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“At Home, Even the Walls Help”: Exploring the Palliative Care Needs, Experiences, Preferences, and Hopes of Older People with Serious Illness in Ukraine

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Preface

Photo courtesy of HelpAge International

> ***"How did we build our houses?***
> ***When you're standing under winter skies,***
> ***and the heavens turn and sail away,***
> ***you know you've got to live somewhere***
> ***you aren't afraid to die."***
>
> **Serhiy Zhadan, Ukrainian poet**

This report is about palliative care for older people with serious illness in Ukraine. Both the palliative care and humanitarian fields are guided by the principle of humanity: to care for anyone suffering the effects of disease, war, or disaster, and upholding the dignity of human life. The exploration of these fields together is garnering interest across the palliative care and humanitarian worlds. In these explorations, it is the experiences, hopes, and dreams of those who would benefit from palliative care in crises that need to be heard.

For older people facing serious illness in Ukraine, pain stemming from illness is entwined with the pain of living through a devastating war: "How can a person rest with a sick heart?" asks one older woman in our research. Living with serious illness is hard, but doing so in the midst of terrible armed conflict is excruciating.

Older people facing serious illness in Ukraine often find solace in the walls of their homes that keep them safe, the roofs they have built, the rooms in which they have tended to children, the gardens they have planted and in which they have sat watching the world, and the memories of long lives well-lived held within. They cherish calm memories, cope in the upturned present, and dream of peaceful futures with endurance and self-reliance. The Ukrainian proverb, "At home, even the walls help," anchors what matters most for those facing serious illness through the war. Comfort comes with the thought that a safe home for living will also be the place of easy and peaceful dying. The comfort found in attachment to memories, lives well-lived, belongings, homes, and land should guide models and interventions of palliative care.

In the armed conflict, many older Ukrainians have lost this core aspect of security and comfort. Their houses have been damaged and destroyed by Russian attacks. They have been forced to flee their homes, homes that may no longer be standing. Many are compelled to live in unfamiliar locations without community or loved ones nearby. In all cases, they live with great uncertainty for their safety and future.

In addition to undermining fundamental psychological safety, war brings serious barriers to accessing medical care, pain relief, and support services people with serious illness are entitled to. Palliative care is integral to the realization of the fundamental human right to health.

It is not easy to talk about or provide care and support during illness, dying, and death in peaceful times. Such conversations and actions are made all the more painful and complex when living and dying through war. How do we best provide care for older people in times of conflict, displacement, loss, and intensified grief?

It is our goal that sharing the voices of older people from Ukraine will change the way governments, policymakers, humanitarian organizations, and health and social care actors think about caring for older people with serious illness in Ukraine and in other humanitarian emergencies and recovery contexts. We hope that when you hear the words of the participants of this research, you will feel the depth of their emotions, sense of fortitude, and desire to strengthen palliative care efforts. All older people with serious illness in Ukraine have the right to continue living in dignity and safety until death, without fear, and in the comfort of home and surrounded by people who care.

Summary and Recommendations

> ***"I felt how difficult it is at an older age, when there are health problems, when there are physical limitations, to lose everything—home, relatives, a certain prosperity and comfort, the usual way of life— and find yourself in another city, in another country, not needed by anyone, to seek help from complete strangers and not to lose faith and hope."***
> **Healthcare worker, Lviv**

HelpAge commissioned this research to explore the palliative care needs, preferences, and hopes of older people with serious illness in Ukraine. Older people and their family members shared their experiences of the dual impact of serious illness and the brutal armed conflict on their physical, emotional, and practical well-being. They described physical pain, emotional and existential suffering, and barriers to accessing healthcare, social services, and other systems, as well as serious difficulties in meeting basic needs. They also reflected on their desires and preferences to receive palliative care and other services designed to alleviate their suffering and uphold their dignity in their homes, places where they find solace and comfort. The research revealed that the role of informal family can be complex and challenging. Older people and their caregivers also reflected on their personal coping mechanisms, including illness and the acceptance of death, self-reliance, spirituality, religion, and finding hope and meaning even in small joys.

The experiences of older people, as well as good practice in palliative care delivery, highlight the need to build on existing palliative care services in Ukraine to develop holistic, multidisciplinary, and integrated care that includes smooth coordination between healthcare and social service delivery and strengthened partnerships with Ukrainian non-governmental organizations (NGOs). It is also crucial that the government invest in home-based and community-based support and services rather than institutionalized care, consistent with the preferences of older people, their rights to autonomy and to live and be included in the community, and Ukraine's commitments as a European Union (EU) candidate country.

The findings in this report reflect qualitative interviews and focus group discussions conducted by HelpAge International Ukraine staff with older people with serious illness, including older people forcibly displaced by the war, as well as family caregivers, health and social care workers, and local government representatives. The research was undertaken in March and April 2024 in the Lviv, Dnipro, and Kharkiv oblasts of Ukraine. These testimonies are supplemented with observational insights from HelpAge staff, informational conversations with experts on palliative care in Ukraine, and secondary data and documentary sources.

Older people are often excluded from research in humanitarian crises, as well as from the planning, implementation, and monitoring of humanitarian response. This research specifically seeks to bring to the forefront the lived experience of older people with serious illness in a country experiencing a brutal war and serious humanitarian emergency. The experiences, perspectives, and voices of older people with serious illness should inform the future design of research on and implementation of palliative care services in Ukraine as well as in humanitarian crises in other countries.

What is palliative care?

Palliative care is a holistic approach designed to improve the quality of life and promote the dignity of people and their families who are facing the problems associated with serious illness.[1] It aims to prevent and relieve physical pain and symptoms, as well as emotional, social, and spiritual suffering, and support grieving families in bereavement. Palliative care is a crucial part of integrated, person-centered care, which is an essential component of Universal Health Coverage,[2] and integral to the human right to the highest attainable standard of health. It is also part of the continuum of care alongside health and well-being promotion, disease and disability prevention, diagnosis and treatment, rehabilitation, and long-term care and support.[3]

Serious illness is defined in this report as a diagnosis of any chronic, life-limiting, or life-threatening illness for which palliative care would be of benefit. Such conditions include, among others, cancer, chronic obstructive pulmonary disease, heart failure, renal failure, liver failure, diabetes, human immunodeficiency virus (HIV), tuberculosis (TB), and progressive neurological diseases (for example, Multiple Sclerosis, Parkinson's Disease, and Alzheimer's Disease). Older people often experience multi-morbidity, or the co-existence of two or more chronic diseases in one person.[4] Multi-morbidity causes a wide range of physical, psychological, social, and practical problems, and requires continuity of support through both palliative care and long-term care.[5]

Palliative care in humanitarian emergencies

In 2018, the World Health Organization (WHO) issued guidance on integrating palliative care and symptom relief into humanitarian response, calling it a medical and ethical imperative.[6] The guide identifies proposed palliative responses to physical, psychological, social, and spiritual suffering experienced by people impacted by armed conflict, epidemics, natural disasters, and other emergencies. To date, there is little evidence of effective palliative care provision in humanitarian response, even where the specific risks for older people and high rates of certain diseases are well-recognized. Humanitarian policy, planning, and actions globally, including in Ukraine, can be doing more to address palliative care and long-term care and their interfaces. Doing so effectively requires at all stages incorporating the views, experiences, and participation of those requiring palliative care, including older people.

Access to health and palliative care and the war in Ukraine

The WHO has estimated that 39 percent of households in Ukraine have at least one member with a chronic illness, with higher rates in eastern Ukraine where the conflict has been most devastating. Russian attacks have decimated healthcare infrastructure in parts of Ukraine, and doctors and healthcare staff have been forced to flee many areas for their safety. People who are displaced within Ukraine can experience serious barriers in identifying doctors and necessary services in new locations. Financial strains compel many to make impossible choices regarding the purchase of medications while forgoing other essentials like food. Barriers to accessing healthcare have increased the risk of disease, disability, and multi-morbidity for older people; delays in new diagnoses and timely access to treatment; and disrupted continuity of care and access to medications for people with pre-existing conditions.[7, 8, 9, 10, 11]

Where many children and younger adults with serious illnesses, particularly cancer, have been urgently evacuated to other countries for care, older people with serious illness overwhelmingly remain in Ukraine, enduring the compound impacts of older age, illness, displacement, and war.[7]

Ukraine has a well-documented history of progress towards improving palliative care service provision through a combination of initiatives from non-governmental organizations (NGOs), the Ministry of Health and the Ministry of Social Policy, and the public healthcare system at different levels.[12, 13, 14]

Despite this progress, many challenges remain in realizing a holistic, integrated, multidisciplinary, and coordinated system of care, particularly within home- and community-based settings. Russia's 2022 full-scale invasion and Ukraine's defense of its territory have led to a decline in already limited resources available for palliative care—including medicines and medical disposables—and further reduced governmental coordination.[3] The conflict has also intensified the invisibility and isolation of older people with serious illness who would likely benefit from palliative care.

In this context, the need for holistic palliative care for older people will only increase. This is particularly true for the most at-risk older people, including those living in or near active conflict zones and those who have been forcibly displaced. It is urgent to understand how to support older people with serious illness in Ukraine in the context of the ongoing emergency and their family caregivers, who are often older people themselves.

The global interest in supporting Ukraine and the influx of humanitarian organizations should create new opportunities for collaboration and for fostering civil society and grassroots initiatives in palliative care, especially at the home and community levels.

Research findings

This research identifies significant concerns for older people with serious illness in Ukraine, as they, their family caregivers, and the health and social care workers who seek to support them face serious illness in the context of a devastating war. The findings also point to important opportunities for understanding contextually relevant palliative care for older people in humanitarian crises, for further research, and for new or strengthened partnerships in healthcare and social service systems and delivery.

The findings, grounded in the voices of older people with serious illness, are summarized in the following figure:

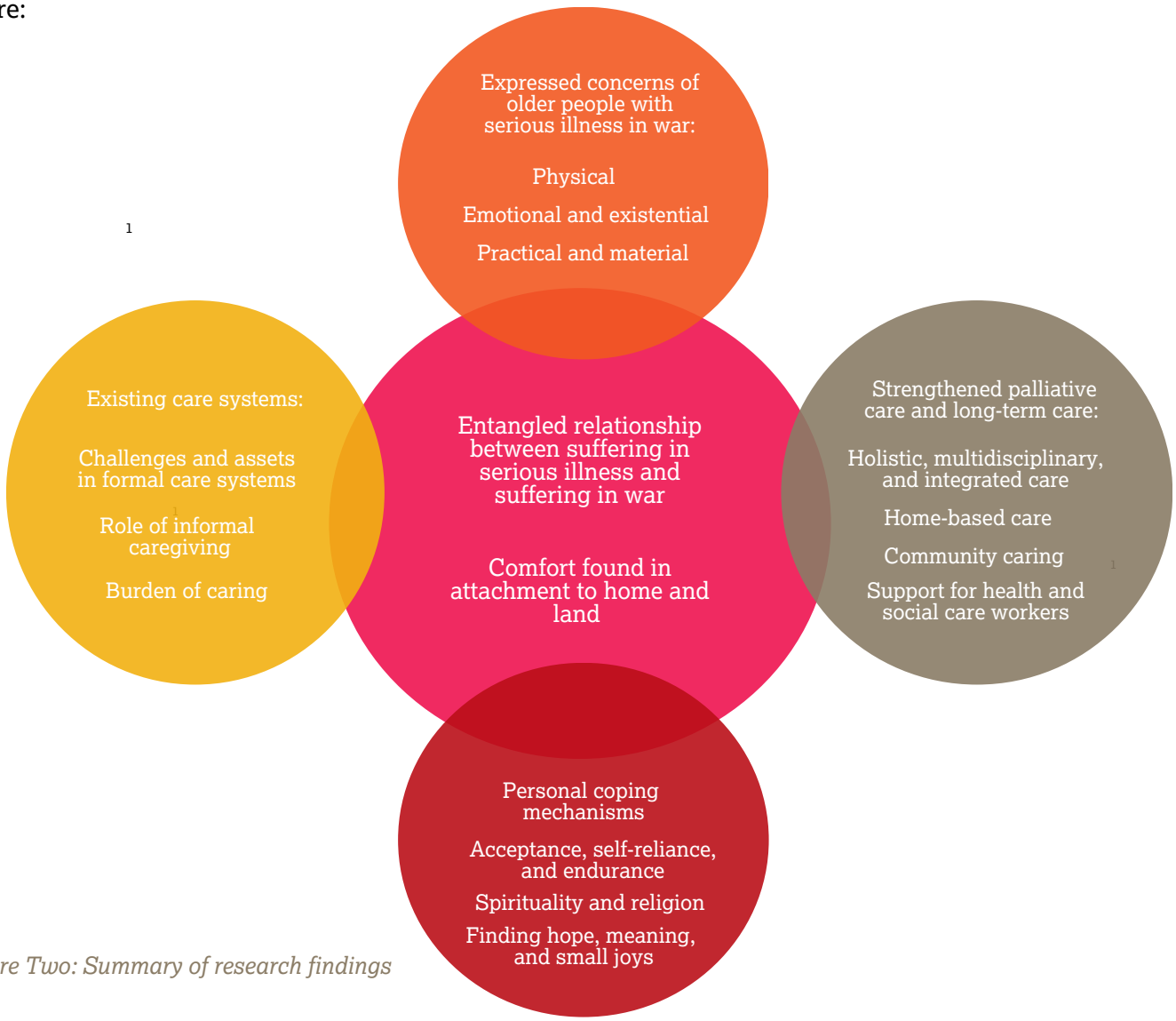

Figure Two: Summary of research findings

Key research findings

1) Older people with serious illness in Ukraine expressed a range of concerns, including physical conditions (pain, other symptoms of disease, and disability); emotional and existential suffering (anxiety and fear, loneliness and grief, loss of hope and meaning, feelings of being a burden, and worries for the future); and practical and material difficulties (meeting basic needs and insufficient income).

2) Older people also reported on barriers to accessing healthcare and other systems (e.g., access to medical care and social services, their desires and realities regarding the preferred location to receive care and support, and access to formal palliative care). In addition, the research revealed that the role of informal family caregivers can be complex and challenging.

3) Older people and their caregivers shared information on their personal coping mechanisms, including illness and the acceptance of death; self-reliance and endurance; spirituality and religion; and finding hope, meaning, and small joys.

4) The experiences of older people, as well as good practice in palliative care delivery, highlight the need for strengthened palliative care and long-term care opportunities, including holistic, multidisciplinary, coordinated, and integrated care and services, home-based palliative care, community-based care and support systems, and support and training for healthcare and social care workers in Ukraine.

Enduring and finding hope through illness and war

Two important themes emerged prominently among the older people and their caregivers in Ukraine whom we interviewed:

1) Illness-related concerns for older people in Ukraine are entangled with, compounded by, and can be inferior to the pain, violence, loss, and injustices inflicted by the war. Pain is both a literal symptom of disease and a result of the impacts of war. Caregivers find caring in non-peaceful times harder since they also experience serious emotional pain and suffering.

2) There is general acceptance by older people of illness, disability, multi-morbidity, and death in older age. For many, death is easy to speak of. It is the devastation of war, with a loss of home, land, and loved ones that erodes security, peace, belonging, and meaning. And, it is in the memories and earnest hope to remain in, or return to, one's home and be surrounded by the love of people who care that comfort can perhaps best be found.

Listening to older people and the way forward

Considering these preferences and experiences of older people in Ukraine, palliative care that focuses solely on the control of individual and disease-related symptoms of serious illness will not alleviate the depths of their suffering, nor adequately support those providing care. Practices that see the whole person, their family, and their caregivers outside a disease framework; understand the root causes and the common experiences of suffering in war; and recognize the political, social, and environmental contexts in which older people live, become ill, and die become critical in how to approach and plan for the future of palliative care in the context of war.

Given the limited timeframe and scope of this research, it did not seek to measure palliative care needs, access, and availability in Ukraine. Rather, it is intended to provide insights into how some older people with serious illness and their caregivers currently experience illness and care; cope with illness, multi-morbidity, and disability through war; and describe their preferences and hopes for the future. Appendix One provides a detailed methodology.

We recognize that older people are often excluded from research in humanitarian crises, are left out of efforts to identify and design solutions on matters that directly affect them, and are devalued for the knowledge and contributions that they bring in responding to their own needs and those of their communities.[15, 16] Older people in Ukraine have explicitly called for diverse forms of community consultation to better understand how to address their current needs and to make humanitarian assistance more inclusive for older people, people with disabilities, and other at-risk groups.[17, 18]

We also recognize that the participation of, and collaboration with, those affected by serious illness is a keystone of person- and community-centered palliative care. Palliative care is a holistic approach that balances health and social needs, experiences, and systems, and should be informed by local and contextually and culturally relevant ways of caring, dying, and grieving. Currently, in global palliative care, few research studies prioritize hearing

directly from older people. Research also suggests that there may be diverging priorities between normative and dominant ways of assessing and capturing palliative care needs according to palliative care professionals and the expressed needs and preferences of older people themselves.[19]

Recommendations

Based on this research—and particularly the experiences that older people, their family caregivers, and health and social care workers have shared—as well as the obligations by governments and humanitarian actors to relieve suffering and uphold human rights and alleviate suffering, we share recommendations on ways to improve and advance quality palliative care in Ukraine. In all cases, older people's voices and lived experiences must inform future palliative care policies, programs, and efforts that are designed to support them with quality and love through illness, dying, and bereavement.

1 International humanitarian organizations, including United Nations (UN) agencies, international non-governmental organizations (NGOs), and participants of the Health Cluster in Ukraine, should ensure that the palliative care and long-term care needs of older people with serious illness across healthcare and social services are identified, prioritized, and integrated into humanitarian response plans, funding, and programs in line with the WHO's 2018 guidance on integrating palliative care and symptom relief into humanitarian response, international human rights standards, and the humanitarian imperative to alleviate suffering.

2 Donors of humanitarian response and recovery in Ukraine should ensure sustained and adequate funding to the government of Ukraine and other humanitarian actors to ensure the provision of palliative care and long-term care for older people with serious illness. They should also fund Ukrainian national and community-based organizations that have expertise in the delivery of palliative care and are working towards strengthened partnerships and systems of care.

3 The government of Ukraine, including the Ministry of Health, the Ministry of Social Policy, and regional and local health and social care departments, as well as international humanitarian organizations and Ukrainian local and community-based organizations, should develop and formalize collaborations at national, regional, and community levels to ensure the consistent provision of quality palliative and long-term care for older people with serious illness. In particular, these collaborations should prioritize:
a) The integration and coordination of holistic and person- and community-centered medical, health, and social systems of care, including referral processes between levels, settings, and multidisciplinary professions of care.
b) Strengthening formal and informal home-based systems, with consideration given to both telehealth and face-to-face care.
c) Education and training of primary care doctors, community-based nursing teams, and other community-based health professionals in palliative care for older people.
d) Expanded education and training for social workers on palliative care for older people, with consideration given to using European competency frameworks.
e) Grief and bereavement care as a priority for healthcare, social care, and community systems.

4 Regional and local health and social care departments, international humanitarian organizations, and Ukrainian local and community-based organizations should work towards strengthening civil society and grassroots initiatives for palliative care for older people and support for caregivers of older people with serious illness. In particular, these efforts should prioritize:
a) Community forums for awareness raising of the importance of palliative care for older people.
b) Community forums for co-designing future research (building on this report) and palliative care and long-term care models relevant to the dynamic social, political, and environmental contexts in which Ukrainian older people live, become sick, and die. They should also prioritize ensuring the genuine participation and inclusion of older people with serious illness, respecting their valuable contributions to society, and their experiences, preferences, and hopes for caring and dying.
c) Home-based care training, support, and respite for family caregivers, recognizing that many carers are older people themselves.
d) Initiatives and processes, both formal and informal, for supporting health and social care workers to debrief, share experiences, navigate the distressing environments in which they work, and support each other.

Background: Older People and Armed Conflict in Ukraine

Ukraine is among the fastest aging countries in the world [20] and is well-known as having the world's 'oldest' humanitarian crisis.[21] Prior to Russia's full-scale military invasion in February 2022, a quarter of the population of Ukraine was over 60 years old, and 1.7 million people were above the age of 80.[22] Thirty percent of all people already in need of assistance before the current invasion were aged 60 years or older.[23] The impact of people fleeing Ukraine for safety in other countries over the past two years has accelerated the demographic transition and changed the population structure of the country, likely for the long term, since older people have disproportionately remained in Ukraine.[22, 24]

The specific impacts of Russia's full-scale invasion on the health, human rights, and well-being of older people in Ukraine have been well-documented.[11, 15, 25, 26, 27] Certain portions of Ukraine's older population face amplified risks, including older women, people over 70 years of age, and older people with disabilities.[21] Older people have been disproportionately represented among those killed and injured in areas close to the frontline.[28] Evacuation efforts are not always accessible to people with disabilities, including older people with disabilities.[21]

Older people are also more likely to continue living in their homes, even in conflict-affected areas, citing strong attachment to land and home.[22] Many face disruption or loss of family and social support that had provided practical or emotional support.[21, 28, 29]

Many older people, including those with serious illness, have faced significant barriers to accessing essential healthcare, medicines, and assistive products during the conflict, particularly if they are immobile, displaced, isolated, or in or near active conflict zones. These factors put them at serious risk of worsened health outcomes, disability, injury, malnutrition, mental health deterioration, and complex long-term care needs.[8, 10, 21, 24, 27, 37, 40, 45, 47]

In a December 2022 WHO survey on health needs and access to healthcare services among adults in Ukraine, one-fifth of respondents with chronic conditions reported not consulting with a doctor when needed, citing self-treatment, insignificant health concerns, and high costs as the main reasons.[8]

These concerns are intensified by obstacles to accessing food, safe drinking water, electricity, and hygiene items such as incontinence aids, toilet paper, and soap,[46] often due to insufficient income and insufficient pensions.[21] A previous HelpAge International survey of older people in Ukraine conducted in late 2022 found that 56 percent could not afford basic needs and 37 percent did not have enough food.[21]

The war in Ukraine has placed a spotlight on the heightened risks faced by older people and strengthened advocacy and action toward addressing their safety, rights, well-being, and dignity.[26] However, the needs of older people with chronic, life-limiting, or life-threatening illness or multi-morbidity, or those who are dying, are largely unexplored in the humanitarian situation in Ukraine,[12] or across humanitarian crises more broadly, as described below.[30, 31]

Photo courtesy of HelpAge International Ukraine

Background: Palliative Care, Including in Humanitarian Emergencies

What is palliative care?

Palliative care is an approach that focuses on improving the quality of life of people and their families who are facing problems associated with life-limiting or life-threatening illness.[1] It aims to prevent and relieve physical, emotional, social, and spiritual suffering and support families in bereavement. Palliative care is a crucial part of integrated, person-centered care, which is an essential component of Universal Health Coverage[2] and part of the continuum of care alongside health and well-being promotion, disease and disability prevention, diagnosis and treatment, rehabilitation, and long-term care services and support [Figure One].[3] Palliative care is a component of the human right to the highest attainable standard of health. A focus on living out one's remaining days with dignity is a central aim of palliative care, with referral to palliative care encouraged from the time of diagnosis of a serious illness and not only when death is near. In this way, the continuum is not linear, and the integration of care across stages is critical. A person may undergo treatment at the same time as receiving rehabilitation, palliative care, and long-term care services and support.

