

Towards new quality standards of long-term care in Slovenia

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Abstract

Research question: What kind of long-term care services the seniors in nursing homes and their relatives, as well as the future users in Slovenia, prefer. Is the ranking list the same as in the USA, like presented by Black and Dobbs (2015, str. 133-152)?

Purpose: This article presents the problems of quality of long-term care and especially nursing as a part thereof. It shows the results of research of what matters most to current residents of Slovenian nursing homes, their relatives and future users of long-term care services in Slovenia.

Method: After our study of the relevant European and OECD literature we found that the development of quality standards and norms in long-term care for seniors can be developed in different ways. To identify the preferred indicators of quality of long-term care, we had three groups of interviews with nursing home residents and their relatives from three Slovenian municipalities and analysed them.

Results: We found that there is a substantial gap between the needs and the availabilities of long-term care arrangements in Slovenia. The results show which indicators of quality of LTC matters most to residents and their relatives and what prefer each group. The ranking list is different for each group and is not the same as the ranking list of Black and Dobbs.

Local administration and society: These findings refer to the positive local administration initiative to develop community services and nursing homes for seniors with decreasing functional capacities by municipalities themselves, or to develop conditions for private investments in local areas that would attract investments in affordable community services and nursing homes for seniors.

Novelty: This study is the first of its kind in Slovenia while its results provide better insight into what matters most to Slovenian seniors and their relatives regarding the quality of their Long Term Care. It also initiated a further study of the first author which lead to her Ph.D. thesis.

Further extension: The study could give different results in the case of metropolitan areas, e.g. for the case of Ljubljana. Therefore the study should be extended to investigate the urban population.

Keywords: long-term care, nursing home, quality of care, homecare.

1 Introduction

This article presents the challenges that policymakers are facing when designing system of quality of long-term care (LTC) services. The purpose of this paper is an overview of what exists and a set of requirements for the organization of the system of quality for the provision of LTC services from the perspective of users, care providers and supervisors. A quality

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management system (QMS) is a collection of business processes focused on consistently meeting customer requirements and enhancing their satisfaction. It is expressed as the organizational goals and aspirations, policies, processes, documented information and resources needed to implement and maintain it. In the context of LTC, the question is how to design the LTC system that will meet user needs, ensure that service providers have adequate working conditions and enable supervisors to monitor compliance of implementation of LTC services with established quality standards. Determining and monitoring the quality of long-term care of an aging population is becoming a major issue for which we have not yet found adequate solutions. Expectations are associated with the culture of the nation, so we have to determine what kind of long-term care we want and how we will finance it. We examined how the quality of long-term care is organised by other Member States of the European Union and OECD countries.

“Long-term care (LTC): Is defined as a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period on help with basic activities of daily living (ADL). This personal care component is frequently provided in combination with help with basic medical services such as nursing care (help with a wound dressing, pain management, medication, health monitoring), as well as prevention, rehabilitation or services of palliative care. Long-term care services can also be combined with lower-level care related to domestic help or help with instrumental activities of daily living (IADL)” OECD (2013).

In Slovenia, LTC is not systematically organized. LTC is provided in the framework of different social sub-systems: Pension system, Health System and Social support system. Law that would systematically regulate financing and provision of LTC is already in preparation for almost 15 years.

According to the OECD definition, quality LTC means that care is effective and safe for the user, that user is at centre stage, that users can trust the service providers, that careers are responsive to the needs of users, that LTC is coordinated among different providers of LTC and especially between nursing and social care, and provided in compliance with standards and norms regulating LTC. It is expected that the user has access to care that is organized, coordinated and integrated within the system of accommodation in sheltered housing, residential communities for the elderly, in the homes of the elderly and nursing homes. Structural quality depends on the capacity of institutions, number of providers of LTC, number of employees, quality of management, care environment and information and communication technology (ICT), used by the institution, and technology assistance, which are crucial for the quality of service provision. The system of quality and safety must be based on indicators that include the structure, processes, and outcomes. OECD classifies different indicators for LTC systems. Criteria for assessing the quality of long-term care are becoming more sophisticated and reliable, but no global standards for assessing the quality of LTC exists yet. Different national authorities have different approaches to quality of LTC and have different approaches to measurement of quality of LTC and different development path to

