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The needs of vulnerable older people in home health care

Disertační práce

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Abstract

The present dissertation, which focuses on the needs of particularly vulnerable older people in home health care, was written within the framework of the PhD study in Longevity at the Faculty of Humanities, Charles University and was carried out as part of the project supported by the Charles University Grant Agency "Met and Unmet Needs of Particularly Vulnerable Older Patients in Home and Inpatient Care" (GA UK No. 760219). The overall aim of the three researcher project, where I was the research coordinator, was to clarify the needs of particularly vulnerable older patients in both home health care and inpatient care, including the needs of patients living with dementia. The aim of this dissertation was to identify the needs of vulnerable older patients in home health care.

This dissertation consists of four papers. At the time of writing, two articles had been published in peer-reviewed journals and two articles were under review. The thesis has chapters in the introduction and conclusion that set the professional articles in context, creating a comprehensive view of the needs of particularly vulnerable older people in home health care. As three of the four peer-reviewed articles submitted have been published (1) or under review (2) in international journals, the entire dissertation is written in English.

Abstrakt

Předkládaná disertační práce, jejímž tématem jsou potřeby starších zranitelných lidí v domácí zdravotní péči, vznikla v rámci doktorského studia Dlouhověkosti na Fakultě humanitních studií Univerzity Karlovy a byla realizována jako součást projektu podpořeného Grantovou agenturou Univerzity Karlovy "Uspokojené a neuspokojené potřeby zvláště vulnerabilních pacientů vyššího věku v domácí a lůžkové péči" (GA UK č. 760219). Celkovým cílem projektu tří řešitelek, kde jsem byla koordinátorem výzkumného projektu, bylo objasnit, jaké jsou potřeby zvláště vulnerabilních pacientů vyššího věku jak v domácí zdravotní péči, tak i v péči nemocniční, včetně potřeb pacientů žijících s demencí. Cílem této disertační práce bylo zjistit, jaké jsou potřeby starších zranitelných pacientů v domácí zdravotní péči.

Tato disertační práce se skládá ze čtyř odborných článků. V době psaní této práce byly publikovány v recenzovaných periodikách dva články a dva články byly v recenzním řízení. V úvodu a závěru je práce doplněna kapitolami, které zasazují odborné články do kontextu a vytváří tak komplexní pohled na potřeby zvláště zranitelných starších lidí v domácí zdravotní péči. Vzhledem k tomu, že tři ze čtyř předložených odborných článků byly publikovány (1) nebo byly v recenzním řízení (2) v mezinárodních časopisech, je celá disertační práce napsána v anglickém jazyce.

Key words

Home health care, older people, needs, experiences, care provision, quality of care, nurses

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1 Introduction

1.1 Needs in the context of care for particularly vulnerable older people

A holistic approach to patients is needed when planning and delivering both health and social care. The principle of a holistic approach is to accept the biological, psychological, social and spiritual needs of the person. Such a holistic view of the person and their needs is the essence of person-centred care (McEvoy and Duffy, 2008). Respecting patients' needs and preferences in the planning and delivery of care is one of the prerequisites for ensuring quality care (WHO, 2020). Taking patients' needs into account also affects their quality of life (Ruggeri *et al.*, 2005).

1.1.1 Characteristics of needs

Physicians, sociologists, philosophers, economists and other representatives of different disciplines have different views on what needs are and what human needs are (Wright, Williams and Wilkinson, 1998). From a scientific perspective, the concept of human needs is an abstraction that is ultimately defined based on 1) scientific knowledge - a paradigm - a consensus of scientists representing different disciplines (biology, psychology, sociology, nursing, etc.), 2) theoretical orientation, and 3) a worldwide view of the issue. If we focus on human needs related to health in particular, we can characterise them from several perspectives. From a biological point of view, human needs reflect physiological or somatic needs related to survival and health; in contrast, psychologists' interest in human needs tends to focus on higher-level needs, which include, for example, needs related to esteem and respect. Social scientists then place human needs in the context of social interaction (Hesook and Kollak, 2006).

1.1.2 Human needs and the motivation to fulfil them

In the same way that human needs are characterized from multiple perspectives, representatives among experts concerned with human needs, their hierarchy, and the motivations for satisfying or fulfilling them have taken or continue to take more or less divergent positions on this issue, which have led to the development of their own theories. In the following text, the views and theories of several representatives are presented in the chronological order. This is not a full list of representatives of the various theories and positions, but is our own selection, which we have made on the basis of a study of the literature and scholarly articles and by mutual agreement of participants of the above mentioned research project focused on vulnerable patients´needs, so as to present different views of human needs and motivations for human action.

Henry Alexander Murray (1893-1988)

Murray divides human needs into primary and secondary. While primary needs are basic physiological needs whose fulfilment is important for survival, Murray sees secondary needs as psychogenic needs whose provision and satisfaction is important for psychological well-being. He also assumes that psychological needs are based on and dependent on physiological needs. Murray differentiates needs into latent and overt needs, which appear in varying degrees and are observable based on an individual's behaviour. A need stems from a desire or decision to do a certain thing in order to achieve certain effects. Thus, an individual's behaviour is triggered by the desire for a satisfying effect, where the action of the individual is completed at the moment the need is fulfilled (Murray and McAdams, 2007).

Viktor Emanuel Frankl (1905–1997)

According to Frankl's theory, people search for meaning in their lives, seeing three ways to give life meaning: 1) to fulfil the act we set out to do, 2) to fulfil the work we create, 3) to live the experience. Frankl states that satisfaction is not usually the goal of human action, but in the case of achieving a goal, it should be a side effect of it. Achieving the goal is the reason for happiness, which comes automatically, spontaneously. This implies that one does not have to pursue happiness (Frankl, 2014).

Abraham Harold Maslow (1908–1970)

According to Maslow, human action is usually motivated by the desire to satisfy needs in the following categories: physiological needs, the need for security, the need for love and belonging, the need for recognition, and the need for self-actualization. Needs are individual to each person and vary with respect to age, gender, social status, health, cultural background, life experiences, etc. Given that human needs are mainly associated with the survival of the individual or the group, Maslow argues that needs falling under the category of physiological needs are among the first to be addressed. In contrast, mental or spiritual needs, i.e. needs at a higher level, are often addressed only after physiological needs (Maslow, 1943).

Chart 1 Maslow’s hierarchy of needs

David Clarence McClelland (1917–1998)

According to McClelland's theory, human behaviour and motivation to act stems from learned (acquired) needs that a person acquires during the course of life. Human action is motivated by a sense of satisfaction with the goal of achieving maximum satisfaction. McClelland states that all people have a need to achieve something, a need for power and a need to belong somewhere, however, for each person the hierarchy of these needs is individual (McClelland, 1987).

Johan Galtung (*1930)

Galtung tentatively divides human needs into four domains (security, freedom, well-being, and identity) with respect to (1) whether the satisfaction of needs is dependent on the person (driven by the person's motivation to satisfy the needs) or on the environment (in the sense of a social environment that lacks the motivational character that drives the satisfaction of needs) and (2) whether the needs are material or non-material in nature (Galtung and Wirak, 1977).

Table 1 Needs according to Galtung

	Dependent on actors	Dependent on structures
Material	Security (violence)	Welfare (misery)
Non-material	Freedom (repression)	Identity (alienation)

Irvin Yalome (*1931)

Yalome defined four basic existential concerns that reflect basic needs and to which one should respond: 1) mortality - the fear of death, man has an instinctive fear of death, 2) freedom - the opposite of death, responsibility for one's own life, man is the author of his own destiny, 3) isolation - loneliness in the interpersonal, intrapersonal and existential sense, 4) meaninglessness - life without meaning, the absence of meaning in life, man is responsible for the meaning of his life (Yalom, 2020).

Victor Vroom (*1932)

According to Vroom, human behaviour is based on the prediction of whether the achievement of a chosen goal will be associated with satisfaction, resulting in a preference for the achievement of certain goals over others. To achieve the set goals, human behaviour is motivated by three factors: 1) expectancy, 2) valence, and 3) instrumentality. Expectancy means that one assumes or expects that a particular action will be followed by a particular outcome. Valence is seen as a psychological value that is tied to an outcome. Thus, a person's motivation for a particular behaviour is determined by the attractiveness of the goal, and Vroom states that the valence (value) of first-order outcomes is determined by the valence (value) of second-order outcomes to which first-order outcomes can lead. Instrumentality is then a measurable value that indicates that a second-order outcome does or does not follow from a first-order outcome (Vroom, 1967)

Edward L. Deci (1942) a Richard M. Ryan (1953)

According to Deci and Ryan's theory of self-determination, the satisfaction of psychological needs has a major impact on well-being. They consider the basic psychological needs to be the need for autonomy, relationships and competence (Deci and Ryan, 2000).

1.1.3 Health care needs

From the perspective of patient care and in the context of the present dissertation, particularly for the older persons, it can be stated that the needs in relation to the provision of both health and social care are not easily defined as it is a complex issue involving multiple inseparable and intertwined components (Asadi-Lari, Packham and Gray, 2003). In particular, two main and often competing aspects of human needs can be found in the literature: 1) motivation, which drives people to satisfy their own needs and guides human behaviour, and 2) an aspect that is shaped by a person's social and cultural environment. These two aspects, whether considered together or separately, are an important starting point for defining needs in the context of health and social care (Hesook and Kollak, 2006). The view of people's needs and the approach to identifying them also varies between professionals involved in care provision (Wright, Williams and Wilkinson, 1998).

From the perspective of patient care, and in the context of the present dissertation, particularly for the older age group, it can be stated that needs in the context of both health and social care provision are not easy to define unambiguously, as it is a complex issue involving multiple inseparable and intertwined components In the literature we can encounter two main and often competing aspects of human needs: (1) motivation, which drives people to satisfy their own needs and guides human behaviour, and (2) an aspect shaped by a person's social and cultural environment. These two aspects, whether considered together or separately, are an important starting point for defining needs in the context of health and social care The view of people's needs and the approach to identifying them also varies between professionals involved in care provision

Health and social care professionals look at the needs of their patients/clients particularly in the context of direct care delivery, where they aim to identify and meet individual needs in the areas of **1) environmental, 2) physical, 3) psychological and 4) social** (Reynolds *et al.*, 2000).

In contrast, Bradshaw (2013), for example, views care needs in a broader, societal context and defines four types of needs: **1) normative needs**, which are based on standards set by the experience of professionals; these needs relate to the level of services provided; **2) felt needs**, which are based on a person's ability to define their need, i.e., it is about what the person wants, what they desire and what their aspirations are; **3) expressed needs**, which are put into context with regard to whether and to what extent people use the services offered and are based on the assumption that a society (community) or an individual who uses many services has a strong need to use these services; **4) comparative needs**, which refer to an objective assessment of the relationship between the availability of services and the health status of individuals or populations. Needs are also viewed in a broader context by Stevens and Gabby (1991), who suggest that health-related needs reflect three interrelated aspects that need to be taken into account when assessing needs: **1) the need for care; 2) the requirement and preference for care; and 3) the provision of care** leading to the satisfaction of needs. Similarly, Haaster et al. (Haaster *et al.*, 1994) view health care-related needs and also divide them into three categories: **1) the problem** faced by the patient; **2) the actions** needed to alleviate or manage the patient's problems; and **3) the services or care** to provide the needed actions.

In view of the above statements, it should be emphasised that the planning and provision of health (and social) care must take into account not only the individual needs of the individuals to be cared for, but also the needs of the community or society. These needs should then be contextualised in relation to individual needs (Reynolds *et al.*, 2000), also bearing in mind that there are still differences between the needs of patients/clients and the services offered (Asadi-Lari, Packham and Gray, 2003). In order to minimise this gap and meet not only the needs of patients/clients but also the needs of both professional and informal carers, it is essential to consider needs in a holistic way?

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1.2 Care for the older people at home in the Czech Republic

Most seniors wish to remain in their social environment in a state of illness or reduced self-sufficiency. The term social environment is deliberately mentioned, as Act No. 108/2006 Coll., on Social Services, as amended (Act No. 108/2006), and considers the social environment to be the natural social environment, which is defined as *"the family and social ties to close persons, the person's household and social ties to other persons with whom he or she shares the household, and places where persons work, are educated and carry out normal social activities"* (MPSV, 2021). In Act No. 372/2011 on Health Services and Conditions of their Provision, as amended (Act No. 372/2011), the social environment is described as the patient's own social environment and subsequently defined as *"the patient's home environment or an environment replacing the patient's home environment, such as a social services facility"* (MZ ČR, 2021c).

Care for the older people in their social environment is provided through field services, both health and social. Unfortunately, it has not yet been possible to link health and social services so that they can be provided simultaneously, both within the same organisation (although some home care agencies and gerontological centres also provide outreach care) and during a single visit of the older patient, despite the fact that the inseparability of the health and social components of care has been proven and it is repeatedly since many decades declared as an important principle in many strategic documents including governmental ones (MPSV, 2014; MPSV, 2016). In a publication entitled Domácí a primární péče včera, dnes a zítra (Home and primary care yesterday, today and tomorrow), published in 1998, it is argued that there is a need to link health care and social services in the provision of outreach care for older people, thereby ensuring the comprehensiveness of care provision for older people in their home environment (Misconiová, 1998). It is therefore surprising that there has been no significant change in this area since 20 years.

The first part of this subchapter is devoted to defining terms related to home care. Then, international and national strategic documents are presented that point to the necessity of providing care for the older people in their home environment and aim to increase the availability of outreach services for older persons and at the same time increase the number of seniors who will stay in their home environment. In the context of these strategic documents, the following section sets out the legislative provisions that legally anchor the provision of care

1.2.1 Terms

In the provision of care for older persons in the home environment, it is important to distinguish between the concepts defining the provision of health and social care, although, as mentioned in the introductory section, it is not possible to separate the health and social components in the provision of such care. The terms defining home care can be found in many encyclopaedias, publications, web references, etc., both foreign and domestic. In our environment, foreign terms have been adopted over time and have now become commonly used[1].

Diderot's Great General Encyclopaedia defines home care as *"care provided in the client's home, in the client's home environment, for the purpose of promoting, maintaining, and*

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[1] The most frequently encountered term in our country is Home care, which refers to home health care.

restoring health or minimizing the effects of illness or incapacity" (Diderot 4, 2001). The General Encyclopaedia of Diderot defines caregiving, to which the English equivalent of home help belongs, as *"an outreach social service enabling persons with limited independence to live in a home environment. It provides, in particular, food delivery, shopping, cleaning'* and refers to the concept of long-term care, which he defines as *'a complex of health and social measures to care for people whose self-sufficiency is threatened or lost. It seeks to ensure a good quality of life in the home (natural) environment. Individual care in cooperation with family and lay initiatives is optimal. Supplementary professional services (nursing care and home care, including hospice care) are used. Where necessary, long-term care is provided in an institutional setting"* (Všeobecná encyklopedie ve čtyřech svazcích. Díl 3, 1996).

There is also an interesting definition of the term home care according to the Universum General Encyclopedia, which in this case refers to the concept of social service (Universum: všeobecná encyklopedie. Díl 2., 2001) subsequently defined as a tool to address a social emergency, which can be, among other things, a care service (Universum: všeobecná encyklopedie. Díl 8., 2001). It describes the nursing service as *"an institution providing assistance to citizens who, because of their age or ill health, are unable to perform the necessary household chores or need to be treated by another person"* (Universum: všeobecná encyklopedie. Díl 7., 2001). Thus, the Universum general encyclopaedia states that in the provision of care services it is possible to treat persons with deteriorating health.

According to the Dictionary of Social Work, home care means *"care provided to sick or dying people in their homes by qualified health professionals, social workers or other professionals, or even lay people"* (Matoušek, 2003). At this point, therefore, the Dictionary of Social Work acknowledges that home care can also be provided by social workers. Elsewhere in the Glossary we can see an interpretation of the term 'care service', where it is clearly stated that it is a social service and then the areas of care to which the provision of care services belongs are listed. Finally, it is stated that *"with the help of this service, the period of relatively independent life of persons in their homes is prolonged"* (Matoušek, 2003). For both of these services, the English equivalent is given as home care.

The definitions of home health care and nursing care are generally the same in the above encyclopaedias. Although, in some cases, there is confusion between home health care and nursing care. This may be because they are two interrelated services that cannot be strictly separated from each other.

Despite the existing variability, in the European context the “home care” is used mostly for health care services, mainly nursing care provided in the home environment. Whereas the “home help” or “care services” mean auxiliary and social services provided in the home environment. In Czech, paradoxically, the term “home care” domesticated in its English origine meaning mainly home nursing care whereas for social services we use other terms (pečovatelská služba). Long-term care (dlouhodobá péče) is a term usually used to define the whole complex and different types of services (health, social and other) that respond to the needs of persons with limited self-sufficiency (Holmerová *et al.*, 2014).

1.2.2 International and national strategic documents

International strategic documents in their declarations consistently point to the need to maintain the current way of life of the older people in their home environment and subsequently declare this in their objectives. This is no different in the national strategy documents, which are mostly based on the international ones.

One of the international strategic documents which, with regard to the human rights of older persons , promotes the stay of seniors in their home environment in its objectives is the United Nations (UN) Principles for Older Persons adopted in 1991. According to one of the UN Principles, seniors should *"live in their own homes for as long as possible"* with regard to independence (Zásady OSN pro seniory, 2020).

The 2002 UN International Plan of Action on Ageing (Madrid International Plan of Action on Ageing 2002) is an international strategic document based on the UN Principles that takes into account the issue of older people staying in their home environment in its objectives. Paragraph 86(c) of this Action Plan identifies the need to develop strategic documents to support people with mental illness or Alzheimer's disease[2] to remain in their

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[2] With increasing age, the number of people living with Alzheimer's disease is increasing in the population. A publication by the Czech Alzheimer's Society states that in 2015 there were an estimated 156,000 people

home environment. Point 105(b) of the Action Plan also points to the need to promote the stay of older people in their home environment as a means of preventing hospital admissions and placements in residential social services, in particular by improving the quality and availability of community-based long-term care for older people (Madridský plán a jiné strategické dokumenty, 2007).

Another international strategic document supporting the retention of older people in their home environment is the Regional Implementation Strategy (RIS) adopted by representatives of the UN member states' ministers at the Berlin Conference in 2002. The RIS was intended to serve as a follow-up to the above-mentioned International Plan of Action on Ageing, with the aim of ensuring the integration of ageing and old age into public policy in the member countries of the United Nations Economic Commission for Europe (UNECE). One of the commitments of the RIS is to *'Improve the quality of life of citizens of all ages and increase the chances of independent and self-sufficient living for older people in good health and social well-being'*, with the proviso that older people should be given the opportunity to decide whether they wish to be cared for at home or in hospital in the event of illness, given that long-term care is more often provided in older people's homes or communities. At the same conference, the UNECE Berlin Ministerial Declaration was signed as justification for the need to adopt RIS (Tomeš et al., 2017). Support for these documents and the implementation of their goals and commitments was expressed by the member countries, including the Czech Republic, in 2007 at the UNECE Conference in León, Spain, by signing the León Ministerial Declaration - Society for Persons of All Ages: Challenges and Opportunities (Leónská ministerská deklarace - Společnost pro osoby v každém věku: výzvy a příležitosti, 2007), followed by the Vienna Ministerial Declaration in 2012 and the Lisbon Ministerial Declaration in 2017 (UNECE, 2012, 2017).

The Strategic Action Plan for Healthy Ageing in Europe, 2012-2020, published by the World Health Organization (WHO), is also one of the documents that highlights the need to ensure health care for older people in their home environment, taking into account people with dementia, including support for informal carers, and the need to link health and social care as evidence-based (WHO, 2012).

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living with dementia. It is predicted that in 2020 there will be 183 thousand people living with Alzheimer's disease and in 2050 even 383 thousand people(Mátl, Mátlová and Holmerová, 2016).

Most recently, the need for older people to remain in their home environment is addressed in the 2016 WHO strategy document, Global Strategy and Action Plan on Ageing and Health, adopted at the 69th WHO Assembly. Objective 3.2 of this document declares the need to situate care for older people as close as possible to the environment in which they live, including the need to provide care for older people in their homes (WHO, 2017).

The Ministry of Labour and Social Affairs (MoLSA) is responsible for the National Action Plan to Promote Positive Ageing for the period 2013 to 2017, which builds on the National Programme for Preparation for Ageing 2008-2012 and the National Programme for Preparation for Ageing 2003-2007 and is based on the objectives and recommendations of the International Plan of Action on Ageing and the UN Principles for Older Persons. One of the priorities of this National Action Plan is the "Quality Environment for the Life of the Older Persons", whereby, in view of the need to support the life of the older persons in their homes, it is necessary to provide developed outreach services. This means outreach health and social services. "Care for the most frail older people with limited self-sufficiency" is another priority of this Action Plan. The vision of this priority *is "A wide range of coherent social and health services, including the involvement of carers, which will respond to the specific needs of older people with limited self-sufficiency"*, followed by a reference to social and health services provided in the home environment of older people. The measure to meet the objectives of this priority is *"Expand the availability of outreach and related respite services for informal caregivers"* (MPSV, 2014).

The Health for All in the 21st Century Programme (Health 21), which is under the responsibility of the Ministry of Health of the Czech Republic (MoH), was adopted by the Government Resolution of the Czech Republic as the Long-term Programme for Improving the Health Status of the Population of the Czech Republic in October 2002 and is based on the WHO international strategic plan "Health 21 - Health for all in the 21st. Century", which was adopted at the 51st WHO Assembly. Health 21, in Goal 5 'Healthy ageing', sets the target of *'increasing by at least 50% by 2020 the proportion of people over 80 years of age who achieve a level of health in their home environment that enables them to maintain their self-sufficiency, self-esteem and place in society'*. This objective is subsequently developed into individual activities. The indicator for monitoring the sub-objectives is the number of community plans and programmes to develop integrated home care. Objective 15 'Integrated Health Sector' lists home care as an integral part of primary care, where the provision of home care leads to a reduction in the incidence of nosocomial infections and a reduction in the financial burden on the system due to a reduction in hospital admissions (MZ ČR, 2008).

The National Strategy for Health Protection and Promotion and Disease Prevention - Health 2020 (National Health Strategy 2020) is another strategic document under the responsibility of the Ministry of Health of the Czech Republic that deals with the issue of care for the older persons in their home environment. The National Health 2020 Strategy was adopted by the Government of the Czech Republic as an implementation tool of the WHO Health 2020 programme in January 2014. Action Plans have been developed for the implementation of individual areas of the National Strategy. Action Plan 8 "Increasing the quality, availability and effectiveness of follow-up, long-term and home care" is elaborated into two areas, namely a) Increasing the quality, availability and effectiveness of follow-up, long-term and home care, b) Increasing the availability of follow-up care, which are subsequently incorporated into a logical framework (MZ ČR, 2014, 2015).

Supporting seniors to stay at home is one of the objectives of the National Action Plan for Alzheimer's Disease and other similar diseases for 2016-2019 (National Action Plan), again under the responsibility of the Ministry of Health of the Czech Republic, which was adopted by the Government of the Czech Republic in February 2016. This is the second National Action Plan, as the preparation of the original National Action Plan for Alzheimer's Disease and Other Related Diseases for 2014-2017 was halted due to changes in the government in the summer of 2013, which affected the composition and activities of the working group for the preparation of this National Action Plan (MZ ČR, 2016).

In the context of international and national strategic documents supporting the stay of older people in their home environment in a state of illness or reduced self-sufficiency, the European Charter for the Older Patient, which, among other things, points to the need to ensure functional and complete services for the older people, including the provision of home care through community services, and considers it desirable and necessary to provide home care for older people who wish to be cared for at home (Madridský plán a jiné strategické dokumenty, 2007).

1.2.3 Legislative framework

The conditions for providing care in the home environment are determined by the legislation in force. At this point, it is necessary to distinguish between the provision of home health care and nursing care, as the provision of these services (care) belongs to two different ministries (home health care - MoH, nursing care - MoLSA) and is governed by different laws, which are unfortunately not coherent to date.

Home health care

According to Section 10 of Act No. 372/2011, home care is considered to be care provided in the patient's own environment and includes nursing, medical rehabilitation and palliative care. This section also states that artificial pulmonary ventilation and dialysis may also be provided in the patient's own social environment (MZ ČR, 2021c). According to Act No. 48/1997 Coll., on Public Health Insurance and on Amendments and Additions to Certain Related Acts, as amended (Act No. 48/1997), home health care is a special outpatient care provided in the patient's own social environment, which belongs to the field of reimbursable services (MZ ČR, 2021a). Home health care is therefore fully covered by public health insurance, provided that the home health care provider has a contract for the provision of home health care with insurance companies.

Home health care is provided by non-medical health personnel, i.e. a general nurse, in accordance with Act No. 96/2004 Coll., on non-medical health professions, as amended (Act No. 96/2004). The competences of the general nurse are defined by Decree No. 55/2011 Coll. on the activities of health professionals and other professional staff, as amended (Decree No 55/2011). Home health care is provided by nurse specialty 925 (Holmerová and Válková).

The performances of specialty 925 are defined by Decree No. 134/1998 Coll., which issues a list of medical performances with point values, as amended (Decree No. 134/1998). This speciality is performed by home health care providers on the basis of a written indication from the patient's general practitioner or on the basis of a written indication from the attending physician at the end of the hospitalisation, who may only indicate home health care for a period of 14 days. The written indication must include a time range for the indicated care (15, 30, 45 and 60 minutes) corresponding to the four types of care visit. These care visits may be combined in one day, but a maximum of three visits per day for a cumulative total of three hours may be made. A signal code - nursing care of a terminal patient - may be reported if there is a need to increase the time limit and number of visits when the patient is in a terminal stage of illness, where the logic suggests that more intensive care may be needed. In the case of care of a patient in a terminal condition, "Physical Assistance in the Provision of Home Health Care" may be indicated by the physician if the physician determines that it is necessary for the procedure indicated by the physician. In addition to indicating the timing of the nursing visits, the physician shall also indicate the material procedures to be performed during the visits. The material procedures that a general nurse may perform in the provision of home health care include:

- examination of the patient's condition by a nurse in the patient's own social environment,
- collection of biological material,
- administration of prescribed parenteral therapy to provide hydration, energy sources and pain management,
- treatment of stomas,
- local treatment,
- enemas, lavage, catheterization, lavage, permanent catheter treatment,
- application of inhalation and medical therapy p.o., s.c., i.m., i.v., p.v, possibly other methods of therapy application or drug instillation,
- training and education in the administration of insulin.

However, for all of the above-mentioned procedures, Decree No. 134/1998 also specifies a time limit. The examination of the patient's condition by a nurse in the patient's own social environment can only be carried out once a week. For the other procedures, there is a limit of 3 times per day, and in the case of training and teaching insulin administration, in addition to the daily limit, there is also a monthly limit of 30 times per month. The exception is the procedure "Nursing care of a patient in terminal condition". In this case, there is no limitation on the frequency of visits and procedures and these are provided according to the needs and the current condition of the patient, based on the indication of the attending physician.

A nursing visit "Introduction, termination of home health care, administrative activities of a home health nurse" may also be reported in connection with the provision of home health care. This visit can only be reported twice per patient per completed cycle of continuous home health care.

The individual nursing visits and the associated material interventions that are carried out in home health care are limited by the performance carriers[3], which are determined by the level of education of the non-medical health professionals:

- D3 - a health professional qualified to practise a health profession without professional supervision with specialised competence in the relevant field or special professional competence.
- D2 - health professional qualified to practise a health profession without professional supervision.
- D1 - health professional qualified to practise a health profession under professional supervision.

Physical assistance in the provision of home health care can be performed by the carrier of performance D1. All other performances can be performed by the carrier of performance D2 with the exception of the performance "Introduction, termination of home health care, administrative activities of a nurse in home health care", where the carrier of performance must be a health care worker with at least D3 qualification (MZ ČR, 2021b).

Finally, it is necessary to point out that the provision of home health care also entails a social care component (i.e. it is health - social care), although this fact is not taken into account in our current legislation. The legislation in question only defines the health services that can be subsequently reported to the insurance company, including time limits for visits[4].

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[3] Performance carrier - the health professional involved in the performance of the performance (MZ ČR, 2021b).

[4] Procedures carried out outside the scope of the indicated care, e.g. hygiene of the patient's intimate parts carried out in the case of a defect in the sacrum, cannot be reported to the insurance company. "Performances" such as talking to the patient and showing interest in his/her well being cannot be mentioned at all.

Care service/personal care

As mentioned in the introduction to this chapter, the provision of (personal) care services is defined in Act No. 108/2006 and in the relevant decrees. According to Article 40 of Act No 108/2006, care is "*a field or outpatient service provided to persons who have reduced self-sufficiency due to age, chronic illness or disability and whose situation requires the assistance of another person.*" The service is provided at specified times in the homes of persons. The provision of this service includes the following basic tasks[5]:

- help to cope with routine personal care tasks,
- assistance with personal hygiene or the provision of conditions for personal hygiene,
- provision of meals or assistance in providing meals,
- assistance with the household,
- facilitating contact with the social environment.

According to Section 116 of Act No. 108/2006, personal care services can be performed by a social services worker after obtaining professional competence. The condition for acquiring professional competence is, with regard to the activities referred to in Section 116, primary, secondary or post-secondary technical education and completion of an accredited qualification course. In order to work as a social services worker, with regard to the activities referred to in Section 116, those who have acquired the qualification to practise the health profession of nursing or occupational therapy pursuant to Act 96/2004 and those who have acquired the qualification to practise as a social worker are not required to complete an accredited course.

The personal care service is one of the social services provided for a fee. The maximum amount of payment for the services provided is regulated by Decree No. 505/2006 Coll., implementing certain provisions of the Social Services Act, as amended (Decree No. 505/2006). The care allowance is intended to cover the cost of care services, which a person with reduced or limited self-sufficiency requiring the assistance of another person is entitled to receive (MPSV, 2021).

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[5] A detailed list of acts provided within the framework of the care service is given in Decree No 505/2006 Coll., implementing certain provisions of the Social Services Act, as amended.

1.2.4 Development of home health care

The emergence of home health care (HHC) agencies, which were mainly founded by or employed by geriatric nurses in HHC, has occurred gradually since the 1990s (Holmerová *et al.*, 2014) and substituted the system of geriatric nurses who were part of the primary care teams in 1980s. The purpose of providing HHC is to enable patients who require health care to maintain, promote or regain health and develop self-sufficiency, including care for patients in the terminal stages of illness, to remain in their home environment for as long as possible, thereby reducing the need for institutional care. Patient care is predominantly provided by HHC agencies on a 7/24 basis, which means that care can be provided 24 hours a day, 7 days a week, 365 days a year (Misconiová, 2011). In 2000, there were a total of 484 HHC agencies in our country. This number has increased by 40.5% to 680 home health care agencies by 2019. During the period under review, the number of HHC agencies was almost constant, with a more significant increase in the number of these agencies each year beginning in 2015 (ÚZIS, 2021).

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2 Analysis of the development of the number of home healthcare patients, hospitalised patients and clients of residential care facilities in the years 2000–2016

Reference:

Dostálová, Vladimira a Iva Holmerová. Analýza vývoje počtu pacientů domácí zdravotní péče, hospitalizovaných pacientů a klientů pobytových zařízení sociálních služeb v letech 2000–2016. *Geriatrie a gerontologie*. 2018/7/3,3,91-130. ISSN 1805-4684.

Abstract

Introduction: Enabling seniors who are ill or have reduced independence to stay at home is a present-day trend. This is supported by both international and national strategic policy documents whose recommendations seek to reduce the number of hospitalisations of seniors and to shift care for seniors into their home environment.

Methods: The available statistics and data were examined and contextualised in order to analyse developments in the numbers of patients in home healthcare, hospitalised patients and clients of residential care facilities.

Result: The number of people aged over 65 increased between 2000 and 2016, as did the number of home health care patients aged over 65 (up 8.68%), but the percentage of patients in this age category treated at home relative to the population of the same age and the number of patients treated in institutions fell from 7.52% in the year 2000 to 5.84% in 2016. The number of hospitalisations of patients over 65 increased by 30.66% between 2000 and 2016. The number of patients moved into residential care facilities also rose in the same period. The rising trend in the number of clients in residential care facilities was pronounced. The number of clients in these facilities increased by 15% between 2006 and 2016. The number of applications for places in care facilities that were not successful also grew in that period, especially in the case of "homes with a special regime" residential services, where there was a 171% increase in the number of unsuccessful applications.

Conclusion: Despite the goals defined in strategic policy documents, there was no increase in the number of patients over the age of 65 in home health care relative to patients from the same age category in recent years. On the contrary, there was a marked increase in the number of hospitalisations of 65+ patients and a rapid increase in the number of clients in residential care facilities, including unsuccessful applications for these services.

Keywords: home health care, hospitalisation, residential care services

Introduction

The Czech population is ageing very rapidly. According to Czech Statistical Office (‘CSO’) data mapping demographic change in the Czech Republic, the number of people over the age of 65 is rising. It is therefore likely that the Czech population reach 2,140,900 people over the age of 65 in 2020, i.e. 20.5% of the total population, with this percentage increasing to 23.9% in 2030 and as much as 32.3% in 2050. In 2016 there were 424,841 people over the age of 80 in the Czech Republic. Their number is likely to rise to 944,608[6] by the middle of the century, which will be approximately 10% of the total population.

The prevalence of chronic illnesses increases with advancing age, which brings related impacts on care requirements. The ageing population therefore makes more use of the Czech health care system. The number of people with reduced independence also increases with advancing age [1]. Seniors can make use of home health care services, in case of suffering from illness or reduced independence. They remain in their social environment and are not dependent on care in inpatient medical facilities. Ageing and old age also raise questions linked to social security for seniors. Most seniors want to remain in their social environment for as long as possible, even when ill or with reduced independence.

This fact informed international and national strategic policy documents seeking to enable seniors to remain at home. Political declarations reflecting the need to enable seniors to remain at home have also been made. International strategic policy documents promoting seniors’ continued stay in the home include the International Plan of Action on Ageing

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[6] According to CSO forecasts from 2013, this is the “low variant”. It is therefore possible that the percentage and number of over-65s in the Czech population will be higher.

issued by the UN in 2002: Article 86(c) refers to the need to draw up programmes to help seniors with mental illness to be able to live at home for as long as possible. Article 105(b) of that document also mentions the need for accessible and community-based care for older persons living alone as a possible alternative to hospitalisation [2]. The UN Principles for Older Persons from 1991 is another international document that prioritises enabling older persons to stay at home for as long as possible. One of the UN principles is to support older people's independence so that they can remain at home for as long as possible [3]. These international documents' goals and recommendations were followed up by the National Action Plan Supporting Positive Ageing for 2013 to 2017, which comes under the Ministry of Labour and Social Affairs of the CR ('MoLSA'). This National Action Plan takes into account the need for seniors to be allowed to remain at home in the section entitled "High-quality Environment for the Life of Seniors", which emphasises the expansion of field services for seniors and adequate civic amenities. The "Care for the Frailest Seniors with Limited Independence" section specifically states that the objective is "to increase the accessibility of field services and the related respite care services for informal carers" [4]. One goal of the Health for Everyone in the 21st Century programme that comes under the Ministry of Health of the CR ('MoH') is to increase by half the proportion of over-80s whose health allows them to remain in their home environment by 2020 [5]. To implement Health 2020, a policy of the World Health Organisation (WHO), the MoH drew up a National Strategy for the Protection and Promotion of Health and Prevention of Illness – Health 2020 (National Strategy), which also sets the goal of "Improving the Quality, Accessibility and Effectiveness of Follow-up, Long-term and Home Care" [6]. One of the most recent strategic documents explicitly mentioning the need to enable old people to remain in their home environment through long-term home health care is the WHO's Global Strategy and Action Plan on Ageing and Health[7] [7].

Political declarations covering the need for home health care include the government's Programme Declaration from January 2018, which specifically states: "We will prepare a long-term care concept with a view to supporting home care and we will strengthen

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[7] There are numerous international and national strategic policy documents dealing with the issue of enabling seniors to stay in their home environment. The ones specified above were selected for the purposes of this paper, however.

contractual freedom between health insurance companies and health care providers within the bounds set by law and under state control" [8].

Methods

Statistical overviews of the Institute of Health Information and Statistics ('the Institute') were used to analyse changes in the number of patients in home health care and in the number of hospitalised patients [9-12]. Population size data are taken from CSO reports [13-15]. Labour and Social Affairs Statistical Yearbooks published by the MoLSA are available for analysing changes in residential care services and in the number of clients [16]. All the data are summarised in tables and charts.

The first part of the following text deals with changes in the number of patients over the age of 65 in home care and changes in the number of hospitalised patients of the same age in the context of the development of the same age cohort in the population between 2000 and 2016. The second part of the text focuses on the development of residential care services providing care mainly for clients aged over 65 and on changes in the number of clients in these facilities in the period from 2006 to 2016.

Development of the number of patients in home health care and hospitalised patients in the context of rising population numbers

The following overview drew on statistical data from the Institute and the CSO from the years 2000 to 2016 and concerning over-65s.

Analysis of the CSO data reveals that there was a marked increase in the number of people aged over 65 since the year 2000. In the year 2000 there were in total 1,423,000 people aged over 65 in the Czech Republic (13.9% of the total population), while in 2016 the figure was 1,988,000 (18.8% of the total population). The number of people aged over 65 grew by 39.77% from the year 2000. The number of people in the highest decennia also rose rapidly. The number of over80s and over-85s grew by 72.95% and 57.69% respectively compared to the year 2000 (Table 1).

Table 1. Number of people aged 65-plus in the Czech population

	65 +	80 +	85 +
2000	1 423 000	244 395	121 800
2005	1 456 391	314 943	97 603
2010	1 635 826	379 682	150 236
2016	1 988 922	422 688	192 072
Increase %	39,77%	72,95%	57,69%

In the year 2000 home health care agencies had 106,939 clients over the age of 65[8]. That represented 7.52% of this age category. The following years brought regular increases in the number of over-65s in home health care. Nevertheless, the following table (Table 2) shows that this increase lagged far behind the growth in the population of over-65s and the growth in the number of hospitalised over-65s. Patients with a chronic illness and also patients with an acute illness made up a large percentage of the over-65s in home health care. Patients recovering from operations and injuries accounted for the smallest percentage.

Table 2. Number of hospitalisations and number of home health care patients compared to the over-65 population

	Population 65+	Hospitalisations 65+	HHC patients 65+
2000	1 423 000	651 706	106 939
2005	1 456 391	781 114	109 851
2010	1 635 826	744 671	113 815
2016	1 988 922	851 499	116 223
Increase %	39,77%	30,66%	8,68%

Paradoxically, then, the number of people aged 65 and over increased between 2000 and 2016 and the number of home health care patients in that age group also increased, but the percentage of patients in this age group in home health care as a proportion of the over-65 population fell (Chart 1).

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[8] Statistical yearbooks of the Institute presenting data on the numbers of patients in home health care do not take into account the number of patients over the age of 80.

Chart 1. Percentage of the 65-plus population relative to the total population and percentage of 65-plus home health care patients relative to the 65-plus population

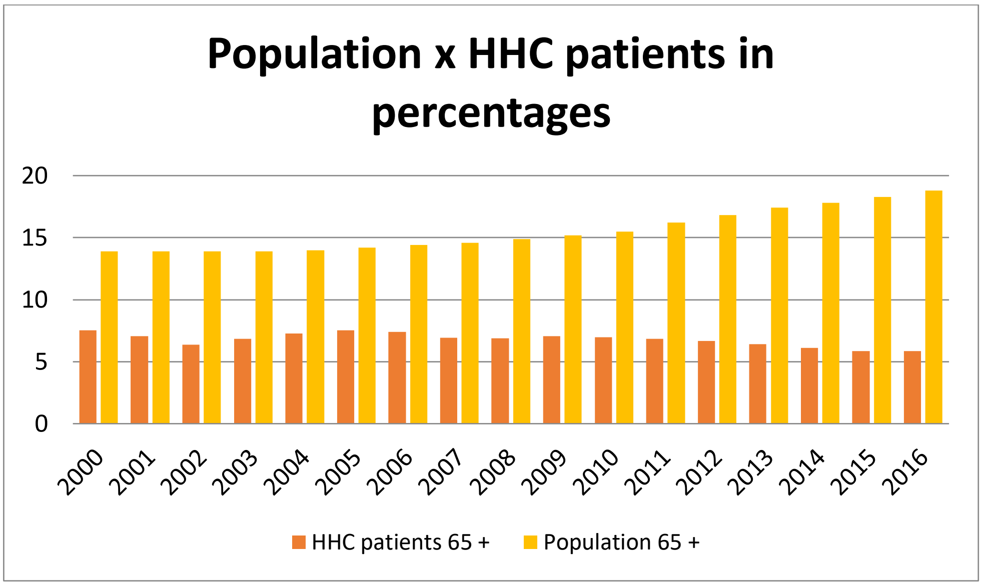
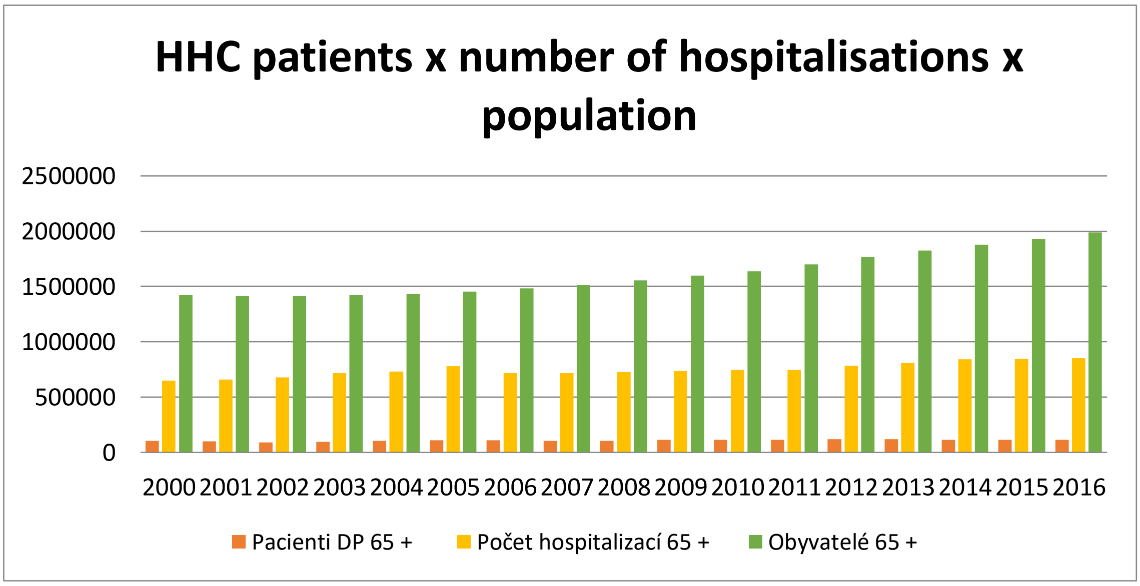


Chart 2 shows the increase in the over-65 population and the increase in the number of hospitalisations of 65-and-older patients in the context of the number of patients of that age receiving home health care.

