Getting Older research project

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EXECUTIVE SUMMARY

Populations around the world are aging rapidly, and this demographic transition is placing new demands on societies to provide comprehensive systems for long-term care at home, in communities or institutions. Patterns of disease in the last years of life are also changing. More people are dying from serious chronic diseases rather than acute illnesses, therefore need help with problems caused by these diseases towards the end of life.

The Getting Older research (hereinafter referred to as "the Research") is being conducted within the scope of the Innovation for Health project (hereinafter referred to as "the Project") implemented by Armenian Caritas and financed by Caritas Austria, Ministry of Health and Social Affairs of Austria, Caritas Spain and Ministry of Labour and Social Affairs of the Republic of Armenia.

Armenia's population is ageing because of increasing life expectancy, low fertility and high levels of emigration. The coronavirus epidemic and the Second Artsakh War have not only dealt a major blow to current demographic developments but are also likely to have a significant impact on the demographic situation in the coming years.

The COVID-19 pandemic in Armenia has severely affected older people in terms of their life and health, social and economic situation. The ability of older people to cover expenses, especially for household services, utilities, food, medicines and medical services has decreased since the COVID-19 outbreak. The conflict between Armenia and Azerbaijan over the Nagorno-Karabakh territory has caused decades of misery for older. While displacement can be devastating to all people, it posed particular challenges for older people.

The Armenian Government's vision towards the elderly care system in Armenia defines Eastern Europe practices as something achievable in the foreseeable future, while practices in Western Europe as something aspiring for further enhancement. people. A draft Strategy of deinstitutionalization of older people's care services and development of alternative community services was elaborated back in 2019 and aims to ensure a dignified ageing process for elderly people within an inclusive society, including increasing participation of older people in community life and decision-making processes. Although the above-mentioned Strategy is still not adopted, the overall vision and the underlying intervention logic are embedded in the decisions adopted by the Government in the following years.

The current legislative and policy framework is siloed. The strategic vision and relevant regulations are being developed exclusively within the Ministry of Labour and Social Affairs, with consultations engaging a limited number of active NGOs from social sector. The cross sectorial collaborations with representatives from healthcare, education, cultural, technological sectors are not common to exercise comprehensive and holistic approach to issues. The siloed approach needs to be revisited and regulatory initiatives should become more inclusive of different levels of state bodies, including local and regional authorities, local community representatives.

The sector of the elderly care is quite mature in terms of the single vision shared by public, non-governmental and private actors of the ecosystem, which made extensive progress towards quality care since Armenia's independence. However, to ultimately ensure decent livelihoods for all elders in Armenia independent of their demographic and socio-economic characteristics, still significant efforts should be put together by the whole ecosystem and beyond.

Uneven geographic distribution of elderly care services makes them inaccessible in many settlements of Armenia, especially those in rural areas, where elderly population is dominating. There are whole regions with no or very small availability of elderly care providers.

The state-owned elderly care facilities lack proper infrastructure resulting in poor living conditions. On the other hand, elderly people receiving home-based care very often are not able to get it in full scope because of deer conditions they live. The latter contributes to health and psychological state complications, which in their turn, require more care and support. Many elderly people are just trapped in this vicious cycle.

Non-state elderly care centers are established and run by NGOs and profit-oriented entities. Overall, the NGOs are the frontiers of the professional elderly care sector in Armenia. This report includes detailed representation of the main three NGOs that are the trailblazers of the pathway towards quality elderly care and shape the sector for over 20 years.

The state institutions and NGOs, being the primary service providers, are in severe lack of funds. State budget allocations are approximately the same for the last 3-5 years, despite the revised and enhanced vision and strategy towards overall sector development.

All NGOs report on donor fatigue at a certain level, and the state funding/grants being insufficient to cover the costs incurred by them while providing service.

Because of high poverty rates among elderly people, the overall sector is not very attractive for a competitive landscape of paid private services to be formed.

The spectrum of elderly care services is quite limited, focused mainly on basic nursing care. Less resources are spent on psychosocial support, rights protection, civic activism and community engagement. Lack of relevant education limits the pool of professional workforce to enter the labour market of elderly care. This also hinders to process of creating truly interdisciplinary teams and get the most out of diverse skillset. Very limited number of volunteers is engaged in elderly care due to lack of awareness among communities on issues of elderly people and challenges of care. Some cultural aspects limit the actual demand for elderly care services, which is way much less than the need. Outsourcing the care or placing an elderly relative in a care facility is still not acceptable in many communities, especially rural settlements.

The field of palliative care is emerging in Armenia. The set of regulatory changes since early 2010s, as well as intensive involvement of dedicated, enthusiastic and visionary healthcare professionals from various public and non-governmental institutions formed proper ground and marked the overall direction towards better palliative care. However, the current health care provision structures within Armenia make palliative care largely deficient, especially for elderly people. Many of patients die at home, with elderly homes/home care limited and/or unaffordable to most. As a result, hospitals often provide long-term care. Within the hospital setting, patients often remain uninformed about their medical condition and information is directed to the family instead.

The developments prior to 2017 in palliative care in Armenia set an important foundation. There was the adoption of a National Strategy on Palliative Care for 2017–2019 and the development of training curricula for doctors and nurses. Since 2017, Armenia's government took further steps towards rolling out palliative care services. In 2018, it approved new regulations around morphine prescribing.

Though the necessary regulations are in place, their actual execution, especially in terms of expanded use of pain medication is still a major challenge, due to lack of awareness of patient rights, limited knowledge of medical practitioners, and common misconceptions among general public.

The state funded palliative care is of a very limited scope. Advocates continue to press the Government to approve the basic benefit package for palliative care as part of universal health coverage. Palliative cares services are provided by a handful of organizations, and the scope of services is quite limited. It is basically about nursing care and provision of proper medication, largely ignoring the importance of quality psychosocial and rehabilitative support, and spiritual services to the patients. Services designated for family members and caregivers are also lacking. The interdisciplinarity of the providing teams are often a matter of formality, to comply with the licensing requirements, rather than actual availability of diverse skillset and modus operandi of the team. Lack of educational programs makes the attraction of quality workforce a huge challenge. Proper research to support evidence-based decision making during the care delivery is also lacking. Communication between palliative care team, patient and family members and caregivers is not smooth. Very often patients are not directly told what disease they are suffering of, and that their condition is fatal.

Non-governmental organizations, like Armenian Caritas, should capitalize on their existing legacy and capacities, to enable the overall ecosystem of elderly care to promote high quality integrated care services through mobilizing larger funds, attracting and nurturing new talent, engaging wider community members and fostering necessary policy reforms. In this sense, recommendations are developed and tailored specifically to Armenian Caritas, as an organization which is not only one of the pioneer NGOs in the fields, but also has specific competencies that differentiate it from other organizations, such as the most long-lasting practical experience in home care services, recognized provider of trainings, a care provider with ambition to integrate palliative approach into elderly care.

TERMS OF REFERENCE

The Getting Older research (hereinafter referred to as "the Research") is being conducted within the scope of the Innovation for Health project (hereinafter referred to as "the Project") implemented by Armenian Caritas and financed by Caritas Austria, Ministry of Health and Social Affairs of Austria, Caritas Spain and Ministry of Labour and Social Affairs of the Republic of Armenia.

Through "Innovation for Health" project, Armenian Caritas tries to improve the healthcare of vulnerable groups through the direct provision of quality integrated care services (including homecare services, distribution of food packages, hygiene items and personal protective equipment, raising their awareness on Covid-19 related protective measures). In a wider sense and for more systemic impact, Armenian Caritas tries to strengthen local health systems by increasing the knowledge of staff, volunteers and other local stakeholders.

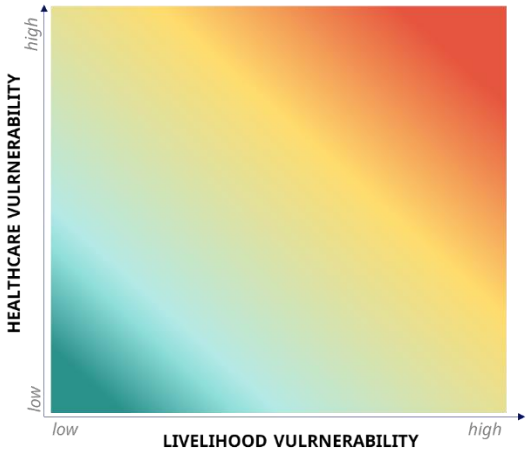
The Research is compiled to fulfil the key objectives of the exercise, which are as follows:

1. To investigate the quality and accessibility of services for elderly care provided by different service providers and to present the challenges and obstacles.
2. To study the accessibility of palliative care in Armenia and the possibilities of its integration into the scope of elderly services.
3. To investigate different funding schemes for services in the field of elderly care, including home and palliative care, among the countries of eastern and western Europe and to provide the comparative analysis of adaptation of some of those schemes to the Armenian reality.
4. To assess the needs for services in the field of active ageing, home care, and palliative care in Armenia and formulate potential fields of activities for NGOs.
5. To submit a comprehensive list of recommendations for the improvement of the quality and accessibility of care services to the elderly people.

Methodology

The overall approach is to construct and conduct the research around the key archetypes of the elderly people. The archetype profiling will be based on the overall level of vulnerability aggregated through a thorough analysis of healthcare psycho-social, and economic needs. The reason behind such framework is the comprehensive and holistic nature of the care, including physical, psychological, social, practical, and other important aspects of integrated care subject to cultural context.

Figure 1: Archetype profiling matrix



The matrix presented on the left that will enable the archetype profiling places each individual case on the intersection of the severity of healthcare vulnerability and severity of livelihood vulnerability, so that

- Severity of healthcare vulnerability starts with no medical condition subject to specialized care and ends with the terminal illness subject to palliative care
- Severity of livelihood vulnerability starts with sufficient assets and wide enough social network for an elder to sustain herself/himself and ends with state of poverty and complete isolation

Since the overarching mission of the Project is to contribute to an improved quality of life of vulnerable population groups, thus the area evolving from yellow to red is considered as the pool of the main target beneficiary cases for Armenian Caritas. Nevertheless, on the Healthcare dimension, the Research will embrace

the overall trajectory of care and all types of services available for the elderly, with the special focus on needs for palliative care.

The following tools for data collection and analysis were selected to answer the research questions as presented in Table 1:

1. Desk review of relevant Project documentation, including other peer projects by Caritas Armenia on Social Inclusion and Care for Elderly, such as Warm Winter 2021, National Home Care, Food for the Elder People, Day Care Centre for the Elderly.
2. General Desk review of relevant national/regional legislative policies as well as related initiatives proposed, state and other donor funded programs targeting similar groups of beneficiaries and/or similar impact, country/regional level statistics on demographic landscape and economic outlook, research papers and study reports. (see Appendix 1)
3. General Desk review of Western and Eastern practices, country cases with regards to geriatrics and gerontology. Country references were designed as per 3 major categories based on quality, availability, and accessibility of palliative care services: Peer, Upper Rank, Best-in-Class care providers. (see Appendix 1)
4. General Desk review / analysis of international and local health care plans (both private and public), insurance coverage and funding schemes on medicine, specialized care, skilled nursing, or hospice facilities. (see Appendix 1)
5. Key informant interviews (see Appendix 2)
6. Expert interviews with main ecosystem players (see Appendix 2)
7. 7 home visits and Deep Dive interviews with 9 beneficiaries of AC (see Appendix 2)

As detailed above, complementary tools (both qualitative and quantitative) were applied for data collection and analysis purposes to capture sufficient evidence and/or draw inferences. The Research is by nature descriptive and where applicable, statistical techniques were employed to organize comparisons, find patterns, measure data trends, validate existing conditions. Relevant recommendations were developed with regards to each archetype separately, allowing scalability / applicability of care as the elderly advance throughout the trajectory of care or simply change the underlying needs.