improvement of the quality. Some member states have developed measures used for the accreditation of quality for LTC service providers regarding quality monitoring system (Germany, Greece, France, Cyprus, Netherlands, Slovakia). Others (Luxembourg) are using clinical guidelines based on scientific evidence. To prevent regional disparities in the implementation of long-term care some countries (Czech Republic, Germany, Estonia, Latvia, Lithuania, Sweden, Slovenia, United Kingdom) use uniform quality assurance mechanisms Long-term care in the European Union (2008, p. 7). Guidelines and quality standards set by the European Union (Voluntary European quality framework for social services, 2010, p. 1-13) require respect for the principles of decent work in the sector, including non-discrimination, social protection, health and safety, social dialogue, decent wages as well as gender equality and, in particular, equal pay for work of equal value, identifying required skills and defining career profiles, employment promotion and adoption of policies that enable the selection of qualified workers with required skills and competencies. The guidelines emphasize the importance of establishing partnerships between education systems and service providers to include traineeships during studies and mentoring programs by experienced workers, the establishment of training programs, lifelong learning programs, mentoring. They receive workers, the certification for workers as well as, where appropriate to establish a network of volunteers and informal careers. The Guidelines provide for the necessary professional development of carers and their skills, emphasizing as well the importance of accessibility and assistive technologies to engage users and social partners in the development of training programs, promotion of social dialogue at all levels, in order to encourage workers and trade unions to actively participate in the development, implementation and evaluation of services which also include volunteers, where appropriate Social Protection Committee (2014, p. 9).

Quality guidelines recommend that potential and actual users of social services and, where appropriate, their families, provide clear, accurate and accessible information, adapted to the specificities of each target group, particularly as regards the types, availability, extent and limitations of the services. Information regarding LTC providers should also include independent evaluation reports and quality assessment. Recommendations require that disabled should have access to the information adapted to their needs, the implementation of a transparent, accessible and user-friendly advice and the introduction of complaint procedures for users, setting up regulatory frameworks and control mechanisms to avoid physical, psychological or financial abuse and to ensure implementation in accordance with the rules regarding health and safety. Recommendations require an adequate number of workers and volunteers involved in service delivery with adequate training. Recommendations put great emphasis on prevention of discrimination and promotion of integration of users in the community. Recommendations also require the confidentiality and security of user data that allows information to be shared, where appropriate, between different service providers, in full compliance with data protection legislation.

Long-term care services should operate by openness and transparency, in compliance with European, national, regional and local legislation and regulations, the principles of efficiency,

effectiveness, and accountability regarding the organizational, social and financial performance of service delivery. The provision of services must be based on the coordination of the relevant public authorities, social partners and stakeholders in the planning, financing LTC program (including a set of priorities within the available budget) and delivery of LTC services. Implementation of the LTC system must be clearly defined, along with responsibilities and relationships between the actors involved in the planning, development, financing, delivery, support, monitoring and evaluation of services. We need to ensure regular planning processes, reviewing and establishing mechanisms for systematic, continuous improvement. Collect the necessary regular feedback on the efficiency and effectiveness of the provision of services of all participants in the system, users, funders and other stakeholders as well as potential users who would like to be included in the system. Establishment of a regular independent review of procedures, outcomes and users' satisfaction and publication of the results is necessary. Advice should be user-friendly. The implementation of a transparent and accessible complaints procedures should be clearly defined Social Protection Committee (2014, p. 9).

Demand for long-term care is growing and exceeds supply. In recent years in Slovenia we tried to meet the growing demand by building new homes for the elderly and by increasing the capacity of existing nursing homes, nursing departments in hospitals, as well as increase the capacity for prolonged hospital treatment. All these measures still do not meet the requirements, which will increase even more over the next 15 to 20 years with the aging of the population (Rupel and Ogorevc, 2010). Qualitative research has shown that the quality of LTC care of the elderly in retirement homes consists of the following items: (1) Healthcare is tailored to individual needs; (2) for the user customized LTC services; (3) The interest to the user; (4) direct contact; (6) the ability to listen; (6) carers shall treat users with dignity; (7) the proximity of the user; (8) to receive information about health care; (9) empathy and compassion, and (10) respect for their values and preferences. Respect for individual choices of residents is emphasized by many authors, but their decision-making capacity is often overlooked by providers of long-term care Beatriz Rodriguez et al. (2013, p. 13-65).