Chart 2. Comparison of the growth of the 65-plus population, number of hospitalised patients aged 65 and over and number of patients aged 65 and over receiving home health care



In view of the results of the previous analysis, the following overview focuses on the possible reason for the percentage fall in the number of home health care patients, based on a comparison of the total number of hospitalisations and the number of patients moved into care and follow-up care facilities. It is not clear from the available Institute data how many patients aged 65 and over were moved into the aforesaid facilities after hospitalisation. This is therefore the total number of patients moved into these facilities regardless of age; it is widely known, however, that most of the patients moved to these facilities were patients aged 65 and over.

As mentioned above, the number of over-65s in the Czech population grew by 39.77% between 2000 and 2016. The number of hospitalisations of patients over the age of 65 increased by 30.66% in that period. Hospitalised patients aged 65 and over accounted for 29.92% of all hospitalisations in the year 2000, 31.78% in 2005, 33.36% in 2010 and 38.1% in 2016 (Table 3).

Table 3. Hospitalisations of people aged 65 and over as a proportion of total hospitalisations

	Total hospitalisations	Hospitalisations 65+	Total hospitalisations accounted for by 65+
2000	2 178 023	651 706	29,92%
2005	2 457 581	781 114	31,78%
2010	2 231 938	744 671	33,36%
2016	2 235 109	851 499	38,10%

In total, 1.81% patients out of the total number of hospitalisations were moved into care and follow-up care facilities in the year 2000, 2.12% in 2005, 3.2% in 2010 and 4.46% in 2016. It is clear, then, that the proportion of patients moved into care and follow-up care facilities grew overall (Table 4).

Table 4. Numbers of hospitalisations and of patients moved into care and follow-up care facilities

	Total hospitalisations	Hospitalisations 65+	N. of patients moved into social care facilities	N. of patients moved into follow-up care facilities
2000	2 178 023	651 706	15 349	24 052
2005	2 457 581	781 114	18 877	33 185
2010	2 231 938	744 671	22 052	49 450
2016	2 235 109	851 499	29 210	70 578

It is clear from the above, then, that while the proportion of patients in home health care fell relative to the population of over-65s between the years 2000 and 2016, the number of patients moved into care and follow-up care facilities grew.

It should be mentioned that the number of total hospitalisations as a proportion of the total population of the Czech Republic has remained almost unchanged since the year 2000 and averages out at 21.75% hospitalisations out of the total population; similarly, the rate of hospitalisation of over-65s as a proportion of the same age category is almost unchanged at 46.68% on average. Hospitalised patients over the age of 85 as a proportion of the population of the same age is on average 67.3%.

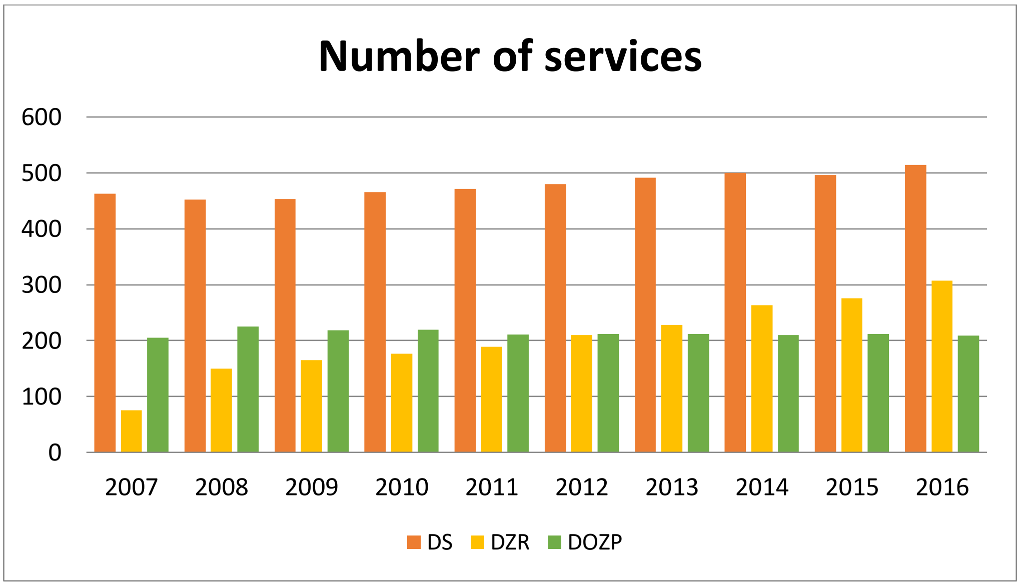
Development of the number of clients in residential care services in the context of the development of residential care services

The analysis of changes in the number of clients in residential care services and of the development of residential care services drew on Labour and Social Affairs Statistical Yearbooks published annually by the MoLSA. Statistical yearbooks from 2005 to 2016 were available for this analysis. Statistical yearbooks from 2005 could not properly be used for the analysis of residential care services as care services were redefined by Act No. 108/2006 Coll., on social services, which was issued in 2006. For example, the statistical yearbooks from 2005 and 2006 use names for social services facilities like ‘Old People’s Home’, ‘Lodging Home for Pensioners’, ‘Institution for Physically Disabled Adult Citizens’, ‘Institution for Physically Disabled Adult Citizens with a Mental Disorder’ etc. For that reason, the cut-off date for the use of statistical yearbooks was 2007. In view of the previous chapter, the analysis focused solely on those residential care facilities that can be assumed to have a large proportion of clients over the age of 65.

These are therefore ‘Seniors’ Homes’ (‘SH’), ‘Homes with a Special Regime’ (‘HSR’) and ‘Homes for Persons with a Disability’ (‘HPD’).

In 2007 the Czech Republic had a total of 463 SHs, 205 HSRs and just 75 HPDs. There was a huge proliferation of HSRs between 2007 and 2016[9], whose number grew by roughly 309% in that period. There was no significant increase in the number of SHs or HPDs. The total number of all these services in 2007 was 743 and in 2016 1,030. This growth was driven by the increase in the number of HSRs. Chart 3 shows the total numbers of the aforesaid residential care services.

Chart 3. Number of residential care services



The period from 2006[10] to 2016 saw a large increase in the number of clients in HSR facilities, while the numbers of clients in SH and HPD facilities remained the same, just as the number of these facilities remained almost unchanged. In 2006 the total number of all clients in the said facilities was 56,015. In 2016 the figure was 64,682, which represents a 15% increase in the number of clients in these facilities. The following two charts (Charts 4 and 5) show the numbers of clients in residential care facilities in absolute terms and in relative terms.

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[9] The huge increase in the number of HSRs is probably linked to the redefinition of social services contained in Act No. 108/2006 Coll.

[10] Data from 2006 are available in the statistical yearbook from 2007 that was used for this analysis.

Chart 4. Number of clients in residential care facilities

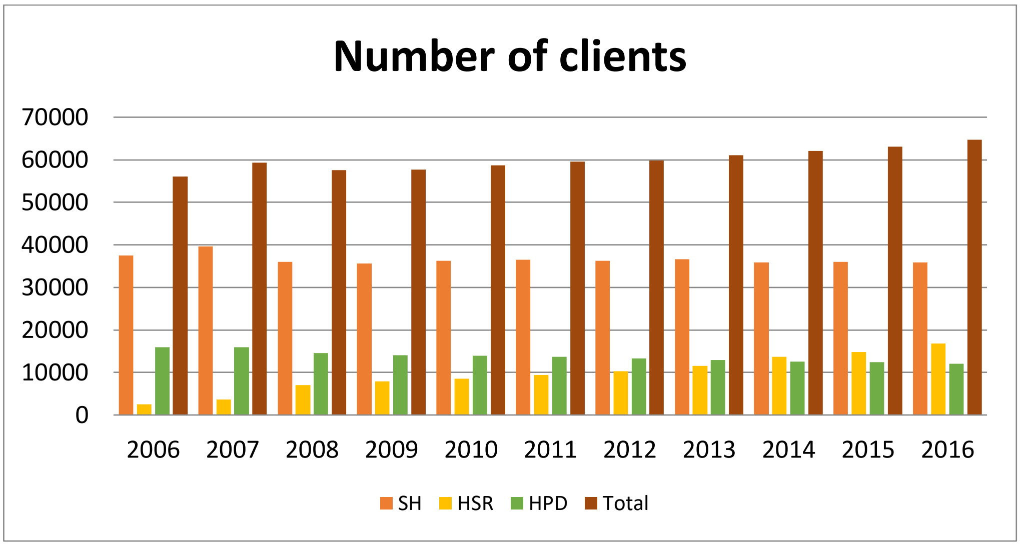
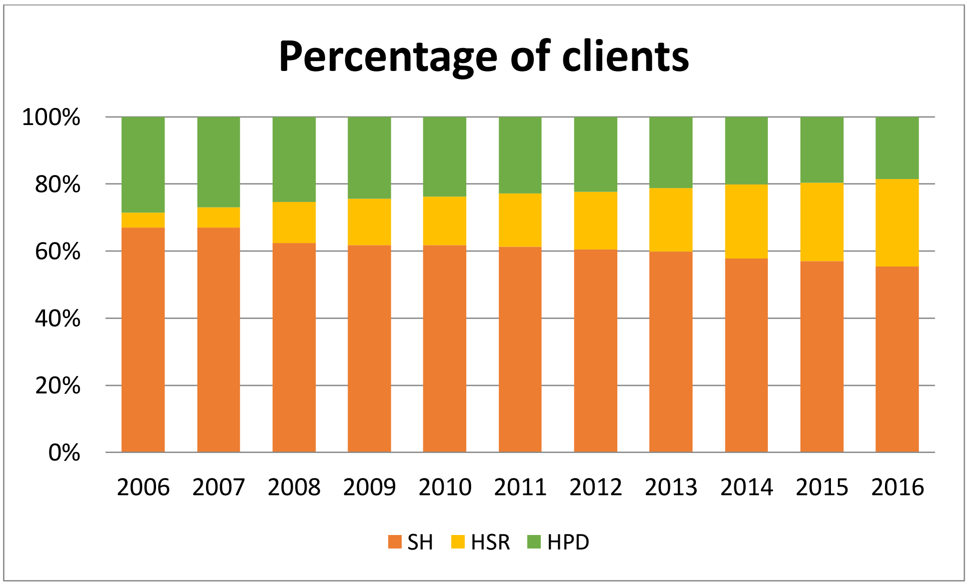


Chart 5. Care facilities in terms of their share of all clients



The results of the following analysis indicate that the numbers and capacities of these facilities are insufficient. The number of unsuccessful applications for places in SHs has increased since 2007. A total of 48,131 unsuccessful applications was registered in 2007, rising to 65,764 in 2016. There was a far bigger increase in unsuccessful applications in the case of HSRs. These applications numbered 7,874 in 2008[11] and 21,334 in 2016. That

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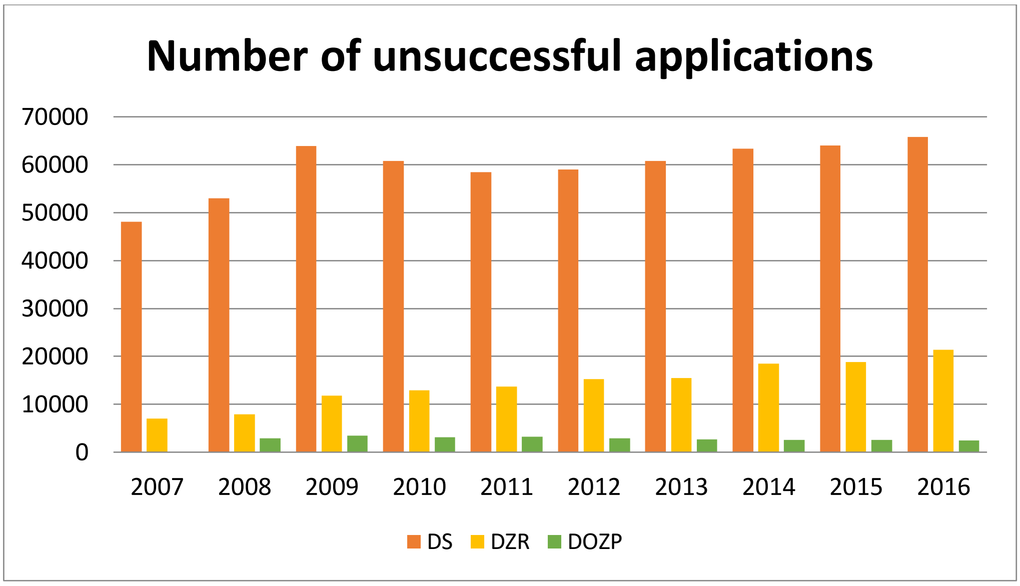
[11] The year 2008 is given here, because the numbers of unsuccessful applications for places in HSR and HPD facilities were merged in the statistical yearbook for 2007.

is an increase of 171%. By contrast, there was a slight fall in the number of unsuccessful applications for places in HPDs (Chart 6).

Chart 6. Number of unsuccessful applications



The question is whether the number of unsuccessful applications per MoLSA's statistical yearbooks takes into account the fact that applicants for places in social care facilities submit multiple applications to multiple facilities, sometimes several years before care services are actually needed. We can therefore only estimate the actual number of applicants whose applications were unsuccessful, but it is most likely to be lower than the stated number of unsuccessful applications.

It still applies, though, that the proportion of unsuccessful applications relative to the growth in the number of clients in care facilities is almost the same.

In 2008 60% of the number of unsuccessful applications for a place in an SH was 60% of the total number of applicants[12]. In 2016 the ratio was 64%. Between 2008 and 2016 there was an overall increase in the number of applicants who failed to secure a place in an SH (Chart 7).

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[12] The numbers of applicants include existing users of the given service.

Chart 7. Ratio of unsuccessful applications for a place in an SH

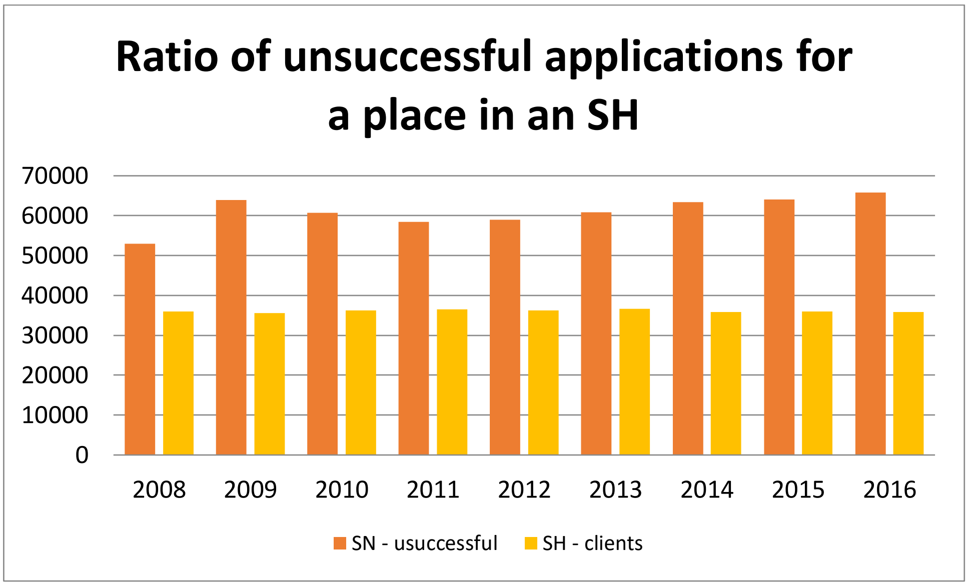
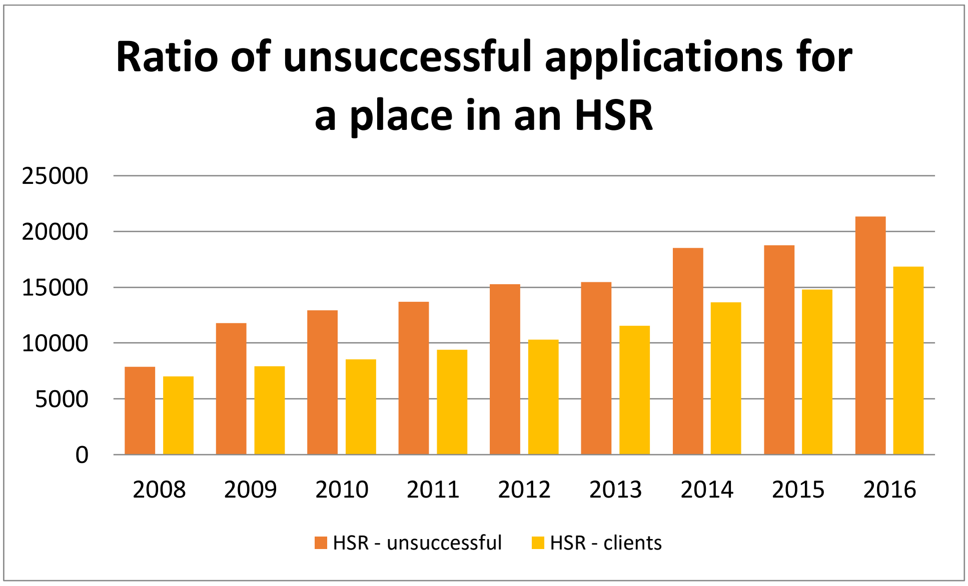


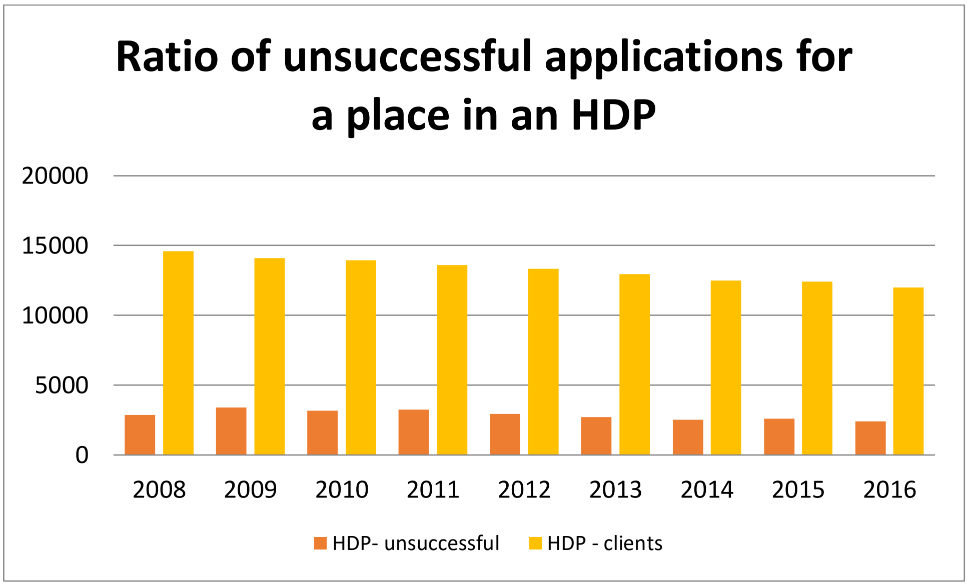
Chart 8 shows that since 2008 there has been an increase in the number of HSR clients and in the number of unsuccessful applications for this service. The ratio between unsuccessful applications and the number of applicants is almost constant, however, at 58% on average.

Chart 8. Ratio of unsuccessful applications for a place in an HSR



In the case of HPDs, the percentage of unsuccessful applications does not exceed the number of clients. The ratio between unsuccessful applications and the total number of applicants is 18% on average (Chart 9).

Chart 9. Ratio of unsuccessful applications for a place in an HPD



Discussion

Between the years 2000 and 2016 the number of people aged 65 and over in the Czech population increased by 39.77% while the number of hospitalisations of patients of the same age rose by 30.66%. In addition, there was a much smaller increase (8.68%) in the number of patients aged 65 and over receiving home health care. Paradoxically, although the number of over-65 patients receiving home health care increased, there was a percentage fall in patients in this age category receiving home health care compared to patients of the same age accessing institutional care.

Just as the number of hospitalised patients aged 65-plus increased between 2000 and 2016, the number of hospitalised patients moved into residential care facilities and follow-up care facilities relative to the total number of hospitalisations also increased[13]. While 1.81% of patients were moved into these facilities in the year 2000, the proportion in 2016 was 4.46%. As the statistics in the Institute's statistical yearbooks do not take into account the age of moved patients, we can only assume that patients aged 65 and over accounted for most of them.

Analysis of changes in the number of clients in residential care services and changes in the total number of residential care facilities reveals that there was an increase in the number of residential care facilities (SH, HSR and HPD) between 2007 and 2016, with

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[13] This fact was flagged up back in 2010 in the Discussion Material on Starting Points for Long-term Care in the Czech Republic [17, p. 47].

the large percentage increase in HSRs evidently caused by the adoption of Act No. 108/2006 Coll., on social services, which redefined care facilities. Nevertheless, there was a 15% increase in the number of clients in these facilities between 2006 and 2016. The analysis also makes clear that the number of unsuccessful applications for places in these facilities increased by 62.2% between 2007 and 2016. It is not known, however, how many potential clients filed multiple applications for places in these residential care facilities in a given year and how many potential clients applied before they were going to need the given care service. The high number of unsuccessful applications for places in residential care facilities may point to a shortage of field services, both medical and social.

It is clear, then, that recent years have brought both a rapid rise in the number of hospitalised over-65s and an increase in the number of patients moved into residential care facilities. Similarly, the number of clients in residential care facilities increased. Although the number of patients aged 65 and over receiving home health care increased slightly, the ratio between these patients and the total population aged 65-plus decreased.

It is fair to say, then, that the above facts are totally at odds with both the international and national strategic plans and programmes that were mentioned in the introduction to this paper and seek to enable seniors to remain in their homes, i.e. to support home health care and in that context field social services. Field social care services are beyond the remit of this paper, but it is reasonable to assume that the state of field social care services will be similar to the state of field health care services, i.e. home health care.

In its programme declaration from January 2018, the current government set itself the goal of supporting long-term care, including care for seniors in their home environment. It is debatable whether this goal specified in the government’s programme declaration will be achieved, either in whole or in part.

Conclusion

It is clear from the conclusions of the analysis that while there was a marked increase in the number of hospitalised patients over the age of 65 in the period under scrutiny, there was a much smaller increase in the number of patients over 65 who were treated in the home and there was an actual fall in the number of these patients relative to the entire population of the same age.

The proportion of patients moved into residential care and residential follow-up care facilities also increased. The period under scrutiny also saw a huge increase in the number of residential care facilities and the number of clients of these services. The rise in the number of unsuccessful applications for residential care services was also considerable.

In the light of the international and national strategic policy documents referred to in the introduction to this paper, including the government's programme declaration, which advocates for enabling seniors to remain in their home environment, and given the results of the aforesaid analyses, in future it would be appropriate to prioritise efforts to enable seniors to remain in the home when implementing the strategic plans; in other words, support should be given to home health care and to long-term care in general. It is clear that care for old people and thus also long-term care straddle the boundary between health and social services, each of which is funded from different sources. When supporting measures to enable seniors to remain in their home environment it is crucial to lay down rules governing the provision of this care, specifically by combining health and social services, and paying particular attention to the funding of these services and support for both formal and informal carers.

This paper was written as part of research task 15-32942A-P09 AZV of the Ministry of Health of the Czech Republic, "Case management as a multifaceted intervention in patients with dementia, its impact on the use of resources and on the quality of life of patients and carers".

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2.1 Discussion

As the previous article was published in 2018, we consider it important to provide an overview of further developments in the analysed areas. As in that article, available data from the Institute of Health Care Services were used to analyse the development of the number of hospitalised patients and patients in home health care (ÚZIS, 2021). Data on population were taken from the website of the Czech Statistical Office (ČSÚ, 2021) and for the analysis of social residential services, data from the Statistical Yearbooks of Labour and Social Affairs of the Ministry of Labour and Social Affairs were used (MPSV, 2020) . As the Institute of Health Information and Statistics has not yet published data from 2019 and 2020, only data from 2017 and 2018 were additionally analysed. Nevertheless, it can still be concluded that the available data give a sufficient overview of the overall development of the monitored areas.

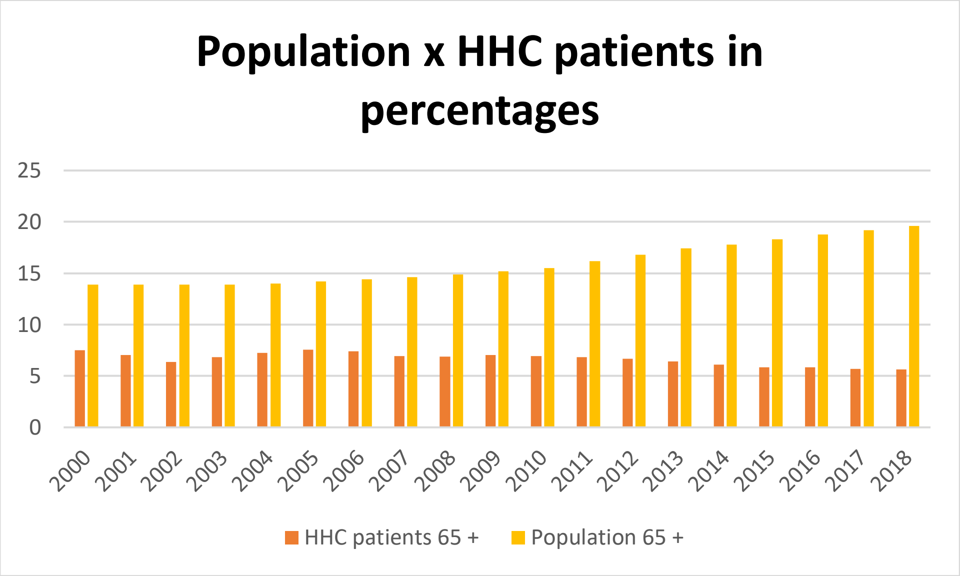
As in the previous analysis, we can observe an increasing trend in the number of population over 65 years of age. In 2018, 19.6% of our population was over 65 years of age. Compared to the year 2000, the population of this age category increased by 46.63% (in 2016 it was 39.77%). Similarly, there was also an increase in the population in the other monitored age categories of 80 and 85 years and above (Table 1).

Table 1 Number of people aged 65-plus in the Czech population

	65 +	80 +	85 +
2000	1 423 000	244 395	121 800
2005	1 456 391	314 943	97 603
2010	1 635 826	379 682	150 236
2016	1 988 922	422 688	192 072
2018	2 086 617	432 907	203 739
Increase %	46,63%	77,13%	67,27%

Unfortunately, we have to state that, similarly to the previous period, the percentage of patients over 65 years of age in home health care has continued to decline in relation to the population over 65 years of age. This is despite the fact that the number of patients aged over 65 in home health care has been on a slight upward trend (Chart 1).

Chart 1 Population and home health care patients in percentages



In the case of the additional analysis of residential social services, there was no significant decrease or increase in the number of people in these services, including unmet requests for these services. As the focus of this paper is on the issue of patients in home health care, the results of this analysis are no longer presented here.

In conclusion, it can be pointed out that despite the objectives of strategic documents, both those of the Ministry of Health and the Ministry of Labour and Social Affairs, which declare to enable people to remain in their social environment in a state of illness or reduced self-sufficiency, there is a growing tendency to place these patients in follow-up care facilities or social care facilities (Table 2).

Table 2 Numbers of hospitalisations and of patients moved into care and follow-up care facilities

	Total hospitalisations	Hospitalisations 65 +	N. of patients moved in social care facilities	N. of patients moved in to follow-up care facilities	% of transfers in relation to the total number of hospitalisations
2000	2 178 023	651 706	15 349	24 052	1,81%
2005	2 457 581	781 114	18 877	33 185	2,12%
2010	2 231 938	744 671	22 052	49 450	3,20%
2016	2 235 109	851 499	29 210	70 578	4,46%
2018	2 200 246	866 701	28 482	82 973	5,06%

In this part of the dissertation, an introductory insight into the issue of home care as such was presented. Home care and its concept in international and national policy documents was defined. Furthermore, the possibilities of providing home care were pointed out with regard to the current legislation. At the same time, an analysis of the development of the number of hospitalized patients and patients in home health care was presented, focusing on the group of patients over 65 years of age. An overview of the development of the number of social care facilities was also given, including the development of the number of clients in these facilities. Finally, the evolution of unmet client requests for these services was outlined.

Even with regard to Chapter 1.2.2, the need for home health care is absolutely indisputable. This fact is highlighted by international and national strategic documents, which in their declarations and objectives set the task of promoting the stay of the older people in their home environment for as long as possible and, in the context of this, of promoting the development of outreach services (health and social). The results of the analysis of the development of home health care since 2000 show that this trend is not evident in our country. The question is why there is no significant increase in the number of patients in home health care? This circumstance may be due to several factors. The reluctance of GPs or attending physicians to prescribe home health care, or unwillingness to prescribe home health care. Furthermore, this may be due to a lack of non-medical health care staff working in home care agencies. Given the recent trends in salaries and wages of health professionals, it is possible that there will be a decline in health professionals working in home health care, as they are still being overlooked in salary increases.

The following part of the dissertation is devoted to the aim of the thesis itself: 'To explore the experiences and needs of particularly vulnerable older patients in home health care'. This is a collection of three peer-reviewed articles published in international peer reviewed journals. The first article focuses on an analysis of the current state of knowledge, i.e. the 'state of the art'. The aim of this article was to find out what is known so far about the needs of older people in home health care. Scoping review was used as the data collection method. The next two articles provide an overview of the experiences and needs of older people in home health care from their own perspective and the needs of older people in home health care from the perspective of general nurses working in home care agencies. For the first of these two articles, 15 individual interviews were conducted with home health care patients in three regions of the country. Three focus group interviews were subsequently conducted with general nurses working in home health care agencies in the same regions. Data collection through group interviews is described in the last, third article.

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3 The Needs of Older People Receiving Home Care: A Scoping Review

Reference:

Dostálová, V., Bártová, A., Bláhová, H., & Holmerová, I. (2020). The needs of older people receiving home care: a scoping review. *Aging Clinical and Experimental Research*. Doi:10.1007/s40520-020-01505-3

Abstract

Background: Most people in a state of illness or reduced self-sufficiency wish to remain in their home environment. Their physiological needs, and their psychological, social and environmental needs, must be fully met when providing care in their home environment. The aim of this study is to provide an overview of the self-perceived needs of older people living with illness or reduced self-sufficiency and receiving professional home care.

Methods: A scoping review of articles published between 2009 and 2018 was conducted by searching six databases and Google Scholar. Inductive thematic analysis was used to analyze data from the articles retrieved.

Results: 15 articles were included in the analysis. Inductive thematic analysis identified six themes: coping with illness; autonomy; relationship with professionals; quality, safe and secure care; role in society; environment.

Conclusion/discussion: Older home care patients living with chronic illness and reduced self-sufficiency are able to express their needs and wishes. Care must therefore be planned in line with recipients' needs and wishes, which requires a holistic approach.

Keywords: wishes, needs, care provision, home care

Introduction

According to a prognosis by the World Health Organization (WHO), 20% of the world's population will be over 60 years of age by 2050 [1] compared with 12% in 2015. People aged 65 and over are expected to live another 19 years, 10 of which will be spent with illness or disability [2]. Advancing age is associated with an increase in geriatric syndromes such as frailty, instability and falls, incontinence and dementia [3].

Despite illness and disability, most people want to live in their home environment [3]. To meet this wish both healthcare and social care are provided in their homes, in line with WHO recommendations [1]. Care and services need to be interconnected and coordinated [4] and tailored to their needs [1] to facilitate autonomy and allow them to remain independent for as long as possible [5].

Human needs, as well as those related to health, can be characterized from different points of view (scientific, psychological, social, economic, etc.) [6–9]. According to Abraham Maslow, human behavior is usually motivated by the desire to satisfy needs in the following categories: physiological, safety, love and belonging, esteem and self-actualization. These needs are individual and vary according age, gender, social status, health status, culture, life experience, etc. [10]. Some researchers investigating the needs of the elderly divide their needs into four categories: environmental, physical, psychological and social [11, 12]. Although Maslow's theory has been criticized [8], nursing theories tend to draw on his ideas [7].

Of the studies examining the needs of older people living with chronic illness or reduced self-sufficiency, some examine the topic from the perspective of professionals and family members rather than the older persons themselves. Some studies also focus primarily on caregiving related needs [13–19]. A number of studies also investigate the needs of older people living in nursing homes or long-term care facilities rather than in their home environment [20–26].

The present study seeks to provide an overview of the self-perceived needs of older people living with illness or reduced self-sufficiency and receiving professional home care.

Methods

Scoping Review Methodology

A scoping review based on a systematic search, selection and synthesis of existing knowledge [27] has been chosen as the appropriate methodology to address the research question. Arksey and O'Malley [28] describe the scoping review methodology as a five-step process involving identifying the research question, identifying relevant studies, study selection, charting the data, and collecting, summarizing and reporting the results. This methodology is recommended by Levac et al. [29] and has been used as a guide for this review.

Search Strategy

Identifying relevant studies

The research team and the librarian developed a detailed overview of suitable search terms. Combinations of keywords relevant to the needs of older people receiving home care were used to search the databases, including: 'frail elderly', 'aged', 'elderly', 'older', 'geriatric', 'home health nursing', 'home health care', 'home care', 'need', 'needs' and 'needs assessment'. Six databases (CINAHL, Web of Science, ProQuest Central, PubMed, Scopus and PsycInfo) and Google Scholar were searched to obtain as many relevant studies as possible. Table 1 lists the exact search string used for each database. The bibliographies for the studies included in the review were also searched. This process ensured that as many resources were identified as possible. The search was completed when it was no longer possible to find other relevant studies, resulting in 826 articles found through databases and 26 articles identified through other sources.

Inclusion and exclusion criteria

The inclusion and exclusion criteria were discussed and selected by the authors V. D. and I. H., and they were reviewed by all authors throughout the process. Articles featured in the review include those using both qualitative and quantitative data to examine the needs of frail older people living in their own homes, sheltered houses or communities and receiving home care that were published in peer-reviewed journals between 2009 and 2018 in either English or Czech. Articles that examined the needs of people diagnosed with dementia, whether hospitalized or living in nursing homes or other long-term care facilities, were excluded from the review. To ensure the quality and transparency of the screening process, the PRISMA recommendation for systematic evaluation was applied [30]; see Figure 1.

Critical appraisal

The Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review [31] was applied independently by the authors V. D., A. B. and I. H. to appraise the quality of the qualitative, quantitative and mixed studies included in the review. No studies were excluded from the review following this appraisal.

Data analysis

An inductive thematic analysis strategy consisting of three successive parts was used to analyze the data from the results section of the articles. Significant terms were first inductively assigned codes according to their meaning and content and sorted into related categories. Categories developed by an open coding process were then grouped again according to related topics [32]. The coding process was carried out by the author V. D. Based on the grouping of assigned terms, 18 related sub-themes were created and were subsequently assessed by the author I. H. In the final phase the sub-themes were grouped according to their context by mutual agreement between the authors V. D. and I. H., resulting in six new themes [Table 2].

Results

A total of 15 articles were analyzed. The most frequently declared aim in these articles was to explore participants' "experience" (n = 4), "needs" (n = 2), "meaning of home care (n = 2)", "independent decisions" (n = 1), "decision-making" (n = 1), "well-being" (n = 1), "sources of strength" (n = 1), "subjective perspectives" (n = 1), "quality of life" (n = 1) and "relationship" (n = 1). Of these 15 studies, 12 used a qualitative design, two used a quantitative design and one study used mixed methods. The most common method of collecting qualitative research data were interviews (n = 12), including in-depth interviews and semi-structured interviews. The questionnaires used in quantitative studies were a questionnaire distributed by mail that focused on respondents' health, well-being and home care (n = 1) and a structured questionnaire with closed and open-ended questions (n = 1) [Table 2].

Themes

Based on the thematic analysis, six themes mentioned by the respondents in the articles reviewed were identified in the studies: 1) “Coping with illness”, 2) “Autonomy”, 3) “Relationship with professionals”, 4) “Quality, safe and secure care”, 5) “Role in society”, and 6) “Environment”. Whenever possible citations from the articles reviewed were used for data analysis rather than the authors’ own interpretation of the data.

1) Coping with Illness

The need to cope with illness was a frequent theme among respondents, who understood that illness or reduced self-sufficiency meant they would have to overcome various obstacles and restrictions to remain in their own environment.

Physical restrictions due to impaired health was one of the reported obstacles that respondents faced. A number of respondents in various studies were experiencing pain, reduced mobility, loss of physical capability, visual and hearing impairment [33–37], increasing fatigue and loss of strength [35]. To overcome these limitations, respondents were aware of the need for both professional and informal care and support from family members or friends [34–41], mainly concerning personal care, assistance, observation and support, and household activities [35, 36]. When talking about professional care, respondents most frequently expressed a need for assistance with personal hygiene, household activities, food preparation and medication management [37, 39].

2) Autonomy

Privacy and freedom

Providing professional home care in older persons’ own environment was described as a restriction, a loss of privacy [38, 42, 43] or a loss of autonomy [35]. Even though some respondents understood that the possibility of remaining in their own environment allowed them to retain some autonomy, they saw home care provision as a curtailing of autonomy, as their home had become a ‘working place for professional carers’ [36]. It was very important for respondents to know the schedule and plan for their care in advance. If respondents were unfamiliar with this, it was perceived as a restriction of their freedom [36, 42, 43]. Home care respondents wanted professional carers to behave as guests in their home and respect their privacy [38]. Inadequate respect for intimacy during care provision was also described as a loss of privacy [42].

Independence

Although respondents were living in a state of illness or reduced self-sufficiency, and were aware of their dependence on the help of both professional and informal carers, they wished to remain as independent as possible [40, 44]. Loss of independence was associated with poor health and limitations, and was described as a negative aspect of ageing [36].

Maintaining autonomy and independence was often characterized as maintaining quality of life [41]. Although maintaining independence was associated with how willing others were to assist with care, and respondents perceived help and care from family members or friends as an opportunity to maintain their independence, they struggled with a sense of placing a burden on family members [36, 43]. Respondents reported satisfaction when their independence was actively promoted in activities that they were able to perform, and when they received positive feedback from carers [39].

Decision-making and participation

Respondents' chief priority was that they be involved in the decision-making process so they could influence care planning and choose among caring actions [36, 38, 42–46]. When planning care, respondents considered it important for their wishes and needs to be heard [36, 43, 44, 46] and for care to be provided in a respectful way [36, 45, 46]. The opportunity to participate in care provision was described as "having control over the situation" [43], or as equal cooperation between nurse and patient [38]. Nevertheless, for some respondents it was difficult to express their needs and wishes, despite being able to participate in care provision [33, 42]. Some of them viewed expressing their needs and wishes as complaining [33]. In some cases respondents reported their inability to adequately express their needs and wishes due to professional carers having insufficient time [38].

Daily activities

Respondents wished to live the lives they were used to [45]. It was important for them to maintain the activities comprising their daily routines; repeated at the same time every day, they created the rhythm of the day [34, 35, 45, 46]. Such routines included personal hygiene [46], eating at the same time every day [35, 46], watching a particular television program, and daily telephone calls to friends and neighbors [35]. Respondents' everyday activities also included leisure activities such as reading books, playing bridge, solving crossword puzzles and Sudoku or having tea or coffee with their loved ones [34, 40], as well as household activities [35, 40].

3) Relationship with Professionals

Establishing a mutual relationship with professional caregivers was seen by respondents as essential [36, 38, 42] and was actively sought by professional caregivers and respondents alike [46]. Sometimes establishing a mutual relationship proved more difficult, especially when many different caregivers were providing care [42]. Some older persons described the relationship with their professional caregivers as professional and friendly [47]. The benefit of their relationship with them was the opportunity for conversation and sharing personal experiences [35, 43], doing things together and having fun [46]. After some time of caring, some respondents considered caregivers their friends [42], or as part of the family [38], and the relationship with professional caregivers reduced respondents' loneliness [42]. The opportunity to establish a relationship with them was seen as an indication of good care. Negative attitudes among professional caregivers when communicating with older people was perceived as a barrier to establishing a relationship [46].

4) Quality, Safe and Secure Care

The provision of formal care in a professional way was important for respondents [46]. Respondents perceived care provided by qualified and experienced staff, with sufficient practical and social skills, to be professional care [33, 36, 38, 44, 46] and described it as 'good care' [46]. The provision of appropriate and continuous care with adequate time allocated was also considered a sign of quality care [38, 46]. Practical skills were assessed according to whether caregivers worked carefully, conscientiously and systematically, and were able to explain to the respondents the interventions they would undertake [38, 46]. Caregivers' social competence, their communication skills and sense of humor, were appreciated [46]. Respondents also expected sufficient empathy and respect from carers [38], as well as help with maintaining respondents' daily routines, such as the timing of personal hygiene and meals [46]. Care was considered poor when carers showed insufficient interest in older people: neglecting their needs, not completing their work, using their working hours for personal matters, as well as when there was the frequent rotating of different carers [46]. In some cases respondents expressed dissatisfaction if they felt they were a burden to caregivers. They described this experience as caregivers' lack of interest in them, their lack of time for work, and a lack of communication [38].