Table 1: Research questions

Questions / Sources		Armenian Caritas Project Documentation	General Desk Review	Key Informant Interviews	Expert Interviews	Beneficiary Interviews
1	**INDUSTRY**					
1.1	What are the key statistics and development trends of Armenian healthcare industry?		×		×	
1.2	What is the share of Elderly Care (palliative care) in the healthcare market?		×			
2	**PROVIDER**					
2.1	Which organizations (private/public/donor funded) are providing care services to elderly (general profiling)?	×	×			
2.2	Which organizations (private/public/donor funded) provide palliative services (general profiling)?		×	×	×	
2.3	Which organizations (private/public/donor funded) and/or individuals can network and cooperate to push the topics on hospice?			×	×	
3	**SERVICES**					

Questions / Sources		Armenian Caritas Project Documentation	General Desk Review	Key Informant Interviews	Expert Interviews	Beneficiary Interviews
3.1	**Type**					
3.1.1	What type of care services are available in Armenia? e.g. medical / specialized, psychosocial, general day care	×	×	×	×	
3.1.2	What type of care services are offered in other countries that are not available in Armenia?		×		×	
3.1.3	Is palliative care accessible in Armenia?		×		×	
3.1.4	What is the adaptability / expansion potential of certain types of cares (including palliative care)?	×	×	×	×	
3.2	**Affordability**					
3.2.1	Are paid care services available in Armenia and how much do they cost?		×	×	×	×
3.2.2	What are key determinants of the price?		×		×	
3.2.3	Who pays for these services (private/public/shared)?			×	×	
3.2.4	How affordable are the Elderly Care services (including palliative care) in relation to individual spending?			×	×	×
3.2.5	Are there relevant country cases that address affordability challenges of the Elderly Care services (including palliative care)?		×		×	
3.2.6	What are the mechanisms for ensuring the continuity and stability of the services?		×	×	×	
3.3	**Accessibility (physical access, awareness, education / culture)**					
3.3.1	Are these services accessible for elderly in terms of geography, drug availability, existing medical practice?	×	×	×	×	×
3.3.2	Are there values and treasures existing in Armenian culture in treating and caring of vulnerable, moribund and grieving people?	×		×	×	×
3.3.3	Which rituals do exist in Armenian culture? How do relatives, friends, the community, neighbors care for vulnerable, moribund and grieving people?	×		×	×	×
3.3.4	What is important to preserve within Armenian culture and what is in danger to disappear in terms of care for vulnerable, moribund and grieving people?		×	×	×	×
3.4	**Quality**					
3.4.1	Is the staff (physicians, nurses, support personnel etc.) professional enough to provide the requested services?	×	×	×	×	×
3.4.2	Are there any relevant degree, non-degree programs, trainings available in Armenia?		×		×	

Questions / Sources		Armenian Caritas Project Documentation	General Desk Review	Key Informant Interviews	Expert Interviews	Beneficiary Interviews
3.4.3	Are there any relevant country cases to address staff professionalism challenges?		×		×	
3.4.4	What type of infrastructure / medical or hospice facilities are deployed by relevant service providers?		×		×	
3.4.5	How widespread is the use of relevant advanced technology (wearables, sensors, telemedicine, assistive technologies etc)?		×	×	×	×
4	**BENEFICIARY**					
4.1	What is socio-economic and demographic characteristics of relevant elderly segment?	×	×	×		×
4.2	What are the key beneficiary archetypes and type of challenges per each identified archetype?	×		×		×
4.3	What is the customer / beneficiary perception of the scope and quality of the Elderly Care (including palliative care)?	×		×		×
5	**LEGISLATIVE FRAMEWORK**					
5.1	What regulatory bodies and regulations / laws (including drafts) govern the sphere of the Elderly Care (including palliative care)?		×		×	
5.2	What are the key legislation gaps in relation to comparable countries and best practice cases and how those gaps can be addressed?		×		×	

Limitations

- Lack of relevant country level statistics regarding elderly care, palliative care
- Reluctance of the key informants and experts to be interviewed
- Private service providers data collected through anonymous calls, online data scraping, as almost all of them rejected to provide information for research purposes

1. CONTEXTUAL ANALYSIS

1.1. Demographic overview

Armenia's population is ageing because of increasing life expectancy, low fertility and high levels of emigration. The coronavirus epidemic and the Second Artsakh War have not only dealt a major blow to current demographic developments but are also likely to have a significant impact on the demographic situation in the coming years.

According to National Statistical Service of Armenia, as of 1 January 2022, the resident population of the Republic of Armenia comprises 2 961 400 people, of which 64% live in the cities, and 34% — in the rural settlements. Around 13% of the population (around 382 thousand people) are aged 65 or older and, according to the United Nations Population Fund, the share is projected to exceed 30% by 2050. Women aged 65 and over comprise 61% of the total number of the older persons, or around 233,000 people.

According to the World Bank, in 2020, the average life expectancy in the Republic of Armenia was 75.2 years (female 78.7, male 71.9), growing at an annual rate of 0.14% since 1974 – 70.4 years. The average life expectancy in the world was 72 years in 2020. Whilst it is encouraging that life expectancy is increasing, years lived in good health are substantially less. In 2019, healthy life expectancy for Armenia was 67.1 years (female 69.1, male 64.9).

According to the United Nations Population Fund, in 2021, the old age dependency ratio, i.e. the percentage of older dependents, people older than 63, to the working-age population, those of 15-64 age, was 24.5%, i.e. the numer of working age people taking care of one older person is 4. According to in 2050 we will have a ratio of 2.9 / 1, which means an increasing social and health burden on the social protection system, that requires adequate policy response.

1.2. Socio-economic overview

Poverty

According to the World Bank , in 2021, the Armenian economy grew by 5.7%, and the consumer price index grew by 7.2%. As a result, no significant change in the poverty level was recorded.

According to National Statistical Service of Armenia , based on the average poverty line, i.e. AMD 48,145 (USD 95.6) per adult equivalent per month, the headcount poverty rate in Armenian was 26.5% of the population in 2021. With regards to the extreme poverty line, i.e. AMD 26,500 (USD 52.6) per adult equivalent per month, the rate was 1.5%.

People of age 65 and more comprise 12.6% of the total poor population. 21.2% of total 65+ aged people are poor, i.e. every 5th person, including 0.6% of them being extremely poor. Around 10% of 65+ aged people live alone, and 50% of them (around 20 thousand) are people in need.

In 2020, the number of pensioners in Armenia was around 467 thousand, and the average retirement pension amounted approximately AMD 44 thousand. The retirement pension remains by far the most important source of income for older people in Armenia, followed by disability and other social allowances, and family support. The Government program for 2021-2026 envisages to equal the minimum pension amount and average pension amount to the costs of the food and consumer baskets by 2026.

Healthcare services

Table 2: Armenian Healthcare Sector

		2019
GDP, USD mln		641
Employment headcount, thou		49
Universal Health coverage index		69
	Hospital beds	40

Number of healthcare personnel and facilities per 1,000	Doctors	47
	Nurses and midwives	57
Out-of-pocket exp. per capita, % of total health exp.		84

Source: National Health Institute of Armenia

Underfunded budget programs, the inequitable distribution of health workers, and the limited involvement of regional authorities in planning negatively affect equitable access to care. The underfunding of budget programs under the Basic Benefits Package contributes to high formal and informal out-of-pocket payments (around 84% of total health expenditure) and financial barriers to accessing needed care. For socially vulnerable and other special categories of the population, including elderly people, the public sector covers most hospital services, with some exceptions.

Health insurance is not well developed, and the pooling of health risks is fragmented. Voluntary health insurance funds through employer-subsidized schemes have very limited coverage (less than 2% of the population predominantly of working age) and account for only 1.2% of total health expenditure.

Since independence, Armenia has received substantial assistance for its health sector from donor agencies and Armenian diaspora organizations. Between 2014 and 2018, the cumulative share of the donor-funded programs in the executed health budget was 6.8%, with the main donors being the World Bank, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and the US Agency for International Development. Humanitarian assistance is provided mainly by Armenian diaspora and non-governmental organizations, including charities. Donor support and humanitarian assistance to Armenia's health sector declined over the last two decades.

1.3. Cultural context

The family has been one of the most important social constructs and institutions in Armenian society. Through centuries of foreign domination and the absence of statehood, it was the family unit that maintained Armenian culture, identity, traditions and belonging. The Armenian family has traditionally been patriarchal in structure, multi-generational (grandparents, including aunts and uncles) and at the center of social life. Economic stability and a greater availability of apartments in the cities of Soviet times in the '70s and '80s, contributed toward a gradual breakdown into smaller family units. But after Soviet collapse, when the economy faced another downturn, families once again regressed toward the multigenerational model.

A recent report, Independence Generation Youth Study Armenia – 2016 commissioned by the Friedrich Ebert Foundation found that in contemporary Armenian society, the family continues to be a powerful cultural symbol and is perceived as one of the most important institutions in the nation's collective narrative.

Historically, the role of representing the family in social and political interactions was ascribed to the eldest man in the family, while the eldest woman ruled domestic matters. With large extended families in the rural regions of the country, the older generation in villages play a big role in the socialization of the youth – preserving and transferring traditions. While sharing living space with other family members, seniors very often make important contributions to the household by caring for sick or disabled family members, taking over tedious and time-consuming housework, and providing otherwise prohibitively expensive childcare.

According to an analysis by the United Nations Economic Commission for Europe, the care for older persons in Armenia is widely seen as the responsibility of the family. The need for external assistance is often interpreted

as personal failure and putting parents in an old-age home is similar to abandoning them. Given that older people in Armenia usually spend a vast majority of their time in their home and many have spent most of their lives in the same neighbourhood, the change of the living environment is especially difficult for them.

1.4. Pandemic and war in Artsakh

The COVID-19 pandemic in Armenia has severely affected older people in terms of their life and health, social and economic situation. The ability of older people to cover expenses, especially for household services, utilities, food, medicines and medical services has decreased since the COVID-19 outbreak. Disruption of social ties with neighbours, community and family, reinforced by limited mobility, are among the main negative social effects of COVID-19 on older people, adversely affecting their emotional state, especially in urban areas. One third of older people have received extra financial or in-kind support during the COVID-19 outbreak from national and local governments, NGOs and international organizations. However, the emergency response could not sufficiently address the needs of older people. Management of COVID-19 cases was shared between government and primary health care institutions but lacked effective organization and coordination.

The conflict between Armenia and Azerbaijan over the Nagorno-Karabakh territory has caused decades of misery for older people. According to Amnesty International older ethnic Armenians were disproportionately subjected to violence in the recent conflict, including war crimes such as extrajudicial executions, as well as torture and other ill-treatment while in Azerbaijani detention.

At the peak of the crisis, according to the Armenian Migration Service, the majority of the population living in Artsakh had fled to Armenia. Among the estimated 91,000 displaced people, 88% were women, children and older persons who were housed in host communities and collective shelters. As of 31 October 2021, the number of displaced people living in a refugee like situation was 28,719, 11% of which were people aged 60 and above. While displacement can be devastating to all people, it posed particular challenges for older people. According to UNHCR Protection Monitoring reports, 89% of elderly people reported to have extensive medical problems. Hypertension, chronic pain, visual impairment, diabetes is very common among this group both among women and men. Relief actor representatives report that older people are overcoming the stress caused by the conflict with great difficulty and cannot accept the loss of their homes.

2. POLICY FRAMEWORK

2.1. Elderly care

The Constitution of the Republic of Armenia proclaims the rights of older people to decent living (art. 84). A set of international frameworks to which Armenia is signatory, including UN 18 Principles for Older Persons, Madrid International Plan of Action on Ageing, provide guidance for development and adoption of relevant policies and legislation.

The Law on Social Assistance envisages provision of social assistance in order to prevent or overcome a difficult life situation, traditionally in the form of consulting, rehabilitation, in-kind support, accommodation, care, legal assistance, pensions and other benefits or employment services.

The main targets of the sectoral policy of the Government of Armenia for the elderly are:

- Ensuring the continuity of care services provided to beneficiaries through the means of the state, encouraging the participation of NGOs;
- Improving the quality of services provided to the beneficiaries;
- Expanding community-based care services;
- Continuously improving the legal framework.