Palliative care services can include, but are not limited to, management of pain and symptoms through various types of medications, including opioids such as morphine and non-opioid analgesics; the provision of psychosocial support services to patients and their relatives; bereavement care in death; training of caregivers in the provision of care; and support to relatives with serious illness. Palliative care also includes the organic and informal support provided by non-specialists, family caregivers, and community networks. Recognizing the material impacts of serious illness on individuals, palliative care can also involve the provision of shelter, food, and essential items to mitigate the effects of conflict, displacement, and poverty on patients and families. Effective palliative care service delivery involves cooperation and coordination across health and social service systems at various levels, as well as with community networks, families, and those who are affected.

Figure One: Palliative care is part of the continuum of essential integrated care (3)

Palliative care is accepted as part of the continuum of care services for older people with serious illness or multi-morbidity, alongside long-term care and support, as elaborated in the action plan for the UN Decade on Healthy Ageing 2020-2030[33] and Integrated Care for Older People (ICOPE).[34]

The increasing need for palliative care globally

It is estimated that people aged 70 years and older currently account for 40 percent of people in need of palliative care worldwide.[32] By 2060, the number of people dying with serious suffering is projected to almost double, driven primarily by increased rates of non-communicable diseases (NCDs), with the fastest increases occurring among older people and people with dementia.[32] NCDs such as dementia, cancer, and respiratory, heart, cardiovascular, and cerebrovascular diseases become more common with age. Multi-morbidity, or the co-existence of two or more chronic diseases in one person,[4] causes a wide range of physical, psychological, and social problems, and leads to complex and multidisciplinary needs for continuity

of care and support. Older people with multi-morbidity are projected to become the main recipients of palliative care in the coming decades.[19] Their requirements may differ from palliative care needs in younger people or people with a single disease,[5] and they may be underserved by palliative care services in systems that have historically been single disease- or cancer-focused.[19] Older women and older people with low socio-economic status are at greater risk of multi-morbidity and inequalities can impede access to care and services.[5] The physical and emotional toll on family caregivers, whose ages are also rising with aging population trends, creates the need for services and support for family and other informal care and support persons as well.[5]

The integration of long-term care and palliative care supports for older people is critical given global population aging and projected requirements for palliative care for older people.[35]

Palliative care in humanitarian emergencies

In 2018, the World Health Organization (WHO) issued guidance on integrating palliative care and symptom relief into the response to humanitarian emergencies, a landmark moment for the field of palliative care in humanitarian settings.[36] Consistent with humanitarian principles, medical ethics, and human rights obligations, the guide states that "all humanitarian responses to emergencies and crises should include palliative care and symptom control. Responses that do not include palliative care are medically deficient and ethically indefensible."

The guide identifies proposed palliative responses to physical, psychological, social, and spiritual suffering experienced by people impacted by armed conflict, epidemics, natural disasters, and other emergencies. It also notes that those who are "chronically ill – along with older persons and young children – may be at particular risk of suffering and death in humanitarian emergencies."[6]

The guide has been criticized by some experts, including for not addressing many of the ethical challenges that arise in palliative care in humanitarian contexts.[36] It is not within the scope of this report to elaborate on those critiques. Despite the existence of the WHO guidance, there has been little action within humanitarian response policies, planning, and programming to develop palliative care in emergencies.[27, 30, 31] Attention to non-communicable diseases (NCDs) has been lacking in humanitarian settings worldwide, despite their global burden.[37] Palliative care for older people with serious illness has not been an explicit priority amidst competing health and social care needs in the context of armed conflict. There is also little discussion or programming to address the interfaces of palliative care and long-term care, including in Ukraine, as reflected in the 2024 Humanitarian Needs Response Plan.[11]

Health conditions and palliative care needs for older people in Ukraine

It was previously estimated that more than 500,000 people with serious illness in Ukraine—and two million members of their families—need palliative care, although data collection systems on palliative care needs are severely lacking.[38] A study of a small sample of older people aged 75 years and older in Kyiv before Russia's full-scale invasion in 2022 found that 36.8 percent had incurable diseases requiring long-term support or palliative care.[39]

Prior to February 2022, NCDs contributed to 91 percent of all deaths, driven largely by cardiovascular diseases (69 percent), cancers, and diabetes.[40, 41] The WHO has estimated that 39 percent of households in Ukraine have at least one member with a chronic illness.[42] One assessment in the Donbas region of Ukraine before the current escalation showed that 70 percent of people older than 60 years had at least one chronic illness.[37] Another study in conflict-affected eastern Ukraine reported that almost all older people (97 percent) had at least one chronic disease.[23]

Incurable communicable diseases such as tuberculosis (TB) and human immunodeficiency virus (HIV) also constitute a serious public health issue in Ukraine, with extremely high incidence and low treatment coverage compared to other countries in Europe.[40, 41] Drug-resistant TB represents 29 percent of all news diagnoses in Ukraine. The proportion of older people living with HIV was expanding before the full-scale invasion, with older people more likely to present with late-stage HIV and have higher mortality rates than younger groups.[43]

There is some evidence that chronic conditions that disproportionately impact older people, such as cancer and cardiovascular disease, have increased.[7, 44]

Palliative Care Service Development in Ukraine

Progress

Ukraine has a well-documented history of progress towards improving palliative care service provision for children and adults through a combination of initiatives from non-governmental organizations (NGOs), the Ukrainian public healthcare system, and the Ministry of Health and the Ministry of Social Policy.[12, 13, 14] Prior to Russia's 2022 full-scale invasion, the country ranked globally at a preliminary stage of palliative care integration into mainstream healthcare services, with the presence of a national palliative care association; a variety of palliative care providers, settings, and education programs; a palliative care strategy and policies; and the availability of morphine and other strong pain-relieving medications.[48]

Awareness-raising activities of the need for palliative care began around 2006, leading to the establishment of the national palliative care NGO, the All-Ukrainian Association of Palliative and Hospice Care, in 2011.[12, 13] The association has a wide-ranging mandate to improve the regulatory framework for palliative care, facilitate access to palliative medications, implement multidisciplinary education and training programs, develop a volunteer movement, and raise public awareness, where the ethos of activities is grounded in the connection of individuals with illness and the social end environmental contexts in which they live. The first national palliative care congress was held in Kyiv in 2012.[12]

National legislation on palliative care gave a blueprint for palliative care service development.[49] Ukraine adopted new drug regulations to improve access to and prescribing of opioid analgesics. The number of hospital inpatient, stand-alone hospice, and mobile palliative care units for children and adults expanded through government-financed packages, and palliative care began to be introduced into undergraduate and postgraduate education for medical staff.[50]

The recognition of palliative care as a social concept in 2016 began to allow for funding and provision within a broader framework of social services.[38] In 2018, the creation of a new National Health Service in Ukraine created opportunities for including palliative care in the basic package of healthcare services, integrating palliative care into primary healthcare, and expanding inpatient beds and mobile services.[14, 51]

Most recently, the Ministry of Health of Ukraine has developed a draft strategy for the development of palliative care in Ukraine through 2027 and an action plan for its implementation, which is currently awaiting approval from the Ministry of Justice.[i] There are several recent legal instruments under the Ministry of Health guiding the organization and provision of palliative care. These include the "Order on improving the organization of palliative care in Ukraine 2020"[49] and the "Order on approval of amendments to the procedure for the provision of palliative care 2023."[53] In April 2024, the Ministry of Social Policy's new "Order on the state standard of social services of palliative care" went into effect. One Ukrainian palliative care expert also informs the researchers that a joint order between the Ministry of Health and the Ministry of Social Policy is being prepared, in recognition of the inseparability of healthcare and social services in palliative care.[ii]

Challenges

Despite this progress and current plans, some palliative care experts in Ukraine believe that the implementation of holistic and quality palliative care across all settings of care in Ukraine is not yet being systematically applied.[iii] Access to palliative care services, pain relief, and healthcare professional training remains extremely low when compared with countries across the rest of Europe.[12, 51] For example, in 2017, average morphine consumption per capita (often used as a proxy for measuring palliative care access) was 0.8mg in Ukraine, compared with an average consumption of 107mg in Europe.[51]

A 2019 report found that palliative care for adults was skewed towards hospital inpatient units (76 percent of total services), while home-based care represented only 6 percent of the total.[51] This

means that those wishing to receive services at home or those residing in rural areas were more likely to lack access to palliative care.[54] Several champions of palliative care in Ukraine are critical of the lack of a system for monitoring quality palliative care across the country.[12, 14, 38]

Another major criticism is that services, particularly inpatient beds funded within the public health system, may be palliative care in name only, absent of the true philosophy of holistic physical, psychosocial, and spiritual care in serious illness, dying, and bereavement and without qualified staff and sufficient funding.[13, 49, 55, iv] Multidisciplinary care for people and their families has been lacking in both ministry governance and in practice, where the work of the Ministry of Health and the Ministry of Social Policy have lacked coordination. There is also a bias towards medical care and symptom management that has meant the social aspects of care are often deprioritized or absent.[12, 13, 38, 55, v] Innovative, multidisciplinary, and home-based initiatives for older people needing palliative care exist but are not systematic.[38, vi]

There are also different understandings in Ukraine of what is meant by palliative care. Social workers supporting older people with palliative needs may conceive of it as medical and nursing care exclusively. In other cases, palliative care may be used to describe what is instead long-term, geriatric, or institutionalized care for older people who may not have access to support services at home but do not have life-limiting illnesses that might necessitate true palliative care.[12, 49] At the same, it is likely that the palliative care needs of older people with serious illness, disability, or multi-morbidity residing in institutionalized care settings are underestimated or are going unmet, given the significant overcrowding and poor conditions and treatment in many residential facilities.[42, 43]

Opportunities in the midst of war

The current war on Ukraine has led to a decline in already insufficient resources and pain relief available for palliative care, has further reduced coordination, and has intensified the invisibility of older people with serious illness who would likely benefit. "We admit that our society was not ready for pain relief to be available in a crisis," wrote palliative care doctor Olena Riga in 2023.[50]
The impacts of the current war on palliative care service provision and efforts to support ongoing care have received little attention in Ukraine.[50, 56]

Although global palliative care guidance for humanitarian response exists, as described above,[6] palliative care and long-term care and support for older people are not currently featured in the response plans of the humanitarian sector in Ukraine.[11] HelpAge International is also aware that older people, including those with serious illness, palliative care needs, or long-term support needs, continue to be neglected in discussions and planning of the Health Cluster in Ukraine.[57]

However, the global interest in Ukraine and the influx of humanitarian NGOs may already be creating new opportunities for collaboration and for stimulating civil society and grassroots initiatives.[13, 38, 50] One multidisciplinary tele-hospice service that started in September 2022 as a collaboration between the All-Ukrainian Association of Palliative and Hospice Care, hospital and healthcare services, and existing hospices and universities is working in eight regions of Ukraine to support children and adults with palliative care needs, with potential for expansion through new civil society partnerships and funding.[viii] Palliative care social worker and advocate Alexander Wolf wrote in 2018, "We believe that NGOs will be the driving force of change in how we care for incurably ill people in Ukraine."[13] Grasping future opportunities requires hearing the needs, experiences, perspectives, and hopes of older people themselves.

Photos courtesy of HelpAge International Ukraine

Research Findings

Overview

Research participants and methodology

This was a qualitative research study seeking to elicit the subjective and lived experiences of older people with serious illness, informal caregivers, and health and social care workers through interviews and focus groups in three oblasts in Ukraine: Lviv in western Ukraine and Dnipro and Kharkiv in eastern Ukraine. Interviews and focus group discussions were conducted in March and April 2024 by HelpAge staff employed in Ukraine. All interviews and focus group discussions were conducted in the participants' language of preference (Ukrainian or Russian).

We conducted 11 semi-structured individual interviews with people over the age of 60 with serious illness and six interviews with family caregivers, also all over the age of 60. These were conducted in-person in the participants' residence, which was either their home or a shelter for temporarily displaced people. Of 11 older people interviewed, six have been internally displaced, either within their own oblast in the east or to the west, and five remain living in their home cities.

