Most older people believe they have important contributions to make in disaster prevention and preparedness and in the process of reconstruction and recovery.[53] Over the past decade, the engagement of communities in designing, implementing, and evaluating interventions in humanitarian emergencies has become standard practice for most humanitarian organisations. Although many different participatory approaches are available, design thinking is an approach with great potential to ensure the inclusion and meaningful participation of older people in humanitarian emergencies.

Design thinking

Design thinking maintains that as long as you stay focused on and listen to the people for whom designs are intended, you can arrive at optimal solutions that meet their needs. Design thinking is now often used in the commercial sector, responding to evidence that only approximately 10% of new products or services successfully identify and respond to end-users' needs. The remaining 90% of products might therefore misuse time, funding, and other resources.[71] A similar discrepancy in the translation of scientific research to novel therapeutics is referred to as the valley of death in translational medicine.[72] When compared with traditional problem-solving methods in health care and public health, design thinking involves greater empathy for the needs of a community, a clearer understanding of the problem, more resource-efficient and cost-effective processes, and solutions with greater end-user satisfaction.[73] The design thinking approach is increasingly used to shape humanitarian interventions, but has not yet specifically been applied to older

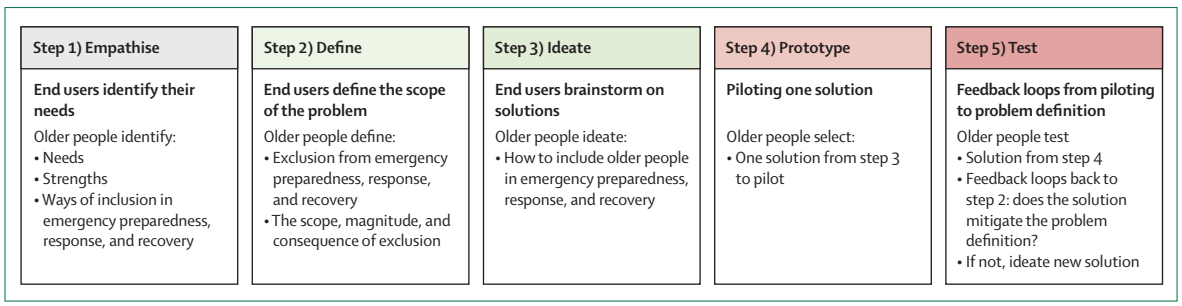

Figure 2: **Design thinking methodology applied to older people in humanitarian emergencies**

people.[74–76] The approach could help identify the needs and desires of older people in humanitarian emergencies, ways in which their strengths can be used in relief efforts, and ways in which they can be included in the preparedness, response, and recovery phases of humanitarian emergencies. This collaboration between humanitarian actors and older people would subsequently contribute to the development of programmes and interventions that are fit for purpose, or that are more appropriate for older people than existing programmes because they would better meet the unique needs and priorities of older people and consider their strengths and knowledge.

Design thinking consists of five non-linear steps: empathise, define, ideate, prototype, and test (figure 2).[73] These steps can be used as follows by humanitarian actors in the design, implementation, and evaluation of programmes and interventions in the preparedness, response, and recovery phases of humanitarian emergencies (panel). These five steps of the design thinking process can facilitate active collaboration between humanitarian actors and older people in the community and can contribute to the inclusion of older people's needs, strengths, and priorities in humanitarian programme design, implementation, and evaluation.

Next steps

We have proposed a theoretical framework that explains how ageism, further compounded by intersecting oppressions, leads to the exclusion of older people from the preparedness, response, and recovery phases of humanitarian emergencies. The exclusion of older people is discriminatory, violates core humanitarian and bioethical principles, and leads to an epistemic injustice. Concretely, we suggest that humanitarian actors adopt participatory approaches with older people in the design, implementation, and evaluation of programmes and interventions in humanitarian contexts. Through these approaches, solutions will be identified by and with older people, leading to community-driven and context-appropriate ways to include the needs, knowledge, and experiences of older people in the preparedness, response, and recovery phases of humanitarian emergencies. Only by actively including older people in

***Panel:* Design thinking steps applied to the design, implementation, and evaluation of interventions for the preparedness, response, and recovery phases of humanitarian emergencies**

Step 1: empathise

Focus on the end users to identify their needs. During the preparedness, response, and recovery phases of humanitarian emergencies, this step includes asking older people from the community what their needs are and how they would like to collaborate in the design, implementation, and evaluation of programmes and interventions (eg, incontinence is identified as a health need and older people have an active role in planning an intervention to meet this need)

Step 2: define

The scope and meaning of the problem are to be defined by older people (eg, no hygiene products being available, incontinence causing shame, stigma, not being able to leave the house, etc)

Step 3: ideate

Focus on a brainstorming process with humanitarian actors and older people to identify potential solutions (eg, education of health-facility staff on incontinence, distribution of hygiene products, and the inclusion of older people in the design, implementation, and evaluation of the intervention)

Step 4: prototype

Follows rapidly on from step 3 to quickly pilot one of the solutions identified (eg, during the next non-food distribution, additional hygiene products for incontinence are included for households in which an older person resides). This intervention is co-designed and co-implemented by older people (eg, older people could help identify households in which older community members live)

Step 5: test

Create feedback loops from the tested solution to the identified problem (eg, did the non-food distribution with additional hygiene products reach the households in which an older person resides? Were the products of acceptable quality? Were there any adverse consequences of the distribution? How was the distribution accompanied by health promotion messaging?)

the design, implementation, and evaluation of programmes and interventions in humanitarian emergencies are we able to fully honour their rights, needs, and strengths and to transform the principle of leave no one behind from a slogan to reality.

Contributors

EvB was responsible for the conceptualisation, literature search, and writing of the original draft manuscript. JvdK, PK, SS, UP, JLB, JS, and OHF contributed to the review and editing of the manuscript.

Declaration of interests

We declare no competing interests.

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