A draft Strategy of deinstitutionalization of older people's care services and development of alternative community services was elaborated back in 2019 and aims to ensure a dignified ageing process for elderly people within an inclusive society, including increasing participation of older people in community life and decision-making processes. With that purpose, it envisages a gradual transition from residential care to community-based service delivery model emphasizing the role of the family and the community in the lives of older people. In the face of Armenia's aging population, the Strategy aims to address the needs of population that are beyond basic care and social protection, prioritizing activities that ensure aging through a healthy active lifestyle. It is believed that such tactical shift will lead to the continuous development of people's physical, social and intellectual potential, their engagement in the social life and decision-making processes. The basic care and social protection still should be provided upon necessity.

Although the above-mentioned Strategy is still not adopted, the overall vision and the underlying intervention logic are embedded in the decisions adopted by the Government in the following years.

A Government decision (Decision 498-L, 08.04.2021) on launching a state program for community-based services aimed at improving the social care services provided to the elderly was adopted in April 2021.

The same year an inter-agency commission was established by the Government (Decision 535-A of May 24, 2021) to steer the efforts aimed at upholding the rights of the elderly.

In accordance with the program for the improvement of care services for the elderly, the Government has envisaged the following actions:

1. Review and reform of the legislation on social care services;
2. Improving the certification process of NGOs providing care for the elderly in terms of transparency and control;
3. Establishing flexible and distinctive procedures for state-sponsored care for the elderly, and improving the competitive grant award process in terms of accessibility and transparency;
4. Full and comprehensive assessment of the needs of the elderly, including those receiving care services in social protection institutions, by individually examining the social, psychological, health status of each of them, their housing conditions, family and social ties, their needs and potential to live independently;
5. Development and approval of terms of references for each service provided by the state, which will comprise service delivery procedures, quantitative- qualitative criteria for service provision, evaluation and methodology;

6. Establishment of day centers (clubs) for entertainment, cultural life, employment and participation of the older persons in community life;
7. Drafting of a legal act on crisis centers for the elderly in vulnerable situations and establishment of at least three crisis centers;
8. Providing the elderly with the opportunity to stay at home for as long as possible, receiving social services;
9. Training of specialists working with the elderly (*social workers, case managers, etc.*) in cooperation with international organizations and NGOs;
10. Continued discussions aimed at the ratification of Article 23 of the European Social Charter (revised) on "*The right of elderly persons to social protection*";
11. Further efforts to ensure decent living conditions for the beneficiaries in the social care facilities.

Another decision (Decision 1744-N, 11.11.2022) on amending Governments prior decisions on procedure, terms, requirements towards the provisions of care services to elderly people and/or people with disabilities, that were regulating the field since 2015. This decision will partially come into force starting from 01 January 2023, and fully starting from 01 January 2024. The terms, conditions and requirements set out by this decision assume provision of care services to

- a narrower group of beneficiaries, i.e. only two groups instead of previous four: A – people not capable of independent living; B – people partially capable of independent living or fully capable but with some difficulties)
- revised list of settings where the care is provided: 1) all day care center; 2) community-based small house; 3) day care center; 4) patient's residence
- revised list of requirements towards infrastructure, provided food and non-food items
- revised scope of provided services, the corresponding staff composition and work schedule

Recently, the Government initiated a process of delegating some social care services to non-governmental organizations. The NGOs are elected through a competitive selection process and are provided with grants for care services. The number of such grants doubled from five in 2019 to ten in 2020. It is believed that thanks to this reform, the provision of services throughout the country will be expanded, different new financing models will be introduced, and the diversity of social services will increase.

A legal framework for personal assistants is also an important legislative initiative ensure the right of people with disabilities, including elderly people, to live independently and be included and integrated into their communities. The Law on the Rights of Persons with Disabilities, adopted in May 2021, defines a specialized personal assistant as an individual who helps a person with a disability and provides for their care and supports them to overcome barriers, including mobility and communication impediments. On August 11, 2022, the government adopted a decision defining the procedure and conditions for providing personal assistant. While the decision will enter into force on January 1, 2024, a pilot program will be launched in 2023, which will provide an opportunity to identify and correct issues within the system.

The elderly care spectrum is organized and delivered by state bodies through the following key layers:

- Ministry of Labour and Social Affairs, including social territorial bodies of the Unified Social Services

Social services provided by social territorial bodies focus generally on vulnerable households. All benefits (apart from the old age benefit) are oriented towards families. Based on a needs assessment and assignment of an insecurity score, vulnerable older people can be entitled to home-based care service, residential care, day-care services or humanitarian support, free health care in the polyclinics and hospitals.

- Local government bodies

Local government bodies are responsible for identifying families and persons in need of social assistance and taking measures to help them. They are also responsible for satisfying the social needs of persons that require

social assistance in their communities through territorial bodies providing social services or other specialized organizations.

- Ministry of Health, including primary healthcare facilities

Primary healthcare facilities are responsible to identify the health-related issues of elderly people and enable the provision of the needed medical assistance.

Although an integrated approach to care is recognized as an important principle of care provision the public care is provided by medical and social facilities in siloed operating mode. In addition to this, the absence of clear segregation of relevant duties between different government administration levels, leads to lack of ownership and accountability for the quality and accessibility of services, as well as ineffective use of resources due to overlaps.

2.2. Palliative care

The framework of legal acts and clinical expertise for provision of palliative care in Armenia includes:

- Criteria for provision of palliative care (RA Minister of Health Order No.45-N 18.10.2017)
- Clinical guidelines for prescribing narcotics and psychotropic substances for management of the pain syndrome (RA Minister of Health Order No.2910-A dated 11.12.2014)
- Clinical guidelines on assessment and management of the patient's pain (RA Minister of Health Order No.751-A, 22.03.2018)
- Guidelines on arrangement of activities of doctors and nurses (RA Minister of Health Order No.2911-A dated 11.12.2014) and others.

In compliance with the RA Government Decree No.642-N dated May 30, 2019 , the drugs within the palliative care framework are provided with full or partial compensation to beneficiaries included in the list of social or special groups of the population.

Palliative care is provided at institutions with a license for provision of out-patient or in-patient palliative care. Palliative care is provided to patients under two schemes: within the framework of the free state-funded healthcare and as a paid service or funded by other sources.

Palliative care is provided by a multidisciplinary team, which includes a doctor, nurse, psychologist, social worker, volunteers, and other specialists, if necessary. Patients, their families and the community can also be involved in the activities of this team.

Palliative care is provided to anyone who has a life-threatening disease or a life- limiting illness with essential restrictions, and the objective is to improve the patients' quality of life. Palliative care aims to alleviate a patient's pain and mitigate the disease-related physical, psychosocial, spiritual, and other problems through early detection and assessment thereof and arrangement of necessary interventions.

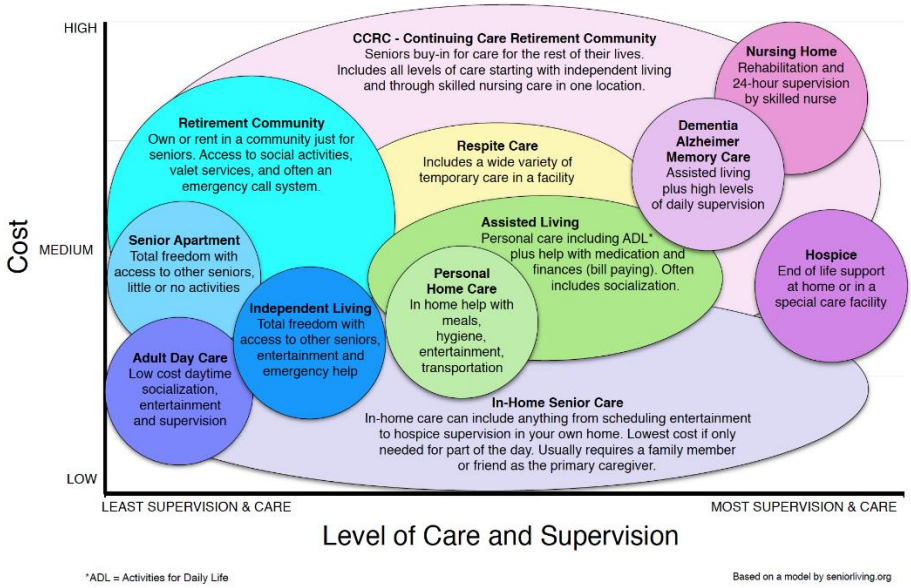
In compliance with the RA Minister of Health Order No.17-N, 15.11.2018 palliative care is provided in the cases of incurable diseases or conditions to patients who are divided into the following main groups: malignant neoplasms, chronic diseases of incurable stages, severe, irreversible post-traumatic consequences, HIV/AIDS, multidrug-resistant tuberculosis, congenital and genetic diseases typical of childhood, patients with severe developmental disorders, etc. Prescription of narcotics and psychotropic drugs within the context of palliative care is carried out with the objective of management of the pain syndrome, as well as in the case of severe short breathing in accordance with clinical guidelines. These drugs can also be prescribed in case of appropriate medical recommendations.

3. SENIOR LIVING SPECTRUM

3.1. General overview of the field

The senior living spectrum clusters the available service options for care in the industry that range from adult day care to hospice. Senior living spectrum is a relevant comprehensive guide (seniorliving.org) to help understand the needs for the elderly and the relevant progression of care throughout the continuum of living. It helps define the type of care that is suitable for the elderly based on the availability of specialists, type of residence and complexity of services provided. Cost component is another significant factor in the spectrum, which increases gradually as the more advanced and complex the needs become over time.

Figure 2: Senior living spectrum



Source: seniorliving.org

Most common care types include:

- In home care , seniors increasingly look to age in place where they feel most comfortable and it also represents the cheapest type of care. Globally there is a tendency to shift senior care to own residence irrespective of the type of service required so it is the type of care that can span from least supervision to most supervision needs and normally is the cheapest compared to counterparts due to low institutional / residency cost. It also creates favourable environment for adoption of modern technology (such as video-surveillance) could be used to provide more security to beneficiaries while filling the gap between home and residential care.
- Adult Day Care, which is non-residential facility (non-institutional) that provides daytime supervision, socialization, and entertainment organized program designed to provide health, social and related support services to adults.
- Independent living facilities or often called retirement communities normally include fully functioning homes, community activities, free meals, and laundry services. The goal of independent living communities is to provide amenities and services, ideal for seniors who may need minor assistance completing their activities of daily living.
- Assisted living communities is an institutional care offering all the amenities of a retirement community, as well as full-time in-home care. In assisted living facilities, residents are provided with 24-hour supervision, including meals, assistance with daily activities, and healthcare services include, eating, bathing, dressing, using the bathroom, taking medication, transportation, housekeeping
- Alzheimer Memory Care, similar to assisted living, but is best suited for adults with progressive cognitive impairments. Such impairments include dementia and Alzheimer's disease and other memory

problems. Core mental functions include memory, language skills, ability to focus and pay attention, ability to reason and problem-solve, and visual perception.

- Nursing home hosts older people that tend to arrive in this institutional care after having been cared for in some way at home or after spending time in assisted living. Their health may be less than robust, but these residents are generally not considered "terminal." For the most part, they don't have an illness or condition that should prove fatal in six months or less. Essentially, nursing home residents tend to require a good deal of help with daily living activities. Staffers such as nurses' aides help with the care, which is available 24 hours a day, seven days a week. Nursing homes are facilities designed for those who are in need of regular medical assistance. Residents staying in nursing homes generally have complex medical needs and require a higher level of care than individuals living in retirement communities or assisted living.
- Hospice staff members should be experts in long-term care. Hospice is both a philosophy of care and a specialized type of health care. Hospice care can be provided wherever an individual resides, including private houses, apartments, assisted living facilities or nursing homes. Hospice delivers a set of specific services at the end of life to residents and their families, which includes medical care, personal care, emotional support, spiritual care, volunteer companionship and grief support. Additionally, hospice provides medical equipment and medications for the terminal disease and related conditions.