5) Role in Society

Loneliness was one of the main problems reported by older people [37, 39]. In the context of ageing, worsening health and reduced self-sufficiency, respondents were aware of how their social role was changing, and they felt they could no longer participate in social life as before [33], or they stated that their participation in society was limited [36].

The opportunity to lead an active social life to help prevent social isolation was crucial for some respondents [41]. Respondents considered it important to maintain the interaction between them and their social environment through their involvement with community groups or social activities outside the home [39], contact with family, friends and professional carers [40], or going out and taking part in leisure activities [41]. However, respondents did not always consider engaging in social life important, in which case they were passive on this issue [33].

6) Environment

Remaining in their own environment was important for respondents, as it allowed them to better cope with declining health. The familiar objects in their homes reminded respondents of their life in the past, while also keeping them in the present [38, 46], meaning they were older persons in a positive sense ("elderly human") [38]. An unfamiliar environment where they were not surrounded by familiar objects caused feelings of stress and anxiety in respondents [46].

Discussion

This scoping review focuses on the needs of older people living with illness or reduced self-sufficiency in their own homes, sheltered houses or communities and receiving home care.

The findings of the present review demonstrate that older people are able to express their needs and wishes when receiving home care. In some articles respondents also described what interventions or strategies they or their carers chose to meet their needs. However, the identification of interventions and strategies was not the aim of this review, and therefore this was not analyzed.

As mentioned in the introduction to this review, health-related needs can be viewed from a variety of perspectives. However, authors have also described various concepts of needs. Bradshaw [48] delineates four types of needs: Normative needs are based on standards established according to the experience of experts and professionals, and they are related to the level of service provided. Felt need is recognized as a subjective feeling when people are able to define their needs or explain what they want. An expressed need is defined according to whether people use health services and to what extent, while comparative need is an objective comparative assessment of the relationship between the availability of healthcare services and the health status of individuals or various groups of the population. According to Stevens and Gabbay [49] health-related needs consist of three interrelated aspects: a feeling of need, an expression of this need and an effective intervention to satisfy the need. In Haaster et al. [50], Toupin et al. divide needs in the healthcare system into three levels: 1) the problems patients are facing; 2) the interventions required alleviating or containing these problems; 3) the services needed to ensure these interventions.

Asadi-Lari et al. [6] point out that there is no consensus in the literature on the definition of needs, and the existing definitions should be redefined to reflect clinical reality, as there is still a gap between patient needs and the services offered.

In order to minimize this gap and meet not only the needs of patients but also of their carers, it is essential to assess their needs comprehensively. Most frequently needs are identified using a variety of questionnaires designed to anticipate potential basic needs. In their systematic research, Figueiredo et al. [51] identify nineteen multidimensional instruments used to assess the needs of older people living in their home environment. These instruments assess needs in five dimensions: 1) physical, 2) psychological, 3) social support and independence, 4) self-rated health behaviors and 5) contextual environment.

As mentioned above, it is important to assess the needs of care recipients and their informal carers alike. Informal carers usually identify their needs concerning care recipients' physical care [13, 14, 19], health information and social support [19], while care recipients state their needs concerning autonomy, personal care, daily and social activities and quality of care [52–57]. This is in line with the results of the present review. More specifically, it is important for older people to overcome any limitations resulting from their physical decline, to maintain their autonomy in terms of their independence, their daily routines and their ability to make decisions about their own care, to establish good relationships with caregivers, to have quality and safe care provided by trained staff, to participate in society and to live in their own environment.

Assessing needs helps healthcare and social care services to provide individual tailored care [11, 58, 59], which promotes the health and well-being of care recipients and their informal caregivers [58, 59]. In other words, satisfying their needs improves their quality of life [60–62].

Implications

The findings presented in this study provide an evidence-based framework that can serve as a guide for person-centered care planning. It is important to take into account the needs and wishes of older adults and tailor care to their needs and wishes. Furthermore, whenever possible patients should be involved in their own care and be allowed to participate in care planning. It is also appropriate to promote patients' independence and support them in their daily routines.

Limitations

Only articles in Czech and English were included in the review, representing a limitation for holistic validity and transferability to different cultural environments. Grey literature was not included in the review.

Conclusion

The present study has set out an overview of the needs of particularly vulnerable and frail older people using home care services. Based on inductive thematic analysis, six key topics were identified to provide an overview of respondents' needs across the articles included in the scoping review. With regard to the extent of the needs identified, these were not only physical but also psychosocial and environmental. Interestingly there was no emphasis on religious or spiritual needs; further research would therefore be appropriate. Additional research, especially qualitative research, will be required to gain a deeper understanding of the needs of frail older people receiving home care.

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Conflict of Interest Declaration

None

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Table 1 Exact Search Strings

Database	Search terms	Records identified
ProQuest Central	ab((frail elderly) OR (aged) OR (elderly)) AND ab((home health nursing) OR (home care) OR (home health care)) AND ti((need) OR (needs))	98
Web of Science	TS=(frail elderly OR aged OR elderly) AND TS=(home health nursing OR home care OR home health care) AND TI=(need OR needs)	165
CINAHL	AB ((frail elderly) OR (aged) OR (elderly)) AND AB ((home health nursing) OR (home care) OR (home health care)) AND TI ((need) OR (needs))	41
PubMed	(((((((((frail elderly[Title/Abstract]) OR aged[Title/Abstract]) AND home health care[Title/Abstract]) AND need[Title]) OR needs[Title]) NOT nursing homes[Title/Abstract]) NOT long term	234
Scopus	(ABS (“frailelderly” OR aged OR elderly) AND A BS (“home health nursing” OR “home care” OR “home health care”) AND TITLE (need OR needs))	44
PsycInfo	TI (elderly or aged or older or elder or geriatric) AND TI(needs) OR TI (needs assessment) AND TI (home care) OR TI (home health care) OR TI (home health nursing) OR TI (home healthcare) NOT TI (nursing home) NOT TI (nursing facility) NOT TI (palliative care)	244
Total number of records		826

Table 2 Summary of Individual Studies

Author/Year/ Country	**Aim**	**Research type**	**Study design and methods**	**Study participants**	**Themes**
Bagchus et al. (2015) Netherlands	To examine how the elderly themselves refer to their age and their needs and wishes for individual and collective participation in home-based care	Qualitative	Semi-structured in-depth interviews	18 participants aged 58–94 (average: 78) with experience as receivers of home care for at least one year	Coping with illness Autonomy Quality, safe and secure care Role in society
Breitholtz et al. (2012) Sweden	To illuminate the meaning of older people's dependence on caregivers' help, and of their opportunity to make independent decisions	Qualitative	Interviews analyzed using a phenomenological hermeneutic method	12 older people aged 80–91 with daily help from the municipal home help services	Autonomy Quality, safe and secure care
Breitholtz et al. (2013) Sweden	To illuminate the meaning of older persons' independent decision making concerning their daily care	Qualitative	Interviews analyzed using a phenomenological hermeneutic method	7 older persons aged 80–91 with daily help from municipal home help services	Autonomy Relationship with professionals
Eloranta et al. (2010) Finland	To explore and compare older home care clients'(65+) and their professionals' perceptions of the clients' psychological well-being	Quantitative	Postal questionnaire	120 home care clients aged 67–96 (average: 84);	Coping with illness Autonomy Role in society

Author/Year/ Country	Aim	Research type	Study design and methods	Study participants	Themes
From et al. (2009) Sweden	To explore older people's lived experience of what good and bad care meant to them when it was offered by community care services	Qualitative	Interviews analyzed using a phenomenological approach	19 participants aged 70–94 cared for by the community services.	Autonomy Relationship with professionals Quality, safe and secure care Environment
Janssen et al. (2012) Netherlands	To examine how older people mobilize sources of strength, often denoted under the concept of resilience, to maintain mastery over their lives in the context of significant threats to their function	Qualitative	Interviews analyzed using narrative analysis	Two older women, Mrs Verhoeven (aged 79) and Mrs Smits (aged 87), living in their home environment and receiving long-term professional care from at least one health and social care organization	Coping with illness Autonomy Role in society
Jarling et al. (2018) Sweden	To describe the meaning of the phenomenon of home care from the perspective of older persons who live alone with multimorbidity	Qualitative	Empirical study based on life-world perspective according to interviews	12 participants, aged 77–90 with a wide range of medical problems and receiving a variety of healthcare and social services	Autonomy Relationship with professionals

Author/Year/ Country	**Aim**	**Research type**	**Study design and methods**	**Study participants**	**Themes**
Liveng (2011) Denmark	To provide knowledge about the subjective perspectives of elderly persons	Qualitative	Grounded and reflective ethnographic approach using semi-structured interviews and observations	Three elderly persons, Mr. C (age not mentioned), Ms T (75 years old) and Mrs R (90 years old), characterized by complex problems	Autonomy
Llobet et al. (2011) Spain	To identify the elements comprising Quality of Life for individuals aged 75 and over and receiving care at home	Mixed methods	Personal interview using questionnaire	26 individuals aged 75 and over (average: 84.5 years) included in a home health care program	Coping with illness Autonomy Role in society
McGarry (2010) United Kingdom	To explore the nature of relationships between nurses and older people within context of their home	Qualitative	Ethnographic approach using semi-structured interviews	13 older patients aged 70–94 receiving care from the district nursing service	Relationship with professionals
Moe et al. (2013) Norway	To illuminate the meaning of receiving help from home nursing care for chronically ill elderly persons living in their own homes	Qualitative	Narrative interviews analyzed by phenomenological hermeneutic interpretations	11 elderly people aged 80–92 (average: 88) living at home with chronic disease, receiving help from nursing care	Coping with illness Autonomy Relationship with professionals Quality, safe and secure care Environment

Author/Year/ Country	Aim	Research type	Study design and methods	Study participants	Themes
Nicholson et al. (2012) United Kingdom	To understand the experience of home-dwelling older people living with frailty	Qualitative	Psychological narrative approaches: Biographic Narrative Interpretative Method and Free Association Narrative Interview Method	17 frail community-dwelling elders aged 86–102 with health and social care services contact	Coping with illness Autonomy
Nicholson et al. (2013) United Kingdom	To understand the experience over time of home-dwelling older people with changing states of frailty	Qualitative	Psychosocial narrative approach and psycho-dynamically informed observation	15 frail older people aged 86–102 living at home with health and social care	Coping with illness Autonomy Relationship with professionals
Randström et al. (2013) Sweden	To explore the experience of older people and their supporting family member in relation to home rehabilitation, with a focus on activity and participation	Qualitative	Descriptive qualitative approach with recurrent interviews	6 older people aged 66–92 (average: 82) who had been treated at a clinic for illness or injury, with an estimated time for rehabilitation at home longer than 4 weeks; 6 family members	Coping with illness Autonomy Relationship with professionals Quality, safe and secure care Role in society
Župančić et al. (2013) Croatia	To explore the everyday needs and activities of geriatric patients	Quantitative	Structured questionnaire with closed and open-ended questions	150 elderly people aged 65 and over who are clients of the Domnius home health care facility	Coping with illness Role in society

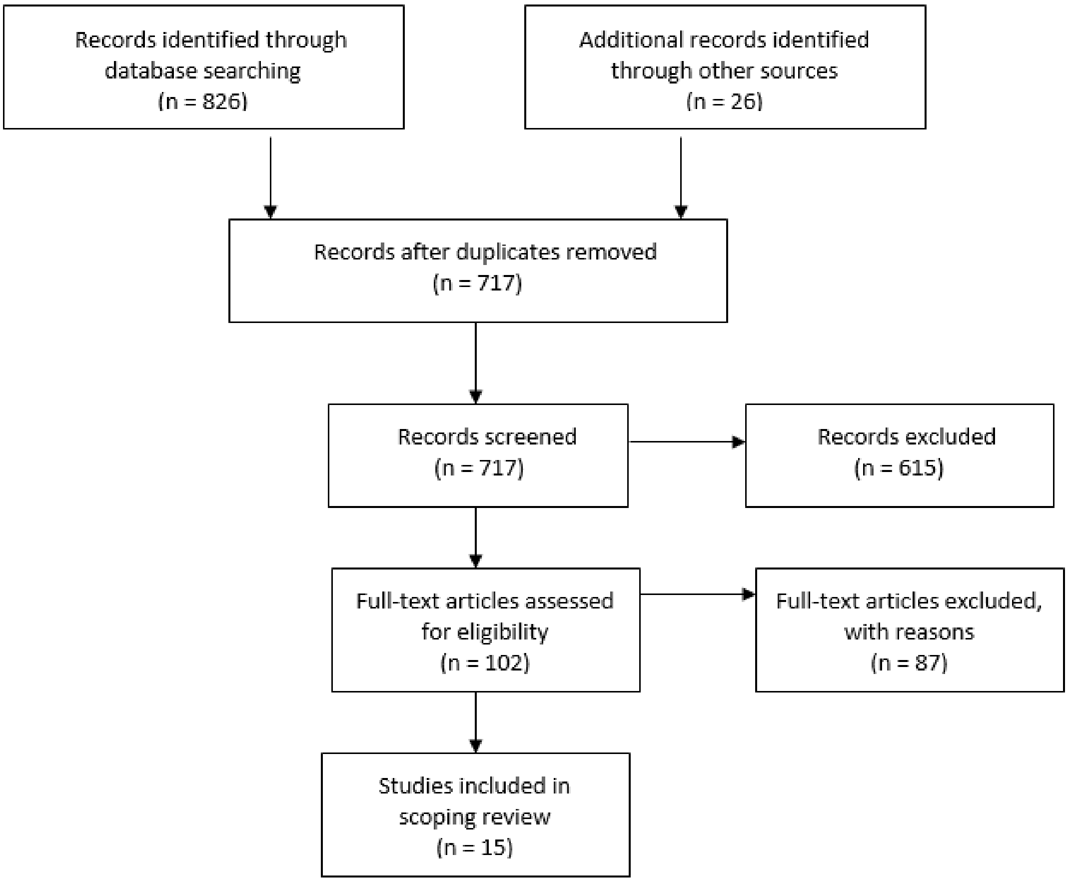

Fig. 1 Search flowchart in accordance with PRISMA guidelines

4 The Experiences and Needs of Frail Older People Receiving Home Health Care: A qualitative study

Reference:

Dostálová, V., Bártová, A., Bláhová, H., & Holmerová, I. The experiences and needs of frail older people receiving home health care: a qualitative study. Currently under review with *International Journal of Older People Nursing*.

Abstract

Background: Due to the rapid aging of the population, there is increasing demand for long-term care in the people's home environment. Such care aims to allow the people to stay at home and avoid hospitalization or other institutional care. In home health care, care must be provided at the highest possible quality, with the focus on the people's needs and experiences.

Objectives: This study explores the experiences and needs of frail older people receiving home health care.

Design and methods: An exploratory descriptive qualitative approach was chosen. Audio-taped semi-structured interviews were conducted with fifteen older people receiving home health care. A content analysis was used to analyse the data collected.

Results: The content analysis identified one main theme, three categories and seven subcategories related to frail older people's needs and experiences of home health care. The main theme was Quality of Care. The first category, Safe and Secure Care, consisted of three subcategories: Education and Experience of Nurses, Information, and Continuity of Care in terms of personnel continuity and regular care. The second category, Autonomy, contained two subcategories: Decision-making and Self-sufficiency. The last category, Relationship with Professionals, consisted of two subcategories: Personality of Nurse and Partnerships.

Conclusion and implication for practice: Older people are able to express their satisfaction or dissatisfaction with home health care. The results of this study revealed that the quality of care is crucial for frail older people. The provision of home health care is inherently highly specific; home care nurses should work to provide the highest possible quality of care.

Keywords: Older people, home health care, quality of care, experiences, needs

Summary statement of implication for practice

What does the research add to existing knowledge in gerontology?

- This study is a qualitative inductive description of the experience and needs of older people living in the Czech Republic who receive home health care.
- Home health care nurses' training and experience are essential not only for the provision of professional nursing care, but also for the provision of professional information and advice to patients. Care provided by trained and experienced nurses is perceived by patients as quality care.
- Continuity of care in the sense of personnel continuity and regular care provision is important for the provision of quality care.
- A nurse's personality and communication skills are very important in building a relationship with the patient.

What are the implications of this new knowledge for nursing care with older people?

- The provision of home health care is inherently highly specific; home care nurses should work to provide the highest possible quality of care. In particular, nurses should focus on ensuring that the care they provide is safe, effective, timely, efficient and person-centred.
- Nurses should proactively identify their patients' needs and wishes in home health care. Care for patients in their home environment should be properly planned in advance, taking account of their needs and wishes. Patients should be actively engaged in care planning.

How could the findings be used to influence policy or practice or research or education?

- Additional research, especially qualitative research focusing on patients' needs as viewed by nurses providing home health care, is required.
- Organisations providing care for patients in their home environment should train nurses to be competent in a holistic approach to patients that takes their biological, social and psychological needs into account.

Introduction

The rapid aging of the population worldwide has resulted in increasing demand for both primary and long-term care. Long-term care allows people with impaired health or reduced self-sufficiency to receive care while respecting their basic rights, freedoms and human dignity (WHO, 2020a). Long-term care therefore aims to give people the highest possible quality of life, together with independence and autonomy, including the opportunity of participating in care. Quality long-term care includes respect for the values, preferences and needs of the individual, and can be provided as home-based care or institutional care, with home health care expanding rapidly in all countries (WHO Study Group on Home-Based Long-Term Care, 2000). According to Eurostat (2018), in the European Union's member states home care was provided in one in five households where there were people requiring assistance due to their long-term health problems. The highest percentages of households receiving home care were recorded in Luxembourg (88%), the Czech Republic (58%) and Denmark (54%).

The provision of home care is based on the aims and principles of long-term care. Home care seeks to allow the people, in particular older people, who is often suffering from complex chronic diseases and reduced self-sufficiency, to remain at home and thus avoid hospitalization or other institutional care (Holmerová et al., 2014). Older people are particularly at risk of developing frailty syndrome as a result of complex chronic diseases that reduce the body's functional reserves, including a reduction in compensatory and adaptive mechanisms. Manifestations of frailty syndrome can be: 1) non-specific (unintentional weight loss, extreme fatigue, frequent infections); 2) falls; 3) delirium and 4) fluctuating disability (Clegg *et al.*, 2013). Therefore it is crucial to secure home care of the highest possible quality (Holmerová et al., 2014).

The literature has various definitions of quality of care, but almost all definitions share similar elements. Shirley and Sanders (Shirley & Sanders, 2016) emphasize that quality of care is a comprehensive concept that covers safety, efficacy, outcomes and patients' experiences. Campbell et al. (2000) define quality of care in terms of "whether individuals can access the health structures and processes of care which they need and whether the care received is effective". According to the World Health Organization, quality of care is: "the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care must be safe, effective, timely, efficient, equitable and person-centred" (WHO, 2020b). The

Institute of Medicine states that in order to ensure high-quality care, it is necessary to provide person-centred care with the following dimensions: 1) respect for patients' values, preferences, and expressed needs; 2) coordinated and integrated care; 3) providing information, communication, and education; 4) ensuring physical comfort; 5) providing emotional support and relieving anxiety; and 6) involving family and friends (Institute of Medicine, 2001). However, to ensure quality care and its improvement, the results of care must be measured. Measuring the quality of care focuses not only on the results of care, but also on patients' satisfaction and experiences (Howell & Zeitlin, 2017).

It is therefore clear that the planning and delivery of person-centred home health care must not only be based on the patient's state of health: it must also take into account the wishes and needs of patients and provide care in a way that preserves the patient's dignity and autonomy. Subsequently, however, it is necessary to evaluate the care provided. This is the only way to ensure that care is provided in the highest possible quality.

To date, there is no research in the Czech Republic focused on the experiences and needs of older people in home health care. Dostálová et al. (2020) conducted a scoping review to find out what is known so far about the needs of older people in home health care. One criterion for including studies in the review was that studies could be in either English and or Czech. However, no studies in the Czech language or studies conducted in the Czech Republic were found. Carrying out such research in the environment of the Czech Republic is therefore essential. Research findings can help understand the needs of older people in home health care. Taking research results into account when planning and delivering home healthcare will also make it possible to provide care of the highest possible quality.

This study explores the experiences and needs of frail older people receiving home health care.

Specifics of providing home health care in the Czech Republic

In the Czech Republic, health care in their home environment is provided by home health care agencies. Home health care agencies can be either public or private[14], and the health care must always be provided in accordance with applicable legislation. Health care is usually provided to patients seven days a week, with a maximum of three visits per day

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[14] Unfortunately, the available data do not specify the percentages of public and private home health care agencies.

with a time allowance of fifteen, thirty or forty-five minutes. The number of visits, their length and the required nursing procedures are determined by the patient's attending physician. Guided by the indication of the attending physician, the nurses plan and subsequently provide care in the patient's home environment. Nurses are obliged to continuously inform the patient's attending physician about the patient's health condition and any changes thereto.

Home health care patients are cared for by "general nurses" who must be properly educated in accordance with European Commission Regulation 2005/36/EC (European Parliament, 2005). Since 2005, general nurses must have at least a bachelor's degree or a three-year education within a post-secondary technical school for the training of general nurses[15] (Ministry of Health, CR, 2021).

Methods

An exploratory descriptive qualitative approach was chosen (Grove *et al.*, 2013). A qualitative descriptive approach is used to directly describe the research area; this approach is based on describing and interpreting the experiences and actions of individuals and groups in a social and cultural context. During data collection the researcher focuses on "what" and "why" (Holly *et al.*, 2014). Data was collected using semi-structured interviews and then subjected to a content analysis (Graneheim & Lundman, 2004).

To ensure the trustworthiness of this study, the recommendation made by Graneheim et al. (2017) was followed. To increase credibility, participants from four different home health care agencies were included in the research to ensure greater diversity and enough data to cover significant variations. To meet the transferability criteria, participants' profiles were compiled and their statements were quoted in the text, which supports the authenticity of the research. The criterion of dependability was fulfilled by the fact that the individual steps of analysis and subsequent processing were continuously discussed by the members of the research team until a consensus was found. All authors discussed the content of the manuscript and agreed on its final form, which ensured confirmability.

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[15] In the following text, the term "nurse" will be used for general nurses.

Participants

A purposive sampling method was chosen to select suitable study participants (Campbell *et al*., 2020). Study participants were selected to match the aim of the research as closely as possible. The inclusion criteria were women and men aged 65 and over living in their own homes and currently receiving home health care, whose medical records featured: 1) more than one chronic disease (without diagnosed dementia or overt cognitive impairment) and 2) reduced self-sufficiency in daily activities assessed according to the Barthel scale (ADL); ADL ≤ 65 (Mahoney & Barthel, 1965).

Participants were recruited from four different home health care agencies (one public, three private) based in three regions of the Czech Republic. Eligible participants were recruited according to predetermined criteria by the head nurses of home health care agencies. The nurse leaders handed over the list of eligible participants to the nurses who provided regular nursing care to the selected participants. The nurses subsequently contacted the selected participants during regular visits to ask whether they agreed to participate in the research. If they were interested in participating in the study, an appropriate date for a semi-structured interview was set by agreement between the nurse, the participant and the researcher. Ten women and five men participated in the study. All participants lived in their own homes, either alone (10) or with family members (5), and received regular assistance from home health care services, ranging from daily to weekly care. Health care included general supervision of the patient's health, medication and insulin administration, wound dressings, blood pressure checks, blood sampling, rehabilitation, etc. Participants' ages ranged from 71 to 92. The main profile of the participants is shown in Table 1. None of the recruited participants refused to participate in the research or dropped out during the research.

Data collection

Data was collected through semi-structured interviews (n=15) conducted between January and August 2020. The original intention was to conduct face-to-face interviews in five regions of the Czech Republic, but due to the coronavirus pandemic and the related restrictions some interviews were conducted by telephone. Coronavirus measures and related restrictions were also a reason to stop collecting data, as cooperation with other home health care agencies was no longer possible, including the possibility of interviewing home health care patients by telephone. For this reason, data collection was performed only in three regions of the Czech Republic.

All interviews were recorded and transcribed verbatim. Of the total number of interviews, six were face-to-face interviews and nine were by telephone. Interviews lasted from 25 to 60 (mean 42) minutes. A list of open-ended questions drafted by all authors served as a guide for the interviews (Table 2). All participants were asked an initial question: “Can you describe your experience of the home health care you’re receiving?” To understand the context of the narrative, participants were asked additional questions such as: “Can you tell me more about what you think? How do you view this situation? What does it mean for you? Can you tell me more about why this is important for you?” All interviews were conducted by the first author. Face-to-face interviews took place in participants’ homes by prior arrangement and home health care nurses were present during these interviews. The presence of nurses during face-to-face interviews with respondents was a requirement of the manager of home health care agencies, as the respondents had known the nurse for a long time and the presence of a stranger in the form of a researcher entering their environment could be undesirable for them. The nurses did not intervene or participate in the interviews. The respondents were not stressed by or anxious about the presence of nurses during the interviews. The dates of the telephone interviews were agreed with the participants in advance. No nurses were present during the telephone conversations, nor were any members of the respondent's family or loved ones present.

Field notes (Phillippi & Lauderdale, 2018) were made during and immediately after the interviews. The notes included both the location where the interview took place and information about the participants (age, whether they live alone or not). Furthermore, the notes included the participants' actions during the interview, their moods, expressions of emotions and other relevant data important for a comprehensive understanding of the participants' statements. The notes also included information on any change in the topics prepared for the interviews, including the justification for the changes.

Data analysis

The analysis utilized inductive content analysis, as described by Graneheim et al. (2017). Content analysis is a systematic method for analysing verbal or written communication using a coding and categorizing approach (Graneheim & Lundman, 2004; Vaismoradi et al., 2013). This method is suitable for exploring an individual’s or a group’s opinions, attitudes and experiences (Downe-Wamboldt, 1992). During the analysis, the manifest content is usually coded first, and then the researchers search for latent content that is formulated as a theme (Graneheim *et al*., 2017).

The analysis process involved several steps that were regularly discussed by all authors. Participants' accounts were generally more broad-ranging than required for the research, and the analysis therefore focused solely on data that was relevant to participants' experiences of home health care. Interviews were reread several times to fully understand their content and significance. Meaning units, words, sentences, and paragraphs related to the objective of this study were first identified and coded as manifest content. These codes were then grouped into seven subcategories according to their similarities. Subsequently, the subcategories were grouped into categories. In the last step, latent content was defined, which resulted in one main theme (Table 3). The main theme, categories and subcategories that emerged during the analysis are presented in Table 4. The results were reported according to Consolidated Criteria for Reporting Qualitative Research guidelines (Tong *et al*., 2007).

Ethical considerations

This study was approved by the Ethics Committee of the Gerontology Centre in Prague (No. 2018/11/276219). All participants were provided with both oral and written information about the study. Oral and written consents were collected from all participants prior to the start of data collection. Emphasis was placed on the voluntary nature of the participants' involvement in the study. Participants were told that they could withdraw from the study at any time without giving a reason. The data was stored in accordance with the General Data Protection Regulation (EU Regulation - GDPR). To maintain confidentiality and to protect participants' personal data, the recorded data was de-identified by code and stored on a password-protected computer, and only the authors had access to this material.

Results

Experiences and needs in the provision of home health care, as viewed by the participants, can be summarized in three main categories: Safe and secure care; Autonomy, and Relationship with professionals. The main theme that we use on this article for these three categories is "Quality of care". This section is structured according to the individual categories, with each category discussed from the participants' perspective. Participants have been quoted verbatim to ensure authenticity.

Safe and secure care

The participants' accounts showed that their general experience of home health care was positive, with care described as *"amazing, great, perfect, excellent"*, etc. Care provided by trained nurses with sufficient experience and good communication skills was perceived by participants to be good. The continuity of nursing personnel and the individual nurses' attitudes were also important to them; such care gave participants reassurance and confidence.

Education and experience

Participants highlighted that nurses needed to be qualified and experienced in order to provide professional care. If participants received care from a qualified and experienced nurse, they perceived this care as safe, and they expressed satisfaction with the care provided, in which case the nurses were viewed as professionals who are able to cope with unexpected situations. Some participants described a trained nurse as someone who "knows what to do". One participant said: *"...it's important for me that she's skilled and qualified... Basically it's important that I always feel safe with her, really feel safe with her..."* (Interviewee 3). Another participant remarked: *"...they have to be qualified. It's not just that. After all, they have to understand this* (medical issues) *..."* (Interviewee 10). If nurses did not demonstrate sufficient knowledge and experience, participants regarded them as amateurs and rejected their care. As one participant said: *"...having an amateur here, I don't know, I wouldn't want that..."* (Interviewee 6).

Information

Nurses' training and experience was closely related to the provision of professional advice and information for patients. For the participants it was very important that nurses not only gave them information about their health status, but also advice on how to improve their health. One participant said: *"...and most importantly, they can advise me. If there's something I don't know, they can give me advice. That's ideal..."* (Interviewee 13).

Participants reported that sometimes the nurses did not know the answers to their questions. Nurses' willingness to search for information if they did not immediately know the answer was appreciated by the participants. As one said, *"...if I ask them something,* *they can answer me. And at the same time, if I ask them a question and they don't know the answer, they'll find out and explain everything to me in detail on their next visit…"* (Interviewee 12). In some cases nurses gave participants information not just about their health status, but also about social security and assistance. Participants expected nurses to take the initiative when providing information, and any lack of information or reluctance to provide information made participants feel insecure. As one participant said: *"...If she doesn't tell me herself, I feel stupid for asking…"* (Interviewee 9).

Continuity

The continuity of care provided – meaning the continuity of personnel and of the care itself –was practically the central theme for the participants. Participants defined personnel continuity as the provision of care by the same nurse. If participants were to have confidence in their care, it was important that they were cared for by the nurse they were used to. If nurses were rotated, patients felt mistrustful and sad. One participant commented: *"... so I don't know if anyone will replace her* (the nurse)*, I don't know. I'd fight for her to stay here…"* (Interviewee 3). The advantage of personnel continuity was that not only were nurses familiar with the participants' health status, but they also had an opportunity to get to know the participants and their other needs and wishes. One participant said: *"...you're used to them and you know what to expect from them, and what they can expect from me…"* (Interviewee 2). If another nurse had to visit instead of the usual one, participants appreciated being informed in advance which nurse would be visiting.

Besides personnel continuity, continuity of care was also important for the participants. They were satisfied if care was provided regularly and nurses agreed with the participants the times for their visits and kept to this schedule. As one participant said, *"...and they visit just as we agreed, and I like that, when people keep their promises…"* (Interviewee 14). As it was important for participants to adhere to the time agreed for a visit, they appreciated being informed in advance of any change to the schedule. They found uncertainty about the timing of visits and any changes to them unpleasant. One participant remarked: *"...it was so annoying, I didn't know when they'd come or even if they'd come…"* (Interviewee 7). Participants planned their daily activities around the time agreed for a visit, and failure to stick to this schedule disrupted their activities. "*It's important for me to know when she's coming... I have that sort of fixed in my mind. And* *if that gets derailed, it throws me off balance. Or, I don't know, I start wondering about what might have happened…"* (Interviewee 2).

Allocating sufficient time for visits was also important for patients. If nurses were in a rush, participants felt uncomfortable, as if they were a nuisance. One participant said: *"... I don't like it if she says 'I'm in a hurry' ... I like it when she makes time for me…"* (Interviewee 10). However, participants realized that nurses have a large number of patients and could not spend as much time with them as they would like. As one participant said: *"... sometimes she has enough time for me and sometimes she doesn't, because she's got another patient…"* (Interviewee 14).

Autonomy

Participants described autonomy in two ways: being involved in the provision of health care in terms of decision-making and cooperation with nurses, and maintaining their self-sufficiency.

Decision-making and cooperation

The opportunity to participate in care provision was crucial for some participants, who expressed their satisfaction at being able to participate in their own care. They were also pleased if nurses were interested in their current health status and adjusted care accordingly; for participants, this meant they were treated with respect. One participant reported: "*It's important* (to discuss care provision with the nurse). *It's important, because I also have days that are pretty good and days that aren't. …When I wasn't feeling well, we didn't exercise. We always agreed on this…"* (Interviewee 13).

Self-sufficiency

Despite the fact that participants were aware of their deteriorating health, which restricted their daily activities, they emphasized the importance of preserving their self-sufficiency and independence as far as possible. This was expressed as the ability to perform simple daily activities such as walking, shopping and preparing food. To maintain these activities, it was important for participants to receive assistance in the form of rehabilitation or other exercises. As one participant commented, "*...I have to get some exercise, and if I don't go out, I have to have some movement…"* (Interviewee 15). Another participant remarked: *"... I do these exercises because I can't keep my balance…"* (Interviewee 2). As part of rehabilitation, nurses, for example, verticalized patients, practised moving from bed to chair with them and, above all, performed walking exercises. Participants were also educated by nurses about the exercises they could perform independently at home and which helped them to maintain or improve their self-sufficiency, as one participant stated: *"...I exercise on my own; the nurse taught me exercises that I do regularly, every day…"* (Interviewee 6).

Relationship with professionals

Personality of the nurse

The personality of the nurses and their approach to the participants played an important role in care. Participants needed nurses to be empathetic, capable of understanding participants' needs and wishes concerning their health status and their personal lives. One participant said: *"It's important that she's nice. She doesn't have to smile all the time, but you need to feel some empathy ..."* (Interviewee 6). Participants described smiling, pleasant and helpful nurses as ideal. A nurse's positive attitude towards a participant not only facilitated communication between them, but also gave the participant the confidence to openly discuss important health issues with the nurse. In their accounts, participants did not hide their fear that they might be cared for by nurses who did not have a positive attitude. One participant expressed: *"...If a nurse visited me and was complaining and being unpleasant, I wouldn't be able to sleep. I'd feel bad…"* (Interviewee 8).

Partnership

For many participants, being at home meant they felt lonely and excluded from social life, as participants expressed: *"…as I am here alone, I have a long time here ... you know, I have almost no friends any more ..."* (Interviewee 3); *"...old age is terrible, that loneliness ... you can't do anything, you can't go anywhere… "*(Interviewee 8). Despite the fact that most of them were in contact with their families and friends, visits by nurses were an opportunity to enhance their social life. One participant noted: "... *I'm sad here, …that's how I find out some information… we talk… about what's new, what's going on, what is on TV ... just about everything…* (Interviewee 11). Participants saw nurses not only as professionals who looked after their health, but also as partners they could talk to, and they looked forward to seeing them. The nurses became part of their lives, which allowed them to develop a relationship with the nurses *"... I always really look forward to them, they are my girls ... I like them very much, all of them..."* (Interviewee 15). In some cases participants thought of nurses as members of the family. One participant said:

"You know, if they didn't visit, the days would feel long, because they brighten up my day when they come… To me, they're like daughters…" (Interviewee 2).

Discussion

This study has sought to explore the experiences and needs of frail older people receiving home health care. Despite the fact that the older people's experiences and needs overlapped, the analysis revealed three main categories related to the objective of this study – Safe and Secure Care, Autonomy, and Relationship with Professionals. These three categories were summarized under one main theme: "Quality of Care".

In general, during the interviews the participants expressed satisfaction with the provision of home health care. They especially drew attention to the opportunity to stay in their home environment during illness or periods of diminished self-sufficiency, which has proved to be a great advantage for them.

As the results of our study showed, the quality of care provided is important for older patients, while one of the features of quality care, according to older patients, is the care provided by trained staff with sufficient experience.

Nurses providing home health care usually work without medical supervision. Their work therefore consists of independent decision-making and depends on their education and experience (Duke & Street, 2005; Williamson, 2007). Holmerová et al. (2018) assert that qualified and trained staff are one of the basic preconditions ensuring quality care. This is in line with other studies that emphasize the importance of the provision of quality care. Their authors consider quality care to be care provided by trained and skilled nurses, and their findings indicate that patients view such care as professional (Bagchus *et al.*, 2015; Moe *et al.*, 2013; Randström *et al.*, 2013). This corresponds to the definition of "professional" in the Cambridge Dictionary (2020): "having the qualities of skilled and trained people".

The results of our study also showed that one of the basic indicators of the quality of care is the involvement of patients in the care provided.

Active participation can lead to better quality healthcare provision, better health outcomes and better quality of life. Patient participation in healthcare provision also indicates an appreciation of the patient's humanity and individuality (Vahdat *et al.*, 2014). This is confirmed by Breitholtz et al. (2013b) who reported that patients involved in the provision of care felt in control of their care, in terms of making decisions in line with their needs and wishes. It is therefore important for patients to be treated with respect and to be regarded as a competent human beings (Liveng, 2011). This can be promoted by involving patients in discussions (McCabe, 2004).

Communication with the patient in the provision of care proved to be very important in our study. It turned out that effective communication not only affects the quality of care, but also supports the individuality of the patient.

Communication must not only concern issues related to care: nurses should also show an interest in their patients' daily lives. Such communication can provide reassurance for the patient and reveal other significant needs or wishes that the patient would not otherwise express (Sundler *et al.*, 2016). Managing effective communication is influenced by the nurse's personality and attitude to patients. The nurse's personality and approach to patients was another topic that emerged from our analysis and was especially emphasized by older patients in the interviews.

In particular, empathy is considered an important personality trait for nurses. In interpersonal communication it plays a vital role in gaining trust and is therefore very important when nurses are building relationships with patients (Wan *et al.*, 2019). Empathy, the ability to understand other people's feelings, facilitates communication between patient and nurse and also helps avoid any conflicts that may arise during care (Duan & Hill, 1996). It is therefore a key part of the nurse-patient relationship (Richardson *et al.*, 2012). The findings of Strandås and Bondas (2018) reveal that a good nurse-patient relationship enhances not only the patient's physical health but also promotes emotional, mental and social well-being. Jarling et al. (2018) point out that sufficient time must be devoted to establishing a relationship between nurse and patient that is based on mutual trust.

In our study, the patients placed great emphasis on continuity of care, in terms of both staff continuity and continuity of care in terms of regular care. The results of studies by From et al. (2009) and Moe et al. (2013) showed that the continuity of care and the allocation of sufficient time are important factors in the assessment of the quality of care for patients.

The continuity of care can be described as a "cornerstone of care" and an "essential element" of general practice (Freeman *et al.*, 2003). According to Hill et al. (2014), continuity of care means care that corresponds not only to health needs, but also to the patient's personal context. They emphasize that maintaining continuity is essential to improve patients' health, especially for patients with multiple diseases.

As already mentioned in this discussion, the quality of care provided (with all its components) is very important when caring for people. Patients are not only very sensitive to the care provided, but the way in which it is provided also has an impact on their quality of life. Henderson (2006) states that nurses providing home health care should be able to assess a patient's health, identify needs and form a relationship with the patient. According to Cohen-Mansfield et al. (2017), in order to provide quality care for older people in their home environment, it is necessary 1) to focus on their needs and treat them with respect, and 2) to establish a good relationship with them. The quality of care therefore depends on nurses' ability to perceive their patients' needs and interact with them. Nurses' skills also include the ability to anticipate situations that may be dangerous to patients.

This is in line with the findings of earlier studies (Breitholtz *et al.*, 2013a; From *et al.*, 2009; McGarry, 2010; Moe *et al.*, 2013; Samuelsson & Wister, 2000) and of the present study.

Limitations of the study

One limitation of this study was the relatively small participant sample as a consequence of the restrictive measures introduced in response to the coronavirus pandemic. As a result of these measures, no further collaboration with home care agencies in the research was possible. In view of these measures, the data collection method also had to be changed during the data collection. Instead of the originally planned face-to-face interviews, part of the interviews were conducted by telephone, which at least made it possible to complete data collection at home health care agencies which, despite the pandemic situation, were willing to complete the research collaboration. Some participants' statements may have been influenced by the presence of nurses from home health care agencies during the face-to-face interviews. It is also necessary to keep in mind the risk of subjectivity in the interpretation of data, which may be caused by the researcher's assumptions (Holly *et al.*, 2014). The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to report important aspects of this study (Tong *et al.*, 2007). Emphasis was also placed on the trustworthiness of this study

(Graneheim *et al*., 2017), which was supported by an effort to describe the methods in detail so that the strengths and weaknesses were understood.

Conclusion

The results of this study show that the quality of care provided is important for older patients. The training and sufficient experience of nurses is essential not only for the provision of professional nursing care but also for the provision of professional information and advice to patients. Ensuring the continuity of care also proves to be essential. This includes both continuity in the sense of personnel continuity, when care is provided mainly by the same nurse, and continuity in the sense of care itself, i.e. regular care. Equally important are the personalities of nurses and their approach to patients. The personality of nurses facilitates both communication between the nurse and the patient, as well as facilitating the establishment of a friendly relationship between the patient and the nurse, which in turn promotes mutual trust.

In general, aging is associated not only with changes in social status, but often also with changes in health status, specifically worsening health. As has been demonstrated, it is important for older people to remain in their own environment for as long as possible. One way they can do this during periods of illness or reduced self-sufficiency is for medical care to be provided in the form of home health care. As the provision of home health care is inherently highly specific, home care nurses should work to provide the highest possible quality of care. The present study has set out an overview of the needs and experiences of frail older people receiving home health care. Additional research, especially qualitative research focusing on patients' needs as viewed by nurses providing home health care, will be required to gain a deeper understanding of the needs of older people in order to ensure quality care.

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Authors' contribution

IH and VD planned the methodology and the design of this study. VD, AB, HB and IH prepared the interview guide. VD conducted the interviews and analysed and interpreted the data with IH's supervision. All authors discussed interview transcripts and analysis during each stage. VD drafted the manuscript under the IH's supervision. AB, HB and IH contributed with complementing perspectives in the interpretations and suggested improvements to the text. All authors read and approved the final manuscript.