We also conducted three in-person focus group discussions with HelpAge-employed social workers in each of the three oblasts and two in-person focus group discussions with healthcare workers in Lviv and Dnipro. Security considerations meant that a focus group discussion with healthcare workers was not conducted in Kharkiv. Additionally, we conducted one interview with a local government representative from social care services and one focus group discussion with three local government healthcare representatives in Lviv.

The author also held informal discussions with selected experts involved in palliative care systems and service development and training and education in Ukraine. These informants provided personal testimony, guidance on documentary sources, and input on the drafting and recommendations of the report.

In addition, more than 70 documentary sources related to the humanitarian, healthcare, social care, and palliative care situation in Ukraine were analyzed and triangulated with the primary research. At the time of this research, Russian forces have continued to regularly attack the Kharkiv region with bombardments and other weapons, and people there and in Dnipro live under regular air raid sirens and concerns for immediate survival.

Appendix One provides a detailed methodology.

Research findings

Our research documented the experience of older people with serious illness, including displaced older people, during the war in Ukraine concerning their physical, emotional, and practical well-being. It also examined how those older people receive care and support and how they and their family members cope in the midst of serious illness and war. Finally, our research looks at how existing palliative care and long-term care services support older people and what can be done to strengthen these services.

Our findings are supplemented with relevant documentary sources.

Cross-cutting themes

The research findings reveal subtle differences between those displaced from their own homes and those remaining in the community, where the displaced report a preoccupation with returning to the comfort of home. Nevertheless, important themes emerged prominently among older people, their caregivers, and others whom we interviewed, irrespective of location or displacement status.

Theme one: The entangled relationship between suffering in serious illness and suffering in war.

The impacts of serious illness or multi-morbidity on older people in Ukraine undoubtedly raise concerns of unmet suffering that may be addressed with strengthened evidence-based palliative care approaches. However, suffering for older people in Ukraine runs deeper. Illness-related concerns are profoundly entangled with, compounded by, and may, in some ways, be inferior to the pain, hopelessness, and injustices inflicted by Russia's war on the country. Pain is both a literal symptom of disease and a result of the impacts of war:

"What emotions can there be because of the war, [or] because of the disease? Of course, nothing good. Constant worries, constantly: 'Oh, it hurts. Oh, when will it stop? Oh, why does it hurt all the time? When will that war end?' These are things that do not leave you for a minute, not for a second, not for an hour, not for a day. Because we live in all that and there is nothing good in it. And that pain, and that war, and those experiences, and worries - all this is very difficult."
Female caregiver, Lviv

"I felt how difficult it is at an older age, when there are health problems, when there are physical limitations, to lose everything —home, relatives, a certain prosperity and comfort, the usual way of life—and find yourself in another city, in another country, not needed by anyone, to seek help from complete strangers and not to lose faith and hope."
Healthcare worker, Lviv

Theme two: The strong sense of attachment to, and comfort found in, home and land.
There is general acceptance by many older people of illness and death in older age. For many, death is easy to speak of. It is the loss of home and community that brings an erosion of security, peace, and belonging. And, it is in the memories and earnest hope to remain in, or return to, one's home and be surrounded by the love of people who care that comfort can perhaps best be found.

"As they say in Ukrainian, at home, even the walls help."
Female caregiver, Kharkiv

Care that focuses only on the control of the individual and disease-related symptoms of serious illness for an older person will not alleviate the depths of their suffering, nor adequately support those providing care. Practices that see the whole person, their family, and their caregivers outside a disease frame; understand the root causes and the common experiences of suffering in war; and recognize the political, social, and environmental contexts in which older people live, become ill, and die become critical in how to approach and plan for the future of palliative care in the context of armed conflict.[31]

The findings of this report, including their intersection with these important cross-cutting themes, are summarized in Figure Two (see page 7).

Expressed concerns of older people with serious illness

In standardized palliative care definitions and assessments, illness-related suffering is usually categorized across physical, social, psychological, and spiritual domains, and models of professional caring tend to follow these domains. In reality, people with serious illness do not think of their concerns in terms of such disconnected categories, nor do they define their solutions as needing to be met by a range of multidisciplinary professionals. Identifying the needs of older people with serious illness in war that may be going unmet or that matter most to them requires hearing their concerns in their words and responding appropriately. Here, we summarize expressed concerns as: physical; emotional and existential; and practical and material.

The research findings reveal subtle differences between those displaced from their own homes and those remaining in their communities, with the displaced offering a preoccupation with returning to the comfort of home. At the time of this research, Russian forces are continuing to regularly attack the Kharkiv region with bombardments and other weapons, and people there and in Dnipro live under regular air raid sirens and concerns for immediate survival. Those residing in the Lviv region are not under regular attacks, although Russian forces do strike in different regions in Ukraine, and the worries of war and the aching of the displaced to return home persist.

Physical concerns
In this study, older people and caregivers express concerns about physical symptoms, namely pain

and respiratory concerns, as well as disabilities that affect mobility—often listing various challenges that indicate patterns of multi-morbidity.

Pain

Interviewees describe uncontrolled pain brought about by disease symptoms and because of disability:

> ***"...How can a person rest with a sick heart...I can't, it's painful. I have intercostal neuralgia [compression of the thoracic nerves causing pain]. And all my muscles are 'knocking' and pulling, starting from my ears. There is a fracture here, there was a lump here, and it did not dissolve for many years, and now it has somehow dispersed...There is such a pinpoint pain here. I start pressing here and I have a sharp pain. I have pain in my elbows. I have pain here. And when the traumatologist felt me, I felt such a sharp pain here, as if the bones are cracking."***
> **Older woman, Lviv**

> ***"...Now my legs don't support me anymore. I'm out of breath all the time. I speak and get out of breath, that's why I speak so slowly. I lie down all the time - everything hurts."***
> **Older man, Lviv**

Two older people explicitly express their desire to die peacefully and free from pain:

> ***"The most important thing is that my legs do not hurt. To die without such pain."***
> **Older woman, Lviv**

> ***"The most important thing is to die easily, so that it doesn't hurt."***
> **Older man, Lviv**

Some say their pain or physical symptoms are being managed through access to medical care, medicines, rehabilitation, and equipment such as portable oxygen, although many are unable to name specific pain medications if they have been prescribed, placing their trust in doctors or family caregivers to manage their medical needs.

Despite descriptions of unmanaged pain, several older people reflect that they do not take medications, believing that it is not healthy:

> ***"I'm not taking painkillers all the time. It's not good for me. When my joints start to hurt really badly, I'll take a pill. Otherwise, I try to endure." [Older woman, Dnipro] Others may prefer to "suffer without them."***
> **Older woman, Dnipro**

Others may not take prescribed medications because they cannot afford them on their low incomes, as described below.

One caregiver explains that her mother has given up on pharmacological pain relief entirely, as no previous interventions have worked to eliminate pain symptoms.

Such sentiments can have various explanations, including inadequate dosing of pain medications or lack of identification of medicines best suited to treat a particular patient's pain; a lack of continuity of pharmacological and non-pharmacological management of severe or chronic pain; a lack of awareness of available pain and symptom management; mistrust in prescribed medications, doctors or the healthcare system; or rationalizing that pain and suffering are inevitable in illness and older age. The multifaceted nature of the experience of pain and pain management for older people in Ukraine needs further exploration.

Other physical symptoms

Some people interviewed described other physical symptoms resulting from their illnesses. One woman had difficulty breathing:

> ***"I have to wear an oxygen mask and it's already difficult to talk."***
> **Older woman, Dnipro**

Another explained that she has reduced physical function:

> ***"My legs and arms don't work, but my mind is fine. A rehabilitation therapist is working with me."***
> **Older woman, Dnipro**

For many participants, though, physical concerns are either not top of mind as compared with emotional, existential, material, and practical challenges, or their implications are discussed as relating directly to other concerns. This reflects previous research on the reported palliative care needs of older people, where social and practical needs are expressed priorities, contrary to the physical needs often defined as a priority by healthcare professionals.[19] This has implications for the need for care that is well-integrated across all these domains and targets interventions around what matters most for older people.

Emotional and existential concerns

Older people with serious illness in Ukraine endure significant emotional and existential suffering, including anxiety and fear; loneliness and grief; loss of hope, meaning, and personhood; feelings of being a burden; and worries for the future. Emotional and existential concerns are very difficult for health and social care providers to know how to support:

> ***"It's probably the hardest. If it's physical support, it's easy. You can say, 'Here's a painkiller shot, it'll make you feel better. But the emotional pain...'"***
> **Social worker, Dnipro**

Descriptions of illness-related emotional and existential suffering are often exacerbated by the turmoil experienced by forced displacement, destroyed homes, loss of loved ones, and ongoing war. For many older people, the concerns of illness itself seem lesser to the impacts of war on their emotional states. This may reflect cultural understanding and acceptance of illness in older age by some people in Ukraine and warrants further exploration. The entanglement of emotional impacts in illness and war has also been found in other research on palliative care in armed conflict.[31]

Anxiety and fear

Not all older people and their caregivers are equally accepting of illness in older age. Some describe constant worries about disease. Illness-related anxiety is described as stemming from the impacts of disease on pain and physical function, or from being away from immediate family who can provide support in the event of medical crises.

In the context of armed conflict, anxiety, stress, and fear related to illness are entangled with the impacts of war on emotional well-being. A previous study by HelpAge International found that 82 percent of older people surveyed in Ukraine reported often or sometimes feeling distress and 76 percent feeling anxious.[21] Many participants in our research describe this entanglement:

> ***"What emotions can there be because of the war, [or] because of the disease? Of course, nothing good. Constant worries, constantly: 'Oh, it hurts. Oh, when will it stop? Oh, why does it hurt all the time? When will that war end?' These are things that do not leave you for a minute, not for a second, not for an hour, not for a day. Because we live in all that and there is nothing good in it. And that pain, and that war, and those experiences, and worries - all this is very difficult."***
> **Female caregiver, Lviv**

Several older people and caregivers describe the stress of war as exacerbating disease, pain, and suffering:

"My condition worsened because of emotions...I'm still anxious, because after every incident, after explosions, my blood sugar and blood pressure go up. My brain doesn't control it... I had to increase the dosage of my medication...Otherwise, I would have been happier, but I was scared every day. I cried a lot because of the war."
Older woman, Dnipro

Health and social care workers also emphasize the complex web of war and deteriorating illness in older people:

"They all go on deteriorating physically. Because it's age, it's war distress, it's high blood pressure."
Social worker, Dnipro

Loneliness and grief

Loneliness can arise when older people with serious illness are left isolated at home or displaced without family members or others to provide accompaniment or support to them:

"Those who are single counted on someone to look after them...a neighbor with a kind heart. Now they are left without friends, without neighbors, without a place to call home."
Social worker, Dnipro

Loneliness is countered by social connection, having family around, or knowing where to go to find healthcare or social support, which can be especially difficult in displacement. One caregiver describes the loneliness that has come with displacement:

"Here we are strangers. There is nothing of ours here. There are no familiar people...We were left alone in a strange city with nothing."
Female caregiver, Dnipro

Loneliness in older people has been reported in previous studies in Ukraine as a main driver of feelings of depression and helplessness.[23]

The loss of, and longing for, loved ones, homes, gardens, pets, and lives left behind can also lead to grief. Such grief is acutely observed by health and social care workers:

"I have an immobile, bedridden, displaced woman...When I come to her, she starts to remember her life at home and cries a lot, saying that she wants to go back home, but there is nowhere to go because her house is completely destroyed...They are constantly reminiscing – 'I had such a beautiful vase' or what 'flowers grew in the yard' and they are constantly crying."
Social worker, Kharkiv

Grief appears less in the self-reporting of older people specifically in relation to their illness. Instead, accepting and enduring illness is more likely to be expressed.