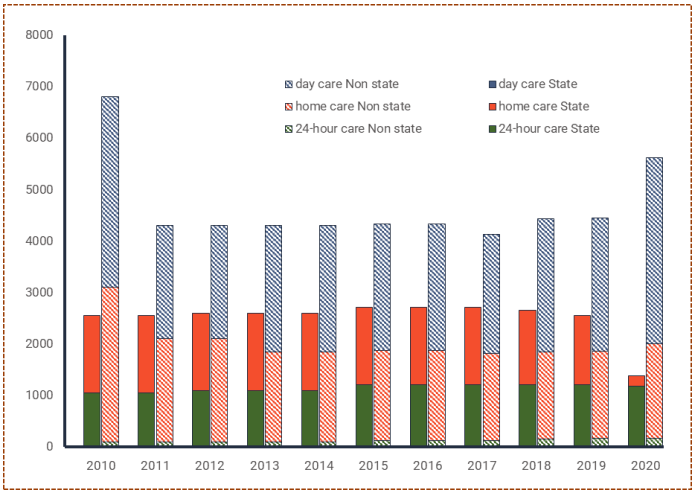
3.2. Service delivery model

Elderly care in Armenia is provided in both institutional and non-institutional (home-based and community-based) settings. Long-term institutional care for the elderly is mostly provided either through the publicly-funded sector, or private providers.

There are two types of public elderly care institutions in the country – general and special, the latter being for people with mental disabilities.

In 2020, 1,380 elderly people received services in state institutions, and 5620 elderly people in non-state institutions. Detailed cares statistics are provided below.

Figure 3: Armenia elderly care statistics (2010-2020)



Source: MLSA

24-hour care centers

As of 1 April 2022, there are 12 institutions providing 24-hour care to elderly people and/or people with disablities (including mental conditions), of which 7 are non-state, the total number of beneficiaries is 1,345.

The entire procedure to get enrolled in the general type nursing home takes a maximum of three days, mainly because there are no waiting lists for. The situation, however, is different for special homes where the procedure might take up to several years because of the scarcity of available places and large number of applicants.

For public settings, the most urgent problem is related to the poor conditions. The second critical problem is related to rooms, which are intended for large numbers of residents and have been constructed without considering the need for personal space. The third pressing issue is limited staffing. One nurse provides care for 30-40 elders, for those who are bedridden the ratio is 1:10, which is a large number for the amount of work that a nurse is required to do. In Norway, the ratio is two caregivers for each senior, in Russia the ratio is 1:5, in France 1:2. Of course, all of these contribute to the poor quality of the services provided.

Home care and day care centers

These two services created to keep elderly and/or disabled people in the community for as long as possible and to prevent them from entering large institutions. The care is provided primarily by non-governmental organizations. The total number of beneficiaries is 2,045 for home care and 3610 for day care services.

Small community-based homes

Small community-based homes are a newly emerging setting. There are such homes operating for people with mental health problems in Lori, Kotayk, Armavir marzes and in the city of Yerevan. In these institutions care is provided by two non-governmental organizations cooperating with the MLSA. The total number of beneficiaries is 36.

The overall state budget for elderly care is around 2.5 billion AMD ($5.1 million), which is primarily spent on medicine, food, clothing, and hygiene products. The cost per person in a general type nursing home is 90,000 AMD/month ($187 US), while for special centers it is 150,000 AMD/month ($311).

3.3. Key non-state service providers

Non-state elderly care centers are established and run by NGOs and profit-oriented entities.

Overall, the NGOs are the frontiers of the professional elderly care sector in Armenia. Below are presented the main three NGOs that are the trailblazers of the pathway towards quality elderly care and shape the sector for over 20 years.

Armenian Caritas (AC) Benevolent NGO

Main beneficiary profile: Isolated and socially vulnerable elderly people, not capable or partially capable of independent living. Overall, 1,100 elderly people benefitted.

Senior Living Spectrum: Assisted Living, Personal Home Care and Adult Day Care

Geography: Shirak, Lori, Gegharkunik, Ararat

Programs/projects:

- National home care: 360 beneficiaries in four regions of Armenia, receiving health and medical support, psychosocial support, assistance in running

PROJECT SPOTLIGHT: NATIONAL HOME CARE

Started in 2002, as a mere food provision to 50 socially vulnerable elderlies, this initiative of the Armenian Caritas has outgrown into a National Home Care program, encompassing a wide range of services delivered to 360 elderlies in 4 regions, 5 towns of Armenia, living in deer conditions, with miserable income, multiple medical conditions and no or limited social ties. The beneficiaries of the Program are provided with 1) regular nursing care; 2) health prophylactics and medical consultations; 3) psycho-social support; 4) food, hygiene items and medicine; 5) rehabilitation and support items; 6) assistance in official and household related procedures; 7) opportunities for better community engagement and cultural life.

The 20-year long journey is something beyond consistent quality care provision. As a pioneer of the field, the success meant setting up and maintaining the entire modus operandi of the elderly care:

1) Setting up and nurturing a dedicated team of professionals powered by volunteers
2) Leveraging Caritas international network to adapt leading practices of elderly care to local realities
3) Defining care protocols from individual needs assessment to intervention plan and periodic monitoring
4) Mobilizing financial resources and in-kind contributions from various donors and supporters
5) Liaising with state bodies at different levels to enhance the policy and regulatory framework
6) Enabling the ecosystem around the elderly care through strategic partnerships and advocacy
7) Sharing knowledge and expertise through trainings and workshops at academic and non-academic settings
8) Raising awareness on issues of elderly life among community members and wider public

the household chores and errands, support in work.
- Day care: 170 beneficiaries provided with social, hygiene and healthcare services, nutrition and entertainment at 3 day-care centers in Gyumri, Tashir and Artashat.
- Humanitarian assistance: 200 beneficiaries in Gyumri provided with dry food rations and subsidy for heating costs.

Funding: International donors (predominantly), Government grant

Service fee: All services are free of charge

The Armenian Red Cross Society (ARCS)

PROJECT SPOTLIGHT: GYUMRI NURSING HOME

Gyumri Nursing home is one of the 10 nursing homes of Armenia run by the RA Government. Since May 2020 the Armenian Red Cross Society took over the management of the nursing home, with the goal to significantly improve the care quality and make a success case for nation-wide replication.

The Gyumri Nursing Home is home for not only older people but also people with disabilities and with chronic diseases in need of permanent care services.

Lack of proper infrastructure and limited resources of care formed the baseline state of the nursing home before the project start.

Mobilizing financial resources from different donors (Austrian Development Agency, the Austrian, Italian and Swiss Red Cross), the ARCS managed to restructure the service delivery model in the following ways:

- Extensive renovation and upgrade of existing infrastructure to enhance living conditions of the residents
- Reset of the organizational structure aiming for redirecting resources from administrative units to actual care providing functions
- Intensive trainings and capacity building for existing staff, attracting new talent, expanding volunteer engagement
- Revisiting the overall logic of the care going beyond basic nursing care to include psychosocial support, activation of social ties and community engagement.

As a result, the annual state budget expenditures on the Gyumri nursing home remained the same, while the value for money is significantly increased.

Main beneficiary profile: Socially vulnerable elderly people, capable of independent living

Senior Living Spectrum: Assisted Living, Personal Home Care, Nursing Home, Independent Living

Geography: Shirak, Lori, Vayots Dzor, Ararat, Aragatsotn, Kotayk and Tavush

Programs/projects:

- Home-based care in three regions - Shirak, Lori and Vayots Dzor - by teams of professional nurses, home helpers and trained volunteers. In 2021, 500 people benefitted.
- Gyumri 24-hour care center - Since May 2020 Armenian Red Cross Society took over the management of the Gyumri Nursing home.
- Psycho-Social support to lonely refugee elderly. In the framework of this program volunteers visit the beneficiaries once a month, help them with housework, and organize social /cultural events.
- Humanitarian assistance: Food packages and support with the organization of social and entertainment events for older people in four regions Ararat, Aragatsotn, Kotayk and Tavush.
- Healthy Active Ageing by supporting older people groups in Lori, Shirak and Vayots Dzor regions. There are overall around 100 beneficiaries and at least 10 initiative community groups from each region.

Funding: International donors, Government grants

Service fee: All services are free of charge. Piloted chargeable home care services recently (AMD 65,000 monthly).

Mission Armenia (MA) Charitable NGO

Main beneficiary profile: Socially vulnerable elderly people incapable of independent living.

Senior Living Spectrum: Assisted Living, Personal Home Care, Adult Day Care, Nursing Home, Independent Living, Memory Care, Senior Apartment

Geography: Ararat, Lori, Shirak, Kotayk, Gegharqunik, Syunik.

Programs/projects:

- Social Houses for temporary accommodation of the elderly, persons with disabilities and refugees.
- Day Care Centers: 20 day care centers to provide employment, opportunity for self-expression, expansion of contacts, acquisition of new skills, and active participation in community life.
- Soup-Kitchens: 27 charitable soup-kitchens, which provide with calorie-rich hot meals once a day.
- 24-hour Service Center "Artsvabuyn" with the capacity to servce up to 45 beneficiaries, located in Artsvanik village, Syunik region. The center provides accommodation and a variety of 24-hour services to those elderlies and persons with disabilities, who have partially or completely lost their ability for independent living.
- Home Care: A variety of home-based social and healthcare.

PROJECT SPOTLIGHT: NRNENI SOCIAL SERVICE CENTER

Functioning since 2007, "Nrneni" multifunctional center has introduced first time in Armenia an entirely new social services provision model of social housing with supportive environment.

Nrneni center is a social house designated exclusively for elderly people without shelter. The center includes

- a housing complex of 30 apartments. 28 apartments of the housing complex are provided to elderly people, while remaining two are occupied by young socially vulnerable families which are engaged in the care delivery process.
- a multifunctional complex for provision of social and healthcare services

The beneficiaries of the center receive nursing care, psychosocial support, food and hygiene items on a regular daily basis. Various events and socializing opportunities are provided to the residents.

The financial sustainability of the center is ensured through paid services of the multifunctional social and health care complex. The proceeds are used to maintain the building infrastructure and cover the costs of the free of charge services to the residents.

Funding: International donors, Government grant (predominantly), revenue from services

Service fee: Some services are chargeable, and are delivered through a separate profit organization fully owned by the MA

Other NGOs

- The Association of Healthcare and Assistance to Older People

Established in 2016, operates in three main fields: healthcare, social care and continuing education of physicians, nurses, caregivers and family members of older person.

In 2018, its sister organization Armenian Association of Geriatrics and Gerontology was founded to focus on the development of geriatric and gerontological services, promoting the recognition and formation of the disciplines of geriatric medicine and gerontology as independent specialties in Armenia, supporting measures to enable older people to remain active, independent and involved in their community, facilitating social engagement, and promoting the development of an integrated care system.

In cooperation with the UNFPA Country Office in Armenia, the Association also organizes the school for caregivers. The school aims to provide knowledge about gerontology and geriatrics, as well as the particularities of older people care.

The Association provides home-based care services in Ijevan (Tavush region) (75 people), in Vayq (Vayots Dzor) (75 people) and Yerevan (85 people).

- Alzheimer's Care Armenia (ACA)

Alzheimer's Care Armenia (ACA) is a US based NGO founded in 2017 by gerontologist Dr. Jane Mahakian with the purpose of raising awareness and developing sustainable programs and services for people with Alzheimer's disease and their families in Armenia.

Partnering with Mission Armenia the organization established the Armenia National Alzheimer's Caregiver helpline. It also founded Memory Clubs in different cities where older adults can fight memory loss through mental exercises and activities.

Since there are no standard procedures for diagnostics, patients are often undiagnosed, misdiagnosed or not diagnosed at all. In order to help with the understanding of the disease, ACA and Data Point Armenia put together the first Alzheimer's Disease Caregiver Guide, with 10,000 copies distributed to primary care physicians throughout the country by the Ministry of Health.

The Brain Health Armenia Project by ACA is a country-wide mobile memory screening and Alzheimer's disease training program in Armenia. The project will collaborate with the Armenian EyeCare Project to provide memory screening throughout Armenia and is endorsed by the Republic of Armenia Ministry of Health. The Brain Health Armenia Project's multidisciplinary team of specially trained experts includes primary care physicians, nurses, psychologists and social workers and will also provide didactic and hands-on training to healthcare professionals and family caregivers to improve the care of the person with dementia in Armenia.

The "Second Start" radio show, launched within the framework of the Alzheimer's Care Armenia Brain Health project in collaboration with Public Radio of RA, is dedicated to the social protection of the elderly.