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Conflict of interest

None

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Table 1 Profile of participants

Interviewee	Gender	Age	Living alone	Living with family	Medical history	ADL score
1	M	78		x	Diabetes; Hypertension; Stroke	10
2	F	92	x		Diabetes; Heart failure; Venous leg ulcer	65
3	F	91	x		Arthritis; Ischemic heart disease; Stroke	50
4	F	77	x		Diabetes; Chronic obstructive pulmonary disease; Venous leg ulcer	60
5	M	65		x	Arthritis; Chronic kidney disease Diabetes; Venous leg ulcer	55
6	M	71		x	Arthritis; Heart failure; Leukaemia	60
7	M	71	x		Diabetes; Multiple sclerosis	40
8	F	71	x		Diabetes; Osteoporosis; Venous leg ulcer	60
9	F	74	x		Asthma; Chronic kidney disease; Hypertension	65
10	M	91		x	Arthritis; Ischemic heart disease	55
11	F	80		x	Hypertension; Osteoporosis	65
12	F	79	x		Autoimmune diseases of the musculoskeletal system; Chronic kidney disease; Ischemic heart disease	60
13	F	75	x		Asthma; Ischemic heart disease	65
14	F	86	x		Diabetes; Hypertension; Osteoporosis; Venous leg ulcer	65
15	F	82	x		Heart failure; Parkinson disease	65

Table 2 Semi-structured interview guide

Can you describe your experience of the home health care you're receiving?
How is this care provided?
What are your needs in relation to the home care you're receiving?
How are those needs taken into account in the provision of home care?
What would ideal care look like?
What would an ideal nurse be like?

Table 3 Example process of analysis

Unit of analysis	**Code**	**Subcategory**	**Category**	**Main theme**
...it's so nice, talking to them (nurses)..., I don't have anyone to talk to like that...	Social contact	Partnership	Relationship with Professionals	Quality of Care
… I'm sad here, …that's how I find out some information… we talk (with nurse)… about what's new, what's going on, what is on TV ... just about everything…	Social contact	Partnership	Relationship with Professionals	
… so I don't know if anyone will replace her (the nurse), I don't know. I'd fight for her to stay here…	Same nurse	Continuity	Safe and Secure Care	

Table 4 Main theme, categories and subcategories

Main theme	Categories	Subcategories
Quality of Care	Safe and Secure Care	Education and Experience Information Continuity
	Autonomy	Decision-making Self-sufficiency
	Relationship with Professionals	Personality of Nurse Partnership

5 The needs of older people in home health care from the nurses' perspective: A qualitative study

Reference:

Dostálová, V., Bártová, A., Bláhová, H., & Holmerová, I. The needs of older people in home health care from the nurses' perspective: a qualitative study. Currently under review with *International Journal of Older People Nursing*.

Abstract

Background: The ageing of the population and the related demographic changes have led to rising numbers of older people in our society, especially vulnerable people of advanced age. Given the prevalence of various sicknesses related to ageing and old age, these people will live in a condition of sickness or reduced self-sufficiency, and significantly more older people will therefore require long-term care. One option is to provide such care in the patient's home setting. If this care and its provision are to be optimal, patients' needs and wishes must be taken into account when planning and providing care. The objective of this study is to ascertain the needs of patients in home health care from the perspective of their nurses.

Methods: Three focus groups were held, attended by a total of seventeen nurses caring for patients aged over 65 in their home environment. All focus groups were recorded and transcribed verbatim. A content analysis was used to analyse the data collected.

Results: The content analysis identified four basic categories and nine subcategories relating to how older people's needs were perceived by the nurses caring for them. The first category, Information, consisted of three subcategories: Home health Care Information, Competencies and health Provision. The second category, Nurses' Professionalism, contained two subcategories: Education and Experiences and Nurse Personality. The third category, Habits and Routines, contained two subcategories: Continuity of Care and Home Environment. The last category, Social Contact consisted also of two categories: Verbal and Physical Contact and Relationship with Professionals.

Conclusion / Discussion: Although the provision of home health care in patients' own environments may encroach on their privacy, it is something they themselves desire and

appreciate. Assessing patients' needs and taking them into account when planning and providing care is one of the essential preconditions for providing professional and quality care. Although nurses providing care for patients in their home environment are able to identify their patients' needs, the needs they identify partly diverge from the patients' needs, especially in two areas: 1) the opportunity to be involved in decision making and care delivery - a need identified by home health care patients, and 2) sufficient information for patients about the principles and options of home health care delivery - need identified by nurses.

Keywords: older people, nurses, needs, home health care

Summary statement of implication for practice

What does the research add to existing knowledge in gerontology?

- This study is a qualitative inductive description of the needs of patients in home health care from the perspective of their nurses it the Czech Republic.
- Although nurses providing care to patients in their home environment are able to identify the needs of their patients, the needs they identify partially diverge from the needs of patients, particularly in two areas:
  1) patient involvement in decision-making and in the provision of care itself;

  2) information about the principles and possibilities of home health care provision.
- Adequate awareness of home health care itself, its possibilities, its provision and the competences of nurses who provide home health care is essential.
- It is important that home health care is planned and delivered with respect to patients habits and routines.

What are the implications of this new knowledge for nursing care with older people?

- When planning home health care, it is appropriate to include patients in planning their own care, to allow them to be involved in their care, and to plan care in line with their needs.
- Before starting home health care, nurses should make patients aware of the principles of home health care. Patients should be adequately informed about the remit of home care nurses and how home health care is delivered.

- Nurses should bear in mind that their perception of patients' needs is not always in line with what patients' needs and wishes are.

How could the findings be used to influence policy or practice or research or education?

- General practitioners and consultants working in hospitals should inform older patients of the options for home health care and should actively offer them this care.
- Nurses’ undergraduate and postgraduate education and their lifelong learning should be oriented towards a holistic approach to patients and person-centred care.
- Organisations providing home health care should train nurses not just in technical skills but also in person-centred care, so that patients’ autonomy will be maintained when planning and providing care, especially with regard to privacy, independence, decision-making and cooperation.

Introduction

This study is part of a project investigating the needs of vulnerable older people aged 65 and over in home care and hospital care. The project focuses especially on how these needs are viewed and identified by the older people (or patients) themselves, and how they are viewed and identified by the nurses caring for them.

With the ageing population and the related demographic changes, society will have an increasing number of people aged 60 and over who in view of their worsening health will require long-term medical care (WHO, 2018) in the form of both hospital care and home care (Holmerová *et al.*, 2014). According to WHO (2017) predictions, by 2050 approximately 20% of the population will be aged 60 and over, compared with 12% in 2015. One consequence of the ageing population is the higher prevalence of various illnesses. Ageing is especially related to an increase in geriatric syndromes such as frailty, instability (falls), incontinence and dementia. Ageing and old age can therefore be characterised by the complexity of older people’s health status and the presence of various syndromes and illnesses (Holmerová *et al.*, 2014), while the needs when caring for such patients have both medical and social aspects (Grimsmo *et al.*, 2018). Although old people often live in a condition of sickness or reduced self-sufficiency, they wish to remain in their own environment for as long as possible (From *et al*., 2009; Moe *et al*., 2013). As it was mentioned above: provision of sufficient home care services (both of health and social type) is for many patients a necessary condition of staying/living longer in their home environment despite complex health conditions.

As older patients expect a comprehensive and holistic approach to their health care (Muszalik *et al.*, 2015), person-centred care based on their needs and wishes, i.e. individually planned care, should be provided (American Geriatrics Society Expert Panel on Person-Centered Care, 2016). Understanding patients' needs will not only result in care being defined with consideration for their individual needs, i.e. person-centred care (Dubuc *et al.*, 2013), but patients perceive care provided in this way to be quality care (Cohen-Mansfield *et al.*, 2017), and it positively affects patients' well-being (Hackert *et al.*, 2019). On the other hand, unsatisfied needs may result in a worsening of patients' health status (Kalánková *et al.*, 2020) and mental health (Alltag *et al.*, 2018). Professional carers should therefore remember to give patients the care the patients want, not the care the carers want (Bassett, 2002). The results of several studies show that nurses and patients frequently have different expectations of the care provided (Poirier & Sossong, 2010; Barrientos & Holmberg, 2018).

Some studies have examined patients' needs in home health care as viewed by the patients themselves. The results of these studies reveal that patients most often identify needs in the following areas: coping with sickness; autonomy (in the sense of freedom and independence, decision-making on the care provided, being involved in the care process, and the opportunity to maintain their daily activities); the relationship with professional carers; quality and safe care; their role in society and living in their own environment (Dostálová *et al.*, 2020). There are also studies focusing on nurses' perception of patients' needs, and their experience of caring with regard to their patients' needs. Nevertheless, these studies do not explicitly examine the needs of patients receiving care in the home environment. The results of these studies show that when caring for patients, nurses consider it important to establish a relationship with the patient that is based on trust (Östman *et al.*, 2020), mutual communication (Romagnoli *et al.*, 2013; Östman *et al.*, 2020), adequate information relating to care (Romagnoli *et al.*, 2013) and appropriate training to ensure the care they provide is of the highest possible standard (Hynninen *et al.*, 2015).

The objective of this study is to ascertain the needs of patients in home health care from the perspective of their nurses.

Methods

A descriptive qualitative approach was chosen for our research (Grove *et al*., 2013). This approach is used to describe a specific research area and is based on describing and interpreting the experiences and actions of people or groups of people in a social and cultural context (Holly *et al.*, 2014). It is particularly important in medical care research, where it focuses on the self-perceptions and perspectives of respondents (Neergaard *et al.*, 2009). During collection in qualitative descriptive studies, researchers mainly focus on clarifying the "who", "what" and "where" (Sandelowski, 2000). Data were collected through focus groups and then subjected to qualitative content analysis (Graneheim & Lundman, 2004). To ensure the reliability of the study, the recommendations of Graneheim et al. (2017) were followed. To increase credibility, participants were selected from three different home health care agencies to ensure greater diversity and sufficient data to provide the opportunity for greater coverage of significant differences. To ensure transferability, participant profiles were compiled and their statements were quoted verbatim, which supported the authenticity of the research. The criterion of dependability was fulfilled by ensuring that the preparatory phase of the research, as well as the process of data collection and subsequent analysis, were discussed by all members of the research team throughout. All members of the research team discussed the content of the manuscript and agreed with the final form of the manuscript, thus ensuring confirmability.

Participants

A purposive sampling method was chosen to select suitable study participants (Campbell *et al.*, 2020). The participants of the study were selected to best match the research objective. The inclusion criteria were as follows: nurses (both women and men), with at least one year of experience in home health care, caring mainly for older patients (65 years and older). A letter and information about the research was sent electronically to the nurse managers of six home health care agencies located in four regions of the Czech Republic[16]. Three of the home health care agencies contacted (one public and two private)

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[16] This selection was consistent with the terms of reference and the aim of the project of which the present study is a part.

located in three regions of the Czech Republic agreed to have their nurses participate in the research.

In total, three focus groups were conducted, involving a total of 17 nurses (only women) who met the inclusion criteria. The length of experience of the home health care nurses ranged from one year to 28 years (mean 8 years). The focus group participants were always from one home health care agency. The researchers arranged a suitable date with the nurse managers of the home health care agency to conduct the focus groups. Prior to the focus groups, the participants were briefed by the researchers on the purpose and objective of the research. Participants were also informed that they could withdraw from the research at any time without giving a reason. Only one nurse withdrew from the research.

Data collection

Data was collected through focus groups (n=3) that took place between February and June 2020. Five nurses participated in the first and second focus groups each, and seven nurses participated in the third focus group. The focus groups took place in the premises of home health care agencies and were conducted in a calm and friendly atmosphere. All focus group interviews were recorded on a dictaphone and then transcribed verbatim. Focus groups lasted between 75 and 90 minutes (mean 80 minutes). A list of open-ended questions (Table xxx), which had been prepared in advance, served as a guide for the researchers to conduct the focus group interviews. All focus group participants were asked two initial questions, "Can you please describe what your patients expect from your care?" followed by, "What is your experience of home health care provision?" To understand the content of participants' statements, participants were asked additional questions such as, "Can you tell us more about what you think as well? How do you perceive the situation? Can you tell us more about why you think this is important for patients?" All focus groups were conducted by the authors of VD and AB.

Field notes (Phillippi & Lauderdale, 2018) were made during and immediately after the focus groups. Notes included the date, time and location of the focus groups and the duration of the focus groups. They also included information about the focus group participants, particularly the length of their experience as a home health nurse. Field notes also included participants' actions during the focus groups, their interactions, mood, expressions and emotions, and other relevant data important for a comprehensive understanding of their accounts.

Data analysis

Data was analysed using inductive content analysis as described by Graneheim et al. (2017). Content analysis is a systematic method used to analyse verbal or written communication through coding and categorisation (Graneheim & Lundman, 2004; Vaismoradi *et al*., 2013). Content analysis is an appropriate method for investigating the opinions, attitudes and experiences of people or groups of people (Downe-Wamboldt, 1992). The analysis process has several steps, and they were regularly discussed by all of the authors. As the participants' responses were relatively broad and went beyond the research question, the analysis only focused on patients' needs from the perspective of the participants (nurses). Each interview was read several times to understand the content and significance of the responses. Meaning units, words, sentences and areas were all assigned codes that were then grouped under 9 subcategories in line with their common meaning. In the final step of the analysis, the subcategories were grouped under categories (Graneheim *et al*., 2017) (Table 1). The subcategories and categories that emerged from the analysis are listed in Table 2.

Ethical considerations

This study was approved by the ethics committee of the Gerontology Centre in Prague (No. 2018/11/276219). All participants were provided with both oral and written information about the study. Oral and written consents were collected from all participants prior to the start of data collection. Emphasis was placed on the voluntary nature of the participants' involvement in the study. The data was stored in accordance with the General Data Protection Regulation (EU Regulation - GDPR). To maintain confidentiality and to protect participants' personal data, the recorded data was de-identified by code and stored on a password-protected computer, and only the authors had access to this material.

Results

On the basis of the analysis of the focus groups, four fundamental categories were defined for older people's needs in home health care as perceived and described by the nurses providing care for these people. These categories are: Information, Nurses' Professionalism, Habits and Routines, and Social Contact. This chapter is structured according to the individual categories, and each category is discussed from the nurses' perspective. The nurses' responses are quoted verbatim in order to retain their authenticity.

Information

Home health care information

Nurses described a need for sufficient information on the provision of health care as one of the fundamental needs for it to be at all possible to provide home care for patients, and for the subsequent provision of home care to proceed as smoothly as possible. When providing health care, nurses often find that their patients have insufficient information on care options and on care itself. Nurses described patients' surprise at the existence of a home health care service and the fact that they were entitled to it.

"Mostly they come back from hospital and I go there for the first time and they tell me they didn't know this kind of service even existed…". (FG, 3)

"But I think an awful lot of people don't know about it. These people really don't know that they're entitled to something like this. They feel they're just being a nuisance. And mostly it's older people who feel this way. I can just hear my grandmother: I don't want to put anyone to any trouble." (FG, 2)

Competencies

When home health care begins, in the nurses' view it is important that patients are informed of the options for home care in the sense of defining the nurses' remit, i.e. familiarising patients with what they are entitled to under home care and when this crosses over into care that is not within the nurses' remit. It is not unusual for patients to initially ask nurses to help them for instance with social support services, which is outside the nurses' remit.

"But you need to set out these rules straight away, on your first or second visit – this is okay, that's okay, but that isn't… They need to be clearly defined right from the start." (FG, 2)

Some patients do initially (and subsequently) ask their nurses for assistance with matters that lie outside health care; the nurses feel a sense of responsibility towards their patients, and they try to satisfy them. This kind of assistance might involve obtaining any medicines or incontinence aids required, providing advice and assistance concerning social security, and also ensuring that the environment the patients live in is suitable.

"...Imagine you go to see someone who's on their own, and they're hungry, and you've gone there to take their blood. And it's cold, and they're shivering under a duvet – well, am I just going to take their blood and then go away again? I wouldn't, would I? So I don't know, I don't do that. I go and get some coal to get the room warm." (FG, 1)

Care provision

The other area where nurses see a need for information concerns the care itself: how it has been defined, how it will be provided, and any changes in care, including any switches from the nurse the patients are used to and any changes in the agreed schedule for visits. According to the nurses, this information is crucial for patients, as they have noticed that insufficient information leaves patients uncertain and afraid.

"...they release them from hospital when they're relatively healthy. And they tell them a nurse will be coming to see them. They don't explain anything to them, so they're waiting to see what that might be... they don't know what's going to happen" (FG, 2)

"...the first thing we explain to them is how we'll be working with them..." (FG, 1)

Nurses' Professionalism

Education and experiences

Nurses described how when providing home health care they worked entirely independently, using their knowledge, skills and experience. The nurses' responses revealed that they often had to answers patients' questions about their health, and the procedures for providing subsequent care. It is not unusual for nurses to "stand in" for doctors.

"They also ask about relatively complicated things, and basically they treat it as though they were talking to a doctor." (FG, 3)

The nurses also said they had to respond quickly to any changes in their patients' health status, without hesitating, and had to be able to provide immediate medical assistance.

"When the time comes we have to know how to act like a professional should, right? Not start trembling and saying oh god, I don't know about this, I don't know how to do this, I don't know what to do." (FG, 3)

Nurse personality

When providing care, it is not just the nurses' training and experience that is important for patients. In the nurses' view, patients are also appreciative if care is provided by a kind, smiling and sympathetic nurse. Patients trust nurses who have these qualities, and they are much more satisfied with the care such nurses provide. For the patients the nurse becomes the central point of care, someone they can always rely on, someone who can support and help them.

"I'm just waiting for you (the nurse) *to tell me what's going to happen."* (a participant quoting her patient, FG, 1)

Habits and Routines

Continuity of care

Providing health care in the patient's home environment interrupts the established daily activities that fill their days. Although providing care in the home environment might initially disrupt patients' habits and routines, after a while it becomes part of their lives, and patients include it among their daily routines. Similarly the nurses also become part of their patients' lives, and patients establish a certain kind of relationship with their nurses. From the nurses' perspective it is very important to stick to the agreed schedule for visits so that patients can maintain their routines. From the nurses' perspective it is also very important for patients that their care is provided by the nurse they are used to. Any change in the provision of care itself, or changes in the agreed schedule for visits, or any change from the nurse they are used to, will disrupt patients' routines and habits. In this context nurses are aware that some of their patients respond very badly to any kind of change, viewing it with fear and uncertainty.

"Older people can't stand changes… they just don't like change. So if someone has to go instead of us, they'll ask when their nurse will be coming back again." (FG, 1)

"They ask us to fix things so that it's only us who'll be visiting them." (FG, 2)

"They're terrified of it (any change of nurse). *They're just afraid of it, aren't they?"* (FG, 1)

Home environment

Nurses consider it very important for patients to have the option of remaining in their home environment while they are sick or have reduced self-sufficiency, and they describe this as one of their patients' needs. From the nurses' responses it emerged that they see the benefits of this option not just in that patients have an opportunity to plan their days in line with their habits, needs and wishes, but also to remain in an environment they know intimately and where they keep their personal possessions.

"They can get up when they want, eat what they want, visit who they want. Chat with this or that neighbour… Mostly they've all got some kind of pet… And even if they can't cope (due to disability)*, they like being at home."* (FG, 3)

Social Contact

Verbal and physical contact

In their answers the nurses described how when providing health care in patients' home environment they found that patients were enthusiastic about home care, and the majority of patients welcomed it, seeing it as positive and beneficial. The nurses thought that one reason for patients' positive response was the opportunity for social contact, which according to the nurses the patients very much lack, sometimes even though they are living with their families. For patients in home care, the nurse's presence is an opportunity to talk about their experiences and their joys and sorrows. Often patients need not just verbal contact with the nurse, but also physical contact.

"Some of them need a hug, they miss that. They don't have anyone who would put their arm around them, praise them for something, tell them they're doing well." (FG, 3)

Some patients expect nurses to serve as information channels, telling them about whatever might be happening outside.

"They want to know everything. The weather, if there are people outside, what it looks like outside. If their families don't take them out, they're stuck at home…" (FG, 2)

Relationship with professionals

It often takes a while for a relationship to develop between the patient and the nurse, for them to get to know one another. A positive relationship between the patient and the nurse is beneficial for both sides and makes care easier, as over time patients come to trust their nurses and find it easier to confide in them about their joys and their worries, and about their medical problems too.

"Initially they're (the patients) *very reserved, when you go there for the first time and the second time and the third time. And then in the end they welcome you, they're glad you've come and they can talk to you."* (FG, 1)

"... it's a kind of intimate relationship." (FG, 1)

When building a relationship, some patients eventually start to see their nurses as part of the family. In some cases patients will begin addressing nurses by their first names (which in Czech society might seem overly familiar), which the nurses generally view as something that automatically happens when their patients trust them.

"... they call us by our first names... then we know they trust us. So that's great really." (FG, 3)

Discussion

The objective of this study was to ascertain the needs of patients in home health care from the nurses' perspective. During the analysis it emerged that patients' needs and how nurses identify them overlap to some extent. Despite this fact, the analysis revealed four categories related to the objective of this study - Information, Nurses' Professionalism, Habits and Routines, and Social Contact.

A need for information proved to be absolutely fundamental. Insufficient information generally makes people afraid and mistrustful, and it is not unusual for it to catalyse adverse situations (Han *et al*., 2011). Romagnoli et al. (2013) point out that home care nurses often find that patients have received insufficient information on options for treatment and care, and nurses consider adequate information to be quite a crucial precondition for the provision of effective care. Our analysis revealed two key aspects concerning information. The first is a lack of awareness concerning health care in patients' home environment. Insufficient awareness of such care may to some extent be due not just to patients being insufficiently informed, but also to the doctors who have the power to prescribe home health care.[17]

The second shortcoming concerns a proper understanding of the services providing home health care. For patients in home health care, it is understandable that we might find

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[17] In the Czech Republic the prescribing and implementation of home health care is governed by an act of parliament and the related implementing decree. Home health care can only be prescribed by the patient's general practitioner or the consultant treating a patient who has been hospitalised.

overlapping health and social needs. This then places demands on home health care nurses in two respects: 1) knowing how to communicate with the patient and explain the options available under home health care, including the nurses' remit, and 2) awareness of an appropriate alternative solution, i.e. in practice recommending a (social) service that can address the client's request.

Communication skills, a familiarity with medical and social matters, and the provision of professional health care all make high demands on nurses' training and previous experience of providing care, and they also emphasise the nurse's personality. Nurses consider these attributes to be a sign of their professionalism (MacIntosh, 2003; Tanaka *et al.*, 2016; Kim & Sim, 2020) and see them as being important and necessary aspects of providing care for patients, which was also what emerged from our analysis. This is in agreement with other authors (Breitholtz *et al.*, 2013a; Moe *et al.*, 2013; Randström *et al.*, 2013; Bagchus *et al.*, 2015), who report that patients perceive care provided by a trained and experienced nurse to be professional and quality care.

In view of dynamic developments in medicine and knowledge in the field of nursing care, there is a requirement for professional training and especially continuing training for nurses (Institute of Medicine, 2010; Price & Reichert, 2017). For nurses providing home health care, this requirement is all the more urgent because they work quite independently, without the supervision and assistance of a doctor, as would be the case in hospital care for instance (Duke & Street, 2005; Williamson, 2007).

Nurses' training should also cover communication, as it is an integral and very essential component of providing health care (Chant *et al.*, 2002; Baghcheghi *et al.*, 2011). Together with empathy, it is an important characteristic in nurses that facilitates establishing a relationship between nurse and patient, and thereby also facilitates the provision of care (Tutton, 2005).

Another area the nurses in our research project identified among their patients' needs included maintaining habits and routines. Habits and routines take shape over the years and reflect a person's individuality and life (Lally *et al.*, 2010; Gardner *et al.*, 2012; Neal *et al.*, 2012). It is not unusual for the scheduling of the day and daily activities to be based on established habits and routines. It is especially important for older people to maintain their habits and routines, as they are less adaptable (From *et al.*, 2009; Liveng, 2011; Nicholson *et al.*, 2013). In our research a need for the continuity of care was particularly resonant in this respect: care would be provided at a pre-arranged time, and by the usual nurse. The results of some studies show that patients see the provision of care in their home environment as a violation of their autonomy (Breitholtz *et al.*, 2013b; Moe, Hellzen & Enmarker, 2013; Nicholson *et al.*, 2013; Jarling *et al.*, 2018), and for this reason they consider it essential for the scheduling of care to be discussed with them in advance and then adhered to, and they prefer it to be adjusted in fit in with their planned activities (From *et al.*, 2009; Randström *et al.*, 2013). Patients also consider it beneficial if care is provided by the nurse they are used to. It is not just that over time patients can establish a relationship with their nurses based on trust (McGarry, 2010; Moe *et al.*, 2013; Jarling *et al.*, 2018), but they also understand that the same nurse will be more familiar with their health status and can better and more swiftly respond to any changes in their health (From *et al.*, 2009; Jarling *et al.*, 2018).

Establishing a relationship with the patient, and thereby reinforcing social contact, was another theme that emerged when analysing our research. People of advanced age, especially those living with sickness or reduced self-sufficiency, often suffer from loneliness and social isolation, even when they are living with their families (Eloranta *et al.*, 2010; Županić *et al.*, 2013). Loneliness and social isolation negatively impact a person's mental health and are associated with the development of a depressive syndrome, particularly for patients of higher age (Barg *et al.*, 2006). A desire for social contact and inclusion in social life tends to be one of the wishes of older people in home health care (Eloranta *et al.*, 2010; Liobet *et al.*, 2011). A relationship between the patient and the nurse not only offsets the patient's feelings of loneliness, but (as was said above) developing a relationship also builds the patient's trust in the nurse (McGarry, 2010; Moe *et al.*, 2013; Jarling *et al.*, 2018). Leslie and Lonneman (2016) report that trust is one of the key aspects of providing health care, and care based on mutual trust has a positive impact on improving a person's health status.

When comparing the results of the present study with the results of studies of how patients perceive their needs in home care (Dostálová *et al.*, 2020), we see that the nurses did not always identify all of the needs that the patients raised and vice-versa. For instance the nurses identified a need to maintain habits and routines, which could be brought under the concept of autonomy, but with regard to autonomy the nurses failed to mention any need for privacy, independence, decision-making and cooperation, which was something the patients stressed. On the other hand the nurses in the present study identified a need for information, which the patients did not consider important. The results of this study are also in partial agreement with the results of studies focusing on patients' needs as viewed by nurses, although these studies did not focus directly on the needs of people in home health care (Romagnoli *et al.*, 2013; Hynninen *et al.*, 2015; Östman *et al.*, 2020).

On the basis of the above, it seems that when planning care for patients in their home environment, care must be planned with consideration for patients' needs, wishes and habits in order to maintain their autonomy and integrity and the opportunity of participating in decision-making and care, i.e. care must be planned and provided as person-centred care.

Limitations of the study

One limitation of this study was the relatively small participant sample as a consequence of the restrictive measures introduced owing to the coronavirus pandemic, which meant that no further focus groups could be held. The original plan was to hold focus groups in four regions of the Czech Republic so that any differences in how nurses perceived patients' needs could be evaluated nationwide. Even so, the results of the study demonstrate that nurses are able to perceive and describe the needs of older patients in home care, especially vulnerable patients of advanced age.

The risk of subjectivity in data interpretation, which may be due to researcher assumptions, should be considered (Holly *et al.*, 2014). The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to record important aspects of this study (Tong *et al*., 2007). Emphasis was also placed on the credibility of this study *(Graneheim et al.*, 2017), which was supported by an attempt to describe the methods in detail so that their strengths and weaknesses were understood.

Conclusion

The provision of home health care for particularly vulnerable patients of advanced age is a contemporary trend and an opportunity for patients to remain in their own environment while in a condition of sickness or reduced self-sufficiency. Although care provided in this way may encroach on patients' privacy, it is something they themselves desire and appreciate. Assessing patients' needs and taking them into account when planning care is one of the essential preconditions for providing professional and quality care. This study shows that nurses providing care for patients in their home environment are able to identify their patients' needs. Nevertheless, the needs they identify partly diverge from the patients' needs. This particularly concerns patients' need to be involved in care and in decision-making on the provision of care. On the other hand, in the nurses' view patients need adequate information on options for care and treatment. This should be borne in mind by nurses and by other professionals who recommend or offer patients home health care, and especially professionals involved in transferring a patient from the hospital setting to the home setting. For a better understanding of the issue of patients' needs and how they are perceived by nurses, more qualitative comparative research should be conducted, both research based on individual interviews or focus groups, and research based on observation during the provision of care.

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Authors' contributions

IH and VD planned the methodology and the design of this study. VD, AB, HB and IH prepared the interview guide. VD and AB conducted the interviews and analysed and interpreted the data with IH's supervision. All authors discussed interview transcripts and analysis during each stage. VD drafted the manuscript under the IH's supervision. AB, HB and IH contributed with complementing perspectives in the interpretations and suggested improvements to the text. All authors read and approved the final manuscript.

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Conflict of interest

None

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Table 1 Example process of analysis

Unit of analysis	**Code**	**Subcategory**	**Category**
…and then when we replace each other, right, so they're (patients) used to us only going for a certain approximate time when we go there, and then if you have somebody extra, you come longer, it's a little bit of a problem with somebody…	Change in care provision	Continuity of care	Habits and Routines
...they need some sort of regimen (patients) and they terribly dislike changing it...some are adaptable without problems and some cling to it (same nurse, agreed visit times) so it's just person to person...	Stereotype	Continuity of care	Habits and Routines
…they release them from hospital when they’re relatively healthy. And they tell them a nurse will be coming to see them. They don’t explain anything to them, so they’re waiting to see what that might be… they don’t know what’s going to happen…	Insufficient information	Care provision	Information
... it's important to inform those patients and tell them what's important, what's less important. I think that's terribly important to them. Some don't cooperate at all, at all, right, so it's the other way around. Again, you're forcing them into something they don't want to do because they've never encountered it	Awareness, care information	Home health care information	Information

(home health care). And they don't even know..

Table 2 Categories and subcategories

Categories	Subcategories
Information	Home health care information Competencies Health provision
Nurses’ Professionalism	Education and experiences Nurse personality
Habits and Routines	Continuity of care Home environment
Social Contact	Verbal and physical contact Relationship with professionals

6 Discussion

Both the analysis of published international studies and our own research conducted in different care settings in the Czech Republic confirm that patients are able to express their wishes and needs related to the professional care they receive. We have also proven that nurses' perspectives on the needs of patients in home health care also well capture the needs and wishes of the patients to whom they provide home health care.

A comparison of the three studies presented showed both the same and different perspectives on the needs of patients in home care from their own and nurses' perspectives. It is quite clear that the defined needs of the two groups of research participants overlap with each other, which is only natural as a result, as these are needs that form part of patients' lives and one need complements or builds on the other. Our summary will focus on comparing all the needs defined by the research participants so that adequate recommendations for practice can then be made on the basis of these needs. We have divided the defined needs into four main areas: 1) Safe and secure care; 2) Autonomy; 3) Habits and routines; and 4) Role in society, with each area being specified. We translate the results of our comparison in the following Table 1, in which we also indicate which areas were defined by the participants in the research presented.

Table 1 Comparison of needs in the research carried out

Areas of needs		Scoping review	Individual interviews	Focus groups
Safe and secure care	Education and experiences	x	x	x
	Information	x	x	x
	Continuity of care	x	x	x
Autonomy	Privacy and freedom	x		
	Independence	x	x	
	Decision-making/cooperation	x	x	
Habits and routines	Daily activities	x	x	
	Own environment	x		x
Role in society	Relationship with nurses	x	x	x
	Personality of nurse	x	x	x
	Verbal and physical contact			x

Safe and secure care

It is evident that when providing health care in the patients' home environment, it is desirable that this care is provided in the highest possible quality. As our comparison shows, not only patients but also nurses are aware of this fact. Patients can be very perceptive about the care they receive, and it is evident that they observe nurses during care and are sensitive not only to their behaviour but also to the actions they perform. The provision of adequate and sufficient information by nurses is an integral part and a sign of quality and safe care. Inadequate or no information to patients and the assumption by nurses that the patient "is informed and therefore knows...everything" can result in unnecessary conflict situations that are in no way desirable in the provision of any health care. The need to maintain continuity of care (both personnel and time), as one of the features of providing quality and safe care, was described by all research participants. The advantage of maintaining personnel continuity is the possibility of establishing a relationship between the patient and the nurse, which by its nature belongs more to the "Role in society" area - thus there is an overlap of defined needs. As in the case of personnel continuity, there is an overlap of needs in the need to maintain temporal continuity, and this need also affects the area of 'Habits and routines' as patients plan their daily activities with regard to the pre-arranged dates of healthcare.

Autonomy

Autonomy, as another area of defined need, was emphasized by patients, not nurses. Autonomy, in the sense of privacy and freedom, was defined only by the patients whose statements were analysed through scoping review. Patients who were participants in our own research did not discuss the need for privacy and freedom in their statements, which does not mean that privacy is neglected and not emphasized by patients in the provision of care. On the contrary, the results of our own research conducted with patients were in complete agreement with the analysis of published international studies, in the area of independence and participation in care. The nurses did not pay any attention to the topic of autonomy during the focus groups and for this reason this need could not be identified. However, this certainly does not suggest that nurses are unable or unwilling to accept this need. We would not dare to draw such a conclusion. However, we believe that nurses need to be mindful of this fact and take it into account when planning and delivering care.

Habits and routines

As well as the needs for autonomy, there was no overwhelming agreement among the research participants in the area of habits and stereotypes. However, all research participants emphasised the need to maintain habits and stereotypes. From the patients' point of view, it is essential that they are allowed to carry out daily activities as they are used to, which is related to the previously stated need to respect the temporal continuity of care. Being able to remain in one's own environment in a state of illness or reduced self-sufficiency is considered important by both patients and nurses. However, the patients with whom we conducted individual interviews did not refer to this need in their statements. As in the above cases, it is not possible to generalise this fact and it can be assumed that if patients are generally satisfied with the provision of home healthcare and consider it desirable, they also value the possibility of remaining in their own environment.

Role in the society

Maintaining a role in the society and participation in the social life were highlighted as a need by all participants in our research. Particular emphasis was then placed, also by all participants, on the need for and the establishment of a reciprocal relationship between the nurse and patients, which, in addition to the social role, has the effect of building trust between patient and nurse, which in turn facilitates not only the provision of health care but also its acceptance by patients. The need for not only verbal but also physical contact described by nurses may be evidence of nurses' ability to perceive patients' needs in this area. As in the previous cases, it cannot be declared responsibly that patients, despite not directly discussing the need for physical contact, are not happy for such contact. However, each person's individual setting will certainly play a role in this case.

In the following, last section of this chapter, we will focus on the key messages and recommendations arising from the research presented, assuming that our recommendations can form a good basis for planning and subsequent quality home health care delivery.

7 Key information for practice

The quality of the care provided is a reflection of the skills and experience of those who provide and deliver the care, with qualified and properly trained staff being one of the fundamental prerequisites for ensuring quality patient care (Holmerová, 2018). With this in mind, and in light of the dynamic development of medicine and knowledge in nursing care, there is a demand for professional education and especially continuing education for nurses (Price and Reichert, 2017). In the case of nurses providing care in the patients' own environment, this requirement is then even more urgent, as they work completely independently without the presence of a doctor and other staff as is usual in outpatient or inpatient care. Thus, the work of nurses in the patient's own environment involves their independent decision making, which is dependent on both their educational background and experience (Duke and Street, 2005; Williamson, 2007). Moreover, care provided by educated and experienced staff is considered by patients to be professional care (Bagchus, Dedding and Bunders, 2015), which is consistent with the definition of 'professional', where being professional means having the characteristics of skilled and trained people (Cambridge Dictionary, 2020).

Nurses' education and experience are related to their ability to provide patients with adequate information regarding the care they receive. Nurses often encounter ill-informed patients during patient care in their own settings, and at the same time, sufficient information is considered by nurses to be quite essential for the provision of effective care (Romagnoli *et al.*, 2013). It should be emphasized that a lack of information generally instils fear and mistrust in people and not infrequently can be an accelerator of unpleasant and undesirable situations (Han, Klein and Arora, 2011).

One of the basic indicators of the quality of care provided is the active involvement of patients in the planning and subsequent provision of care. Active patient participation in both respects not only leads to better quality care delivery, but also leads to better health outcomes and thus improved quality of life for patients. Patient involvement in care planning and delivery (decision-making) is seen by patients as a recognition of the patient's humanity and individuality (Vahdat *et al.*, 2014). Patients who are allowed to participate in the delivery of care feel a greater sense of control over the care provided in terms of being able to influence care with respect to their wants and needs (Breitholtz, Snellman and Fagerberg, 2013). Patients should therefore be treated with respect and as competent beings who are capable of making decisions for themselves (Liveng, 2011), which can be achieved by actively involving patients in discussions regarding their care (McCabe, 2004). From the above, it is evident that communication with patients not only about care is an integral part of the care provided and nurses' communication skills and abilities, in addition to education and experience, are also an indicator of the quality of care provided and a manifestation of nurses' professionalism (Kim and Sim, 2020).

Nurses' communication skills and abilities are influenced by both the nurse's personality and her approach to the patient. In this case, the ability of empathy plays an important role, which is considered as one of the essential personality traits of nurses that plays an important role in gaining patients' trust and building relationships between patients and nurses (Wan *et al.*, 2019). Empathy, the ability to understand other people's feelings, not only facilitates communication between patient and nurse, but also helps to prevent conflicts that may arise during care (Duan and Hill, 1996). A positive patient-nurse relationship has been shown to increase both the patient's physical health and also promote emotional, mental and social well-being (Strandås and Bondas, 2018).

Establishing a mutual relationship between patient and nurse that is based on understanding and trust requires a certain amount of time, the length of which depends on the individuality of the patient as well as the nurses' communication skills and level of empathy (Jarling *et al.*, 2018). The reciprocal relationship between patient and nurse alleviates patients' feelings of social isolation and loneliness, with loneliness and social isolation being associated with the development of depressive syndrome, particularly in older patients (Barg *et al.*, 2006). It should be remembered that older people, and especially those living with illness or reduced self-sufficiency, often suffer from loneliness or social isolation, despite some of them living with loved ones (Eloranta *et al.*, 2010). The desire for social contact and inclusion is often not one of the wishes of older people in home health care (Liobet *et al.*, 2011).

The maintenance of habits and stereotypes is an area that is also an integral part of the care provided in the patients' own environment and the degree to which it is fulfilled determines the patients' perception of the quality of care provided. As habits and stereotypes are formed over years and reflect the individuality of the individual (Gardner, Lally and Wardle, 2012), they form the basis of patients' daily activities that make up their daily routines. It should be remembered that, particularly for older people, who tend to have a reduced capacity to adapt, it is the maintenance of habits and stereotypes that is important (Nicholson *et al.*, 2013). Closely related to the maintenance of habits and routines is the personnel and temporal continuity of the care provided. The provision of care in patients' own environment, which supports their identity and autonomy (Wahl *et al.*, 2006), is perceived by patients as a violation of their autonomy (Jarling *et al.*, 2018), and it is therefore desirable that the time of care provided is discussed with them well in advance and subsequently adhered to, with patients preferring that the time of care provided is adapted to their programmed activities (Randström *et al.*, 2013). Likewise, the provision of care by a nurse to whom patients are accustomed is considered beneficial by patients, not only because of the opportunity to develop a trusting relationship with the nurse, as already mentioned, but also because of personal continuity, whereby patients are aware that the nurse who regularly provides their care is, or should be, sufficiently familiar with their health status to be able to react more quickly and easily to any changes related to their health (From, Johansson and Athlin, 2009; Jarling *et al.*, 2018).

Based on the above, it can be concluded that when planning care for patients in their own environment, it is necessary to plan care taking into account the needs, wishes and habits of patients in order to preserve their autonomy, integrity, decision-making and participation in care, i.e. in effect planning and delivering person-centred care (Institute of Medicine, 2001).

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8 Implications

What the results of our research highlight:

- Our research has helped to shed light on the perceived needs of patients in home health care in the Czech Republic, both from the perspective of patients themselves and from the perspective of nurses.
- Patient needs identified by patients themselves are not always in line with those identified by nurses.
- Patients lack sufficient information on the principles and possibilities of home healthcare provision, which in turn complicates the provision of home care itself, especially in its initiation.
- Home health care nurses' training and experience are essential not only for the provision of professional nursing care, but also for the provision of professional information and advice to patients. Care provided by trained and experienced nurses is perceived by patients as quality care.
- Continuity of care in the sense of personnel continuity and regular care provision is important for the provision of quality care.
- The personality of nurses and their communication skills and abilities, as well as empathy, are essential in building the relationship between patient and nurse.

What are the implications of our findings for the work of nurses caring for patients in their home environment:

- Patients should be informed in advance about the principles and possibilities of home care by their GPs or other treating physicians who recommend or prescribe home care.
- Patients should be made aware of the principles of home care by nurses before the actual provision of home care begins. Patients need to be adequately informed about the competences of the nurses providing home care.
- The provision of home health care is inherently highly specific; home care nurses should work to provide the highest possible quality of care. In particular, nurses should focus on ensuring that the care they provide is safe, effective, timely, efficient and person-centred.

- The way in which home care will be provided should be communicated and agreed with patients in advance, including the timing of visits which must then be adhered to. Patients should be informed well in advance if the appointment date changes.
- When planning home health care, it is advisable to include patients in care planning and to allow them to participate in care and to plan care with their needs in mind. Nurses should therefore actively find out what patients' wishes and needs are.

How our results should practically influence strategies and approaches to care delivery, including in the field of education:

- Undergraduate, postgraduate and lifelong nurse education should be oriented towards a holistic approach to the patient and person-centred care.
- Undergraduate, postgraduate, and lifelong nurse education should also include personality training with a focus on communication skills.
- Home health care organizations should:
    - educate nurses not only in technical skills but also in person-centred care so that patient autonomy is maintained in care planning and subsequent delivery, particularly in the areas of privacy, independence, participation in care and decision-making,
    - have a system for assessing patients' needs, or have a battery of valid and easy-to-use tools suitable for assessing patients' needs,
    - ensure that care is planned with patients' needs in mind and that patients are partners in the planning and delivery of care,
    - continuously evaluate the care plan and update the care plan in a timely manner, taking into account the patient's health status and needs.