Loss of hope and meaning

The compounded impacts of illness and war can lead to a sense of hopelessness and loss of purpose. For some older people, physical pain and symptoms in illness can deplete joy:

"I don't live, I suffer...I am not able to do anything anymore. I am almost always in bed...I can neither walk nor live...no one can help me with anything."
Older man, Lviv

As one person voiced sadly:

"Life is no longer life."
Older woman, Lviv

Many health and social care workers discuss the loss of meaning and identity of older people, reflecting that they feel they are no longer making a useful contribution to society:

> *"Every morning, they wake up in stress, fall asleep in stress. There is only one thought in your head - who needs us now?"*
> **Social worker, Dnipro**

> *"People have worked all their lives, and now [they feel that] nobody needs them except relatives."*
> **Social worker, Dnipro**

For many, meaning and purpose in life often relate to participation in meaningful activities.[19]

Feelings of being a burden

Older people express concerns of being physical or emotional burdens to their families and the wider community:

> *"...My wife can't work [because she takes care of me]. I'm completely helpless...I'm tormenting my wife. How much she has suffered with me!"*
> **Older man, Lviv**

Some even voice that death is the solution to their sense of being a burden:

> *"I bother them [my children] more because I want to hear from them every day...[I want] to die myself and not to torment my children. That would be better."*
> **Older woman, Lviv**

Caregivers also describe the burdens older people feel amidst illness and the war:

> *"Now her worries have been exacerbated by the war, and we are not able to buy the necessary medicines, and she is worried that she cannot do anything. Especially that I can't help her. She is suffering and has a sense of guilt."*
> **Female caregiver, Dnipro**

Worries about the future

Older people in Ukraine describe their anxiety about the future. Illness progression and even death are secondary to worries about the ongoing war. This is true for those continuing to live under direct threat of bombing and other attacks:

> *"We still can't get used to these sirens. We react to explosions very strongly. Mum is very worried. We do not know where to go, what to do at this moment. There is no hope, no stability, we don't know what will happen."*
> **Female caregiver, Dnipro**

Those who are displaced also worry that they may not be able to return to homes and lives they left behind when fleeing for their safety:

> *"Sometimes there is a feeling of hopelessness, because of the war we abandoned everything: chickens, geese, dogs, and fled to Kharkiv. It is hard to realise that maybe we will never come back."*
> **Female caregiver, Kharviv**

One social worker describes that having a stable and comfortable home means that:

> *"People would not be afraid of tomorrow, afraid that no one would come and give them help tomorrow."*
> **Social worker, Dnipro**

Some older people express particular distress around what future awaits their spouses, children, and grandchildren:

> *"Very soon it will be my 88th year. What do I have to worry about?...The most disturbing thing is how the children are living."*
> **Older woman, Lviv**

> *"I have a life-limiting illness, unfortunately. Although I have a very good doctor. My main wish now is to live at least one day longer than Putin. I am also very worried about my children and grandchildren. I want them to live in a free Ukraine. No matter how strange it sounds, I can be considered already dead. And my children and grandchildren still have to live and live."*
> **Older man, Kharkiv**

Practical and material concerns

Practical and material concerns of older people with serious illness in Ukraine relate to difficulties meeting basic needs, often as a result of insufficient income and poverty. This reflects that palliative care support goes beyond illness and must also take into account the social, environmental, and political context in which people experience their illness. As one social worker summarizes:

> *"The beneficiaries want material assistance. They are homeless, plus sick, plus there are the bedridden. They've lost everything. Psychological help is understandable. But everyone wants material aid."*
> **Social worker, Dnipro**

Difficulty meeting basic needs

Basic needs include sufficient food, access to healthcare and medicines, and appropriate and affordable housing. Some older people and caregivers feel that their basic needs are being sufficiently met and that they are able to survive on very little:

> *"I do not need any clothes. No money needed. You need to eat, and that's it."*
> **Older woman, Lviv**

This links to a sense of self-reliance and endurance, discussed later.

Many, however, report struggling to meet basic needs. People with serious illness often have more expenses than others, as they may require more (or more costly) medications, specialized food, and other items to be free of pain and live in dignity. The inability of older people in Ukraine to meet their basic needs is directly linked to low pensions. Some in our study describe painful trade-offs in how to divide minimal resources between medicines and items such as incontinence aids, clothes, food, rent, and heating in the winter.

As one caregiver said:

> *"Unfortunately, today everything rests on financial needs in the first place."*
> **Male caregiver, Lviv**

Some older people can only afford to merely survive:

> *"...They want to eat the food they used to eat. They still want sausage and cheese...They don't have enough money for a normal life at all...They live very badly."*
> **Social worker, Dnipro**

Despite a policy of free healthcare in Ukraine, not all medicines and items are covered under the no-cost scheme. Thus, the cost of medicines and medical disposables, such as incontinence aids or catheters, can be prohibitive for those facing serious illness or multi-morbidity, exacerbated by the impacts of the war on the costs of daily living:

> *"Drug prices are now sky-high, the same with [adult] diapers."*
> **Social worker, Lviv**

One older person reports spending an entire pension on medicines. Others describe not being able to afford prescribed medicines and so having to go without. The cost of transport such as taxi hire to access medical treatment is also prohibitive for many older people.

Additionally, private housing rental costs place enormous burdens on older people and can be greater for those with illness and their caregivers who may not have any other income than pensions. Older people are often locked out of the rental market by unsustainably low pensions.[45] Concerns about pensions have consistently been raised by older people in HelpAge's research and consultations, including before Russia's full-scale invasion, and serious illness only exacerbates these burdens.[24]

Lack of accessibility leads to isolation and suffering

Several older people discuss how their disabilities, including those that impact walking, and the lack of accessibility impact their quality of life. There is a lack of practical assistance, rehabilitation, and supply of assistive products, such as wheelchairs or walking aids, in Ukraine. A WHO report in Eastern Ukraine before the current escalation showed over half of older people needed assistive products, including walking frames and toilet chairs.[23]

Several older people described losing out on meaningful social, community, and other experiences because of the lack of accessibility and assistive devices:

> *"...As long as I could walk. And now, of course, I want to go to church, and confess, and hear the service. But now I can't do anything, that's it."*
> **Older woman, Lviv**

> *"Last year in the summer I went out twice for two hours, otherwise I was in the house all year round, because I could no longer walk...I go around the house; I don't go outside. During the night, I use a bucket seven or eight times [for toileting]."*
> **Older woman, Lviv**

The need for assistance with practical or personal care has compelled some older people with serious illness to evacuate in order to secure they support they required. One older person spoke of the complex web of war, displacement, and a diagnosis of serious illness and multi-morbidity:

> *"From the first days of the war our village was occupied...my daughter asked us to leave immediately, but we refused because we had a large household. It was a pity to leave. We lived like that until I got sick and was diagnosed with prostate cancer. I also started having partial memory loss...We could not manage the household or even provide for ourselves. She saw this state of affairs and again insisted that we leave the occupied area...We ran for seven days, it was very hard because of my illness."*
> **Older man, Kharkiv**

Access and use of healthcare and social service systems

Quality palliative care for older people with serious illness involves an integrated and coordinated grid of formal medical, healthcare, and social service systems, and informal caring and support by family and community networks. Older people with serious illness will have varied experiences of accessing these services, and place different weights on what types and settings matter most to them. Caregiving, particularly in the context of active armed conflict, can be both rewarding and immensely challenging. Here, we discuss existing caring systems under sub-themes of: challenges and assets in formal care systems; the role of informal caring; and the burden of caring.

Access, shortcomings, and assets in healthcare and social service systems

Older people with serious illness reported obstacles to accessing medical care as a result of the armed conflict. For those in areas of active hostilities, medical facilities have been damaged or destroyed, medicines are scarce, and some medical personnel have evacuated. Older people who are displaced due to the war report identifying medical professionals and services in new locations.

There are also gaps in the extent to which care meets the criteria of holistic and multidisciplinary palliative care for those who would benefit. Medical care is described as being in the domain of doctors and nurses, while material, practical, and emotional care are under the remit of social workers, volunteers, and family caregivers, without clear systems of coordinated care. Older people also have specific preferences in place and type of care that are not always coherent with care system realities or with the opinions and decisions of health and social care workers, discussed below.

Access to healthcare

The war has had significant impacts on access to medical care for those with serious illness. Older people and caregivers displaced from occupied or shelled areas describe the challenges in accessing healthcare or medicines before fleeing, as their usual Ukrainian doctors, healthcare workers, and pharmacists had also fled. Some reflect on the relief in then being able to find good medical care once arriving in their displaced setting:

> ***"It was hard when my mother lived under [Russian] occupation, fell, and lay on the ground for half a day and began to say goodbye to her life. Later, when my mum was moved to Kharkiv, things got better."***
> **Female caregiver, Kharkiv**

For many, internal displacement has ruptured continuity of relationships and treatment with trusted hospitals and medical professionals. Some older people may face serious difficulty navigating an entirely new healthcare setting:

> ***"Of course, the war had an impact. Things were completely different at home, there was no such stress, and I knew people in my city (not so much doctors, at least in hospitals). In a new city, you have to look for all the contacts."***
> **Male caregiver, Lviv**

Healthcare workers also identify displacement as a major challenge in supporting older people with serious illness:

> ***"Once they get to a foreign city, without any contacts or acquaintances, they get lost, and we see this too...when they find themselves here without documents, without disability certificates, and they have to do everything again, and the previous information about their previous illnesses is lost...We simply do not know who this person is."***
> **Local government healthcare representative, Lviv**

The lack of sufficient involvement of primary care doctors for older people with serious illness is identified as a concern by some health and social care workers. Influxes of displaced older people with serious illnesses, who have often fled without family members, creates stress on already overwhelmed healthcare and social service systems in parts of Ukraine. WHO surveys on healthcare needs and access for adults in Ukraine in 2023 and 2024 report that those who are internally displaced have less access to family doctors than those in local communities, with one-fifth of those internally displaced having no access to a family doctor.[8, 10]

Cost of medications, particularly in light of income insecurity and the impacts of the conflict on prices, or reluctance to take medicines may also make some older people hesitant to seek healthcare or follow medical recommendations. Some older people and caregivers describe seeking out alternative medicines in addition to or in place of pharmacological therapies, or when medications have not been able to alleviate pain:

> ***"...Earlier her pain was slightly offset, relieved by these non-steroid drugs, then rubbing was done with different folk remedies - with mustard, with honey, with horseradish, and with cabbage. And what we haven't tried!"***
> **Female caregiver, Lviv**

Some older people and caregivers may not always seek out medical care except in emergencies, perhaps reflecting a lack of knowledge of what services are available to them, rationalizing that health deterioration is part of getting older, or owing to deep stoicism and endurance, discussed later. Some older people describe that they do not like going to the hospital, may be fearful of admission or institutionalization, or would prefer to stay in the comfort of home:

> ***"...My mother doesn't like hospitals and would rather be at home. She likes TV, to be alone, and for me to come visit."***
> **Male caregiver, Lviv**

Minimizing the use of services and relying more on family networks has been reported in studies on older people with multi-morbidity in other settings.[19]

At the same time, some people interviewed generally trust medical professionals with their healthcare. Several described their gratitude at medical care received:

> ***"When my husband underwent surgery in Kharkiv and I saw how carefully and caringly he was treated, I felt first relief, then gratitude, and the feeling of loneliness immediately disappeared."***
> **Female caregiver, Kharkiv**

Social service systems and the role of social workers

Much support and care for older people, including during the armed conflict, comes in the form of paid or voluntary community social workers often engaged outside the government system by charitable organizations such as HelpAge, the Ukrainian Red Cross, and Caritas.[58] In this research, older people and caregivers who are visited by a social worker show great appreciation for the support they receive:

> ***"I am especially happy that I have a social worker. She is like a second mother to us."***
> **Female caregiver, Kharkiv**

Social workers provide different forms of support and advice to older people and family caregivers, in some cases providing material assistance such as hygiene kits and incontinence aids, sourcing assistive devices, and offering psychosocial support. Social workers also fill important gaps in care that should otherwise be provided by the healthcare system, and their absence is felt if they are not available.