ACA partnered with Expper Technologies, to bring Robin the Robot to the residents of the Nork Old Age Home. Robin was previously used at the UCLA Mattel Children's Hospital to provide emotional support to the young patients. The idea is that the same experience could be "life-changing" for the older.

Memory Café Yerevan is another project by ACA, where elderly people with memory impairments have the opportunity to spend their daily life interestingly, learn new things, follow the rules of a healthy lifestyle that trains memory and slows down aging.

Network of organizations working on older people issues

The NGOs actively collaborate with each other and try to consolidate their efforts for a better impact. In December 2015, through the initiative of Caritas Armenia, the Network of organizations working on older people issues was established to include state bodies, international organizations and civil society.

Currently its members are: Caritas Armenia, ARCS, Mission Armenia, Association of Healthcare and Assistance to Older People, UNFPA Country Office in Armenia, MLSA Department of Older People and People with Disabilities, MLSA Research Institute, OXFAM, Center for Health Care Research of the American University of Armenia.

The Network members meet regularly to discuss legislative changes, reform packages, existing issues and gaps. In particular, the Network was actively involved in drafting and reviewing legal acts related to standards for services provided to older people both in 2017 and 2022. It also generates ideas and coordinates implementation of joint projects targeted to the needs of older people.

Private service providers

Private sector provides services across the spectrum, still specialized either in nursing and assisted living, or outgoing services at home. In terms of geographical dispersion of private players, the services can be considered unevenly provided across the country raising further concern in terms of accessibility for population in rural areas.

The services range in private companies, a few are established medical centres (Ava Med, Khnami, Alpha Beta) which conditions the availability of more qualified nursing staff, physicians, in house diagnostics capabilities. However, with a price range of 10,000 – 25,000 AMD per 24 hours - depending on the severity of the care needed and actual outcomes - the services remain largely out of reach for the poor and independent elders whose main income comprises of pension. In terms of workforce trainings, private provides mostly rely on themselves to provide continuous trainings to nurses.

Below are key private service providers with their services mapped against senior living spectrum.

Table 3: Elderly care service providers in private sector

Providers \ Services	Home Care	Day Care	Assisted living	Nursing home	Memory care	Palliative Care	Hospice	Geography
Yerevan home care	×							Yerevan
AVAG SERUND Care Center	×		×					Yerevan
Ava Med. Tun Clinics Centre for Health and Palliative Care				×		×		Yerevan
KHNAMI Health and Palliative Care Center	×			×		×		Yerevan
ALPHA BETA PLUS Palliative Care & Post Stress Rehabilitation Center				×	×	×		Yerevan
AREVMED Hospice			×			×	×	Yerevan
VITAcare Senior Home Care and Elderly Care Services	×							Yerevan
BARI KHNAMQ Patient, Senior and Elderly Care	×							Yerevan
MEDUNI Hospice and Palliative Care Center						×	×	Yerevan
Masis Hospice						×	×	Ararat
CardioMed Family Medical Center						×		Yerevan
MasterMed	×							Armavir
Ajapnyak Medical Center						×		Yerevan
ArtMed Medical Rehabilitation Center						×		Yerevan

3.4. Elderly care in Eastern and Western Europe

The Armenian Government's vision towards the elderly care system in Armenia defines Eastern Europe practices as something achievable in the foreseeable future, while practices in Western Europe as something aspiring for further enhancement. The vision accepts that North American practices are too far-fetched for current Armenia's socio-economic situation.

In terms of financial sustainability, services financed from county budgets are more developed and financially more stable than those financed from local budgets, as counties have more resources. Currently, the majority of the current and projected public expenditure is spent on residential care but efforts are drawn to shift to home care (it is also cheaper). Europe is a bit different in the sense that they have immigrant carers (grey market). Main expenditure can be split unevenly in between:

- residential care : biggest share due to institutional costs
- cash benefits / cash programmes
- home care : normally smallest share

Some policies tilt in the direction of incentivising residential care, which is arguably an unsustainable and more expensive policy. More than financial sustainability in itself, what seems important is to improve the efficiency and efficacy of LTC public expenditure. Strengthening governance would help to achieve the intended efficiency gains. There might be room to optimise the care mix to increase the cost-efficiency of the long-term care system.

Access and affordability is closely regulated by supply and demand. In terms of demand, the first estimate can be based on the share of people aged 65 and over with severe difficulty in activities of daily living (ADLs). Waiting times is a good measure for accessibility as well as unmet need. The supply of LTC services has not entirely followed the demographic trends.

Some are partially subsidised by the state or the municipality (for certain social groups), while the rest is paid out of pocket. Nordic countries, Sweden etc are heavily subsidised and the out-of-pocket spending has been estimated to be very low. Thus, the availability of services increasingly depends on the ability of the service user to pay, which leads to an increased risk of poverty for those using these services.

The less public funding, the more coverage of services is insufficient and unequal.

Inefficiencies are exacerbated by the separation of health and social care. So effective cooperation between healthcare and social care is seen as a prerequisite for a well functioning system. Different funding sources and the very clear institutional and professional separation do not encourage these areas to coordinate care and provide services.

According to an ESPN report, access and availability in relation to LTC was easiest in Belgium, Cyprus, Denmark, Luxembourg, and the Netherlands. However, since the number of care recipients is projected to increase, this would require a massive expansion, both in homecare and in residential settings where physical expansion of new facilities and services should be implemented.

Cost determinants in EU: Overall, in contrast to health care, where higher spending as a consequence of ageing is partly due to increasing age-cost profiles, ageing affects LTC spending mainly through increases in the number of dependent people. Whether a country relies mainly on formal care or informal care and whether formal care is largely provided in institutions or at home are important determinants of public expenditure on LTC. Formal long-term care includes both in-kind care and cash benefits. In-kind long-term care is provided by professionals at home or in an institution (such as care centres and nursing homes). Cash benefits are payments which can be used to purchase formal care at home or in an institution or which can be paid to informal caregivers as income support.

Countries such as Denmark the Netherlands and Sweden rely mostly on formal care, while countries such as Bulgaria, Cyprus, Estonia, Lithuania, Latvia, Romania and Croatia rely almost exclusively on informal care. (More developed vs less developed within EU). It is important to mention that most of these countries already have incorporated these into their reforms and policies, even when current expenditure is already high.

COUNTRY SPOTLIGHT: ROMANIA

Romania has one of the lowest GDP per capita within Europe while the old age dependency ratio is estimated to be higher than average in EU27. The share of out-of-pocket expenditures is high. The Romanian elderly care is mainly informal care based as most Romanians think that young people should assume the responsibility for taking care of their parents (89%).

The demand for community-based social and home care is very high because people prefer to stay at home within family boundaries; 95% of the patients die at home. Thus, with the implementation of "Social Protection and Social Inclusion 2008–2010 Romania", the country has made efforts to further develop home care. For example, home care services for elderly people can be publicly financed with limited number of hours, depending on the condition of the patient.

Another step stone in developing home care is that Romania makes necessary interventions in the quality of care and fosters establishment of the network of home care by different actors. Carers for elderly and carers for ill people complete a six-month training programme on care for elderly, and receive a certificate. While the content of education is controlled through the National Council that provides accreditation to the educational institutes, yet, the training is only provided by NGO's. There is a healthy mix of public and (not-for-profit) private in provision of home care. Usually there is no competition between providers, as there is a lack of supply.

In addition, a client co-payment system has been introduced since 1st January 2010, both for social and health care system to secure a basic care provision for insured people while ensuring the sustainability long term.

4. PALLIATIVE CARE: A CLOSER LOOK

4.1. General overview

The demand for Palliative Care is growing due to global demographic changes, including an increasingly aging society and wider prevalence of non-communicable diseases (NCDs); diseases that account for 68% of worldwide deaths.

Palliative Care is most needed in low- and middle- income countries such as Armenia. However, the current health care provision structures within Armenia make palliative care largely deficient, especially for elderly people. Many of patients die at home, with elderly homes/home care limited and/or unaffordable to most. As a result, hospitals often provide long-term care. Within the hospital setting, patients often remain uninformed about their medical condition and information is directed to the family instead.

NCDs, especially cardiovascular diseases and cancer, are the primary cause of death in Armenia. The research paper "Palliative Care education in Armenia: perspectives of first-year Armenian physician residents" estimates that approximately 60–70% of Armenia's end-of-life patients would benefit from palliative care.

According to "Progress Update: Development of Palliative Care From 2017 to 2020 in Five Countries in Eurasia" research paper, in the regional context, Armenia remains behind other countries in terms of its development with no specific palliative care education at all and lack of specialized care for patients with incurable illnesses.

Experiences suggest that a strategy that initially emphasizes training, technical assistance, and engagement to create the building blocks for palliative care combined with or followed by public advocacy and campaigning to demand roll out of services can result in significant advances. Continued progress, however, is not guaranteed, especially considering the COVID-19 pandemic and dwindling donor support.

The developments prior to 2017 in palliative care in Armenia set an important foundation. There was the adoption of a National Strategy on Palliative Care for 2017–2019 and the development of training curricula for doctors and nurses. Regarding the drug policy, although oral morphine was added to the essential medicines list, the medicine was not actually available and injectable morphine remained subject to highly restrictive regulations. In terms of financing, there were no budget allocations to palliative care.

Following the adoption of Armenia's national strategy, Open Society Foundations-Armenia (OSFA) shifted its strategic focus. The support to develop policies on palliative care and build provider capacity started to be paralleled with the support to advocacy, e.g. leadership and advocacy trainings for palliative care providers; monitoring of access to palliative care and medications for pain treatment by human rights advocates; awareness raising and "know your rights" activities for patients and families.

OSFA also continued to support some clinical training and accreditation programs and funded a study to estimate the cost of home-based and in-patient palliative care services in Armenia. International advocacy was initiated with Human Rights Watch and the UN Special Rapporteur on the Right to Health.

Since 2017, Armenia's government took further steps towards rolling out palliative care services. In 2018, it approved new regulations around morphine prescribing, repealing the highly restrictive norms that limited prescribing to oncologists and required multiple doctors to sign off on prescriptions for patients at home. In 2017, oral morphine was registered as an approved medicine and a three-year supply procured. Use of morphine for palliative care has increased since steadily although it remains underutilized.

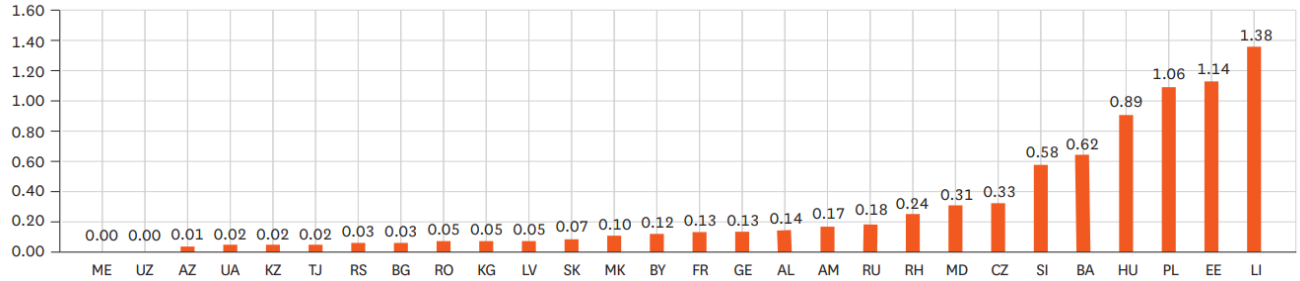
4.2. Service delivery model

In Armenia, palliative care can be provided in various settings:

1. Outpatient palliative care is provided at the primary healthcare centers (PHC) of the Republic of Armenia (polyclinic) by a multidisciplinary team of palliative care clinics (24-hour medical surveillance in non-treatable cases, including home visits).
2. Mobile palliative care is provided by a respective multidisciplinary mobile team to a patient who is unable to move on his/her own, or whose transfer is complicated or at the patient's request.
3. Hospital (in-patient) palliative care is provided by a multidisciplinary team in a hospital setting at a palliative care unit or a unit with specifically assigned beds or service.
4. Hospice, where palliative care is provided by a multidisciplinary team to patients in the final stages of their disease who require continuous provision of in-patient care.