Conclusion

The present dissertation, which focuses on the needs of particularly vulnerable older people in home health care, was written as part of the doctoral study of Longevity at the Faculty of Humanities, Charles University. In its conception, it is a thesis that is mainly composed of articles published in peer-reviewed journals that represent the results of research conducted during the doctoral studies. The research first involved an analysis of documents. The aim was to shed light on the evolution of long-term care in our country between 2000 and 2016. In the next phase, research was conducted to find out, through the analysis of available scientific articles, what is known so far about the needs of older people in home care. In the case of this research, only foreign sources were used for the analysis. At this stage, the research confirmed our fearful assumption that in our country the needs of particularly vulnerable older people in home health care have not yet been sufficiently researched or the research results have not been published in foreign impact journals. This analysis provided insight into the needs of older people from their own perspective and provided a sound basis for our own research. The next two studies aimed first to elucidate the needs and experiences of vulnerable and frail people aged over 65 in home health care, with whom individual semi-structured interviews were conducted. Given that professionals caring for people in their own settings should base their care planning and delivery on their needs and take these needs into account when providing care, research was undertaken that aimed to explore the needs of particularly vulnerable older people in home healthcare from the perspective of general nurses. A focus group technique was used to establish the general nurses' perspective on the needs of the patients they care for in their own setting. A summary of the research findings and recommendations for practice is given in the final section of this thesis. The text of the thesis is supplemented by chapters designed to introduce the reader to the issue of human needs and to the issue of long-term care in our country, which undoubtedly includes home care. The legislative anchorage of home care, both medical and social, is not omitted in this part.

Appendices

Appendix A – Research materials

Appendix A1. Consent form – Individual interviews

Souhlas s využitím získaných informací z individuálního rozhovoru

Nositel projektu: Univerzita Karlova, Fakulta humanitních studií, Studia dlouhověkosti, U Kříže 8, Praha 5, 158 00

Název projektu: Uspokojené a neuspokojené potřeby zvláště zranitelných (vulnerabilních) pacientů vyššího věku v domácí a lůžkové péči

Trvání projektu: 2019–2021

Cíl sběru dat: cílem sběru dat je získat informace o vlastním vnímání potřeb pacientů vyššího věku v domácí zdravotní péči a v akutní lůžkové péči včetně pohledu na tyto potřeby ze strany profesionálních pečujících, zejména všeobecných sester.

Archivace a zpřístupnění dat: Neanonymizované informace z rozhovorů jsou přístupné pouze řešitelům projektu.

Anonymizované informace z rozhovorů budou archivovány pro účely dalších analýz. Anonymizace znamená odstranění osobních údajů, aby nebyla umožněna identifikace konkrétních osob a organizací. Data budou archivována na Fakultě humanitních studií, v oddělení doktorských studií (Studia dlouhověkosti) a budou přístupná řešitelům projektu Mgr. Alžbětě Bártové, Mgr. Haně Bláhové, Mgr. Vladimíře Dostálové a doc. MUDr. Ivě Holmerové, Ph.D. Data nebudou nikde zveřejněna, budou zpracovávána jako anonymizovaná a budou dodrženy zásady etického přístupu, ochrany osobnosti i práv všech dotčených osob.

Informovaný souhlas

Dne ________________ jsem poskytl/a výzkumný rozhovor v rámci projektu „Uspokojené a neuspokojené potřeby zvláště zranitelných (vulnerabilních) pacientů vyššího věku v domácí a lůžkové péči“. Na analýze dat zjištěných z rozhovorů se podílejí řešitelé projektu: Mgr. Alžběta Bártová, Mgr. Hana Bláhová, Mgr. Vladimíra Dostálová a doc. MUDr. Iva Holmerová, Ph.D.

Souhlasím se zpracováním, archivací a další analýzou rozhovoru, který jsem poskytl za těchto podmínek:

- záznam rozhovoru bude uchován jen v anonymizované podobě bez souvislosti s mým jménem a kontaktem na moji osobu, a bez uvedení adresy mého bydliště, pouze s uvedením kraje, ve kterém žiji.

V případě, že úryvky z tohoto rozhovoru budou součástí publikací nebo veřejných prezentací výsledků výzkumu:

- smí být uvedeny jen v anonymizované podobě bez mého jména a souvislosti s mojí osobou.

Po skončení projektu Uspokojené a neuspokojené potřeby zvláště zranitelných (vulnerabilních) pacientů vyššího věku v domácí a lůžkové péči, smí být anonymizovaný rozhovor:

☐ zpracováván jen výzkumníky jmenovanými v tomto souhlasu pouze pro účel tohoto projektu.

Jméno respondenta:

Podpis respondenta:

Jméno výzkumníka:

Podpis výzkumníka:

Appendix A2. Consent form – Focus Groups

Souhlas s využitím získaných informací ze skupinového rozhovoru

Nositel projektu: Univerzita Karlova, Fakulta humanitních studií, Studia dlouhověkosti, U Kříže 8, Praha 5, 158 00

Název projektu: Uspokojené a neuspokojené potřeby zvláště zranitelných (vulnerabilních) pacientů vyššího věku v domácí a lůžkové péči

Trvání projektu: 2019–2021

Cíl sběru dat: cílem sběru dat je získat informace o vlastním vnímání potřeb pacientů vyššího věku v domácí zdravotní péči a v akutní lůžkové péči včetně pohledu na tyto potřeby ze strany profesionálních pečujících, zejména všeobecných sester.

Archivace a zpřístupnění dat: Neanonymizované informace z rozhovorů jsou přístupné pouze řešitelům projektu.

Anonymizované informace z rozhovorů budou archivovány pro účely dalších analýz. Anonymizace znamená odstranění osobních údajů, aby nebyla umožněna identifikace konkrétních osob a organizací. Data budou archivována na Fakultě humanitních studií, v oddělení doktorských studií (Studia dlouhověkosti) a budou přístupná řešitelům projektu Mgr. Alžbětě Bártové, Mgr. Haně Bláhové, Mgr. Vladimíře Dostálové a doc. MUDr. Ivě Holmerové, Ph.D. Data nebudou nikde zveřejněna, budou zpracovávána jako anonymizovaná a budou dodrženy zásady etického přístupu, ochrany osobnosti i práv všech dotčených osob.

Informovaný souhlas

Dne ________________ jsem poskytl/a výzkumný rozhovor v rámci projektu „Uspokojené a neuspokojené potřeby zvláště zranitelných (vulnerabilních) pacientů vyššího věku v domácí a lůžkové péči“. Na analýze dat zjištěných z rozhovorů se podílejí řešitelé projektu: Mgr. Alžběta Bártová, Mgr. Hana Bláhová, Mgr. Vladimíra Dostálová a doc. MUDr. Iva Holmerová, Ph.D.

Souhlasím se zpracováním, archivací a další analýzou rozhovoru, který jsem poskytl za těchto podmínek:

- záznam rozhovoru bude uchován jen v anonymizované podobě bez souvislosti s mým jménem a kontaktem na moji osobu, a bez uvedení názvu organizace, ve které pracuji, pouze s uvedením jejího typu (například domácí péče; zařízení lůžkové péče) a kraje, ve kterém se organizace nachází.

V případě, že úryvky z tohoto rozhovoru budou součástí publikací nebo veřejných prezentací výsledků výzkumu:

- smí být uvedeny jen v anonymizované podobě bez mého jména a souvislosti s mojí osobou.

Po skončení projektu Uspokojené a neuspokojené potřeby zvláště zdranitelných (vulnerabilních) pacientů vyššího věku v domácí a lůžkové péči, smí být anonymizovaný rozhovor:

☐ zpracováván jen výzkumníky jmenovanými v tomto souhlasu pouze pro účel tohoto projektu.

Jméno respondenta:

Podpis respondenta:

Jméno výzkumníka:

Podpis výzkumníka:

Appendix A3. Ethical approval

Etická komise Gerontologického centra v Praze 8

se seznámila s návrhem výzkumného projektu

GAUK pod registračním číslem 760219

s názvem

„Uspokojené a neuspokojené potřeby zvláště vulnerabilních pacientů vyššího věku v domácí a lůžkové péči“

„Saturated and unsaturated needs of vulnerable older patients in the health care inhospital and home care“

Jedná se o projekt, zaměřený na vulnerabilní pacienti vyššího věku, jehož cílem je rozšířit poznání této problematiky. Budou provedeny review dostupné literatury a šetření potřeb zvláště vulnerabilních lidí vyššího věku ve zdravotní péči.

Projekt sestává z výsledků literárního šetření a z vlastního výzkumu s následným návrhem nástroje hodnocení potřeb zvláště vulnerabilních lidí vyššího věku ve zdravotní péči, doporučení dobré praxe a obsahu vzdělávacího programu pro zdravotnické pracovníky.

Etická komise byla informována o cíli této studie, o postupech a o tom, co se od zúčastněných osob očekává, studie jako taková má výzkumný - kvalitativní charakter. Bude vytvořen návrh nástroje (struktura dotazování či škála) pro šetření potřeb zvláště vulnerabilních pacientů ve vyšším věku.

Po prostudování návrhu a záměru výše uvedeného projekt, po seznámení se s jeho cíli a metodami komise konstatuje, že výše uvedený projekt neodporuje etickým normám, je zcela humánní, může zvýšit dlouhodobou udržitelnost a přispět tak ke zlepšení zdravotního stavu a kvality života vuknerabilních pacientů ve vyšším věku.

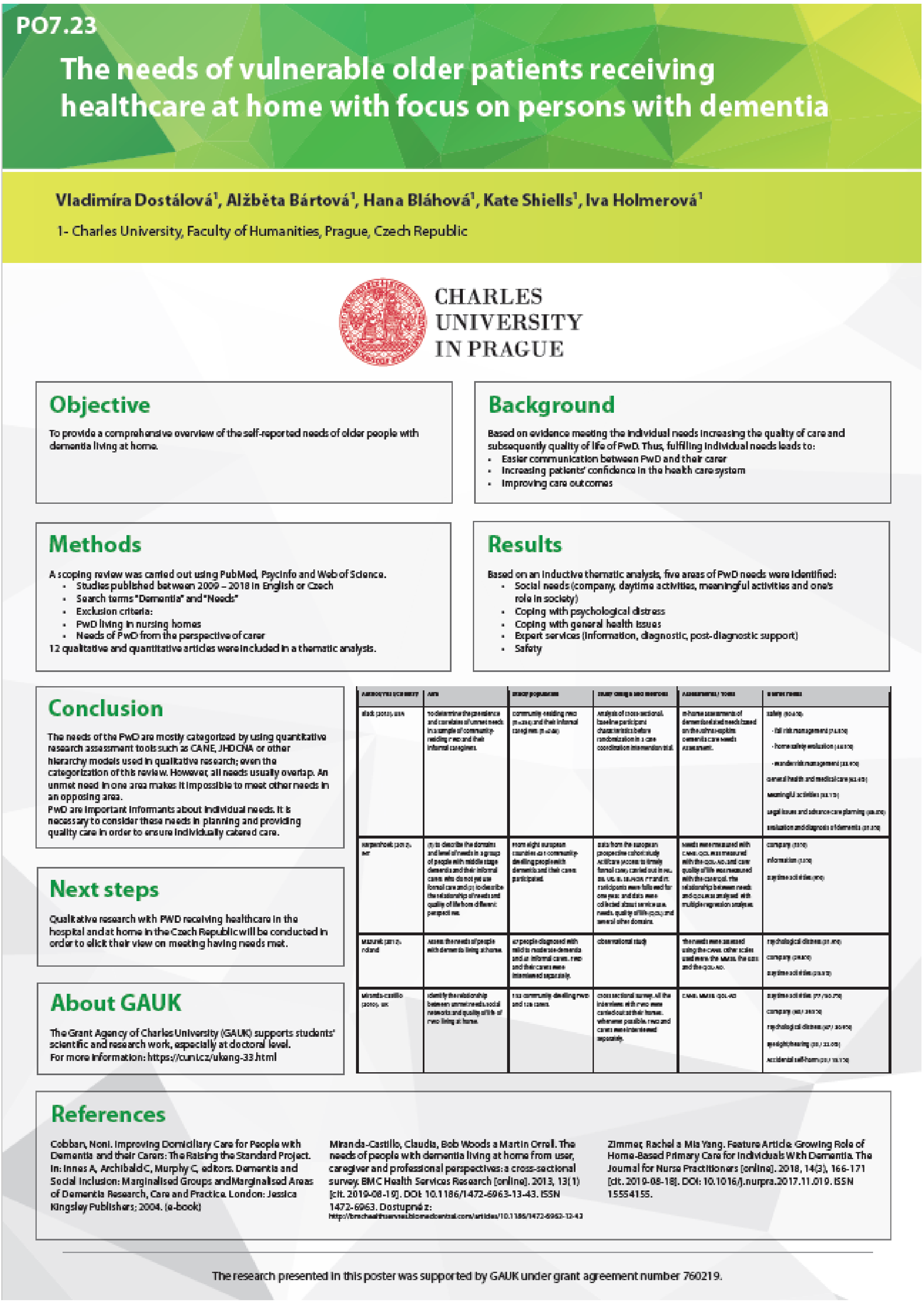
Proti výše uvedenému projektu etická komise nemá námitek.

PhDr. Eva Jarolímová, Ph.D.
předsedkyně etické komise
v Praze dne 2. 11. 2018

Gerontologické centrum
Šimůnkova 1600, Praha 8
ETICKÁ KOMISE

Appendix B – Presentations at conferences

Appendix B1. Poster delivered at Alzheimer Europe Conference 2019



PO7.23

The needs of vulnerable older patients receiving healthcare at home with focus on persons with dementia

Vladimíra Dostálová[1], **Alžběta Bártová**[1], **Hana Bláhová**[1], **Kate Shiells**[1], **Iva Holmerová**[1]

1- Charles University, Faculty of Humanities, Prague, Czech Republic

CHARLES
UNIVERSITY
IN PRAGUE

Objective

To provide a comprehensive overview of the self-reported needs of older people with dementia living at home.

Background

Based on evidence meeting the individual needs increasing the quality of care and subsequently quality of life of PwD. Thus, fulfiling individual needs leads to:

- Easier communication between PwD and their carer
- Increasing patients' confidence in the health care system
- Improving care outcomes

Methods

A scoping review was carried out using PubMed, PsycInfo and Web of Science.

- Studies published between 2009 – 2018 in English or Czech
- Search terms "Dementia" and "Needs"
- Exclusion criteria:
- PwD living in nursing homes
- Needs of PwD from the perspective of carer

12 qualitative and quantitative articles were included in a thematic analysis.

Results

Based on an inductive thematic analysis, five areas of PwD needs were identified:

- Social needs (company, daytime activities, meaningful activities and one's role in society)
- Coping with psychological distress
- Coping with general health issues
- Expert services (information, diagnostic, post-diagnostic support)
- Safety

Conclusion

The needs of the PwD are mostly categorized by using quantitative research assessment tools such as CANE, JHDCNA or other hierarchy models used in qualitative research; even the categorization of this review. However, all needs usually overlap. An unmet need in one area makes it impossible to meet other needs in an opposing area.

PwD are important informants about individual needs. It is necessary to consider these needs in planning and providing quality care in order to ensure individually catered care.

Next steps

Qualitative research with PWD receiving healthcare in the hospital and at home in the Czech Republic will be conducted in order to elicit their view on meeting having needs met.

About GAUK

The Grant Agency of Charles University (GAUK) supports students' scientific and research work, especially at doctoral level.
For more information: https://cuni.cz/ukeng-33.html

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Miranda-Castillo, Claudia, Bob Woods a Martin Orrell. The needs of people with dementia living at home from user, caregiver and professional perspectives: a cross-sectional survey. BMC Health Services Research [online]. 2013, 13(1) [cit. 2019-08-19]. DOI: 10.1186/1472-6963-13-43. ISSN 1472-6963. Dostupné z: http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-43

Zimmer, Rachel a Mia Yang. Feature Article: Growing Role of Home-Based Primary Care for Individuals With Dementia. The Journal for Nurse Practitioners [online]. 2018, 14(3), 166-171 [cit. 2019-08-18]. DOI: 10.1016/j.nurpra.2017.11.019. ISSN 15554155.

The research presented in this poster was supported by GAUK under grant agreement number 760219.

Appendix B2. Oral presentation at Krems Conference 2020

Perception of professional carers on quality of care of home dwelling people

Vladimira Dostalova[1],
Alzbeta Bartova[2], Hana Blahova[2] & Iva Holmerova[2]

[1] vladka.dostalova@seznam.cz, Charles University, Faculty of Humanities
[2] Charles University, Faculty of Humanities

Keywords: *dementia, home care, quality*

Background: The number of people with dementia and the demand for long-term care provided in person's home environment is increasing. The aim of such care is to enable the person to stay at home as long as possible and to prevent hospitalization or other institutional care. When providing care in the home environment it is necessary to focus on patient's needs and experiences. The aim of this presentation is to provide our findings on quality of care of home dwelling people from the perception of professional carers. This study was funded by the Grant Agency of Charles University, project n. 760219 (Met and unmet needs of vulnerable older patients receiving healthcare at home and in hospital).

Methodology: A total of 3 focus groups with home health care nurses and 9 face to face semi-structures interviews with social care workers were conducted. An exploratory-descriptive qualitative approach was chosen. During data collection, the researchers focused on the areas of "what" and "why". Data were analysed in the means of content analysis. To ensure the trustworthiness of this study, the recommendation of Graneheim, Lindgren and Lundman (2017) was followed.

Results: According to content analysis three main areas were identified. 1) Needs assessment method; 2) Settings for a care plane; 3) Communication with other carers

including professionals. The starting point for ensuring all three areas is 1) to targeted education of (not only) caring professionals and 2) following the principles of case management.

Discussion: Professional caregivers are aware of the need to provide patients in home care of the best possible quality. These caregivers consider as important to identify the needs of their patients and to tailor care to those needs. The key is therefore undoubtedly the setting of individualized and person-centred care. High-quality communication between caring professionals and mutual information sharing is essential.

DONAU UNIVERSITÄT KREMS

Second Krems Dementia Conference - Dealing with Dementia: prevention, timely
detection and awareness- Coordinated efforts between East and West
VIRTUAL16.-18. November 2020

Perception of professional carers
on quality of care of home
dwelling people

Vladimira Dostalova, Alzbeta Bartova, Hana Blahova
& Iva Holmerova

Appendix C – List of Co-author publications

Bártová, A., Holmerová, I., Dostálová, V., Bláhová, H., Šteffl, M. (2021) Self-Reported Needs of People with Dementia Living at Home: A Scoping Review. *Camberwell Assessment of Need for the Elderly: CANE, 2021.* Cambridge University Press. doi: 10.1017/97819111623373.

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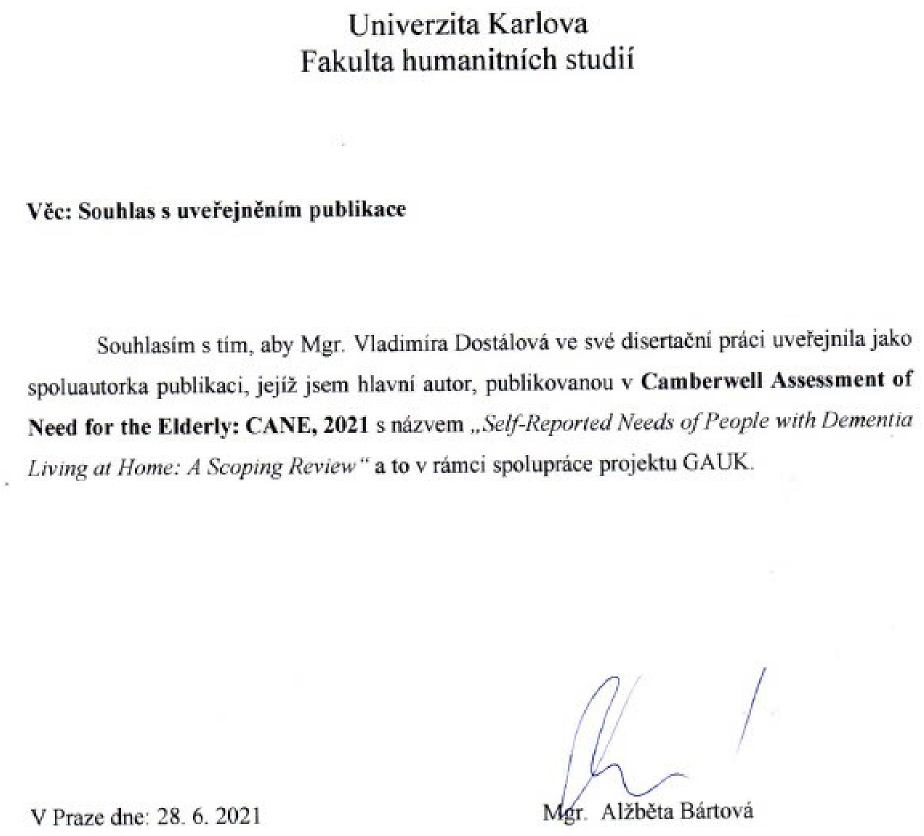
Chirico I., Chattat R., Dostálová V., Povolná P., Holmerová I., de Vugt ME., Janssen N., Dassen F., Sánchez-Gómez MC., García-Peñalvo FJ., Franco-Martín MA., Ottoboni G. (2021) The Integration of Psychosocial Care into National Dementia Strategies across Europe: Evidence from the Skills in DEmentia Care (SiDECar) Project. *Int J Environ Res Public Health.* 2021 Mar 25;18(7):3422. doi: 10.3390/ijerph18073422. PMID: 33806158; PMCID: PMC8036745.

Bláhová, H., Bártová, A., Dostálová, V & Holmerová, I. (2020) The needs of older patients in hospital care: a scoping review. *Aging Clinical and Experimental Research.* Doi: 10.1007/s40520-020-01734-6

Holmerová, Iva, Vladimíra Dostálová, Petr Procházka a Michal Šteffl. (2019) Ekonomické aspekty poskytování péče lidem žijícím v domácím prostředí. In: Holmerová, Iva. *Case management v péči o lidi žijící s demencí. Koordinace péče zaměřená na člověka.* Praha: Univerzita Karlova v Praze. ISBN 9788075710314

Appendix C1. Self-Reported Needs of People with Dementia Living at Home: A Scoping Review



Univerzita Karlova
Fakulta humanitních studií

Věc: Souhlas s uveřejněním publikace

Souhlasím s tím, aby Mgr. Vladimíra Dostálová ve své disertační práci uveřejnila jako spoluautorka publikaci, jejíž jsem hlavní autor, publikovanou v **Camberwell Assessment of Need for the Elderly: CANE, 2021** s názvem *„Self-Reported Needs of People with Dementia Living at Home: A Scoping Review"* a to v rámci spolupráce projektu GAUK.

V Praze dne: 28. 6. 2021

Mgr. Alžběta Bártová

2

Self-Reported Needs of People with Dementia Living at Home

A Scoping Review

Alžběta Bártová, Iva Holmerová, Vladimíra Dostálová, Hana Bláhová and Michal Šteffl

2.1 Introduction

Demographic changes are associated with an increased number of people with dementia.[1] Cognitive communication disorders and reduced ability to use the environment to meet one's own needs are part of the dementia syndrome.[2] The relationship between meeting one´s needs and quality of life is generally accepted.[3] Quality of life is a very broad concept with different dimensions which can be approached from many perspectives. Also, needs can be approached from different perspectives: for example, objective and subjective.[4] Objective needs can be measured by relevant tools or reported by family or professional carers,[5] whereas subjective needs are based on individual feelings and self-perception.[6,7] Previous studies have shown that a higher quality of life is related to a lower number of unmet needs.[6,8,9] To ensure an adequate quality of life for a person with dementia, it is necessary to focus on meeting their objective as well as subjective needs.

Understanding and meeting the needs of people with dementia are particularly problematic because of dementia symptoms, for example, changed comprehension and difficulties in communication. However, the care experiences of people with dementia bring meaningful and useful information about their needs.[10] Identifying the individual needs of a person with dementia is essential to ensure person-centred care[5,11] and to avoid or delay institutionalisation.[11]

There is an increasing amount of research that focuses on meeting the needs of people with dementia. However, most of this research is carried out in residential establishments. Available research on the needs of people with dementia living in their home environment focuses mostly on the carers' perspective, and some studies focus directly on carers' needs.[12] Although family carers play an important role in identifying and addressing the unmet needs of care recipients,[13] people with dementia are important informants about their own life and subjective well-being.[14,15] Previous studies have pointed out that people with dementia typically report a significantly lower number of unmet needs than their carers.[7–9,16,17] Even though differences between perspectives confirm the importance of examining the self-reported needs of people with dementia,[9] there is a lack of studies evaluating the subjective needs of people with dementia.[5,12,18] The aim of this scoping review therefore is to provide an overview of the self-reported needs of home-dwelling people with dementia.

2.2 Method

2.2.1 Scoping Review Methodology

In order to provide an overview of this area and because of the lack of current research, a scoping review was selected as the appropriate methodology for this study. A scoping review maps the nature and extent of research and determines gaps in research activity to direct future research.[19] The scoping review methodology is described as a six-stage framework: (1) identifying the research question, (2) searching for relevant studies, (3) selecting studies, (4) charting the data, (5) collating, summarising and reporting the results and (6) consulting with stakeholders to inform or validate study findings.[20] Recommendations to clarify and enhance each stage[21] were used for the purposes of this review.

2.2.2 Search Strategy

The databases PubMed, Web of Science, PsycINFO and Scopus were used in the search, which took place during August and September 2019. The search was initially narrowed to include articles published between January 2009 and August 2019 in English or Czech using search terms 'dementia' and 'needs', which resulted in a total of 814 articles, and 18 articles were identified through other sources.

2.2.3 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were decided upon through discussion by authors AB, VD and IH and were reviewed by all authors throughout the process. Articles of both quantitative and qualitative study designs were included. After discarding duplicates, the authors identified appropriate studies using the primary inclusion criteria, that is, exploring the needs of people with dementia. Articles that examined the needs of people with dementia in a hospital or a long-term care facility were excluded from the review. Studies not seeking to obtain views of people with dementia themselves were not included. To ensure the quality and transparency of the screening process, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendation for systematic evaluation was carried out (Figure 2.1).

2.3 Results

2.3.1 Study Characteristics

The final review includes 13 studies both quantitative ($n = 11$) and qualitative ($n = 2$). Most of the quantitative studies were cross-sectional ($n = 8$); fewer were longitudinal ($n = 3$). As a measurement tool, the Camberwell Assessment of Needs for the Elderly (CANE) was used in most quantitative studies ($n = 7$), then the Johns Hopkins Dementia Care Needs Assessment (JHDCNA) was used in three quantitative studies, and finally, the DelpHi Standard was used in one study. Semi-structured and narrative interviews were used in qualitative studies. In addition to people with dementia, family caregivers (whose responses and results are not included in the survey) participated in most studies ($n = 12$). All selected studies focused on people with dementia living in the community. Table 2.1 provides a summary of the individual studies.

2.3.2 Domains of Reported Needs

Clear division of needs is difficult.[22] In the available studies included in this scoping review, the

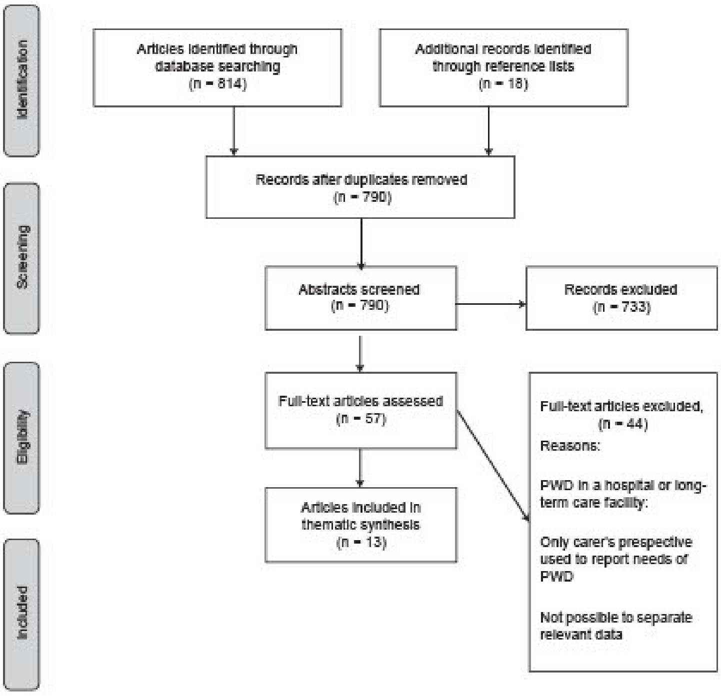


Figure 2.1 Search flowchart in accordance with PRISMA guidelines

Table 2.1 Summary of Articles Used in Thematic Analysis

Author (Year)/ Country	Aim	Study Population	Research Type	Assessments/ Tools	Reported Needs
Black et al. (2013)/USA	To determine the prevalence and correlates of unmet needs in a sample of community-residing people with dementia and their family caregivers	Community-residing persons with dementia (*n* = 254) and their family caregivers (*n* = 246)	Quantitative	JHDCNA	Safety: · Fall risk management · Home safety evaluation · Wander risk management General health and medical care Meaningful activities Legal issues and advance care planning Evaluation and diagnosis of dementia
Black et al. (2019)/USA	Determine the percentage of people with dementia having unmet needs and significant correlates of unmet needs in people with dementia	Community-living people with dementia and their family caregivers (*n*= 646)	Quantitative	JHDCNA	Home/personal safety · Need for emergency planning · Fall risk management · Medication use General healthcare Daily activities Neuropsychiatric symptoms management Legal issues and advance care planning
Eichler et al. (2016)/ Germany	To describe the number and types of unmet needs of German primary care patients screened positive for dementia and factors associated with the number of unmet needs	227 persons with dementia (≥70 years, living at home) of the intervention group who had screened positive for dementia	Quantitative	DelpHi Standard of Optimum Care	Social counselling and legal support mainly in power of attorney/legal representative Social integration/physical activities Pharmaceutical treatment and care Mobility limitation/risk of fall
Górska et al. (2013)/UK	This study aimed to develop a deeper understanding of the lived experience of people with dementia regarding their service-related needs	31 participants: 12 persons with dementia (39%) and 19 unpaid carers (61%)	Qualitative	Semi-structured, narrative interviews	· Diagnostic services · Post-diagnostic support · Coordination · Continuity · Non-pharmacological intervention
Johnston et al. (2011)/ USA	Determine whether a telephone screening method could identify individuals in the community in need of care for dementia; develop a multidimensional needs assessment tool for identifying the unmet needs related to memory disorders in the home setting	13 persons with dementia and carers	Quantitative	JHDCNA	Need for a dementia workup General medical care Environmental safety Assistance with activities of daily living impairments Access to meaningful activities

Kerpershoek et al. (2017)/INT	To describe the domains and level of needs in a group of people with dementia and their family carers who do not yet use formal care and to describe the relationship of needs and quality of life from different perspectives	451 community-dwelling people with dementia and their carers participated from eight European countries	Quantitative	CANE	Company Information Daytime activities
Mazurek et al. (2017)/ Poland	Assess the needs of people with dementia living at home	47 people diagnosed with mild to moderate dementia and 41 family carers	Quantitative	CANE	Psychological distress Company Daytime activities
Mazurek et al. (2019)/ Poland	Investigate whether the Meeting Centres Support Programme (MCSP) is effective in meeting the needs of older people with dementia	47 people diagnosed with mild to moderate dementia and 42 family carers	Quantitative	CANE	Daytime activities Psychological distress Company Memory
Miranda-Castillo et al. (2010)/UK	Identify the relationship between unmet needs, social networks and quality of life of people with dementia living at home	152 community-dwelling people with dementia and 128 carers	Quantitative	CANE	Daytime activities Company Psychological distress Eyesight/hearing Accidental self-harm
Miranda-Castillo et al. (2010)/UK	Identify the needs of people with dementia living alone and to compare the needs of people with dementia living alone versus those living with others	Of 152 people with dementia, one-third of the people with dementia (*n*= 50) were living alone and 128 carers	Quantitative	CANE	Daytime activities Company Psychological distress Eyesight/hearing Accidental self-harm
Miranda-Castillo et al. (2013)/UK	Compare perspectives on perceived needs among community-residing people with dementia, their family caregivers and professionals	125 community-dwelling people with dementia and carers	Quantitative	CANE	Psychological distress Daytime activities Company Information Eyesight/hearing
Morrisby et al. (2018)/ Australia	To identify care and support needs, as reported by people with dementia and their spousal carers living in the community in metropolitan western Australia	10 dyads of spousal carers and people with dementia	Qualitative	Semi-structured interviews	Environmental enablers to support care Adaptation of daily life roles
van der Roest et al. (2009)/Netherlands	Assess the needs of community-dwelling people with dementia as reported by themselves and by their family carers; provide insight into the service use and gaps between needs and the availability of services	236 community-dwelling people with dementia and 322 family carers interviewed separately	Quantitative	CANE	Memory Information Company Psychological distress Daytime activities

communicated needs are categorised either through domains of individual questionnaires or by placing them in hierarchical needs models. However, the categories overlap, and the sorting is not exact. Needs interact with each other when an unmet need in one area causes an unmet need in another area.[14]

Each of the three assessments used in quantitative research contains different domains and numbers of items. Therefore, differences in unmet needs are reported in terms of using different assessments as well as needs reported in qualitative studies. A total of seven most frequently reported needs were identified according to the CANE assessment: information, company, daytime activities, psychological distress, memory, eyesight/hearing and accidental self-harm. Six most commonly mentioned needs were identified using the JHDCNA in the following areas: dementia evaluation or diagnosis, dementia workup, legal issues and advance care planning, meaningful/daily activities, general health and medical care and safety home and personal. DelpHi Standard of Optimum Care shows unmet needs in the following domains: social counselling and legal support mainly in power of attorney/legal representative, the need to increase physical activities listed in domain of social integration, pharmaceutical treatment and care and nursing treatment and care, especially in case of mobility limitation/risk of fall. In qualitative studies, people with dementia identified their unmet needs in the following areas: diagnosis, post-diagnostic care, environmental support, meaningful activities and roles and safe home and community.

To achieve the aim of the scoping review, a thematic analysis was chosen to unify reported needs. For thematic analyses, the constant comparative method has been used,[23] which revealed a total of five themes specified by subthemes: environmental needs (dementia evaluation or diagnosis, post-diagnostic support), social needs (company, meaningful activities and roles), psychological needs (psychological distress, memory), biological/physical needs (general physical health) and need of safety (home, personal and environmental).

2.3.3 Environmental Needs: Expert Services and Environmental Enabling Factors

2.3.3.1 Dementia Evaluation or Diagnosis

Timely diagnosis was seen as an essential factor to access optimal services and drugs. Delayed diagnosis has often been associated with lost opportunities to better manage the condition.[24] In one study, almost one-third of the people with dementia did not get prior dementia evaluation or diagnosis.[25] Numerous obstacles have been identified in obtaining a diagnosis, mainly due to inappropriate attitudes of primary care physicians. In some cases, especially when concerns were raised in the very early stages of dementia, it was reported that study participants[24] were advised to treat their symptoms as signs of normal ageing. Lack of communication between the services involved (primary care and specialised services) was cited as another possible cause of a delayed diagnosis. Insufficient coordination of the services forces people with dementia or their carers to secure medical examinations and transfer of information between services.[24] Many people with dementia identified unmet needs in the post-diagnostic phase: during the process from diagnosis to ongoing care. They experienced a lack of empathy from healthcare professionals and inconsistency of care provided (e.g., lack of referral to support services).[18]

2.3.3.2 Post-Diagnostic Support

Information and Coordination. People with dementia highly appreciate the continuous communication and information about their condition from diagnosis to referral to other available services. Better provision of information can help people with dementia to more accurately consider their needs; it also helps them to cope better with disease and to better use available services.[17] The need for access to information at one single place and coordination of available services have been identified as important for effective case management.[24] The need for information was reported by people with dementia as one of the most frequent unmet needs in a total of three studies.[7,8,17] The people directly reported that they either did not receive information at all or the received information was scarce or unclear (e.g., only printed without further explanation).[17] One study even stated that the area dementia workup was the most frequent (9/11) unmet need.[26] Information should be specifically adapted to individual needs and wishes and must be appropriate to the stage of the disease. The fact that people with dementia are experiencing the need for access to information should raise concerns in the current healthcare system and requires more attention.[26]

Continuity. Optimal care and access to quality services that meet the individual needs of people with dementia often result in strong and lasting relationships with service providers.[18] Continuity of care and especially appropriate involvement of health and welfare professionals were considered necessary for the provision of quality care.[24] People with dementia may have difficulties in recognising and remembering new people; they need enough time to develop a positive relationship. Discontinuity of services and frequent changes of service providers may cause increased anxiety for a person with dementia. While ensuring continuity of care services for people with dementia, service providers must also support their sense of confidentiality and security.[24]

Access to Non-Pharmacological Interventions/Psychosocial Interventions. The need for accessibility and availability of non-pharmacological interventions is also important. These interventions support identity and social participation and mitigate changes in physical and mental health. Prevention of reduced activity and interest has been highlighted as an essential element of high-quality care.[24]

Legal Issues and Advance Care Planning. The area of legal issues and advance care planning includes different items: choosing a person who will ensure the general and medical power of attorney for a person with dementia, documenting the last wishes and overseeing the estate.[11,25] Timely planning of these issues needs to be addressed well in advance while a person with dementia has decision-making capacity.[13] Social counselling and legal support were reported mainly in the area of power of attorney/legal representative.[11]

2.3.4 Social Needs

Social needs are among the most frequently mentioned needs in 12 of 13 studies. The most frequently mentioned themes in this domain are company[6–9,16,27] and meaningful daytime activities,[6–9,13,16,17,25,27] which are any activities that enable a person with dementia to engage in appropriate social, stimulating or leisure activities.[17] Losing meaningful activities and relationships, being useful for others or intimacy with a partner and the potential conflicts with relatives were specific situations that persons with dementia have listed under the item daytime activities and company.[17] Social integration,[11] everyday activities (e.g., household) and social roles (e.g., active grandparent role) are needed to maintain feelings of self-worth. Maintaining and continuing important roles or developing new roles requires the support of carers and sometimes also support services.[18] More than half of people with dementia reported unmet needs for meaningful activities that were described as day-care needs, visiting centres and home activities.[25] Unmet needs in daytime activities also include the need for help and support in the activities of daily living (ADLs), lack of meaningful activity or daily structure and physical inactivity or social isolation.[6] A supportive and knowledgeable social environment is also an important social need. The need for social support has three levels: family, friends and wider social networks.[18]

2.3.5 Psychological Needs: Mental State, Cognitive Functions and Memory

Coping and support in coping with the psychological distress and negative feelings such as anger, sadness, loneliness, confusion and fear[17] are the most frequently communicated self-reported needs of people with dementia living at home; they have been detected in more than half of studies.[6,7,9,17,27] Coping with memory problems is an area reported by people with dementia as one of the most commonly perceived unmet needs in two studies.[7,16]

2.3.6 Biological/Physical Needs: General Physical Health

General physical health includes requirements such as the need for dental care, specialist medical care, incontinence management and coping with polypharmacotherapy, eyesight and hearing problems compensation or support in solving malnutrition and dehydration problems.

Commutation of Chronic Health Problems. Poly-morbidity often results in polypharmacy, and a person with dementia often has no cognitive capacity to manage such a condition.[13] In the domain of pharmaceutical treatment and care,[11] the most reported need is treatment with anti-dementia drugs, which could also be a topic of discussion because of the limited effect of these drugs.[11] Unmet needs in general health and medical care were identified in three studies.[13,25,26] One study highlighted pharmaceutical treatment as an unmet need.[11] Eyesight/hearing problems management and compensation were specifically mentioned as an unmet need in three studies.[6,16,17,27] Sensory problems have a great influence on the ability to communicate (not only) for people with dementia. The unmet needs in eyesight/hearing indicate that a better treatment and/or compensation of these symptoms may enable better communication.[17]

2.3.7 Need for Safety

The care of home-dwelling people with dementia presents a great challenge, especially in ensuring safety. Safety issues may not be easily detected during formal care visits but may lead to a higher need for healthcare and a lower quality of life.[13] The need for safety,[25] specifically home and personal safety,[13] or environmental safety,[14] was reported as an important domain in three studies.[13,25,26] The most common need reported in this domain was avoiding the risk of falls,[13,25] wandering management,[25] and help with drug use.[13] Many people with dementia reported the need for a plan for dealing with emergencies (e.g., power outages)[13] or an emergency card for hospitalisation (which is a card identifying that the person has dementia and who their carers are and provides carer details).[11] The area of safety also includes safe driving, safe management of weapons and domestic tools[25] and prevention of abuse, neglect, or exploitation and fraud.[13] Accidental self-harm and creating dangerous situations unintentionally were listed as high in two studies.[6,27] Safety in the home and community and factors such as familiarity with surroundings, proximity of social support, safety and access to services were identified as reasons for wanting to remain living in their respective communities.[18]

2.4 Discussion

This scoping review provides a survey of self-reported needs of home-dwelling people with dementia. This population has been under-represented in research, even though meeting the individual needs of people with dementia is necessary for ensuring optimal care. The analysis of articles shows that people with dementia are able to express and communicate their needs themselves. Therefore, their experiences should be taken into account in person-centred care planning.