Some describe instances of older people turning to them as the resource for different types of assistance:

> ***"I also help to solve some domestic problems at any time in the beneficiaries' lives."***
> **Social worker, Kharkiv**

Others may reach out for medical advice:

> ***"A man called and said that he was in pain. He had a first aid kit in front of him, but he did not remember which pill to take...And on the phone he tells me what kind of pills he has in front of him. And I can help him in this way."***
> **Social worker, Dnipro**

Social workers can also serve as care coordinators in the event of medical issues or deterioration. The breadth of expectations on social workers may occur without always having the appropriate skills or training to take on higher levels of care or care that might be more suited to trained medical professionals. They may also not be paid salaries that are commensurate with the services they offer.

Psychological support for older people with serious illness is identified, at its most basic and imperative level, as accompaniment, having someone to visit or call, and having someone to talk to who cares. Some participants describe their role in psychological support as providing support during loneliness, grief, or suffering by being upbeat and positive and offering humor; sharing a cup of tea or baking cakes; or even sharing an alcoholic drink together. As one social worker describes:

"The only thing to do is to switch to another topic. For example, 'look, today it's spring, acacia blossoms, beautiful kitties are walking in the yard.' You can overload people on some positive emotion."
Social worker, Dnipro

Many older people and caregivers are not inclined to talk about personal issues or share their feelings. At the same time, many do find comfort in being able to open up about their concerns and sadness:

"I am generally a closed person...but you somehow managed to talk to me. I somehow shared with you, and I became brighter on the soul."
Female caregiver, Kharkiv

Small but potent acts of compassion [59] of just being with a person, holding a hand, or listening are also significant:

"At some point in the conversation, the woman took my hand and held me for a while."
Healthcare worker, Lviv

"Someone has become lonely here. Or someone's children died there. Here you can only hug and just be silent. Here you don't need to say words. Words like 'time heals' don't work at all. You just listen quietly."
Social worker, Dnipro

Most participants do not necessarily see a need for psychological care from trained psychologists, but rather believe that everyone has a role to play in providing basic psychological support to older people with serious illness.

Some social workers also describe the mutual support and friendships that form in supporting an older person with serious illness and during the war:

"...When there's shelling, when there's an alarm, they call to support me. I don't want to say give me a boost. But they call to support me...this conversation can go on for two hours or more. I've cooked a meal, I've already eaten. And they comfort me. They tell me. They trust me."
Social worker, Dnipro

Preferences and realities of place of care

Almost all participants in this research reflect on place of care. Many health and social care workers look to the large numbers of older people in Ukraine who do not have the support of family caregivers and describe the importance of a future system of palliative care reliant on residential care, including geriatric facilities, hospices, and inpatient palliative care beds. Palliative care can be seen as synonymous with long-term care:

"We have a lot of people who are just living out their time. They have been left behind by their families and are lonely. We need institutions where there is medical care in the form of supervision by nurses...Such institutions should be in Ukraine."
Healthcare worker, Lviv

Institutional care may also seem like a solution to the burden some caregivers experience:

"It would be ideal if a person were in a hospital, where they are looked after and fed as much as possible."
Male caregiver, Lviv

However, these sentiments do not reflect the preferences of older people themselves interviewed in this research. All older participants are living in

their own homes, rented accommodation, or small shelters, and not in residential institutions. They make clear the preference to stay at home for care. As one older person says, supported by a caregiver:

> ***"I feel good at home."***
> **Older woman, Lviv**
>
> ***"God forbid, she doesn't want to go anywhere. She's better at home."***
> **Female caregiver, Lviv**

Many would like to receive medical treatment and also be supported by family at home:

> ***"The most valuable thing is that I have treatment and that my daughter takes care of me."***
> **Older man, Dnipro**

> ***"[What is most valuable to you?]...family care."***
> **Older man, Dnipro**

The importance of place of death in serious illness and in displacement is again inextricably linked with the impacts of the war and the deep desire to return to one's own home:

> ***"Sometimes you hear the following: the trees seem to be the same as at home, the people are the same, the doctors are reliable, but I still want to go home. I want to die on my own land."***
> **Social worker, Kharkiv**

These opinions are supported by previous studies in Ukraine, where residential institutions are rejected in favor of strengthened home-based care and, in particular, greater social supports at home.[24, 45, 39] Views on increasing institutional beds are at odds with advocacy efforts to counter rising institutionalization, as well as with the Ukrainian government's stated commitment to move away from residential care, in line with international human rights standards and as an EU candidate country.[45] These views also seem to diminish the value, contributions, and strength of older people in Ukraine and their preferences. Segregated, institutionalized care can have negative outcomes for older people and can infringe upon their human rights.[19, 44]

A comprehensive system of home- and community-based care for older people with palliative care needs is not well-established in Ukraine.[38, 51] Future models of palliative care and long-term care must try to balance the practical realities of a changed population with increased demands for healthcare and social services, alongside the wishes of older people living with serious illness or multi-morbidity.

Understanding of, and access to, formal palliative care services

Some participants in this research are involved in direct palliative care service delivery, and all health and social care workers interviewed have an awareness and understanding of palliative care for older people. Standardized palliative care definitions learned through specialist or basic training are cited by participants. This may reflect the level of experience and access to training of participants in this research, however, and is not necessarily indicative of palliative care awareness and understanding for health and social care workers across Ukraine. An understanding of palliative care grounded in standardized classifications also does not always align with the attitudes, practice, and preferences described by participants, particularly concerning person- and community-centered care and choice around place of care and death.

Caregivers in Kharkiv describe receiving multidisciplinary, home-based palliative care involving both medical staff (doctors and nurses) and social workers. These services allow people to receive quality care and support, both specialized and informal, in the comfort of their own homes:

> ***"Now a doctor and a nurse come to us twice a week to monitor my husband's condition. We also have the most wonderful social worker, who solves all the problems at home."***
> **Female caregiver, Kharkiv**

"First of all, we receive help from the state, doctors from the palliative care team visit us all the time, and a social worker comes to us."
Female caregiver, Kharkiv

Healthcare participants describe current inpatient hospital palliative care, which is the predominant form of palliative care delivery in Ukraine. Quality of life, attending to the individual and their goals, and honoring last wishes even in the face of progressive and incurable illness are reflected as priorities. For example:

"We had a case when the team was involved in fulfilling the patient's last wish. They helped with transportation to the sea. A mobile team took him from Lviv to Odesa, as his last wish was to see the sea."
Local government healthcare representative, Lviv

However, some also discuss that a focus on inpatient medical and nursing care without the involvement of allied healthcare or social care professionals seems to limit the quality of care to a primary focus on the medical needs, rather than a holistic view:

"From a medical point of view, we are provided with medicines...and all kinds of devices, beds. But walking with the sick, taking them outside, expanding their leisure time...Puzzles or game of checkers...It's not easy to spend a day inside four walls."
Healthcare worker, Dnipro

Participants also discuss that inpatient palliative care can sometimes be conflated with institutional geriatric care:

"...We are not a home for the elderly with no one to look after them. We are a medical department for people with incurable diseases."
Healthcare worker, Dnipro

Ukraine faces a significant challenge in determining the overlaps or distinctions between these separated systems of care, particularly for older people with multi-morbidity, unclear illness trajectories, and vast social needs.[19]

Role of informal caregiving

For older people who still have family in Ukraine and live at home, the bulk of support and care is undertaken by informal caregivers such as children and spouses.[12, 38] Many older people in this research report moving homes to live with or be near their children in the face of serious illness and forced evacuation. Extended family, including grandchildren, provide emotional support on the phone when they cannot be close. In some cases, families support with the tasks of daily living and (sometimes heavy) personal care, such as showering, using the bathroom, and bed-based care. They also assist with medicines, healthcare coordination, and liaising with doctors and provide love and accompaniment:

"My husband is with me 24 hours a day...He knows how to do the work. Both female and male work...We lived together for...56 years. A reliable friend and life partner...First, he feeds me...Helps me to sit up in bed...does laundry and this and that."
Older woman, Dnipro

One older person describes how she has tried using professional psychological phone support, but much prefers the intimate, calming presence of talking with her daughter. For one caregiver, the event of serious illness has strengthened her relationship with her mother. Participants describe their support for an older relative as manifesting out of love or a sense of duty:

"Because our beneficiaries have nothing left, there is no inheritance. She is acting out of love."
Social worker, Dnipro

"She did a lot of good for me in life and gave most of her life to me. And it is my sacred duty."
Female caregiver, Lviv

Neighbors and community members also play a role in supporting older people with serious illness, especially for those left behind and alone in war, or in the frenzy of evacuations. Even passers-by were identified as having a role to play in supporting older people with serious illness. Older people can provide mutual company for other older people, and social workers can play a role in facilitating relationships:

> ***"I have people who are strangers to each other, but they rent one apartment…I've brought them together. And now they're talking to each other…It's mutual help."***
> **Social worker, Dnipro**

But many community members are themselves older and not necessarily able to provide significant support, or older people and caregivers may be reluctant to ask neighbors for assistance. Altered living arrangements of older people in displacement can create uncomfortable or challenging dynamics, as in this case in which a social worker describes:

> ***"I have one woman. She is alone. She rents one room in an apartment. And in that apartment, the owners are a husband and wife. The husband is a bedridden man. The wife goes to work all day. And this grandmother has to help this man. And because of this, she tries to go somewhere for the whole day, not to take care of him."***
> **Social worker, Dnipro**

There is scope to strengthen or expand the role of community groups and volunteers, particularly for those needing palliative care but who are not fortunate to have the support of family. The participation of communities in caring for isolated older people because of war-related changes in demographics and disease burden is identified as an urgent priority.

Burden of caring

Burden of informal caregiving

Older people with family members often have no access to formal government or charity social supports, as these are prioritized for older people without family to support them. This can be a significant burden, as all informal caregivers in this research, both spouses and children, are older themselves and may have their own health issues

> ***"I am 68 years old. I am a pensioner. I take care of my mother."***
> **Female caregiver, Lviv**

Informal caregivers may also have to balance the demands of working and full-time caregiving, or be forced to leave paid employment.

Personal care and support can be taxing, overwhelming, and isolating and can impact the health and well-being of the person supporting, with few opportunities to share the weight of care:[5]

> ***"I don't have much time to spend with her because I have things to do. Everything is on me. I have to deal with it all."***
> **Female caregiver, Dnipro**

Health and social care workers identify the enormous unmet need for relieving carers from practical or social caregiving tasks:

> ***"Caregivers need help even more. They meet us with tears in their eyes and say that it is very difficult to be constantly with a sick mother 24/7."***
> **Social worker, Lviv**

Impacts of caregiving on health and social care workers

Health and social care workers also discuss the impact that caring for older people with serious illness through the conflict has on them personally. They work through the threats and danger of bombardment and other attacks, hardships of displacement, financial concerns, unmet basic needs, and the losses, grief, and fear of the ongoing armed conflict. It can be hard to compassionately care and hold the suffering of others where grief is proximal and personally felt.

One social worker describes the accumulation of caring for older people with very complex needs and the load that social workers need to carry with minimal supports:

"In another family, the daughter…takes me to her mother's room and leaves me there. And I'm alone with her there…She is constantly trying to do something: either climbing the walls, or trying to climb out the window, or stabbing herself right in front of me, choking on something. Then, when I leave her, I stand in the street and take a long time to come to my senses, thinking about what to do. And I get a headache for the whole day until night…all this is accumulating in me, and I can't dump it all on someone. I brought it home. I can't yell at anyone."
Social worker, Dnipro

Several participants called for systems of psychological support for health and social care workers to aid their ability to provide compassionate palliative care.