2 Demographic changes driving demand for long-term care

Due to the steady decrease in fertility and increase in the life expectancy of the population in the last century, the age structure of the population of Europe, as well as in Slovenia, have changed dramatically. According to our calculation based on Aging Report 2015 the average expected 10-year growth rate of 65+ cohorts is 16.5%, the growth rate of the proportion of 80+ cohorts is even higher. By 2045 the share of 80+ is expected to double, and by 2060 it is expected to triple (EK, 2015). The aging index as an indicator of the relationship between the number of 65+ regardless of the number of inhabitants in cohorts under 15 years old is already well more than 100. By 2060, however, population projections EUROPOP2013 are predicting that aging index will exceed 200. The dynamics of the age structure of the EU-28

in the second half the twentieth century and its projection for 2060 predicts that the share of the active population aged 15 to 64 years from the extremes, reached in the nineties, will fall by around 10% in the absolute term (EK, 2015). While the proportion of young monotonically decreases and projections show moderation in the dynamics of the decline in the proportion of young people, the proportion aged 65+, in particular the proportion aged 80+ in Europe is rising sharply, which not only endangers long-term sustainability and solvency of the pension funds of Europe but also requires an appropriate reorganization and in particular additional funding for long-term care for the elderly (EK, 2015), and even a new approach to caring for aging Europeans.

The age structure of the population of Slovenia shares the fate of the aging of Europe and the dynamics of the aging of Slovenian population is among the faster-aging populations in Europe (EK, 2015). While on the territory of present Slovenia in 1869, at a time when our great-grandfathers and great-grandmothers were born, only 5% of the population was 65+, at independence in 1991, more than 11% of the population was 65+, and in 2008 we had already 16.4% of the population aged 65+. An increased proportion of the elderly population presents many challenges for our existing institutions (EK, 2015). Planners of social protection systems are facing different problems than at the time of the industrial revolution, especially regarding retirement income, health care, and long-term care provision. The process of population aging subtly undermines good relations between the generations and calls for the development of new relations in society.

We have to decide: (a) to maintain standards, respecting the norms and to increase the volume of public funds to finance the supply of LTC, which means happy healthcare workers and the good care for elderly; (B) or require high work norms for care workers with lower standards of care, which leads to a reduction in the quality of care and unhappy care providers. Public expenditure on health care in the structure of GDP in Europe are different. Slovenia is below average, and the median of European countries and the planned dynamics is even lower than in most countries.

Table 1: Public health expenditure in the structure of GDP and projections

Country	2013	2060	Country	2013	2060	Country	2013	2060	Country	2013	2060
BE	6.0	6.8	EL	6.6	8.4	LT	4.2	4.5	PT	6.0	9.4
BG	4.0	4.6	ES	5.9	7.2	LU	4.6	5.5	RO	3.8	5.1
CZ	5.7	7.3	FR	7.7	9.2	HU	4.7	5.9	SI	5.7	7.4
DK	8.1	9.5	HR	5.7	8.0	MT	5.7	8.7	SK	5.7	8.2
DE	7.6	8.8	IT	6.1	7.2	NL	7.2	8.7	FI	7.8	9.3
EE	4.4	5.3	CY	3.0	3.3	AT	6.9	8.9	SE	6.9	7.7
IE	6.0	7.6	LV	3.8	4.6	PL	4.2	5.8	UK	7.8	9.8
									EU28	6.9	8.4
									EA	7.0	8.2

Source: Ageing Report 2015

Most of the nursing of older people is financed by the state through Health insurance fund, while the majority of social care in the context of long-term care is financed by the users

themselves and their families. For all who are dependent on others for assistance with activities of daily living, such aid is not adequately financed from social insurance institutes. Thus, OECD report (2007) shows that larger part of LTC expenditure in Slovenia is financed by private expenditures than in most European countries. Most of the financing for nursing comes from the health insurance institute, while in Slovenia direct financing from the public budget is among the lowest in the EU. Due to lack of financing for the proper provision of services in nursing homes older people have a growing negative attitude to the idea that after a substantial decline in functional capacities they should move into a nursing home. This is due to inappropriate work norms and standards of care in nursing homes as well as the inappropriate categorization of residents by Pension and Disability Institute.