Needs and priorities in their perception are multidimensional and unique in each individual, and they change throughout life, vary according to the level of cognitive impairment and functional abilities and differ in the various subtypes and stages of dementia.[22,25] Needs assessment should include previous life experiences, cultural backgrounds, preferences and identity.[28] Therefore, when assessing self-reported needs, it is necessary to include the biological, psychological, social and environmental contexts of a person with dementia so that a unique assessment of that person's needs can be made to provide person-centred care.[22]

Environmental needs include a wide range of themes and specific topics in which people with dementia express their needs. The first theme is diagnosis and dementia evaluation. The onset of dementia syndrome is usually gradual and inconspicuous, and symptoms of the disease are often considered as regular aging. Initial symptoms of dementia are often unrecognised by people with dementia, their families and even health or social care professionals. Overlapping symptoms and poly-morbidity in older age make the diagnostic process even more difficult.[28] Another barrier to recognising dementia is that people with dementia often overestimate their abilities despite the actual state.[29] However, timely diagnosis is crucial for an appropriate assessment of the needs of a person with dementia and any changes that occur as the disease progresses.[30] Lack of communication between involved professionals and/or services occurs during the diagnostic process as well as during post-diagnostic support, which was another frequently occurring theme conveyed. Throughout the disease, access to information and coordination and continuity of care are identically identified as crucial. Furthermore, the access to non-pharmacological interventions and the need for dealing with legal issues and advance care planning were reported. An appropriate approach to meet these needs is case management.[28]

Other significant themes people with dementia reported include the need for company and meaningful roles and activities, as well as coping with psychological distress and the need for safety. Regardless of the need for division into themes, it can be assumed that if one main need is met, it will affect the perception of other needs. At some point, the fulfilled needs can drive away feelings of fear, sadness and anger and allow for a positive experience.[14] Because of communication difficulties, people with dementia may express their needs through non-normative behaviours. Evidence shows the link between behavioural and psychological symptoms in dementia (BPSD) and unmet needs,[31] for example, meaningful activities that focus on the individual interests and preserved skills of a person with dementia that increase that person's involvement, reduce BPSD and improve overall quality of life.[32] People with dementia express their needs through different behaviours, whereas a single type of behaviour can also convey different needs. The underlying needs associated with these behaviours thus must be understood before carrying out a person-centred care intervention.[32]

Biological needs are reported by people with dementia as a need for general and special medical care. One specific topic was the need for help with post-dementia changes, such as the ability to cope with drug management. The ageing of the population should be viewed as one of the main achievements of current healthcare. However, optimal management of healthcare for people with dementia is still a challenge that needs to be addressed in order to provide the basic human needs necessary to meet the full spectrum of individual needs and enable a person with dementia to live at home for as long as possible.

2.5 Implications

The findings presented in this scoping review provide an evidence-based framework that can serve as a guide in planning better care of people with dementia living at home. This review provides evidence that people with dementia are able to express their needs. Therefore, their perspective should be included in planning person-centred care together with a proxy account and observation.

2.6 Future Research

Several measurement tools have been used in quantitative studies to identify the needs of people with dementia; three of them were included in this scoping review (CANE, JHDCNA and the DelpHi Standard of Optimum Care). Each assessment described contained different domains and numbers of items, and comparing their results is almost impossible. This might be the reason for differences in numbers and frequency or even the existence of different needs reported in various studies. In addition, other findings and differences have been shown in qualitative research. Further research on the needs of people with dementia, especially needs that those with dementia can formulate themselves, is still very necessary. An optimal needs-assessment instrument should assess needs comprehensively, be sensitive to change, allow re-evaluation of needs and leave additional space for written comments that go beyond the standardised needs items.[22]

2.7 Limitations

Four databases were used to search for articles; therefore, some articles may have been missed. The fact that most of the articles are in English can also mean that the results are more representative of a European or Western perspective.

2.8 Conclusion

The increasing numbers of people living with dementia need better support and care that can lead to a better quality of life. This review has shown that people with dementia themselves are important informants about their subjective needs and care experience, and therefore, they should not be neglected in research anymore. A total of five main themes were identified across the articles used in this scoping review. This provides evidence of a wide range of needs people with dementia experience in biological, psychological, social and environmental areas and the area of safety. To ensure optimal care, a comprehensive needs assessment in which the perceptions of people living with dementia are included is essential.

Disclosure Statement

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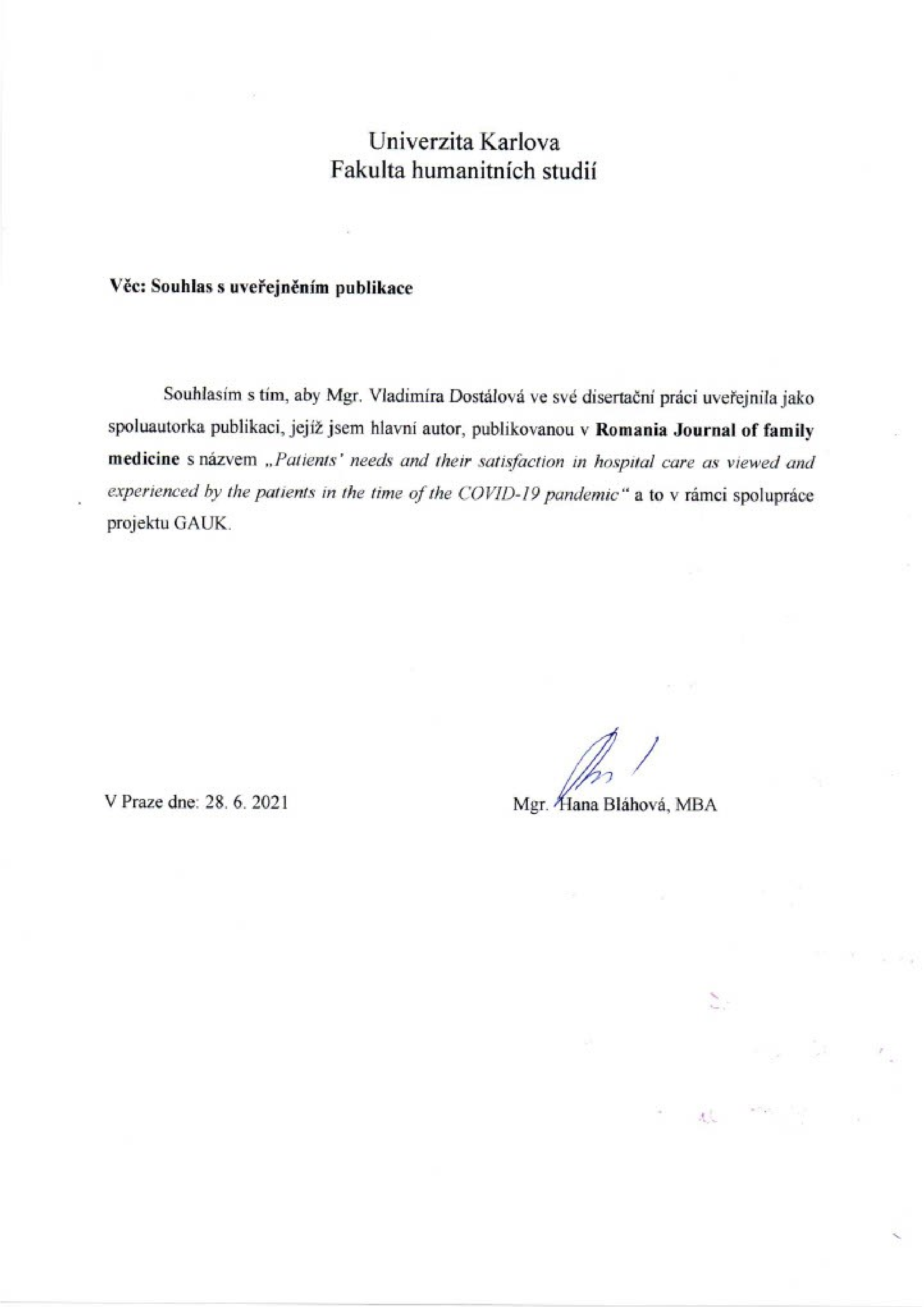
Appendix C2. Patients' needs and their satisfaction in hospital care as viewed and experienced by the patients in the time of the COVID-19 pandemic



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RESEARCH

Original article

Patients' needs and their satisfaction in hospital care as viewed and experienced by the patients in the time of the COVID-19 pandemic

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Abstract

Introduction: In the context of an ageing population, problems in care for frail older patients and their specific requirements have increasingly been highlighted. In the COVID-19 pandemic hospitals play even more important role and provide continuum of care also to older persons. Therefore it is even more important to ensure comprehensive care for older patients, including satisfying all of their needs. *Objective:* This study's objective is to investigate older adult's experiences and opinions of how their needs are satisfied in hospital care in the time of COVID-19 pandemic. *Method:* A qualitative research method was chosen. Data was collected by means of semi-structured interviews. *Results:* A total of 12 interviews with patients aged over 80 were evaluated. An analysis was performed and four principal aspects of care for older people were identified: quality of care; satisfying patients' needs; personality of the carers; autonomy and dignity.

Keywords: *older adult, hospitalisation, patients' needs, hospital care*

CERECTARE

Articole originale

Nevoile pacienților și satisfacția lor cu îngrijirea spitalicească așa cum au fost văzute și experimentate de pacienți în timpul pandemiei COVID-19

Rezumat

Introducere: În contextul îmbătrânirii populației, problemele în îngrijirea pacienților vârstnici fragili și cerințele lor specifice au fost evidențiate din ce în ce mai mult. În pandemia COVID-19, spitalele covid joacă un rol și mai important și oferă continuitate în îngrijire și persoanelor în vârstă. Prin urmare, este și mai important să se asigure o îngrijire cuprinzătoare pentru pacienții vârstnici, inclusiv satisfacerea tuturor nevoilor acestora. *Obiectiv:* Obiectivul acestui studiu este de a investiga experiențele și opiniile adulților în vârstă despre modul în care nevoile lor sunt satisfăcute în îngrijirea spitalicească în timpul pandemiei COVID-19. *Metodă:* A fost aleasă o metodă de cercetare calitativă. Datele au fost colectate prin intermediul interviurilor semi-structurate. *Rezultate:* Au fost evaluate un total de 12 interviuri cu pacienți cu vârsta peste 80 de ani. A fost efectuată o analiză și au fost identificate patru aspecte principale ale îngrijirii persoanelor în vârstă: calitatea îngrijirii; satisfacerea nevoilor pacienților; personalitatea îngrijitorilor; autonomie și demnitate.

Cuvinte cheie: *adulți în vârstă, spitalizare, nevoile pacienților, îngrijire în spital*

Introduction

The COVID-19 pandemic caused extreme burden on hospital care. Due to the demands on technical equipment, especially the provision of oxygen therapy, hospitals have been providing care in the entire spectrum from resuscitation, intensive and acute care to aftercare, rehabilitation and palliative care. In hospitals, the palliative care has received more recognition, and during the pandemic the palliative care teams and departments in hospitals have been set up.

The ageing population and geriatric care

The ageing population is a global problem in the majority of countries, and one of the defining characteristics of contemporary society. Several aspects are known to play a key role in this (improvements in the standard of living, advances in medicine, etc.). For the world as a whole, the number of people aged over 80 is rising by 4.0% annually on average (1, 2).

Statistics show that the proportion of older persons is increasing also in the Czech Republic. In 2016 life expectancy was 76.1 years for men and 82.1 years for women, and these figures continue to rise (3). In the context of this data, problems in care and treatment for older patients and their specific requirements have increasingly been highlighted. These problems include frequent polymorbidity, changes in all organ systems, differences in the symptoms of sickness, the presence of geriatric syndromes, multimorbidity and polypragmasia (4). One of the significant geriatric syndromes is frailty, where there is a reduction in the organism's fitness, resilience and adaptability as functional changes (mental, mobility-related and nutritional) accumulate (5, 6). These changes are particularly apparent with persons aged 75–80 years, when multimorbidity tends to be the rule rather than the exception (7). It is also true that the ageing of the population has led to an increase in the number of older adult requiring medical care, whether in general practitioners' surgeries or in various medical facilities (8). A knowledge of geriatric medicine and an interdisciplinary approach to these patients appears to be essential. In care for older persons, it is important that there is an attempt to optimise their functional condition despite their frequently diminished intrinsic capacity if the highest possible quality of life is to be achieved (2, 9).

Care for older people in the hospital setting and the quality of care

It is clear that older people are admitted to medical facilities' acute inpatient wards with increasing frequency. For older people, the duration of hospitalisation is markedly longer than for younger patients: while the average duration of hospitalisation is 1.8 days for persons aged 50–54, for persons aged over 85 this figure is approximately 7 days (10). These data are subsequently changing with the COVID-19 pandemic, as it is becoming apparent that hospitalisation of older persons with COVID-19 are even longer. Moreover, there is ample evidence that older patients in hospital care are more exposed to a variety of risks and stressors, including considerable physical and psychological stress, the fact that they have been taken out of their social environment, negative incidents such as falls, postoperative complications, negative reactions to pain and drugs, loss of mobility and functional decline. Also typical are cognitive and behavioural disorders that tend to result in delirium, with agitation, anxiety, confusion, hallucinations and/or aggression (11, 12).

There are also increasing numbers of patients who need palliative care and also e.g. patients with dementia, placing high demands on nursing and requiring an individual approach (13). However, this is frequently beyond hospitals' realistic capacities. Health professionals lack the training and practical skills to care for such patients (5) despite many improvements especially in the palliative care provision in last years. Other authors have pointed to unsatisfactory care for older adults with dementia, remarking that health professionals' traditional training is inadequate and needs to be adapted to the specific requirements of care for such patients. Authors also stress that despite health professionals' efforts to provide quality care, there tend to be additional limitations and factors such as the organisation of their work and the hospital setting (14). From the perspective of patients and their families, all of this is magnified by poor outcomes of treatment and care during hospitalisation, previous poor experiences, mortality and the institutionalisation of patients (5). From the above, and from the other publications available, it is clear that care for older people in hospitals is not optimal, and in many ways patients' needs and autonomy are not respected (15).

In view of these factors, and in the context of good practice in long-term and geriatric care for these patients, there is an emphasis on improving the quality of care. Care should be integrated, planned and directed towards the patient's individual needs. Kindness, sustained support for the family and relatives, the establishing of positive cooperation, and communication are all important. Furthermore, many authors stress that patients with limited self-sufficiency are more vulnerable and their autonomy is more in jeopardy. What is important is a holistic approach and an attempt to improve or at least maintain their quality of life (16).

The present study follows on from earlier research and publications, specifically scoping reviews of Czech (17) and foreign literature (18) revealing that care for older people and an awareness of how their needs are satisfied in hospital are based more on a theoretical perspective, or on general considerations about the quality of care. However, when evaluating the quality of care, patients' opinions and experiences are the best source of information and offer a true picture of real practice. They are the starting point for desirable improvements in practice.

This study's objective is to investigate older people's experiences and opinions of the satisfying of their needs in hospital care.

Research methods

A qualitative research method was chosen. It is based on an interpretative paradigm where the focus is on understanding the significance of human behaviour and experiences with the aim of obtaining a detailed account of the views of the individuals surveyed (19). This approach encompasses collecting and analysing data, and evaluating and highlighting important aspects and the problems examined in the respondents' authentic environment.

The relationship between researcher and respondent is important for analysing and decoding the information and presenting the results of how people perceive and experience their situation in the real environment (20). Data was collected by means of semi-structured interviews. Strauss and Corbin's recommendations were followed to ensure the accuracy and reliability of the study's results (19).

A total of 12 semi-structured interviews were conducted with patients in post-acute wards at three hospitals (in Prague, the Liberec Region and the Karlovy Vary Region). The inclusion criteria were that respondents should be over 80 years of age, that both sexes were represented, and that respondents had retained the ability to communicate. The patients' mobility was not taken into account. None of the respondents had been found to have dementia. A precondition for including the probands was that they had been hospitalised for at least two weeks.

The respondents were selected in collaboration with social workers, and account was taken of how willing respondents were to cooperate. In all of the medical facilities, privacy was ensured during the interviews, including for immobile patients. All patients were dependent on assistance from the staff and the provision of basic nursing and medical care, and without assistance they only had limited movement.

Interviews were conducted between February and July 2020 (during the first wave of the COVID-19 pandemic). The individual interviews lasted 15–30 minutes depending on patients' health status. Before starting an interview it was important to create an atmosphere of mutual trust and positive interaction.

The questions were open questions that were drafted and communicated in collaboration with the research team. Initially, all respondents were asked a key question: *Can you describe your experiences, opinions and feelings about the medical care you are currently receiving in hospital?* In order to participants would better understand the context of the interview (the issue under examination), additional questions were asked to prompt them, such as: What do you think is important in caring for you? Can you describe how the staff help you in daily care? In what ways are the staff interested in what you need? All interviews were anonymised. Audio recordings were made, and the interviews were subsequently transcribed verbatim.

Data analysis

Data analysis consists of the systematic organising of the data (text) acquired in the form of open coding, with the aim of decoding the text analysed to reveal its themes, regularities and contexts. In open coding the researcher repeatedly reads a text (the individual words, sentences and lines) and breaks it down into units with assigned codes. The units are then reordered under individual categories and subsequently interpreted (20). The process of the analysis and its individual steps were regularly consulted within the research team. A qualitative content analysis was chosen, following Graneheim, Lindgren and Lundman's methodology (21). During the analysis there was an emphasis on the following questions: *"What is evident here? What are people trying to tell me, or what is going on? What is the significance of these stories?"*

The first phase of the analysis was inductive, looking for similarities and differences in the data obtained, and subsequently understanding them, moving from the concrete and specific to abstract and general themes (categories). The individual interviews were then coded and grouped under lexical units – the main categories. These were the basis for creating the subcategories. The entire process was repeatedly reviewed and amended as necessary. The next phase was deductive, moving from the theory to the data, or from the general to the more concrete. A total of four categories with several subcategories were defined, as presented in table 1.

Table 1. Categories and subcategories

Categories	Subcategories
Quality of care	Organisation of care Setting
Satisfying patients' needs	Mobility and self-sufficiency Personal hygiene Food and hydration Pain Privacy Loneliness
Personality of the carers	Nurse Doctor
Autonomy	Cooperation and communication Decision-making

Ethical considerations

This study was approved by the ethics committee of the Gerontology Centre in Prague on 2 November 2018. All participants in the research signed informed consent forms. The audio recordings and transcriptions of the interviews were anonymized, and have been stored with password-protected access.

Research results

The hospitalisation of frail older patients cannot always be avoided. The reason is usually an acute worsening in their health status, with a need for diagnosis, treatment and care that cannot be provided in the home setting. Such a patient remains isolated and more or less dependent on the care of others. This matter has become even more accentuated now with the COVID-19 pandemic. A need for mutual trust, cooperation and respect for the patient is even more important. . Based on the research analysis, these people's experiences and needs have been divided into *four main categories:* perceptions of the quality of medical and nursing care; satisfying patients' needs; personality of the carers; autonomy and dignity.

1. Perceptions of the quality of medical and nursing care

The results of the survey generally show that the patients viewed medical care and nursing in inpatient facilities as mostly satisfactory. The research participants expressed this for instance as follows: *"For me, the care here is good. I can't say there's anything I'd mind. I've got basic care. So I'm about 50% satisfied, it's all right…"* Or: *"…I'm satisfied, I've got care, on the whole I can tell them what I want…"* One of them commented: *"It's above average here, and generally better than elsewhere…"* Another participant said: "*I'm in the best hands here, my experience has been good."*

Organisation of care and the setting

It was also evident from the survey that the perception of the quality of care was greatly influenced by the hospital setting, the size and furnishings of the rooms, the overall organisation of care, repeated hospitalisation and any leisure activities. Patients who had repeatedly been hospitalised in the same facility expressed much greater satisfaction than other clients. For example one of the patients said: *"I've been here several times before, I know most of the staff by name… They all welcomed me back, and I know this place well. Everything here is top quality."* The hospital setting was evaluated as follows: *"It's pretty full here, and the rooms are small…"* or *"When there are visits there's no room at all, and you can hear everything, there's no privacy…"* One of the patients commented on the organisation of care: *"It's irregular, several people come running in and then there's a quick visit and then we don't see anyone again for a long time. If we ring the bell, they do what we want."* Another patient said: *"… they run in, quickly pull the sheet down and then back up again, and they don't ask us any questions…."* One of the patients expressed dissatisfaction about the light always being on in her room: *"Why is the light always on, even at night? If I ask, one of the nurses will turn it off, and then someone switches it back on again. It costs money and it hurts my eyes, and it's always bothering me."*

Several respondents reported that the nurses were very busy and in consequence would sometimes forget what a patient had asked for. This was expressed as follows: *"…you have to ask them, and make sure they do it. They've got a lot on, and obviously they forget, probably because they've got a lot of work, and some things they don't remember…"*

One of the medical facilities was exceptional in having a regular programme for all patients, and patients were involved in various activities regardless of their mobility. These included art projects, culture (reading and playing the piano) and baking. All of these activities were organised by a social worker in collaboration with the hospital's volunteer centre. Some of the more active patients also contributed; for instance one of the clients had formerly travelled a great deal, and she talked about what she'd experienced on her travels. The patients remarked: *"…we've always got something to do, we've got a programme, and it's like family here, I'm not lonely and we get to meet one another…"*

2. Satisfying patients' needs

Mobility and self-sufficiency

Patients realise that the scope of their needs depends principally on their level of mobility and self-sufficiency. The majority of patients reported that they had felt most helpless when they were first hospitalised and had been in much worse health. Their fears were magnified by the fact that they were unfamiliar with the setting and the staff. Respondents agreed that the worst thing was helplessness and depending on others. They expressed this as follows: *"Assistance from the staff is important, I'll be glad when they won't have to wait on me hand and foot, I need movement and physiotherapy, I'm looking forward to being on crutches, I'll learn to walk so I can go home, I'm looking forward to that…"* Another patient said: *"In my care it's important that everything's coordinated, depending on how self-sufficient you are, what's important for me now is movement and physiotherapy."*

Personal hygiene

The survey revealed that personal hygiene was more important for women than for men. The men were less demanding in this respect, generally only needing a basic wash. For the women, their habits and appearance – how they did their hair, and the creams they used – played a key role. During the interviews, when discussing various needs hygiene was the one that was mentioned most often. One of the female patients said: *"What's most important for me, and what makes me happy, is when they give me a proper bath."* Another woman commented: *"My heel was a bit sore, so I could only lie in bed, it was painful and one of nurses did a beautiful job rubbing cream on me after I'd had a bath, one of them will always remember to do it and another doesn't take it seriously even if I ask her."*

Food and hydration

From patients' responses it generally emerged that food was not all that important during hospitalisation, especially for men. The priority for most patients was their health status and the possibility of going home as soon as possible, but even so their opinions on the catering were very critical. One of the female patients commented: *"The food's good, I'm used to everything, but I don't like the sauces. There's plenty to drink* *and they're always telling us to drink something. Ladislav is always giving us something to drink, he's wonderful in that way..."* Another woman said: *"I'm confused, I'm supposed to have a nutritional drink and sometimes I get it and sometimes I don't. I asked the nurses why not, and then they brought it without saying anything, they've probably got so much work they forget."* Another female patient was also critical: *"What you can say you want, but it doesn't happen, is food. They ask you what you want but they only ever offer special diets, which you don't want to eat, and it's always mince with some kind of sauce."* The male patients also commented on the food: *"It doesn't bother me, it's the same in all hospitals, we'll eat properly when we're home again. I like eating, but here I'll eat everything and the way I look at it is that I'm in hospital and the food isn't all that important."*

Pain

Pain is usually monitored regularly and is not neglected. This was expressed in this way: *"The nurses always ask you about pain, and again when there's a visit, and whenever I say something's hurting, I get medicine. Something does hurt now and then, but that's normal at our age, and they make sure I don't suffer. I can tell them if something's hurting me."*

Privacy

The patient's privacy is of fundamental importance, but this is very often overlooked in hospital. One of the greatest problems is when a patient needs the toilet, especially if the patient cannot get out of bed and is reliant on assistance. Privacy is not only violated by medical workers, but also by how visitors behave and how considerate they are. One of the patients remarked: *"When there are visitors in the rooms, they don't know how to behave, yesterday the woman in the next room had to go to the toilet and the people were still there…"* In general the survey revealed that visits were important for patients, who looked forward to them, but they could be exhausting and often there was no privacy for visits.

Loneliness

Some patients felt lonely, and they worried about their families, saying: *"I'm on my own here and I feel lonely, there's no one here with me. I miss my dog and I'm looking forward to seeing him again. I'm worried about my husband, he's lost without me and he can't do anything for himself. I'm looking forward to going home, I don't like being in hospital."*

3. Personality of the carers

From what the patients said it emerged that nurses were the most important people in their care, because nurses spend much more time with patients than doctors. The patients were less critical about the personality of the doctors, who they see more as experts to whom they can turn and who have the authority to make decisions. The patients described the most important characteristics for nurses as follows: *"…she should be kind, helpful, sweet-natured, supportive and interested in people, and she should always have a kind word."* The patients' evaluations varied, and it seems that essentially this depended on which nurse happened to be on duty: *"The nurses and their attitude are the most important, because they spend more time with us than the doctor. They're helpful, it's all right, sometimes they're interested and sometimes they're not, I can tell them what I want but sometimes it takes a while. I prefer to agree with them and I don't complain, because they might be mean to me. Some of the nurses are really kind and some aren't, it depends who's on duty. No one asks me what I need, I try to be independent."* Nurses' approach to caring for patients varied: *"Some are happy to help me and some aren't. There's a little nurse here with black hair, she's livelier and she does everything I ask, and then there's another one who doesn't take me seriously and is surprised if I've got some kind of problem."* Another respondent said: *"Some of the nurses try, they straighten my pillow or blanket."* Another comment about nurses was: *"The nurses ask me what I want, not all of them, they aren't all angels, but mostly they're nice. There's one here who really shouldn't be doing this job."* One of the patients talked about an argument with a nurse, and was afraid there would be further unpleasantness: *"I spilt some water on the bedside table, I couldn't help it, and the nurse wasn't happy about that and told me to clean it up myself, so I wiped it with a tissue, seeing how she didn't like it, so she wouldn't be angry. She isn't a good nurse, but I can't tell her that…"*

Evaluations of doctors were expressed as follows: *"They come here every day or if your condition gets worse, they ask about everything and tell the nurses what to do. The doctors are excellent. Especially the senior consultant, she's wonderful, she even talks to my family about when I can go back home. The doctors ask questions and they're attentive."*

It is interesting that none of the respondents talked about any shortcomings in nurses' professionalism, skills and experience. When asked how they rated the nurses as professionals, the respondents answered: *"The nurses know what they're doing, they're good at their work, only with some of them it's a shame they aren't nicer to us."*

4. Autonomy and dignity

The need for trust, cooperation, communication and respect for the patient was often mentioned. The respondents described autonomy and dignity primarily as a willingness to cooperate and communicate, respect for the patient, and the opportunity to be included in decision making. However, it emerged from what the patients said that it is the doctor who ultimately decides. Patients were also concerned with what their families would think; their families were worried about them and helped them.

Cooperation and communication

Cooperation between the patient and the staff was mostly rated positively. For instance: *"I can tell them what I want or what I need. I try to do things myself, but they'll help me if I need something and can't manage it myself. I talk to all of them and they're interested, we talk about everything, I can ask them what I like and they'll reply. If there's time we'll talk about everything."* It was clear from the survey that none of the respondents wanted to provoke conflicts, and they would make compromises if necessary. Only one of the more assertive patients added: *"I tell them what I think, whether it's nice or not, that's the way I am, and I stick up for myself…"*

Decision-making

Here the patients generally said that the health professionals, the doctors and nurses, knew best, and it was best to trust their opinions and advice. They expressed this as follows: *"I trust what the doctor says. What's important is what the doctor thinks, and you can't do much about that. I can say what I like, but the doctors know best, they understand everything."*

Discussion

The objective of this study was to examine older people's experiences, needs and opinions of the quality of care in the hospital setting. The interviews revealed that patients were generally satisfied with the standard of care, and their experiences were largely positive. However, the survey also highlighted a number of areas that patients considered important, and aspects that they thought were negative and in need of improvement. It was evident that in many respects the quality of care is influenced by the organisation of work and the hospital setting, as well as nurses having insufficient time for their work, and established care routines that do not adequately reflect patients' needs. Several authors have also emphasised this, mentioning that it is important that staff are able to respond to the complexity of a patient's circumstances, comorbidity and degree of disability. It is important to adapt care to ensure it is coordinated teamwork based on the patient's needs. Staff skills, the volume of work and the time required to care for such patients must all be dovetailed (15).

There are many factors that influence the satisfying of patients' needs, and their requirements are entirely individual. An assessment of the patient's self-sufficiency is important. The manner in which needs are satisfied, and to what extent, is influenced by the patient's sickness and overall health status, but also by the patient's personality, the hospital setting, interpersonal relationships and the individual staff members and their professionalism (22). In this research study, the satisfaction of the patient's needs was particularly influenced by their age and abilities in terms of self-sufficiency and functioning. Respondents considered the greatest limitation to be the fact that they were incapable of movement and self-care. Older people defined their most important needs as personal hygiene, food and hydration, pain management and privacy. The survey revealed that what is most important for older people is that their basic needs are met. It is evident when satisfying needs that what is fundamental is the individual's ability to cope with tasks related to their basic needs, i.e. their degree of self-sufficiency. Representatives from non-governmental organisations caring for older people in the Czech Republic point out that in the hierarchical structure of older people's needs, their basic needs are the first to be satisfied in order that their other needs are also satisfied (23). In addition, it is possible that older people are from a generation where people are embarrassed to talk about their needs and express their wishes. The necessity of primarily satisfying basic needs is based on Maslow's theory of motivation (24). The greatest emphasis was on personal hygiene and going to the toilet. Some respondents also expressed feelings of loneliness. These findings have been highlighted by other authors, who stress that elderly patients need greater care and assistance with performing their daily activities. An awareness of the patient's functional condition and the level of care required are key (25).

In care for older people the priority is the need for comprehensive geriatric care focusing on frailty and other factors in their care, especially physical and psychological factors. It is important to develop a coordinated and integrated care plan, and to regularly update it. Authors point to the need to revise care for older people, where geriatricians should play the primary role [26]. According to Cichá and Dorková (27) geriatric care should be based on managing geriatric syndromes, which are common among elderly patients and include frailty, dementia, instability, immobility, incontinence, iatrogenicity, etc.

The perception of the quality of hospital care is significantly influenced by the personality of the nurses. The patients in this study repeatedly referred to this, and they also commented that not all nurses were kind and helpful. Some respondents described inappropriate behaviour by nurses. They confirmed that the nurses' personality and conduct are the most important aspects of their care. In the context of caring for older and frail patients, the nurse is defined as follows: *"The nurse knows the current need for nursing care and its results, and knows how to make a qualified estimate of the need for future nursing care, and define it, within a particular nursing timeframe (generally a matter of weeks for post-acute care and months for long-term care)"* (16). Holmerová et al (28) point to the need to amend the spectrum and qualifications of health professionals, as geriatrics is still only a marginal part of their training. Many authors stress the need for familiarity with geriatrics, long-term care and social care (26, 29, 30). The studies available also reveal that the level of knowledge of geriatrics, and nurses' training, affect the overall quality of care (31). However, the results of the current survey were that patients did not mention any need for the standard of nurses' training. This may be due to the cultural context of care in the Czech Republic, where nurses are viewed not as professionals in their own right but as assistants to the doctors. Such stereotypes are probably a consequence of the historical context of the training system for nurses and their status in the Czech Republic.

Positive cooperation and communication with patients and their families is the foundation of successful care. Research studies likewise point to the need to promote dignity and autonomy, which are most in jeopardy among frail elderly patients, especially in hospitals where there is more emphasis on rapid and effective treatment than on the approach to patients. Patients themselves refer to shortcomings in this respect (32). It is stressed that besides quality nursing care, fundamental ethical principles must also be respected, above all respect for dignity, autonomy and the right to make decisions. Older people also have to be protected from age discrimination or ageism (27). This study's findings generally indicate good cooperation and communication between patients and health professionals, and none of the respondents expressed any feelings of discrimination or being unable to express themselves as necessary and communicate their wishes and needs. Regarding the opportunity to make decisions, it is evident that patients prefer the doctor to decide, and they have no misgivings about their doctors' care and knowledge.

Strengths and weaknesses of the research project

This qualitative research project was conducted in line with the methodology and rules for empirical research (20, 21). The individual steps were discussed within the team and planned in advance, focusing on the credibility and reliability of the results and the need to retain authenticity. The sample number of respondents was affected by the epidemiological situation for COVID-19. Although these results cannot be generalised, they can serve as an important source of information and a starting point for any attempt to improve the true situation, and not merely in the hospitals where the survey was conducted.

Conclusion

Old age is characterised by many specific factors, and care for older people is currently becoming the centre of attention, and not only for the professionals who care for these patients. Comorbidities, geriatric syndromes, declining functional capacities and increasing problems in the social area mean that older persons are hospitalised more frequently, but it is clear that the standard of care is insufficient and fails to take account of frail older patients' needs. This study has highlighted older patients' needs and experience in hospital. An analysis was performed and four principal aspects of care for older people were identified: quality of care; satisfying patients' needs; personality of the carers; autonomy and dignity. It is evident from the research project that what is most important for older people is self-sufficiency and the satisfying of their basic needs. In the context of their care they emphasised the personality of the nurses, especially kind words and support. In the quality of care for older persons, there is a need for geriatrically informed medicine and a comprehensive geriatric evaluation of the patient.

Despite the small number of research participants, it is clear that this is one of the few studies conducted in the Czech Republic to research older people's opinions. However, this may serve as a stimulus to improve care for older people.

Conflict of interes:none/**Conflict de interese:** nu există

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Availability of data and materials

The datasets generated and analysed during the current study are available from the corresponding author on reasonable request.

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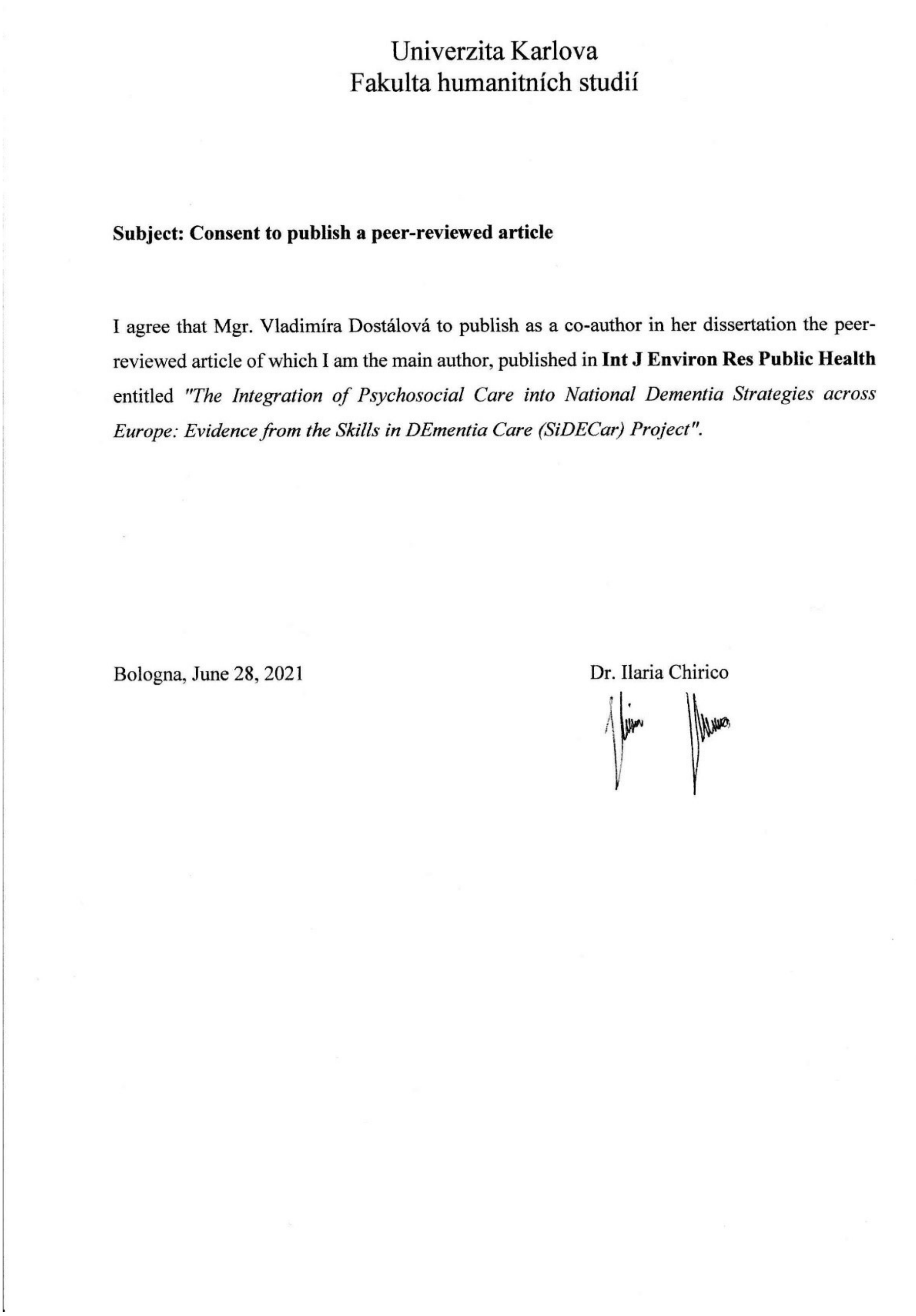
Appendix C3. The Integration of Psychosocial Care into National Dementia Strategies across Europe: Evidence from the Skills in DEmentia Care (SiDECar) Project



Univerzita Karlova
Fakulta humanitních studií

Subject: Consent to publish a peer-reviewed article

I agree that Mgr. Vladimíra Dostálová to publish as a co-author in her dissertation the peer-reviewed article of which I am the main author, published in **Int J Environ Res Public Health** entitled *"The Integration of Psychosocial Care into National Dementia Strategies across Europe: Evidence from the Skills in DEmentia Care (SiDECar) Project"*.

Bologna, June 28, 2021

Dr. Ilaria Chirico

International Journal of
Environmental Research and Public Health

Article

The Integration of Psychosocial Care into National Dementia Strategies across Europe: Evidence from the Skills in DEmentia Care (SiDECar) Project

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Abstract: There is evidence supporting the use of psychosocial interventions in dementia care. Due to the role of policy in clinical practice, the present study investigates whether and how the issue of psychosocial care and interventions has been addressed in the national dementia plans and strategies across Europe. A total of 26 national documents were found. They were analyzed by content analysis to identify the main pillars associated with the topic of psychosocial care and interventions. Specifically, three categories emerged: (1) Treatment, (2) Education, and (3) Research. The first one was further divided into three subcategories: (1) Person-centred conceptual framework, (2) Psychosocial interventions, and (3) Health and social services networks. Overall, the topic of psychosocial care and interventions has been addressed in all the country policies. However, the amount of information provided differs across the documents, with only the category of 'Treatment' covering all of them. Furthermore, on the basis of the existing policies, how the provision of psychosocial care and interventions would be enabled, and how it would be assessed are not fully apparent yet. Findings highlight the importance of policies based on a comprehensive and well-integrated system of care, where the issue of psychosocial care and interventions is fully embedded.

Keywords: psychosocial care; psychosocial intervention; policy; national strategies; dementia; Europe; health priorities; quality of life; Alzheimer's disease; caregivers

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1. Introduction

Dementia is one of the major global causes of disability and dependency among older people [1]. Nowadays, it is considered a global public health priority [2]. In Europe, 10 million people have been diagnosed with dementia. The majority of them are cared for by informal carers, i.e., relatives and/or friends who may be exposed to physical, emotional and economic burdens causing severe consequences for own their health [3]. High-quality and multidisciplinary interventions are urgently needed to help people with dementia and their carers to cope with symptoms and to improve their quality of life. Among them, there are a growing number of psychosocial interventions with established effectiveness [4–8].

Psychosocial interventions encompass physical, cognitive or social activities (Table 1). They have a twofold aim: on the one hand, they attempt to maintain or improve personal functioning, interpersonal relationships and well-being in people with dementia; on the other hand, they try to minimize the risk of future disability [5,9]. During the design and the development of these interventions, person's history, family and social context, and stigma reduction are taken into account [10].

Table 1. List of psychosocial interventions.

Interventions	Definition/Examples
Carer interventions	Psychoeducation, cognitive behavioral therapy, counselling
Physical activities	Seated exercise, walking, strength training
Reminiscence	Therapy based on the use of human senses to help people with dementia remember events, people and places from their past
Multisensory stimulation/Snoezelen	Non-directive therapy aimed at providing a multi-sensory experience or single sensory focus, by adapting the lighting, atmosphere, sounds, and textures to the person's needs
Massage/touch	Regular massage forms (i.e., a touch with some pressure is applied in a moving way on parts of the body); therapies focused on finger pressure on specific points; 'therapeutic touch' (i.e., interventions where the therapist's hands may be held at a short distance from the person's body)
Behavior management	Techniques based on the ABC model where the focus is on identifying the A (antecedent or activating event), that lead to the B (challenging behavior), and examining the C (consequence) of the behavior. The aim is to improve carer's ability to identify and reduce triggers for behavioral and psychological symptoms of dementia
Cognitive-behavioral therapy	Talking therapy that helps people to understand links between their thoughts, feelings and behaviors, and use this understanding to make positive changes
Recreational activities	Scrapbooking activities, housework and daily tasks, gardening activities
Environmental design	Use of natural light; providing good tonal contrast between flooring, skirtings, walls and doors; minimizing noise sources and ensuring good acoustics by construction and sound absorbent materials, such as floating floors and decorative acoustic wall panels
Cognitive stimulation	Program of themed activities (e.g., discussion of past and present events and topics of interest, word games, puzzles) designed to increase people with dementia's cognitive and social functioning, and ultimately, their quality of life
Music therapy	Therapy aimed at stimulating different brain areas thus helping the person to express feelings and connect with past memories (e.g., playing music that is significant, listening to favourite pieces of recorded music, singing)
Aromatherapy	Therapy based on the use of aromatic plants or essential oils to reduce symptoms of anxiety and depression. The mechanism consists of the activation of the olfactory receptors and, consequently, of the brain areas associated with emotional regulation
Animal-assisted therapy	Supportive goal-oriented intervention based on human-animal interaction. It allows people with dementia to initiate a social interaction with an animal (dog, horse) in a controlled manner. It is associated with decreased loneliness and agitation, and increased motivation, pleasure and relaxation
Reality orientation	Therapy aimed at increasing cognitive stimulation by orienting people with dementia to the present (e.g., talking about orientation, including the day, time of day, date and season; using people's name frequently; discussing current events)
Memory training	Program designed to improve people's attention, concentration, and working and long-term memory (e.g., number mnemonics, story mnemonics, the method of loci)
Validation	Therapy aimed at promoting carer's ability to listen attentively and respond respectfully to the person with dementia, who can struggle to express basic needs (e.g., use of a clear, low-pitched, and loving tone of voice; eye contact; avoiding to argue)
Emotion-oriented care	Care including different approaches (e.g., validation, reminiscence, sensory integration) designed to increase people with dementia's emotional and social functioning and, ultimately, their quality of life. Focus is on supporting them in the process of coping with the disease, by linking up with individual functional possibilities, and the person's subjective experience

Note: Retrieved from [8].