The European Association for Palliative Care (EAPC) recommends two specialized palliative care services every 100.000 inhabitants (1 home care team and 1 hospital team). In this term, Armenia is ranked quite low, 0,17, although ahead of some comparable countries (see the figure below).

Figure 4: Home palliative care specialized services



Source: EAPC

Palliative care is an uninterrupted service provided 24/7. At polyclinics, palliative care services are provided during the work hours of the institution, including home visits.

The principles of palliative care are:

- ascertain life by accepting death as a natural phenomenon,
- exercise control of pain and other heavy symptoms,
- neither hasten nor delay the death,
- if necessary, include psychosocial and spiritual vectors in the medical care provided to the patient.

The activity of the multidisciplinary team specialists providing palliative care has the following principles:

- respect the dignity of the patient and his/her family,
- respond within their competence and show respect to the patient and his/her family members,
- respect the patient's choice of appropriate intervention, and administer the chosen intervention with informed consent,
- assess and direct, as needed, towards the receipt of psychosocial and spiritual support;
- ensure the continuity of palliative care, as needed,
- respect the right of the patient or his/her legal representative to refuse treatment.

In 2020, the Armenian government approved a budget to support 17 inpatient and home-based palliative care services, covering salaries for physicians, nurses, transportation, and medicines. Services of psychologists and social workers are covered only in some cases due to funding limitations. The number of palliative care

services grew significantly with 23 services licensed to provide palliative care, more than ten supported by state funds as of February 2021.

During 2018-2020, 16 medical organizations were licensed to provide palliative care and service, of which 10 inpatient (6 in Yerevan and 4 in the regions) and 6 are outpatient (3 in Yerevan and 3 in the regions). In 2019, state funded outpatient and outgoing palliative care was established in 13 polyclinic in Yerevan and Masis Hospice in Masis. As of 2020, state funded outpatient palliative care was available in 7 medical centers (1 in Yerevan and 6 in the regions).

CASE REFERENCE: DIAKONISSESTIFTELSEN (DENMARK)

Denmark has universal health coverage and long-term care is ranked among the best in Europe. It relies mostly on formal care. In the last decades, the general philosophy of the elderly care is home based. Diakonissestiftelsen is Denmark's leading supplier of care and welfare services, including one of the first hospices founded in the country. The hospice accepts elders upon referral by hospital when the terminal disease has left only a few weeks to live. Thus, hospice care period is limited to 2 or 3 weeks before the death and if the patient shows any signs of improvement, then is likely to return to hospital. The staff of hospice consists of: Nurses, doctors, therapist, music therapists, priest, social worker and volunteers, all of whom support to transition to death.

Hospice services are not limited to hospice care, so they carry out activities and campaigns to spread and strengthen the practice, namely:

- Nurse trainings: Hospice runs 6 month long specialized nurse programs, that provides specialization in hospice care. Along the training and mentorship, the nurses are obliged to read assigned books on palliative medicine, symptom management and communication before they can commit to the hospice care practice.
- Communication: Despite the fact that the hospice does many death awareness campaigns, still physicians have hard time to talk about it. The special communication to patients and relatives is a common practice in hospice and a key advantage compared to hospital and other care.
- Educational programs: The hospice does partnerships with other health practices and institutions, to share best practices with nursing homes specialized on Palliative Care, NGOs that run elderly homes, nursing schools, focused on how to embed palliative and hospice care into general elderly care.

The list of Institutions providing palliative care, as well as organizations included in the wider ecosystem are mapped below:

Table 4: Palliative care ecosystem actors in Armenia

Organizations / Primary Focus		Description	Regulatory	Service Delivery	Funding	Education	Research	Legal Protection	Advocacy
1	Ministry of Health	State regulatory body for healthcare sector	X		X				
2	Ministry of Labour and Social Affairs	State regulatory body for social sector, including social care delivery	X						
3	National Institute of Health	Operates under the supervision of Ministry of Health of Armenia to carry out activities aimed at development of healthcare in Armenia.	X			X	X		
4	Yerevan State Medical University	Leading academic institution in Armenia				X	X		
5	American University of Armenia (Turpanjian College of Health Sciences)	Interdisciplinary training and development of health professionals and others to be leaders in public health, health services research and evaluation, and health care delivery and management.				X	X		
6	Yerevan State Basic Medical College	A leading educational institution preparing qualified medical personnel of the middle level through its branches in Yerevan and in regions of Armenia.				X	X		
7	Institute of Cancer and Crisis	A non-profit organization that aims to explore and mitigate the impact of the crisis on cancer patients.					X		X
8	Alzheimer disease Armenian Association	Provides caregiver meetings, educational events, helpline.				X			X
9	Open Society Foundations Armenia	Civil organization to promote and protect human rights, rule of law, justice, accountability, and transparency.			X	X	X	X	X
10	HENARAN charitable foundation	Charitable foundation to support cancer patients and survivors, their family members and caregivers.				X			X
11	City of Smile Foundation	Charitable foundation to support people with oncological and hematological diseases, and their families.			X				X
12	The Office of the Human Rights Defender of Armenia	Provides protection for the individuals where their human rights and freedoms have been violated by state or local authorities.						X	X
13	The Armenian Association of Pain Control and Palliative Care	Establishment and development of Palliative Care Centers and Hospices in Armenia.		X		X	X		X
14	Real World, Real People NGO	Human rights organization which advocates for access to palliative care and pain relief.						X	X

Organizations / Primary Focus	Description	Regulatory	Service Delivery	Funding	Education	Research	Legal Protection	Advocacy
15 Patients' Rights and Protection Center	Organization carries out research and educational projects, policy analysis.				X	X	X	X
16 Center for Rights Development NGO	Advocacy of human rights in patient care and assistance to health care practitioners, professionals, attorneys, patients or anyone interested in learning more about the health care law, regulations and medical ethics worldwide and in Armenia.						X	X
17 Armenian Psycho-Oncology Association	An organization to advance the science and practice of psychosocial care for people affected		X		X	X		X
18 Armenian Association of Social Workers	The Armenian Association of Social Workers is a professional structure which unites social workers and combines the existing scientific and practical potential in the field.				X			X
19 Armenian Volunteers Corps/Birthright Armenia	Volunteer internship enhancement program that also offers travel fellowships to eligible participants to assist in the development of Armenia.							X
20 The National Center of Oncology after V.A.Fanarjyan	The National Center of Oncology after V.A.Fanarjyan under the Ministry of Health of the Republic of Armenia is the only comprehensive cancer care hospital in Armenia.				X	X		X
21 Palliative Care Clinic at NCO after Fanarjyan	Public service provider		X					
22 Ijevan Primary Healthcare Center	Public service provider		X					
23 Arteni Primary Healthcare Center	Public service provider		X					
24 Vayk Medical Union	Public service provider		X					
25 Yerevan N13 Polyclinic	Public service provider		X					
26 Yerevan N17 Polyclinic	Public service provider		X					
27 Ava Med. Tun Clinics Centre for Health and Palliative Care	Private service provider		X					
28 KHNAMI Health and Palliative Care Center	Private service provider		X					
29 ALPHA BETA PLUS Palliative Care & Post Stress Rehabilitation Center	Private service provider		X					
30 AREVMED Hospice	Private service provider		X					
31 MEDUNI Hospice and Palliative Care Center	Private service provider		X					
32 Masis Hospice	Private service provider		X					
33 CardioMed Family Medical Center	Private service provider		X					
34 Ajapnyak Medical Center	Private service provider		X					
35 ArtMed Medical Rehabilitation Center	Private service provider		X					

4.3. Pain relief

Pain relief is the pillar of palliative care. Within it, morphine is considered the most appropriate medicine to treat moderate -to -severe pain in palliative care patients and has been used as a proxy to assess palliative care development.

There are no effective analgesics other than narcotic (opioid) analgesics for treatment of moderate to severe chronic pain. Therefore, strong narcotic (opioid) analgesics are the necessary element within the framework of treatment of pain. Unfortunately, the lack of knowledge about opioid use and the associated fear often hinder the effective treatment of pain both in children and adults. The effectiveness of strong opioids for the treatment of pain has been proven: the indirect data and considerations derived from treatment of chronic, non-cancerous pain in adults justify the inclusion of morphine into the WHO list of essential drugs to be used for treatment of moderate to severe pain in adults and children.

Even with recent 2019 structural changes and availability of medication, combined with international guidance indicating oral morphine is the gold standard for combatting severe pain, access to opioid pain medicine remains a significant challenge in Armenia.

Misconception related to the use of opioids exists. People think that prescription of opioids means that patient has a few days left, while in reality, the use of opioids in correct dosage and frequency, can provide pain relief and prolong life for months and even years.

4.4. Education/Workforce

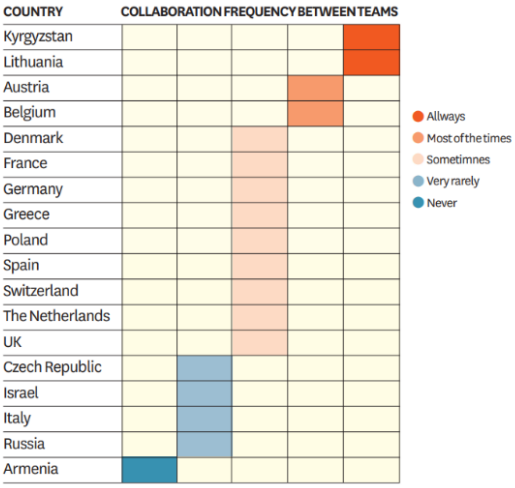
Palliative care education appears to be sporadically integrated in Armenia, although the lack of proper education programs is considered a major barrier to the development and integration of palliative care within existing health care systems worldwide.

According to “Palliative Care education in Armenia: perspectives of first-year Armenian physician residents” research paper, a number of healthcare professionals intentionally exclude palliative care as an option for their medical career. The reason are emotional difficulties to deal with patients, as well as the complexity of care.

Multidisciplinary teams are believed to benefit both the patient and the team. However, the medical specialists seem to prevail in the team structure. There is wide scarcity in specialists of psychological, social care, spiritual services in a multidisciplinary palliative care teams.

The collaboration between palliative care teams and long-term care facility staff shows that Armenia is the poorest in terms of collaboration compared both with European and other central Asian countries.

Figure 5: Collaboration between teams



Source: EAPC

In addition to the scarcity of palliative care trainings in academic and non academic settings, intensified practical education with patient contact and access to diverse teaching material is also a big challenge. The existing educational programs largely miss the following parts: communication ("breaking bad news"), emotional/ psychological support of palliative care patients/families, pain and symptom management, typical palliative care diseases and related problems, diagnosing dying and evidence-based approaches to support dying patients.

The following courses were designed and introduced in Armenia's main medical education instititutions:

- Yerevan State Medical University: Palliative Medical Support postgraduate program which is taught to students with family doctor specialization
- Yerevan State Medical University: 1-week and 2-week continued medical education programs for nurses
- National Institute of Health: Organized a course on "Current trends on palliative medical care for non-oncological diseases"
- Palliative medical care (4 month) and Palliative nursing (3 month) are added as narrow specializations in the overall medical curriculum
- Yerevan Basic Medical College: Palliative care is included as a study topic in General Patient Care and Nursing classes
- Yerevan State University: Practical Psychology Center implemented a pilot 48-hour course on general care with corresponding tutoring guidance, which included 6-hour classes on palliative care and social care each.

The certified continued medical education website www.cme.am has a separate section on Palliative Care.

4.5. Community engagement

In some countries, certain hospices and organizations are only run by volunteers, e.g. Germany for example, the volunteer sector has over 1300 volunteer organizations called Ambulanter Hospizdienst (hospice home services or volunteer hospices), however Armenia shows one of the lowest volunteer involvement in the sector.