3 Method

Based on our previous study of foreign literature and our cooperation with Professor Debra Dobbs at the University of South Florida, we follow her hypotheses, what matters most. She and her colleagues found out that dignity and financial safety is the most important indicator for quality of LTC. Is in Slovenia the same? Therefore, the survey, which was conducted in 2010 involved 360 persons in Slovenia. We have conducted interviews with residents of nursing homes and their relatives. All were aware of the purpose of the survey, and they agreed to participate in the survey. We have conducted interviews with 126 residents of nursing homes: 45 in the nursing home A, 40 in nursing home B and 41 in the nursing home C.

127 relatives of residents in nursing homes were also interviewed. Part of the questionnaires was sent by mail, and the rest of the survey was in the form of an interview. In the nursing home A, we have interviewed 42 relatives in the nursing home B we have interviewed 32 relatives and in the nursing home C we received 53 questionnaires from relatives out of 100 sent.

Future users were directly surveyed on 107 different locations across Slovenia. When interviewing residents, we have received help from nursing homes where they resided. The interviews were conducted with a group of residents, who were able to understand the questions. Questions had to be explained to them. We had randomly selected relatives of residents in two nursing homes when they came to visit their relatives in the nursing home. In one nursing home questioner was sent by mail.

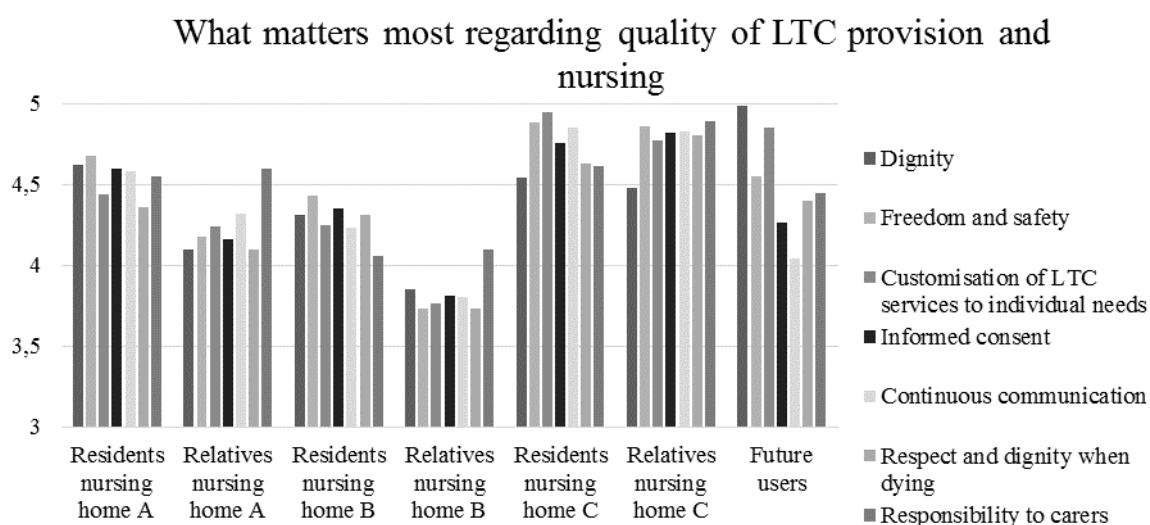
4 Results

Maintaining dignity is on the top of the requirements of both current and future users, as shown in Figure 1. It is also written in the European Charter of the Rights and Responsibilities of Older People in Need of Long Term Care and Support (2010, p.6 - 25) and specifies the following rights:

- the right to dignity, physical and mental well-being, freedom and security;
- the right to self-determination;
- the right to privacy;
- the right to high quality and tailored care;
- the right to information according to your needs, to advice and informed consent;
- Right to continued communication, participation in society and cultural activity;
- the right to freedom of expression, thought and belief: belief, culture and religion;
- the right to palliative care and support, and to respect and dignity in dying and in death;
- the right to redress.