Empirical evidence has shown that psychosocial interventions are more cost-effective and have less side effects than anti-dementia drugs [8]. Moreover, there is evidence for their effectiveness across several areas of individual functioning, and different types and stages of dementia [7]. A recent synthesis of systematic reviews [5] found that a multi-component exercise with sufficient intensity improves people with dementia's physical and cognitive functions, as well as their daily living activities. Moreover, the use of group cognitive stimulation was associated with people with dementia's increased cognitive abilities, social functioning and quality of life.

Nowadays, psychosocial interventions are highly recommended for treating people with dementia's neuropsychiatric symptoms and behavioural changes that are particularly difficult to manage by family and/or friends [11–13]. Environmental adjustments, such as lifestyle support, are generally first-line interventions [14]. For example, in this context, individualized music therapy, bright light treatment, and aromatherapy have been found to positively impact people with dementia's agitation and aggression [15,16]. Furthermore, teaching caregivers techniques to manage people with dementia's behaviour problems can make home living less challenging for both the person with dementia and family members [17]. Specifically, there is good evidence that group interventions consisting of both educational components focused on enhancing caregivers' knowledge of dementia and the caring role, and having a therapeutic component (for example, cognitive behavioural therapy), reduce caregivers' psychological burden and delay institutionalization [4,18–23]. Moreover, incorporating a technological component via telephone/online support could be more cost-effective [4].

However, despite the evidence, concrete actions to translate research into practice are sparse and inconsistent worldwide [2]. A lack of public and specific specialist/professional knowledge about dementia often results in stigmatization and barriers to diagnosis and appropriate care. Hence, dementia is often under and/or not timely diagnosed, leading to fragmented or completely lacking care pathways [1]. Moreover, investments in drug discovery and development have become mostly unsuccessful [24], making it urgent to establish which treatments are effective for people with dementia and their carers.

In this context, policies play a crucial role in addressing dementia challenges and establishing what is needed to meet these challenges to improve care quality. A recent review [25] analyzed global and European dementia policies to identify current challenges and gaps. Results depicted a scenario of high inconsistency and fragmentation with dramatic consequences which could affect, in particular, low and middle-income countries in the next years. Indeed, a significant variability was found among the policy documents, ranging from drafts to full strategies and plans whose implementation is mostly beginning with an unknown impact. The authors concluded that each country should set its national priorities, i.e., what it is needed to achieve for its citizens with dementia and their carers.

To our knowledge, no previous studies have been conducted investigating whether and how the issue of psychosocial care and interventions has been addressed in the national dementia plans and strategies across Europe. Due to the importance of implementing psychosocial interventions in everyday practice, the present study aims to analyze European policy documents and check whether they include reference, or full sections, devoted to psychosocial care and interventions.

This study was one of the two pillars of the Erasmus+ project entitled 'Skills in DEmentia Care-Building psychosocial knowledge and best practice in dementia care' (SiDECar) [26]. The two pillars form the basis for developing higher education curricula of studies to deliver an evidence-based, and well-systematized body of knowledge and skills on psychosocial care in dementia [27].

2. Materials and Methods

The search and analysis of European dementia plans and strategies lasted from January 2019 to October 2020. Specifically, the search interested only those countries whose organizations are members of the Alzheimer Europe (Table 2).

At first, documents were searched on the Alzheimer Europe website [28] and, if they were not indicated in that website, Alzheimer Disease International website was investigated [29]. If no document was available from any of the two websites, the search was performed using the Google search engine.

Since the Cypriot dementia strategy was advertised on the Alzheimer Europe website, although not retrievable, the authors sent a support request to AE to include this document in the list. Belgium provided the strategy of one region only, i.e., Flanders. For what concerns the United Kingdom (UK), the strategies were provided per countries, i.e., England, Northern Ireland, Scotland, and Wales. Once the documents were retrieved, if needed, they were fully translated into English by two authors (IC, VD).

Initially, all the documents were thoroughly read to check whether they include references to psychosocial care and interventions. Subsequently, the parts of the texts focused on psychosocial care and interventions were marked and analyzed by content analysis [30,31]. Thus, the relevant parts of the texts were summarized in codes, and grouped into categories and subcategories according to similarity across the codes [32]. Data analysis was performed independently by two researchers experienced in content analysis (VD, PP). Disagreements were resolved through discussion with a third author (IC). All co-authors approved every step of this analysis. The coding structure with categories, subcategories and codes is included in Supplementary Table S1.

Table 2. Overview of National Dementia Plans and Strategies across Europe.

Country	Name and Year of Publication	Source				Categories		
		AE	ADI	Google	Available on Request (n = 1)	Treatment	Education	Research
		(n = 15)	(n = 8)	(n = 2)		(n = 26)	(n = 12)	(n = 7)
Austria	National Dementia Strategy: Living well with dementia (2015)		X			X		
Belgium	Flanders Dementia Strategy (2016–2019)	X				X		
Cyprus	National strategic Plan for Dementia (2012–2017)				X	X		
Czech Republic	National Action Plan for Alzheimer's disease and other related diseases (2016–2019)	X				X	X	
Denmark	A safe and dignity life with dementia: National Dementia Action Plan (2017–2025)		X			X	X	
Finland	National Memory Program: Creating a 'Memory friendly' Finland (2013–2020)	X				X	X	X
France	National Plan for neurodegenerative diseases (2014–2019)	X				X	X	X
Germany	National Dementia Strategy (2020)		X			X		X
Greece	National Action Plan for Dementia-Alzheimer's disease (2015–2020)		X			X		
Iceland	Action Plan for services for people with dementia (2020)	X				X		
Ireland	The Irish National Dementia Strategy (2014)	X				X	X	X
Israel	Addressing Alzheimer ´s and other types of dementia: Israeli National Strategy (2013)	X				X		
Italy	Italian National Dementia Strategy (2014)	X				X	X	
Luxembourg	Final report of the Steering Committee on the development of a National Dementia Action Plan (2013)	X				X		
Malta	Empowering change: National Dementia Strategy in the Maltese Islands (2015–2023)	X				X	X	X
Netherlands	Dementia Delta Plan (2012–2020)		X			X	X	X
Norway	Dementia Plan: A more dementia-friendly society (2015)	X				X	X	
Portugal	Action Plan and Budget (2018)			X		X	X	
Slovenia	Dementia Control Strategy within 2020 (2016)	X				X	X	
Spain	Comprehensive Plan for Alzheimer's and other dementias (2019–2023)		X			X	X	X
Sweden	National Strategy for caring for people with dementia (2018)			X		X		
Switzerland	National Dementia Strategy (2014–2019): Achieved results (2014–2016) and priorities (2017–2019)		X			X		
United Kingdom-England	Living well with dementia: National Dementia Strategy (2009)	X				X		
United Kingdom-Northern Ireland	Improving dementia services in Northern Ireland: A regional Strategy (2011)	X				X		
United Kingdom-Scotland	Scotland's National Dementia Strategy (2017–2020)		X			X		
United Kingdom-Wales	Dementia Action Plan for Wales (2018–2022)	X				X		

Notes: Alzheimer Europe (AE) members. Retrieved from [33]. Abbreviations: ADI, Alzheimer Disease International. Bosnia Herzegovina, Bulgaria, Croatia, Estonia, Hungaria, Jersey, Montenegro, North Macedonia, Poland, Romania, Slovakia, and Turkey do not have a National Dementia Plan/Strategy.

3. Results

As shown in Table 2, a total of 26 national documents were found: 15 derived from AE, eight from ADI, 2 from the Google search, and one (i.e., the Cypriot strategy) was available on request. All documents were published between the years 2009 and 2020.

Five documents were available in English as coming from English-speaking countries (Ireland, England, North Ireland, Scotland, Wales). The ones translated into English by the national governments were eight (Belgium, Denmark, Finland, Greece, Israel, Malta, Norway, Switzerland). Two documents (Italy, Luxembourg) were available in an unofficial English translation. The remaining documents (Austria, Cyprus, Czech Republic, France, Germany, Iceland, Netherlands, Portugal, Slovenia, Spain, Sweden) were translated into English.

The content analysis revealed that the main categories associated with psychosocial care and interventions were homogeneous across the documents. Specifically, three main pillars emerged: (1) Treatment, (2) Education, and (3) Research.

Moreover, the analysis suggested dividing the first category into three subcategories: (1) Person-centred conceptual framework, (2) Psychosocial interventions, and (3) Health and social services networks.

Overall, as shown in Table 2, the topic of psychosocial care and interventions was addressed in all the 26 national documents, with the category of 'Treatment' covering all of them. However, while the discussion was quite general in some documents, in others, more detailed information was provided.

3.1. Treatment

Results show an emphasis on the increasing referral to psychosocial care for people with dementia as an integral part of dementia care in all the reviewed documents. The focus is intended in terms of a multidisciplinary approach involving medical treatments and psychosocial interventions to improve people with dementia's symptomatic profile, quality of life, and social inclusion. Specifically, regarding the prevention and management of the behavioural and psychological symptoms of dementia (BPSD), the Irish National Plan explicitly states that antipsychotic drugs should be used only when psychosocial interventions are not effective. Similarly, in the Swedish National Plan, psychosocial care is highly recommended as the first-line approach in dealing with BPSD, and consists of an adaptation of physical and social environment.

3.1.1. Person-Centred Conceptual Framework

Concerning the conceptual framework underpinning the interventions for people with dementia, reference is made to the nature of the psychosocial concept of care. As reported by the Austrian National Dementia Strategy, this perspective emphasizes the importance of the individual-centred needs assessment, focusing on people with dementia's personal abilities and resources. Similarly, the Northern Ireland Dementia Strategy explicitly states that psychosocial interventions should promote people with dementia's independence, while maintaining a good functioning in terms of physical and cognitive skills, emotional and psychological well-being. The Portuguese Dementia Strategy recommends a person-centred care model focusing on including people with dementia and their families in society, while encouraging their active participation in community life. The Maltese Strategy mentions the importance of developing programs of purposeful and therapeutic activities that maintain the person with dementia active and engaged in meaningful occupations. Similarly, the Swedish National Dementia Strategy recommends implementing different support measures to cover several needs of people with dementia, including special housing and day-to-day activities. Furthermore, an innovative element of the Dutch National Plan concerns the development of e-health applications, including domotics, to foster people with dementia's autonomy, and shared decisions through different disease stages.

3.1.2. Psychosocial Interventions

Concerning clinical practice, reference is made to specific types of psychosocial interventions, such as physical activities (Cyprus, Denmark, France, Germany, Greece, Malta, Norway, Portugal, Spain, Sweden, England, Wales), cognitive stimulation (Cyprus, France, Greece, Norway, Portugal, Spain, Wales), music therapy (Norway, Portugal, Sweeden, England), and occupational therapy (Cyprus, Greece, Portugal, Wales). Speech therapy (Cyprus, Greece), sensory stimulation (Cyprus, Portugal), and art therapy (Greece, England) are also recommended as appropriate psychosocial interventions. The Portuguese Dementia Strategy recommends the use of garden walks, cooking, animal-assisted therapy, Snoezelen, reminiscence, play activities, multisensory and motor stimulation, and hydrotherapy. Several strategies (Belgium, Denmark, England, Germany, Ireland, Malta, Northern Ireland, Norway, Portugal, Slovenia, Wales) emphasize the need to ensure dementia-sensitive environments, which can improve people with dementia's sense of direction, mobility, and safety within residential care settings, hospitals, community health services, private home, shops or public spaces. New buildings should be constructed or renovated to become friendly, inclusive, and supportive for people with dementia. For example, according to the Irish National Plan, hospital wards should be carefully designed in terms of environment, i.e., safe walking spaces, use of colour, lighting, signage, orientation cues and space used to promote social interactions. The Norwegian National Strategy recommends constructions to be based on universal design principles, adapted to people with dementia and their impairments, and equipped for the use of electronic aids to daily living, such as alarm technology, and other welfare devices.

3.1.3. Health and Social Services Networks

Cooperation and networking among health and social services are also mentioned in all the documents. In particular, the Greek Action Plan for Dementia and Alzheimer's Disease stresses the importance to strengthen the existing day-care centres of the Psychargos program [34] with multi-professional teams (e.g., nurses, occupational therapists, social workers). The Pillar number 2 in the Dutch Dementia Plan, called 'Dementia care for each other', aims to provide customized support to partnerships through a knowledge network where available knowledge, good practice, experiences, and tools are easily accessible digitally or live, via thematic meetings. Furthermore, the Objective number 6 in the National Dementia Strategy of England highlights the need to integrate community services to obtain a more straightforward route to access services, and a more coordinated delivery of services.

3.2. Education

The need for appropriate education and training about psychosocial interventions features 12 documents (Czech Republic, Denmark, Finland, France, Ireland, Italy, Malta, Netherlands, Norway, Portugal, Slovenia, Spain). Specifically, nine of them highlight the importance to develop and offer adequate programs of education and trainings both for professional carers from different specialities (Denmark, Finland, France, Malta, the Netherlands, Norway, Portugal, Slovenia, Spain), and informal carers (Ireland, Portugal, Spain).

A common principle is that education should be evidence-based and provide professionals with knowledge and skills on how to deliver psychosocial interventions in different care settings. Moreover, professionals should be trained to support people with dementia's identity and quality of life until the later stages of the disease.

Both the French and Spanish National Plans refer to cognitive stimulation as a content upon which education should focus. Furthermore, the Italian National Dementia Strategy stresses the need to develop documents and guidelines based upon experts' consensus, and to guarantee continuing education on psychosocial interventions. At the same time, this document does not specify any education target group.

Similarly, the need to develop and disseminate handbooks with related knowledge-based recommendations are mentioned in the Czech Republic's, Danish and Dutch National Dementia Plans. Such proposals aim to strengthen social and health professional practice and ensure a shared and coherent approach in dementia. Specifically, the Dutch Dementia Plan includes a training program called 'Dealing with dementia' aimed at a dementia-friendly society. It offers specific evidence-based courses for different target groups, i.e., individuals, companies and municipalities, to increase public awareness about dementia, and people's ability to cope with this chronic condition.

The Portuguese Dementia Strategy mentions the importance of providing education on health, psychosocial and related fields for students (during undergraduate and post-graduate studies), formal and informal caregivers. According to the Norwegian Dementia Plan, the 'Dementia ABC education program' and the 'Psychosocial Intervention ABC educational program' should be developed and promoted by the Ministry of Health and Care Services for municipal health and care services personnel.

3.3. Research

References to research are included in seven out of 26 documents (Finland, France, Germany, Ireland, Malta, Netherlands, Spain). Emphasis is placed on the need to translate the knowledge already gained in this area into practice, and increase the quality of care for people with dementia via data collecting policies about the effectiveness of psychosocial interventions. Finland's National Memory Program states that more studies are needed to better understand the implementation of psychosocial interventions into routine clinical practice, including technological innovations, and to disseminate these results across services. The German National Dementia Strategy suggests that ecological studies may investigate the weight of the various psychosocial factors, along with research on the optimization of healthcare processes. Furthermore, the Spanish National Dementia Plan emphasizes the need to support research on the physical and psychosocial needs of people with dementia, as to develop innovative models of care or technologies. Similarly, the Dutch Dementia Plan mentions the importance of research on innovations and new technology, including home automation.

4. Discussion

This study investigates whether and how the issue of psychosocial care and interventions is dealt within the national dementia strategies and plans across Europe. Results have shown that, at different levels of detail, all the documents refer to a model of integrated care and support consisting of medical treatments and psychosocial interventions. The analysis has identified 3 main pillars of psychosocial care and interventions: 'Treatment', 'Education', and 'Research'.

Regarding the category 'Treatment', it is generally recognized that psychosocial interventions should enable people with dementia to retain their functional ability and autonomy, reduce behavioural and psychological symptoms, and improve their quality of life. The theoretical framework represented by the *person-centred* model of care [35,36] implies that people with dementia should be valued as persons with the same dignity as others, and should be treated with respect as for their own life history, experiences, personality, as well as for the cultural and social contexts to which they belong. This idea is central as it is strictly associated with the formulation, choice and use of psychosocial interventions. A similar approach is radically different from the 'industrialized' vision of the care where people are dealt with as a series of tasks by professionals [7].

The *person-centred* (preferable to the alternative *patient-centred*) model of care highlights the importance of taking actions tailored to the individual needs, desires and preferences, which are immanent in people well beyond their disease. In this context, attention must be paid to people with dementia's active participation and inclusion in the community life.

Concerning clinical practice, more than half of the documents mention various psychosocial interventions including physical activities, cognitive stimulation, music, occupational, speech and art therapy, sensory stimulation and so on. In this context, the focus is also on the environmental design, which needs to be carefully considered to help people with dementia to find their way around, reduce confusion and increase independence. The underpinning idea is that people are as constrained as the environment causes them to be. In this sense, attention should be paid to the use of natural light, colour coding for walls, personalized doors, orientation cues, gardens with different areas to encourage different sensory experiences and so on.

Although some information is provided within the documents, the targets of psychosocial interventions for people with dementia are often omitted (e.g., functional abilities, behaviour, emotions). No specifications are also provided for their use in different types and stages of dementia. Furthermore, since the empirical support for various types of psychosocial interventions differs [5], this aspect should be addressed by existing policies to provide appropriate care.

Moreover, it is important to underline that the area of psychosocial interventions for informal carers is widely neglected. Indeed, while a general need for support has been mentioned, no indication of specific interventions has been provided [4].

The analyzed documents also highlight that professionals from different services should collaborate when handling matters concerning people with dementia and their families to provide holistic and integrated health and social care. This aspect is crucial since the complex range of cognitive, physical, social, and emotional issues that dementia rises cannot be easily managed by a single professional. In this regard, positive effects of using a multidisciplinary diagnostic approach have been found on people with dementia's health-related quality of life and confirmed at follow-up [37]. For example, in the Netherlands, by stimulating collaboration, *DementiaNet* has enhanced professional knowledge and skills and increased quality of care and clinicians' ability to take leadership roles in a collaborative network [38]. In Germany, dementia care networks include a growing number of community-based support services for people with dementia and their caregivers. They offer personal care and support while providing a single entry point to social services, thus overcoming the interface problem [39].

Concerning the second pillar 'Education', the emphasis is placed on the importance of education and training programs. However, targets (i.e., professions, staff qualifications, informal carers), features, and potential courses' contents are often unmentioned. In the case they are conceived for professionals, the education and training for families would remain strongly neglected with severe consequences for the considerable amount of informal and unpaid caregivers in need of support and care [27]. It seems that, nowadays, the quality of care mostly depends on each professional's theoretical and practical knowledge, personal and professional experiences and, not least, on the rules of the institutions/services/agencies he/she works for. Consequently, much more effort should be deployed to establish the best practices for social and health care practitioners. The final aim is to ensure adequate support and evidence-based interventions for people with dementia and their families.

Concerning the last category 'Research', although it results in a few documents only, it underlines the need to carry out studies on the effectiveness of psychosocial interventions to understand better how interventions work in practice. Indeed, as highlighted in the literature [7,10,40], many complex interventions are not evaluated to a standard for different reasons. Among them are a lack of standardized measurement instruments for process evaluations, and the fact that these assessments may be time-consuming, and of less interest than effect analyses.

Overall, the amount of information provided differs across the country policies, with only the category of 'Treatment' covering all of them. Furthermore, on the basis of these documents, how the provision of psychosocial care and interventions would be enabled, and how it would be assessed are not fully apparent yet.

Such a scenario could reflect recent research findings suggesting that, although progress has been made in developing and evaluating psychosocial interventions, just few of them are widely accepted and implemented among different regions [22,40]. Reasons are several. Firstly, many interventions neither have a practice manual nor a specific description of the process, making it difficult to replicate in practice. Moreover, very few data are available on the acceptability of the interventions to the target/s, which may directly impact their dissemination and use [22,41,42]. Specifically, the acceptability refers to intended recipients' judgment on whether intervention procedures are appropriate, fair, and reasonable [43]. A Japanese study [44] on the DEMBASE® program has found that the facilitators for implementing psychosocial interventions include program available for care managers and offered at no charge, feedback on professionals' work, and media coverage (e.g., nationwide newspapers and television). The barriers include professionals from different organizations who find it challenging to participate in interdisciplinary discussion meetings; and unpaid work as there is often no compensation for additional time associated with training and supervision. Results from a Dutch study [45] on the implementation of the Dementia Care Mapping in care homes show that facilitators are: professional's confidence, ability to engage staff members, and effective leadership within the organization. Instead, challenges are: high staff turnover rates, low staff educational levels and confidence, lack of time, and managerial or organizational support. Similarly, Kloos and colleagues [46] have found a range of determinants including teamwork, leadership, and organizational factors such as staffing, workload, flexibility of the organization, and availability of a clear implementation plan.

Although research in this area is still limited, it is important to highlight that barriers and facilitators are country-specific (i.e., depending on culture, socio-economic factors). Such an element should be part of the following analysis about the impact of barriers and facilitators on intervention plans. To this aim, since the culture of the care home and systems issues are crucial, 'bottom-up' approaches should involve home staff, managers and providers in the design of interventions [45].

Strengths and Limitations

Strengths include the comprehensive overview of national dementia strategies and plans of European countries. To our knowledge, no studies so far have focused on the issue of psychosocial care and interventions in the context of national dementia strategies and plans across Europe. In doing so, this study has been carefully planned, and a priori and well-defined qualitative research methodology has been used by starting from a systematic search strategy of all documents. Every stage of this project has been accurately evaluated and monitored by a panel of researchers. Nevertheless, some limitations should be kept in mind when reading our results. Local policies are not the focus of our study and, therefore, have not been included. Another question is also to what extent these policy documents reflect the actual clinical practice in each country. As previously discussed, research in this area is very recent, and future efforts should be put into the identification and understanding of the barriers to the implementation of psychosocial interventions into practice and, consequently, how to deal with them [47].

5. Conclusions

Key points and recommendations are reported in Table 3. if a well-defined set of policies and procedures are needed to regulate health and social systems, no strategy, plan or policy will be successful without proper political efforts, adequate financial investments, service accessibility, and appropriate organizational structures. Multiple and simultaneous efforts by different stakeholders are required, and all of them should be based on a shared vision, values and practices when working in this field. Policies should be harmonized across Europe and based on a comprehensive and well-integrated system of care, where psychosocial care and interventions are fully developed. Specifically, each document should provide a clearer picture of how psychosocial care and interventions would be enabled.

Research is necessary on the country-specific basis to investigate the impact of barriers and facilitators upon implementing the psychosocial interventions. Well-designed education and training programs are needed for students and both formal and informal caregivers. Finally, as working groups of people with dementia, public and private associations of formal and informal carers are growing worldwide, policy should promote and facilitate public awareness about dementia, and the development of more dementia-friendly societies. All these actions, taken together, can contribute to the improvement of dementia care, policies, and psychosocial professional culture.

Table 3. Key points and recommendations.

Key Points and Recommendations
• There is increasing evidence supporting the use of psychosocial interventions in dementia care. However, concrete actions to translate research into practice are sparse and inconsistent worldwide. • Policies serve as the bases for the translation of research findings into everyday clinical practice. • The European dementia strategies and plans refer to a model of integrated care and support consisting of medical treatments and psychosocial interventions. However, the amount of information on the latter differs across country policies, with major gaps in the areas of education and research. • Policies should be harmonized across Europe and based on a comprehensive and well-integrated system of care, where psychosocial care and interventions are fully embedded. Specifically, they should provide a clearer picture of how psychosocial care and interventions would be enabled and assessed. • Only those psychosocial interventions for people with dementia with substantial evidence for efficacy should be recommended. Aims as well as recommendations for their use in different types and stages of dementia should be clearly stated. The same methodology should be followed when addressing the issue of psychosocial interventions for informal carers. • Each policy should emphasize the need for developing evidence-based education and training programs. Aims as well as target groups should be identified. To increase public awareness, equal attention should be paid to community education. • Each policy should promote the need for research on the effectiveness of psychosocial interventions, with focus on identifying country-specific barriers and facilitators to their implementation. • Policy changes may be necessary, but not sufficient for an effective implementation of psychosocial interventions into practice. Multiple and simultaneous actions (e.g., political efforts, adequate financial investments, service design) are needed. All of them should be based on the adoption of the person-centred model of care.

Supplementary Materials: The following is available online at https://www.mdpi.com/1660-4601/18/7/3422/s1, Table S1: Coding structure with categories, subcategories and codes.

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Data Availability Statement: The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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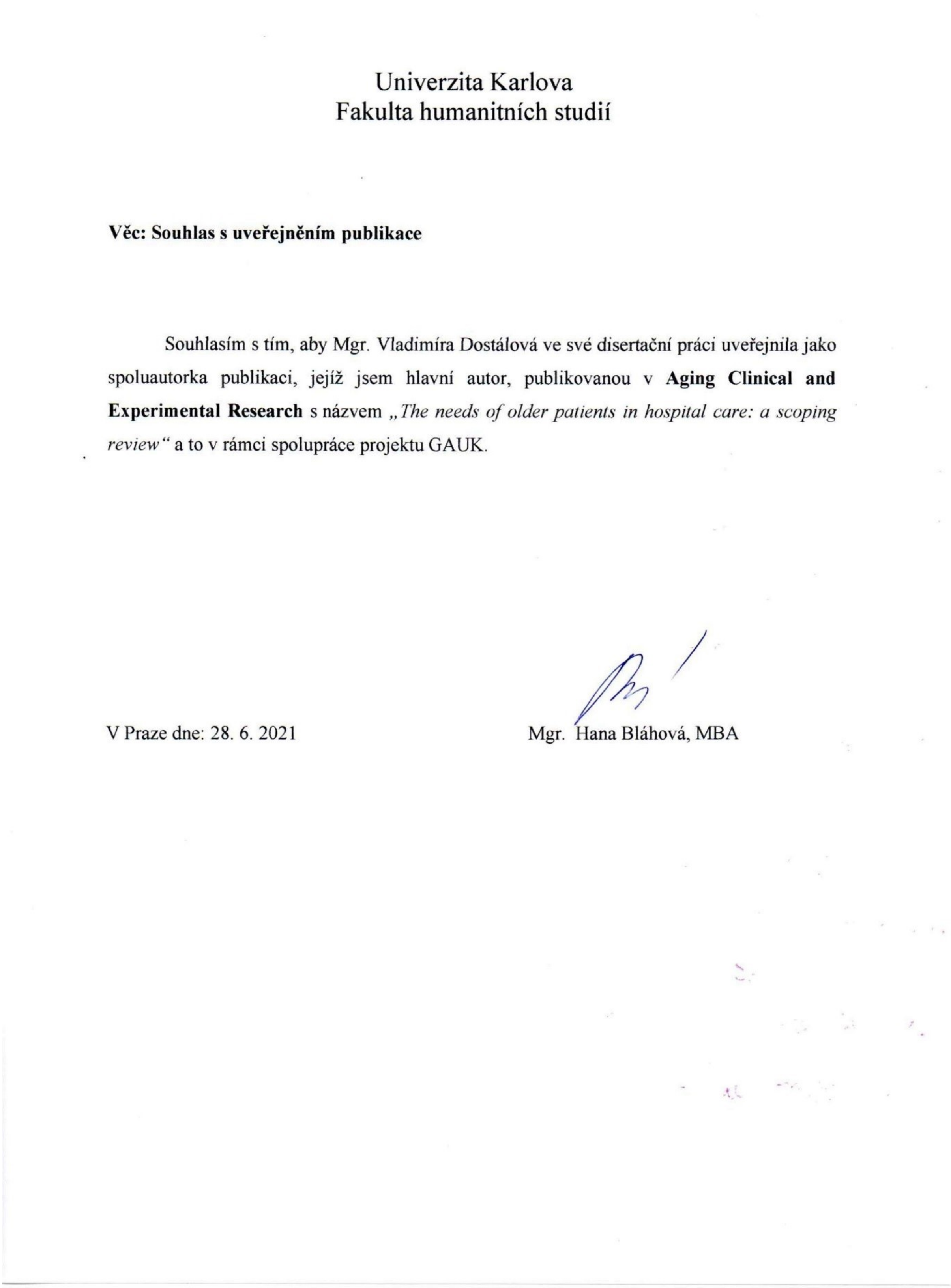
Appendix C4. The needs of older patients in hospital care: a scoping review



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REVIEW

The needs of older patients in hospital care: a scoping review

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Abstract

Background Research into care for older patients in the hospital environment has become an increasingly valuable source of information, as it gives feedback on the quality of hospital care provided. The aim of this study is to provide a comprehensive overview of the self-reported needs of older people in hospital care.

Methods The scoping review was conducted by searching the following databases: Medline, Web of Science, ProQuest Central, Scopus, Cinahl, PsycINFO and Summon.

Results The search identified articles focusing on older people in hospital care. The majority of these articles address the system and quality of care for seniors at a somewhat general and theoretical level. Met and unmet needs were assessed by a variety of test methods focusing mainly on medical issues (e.g., Mini-Nutritional Assessment, ADLs—activities of daily living, Abbey Pain Scale) and mostly from the perspective of hospital staff, carers and relatives. Only 15 articles used assessments based on information and opinions obtained from the seniors themseAbstract_Paralves (self-reported needs). A thematic analysis revealed seven main themes: conduct and care in emergency departments, dignity, nutritional care, satisfaction of patients' needs, pain, caring with respect, decision-making and spiritual needs.

Conclusion/discussion The results of this scoping review suggest that more attention should be focused on information acquired from the patients themselves, as it is only the patient, however, old or frail, who can offer an accurate perspective on met or unmet needs and the quality of care provided.

Keywords Needs · Hospital · Acute care · Senior

Introduction

Hospital care and older patients

Statistical data confirm that the number of frail patients in need of acute hospital care has been rising [1]. It has been demonstrated that these people face enormous physical and mental stress, which increases the risk of further health problems. With older patients, it is very important to be aware of the need for a differentiated and individual approach. This is also why acute health care providers must be ready to promptly identify older patients' immediate needs and respond accordingly [1].

Although the number of older and frail patients has continued to rise, it is evident that in many respects, hospital care fails to accommodate their needs. This may also impact clinical outcomes such as morbidity and mortality, which are poorer in this group compared with other patients; this may not necessarily be due to their age. Professionals and laypersons alike have repeatedly pointed out that the existing system of health care for seniors is suboptimal, and that hospital care should be adjusted for seniors. All of the aforementioned arguments demonstrate the necessity of improving the quality of health care in hospitals. The objective is not just well-organized and interconnected care, but care that is also directed towards meeting patients' needs [1].

Hospitalization and older people: a review

Research into care for older patients in the hospital environment has become an increasingly valuable source of information, as it gives feedback on the quality of hospital care provided. The authors of published works on this topic agree that acute hospital care must be adapted as soon as possible to ensure it is better suited to the requirements of older

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people, especially those with frailty and dementia [2]. This topic is also related to a higher incidence of comorbidity in older patients and the increasing frequency of their hospitalization. Due to this last factor, the entire healthcare system is overstretched, especially concerning acute care. Geriatric expertise should be required when treating these patients [3]. Some of the studies based on information acquired from seniors in hospital care refer to their somewhat limited opportunities for decision-making. Patients describe the current healthcare system as an institution of power that does not allow them to express their preferences. This is quite disturbing, as participation in decision-making is related to a higher level of patient satisfaction and better care outcomes [4].

From the publications available, there is no question that care for older people is quite a frequent topic. However, most articles focus on the issue of frailty in the context of specific diseases. Among the most frequently mentioned diseases are cardiovascular diseases, surgical and orthopedic interventions, cancer, blood diseases, respiratory diseases, metabolic diseases and infectious diseases, often viewed from the perspective of potential risks and complications (surgery and anesthesia risks, side effects of medication, falls, decubitus ulcers, incontinence, sleep disorders, etc.). There is also some focus on ethical issues such as dignity and decision-making, and on preventative measures (vaccination). Only some studies focus on multicomponent geriatric syndromes and complex interventions, also including hydration, nutrition and rehabilitation.

There have been many studies and reviews concerning older people in hospital. However, their main source of information is hospital staff or data from hospital databases and patients' documentation. Our search, therefore, concentrated on articles that answered the research question—"Which needs of seniors in hospital care are met and which are not?". Using this question, a number of articles and studies examining the needs of older people in hospital care were identified, but these needs are evaluated more from the perspective of professionals and family members than of the older people themselves. However, it must be stressed that patients' opinions and their experience of hospital care are the best source of information and reflect real practice. This study, therefore, focuses on research into older people's self-reported needs and their experience of hospital care: in other words, an assessment from their point of view.

Methods

In view of the defined research question and the surprising lack of studies in this field, a list of references was prepared in line with PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) [5]. The research question was defined using the PICO model [6], i.e., studies concerning the needs of seniors in hospital care were identified. The following databases were searched: Medline, Web of Science, ProQuest Central, Scopus, Cinahl, PsycINFO and Summon. As the Summon search engine allows all accessible information sources in the National Medical Library to be searched, the final step was to compare the results from the other databases with the results produced by Summon. In this way, another five articles covering our research field were added. The search was conducted between May and August 2019. Figure 1 shows the search results, starting with a total of 837 articles identified, and the number of articles ultimately selected.

Inclusion and exclusion criteria, limitations

The search focused on studies published during the last ten years, using the key words "needs", "unmet needs", "older people", "senior", "elderly people" (aged 65 or 65+), "acute health care", "hospital care", "quality of life", "geriatric" and their combinations, with Boolean operators. Table 1 shows the exact search string used for each database. Only English-language articles that were relevant to the research question and had been reviewed in professional journals were included. Initially duplicates were discarded, together with other studies on the basis of their titles and abstracts. The remaining articles were subjected to a full-text analysis. The selection was narrowed to publications concerning the needs of seniors, the most frequent risks, the quality and safety of care in the context of related ethical issues (the decision-making process, dignity). The final selection was made by recognizing that the people best able to provide information on the present situation concerning the needs of frail older patients in hospital are the patients themselves. Table 2 lists the search criteria. Studies concerning patients receiving palliative care were discarded, as this care is narrowly specific and long term, as were articles whose titles and abstracts clearly indicated that they were unrelated to the topic in question.

Although seven databases were searched, it was obvious that some of the publications, including some important information from gray literature, could be omitted. The search was limited to articles written in English only, meaning that the results may only represent certain countries.

Data analysis

On the basis of the research question, the chosen key words and the search criteria defined, 785 studies were identified after excluding any duplicates. Next their relevance was evaluated. The first phase was to evaluate their titles and abstracts for their relevance to the research question. Elimination criteria were used in this phase. The second phase was to evaluate the full text of the articles by means of a

Fig. 1 Flowchart

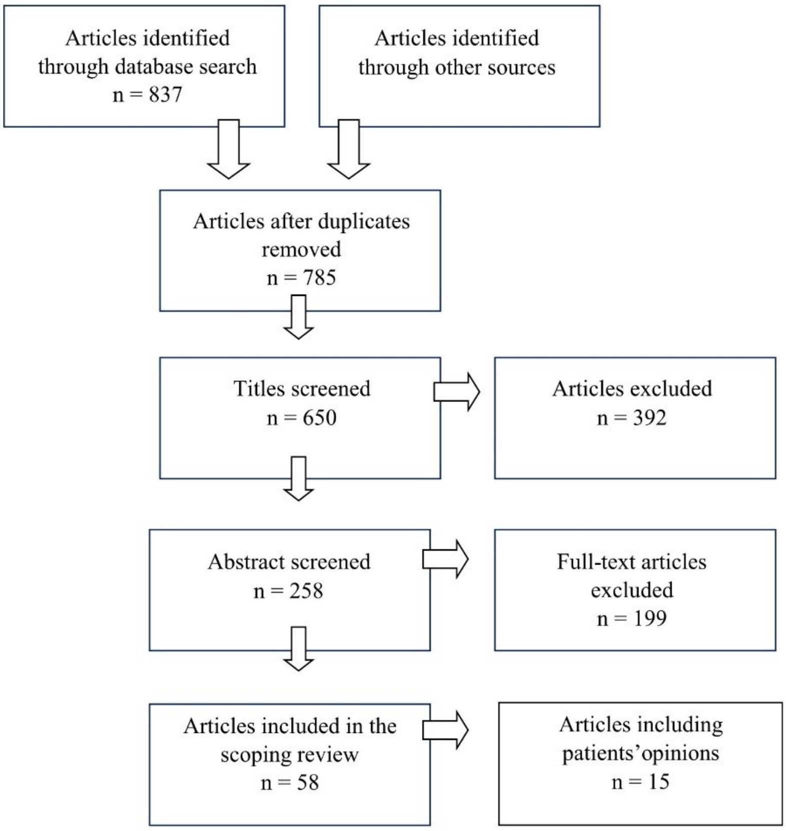

Table 1 Exact search strings

Database	Search terms	Records identified
ProQuest Central	ab((needs)OR (unmet needs) AND ab((older people) OR (senior citizens) OR (elderly people)) AND ti((hospital care) OR (senior in hospital))	83
Medline	(needs of seniors[Title/Abstract]) OR aged[Title/Abstract]) AND hospital care[Title/Abstract]) OR in hospital [Title/Abstract]) AND disability[Title]) OR illness[Title]) NOT palliative care[Title/Abstract]	231
Web of Science	TS=(needs OR unmet needs) AND TS=(older people OR senior OR elderly people) AND TS=(hospital care OR acute health) AND TI=(quality of life)	186
CINAHL	AB ((wishes or needs) AND AB ((older adults or elderly or geriatric or geriatrics or aging or senior or seniors or older people or aged 65+) AND AB (hospital care or acute care)	32
Scopus	(TITLE ("senior") AND TITLE ("needs" OR "unmet needs" OR "wish") AND TITLE (in hospital OR hospital care))	124
Summon	((TitleCombined:(needs)) OR (TitleCombined:(unmet needs))) AND ((TitleCombined:(senior)) OR (TitleCombined:(older people))) AND (TitleCombined:(hospital care)	50
PsycInfo	TI (needs or support or requirement or care) AND TI(older adults or elderly or geriatric or geriatrics or aging or senior or seniors or older people or aged 65 or 65+AND TI (hospital care or acute care or inpatient care)	131
Total number of records		837

Table 2 Inclusion and exclusion criteria

Inclusion and exclusion criteria	
Inclusion criteria	Exclusion criteria
Publications from 2009 to 2019	Duplicate articles
English language	Theoretical analysis and assessment: integrative review, systematic review, scoping review
Reviewed articles	Palliative care
Keywords: "needs", "unmet needs", "older people", "senior", "elderly people" (aged 65 or 65+), "acute health care", "hospital care", "quality of life", "geriatric"	Views of relatives, carers and representatives
	Conference reports, editorials, books and dissertations

thematic analysis. The articles were subsequently divided into quantitative and qualitative studies on the basis of the method and approach used. The final selection, therefore, contains articles where the issue of needs is assessed by the patients themselves. The publications selected are listed and summarized in Table 3, with the following information: author, year and country of publishing; research aim; research type; study participants; study design and methods; themes covered by the research.

Results

A total of 15 articles were analyzed. The final number of articles evaluated from the patient's point of view ($n = 15$) included both qualitative ($n = 12$) and quantitative ($n = 2$) research, or a combination of the two ($n = 1$). Interviews were the most frequent method ($n = 9$), combined in one case with observation. Other methods were focus groups ($n = 3$) and questionnaires ($n = 3$). One study assessing patients who were unable to communicate used a combination of testing methods by critically comparing the quality of care actually provided to the standards set for care. The most frequent aims (areas) were to examine patients' needs ($n = 7$), dignity ($n = 4$), nutrition ($n = 1$), pain ($n = 1$), respect—conduct, listening, patience, the need to help ($n = 1$), satisfaction—assurance, loneliness, limitations ($n = 1$), and conduct in emergency departments ($n = 1$). Seven main themes emerged from the thematic analysis: conduct and care in emergency departments, dignity, nutritional care, satisfaction of patients' needs, pain, caring with respect, decision-making and spiritual needs (Table 4).

Themes

Care in emergency departments

Seniors described the emergency department environment as a chaotic, noisy and crowded place where it was difficult to move around and orient themselves. There was no appropriate furniture or facilities specially adapted for older people, who encountered barriers to movement, discomfort and a lack of privacy. Seniors generally expressed dissatisfaction in all aspects of their physical, emotional and social needs. The main disruptions concerned their needs for sleep, food and hydration, as well as hygiene and patient mobility. In respondents' opinion, hospital staff were extremely busy and were unable to provide proper care for patients. Sick people received insufficient information, resulting in fear and a sense of insecurity. Patients stressed the need for understanding, patience and better communication. From their point of view, it was difficult to distinguish staff members' ranking and responsibilities. In the same study, health professionals also voiced this opinion, and they emphasized the need for education and special training in caring for senior patients. Pain management was rated positively [7].