Personal coping mechanisms

Older people and their family caregivers describe important personal coping mechanisms alongside care systems. Here, we summarize these as: acceptance and endurance; spirituality and religion; and finding hope, meaning, and small joys. The personal coping mechanisms, desires, and preferences of older people are again sometimes at odds with what health and social care workers say is most important. This has significant implications for models of caregiving in the future of palliative care.

Acceptance, self-reliance, and endurance

The older people interviewed in this research display a characteristic stoicism. Many older people and caregivers affected by serious illness relay acceptance and endurance in their words and stories, describing not needing or wanting to seek support for physical, practical, emotional, or existential concerns, even if they had previously discussed the presence of such concerns.

Illness and death acceptance

Serious illness and older age tend to be straightforwardly accepted by older people and their caregivers in this research:

"I have to live with this diagnosis…I understand that there is a need [to be calm]. Nothing will change."
Older woman, Dnipro

"There's no escaping it. After all, age and diseases, and you just need to care for and help as much as possible."
Female caregiver, Lviv

Death or the closeness of end of life are also accepted, and easy to speak of for many:

"I am not afraid of death"
Older man, Lviv

Some believe that it is fate or God that has brought them to their disease and give thanks for lives well-lived and nearing the end of life with no regrets.

Such acceptance seems to extend to a mindset of not dwelling on difficulties or suffering for too long, but getting on with life with tolerance and meaning. Some older people speak of the miracle of still being alive through war experiences, where current concerns around illness and aging may pale in comparison:

"I barely made it out alive…I can't walk, but it's not a big deal anymore."
Older woman, Kharkiv

Some also voice that emotions do not help with influencing the outcome of either disease or war.

Self-reliance and endurance

Older people in this research show extraordinary self-reliance and perseverance. Some older people and caregivers, including caregivers with health problems themselves, describe not asking for help, even if it might seem important:

"For now, we are coping on our own, while our health still allows. Although we are sick themselves. My husband is already sick, and I am sick, but we are coping on our own, so we did not go anywhere, did not ask anyone for help... We try to cope with ourselves, to reassure ourselves that there is no escape, that such a fate has fallen on our lives. And we have to live with it somehow, put up with it and fight with fear, and overcome ourselves, and occupy ourselves with something, distract ourselves in order to think less about the war, about diseases."
Female caregiver, Lviv

Those living in the eastern parts of the country, which have faced the most relentless attacks as well as occupation in many areas, show great endurance and pragmatism in basic survival:

"Our grandmothers are all prepared: they have water and candles."
Social worker, Dnipro

They are not used to counting on outside help, do not necessarily look for it, and in some cases may not trust it:

"We didn't walk around with our hand extended [begging]."
Older woman, Dnipro

"We hope only for ourselves. And for the war to end this year...You have to believe in yourself."
Older woman, Dnipro

These sentiments do not mean that older people will reject medical care and support, but that many do need to continue to feel a sense of purpose and self-reliance through any assistance and healthcare provided.

Spirituality and religion

Religion is an important mechanism for many older people and their family caregivers in this research to cope with both serious illness and war, which coexists with self-reliance and belief in supporting oneself. Living through illness, but particularly the horrors of war, has reportedly strengthened many participants' belief in God. The importance of faith in God is described by participants in both eastern and western oblasts:

"I'm ex-military, so I didn't believe in God before. In Soviet times, believing in God was forbidden...Now after what I've been through, I would define my belief in God by the words 'I have to believe.' My faith in God has changed me, of course, but I still have to set myself up for everything to be all right, you know? To forget everything that we suffered during the period of life in the occupation and to continue to live and believe in everything good."
Older man, Kharkiv

Protection from shelling and the war's end in particular are seen as being in the hands of God:

"A disease is a disease. We all now live with great faith in God. He will help us...the most terrible thing that exists now is to get out of that war somehow, so that peace and tranquillity reign in the world, in the country."
Female caregiver, Lviv

"He [God] helps me from all sides, especially when missiles are flying from Belgorod in Russia to Kharkiv. You know that air defence is of no use. It depends only on God whether the two of us will survive or whether a missile will hit our house. I start praying as soon as the air raid happens and ask God for protection. Since my mother became ill and my children went to serve in the armed forces, I start every day with prayer."
Female caregiver, Kharkiv

Older people describe enjoying attending church, and those unable to get out due to their illness or disability describe the calming effect of icons, prayers, reading the Bible, and using holy water brought by parishioners to home. One older person openly voices their religious wishes towards the end of life at home:

> ***"I can't go to church. We will call a priest when the time comes."***
> **Older man, Lviv**

Religion can be a barrier to accessing formal healthcare and support, however. In Ukraine, an individual taxpayer number and passport are needed to access free-of-charge medical services, including specialist palliative care. Some Orthodox Christians, particularly in the west of Ukraine, refuse to get an individual taxpayer number due to religious beliefs, based on an interpretation from the Book of Revelation in the New Testament of the Bible where having such a number is viewed as satanic or a path to eternal suffering. One older person describes her strong belief in refusing a taxpayer number:

> ***"They forced me to get an identification number. I said that I will starve, I will suffer, but I will not betray my faith...if I also sell my faith, I'm a dead soul."***
> **Older woman, Lviv**

Such beliefs may prevent people from getting the medical help they need.

Spirituality beyond religious beliefs is discussed in the context of maintaining a sense of hope, purpose and meaning, and believing in the strength of oneself. One older person describes symbols of spirituality and healing found in nature in the hope of her recovery:

> ***"I believe that when you get very sick...the moon and the sun heal you...I'll pour [water] at dawn, to make me healthy...Stones rolled into the Dnipro River over the years and turned into sand... Glands, lungs, liver, stomach, you know...water.."***
> **Older woman, Dnipro**

Finding hope, meaning, and small joys

Many older people and caregivers in Ukraine also maintain hope that things will get better or they will recover from their disease:

> ***"I still want to live...the desire to make it go away...I want to believe in recovery. I strive for it."***
> **Older woman, Dnipro**

Hope is an important coping mechanism in serious illness for people all around the world, even if death is also easy to speak of.

Social connection, particularly having family around in the home or on the phone, or spending time with volunteers and social workers is calming and provides hope and meaning. One healthcare worker observes a usually reserved older person with serious illness enjoying simply being around people out of the isolation of home:

> ***"The pleasure of staying in a cozy café was noticeable...he had just returned from his daily breakfast at the church, which was organized by volunteers."***
> **Healthcare worker, Lviv**

Social connection also brings joy:

> ***"My wife will take me by the hand, look at me like when I was young, and I feel good!"***
> **Older man, Lviv**

Many older people speak of trying to find identity and meaning through small joys or distractions in daily living:

> ***"I love listening to music. What am I left to do? I still listen to the radio and sing a little...And this summer, as I live, I can sit at least a little outside... Yes, maybe I'll sit on that swing."***
> **Older woman, Lviv**

Hope endures in serious illness even near the end of life and in the smallest joys, an important reminder for those caring for older people through such times:

"I have a patient with stage 4 cancer…the hospital gave him a poor prognosis and said that there was very little time left. But the patient told me: 'I will not die until I see my grandson'…Recently, his grandson was born. You should have seen the happy eyes of the grandfather! Now he says: 'I want to hear my grandson's first word!' What can you feel here?"
Healthcare worker, Lviv

For many older people, there is a deep yearning to put behind the suffering of the war and to continue living on after the war has ended. The hope of surviving the war and surviving serious illness are almost impossible to separate:

"I pray that the war will end as soon as possible…I also ask Him to give my husband's health so that we can return together to our dogs, cats, ducks and chickens."
Female caregiver, Kharkiv

The miracle of war survival is a stark reminder of the importance and hope of living:

"There was such a feeling when we escaped from our town here under the shelling, and I realised that we survived and that is the most important thing: life."
Older woman, Dnipro

The idea of being or returning home is also an important hope for many:

"The most important thing for me and my mother is that the war ends. I want everyone to come home alive. I want to take my mother and go to my home in the Kharkiv region…I really want to go home, and it is impossible to put it into words. As they say in Ukrainian, at home, even the walls help."
Female caregiver, Kharkiv

Translating older peoples' preferences into future directions of palliative care and long-term care in Ukraine

This section describes participants' views on the future of palliative care in Ukraine. Here, we summarize these as the need for holistic, multidisciplinary, and integrated care; coordination between government healthcare and social service delivery; and strengthened partnerships with Ukrainian NGOs. It is also crucial that the government invest in home-based and community-based support and care rather than institutionalized care, consistent with the preferences of older people and their rights to live and be included in the community. Support and training for health and social care workers are also essential components of comprehensive palliative care programming. The views described should be read in context of all that has come before—the concerns, preferences, and hopes of older people with serious illness in war, their personal coping mechanisms, and the existing challenges and assets in formal support services and informal caregiving.

The need for holistic, multidisciplinary, coordinated, and integrated care

Despite some important advances in the palliative care system in Ukraine, holistic, multidisciplinary, and coordinated palliative care prepared to address physical, emotional, social, and spiritual aspects of serious illness has not received sufficient attention or funding from the national government down to primary and community healthcare and social service systems. Palliative care is also not well-integrated with long-term care and support. Palliative care and long-term care systems, as noted above, remain largely concentrated in residential and hospital settings, rather than in communities, where older people prefer to receive services.

Cost should not be a barrier to accessing quality, integrated palliative care services. As described above, older people often have insufficient income to pay for medical care, medicines, and social services. Their health and well-being can deteriorate significantly if they forgo treatment due to cost or are forced to choose between treatment and medicines and food or adequate housing.

Coordination between health and social care systems is piecemeal and often reliant on local relationships and informal referral mechanisms. Inpatient hospital units, focused on medical and nursing care, do not always offer multidisciplinary professional care, particularly for social, practical, and emotional support, which older people with serious illness have highlighted as crucial elements of the services they require. It is social workers and family caregivers who carry the weight of coordinating and delivering support and care for older people at home, in temporary shelters for displaced persons, or institutions. Social workers are not well-paid and not always paid on time, leaving the profession understaffed:

> ***"Not many people are interested in working as social workers."***
> **Local government social care representative, Lviv**

Several participants discuss the need for coordination between government ministries:

> ***"The activities of the multidisciplinary team [for palliative care patients] are regulated by the procedure for interaction between palliative care providers and social service providers approved by the Ministry of Health of Ukraine and the Ministry of Social Policy of Ukraine, but in practice communication between the two ministries or departments leaves much to be desired."***
> **Healthcare worker, Lviv**

Better coordinated and more seamless care across services requires improving understanding of the respective roles of both health and social ministries in palliative care service delivery, improved referral pathways between providers, and government legislation, including on patient information sharing between medical and social care systems.

Civil society organizations play a critical role in supporting older people in Ukraine, but health and social care workers may not know where to find information about these organizations and their activities. State and NGO providers are not always well-coordinated:

> ***"A civil society organization often cannot find a beneficiary, and healthcare services have beneficiaries and do not know which civil society organization to contact for help with further patient support."***
> **Social worker, Lviv**

NGOs could play a crucial, strengthened role in palliative care services in Ukraine through formalized partnerships and coordinated systems and services.