The results of survey show that for residents of nursing homes matters most dignity, privacy, professional staff and autonomy to manage their own activities. The doctor needs to be professional and the residents would like to have timely information regarding the state of their health. They want proper communication during illness and proper, respectful treatment of dementia. They want a room with a shower. They want to be able to decide on the time of getting up and time of going to bed. They expect responses to complaints. They want to live un accordance with their religion. For them, it is important to have a library in the nursing home (see Figure 1).

Figure 1: What matters most to seniors in nursing facilities



Maintaining dignity is on the top of the requirements of both current and future users, which is also evident from Figure 1.

The results further indicate that users of LTC wish that the care is provided in small groups. They would like their municipality to increase the range of services of home care and to develop community services for seniors with the appropriate range of services in local places where seniors lived in their working age life. Users of LTC services want to have access to LTC services accessible from their homes and if not that proper accommodation would be

provided for them in the community and they would not need to move far from the place where they lived before the decline of their functional abilities. As can be seen from Figure 3, the future occupants prefer professional staff. For current residents who already reside in a nursing home, the top priority is that staff should take more time to listen to them and be more patient (Figure 3). For the realization of these desires, it is necessary to change the norms and standards of LTC. In the survey, respondents expressed a wish that they would have more autonomy to be able to look after themselves as far as possible, to be independent as long as possible, and then after an additional decline in their functional capacities to have access to assistance of volunteers. They also expressed interest in the possibility of a 24-hour call for help, an organisation of day care on the municipality level and home care provision. Older people want to stay in smaller nursing homes in the vicinity of their hometowns. They want qualified personnel, which is communicative and able to empathize. Expect retirement community which would provide services in a community setting, which will be embedded within their hometown environment and will offer users the possibility of quality accommodation and versatile operation (Figure 4). The supply of LTC services seems very important for residents. It is important for them not to interrupt therapy due to relocation and the timely visit to the doctor in case of illness (Figure 4).

Figure 2: Differences in priorities between current residents in nursing homes, their relatives and future users of LTC