Figure 6: Volunteering in hospice and palliative care in 15 European countries

COUNTRY	VOLUNTEERS HOSPICES ORGANISATIONS	VOLUNTEERS	ANY TRAINING PROGRAMMES (OR CURRICULA) FOR VOLUNTEERS		ANY DATA COLLECTION SYSTEMS TO TRACK VOLUNTEERS´ ACTIVITY		COMPASSIONATE COMMUNITIES			VOLUNTEERS REPRESENTATION IN THE NATIONAL PC ASSOCIATION		GOVERNMENT FUNDING FOR PC VOLUNTEERING ACTIVITIES	
			YES	N/S	YES	NO	YES	NO	N/A	YES	NO	YES	N/S
Armenia	0	0-10	○	●	○	●	○	○	●	○	●	○	●
Austria	184	>1000	●	○	●	○	●	○	○	●	○	●	○
Belgium	84	>1000	●	○	○	●	○	●	○	○	●	○	●
Czech Republic	12	100-500	●	○	●	○	○	●	○	○	●	●	○
France	NA	>1000	●	○	●	○	●	○	○	●	○	●	○
Germany	1316	>1000	●	○	○	●	●	○	○	●	○	●	○
Hungary	5	100-500	●	○	○	●	○	○	●	●	○	○	●
Italy	NA	>1000	●	○	○	●	●	○	○	●	○	○	●
Poland	20	>1000	●	○	●	○	○	●	○	○	●	○	●
Portugal	NA	100-500	●	○	○	●	○	●	○	○	●	○	●
Romania	NA	500-1000	●	○	●	○	○	●	○	○	●	○	●
Serbia	1	100-500	●	○	●	○	○	●	○	○	●	○	●
Switzerland	30	500-1000	●	○	○	●	○	●	○	○	●	●	○
The Netherlands	91	>1000	●	○	●	○	●	○	○	●	○	●	○
United Kingdom	NA	>1000	●	○	●	○	●	○	○	○	●	○	●

N/A: Not Accurate.
N/S: Not stated.

Training for volunteers is widely provided in Europe but may differ between countries with regard to the context/level of training, except for Armenia that does not refer any type of training programme for volunteers in palliative care.

The need of education of the wider public about palliative care is mentioned in many reports and research papers. In particular, misconceptions exist such as “Palliative Care equals oncological care” or that the “goal of Palliative Care is to pro- long life”, indicating a lack of experience, understanding and potentially supportive skills/abilities.

The limited knowledge on the existence and aims of palliative care matches the limited availability and development of palliative care services. Identified characteristics of care within Armenia are the majority of care occurring at home, uninformed patients, importance of the family and limited accessibility of palliative care. Varying understanding of Spiritual Care (“Spiritual care equals religion”) and Social Care might indicate a wider lack of conceptual understanding of the aims and principles of palliative care.

The largest campaign on public awareness called “Life without Pain” was conducted by physicians, providers, patients and their families, and non-governmental organizations conducted a campaign back in 2016. The campaign mobilized thousands of people through social media, face to face discussions, and meetings, emphasizing that access to oral opioids for pain relief is essential for quality palliative care and could transform the lives of tens of thousands of people in need of palliative care in Armenia.

4.6. Cultural aspects

Communication between palliative care team, patient and family members and caregivers is not smooth. Very often patients are not directly told what disease they are suffering of, and that their condition is fatal. Although this is a breach of personal data privacy, still it is largely practiced.

Open conversations about death are not common. People prefer to stay with the dying patient in silence or give them unsubstantiated hope letting them into some denial state. The “celebration of life” of the dying patient and “expression of gratitude” for what she/he has done in their life is very rare in Armenia.

Instead of spiritual conversations, a priest is invited to the patient mostly on the last day of her/his life for reconciliation (confession) This is common exclusively in Christian families.

5. FINDINGS AND CONCLUSIONS

5.1. Elderly Care

The current socio-economic situation of Armenia, especially in the context of COVID-19 and war in 2020, makes the life of older population quite challenging. The sector of the elderly care is quite mature in terms of the single vision shared by public, non-governmental and private actors of the ecosystem, which made extensive progress towards quality care since Armenia's independence. However, to ultimately ensure decent livelihoods for all elders in Armenia independent of their demographic and socio-economic characteristics, still significant efforts should be put together by the whole ecosystem and beyond towards the following challenges.

- Regulatory framework
- The current legislative and policy framework is siloed. The strategic vision and relevant regulations are being developed exclusively within the Ministry of Labour and Social Affairs, with consultations engaging a limited number of active NGOs from social sector. The cross sectorial collaborations with representatives from healthcare, education, cultural, technological sectors are not common to exercise comprehensive and holistic approach to issues. The siloed approach also needs to be revisited and regulatory initiatives should become more inclusive of different levels of state bodies, including local and regional authorities, local community representatives.
- The case reference and management mechanisms between social and medical institutions are not functioning efficiently leading to delayed care provision or provision with limited scope.
- Very often elderly people lack awareness of their rights and do not get the services/assistance they entitled to in a timely manner and in full scope
- Accessibility
- Uneven geographic distribution of elderly care services makes them inaccessible in many settlements of Armenia, especially those in rural areas, where elderly population is dominating. There are whole regions with no or very small availability of elderly care providers.
- Enrolment into elderly care facilities can be quite challenging and bureaucratically scrutinized due to limited spots. Queues may take longer than a year to get accepted into care facilities, especially those of specialized nature.
- The state-owned elderly care facilities lack proper infrastructure resulting in poor living conditions. On the other hand, elderly people receiving home-based care very often are not able to get it in full scope because of deer conditions they live. The latter contributes to health and psychological state complications, which in their turn, require more care and support. Many elderly people are just trapped in this vicious cycle.
- Affordability
- Because of high poverty rates among elderly people, the overall sector is not very attractive for a competitive landscape of paid private services to be formed.
- Meanwhile, the state institutions and NGOs, being the primary service providers, are in severe lack of funds. State budget allocations are approximately the same for the last 3-5 years, despite the revised and enhanced vision and strategy towards overall sector development.
- All NGOs report on donor fatigue at a certain level, and the state funding/grants being insufficient to cover the costs incurred by them while providing service.
- Insurance coverage can be considered as non-existent for this population group. New funding schemes are crucial for further development of the sector.
- There is quite limited support and engagement from the corporate sector, mainly due to lack of awareness on existing challenges of elderly care and possibilities of cooperation.
- Service delivery
- The spectrum of elderly care services is quite limited, focused mainly on basic nursing care. Less resources are spent on psychosocial support, rights protection, civic activism and community engagement.

- There are no generally accepted care delivery protocols that are used in the sector. Each provider has its own protocol and usual set of procedures they follow while delivering the care. Very often those protocols are verbal and not properly documented
- Lack of relevant education limits the pool of professional workforce to enter the labour market of elderly care. This also hinders to process of creating truly interdisciplinary teams and get the most out of diverse skillset.
- Very limited number of volunteers is engaged in elderly care due to lack of awareness among communities on issues of elderly people and challenges of care.
- The advancement of various technologies is not harnessed by the sector at all. All the processes are dominated by manual work, starting from actual care delivery ended with relevant information management.

culture: reluctance to outsource care, elderly sense of burden, isolation,

- Cultural aspects
- Some cultural aspects limit the actual demand for elderly care services, which is way much less than the need. Outsourcing the care or placing an elderly relative in a care facility is still not acceptable in many communities, especially rural settlements.
- Because the field dominating state and NGO operated care facilities primarily target socially vulnerable populations, the other population groups of better livelihoods avoid referring to those facilities, as they don't want to be perceived as poor.

5.2. Palliative Care

The field of palliative care is emerging in Armenia. The set of regulatory changes since early 2010s, as well as intensive involvement of dedicated, enthusiastic and visionary healthcare professionals from various public and non-governmental institutions formed proper ground and marked the overall direction towards better palliative care.

Key remaining challenges, especially from elderly care perspective, include:

- Regulatory framework
  Though the necessary regulations are in place, their actual execution, especially in terms of expanded use of pain medication is still a major challenge, due to lack of awareness of patient rights, limited knowledge of medical practitioners, and common misconceptions among general public.
- Affordability
  The state funded palliative care is of a very limited scope. Advocates continue to press the Government to approve the basic benefit package for palliative care as part of universal health coverage.
- Accessibility
  The palliative care is extensively deficient in Armenia. Moreover, the limited offering is largely focused on paediatric palliative, leaving elderly patients aside. Also, as in the whole world, in Armenia as well the palliative care is predominantly focused on oncological treatment, while chronic diseases are more common among elderly people.
- Service delivery
- Palliative cares services are provided by a handful of organizations, and the scope of services is quite limited. It is basically about nursing care and provision of proper medication, largely ignoring the importance of quality psychosocial and rehabilitative support, and spiritual services to the patients. Services designated for family members and caregivers are also lacking.
- The interdisciplinarity of the providing teams are often a matter of formality, to comply with the licensing requirements, rather than actual availability of diverse skillset and modus operandi of the team.

- Lack of educational programs makes the attraction of quality workforce a huge challenge. Additionally, specialists generally have low motivation to be engaged in palliative care services due to emotional distress and burnout.
- Proper research to support evidence-based decision making during the care delivery is also lacking.

• Cultural aspects

- Communication between palliative care team, patient and family members and caregivers is not smooth. Very often patients are not directly told what disease they are suffering of, and that their condition is fatal. Although this is a breach of personal data privacy, still it is largely practiced.
- Open conversations about death are not common. People prefer to stay with the dying patient in silence or give them unsubstantiated hope letting them into some denial state. The "celebration of life" of the dying patient and "expression of gratitude" for what she/he has done in their life is very rare in Armenia.
- Instead of spiritual conversations, a priest is invited to the patient mostly on the last day of her/his life for reconciliation (confession) This is common exclusively in Christian families.
- Misconception about palliative care exist. In particular, even medical practitioners very often consider palliative care as a way of prolonging patients' life. Another huge misconception is related to the use of opioids. People think that prescription of opioids means that patient has a few days left, while in reality, the use of opioids in correct dosage and frequency, can provide pain relief and prolong life for months and even years.

6. RECOMMENDATIONS

In view of challenges within the fields of elderly care and palliative care, the legacy and capabilities of the pioneer NGOs is invaluable. The below recommendations are developed and tailored specifically to Armenian Caritas, as an organization which is not only one of the pioneer NGOs in the fields, but also has specific competencies that differentiate it from other organizations, such as the most long-lasting practical experience in home care services, recognized provider of trainings, a care provider with ambition to integrate palliative approach into elderly care.

The recommendations are structured in a way that support and strengthen each specific role that Armenian Caritas plays or is aspired to play in the elderly care ecosystem: 1) Service Provider 2) Educator 3) Ecosystem Enabler 4) Advocate

6.1. Service Provider

- Elderly care services

Launching paid elderly care services

The current service delivery model of the elderly care by Armenian Caritas is highly regarded by donors, state bodies, peer NGOs and beneficiaries. The main issue related to the current services is their financial sustainability, since the state grants are quite small and there is a decline in donor funds during the last years. In view of this developments, the launch of paid services becomes a sensible way out. Below provided considerations should be taken into account for smooth transition to a new delivery setup:

- Start with a pilot in a geographic area where the success of the pilot is more feasible. Feasibility criteria can include: relatively more families with elderly people that can afford paid services; less conservative communities in terms of care outsourcing; availability of quality worforce/volunteers.
- Design the pilot case, which includes description of the pilot program, range/type of services to be oferred, estimates of potential number of customers, modus operandi, estimates of revenues and costs, monitoring framework to capture the learnings from the pilot. A quick survey can be conducted to validate some options of ultimate price.
- The range of services within the pilot can be not only permanent long-term home care services but also short-term engagements when an elderly person has temporary health detoriation/injury and requires ad hoc assistance which is charged on a daily basis.
- Develop pilot's communication strategy, so that it is positioned under a different name, e.g. ABCD powered by Armenian Caritas. The purpose of this is to eliminate two misconceptions: 1) customers do not use Armenian Caritas services, they will be perceived as socially vulnerable people; 2) customers perceive Armenian Caritas as a charity and expect to get everything free of charge. The core of the communication strategy should be promoting Armenian Caritas's expertise in the fields, not the charitable nature of its activities.
- Find donors to cover the pilot design and launch expenses.
- Closely monitor and evaluate the pilot, so that learnings can be effectively applied during its replication.
- In case pilot succeeds, or at least the failure is properly reasoned and can be prevented in future thanks to the learnings acquired during the piloting, develope pilot replication plan for other geographic areas following the same logic that was used during the piloting.