Investment in home-based and community-based support and care

Reflecting the wishes of older people with serious illness in this research to receive support and care and to die at home, the Ukrainian government and its partners must strengthen multidisciplinary and coordinated home- and community-based care systems, rather than increasing beds in institutionalized care.[9]

Overcrowded and overwhelmed residential long-term care facilities face serious challenges in providing quality care. A local government representative highlights the combined challenges of displacement and problems with institutions:

> ***"The majority of older people are alone without family and caregivers. This is a big challenge... all the displaced people are accumulated in the western region...Institutions are overcrowded...they are not repaired, [there are a] lack of commodities, a limited number of staff...Family doctors and specialists are not paid, they are not willing to continue their services. There is no budget...There are other priorities for government such as security reinforcement, no budget for care of institutions and care for older people... [There is a] large number of people, [many of whom are] bedridden. There is no proper shelter with poor ventilation. They cannot go out. [They have] no one to speak with them. They are deprived of food and basic services."***
> **Local government social care representative, Lviv**

Primary care doctors do not currently seem to play a significant role in home visits or in supporting basic community palliative care, and may lack awareness and training of palliative care and their role in service delivery. Social workers describe the urgent need for supplementing their psychological and basic social support provision, as well as the care already provided by many family caregivers, with nursing and personal care in the home:

> ***"...We need the government to allocate more money for support, so that they can receive decent help...if they are at home, then help can be to wash, change, but this is what relatives do. And we just bring the necessary hygiene products, mobility aids, diapers, to talk."***
> **Social worker, Dnipro**

Free social transport schemes are also identified as a priority, especially to accessing medical care. In this way, older people would be better enabled to stay at home for as long as possible rather than enter institutionalized care, often against their wishes and preferences.

Community caregiving

Health and social care participants speak of the need to strengthen the role of community and civil society in supporting older people with serious illness and their caregivers. Raising awareness of palliative care needs in communities through community forums is a first step. There is also an opportunity to use palliative care as a catalyst for fostering grassroots initiatives and strengthening the role of civil society in caring systems in Ukraine:[13, 38]

> ***"We should not be silent about it in order to attract people, volunteers, and financial contributions, because this is the humanity of our society."***
> **Local government healthcare representative, Lviv**

Social workers speak of the importance of community systems, which can provide respite for overwhelmed family caregivers. Creating Community and neighborhood caring networks around older people to address local needs and support both informal families (and also considering the needs of older caregivers) and formal professional palliative care systems is a cornerstone of the Compassionate Communities model and public health palliative care approaches.[60, 61, 62]

Participants also discuss the need to implement processes for basic carer skills training and self-care education for family caregivers. Bereavement care is not a well-recognized part of palliative or older persons' care in Ukraine. Neighbor and community support systems could play an important role in supporting caregivers in death and grief.

Support for health and social care workers

This research identifies the need for systems to better support Ukrainian health and social care workers who provide care for older people with serious illness and complex needs while working against the backdrop of their own challenging situations. Providing space for self-care and formal workplace supervision is important in any palliative care setting to prevent moral distress or burnout. This need becomes even more important when living and caring through war.

Health and social care workers in this research recognize the importance of holding space for sharing experiences, debriefing, and supporting each other. Even the process of speaking in a focus group brings benefits:

> ***"Sharing information is very important, even with each other, so we need to have meetings like today more often. Sharing information will make your job easier."***
> **Social worker, Lviv**

One suggestion is to start informal Viber groups amongst colleagues. They also identify the benefits of more formal psychological training and support to enable them to deliver quality and compassionate care.

Conclusion

This research has identified significant concerns and challenges for older people with serious illness in Ukraine, as they, their family caregivers, and the health and social care workers who seek to support them tackle serious illness, suffering, and caring within the political, environmental, and social context of the ongoing armed conflict. Older people in this research tolerate older age and illness and face the prospect of death with grace, self-reliance, and fortitude. The findings also point to important opportunities for understanding contextually relevant palliative care for older people in war, for further research, and for new or strengthened partnerships in care systems and care delivery that are yet to be embraced or realized.

The relationships between medical care and social services—and between long-term care and support, geriatric care, and palliative care—need in-depth exploration where the structure of demographics, epidemiology, and social support systems have been dramatically altered in Ukraine for the extended future. Efforts to strengthen formal care systems need to closely consider not only gaps in existing policies, models, and interventions, but the critical role of social, family, and community caregiving and the strength of personal coping mechanisms of older people. Above all, older people's voices and lived experiences must inform future palliative care policies, programs, and efforts that are designed to support them with quality and love in their last years, months, weeks, or days of life.

Appendix One: Methodology

Qualitative research

This was a qualitative research study seeking to elicit the subjective and lived experiences of older people with serious illness, informal caregivers, and health and social care workers across three oblasts in Ukraine: Lviv, Dnipro, and Kharkiv. Interviews and focus group discussions were conducted throughout March and April 2024 by HelpAge staff employed in Ukraine. HelpAge staff undertook online qualitative research training in early March 2024 facilitated by the report author.

We conducted 11 semi-structured individual interviews with older people with serious illness and six interviews with family caregivers. These were conducted in-person in the participants' place of living (i.e., home or shelter). One older person requested to be interviewed in a local café. HelpAge interviewers also recorded observation notes following interviews with older people using a semi-structured ethnographic observation guide. Interviews lasted between 20 minutes and two-and-a-half hours.

Criteria for inclusion for older people and informal caregivers to participate in this study were: beneficiaries of existing HelpAge programs (or informally caring for a beneficiary); over 60 years (or informally caring for a person over 60 years); a formal diagnosis of a chronic or life-limiting illness or multi-morbidity, or informally caring for a person with a chronic or life-limiting illness or multi-morbidity (for example, cancer, chronic obstructive pulmonary disease [COPD], heart failure, renal failure, liver failure, diabetes, HIV, TB, neurological disease, Multiple Sclerosis, Parkinson's Disease, Motor Neurone Disease, etc.); and living or caring at home or in a shelter (displaced or local). Table One provides a summary of participant information of older people and caregivers.

We also conducted three in-person focus group discussions with HelpAge-employed social workers across each oblast, and two in-person focus group discussions with healthcare workers in Lviv and Dnipro. Security challenges meant that a focus group discussion with healthcare workers was not conducted in Kharkiv. Table Two provides a summary of participant information of health and social care workers.

Interviews and focus group discussions were conducted in-person with local government ministry staff in Lviv: one interview with a local government representative from social care and one focus group discussion with three local government healthcare representatives.

All interviews and focus group discussions were conducted in the participants' language of preference (Ukrainian or Russian). Interviews and focus group discussions were audio-recorded, transcribed verbatim, and translated into English by a qualified HelpAge-employed translator. Fully anonymized transcripts were thematically coded and analyzed by the report author remotely and discussed with the HelpAge team before report write-up.

The author also held informal discussions with selected experts involved in palliative care systems and service development and training and education in Ukraine. These informants provided personal testimony, guidance on documentary sources, and input on the drafting and recommendations of the report.

Documentary analysis

Documentary sources related to the health and social context in Ukraine were analyzed as collateral data sources and triangulated with the primary research. This included analysis of more than 70 documents concerning the humanitarian situation in Ukraine; the historical and current state of health, social care, and palliative care services; and the burden of mortality and morbidity for older people.

Additional data concerning older persons' basic needs, access to healthcare, social support systems, emotional states, and coping mechanisms was drawn from an existing data set of a representative survey of older people in Ukraine conducted by HelpAge International in late 2022.[15]

Documentary analysis included:

- Peer-reviewed journal papers
- Non-peer reviewed papers including editorials, comments, and correspondence
- HelpAge documents and reports
- Other NGO and UN documents
- Ukraine Health Cluster documents
- Relevant blogs and news articles (e.g., E-Hospice, European Association of Palliative Care)
- Applicable legislation and policies relevant to palliative care in Ukraine

Ethical and security considerations

Ethical and security risks and mitigation strategies included:

- Confidentiality and data storage: Participants were provided with a Plain Language Statement on the project and written consent was obtained to participate in the research. Only one interview participant declined to be audio-recorded and hand-written notes were taken instead. Audio recordings were uploaded to password protected computers and deleted from portable devices immediately after interviews. Personal information was kept separate from interview transcripts. Pseudonyms have been used for all quotes in this report.
- Distress for the participants: The research hinged on discussions exploring the sensitive topic of illness, death, and dying in a conflict setting. Interviewers needed training in how to respond to any distress arising from participants, how to cease interviews in the event of significant distress, and how to refer participants to their social worker or the HelpAge mental health team if required.
- Distress for the interviewers: The interview process risked being equally distressing for interviewers, who were themselves a part of the Ukrainian community. Informal and formal processes were put in place for debriefing with HelpAge staff involved in conducting interviewers.
- Safety risks and security: HelpAge staff needed to ensure that security and safety risks to both interviewers and participants were appropriately mitigated. In particular, security clearances were required for group gatherings for focus group discussions and appropriate security clearance needed to be obtained for travel to Kharkiv.

Research limitations

This was a small research project in which the primary focus was the views and lived experiences of older people and their informal caregivers. It involved participants from three oblasts only. While some differences in the experiences of older people and family caregivers between eastern and western parts of the country—and between internally displaced and local residents—could be surmised, it was not possible to understand these differences in detail. The research only included older people residing in homes or shelters and did not include the voices of those with serious illness in hospitals, hospices, or residential institutions.

Focus group discussions and interviews with health and social care workers were supplementary, and the number and spread of healthcare disciplines was limited, with only doctors and nurses participating and no representation from allied healthcare staff. Future research should more fully explore the views of multidisciplinary health and social care workers to understand how their experiences and perspectives may align or diverge from those of older people and informal caregivers.

The methodology also included a small number of local government representatives from health and social care as supplementary. However, it was beyond the scope of this report to include senior national government officials. Such representation may also be the focus of future research on a national vision, policies, plans, and legal frameworks for palliative care.

We also recognize the limitations in this methodology in exploring lived experience without a process for designing future palliative care research or implementation in collaboration with older people themselves. In several of the interviews with older people and caregivers, our interviewers were left with an acute sense of inability to offer any care or next steps. We advocate for next steps in the development of palliative care in conflict-affected Ukraine to ensure older people and community members are included in design processes.

Table One. Participant information: Older people and informal caregivers

Participant type	Number	Gender	Age range	Displaced/local	Place of living	Diagnoses
Lviv						
Older people	N = 4	F = 2 M = 2	60-69 = 1 70-79 = 2 80+ = 1	Displaced = 3 Local = 1	Shelter, own home	Malignancy, cardiovascular disease
Informal caregivers	N = 2	F = 1 M = 1	60-69 = 2 70-79 = 0 80+ = 0	Displaced = 1 Local = 1	Own home	
Dnipro						
Older people	N = 5	F = 5 M = 0	60-69 = 0 70-79 = 3 80+ = 2	Displaced = 1 Local = 4	Rented housing, own home	Malignancy, diabetes, heart failure, myocardial infarction
Informal caregivers	N = 2	F = 1 M = 1	60-69 = 2 70-79 = 0 80+ = 0	Displaced = 1 Local = 1	Rented housing, own home	
Kharkiv						
Older people	N = 2	F = 1 M = 1	60-69 = 0 70-79 = 0 80+ = 2	Displaced = 2 Local = 0	Rented housing	Multi-morbidity (malignancy, hypertension, dementia, diabetes)
Informal caregivers	N = 2	F = 2 M = 0	60-69 = 1 70-79 = 1 80+ = 0	Displaced = 2 Local = 0	Rented housing	

Table Two. Participant information: Health and social care workers

Participant type	Number	Gender	Professional background	Years of experience	Place of work
Lviv					
Healthcare workers	N = 6	F = 5 M = 1	Doctor = 3 Nurse = 3 Allied health = 0	<5 = 0 5-10 = 2 10+ = 4	Outpatient clinic
Social workers	N = 4	F = 4 M = 0		<5 = 3 5-10 = 0 10+ = 1	HelpAge International Ukraine
Dnipro					
Healthcare workers	N = 4	F = 4 M = 0	Doctor = 4 Nurse = 0 Allied health = 0	<5 = 4 5-10 = 0 10+ =0	Outpatient clinic
Social workers	N = 4	F = 4 M = 0		<5 = 3 5-10 = 0 10+ =1	HelpAge International Ukraine
Kharkiv					
Social workers	N = 4	F = 4 M = 0		<5 = 3 5-10 = 0 10+ =1	HelpAge International Ukraine

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