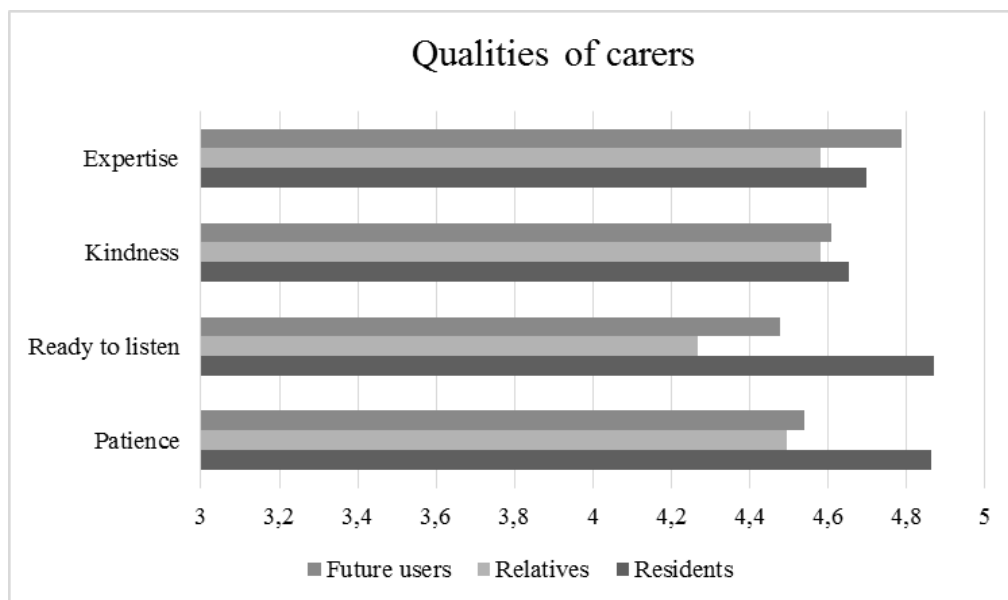


Figure 3: Importance of caregiver competence in the eyes of residents

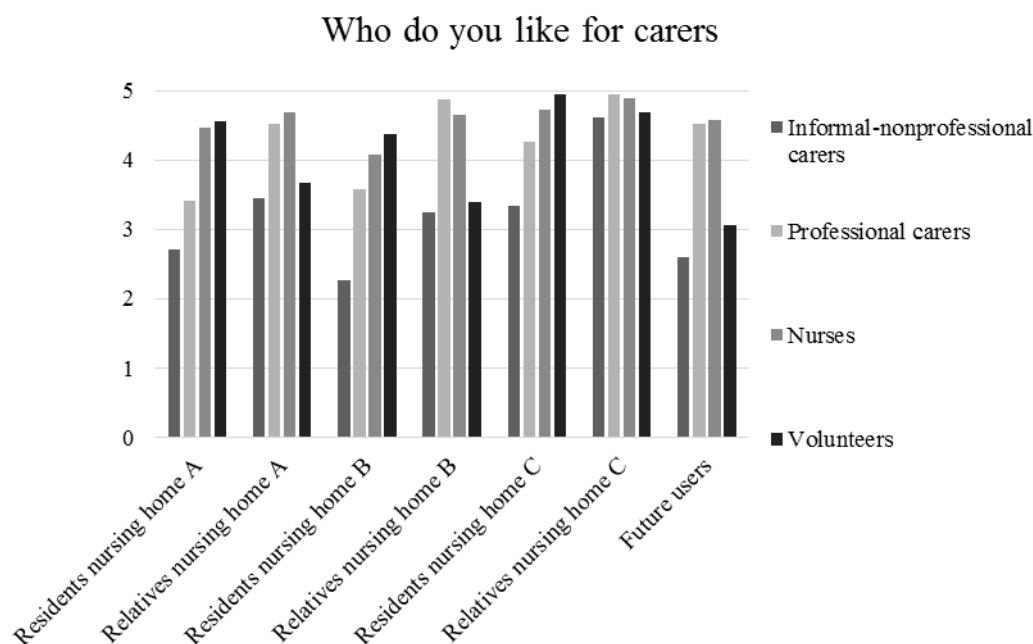
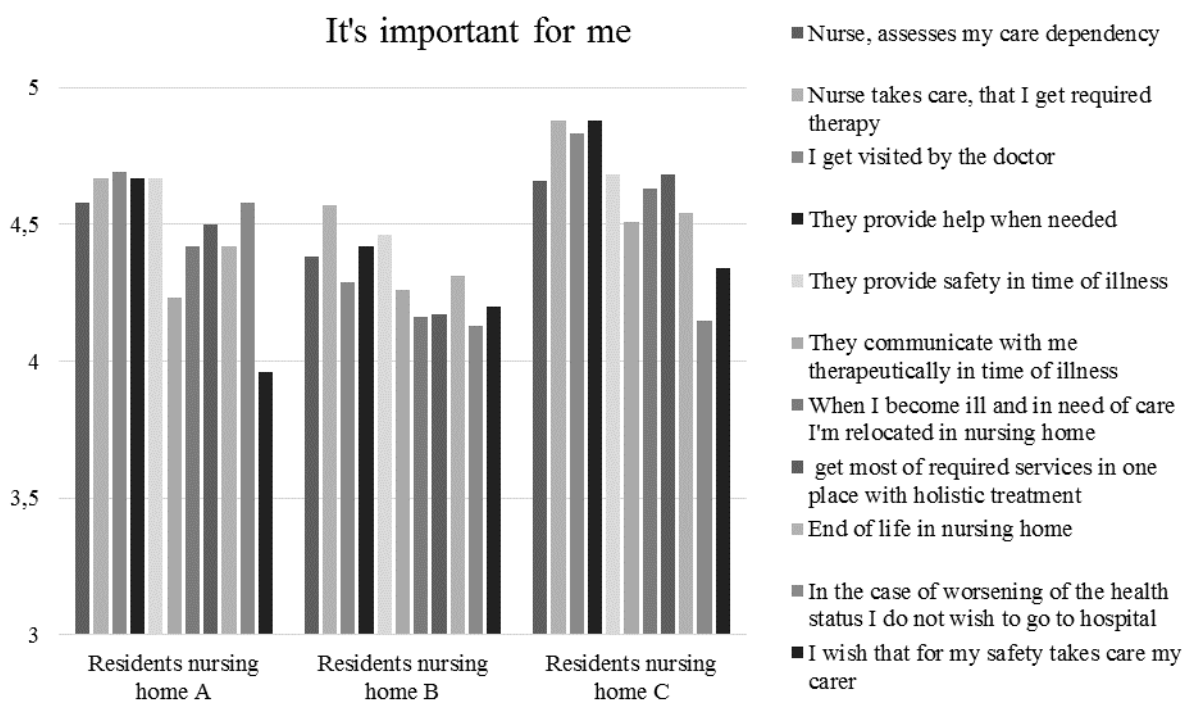