- Palliative care services

Introducing palliative approach to elderly care

Assuming that Armenian Caritas plans to provide only the care component of the services, it is reasonable to start with introducing palliative approach to the elderly care, which means the following:

- Identify several cases (at least 3-5) from Armenian Caritas's existing beneficiaries that have terminal illness
- Define success criteria and reconsider the selected beneficiary intervention plans accordingly
- Define/revise care delivery protocols accordingly
- Form a palliative care team within the care delivey staff and train them acccordingly
- Closely monitor case management in terms of change in activities of the care delivery team, change in volume/type of allocated resources
- Collect feedback from the patient, their family (if any), medical personnel working with the patient
- Evaluate the introduction of palliative approach in terms of a success or failure
- Seek technical assistance, capacity building opportunities from partners/donors
- Find donors to cover the expenses (if any) related to the exercise

Externalizing the palliative care services

Once the palliative appoach is successfully introduced to the exsiting elderly care delivery model, the developed internal competencies can be externalized/marketed in the following way:

- Start with a pilot in a geographic area where the success of the pilot is more feasible. Feasibility criteria can include: existance of a licensed outpatient palliative care institution in the area; willingnes of the licensed medical institution to consider partnership opportunities; existence of relevant elderly patients that can afford care services; less conservative communities in terms of care outsourcing; availability of quality worforce/volunteers.
- Design the pilot case, which includes description of the pilot program, range/type of services to be offerred, estimates of potential number of customers, modus operandi, estimates of revenues and costs, monitoring framework to capture the learnings from the pilot. A quick survey can be conducted to validate some options of ultimate price.
- The range of services within the pilot can include home care services with palliative approach, home based palliative care, home-based hospice services.
- Develop pilot's communication strategy, so that it is positioned under a different name, e.g. ABCD powered by Armenian Caritas. The purpose of this is to eliminate two misconceptions: 1) customers do not use Armenian Caritas services, they will be perceived as socially vulnerable people; 2) customers perceive Armenian Caritas as a charity and expect to get everything free of charge. The core of the communication strategy should be promoting Armenian Caritas's expertise in the fields, not the charitable nature of its activities.
- Find donors to cover the pilot design and launch expenses.
- Closely monitor and evaluate the pilot, so that learnings can be effectively applied during its replication.
- In case pilot succeeds, or at least the failure is properly reasoned and can be prevented in future thanks to the learnings acquired during the piloting, develope pilot replication plan for other geographic areas following the same logic that was used during the piloting.

Becoming a licensed provider of outpatient palliative care and hospice care

Once the palliative and hospice care is successfully externalized, starting a licensing procedure in home based palliative and hospiec care services can be considered. This option is less costly, as the requirements towards infrastructure and medical facilities is minimal, while the requirements regarding the workforce are assumed to be already met during the pilot project above.

Again a clearly defined business case should be developed and validated before starting the process. The logic behind the case can be as described in the pilot.

The following components within the hospice care, which are especially deficient among current palliative/hospice care providers, can be considered as potential offering to customers:

- Spiritual services
- Medical services/nursing care
- Home care aide services
- On-call care
- Respite care
- Bereavement support

Introducing provider services for potential partners

Cooperations with Yerevan based private palliative care clinics can be considered. Armenian Caritas palliative care team can be the provider of home-based services to the patients of those clinics who live outside Yerevan, in the geographic focus areas of Armenian Caritas.

6.2. Educator

Strategic partnerships with relevant educational institutions (see Table 4 for the detailed list) can be discussed and implemented. Options can include:

- Introducing existing training courses currently ran by Armenian Caritas team to new audience
- Extending the existing educational/training courses provided by an educational institution with new modules to be delivered by Armenian Caritas team, e.g. adding geriatric lens to the general care delivery
- Developing and delivering new courses/classes jointly
- Internships of students at Armenian Caritas elderly care units
- Joint research projects on elderly care/palliative care

The aim of such partnerships should be increase students/practitioners' motivation towards careers in elderly care services, as well as enhance the quality of the workforce.

Such partnerships can be funded through state programs, donor assistance aimed which target quality education, life-long education or similar impact themes.

Some courses/classes can be provided as paid services to medical institutions/individual practitioners. For such cases, there might be a need to get Continued Medical Education course accreditation.

Pre-recorded education courses also can be developed and provided at relevant online education platforms.

6.3. Advocate/Ecosystem Enabler

Defining core themes/topics for advocacy

With its current engagement in elderly care and positioning within the ecosystem, Armenian Caritas has huge power for advocating various topics of its interest or urge. Clear definition of 3 to 5 such topics should streamline that power and make the efforts more targeted. Those selected topics can include:

- Enhanced regulatory framework for elderly care or care component within the palliative care
- Education/research in geriatrics/gerentology
- Community awareness of needs and desires of socially vulnerable elderly people
- Corporate Social Responsibility focusing on needs of elderly people
- Volunteerism in elderly care
- Overcoming misconceptions related to palliative care
- Creating culture for hospice care

Developing and implementing advocacy activities

For each advocacy theme/topic, relevant partners within the ecosystem should be selected and appropriate instruments should be defined. Again, state funds and donor assistance should be considered to deliver such advocacy activities, especially in case of a large-scale campaign. For donors interested in selected themes/topics, Armenian Caritas can be a partner of choice, as it has invaluable legacy and good reputation in the field.

Overcoming silo-ed policy/regulatory framework

Through already established platforms of communication, i.e. network of protection of elderly people, inter-agency commission, Armenian Caritas can try bringing together the social and healthcare perspectives on issues of elderly people. This can be by inviting representatives from regulatory bodies, policy makers from both sectors and moderating joint discussions.

Armenian Caritas also can reshape its communication/collaboration with local authorities for a greater efficeincy, in order to move from the current individualized case management (solving issues for each individual case separately) to more systatic and comprehensive problem solving approach. The latter assumes aggregation of individual cases into certain groups of systemic problems and discussing the possible solutions with local authorities with certain frequency, e.g. quarterly. This does not mean that individual case management should not be exercised, but if those cases are common then a more profound solution is needed to address the root cause.

Regarding the individual case management, it also can be implemented with greater efficiency if there will be a referral mechanism between Armenian Caritas and patients right protection NGOs or the Office of Human Rights Defender.

Tapping into new pools of funds

In addition to traditional source of funds, i.e. Caritas international network and state budget, the following sources of funds can be explored:

- Private foundations generally interested funding social care or healthcare projects but lacking information/focus on elderly care
- Corporate firms that spend extensive funds on Social Corporare Responsibility activities, but don't have elderly care in their „menu of social challenges"
- Donor assistance that is targeting sectors where elderly care is a cross-cutting challenge/direction of activity, e.g. education in medical institutions, digitalization of healthcare services, patients right protection, healthcare research.
- Crowdfunding platforms, e.g. ReArmenia, Patreon, to raise funds on specific initiatives

Joint projects with specific industries (suggestions below are just examples)

- Partnering with entities within technologyical sector to develop, for example, information systems for patient data proecssing, applications for community awareness campaigns, assistive technologies, etc.
- Partnering with entities from media industry, e.g. online media, TV, Radio, to launch series of media content on issues of elderly life or other topics
- Partnering with entities in food industry or retail sector to establish a food bank for elderly people
- Partnering with social enterprises to engage elderly people in their activities through matching their skills/interests with the enterprise activities

APPENDIX

Appendix 1: List of interviewees

	Interviewee	Position/Organization	Date
1	Tigranuhi Tarakhcyan	Armenian Caritas	13 May 2022 17 May 2022 11 July 2022
2	Elisabeth Haun	Armenian Caritas	17 May 2022
3	Flora Sargsyan and the team of National Home Care in Gyumri	Armenian Caritas	21 June 2022
4	Andranik Yeghiazaryan and the team of National Home Care in Gavar	Armenian Caritas	16 June 2022
5	Christina Ispiryan	Armenian Red Cross Society	01 August 2022
6	Anna Grigoryan	Mission Armenia	04 August 2022
7	Anahit Gevorgyan	Ministry of Labor and Social Affairs	04 August 2022
8	Laura Gasparyan and the team of Human Rights Defender office	Human Rights Defender office	03 August
9	Rafik Nahapetyan	Ethnograph, Yerevan State University	15 September 2022

Appendix 2: List of reviewed documents and literature

Legislative acts

1. Program of Activities of the Government of RA for 2021 – 2026
2. Strategy of deinstitutionalization of older people's care services and development of alternative community services, 2019
3. Government decision 1744-N on amending Governments prior decisions on procedure, terms, requirements towards the provisions of care services to elderly people and/or people with disabilities, 11.11.2022
4. Government decision 498-L on launching a state program for community-based services, 08.04.2021
5. The Law on the Rights of Persons with Disabilities, 2021
6. Government decision 194-N on the procedure and conditions for providing personal assistant, 05.05.2021
7. RA Minister of Health Order No.45-N on criteria for provision of palliative care, 18.10.2017
8. RA Minister of Health Order No.2910-A on clinical guidelines for prescribing narcotics and psychotropic substances for management of the pain syndrome, 11.12.2014
9. RA Minister of Health Order No.751-A on clinical guidelines on assessment and management of the patient's pain, 22.03.2018
10. RA Minister of Health Order No.2911-A on guidelines on arrangement of activities of doctors and nurses, 11.12.2014
11. RA Government Decree N 642-N on social or special groups of population and the list of medical conditions, eligible for full or partial compensation for medicine, 30 May 2019

Reports, analysis, research papers

1. Progress Update: Development of Palliative Care From 2017 to 2020 in Five Countries in Eurasia, Lohman et al., 2022
2. Palliative Care education in Armenia: perspectives of first-year Armenian physician residents, Hagedorn et al., 2022
3. Overview of Cancer Control in Armenia and Policy Implications, Bedirian et al., 2022
4. Inputs from Armenia "Guiding questions for the twelfth session of the General Assembly open-ended working group for the purpose of strengthening the protection of the human rights of older persons", UN, 2022
5. "Last to Flee: Older People's Experience of War Crimes and Displacement in the Nagorno-Karabakh Conflict", Amnesty International, 2022
6. Long-Term Care Report, EC, 2021
7. Assessing the development of palliative care worldwide: a set of actionable indicators, WHO, 2021
8. Impact study of COVID-19 on older people and caregivers in Armenia, ARCS, 2020
9. Palliative Care for Cancer Patients in Armenia: A Silent Pain, Movsesyan et al., 2020
10. Global AgeWatch Index and Insights, 2020
11. Lived Experience Of Participation In Daily Occupations Among Older People Living In Social House In Armenia, Harutyunyan et al.,2020
12. Spending on long-term care, OECD, 2020
13. A dignified elderly care in Denmark, Healthcare Denmark, 2020
14. Technical Series in Primary Care, Integrated Care for Older People, WHO, 2018

15. The Aging Report, EC, 2018
16. Integrating Palliative Care and symptom relief into primary health care, WHO, 2018
17. Palliative care and human rights in patient care: an Armenia case study, De Luca et al., 2017
18. Development of Palliative Care in Armenia, Papikyan et al., 2017
19. "All I Can Do Is Cry"
20. Cancer and the Struggle for Palliative Care in Armenia, Human Rights Watch, 2015
21. Active Ageing in CIS Countries: Semantics, Challenges, and Responses, Sidorenko&Zaidi, 2013

Journalistic pieces

1. "Let Me Take Your Pain": Palliative Care in Armenia, EVN Report, 2022
2. Armenia's Deepening Demographic Challenge: Covid-19, Artsakh War Compound the Problem, Hetq, 2020
3. A Small Room in a Big Building: Armenia's Senior Citizens, EVN Report, 2019
4. Palliative Care: The Right to Life with Dignity, EVN Report, 2018
5. 'It's better to die': the struggle to survive poverty in Armenia, The Guardian, 2018
6. Progress and struggle for palliative care in Armenia, eHospice, 2016
7. Armenians Struggle for the Right to Die without Pain, EurasiaNet, 2014
8. Palliative Care Falls Short in Armenia, IWPR, 2013
9. Growing Old in Armenia: The Role of Seniors in Evolving Armenian Families, ArmeniaNow, 2012