Figure 4: The importance of individual services



In the context of the development of standards and norms for the long-term care, it is important, however, to take into account the wishes of patients and the priority given to the tasks that appear to be key for residents.

5 Discussion

Extended professional board for the care at the Chamber of Nurses and Midwives Association of Slovenia - Association of professional associations of nurses, midwives of Slovenia together with the Trade Union of Health Workers of Slovenia implemented the research of the needs for new staff regulations issued by the Blue Book standards and norms in health care and nursing (2013). This study should be seriously considered regarding adequate coverage of the costs of human resources in long-term care and norms. For high-quality, long-term care in Slovenia, it is necessary to develop proper standards and norms with an appropriate burden for the carers and evaluate the work in this activity. At the systemic regulation of the field of long-term care, it is essential to agree on what level of service should be borne by insurance for long-term care accordingly and spatial conditions linked to a set of standards for each category of care and to calculate the real price for LTC services provided in each category of care. Based on these calculations necessary information to connect to the projection of demographic trends, to develop demographic tables of multiple decrement Bogataj et al. (2015, p. 59-80) and to carry out an actuarial calculation of contribution rates for the basic standard of LTC service provision.

Future research of systems of quality management should consider the development of personalized long-term care from the formation of an individual plan and through continuous monitoring of the implementation of personalized care. In accordance with the methodology for pricing of the LTC services through costs incurred by each category of care. European Charter emphasizes personalized care for all involved in the LTC to increase the autonomy of persons with declining functional capacities dependent on the help of others.

We, as the society, need to answer the following questions and develop following projections:

1. What standard of long-term care and nursing we want to be publicly financed - what is standard, what is above standard;
2. Develop the demographic projections with different categories of dependence based on multiple decrement model of decreasing functional capacities of older people.
3. We have to reach a social consensus regarding the financing of the standard LTC services and determine the structure of financing: directly from the public budget or through social insurance funds.

6 Conclusion

In an old age not only physical capacities decline but also cognitive abilities. The level of dependence on the help of others increases with age, and the proportion of the elderly population, especially very old (80+) is expected to triple in the next 45 years. According to data from the US Alzheimer's Association, every third elderly person at death also has developed dementia. To consider this fact is particularly necessary in the process of developing long-term care plans and the legal basis for its implementation. Self-care of the elderly is highly dependent on the built environment in which they live, and it may represent a lower cost of care. In the framework of deinstitutionalization, we need to develop new types of community care and new residential communities for older people, such as the village for the elderly and similar structure of apartments that are adapted to the functional capacities and the needs of the elderly. With proper build environment and assisted living services, elderly dependent on the help of others can remain for a very long time in the community with minimal assistance and LTC services. Thus, the provision of adequate infrastructure and housing adapted to needs of elderly and adequate networks of LTC services directly affects the rate of supply. We need to develop the necessary technical bases for the organization of the system of LTC with quality services that are perceived as such from perspectives of users, providers, and supervisors. Quality management must anticipate changes in the quality system, because of the need for quality and range of services from generation to generation change, so the dynamic aspect is necessary. We can expect some changes also regarding the ranking of main indicators of quality of care as future users have different priorities than current users of LTC. Nonetheless like in papers of Black and Dobbs (2015, p. 133-152), the dignity and respect of seniors' wishes are on the top of the rank list.

Slovenia and its local communities have not yet developed the comprehensive quantitative research what the current and prospective users require from LTC services. Higher quality of long-term care will be provided for users when it will provide services closer to users' wishes, of course within financial possibilities. Without categorization, it is impossible to develop the long-term plan regarding the number of users in each category of care. Without projected number of users in each category, it is impossible to plan the personnel, spatial and financial requirements and develop long-term reform program for LTC. It is necessary to establish much more precise norms and standards of long-term care and better connect with the public-private initiative. We will need to include in the planning process also users of LTC, as far as possible. The essence of the entire system is the satisfaction of customers-payers, employees, and taxpayers, and their needs should be harmonized, and the desired output reached a compromise. The problems that arise in measuring the quality of LTC services are subjective and objective in nature, as for how to measure the quality of life of older people. It is necessary to register and try to minimize the number of adverse events that occur in the LTC as proposed by OECD.

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Povzetek:

Razvoj novih standardov kakovosti oskrbe starostnikov v Sloveniji

Raziskovalno vprašanje: Izpostavljamo vprašanje, katere vrste storitev dolgotrajne oskrbe si želijo najbolj tisti starejši, ki že koristijo te storitve v domovih za ostarele, njihovi svojci, pa tudi prihodnji slovenski uporabniki. Je prednostni seznam enak kot v predstavitvi prednostne liste v ZDA, kot to navajata Black in Dobbs (2015, str. 133-152)?

Namen: Prispevek podaja problematiko kakovosti dolgotrajne oskrbe in predvsem zdravstvene nege kot njenega dela. Navaja rezultate raziskave o tem, kaj je najbolj pomembno za sedanje prebivalce slovenskih domov za ostarele, njihove sorodnike in bodoče uporabnike dolgotrajne oskrbe v Sloveniji.

Metoda: Po študiju ustrezne evropske in OECD literature smo ugotovili, da se lahko razvoj standardov kakovosti in norm v dolgotrajni oskrbi za starejše odvija na različne načine. Da bi opredelili prednostne kazalce kakovosti dolgotrajne oskrbe, smo organizirali 3 skupine intervjujev: oskrbovancev v domovih za starostnike, njihovih sorodnikov in potencialnih uporabnikov iz treh slovenskih občin.

Rezultati: Ugotovili smo, da obstaja velika vrzel med potrebami in razpoložljivimi storitvami dolgotrajne oskrbe v Sloveniji. Rezultati so pokazali, kateri kazalniki kakovosti dolgotrajne oskrbe so najbolj pomembni za posamezne skupine in tudi, da se med skupinami in rezultati Black in Dobbs po pomembnosti razlikujejo.

Lokalna skupnost in družba: Te ugotovitve kažejo na pozitivno pobudo lokalnih skupnosti, da razvijejo dolgotrajno oskrbo na domu in v skupnosti, kakor tudi v domovih za starejše z zmanjšanimi funkcionalnimi zmožnostmi sami, ali pa da razvijejo pogoje za zasebne naložbe v lokalnih območjih, da bi pritegnili naložbe v cenovno dostopne storitve v skupnosti in v domovih za ostarele.

Novost: Ta študija je prva te vrste v Sloveniji, medtem ko njeni rezultati dajejo boljši vpogled v to, kaj je najbolj pomembno za slovenske upokojence, kakor tudi njihove svojce in bodoče uporabnike glede kakovosti njihove dolgotrajne oskrbe. Ti rezultati so sprožili nadaljnje študije prve avtorice, ki je privedla do doktorske disertacije.

Smernice za nadaljnje delo: Študija bi lahko dala drugačne rezultate v primeru, ko bi jo izvedli v večjih mestih, npr. v Ljubljani, zato je treba študijo razširiti na področje prebivalstva večjih mest.

Ključne besede: dolgotrajna oskrba, dom za ostarele, kakovost oskrbe, nega na domu.