Dignity

Both medical staff and patients agree that the concept of dignity is difficult to define, but they are in agreement on its importance. Seniors think there is insufficient privacy and dignity in hospital. The negative aspects they list are loss of control over themselves, helplessness, humiliation, isolation and a sense of being ignored. They feel their treatment lacks compassion and empathy. At the same time, however, they report that their dignity was respected during care. Medical staff understand the importance of dignity in care but lack appropriate education and practical training. The research confirms that care for older people is predominantly focused on routine work and discharging one's duties, while the personal aspect is often neglected [8, 9].

Nutritional care

In general, patients were satisfied with hospital food. Some negative aspects included food that was unappetizing or poorly presented and the omitting of food due to medical examinations, although patients mostly confirmed that they received food afterwards. An important comment is that patients noticed a shortage of staff during mealtimes, which presented problems for patients who needed assistance with eating. There was universal lack of food culture and work organization. The need for personal assistance during meals

Table 3 Summary of Individual Studies

Author/Year/Country	Aim	Research type	Study participants	Study design/methods	Themes
Bonetti et al. [10] (2017) Italy	To assess the quality of nutritional care and patients' perception of the quality of food and nutritional care	Qualitative	12 hospitals in the north of Italy, patients aged over 85	Semi-structured patient interviews	1. The quality of nutritional care 2. Nutritional culture and assistance
Calnan et.al. [9] (2012) UK	The study examined the experiences of older people in acute National Health Service (NHS) Trusts in relation to dignified care and the organizational, occupational and cultural factors affecting it	Qualitative	4 acute hospitals, patients aged over 65	Interviews with older people recently discharged from hospital, observation	1. Quality of patient care in the acute care department: care, environment, communication, information, decision-making
Ekdahl et al. [4] (2010) Sweden	To deepen the knowledge of frail elderly patients' preferences for participating in medical decision-making during hospitalization	Qualitative	5 qualitative interviews of frail elderly patients aged over 75	Semi-structured patient interviews	1. Options for patients to participate in decision-making and express their needs and wishes 2. Cooperation between patients and staff
Green et al. [14] (2012) UK	To present findings from a service user controlled research project, essentially seeking to provide a commentary by older people on their experiences as hospital visitors or as patients receiving visitors	Qualitative	older people aged over 50, 65% aged over 70	Focus groups	1. Arrangements for visits and their quality—set times and rules for visitors, communication with staff
Hodge and Wolosin [20] (2012) United States	To explore and appreciate the spiritual dimension—the relationship between addressing spiritual needs and overall perceptions/satisfaction with care	Quantitative	4112 adults aged over 65 discharged from hospital during a 12-month period	To test the study's hypothesis, a secondary data analysis of inpatient satisfaction data was conducted. The data were obtained from Press Ganey, a private company specializing in measuring patient satisfaction	1. Patients' spiritual needs 2. Satisfaction 3. Admission to the hospital—environment, visits, privacy
Kalfoss [11] (2010) Norway	To examine the conditions that facilitate good quality of life (QoL) in old age for hospitalized adults	Qualitative	Aged 60+	Focus group interviews	1. Quality of life—health, needs, mobility, care service, psychological well-being, personal competence
Kelley et al. [7] (2011) Canada	To assess the environment of an emergency department (ED) and its impact on care for adults aged 75+, using a "senior-friendly" conceptual framework that included the physical environment, social climate, hospital policies and procedures, and the wider healthcare system	Qualitative and Quantitative	1 emergency department, patients aged 75+, staff	Interviews with seniors or their proxy decision-makers, staff and key community informants; on-site observations; staff survey; hospital administrative data	1. Organization and quality of care for patients in acute care 2. Decision-making 3. Communication 4. Environment

Table 3 (continued)

Author/Year/Country	Aim	Research type	Study participants	Study design/methods	Themes
Kluit et al. [17] (2018) Netherlands	To gain insight into how the decision to hospitalize was made from the perspective of older patients with unplanned hospital admissions	Qualitative	Patients aged 70+, their next of kin and general practitioners	Interviews about the decision-making process leading to hospitalization	1. Decision-making in planned patient care
Koskenniemi et al. [16] (2012) Finland	To describe the experiences of older patients and their next of kin with regard to respect in caregiving in an acute hospital	Qualitative	Patients aged 75+ in acute care, with hip fractures	Open interviews	1. Respect in patient care—politeness, patience, reassurance, responding to information needs 2. Assistance with basic needs 3. Appreciation of older people in society 4. Nursing culture 5. Information flow
Lambert et al. [12] (2009) UK	This study focuses on the strengths and weaknesses of the quality of nursing through two internationally used assessment tools	Quantitative	Participants, aged 65+ living in care homes or awaiting hospital discharge; 5 NHS hospitals in South-West Wales	EASY-Care and MDS-RAI and structured questionnaires	1. Quality of various aspects of nursing 2. Satisfying needs
Macmillan [19] (2016) UK	To explore the impact of hospital discharge on the wider wellbeing of older people and potential implications for mental health	Qualitative	1300 people aged over 65	Inductive qualitative research, focus group interviews	1. The process of preparing patients for discharge 2. Care planning 3. Provision of information
McLiesh et al. [15] (2009) UK	This project focuses on pain management and in particular assessing older people with communication difficulties	Quantitative	Older people aged 68–96	Abbey Pain Scale, comparison of practice with care standards, audit	1. Focus on elderly patients who are unable to communicate their pain management needs verbally 2. Pain assessment and measures taken 3. Pain assessment and response 4. Communication 5. Documentation, analgesic treatment
Meide et al. [18] (2014) Netherlands	To evaluate the ethical aspect of care in connection with the experience of hospitalized elderly patients	Qualitative	Patients aged 75+ were shadowed from admission to discharge	Qualitative observational shadowing—observation	1. Decision-making 2. Security and safety 3. Communication 4. Participating in care
Munch et al. [13] (2016) Denmark	To explore how older patients experience constipation and the strategies they use to handle this condition before and during hospitalization	Qualitative	Patients aged 61–91 during hospitalization	Semi-structured interviews; data were analyzed using content analysis; average interview duration 17 min (range 6–45 min); interviews were recorded and transcribed verbatim	1. Difficulties in voiding the bowels— the balance between constipation and diarrhea

Table 3 (continued)

Author/Year/Country	Aim	Research type	Study participants	Study design/methods	Themes
Tauber-Gilmore et al. [8] (2017) UK	To report the findings from interviews conducted as part of a wider study on interventions to support dignified care for older people in acute hospital care. Patients and staff priorities regarding dignity	Qualitative	13 patients aged 65+ and 38 healthcare professionals	Interview data; interviews were transcribed verbatim and subjected to thematic analysis	1. The importance of dignity and its impact on patient care 2. Staff conduct 3. Principles of dignity

was stressed, as was the need for improvements in the entire catering area to help prevent malnutrition in older people [10].

Basic needs of the patient

For patients, the most important aspects of their hospital stay are good health, a sense of ease, and the satisfying of their basic needs [11]. Negative aspects in this area include minimal efforts by hospital staff to recognize their problems, poor communication and a lack of information. Seniors stressed the need for more patience, complaining that staff did not make sufficient time for them. Nutrition management was evaluated quite positively. Sick people often felt confined, lonely and disrespected, and they lacked any mental support. Care was seen as deficient in matters of decision-making, sleep, daily activities and social support [12].

Another area that was negatively rated concerned patients' bowel movements, where disorders are relatively common in higher age groups. It must be stressed that this is distinctly detrimental to patients' sense of well-being. Researchers emphasize the importance of routine monitoring here, with the optimal resolution of any problems [13].

One of the studies also indicated that visits (and better visiting conditions) were an important element for patients and their sense of well-being [14].

Pain

In many cases, pain management was inadequate, especially if patients had communication problems. Patients who are able to communicate verbally usually receive appropriate treatment for pain. The results showed that it is necessary to raise awareness of the difficulties concerning pain assessment and treatment for older people who cannot communicate their problems verbally. Pain was documented and assessed, but most records (93%) only included a general description, and assessments were unsystematic. A negative aspect is that 62% of respondents did not receive analgesia before painful interventions or mobilization. Only in 33% of cases was pain reassessed following the application of analgesics [15].

Respect and decision-making

A readiness to help even without the patient requesting assistance was an important priority for respondents. The study confirms that respect provides a positive emotional backdrop for communication between staff and patients. Patients expressed worry, fear or even panic about the future. They thought staff should perceive such reactions and help dispel these notions. They stressed the need for information and a sensitive, individual approach. In research on this topic

Table 4 Specific experiences and needs by theme

Analytical theme	Experiences subthemes	Needs subthemes
Needs in emergency care	Needs assessment and environment	Approach to patients Expectations Communication Food and drink
Dignity	Perception of dignity as viewed by patients, families and healthcare professionals	Perception of dignity Understanding Experience Conduct and communication Organizational culture
Nutritional care	Quality of catering and nutritional care	Food quality Serving food Tastiness and quality of food
Patients' needs	Focus on selected areas	Admission process Decision-making Quality of care and satisfaction with treatment Mental support Pain Communication Nutrition and hydration Sleep Skin care Self-care and self-concept Constipation Perception of risks Quality of life
Pain	Pain management in patients with reduced ability to communicate	Pain assessment Pain management measures Medical staff activities Documentation Communication
Respect in care and the decision-making process during hospitalization	Communication and the opportunity to participate in the decision-making process	Conduct Decision-making Listening Patience Need to help
Spiritual needs in the context of satisfaction with care	Respect for faith and identification of spiritual needs	Overall satisfaction with separate areas of care—loneliness, insecurity

the patient was often considered a passive recipient of care, someone who is incapable or unable to make decisions. There are several reasons for this. Sudden hospitalization, combined with surgery, pain and certain drugs, obviously does not aid decision-making abilities. Older people in general found the hospital environment chaotic and rigid, with staff who were not interested in showing respect. It was emphasized that apart from their professional knowledge and skills, staff members' personal qualities, their values and attitude to patients, are of great importance, and these characteristics are crucial for understanding and responding to older patients' needs [16–18].

According to Macmillan [19], older people often felt they were not ready for discharge because they had not been involved in planning their discharge, or had received insufficient information, and they also experienced difficulties in accessing essential services and support.

Care for spiritual needs

Patients consider the satisfaction of their spiritual needs to be an important aspect of care. It contributes to their general well-being and affects their assessment of other aspects of hospital care. However, patients' spiritual needs are often ignored. Medical staff respect their patients' beliefs and spiritual needs, but lack the skills required to satisfy these needs [11, 20].

Discussion

This scoping review has focused on the needs of older patients in hospital care. The results and conclusions of the reviewed studies have revealed the necessity of amending care for seniors and improving training and education for medical staff, and some studies have also suggested appropriate strategies and made recommendations on adapting the hospital environment to ensure it is better suited to the needs of older patients.

Conclusions of many authors are similar to results of this scoping review. For instance, Heckman, Molnar and Lee [3] believe the system of healthcare for this group of patients requires immediate transformation, and they propose that geriatric medicine should play an important role in this respect. Here, the authors stress that a debate must be opened immediately with all stakeholders, especially health ministries, geriatricians and old people's associations. They also call for a change in health professionals' training, and they highlight the need to ensure that there are sufficient qualified geriatricians [3].

Edvardsson and Nay [2] also point out that the acute hospital care environment does not satisfy the requirements for care for older people and significantly increases the risk of complications. It is not the authors' intention to criticize health professionals in acute care departments, but to try to improve this care and change the hospital environment [2].

The results of this scoping review have demonstrated that older people are willing and able to express their needs and wishes when receiving hospital care. However, as Ekdahl, Andersson and Friedrichsen report, [4] insufficient account is taken of patients' opinions and wishes. The conclusions of their study indicate that patients' voices are not heard, and moreover, that they do not receive sufficient information in a form they can understand [4].

Based on the information available, it is clear that there have been a number of studies addressing the needs of patients in hospital care. However, the majority of them are based on general information and theoretical foundations, and only rarely they present patients' opinions and feelings. An opportunity for patients to express their needs and expectations is a fundamental part of care, regardless of patients' age and vulnerability.

There is quite evidently a gap in the literature, as self-reported needs have been relatively neglected as a topic.

Implications

The findings of this scoping review can contribute to improving care for patients in hospitals. It is clear from the results that patients' opinions and experiences are a valuable source of information, and they should provide motivation and guidance in efforts to optimize the care of them. This should be taken into considerations about the future care for patients and the research on needs of older patients in hospitals.

Conclusion

This review has examined the needs that older patients perceive as the most important. It has pointed to seven themes that give foundation to the magnitude of patients' needs, but it has also indicated areas that receive insufficient attention. Neglected needs include for instance basic physiological requirements such as the need for hygiene or defecation. Little attention is paid to meaningful daily activity or patient participation, nor to the possibility of involving patients in care, nor to self-realization or spiritual needs.

More research is needed to fill in the missing information and above all to provide up-to-date evidence concerning the quality of care for patients requiring acute care. Future research could at the same time contribute to improvements in national strategies and better health care for frail older people. It would be interesting to compare the opinions and experiences of patients, their carers and relatives. Qualitative research would seem to be the optimal way of acquiring additional information.

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Compliance with ethical standards

Conflict of interest On behalf of all of the authors, the corresponding author states that there is no conflict of interest.

Ethical approval Not conducted, as this is a scoping review.

Informed consent Not conducted, as this is a scoping review.

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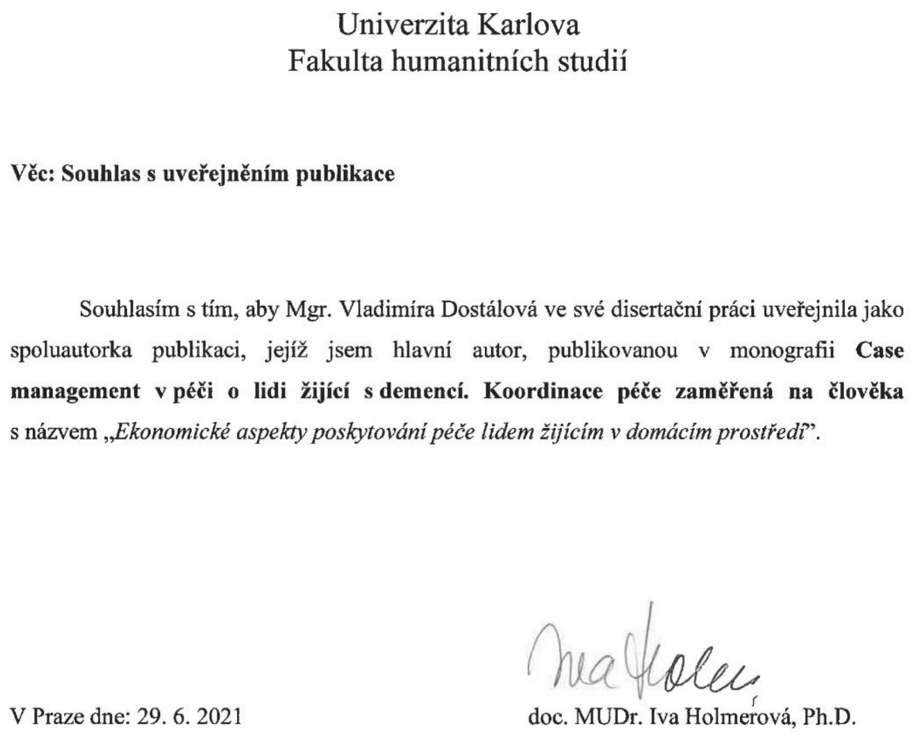
Appendix C5. Ekonomické aspekty poskytování péče lidem žijícím v domácím prostředí



Univerzita Karlova
Fakulta humanitních studií

Věc: Souhlas s uveřejněním publikace

Souhlasím s tím, aby Mgr. Vladimíra Dostálová ve své disertační práci uveřejnila jako spoluautorka publikaci, jejíž jsem hlavní autor, publikovanou v monografii **Case management v péči o lidi žijící s demencí. Koordinace péče zaměřená na člověka** s názvem „*Ekonomické aspekty poskytování péče lidem žijícím v domácím prostředí*".

V Praze dne: 29. 6. 2021

doc. MUDr. Iva Holmerová, Ph.D.

Ekonomické aspekty poskytování péče lidem žijícím s demencí v domácím prostředí

Iva Holmerová
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V rámci výzkumného projektu zabývajícího se case managementem jsme uskutečnili několik ekonomických analýz, které se týkaly jak péče v domácím prostředí, tak v prostředí ústavním (zdravotnického i sociálního typu). V následující kapitole se zaměřujeme na ekonomickou problematiku péče v domácím prostředí, protože úzce souvisí s dostupností služeb a možnostmi jejich začlenění do plánu péče, zatímco v ústavním prostředí hrají roli i další faktory, na které se zaměřujeme v jiné části této publikace. První ze studií je zaměřena na péči o lidi žijící s demencí v domácím prostředí.[154] Vycházela z dat získaných prostřednictvím lékařů specialistů, kteří poskytovali péči lidem žijícím s demencí. Jednalo se o neurology, psychiatry a geriatry. Ve studii byli zařazeni zejména pacienti, kterým byla předepisována kognitiva, tedy jednalo se o pacienty s rozvinutým syndromem demence. (Podrobnější informace ohledně metodiky, získání a zpracování dat jsou uvedeny ve zmíněné publikaci.) Tato studie byla první, která se snažila určit celkové náklady na demenci v České republice na základě dat získaných od lidí žijících s demencí a jejich rodinných příslušníků za využití české verze dotazníku RUD.[155] RUD je komplexní nástroj, který zahrnuje estimace přímých nákladů na lékařskou a zdravotní péči všeobecně jak u pacientů, tak u jejich pečujících, včetně nákladů

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[154] Holmerová, Iva – et al.: Costs of dementia in the Czech Republic. *The European Journal of Health Economics*, 2017, 18(8), s. 979–986.

[155] Wimo, Anders – Jönsson, Linus – Zbrozek, Arthur S.: The Resource Utilization in Dementia (RUD) instrument is valid for assessing informal care time in community-living patients with dementia. *The journal of nutrition, health & aging*, 2010, 14(8), s. 685–690.

na sociální péči a nepřímých nákladů, počítaje v to neformální náklady na péči. **Průměrná cena za péči o člověka žijícího s rozvinutým syndromem demence v domácím prostředí v České republice činila 1970 eur** měsíčně, což odpovídá 23 640 eur ročně. To odpovídá odhadu nákladů na péči o pacienty s demencí v České republice, který by bylo možné učinit na základě údajů o nákladech v zemích východní Evropy (11 342–12 104 dolarů) a západní Evropy (33 035–35 255 eur) podle publikace Alzheimer's Disease International – *Světové zprávy o Alzheimerově chorobě 2015.*[156] Náš odhad přímých nákladů byl však vyšší než náklady předložené Mohelskou a kol., kteří odhadovali,[157] že průměrné roční náklady na českou ambulantní léčbu činily pouze 1842 eur. Je však třeba poznamenat, že Mohelská et al. nezahrnovali náklady spojené s neformální péčí, což může vysvětlit, proč jsou náklady odhadnuté v naší studii vyšší.

Celková doba neformální péče se zvyšovala se závažností kognitivní poruchy měřené prostřednictvím MMSE.[158] Pacienti s těžší demencí vyžadovali více než dvojnásobek doby péče ve srovnání s mírnou demencí. Doba neformální péče o pacienty s demencí v České republice byla podobná době neformální péče zjištěné v některých dalších studiích, kdy se doba neformální péče pohybovala od 88 hodin měsíčně u pacientů s mírnou demencí až 320 hodin za měsíc u pacientů s rozvinutou demencí, a dokonce až 480 hodin za měsíc u pacientů s těžkou demencí. Všechny náklady vzrostly se závažností kognitivní poruchy. Podrobnější informace i prameny jsou uvedeny opět ve výše zmíněném článku. Je však důležité poznamenat, že při zjišťování nákladů na péči vznikaly určité problémy, a to především v důsledku velmi omezené možnosti získání dat o péči zejména z oblasti práce a sociálních věcí. V průběhu studie docházelo také k velmi významným změnám organizace a financování

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[156] Prince, Martin – et al.: *World Alzheimer Report 2015. The Global Impact of Dementia.* Alzheimer's Disease International (ADI), London 2015.

[157] Mohelska, Hana – et al.: Alzheimer's disease and its treatment costs: case study in the Czech Republic. *Neuropsychiatric disease and treatment*, 2015, 11, s. 2349.

[158] Folstein, M. F., Folstein, S. E., McHugh, P. R., „Mini-mental state"...*op. cit.*

zdravotnických služeb, což rovněž mohlo ovlivnit podíl přímých nákladů na péči, který byl ve srovnání s nepřímými náklady velmi nízký. Dalším omezením této studie byla poměrně malá velikost vzorku, především pro stanovení nákladů na sociální péči. Nicméně jsme zjistili, že dotazník RUD je možný a užitečný pro odhad nákladů na demenci v České republice, což naznačuje, že může být použit také v zemích s podobnými systémy zdravotní a sociální péče (tj. většina zemí střední a východní Evropy, které sdílejí podobný historický vývoj jejich systémů zdravotní a sociální péče v posledních desetiletích). Údaje z této studie mohou být proto použity k odhadu těchto nákladů v podobných zemích, které nemají údaje o celkových nákladech na demenci. Domníváme se, že jsme v rámci této studie přinesli jeden ze závažných argumentů pro uvažování o problematice demence i z ekonomického pohledu. Jde zejména o to, že **péče o pacienty s demencí v domácím prostředí a prostřednictvím rodinných příslušníků není v žádném případě péčí, která by z celkového pohledu byla péčí „zadarmo“. Naopak: po započtení veškerých nákladů na formální i neformální péči se jedná o péči, která svými náklady odpovídá jiným formám péče.**

Kromě nákladů na péči o lidi žijící s demencí jsme se zabývali také faktorem, na který je v současné době pamatováno jen okrajově, jedná se **syndrom frailty, který se projevuje mimo jiné svalovou slabost**í, u kterého jsme předpokládali též významný efekt na výši nákladů na zdravotní péči. Frailty často provází demenci a pravděpodobně ji lze do určité míry ovlivnit adekvátními intervencemi nutričními, pohybovými, a to i u pacientů s demencí, což by mohlo vést alespoň k částečné redukci nákladů na zdravotní péči. Pro tento účel jsme využili dat ze studie SHARE. Podle našich výsledků, které byly publikovány,[159] má svalová slabost významný dopad na výdaje na zdravotní péči, obzvláště ve vztahu k přímým nákladům. Proto i přes potenciální omezení této

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[159] Steffl, Michal – et al.: The increase in health care costs associated with muscle weakness in older people without long-term illnesses in the Czech Republic: results from the Survey of Health, Ageing and Retirement in Europe (SHARE). *Clinical interventions in aging*, 2017, 12, s. 2003.

studie je důležité zvážit vhodné intervence, které by mohly být zavedeny, aby se snížilo riziko svalové slabosti, což může následně snížit související náklady na zdravotní péči. Fyzická aktivita byla předtím identifikována jako vhodná intervence k snížení rizika svalové slabosti. Intervence zahrnující fyzickou aktivitu mohou být proto spojeny s úsporou nákladů. V této souvislosti by výsledky naší studie měly vést k zvýšenému zájmu o realizaci programů fyzické aktivity pro seniory, a to pro seniory s demencí.

Dále jsme se v průběhu řešení výzkumného projektu zaměřili na problematiku poskytování služeb v domácím prostředí. Důvodem byla zejména skutečnost, že podle našich zjištění z rozhovorů s pracovníky i rodinnými pečujícími, z workshopů, které se v průběhu projektu uskutečnily, a především z dat o péči, jak jsou publikována Ústavem zdravotnických informací a statistiky (UZIS) i ministerstvem práce a sociálních věcí, je zřejmé, že nedochází k žádoucímu rozvoji terénních služeb, a to i přes politické a jiné deklarace a záměry, včetně například *Programového prohlášení vlády* z ledna 2018, kde je přímo uvedeno: *„Připravíme koncepci dlouhodobé péče s cílem podpořit domácí péči a posílíme smluvní volnost mezi zdravotními pojišťovnami a poskytovateli zdravotní péče v mantinelech stanovených zákonem a pod kontrolou státu.“* Na okraj je dlužno podotknout, že toto prohlášení není unikátním, ale snahy o zajištění dlouhodobé péče, posílení péče v domácím prostředí atd. se objevují ve vládních prohlášeních již historicky, a to aniž by byly posléze fakticky naplněny. **Naopak dochází spíše k navyšování institucionálních kapacit, a to jak ve zdravotnictví, tak v sociální sféře, zatímco k adekvátnímu navýšení kapacit ambulantních a terénních služeb nedochází, respektive nedochází v žádoucí míře.**

Na tuto skutečnost jsme poukazovali již v předchozích publikacích[160] a ve výzkumném projektu zabývajícím se case managementem jsme se

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[160] Holmerová, Iva: *Dlouhodobá péče: geriatrické aspekty a kvalita péče.* Grada, Praha 2014.

jí dále podrobněji zabývali. Výsledky byly publikovány v práci *Analýza vývoje počtu pacientů domácí zdravotní péče, hospitalizovaných pacientů a klientů pobytových zařízení sociálních služeb v letech 2000–2016*[161]. Níže uvádíme některá fakta z této publikované práce.

V roce 2000 bylo ošetřeno agenturami domácí zdravotní péče 106 939 pacientů starších 65 let. Jednalo se o 7,52 % této věkové kategorie. V následujících letech docházelo k pravidelnému nárůstu počtu pacientů v domácí zdravotní péči starších 65 let. Nicméně následující tabulka (tabulka 2) ukazuje, že tento nárůst byl v poměru k populaci a nárůstu počtu hospitalizací pacientů starších 65 let výrazně menší. Velké procento pacientů starších 65 let v domácí zdravotní péči byli pacienti s chronickým onemocněním a dále pacienti s akutním onemocněním. Nejmenší část tvořili pacienti po operacích a úrazech.

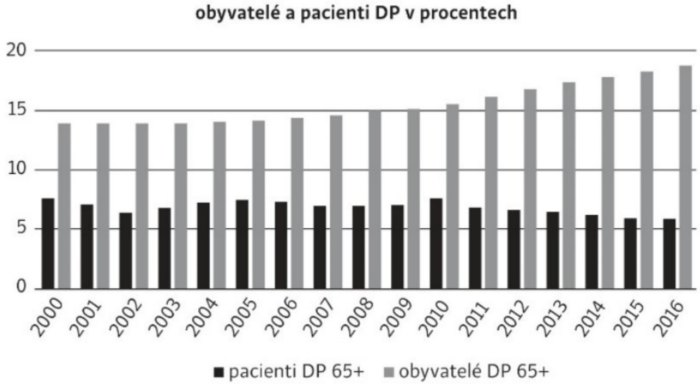
	obyvatelé 65+	hospitalizace 65+	pacienti DP 65+
2000	1 423 000	651 706	106 939
2005	1 456 391	781 114	109 851
2010	1 635 826	744 671	113 815
2016	1 988 922	851 499	116 223
nárůst %	39,77 %	30,66 %	8,68 %

Počet hospitalizací a počet pacientů, kterým je poskytována domácí péče, v porovnání s počtem obyvatel 65+

Paradoxně tedy došlo k tomu, že počet obyvatel starších 65 let mezi lety 2000 a 2016 vzrostl, rovněž stoupl počet pacientů domácí zdravotní péče starších 65 let, ale procento pacientů této věkové kategorie v domácí zdravotní péči k celkové populaci obyvatel starších 65 let naopak kleslo.

[161] Dostálová, Vladimíra – Holmerová, Iva: Analýza vývoje počtu pacientů domácí zdravotní péče, hospitalizovaných pacientů a klientů pobytových zařízení sociálních služeb v letech 2000–2016. *Geriatrie a gerontologie*, 2018, 7(3), s. 99–105.

Z následujícího obrázku je patrný nárůst počtu populace 65+, stejně tak i nárůst počtu hospitalizací pacientů 65+, a to v kontextu s počtem paceintů 65+ ošetřených v rámci domácí zdravotní péče.



Procento obyvatel 65+ vzhledem k celkové populaci a procento pacientů 65+, kterým je poskytována domácí péče, vzhledem k populaci 65+

Dále jsme sledovali vývoj počtu klientů v ústavních zařízeních sociálních služeb (do míry, kterou nám umožňovala data získaná ze statistik MPSV).

Mezi lety 2006 a 2016 byl zaznamenán velký nárůst počtu klientů v zařízeních DZR, počty klientů v DS a DOZP vesměs v tomto období byly stejné, stejně jako byl téměř neměnný počet těchto zařízení. V roce 2006 byl celkový počet všech klientů v uvedených zařízeních 56 015, v roce 2016 byl tento počet 64 682, což znamená **15% nárůst počtu klientů v těchto zařízeních**.

Je tedy zřejmé, že v posledních letech docházelo **k výraznému nárůstu počtu hospitalizovaných pacientů starších 65 let** i k růstu počtu pacientů přeložených do pobytových zařízení sociálních služeb.

Stejně tak docházelo k zvýšení počtu klientů v pobytových zařízeních sociálních služeb. I přes to, že počet pacientů starších 65 let ošetřených v rámci domácí zdravotní péče nepatrně vzrostl, došlo k procentuálnímu poklesu těchto pacientů domácí péče starších 65 let vzhledem k celkové populaci 65 let a více.

ANALÝZA FINANCOVÁNÍ DOMÁCÍ PÉČE A DOMÁCÍ ASISTENCE O GERIATRICKÉ PACIENTY (VČETNĚ PACIENTŮ ŽIJÍCÍCH S DEMENCÍ) V MODELOVÉ SITUACI GERONTOLOGICKÉHO CENTRA

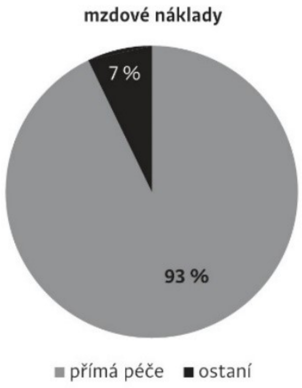
Výše uvedené skutečnosti považujeme za zásadní: **v rozporu s politickými deklaracemi o rozvoji služeb v domácím prostředí člověka, umožnění co nejdelšího setrvání v přirozeném prostředí atd., o „deinstitucionalizaci“ dochází v podstatě k snižování dostupnosti profesionální péče v domácím prostředí**, jak dokazujeme v případě domácí zdravotní péče, a to paralelně s trvajícím zvyšováním kapacity ústavních služeb. U pečovatelské služby a dalších terénních sociálních služeb nebylo možné data analyzovat, protože způsob jejich získávání a prezentace ze strany MPSV nám to neumožnil. To bylo důvodem, proč jsme považovali za nutné zabývat se ekonomickými podmínkami poskytování terénních služeb, jak sociálního charakteru, tak zdravotnického charakteru. Pro toto šetření jsme zvolili modelový případ domácí zdravotní péče (zdravotní péče) a osobní asistence (sociální služba) Gerontologického centra, které je příspěvkovou organizací městské části Praha 8, je zaměřeno na problematiku péče o seniory a snaží se o poskytování služeb dle potřeb občanů, a to za dodržování předpisů platných v obou resortech pro poskytování daných služeb, včetně vyhlášek upravujících dobu návštěv u pacienta a podobně.

DOMÁCÍ PÉČE GERONTOLOGICKÉHO CENTRA

Domácí péče (zdravotní služba) většinou navazuje na hospitalizaci na lůžkovém oddělení Gerontologického centra. Umožňuje tak i rychlejší návrat do domácího prostředí. Pacienti, kteří jsou do domácí péče předáváni, zpravidla potřebují náročnou péči, protože se jedná o multimorbidní geriatrické pacienty. Domácí péči na dva týdny po hospitalizaci může předepsat lékař Gerontologického centra, její další pokračování už potvrzuje příslušný praktický lékař, který obvykle indikuje pouze velmi závažné situace. Pacienty „z ulice" domácí péče prakticky nemá, protože ti jsou v péči praktických lékařů a jejich sester, eventuálně komerčně zaměřených agentur domácí péče, které do své péče zpravidla takto náročné geriatrické pacienty nepřijímají.

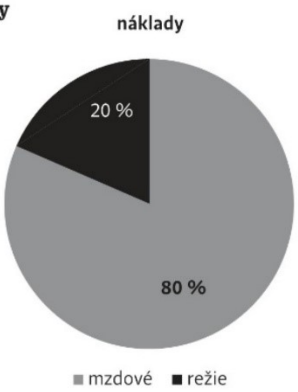
Domácí péče přijímá všechny pacienty, kteří tuto péči potřebují, i ty u kterých je péče velice časově i materiálově náročná. O tyto pacienty komerční domácí péče nestojí. Dalším problémem v tomto směru je indikace a předepisování poukazů obvodními lékaři. Ti v rámci svých úsporných opatření často předepisují výkony, které nepostačují na poskytnutí kvalitní zdravotní péče. Zdravotní sestra mnohdy musí, pokud chce poskytnout kvalitní péči, udělat i ty úkony, které nebudou zdravotní pojišťovnou proplaceny.

Domácí péče – mzdové náklady



Mzdové náklady domácí péče Gerontologického centra se dělí mezi kapitoly přímá péče a ostatní (administrativní a provozní personál).

Celkové náklady



Z celkových nákladů domácí péče Gerontologického centra jsou 80 % mzdové náklady ve výše uvedeném členění a 20 % činí režie (náklady na provoz osobních vozidel, energie a další náklady spojené s administrací HC, například IT služby potřebné pro vykazování péče pro zdravotní pojišťovny atd.).

Gerontologické centrum má smlouvu se všemi zdravotními pojišťovnami na domácí zdravotní péči, tedy odbornost 915. V následující tabulce jsou vyčísleny výkony, jejich časová náročnost a bodové ohodnocení.

kód	název	body	čas/min.
O6311	Zavedení, ukončení domácí péče	377	60
O6313	Ošetřovací návštěva Typ I	169	30
O6314	Časová dispozice	7	5
O6315	Ošetřovací návštěva Typ II	254	45
O6316	Časová dispozice	13	10
O6317	Ošetřovací návštěva Typ III	338	60

kód	název	body	čas/min.
O6318	Ošetřovací návštěva Typ IV	81	15
O6319	Fyzická asistence při poskytování domácí péče	138	30
O6321	Vyšetření stavu pacienta sestrou ve vlastním prostředí	13	0
O6323	Odběr biologického materiálu	15	0
O6325	Aplikace ordinované parenterální terapie	21	0
O6327	Ošetření stomií	23	0
O6329	Lokální ošetření	21	0
O6331	Klisma, výplachy, cévkování	22	0
O6333	Aplikace léčebné a inhalační terapie	5	0
O6335	Nácvik a zaučování inzulinu	7	0

POSOUZENÍ EKONOMICKÉ RENTABILITY TERÉNNÍCH SLUŽEB V AKTUALIZACI ZA ROK 2017

Výnosy, 1 hodina práce všeobecné sestry

Dle úhradové vyhlášky č. 348/2016 Sb., která přepočítává cenu bodu dle skutečných vykázaných bodů hodnoceného období a bodů vykázaných v referenčním období a počtem pojištěnců v daném období a referenčním, stanovila z tohoto výpočtu cenu za 1 bod na 1,02 Kč. Nejfrekventovanější výkon v domácí péči, kód 06315, má hodnotu 254 bodů, a je tedy ohodnocen 259 Kč s časovým limitem 45 minut. Počítáme-li 15 minut na přesun k dalšímu pacientovi, je částka za výkony za hodinu práce konečná. Tento výkon se dá kombinovat s výkony: lokální ošetření, ošetření stomií, odběr biologického materiálu atd. Tyto výkony nemají časový limit, zároveň jsou ale určené na úhradu zdravotnického materiálu použitého na provedené ošetření.

Úhrada za dopravu k pacientovi je za návštěvu u pacienta v jeho domácím prostředí pro GC stanovena paušálem ve výši 28 Kč.

Náklady na 1 hodinu práce všeobecné sestry

Pro tuto náročnou činnost je zapotřebí, aby byla sestra schopna pracovat samostatně a zodpovědně, východiskem toho jsou samozřejmě také adekvátní kvalifikace a zkušenost. V tomto typu domácí péče tedy nelze zaměstnávat sestry bez dostatečné praxe, kvalifikace a zkušenosti. Základní tabulková mzda činí 26 060 Kč + osobní ohodnocení 1000 Kč + geriatrický příplatek 1100 Kč. Celkem za rok 337 920 Kč. S odvody za organizaci to činí 459 571 Kč. Jedná se o všeobecnou sestru s vysokoškolským vzděláním (Bc.) a s 18letou praxí; 459 571 + 20 % režijních nákladů = 551 482 Kč na jednu sestru na rok.

Počet pracovních hodin za rok je 2000, pokud odečteme pět týdnů dovolené – 200 hodin, 2000 – 200 = 1800 hodin. Na přesun k pacientovi je potřeba 15 minut, tj. 25 % hodiny; 1800 – 25 % = 1350 hodin za rok; 551 482 : 1356 = 409 Kč.

Mzdové náklady na hodinu přímé péče všeobecné sestry jsou tedy 409 Kč.

Shrnutí

Náklady na 1 hodinu práce všeobecné sestry v Kč

celkové náklady včetně režie
409

Výnosy od ZP za výkon trvající s dopravou 1 hodinu v Kč

výkony	doprava	celkem
259	28	287

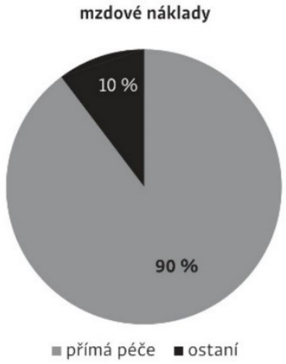
náklady celkem	výnosy celkem	rozdíl
409	287	122

Z výše uvedené analýzy, která je modelována na optimální stav (bez pracovní neschopnosti, fluktuace personálu atd.), zjevně vychází, že **pokud zařízení postupuje dle všech pravidel, jen těžko lze provozovat ziskovou domácí péči**. Úhrada ve výši 287 Kč nepokryje ani mzdové náklady a v průběhu poskytování služby dochází ke ztrátě.

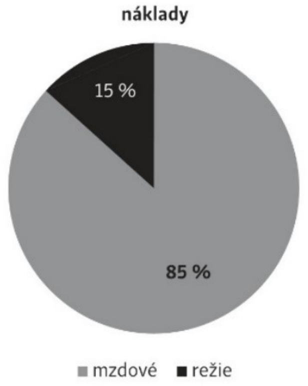
Osobní asistence Gerontologického centra

Osobní asistence (sociální služba) opět přijímá zpravidla pacienty z lůžkového oddělení, z domácího prostředí jsou požadavky zejména na péči o pacienty s demencí. Kombinace problematiky demencí a geriatrické tak činí tuto službu opět náročnější, než je například domácí asistence u mladších lidí se zdravotním postižením (které naše služba nemá jako cílovou skupinu definované).

Mzdové náklady osobní asistence Gerontologického centra mají následující rozložení: přímá péče a ostatní (administrativní a provozní personál).



Z celkových nákladů osobní asistence Gerontologického centra činí 85 % mzdové náklady v níže vedeném členění a 15 % režie (náklady na dopravu asistentek, energie a další náklady spojené s kanceláří HC, zajištění PC atd.).



Posouzení ekonomické rentability rok 2018

Základní tabulková mzda činí 22 320 Kč. + osobní ohodnocení 1000 Kč + geriatrický příplatek 1100 Kč. Celkem za rok 293 040 Kč, s odvody 398 534 Kč.

Jedná se o sociální pracovnici se středoškolským vzděláním a se 7letou praxí.

Režijní náklady jsou zhruba ve výši 15 % (zpracování mzdového a finančního účetnictví, náklady na prostory kanceláře, doprava za klienty, povinné vzdělávání atd.): 302 736 + 15 % = 458 315 Kč.

Osobní asistentka potřebuje na dopravu ke klientovi a na zpracování dokumentace zhruba 20 minut, j. 33 % každé pracovní hodiny. Z celkového počtu pracovních hodin za rok tedy odečteme 33 % hodin, tento čas nemohou být asistentky u klientů, a tudíž ho nemohou klientům účtovat a nelze tento čas účtovat do dotací na sociální služby.

Počet pracovních hodin za rok je 2000, pokud ještě odečteme šest týdnů dovolené (pět týdnů řádné a týden dodatkové za práci s klienty s demencí) – 240 hodin, osobní asistentka pracuje 1760 hodin v roce; 1760 – 33,3 % = 1172 hodin; 458 315 : 1172 = 391 Kč.

Náklady na 1 hodinu přímé péče jsou **391 Kč**.

Výnosy

Platba od klienta může být maximálně ve výši **130 Kč** za hodinu přímé péče.

Další příjmy budeme modelovat na příjmech osobní asistence GC.

Dotace od MHMP v roce 2018 byla na osobní asistence ve výši 545 000 Kč.

Grant od MHMP v roce 2018 byl 528 000 Kč.

Osobní asistentky byly u klientů 5000 hodin.

1 073 000 : 5 000 = **214,6 Kč**

Výnosy od MHMP na hodinu přímé péče jsou **215 Kč**.

náklady 1 hodinu přímé péče	výnosy od klientů a dotací	rozdíl
391	345	46

Tento výpočet vychází z optimálního stavu. Do časové náročnosti asistentek není započítáno povinné vzdělávání, pracovní neschopnost či fluktuace. I takto generuje každá hodina přímé péče ztrátu ve výši 46 Kč.

Výše uvedené výsledky korespondují s názorem Sekce domácí péče České asociace sester, která upozorňuje ještě na další závažnou skutečnost, a to indikování domácí péče a jejího rozsahu výhradně lékaři bez nemožnosti tuto situaci ovlivnit ze strany sester, tedy nerespektování jejich odbornosti omezuje i možnost poskytování péče dle objektivně hodnocených potřeb pacienta.

„Ačkoli je domácí ošetřovatelská péče nositelem samostatného výkonu, zdravotní pojišťovny neuznávají kompetenci všeobecné sestry ve vedení ošetřovatelského procesu. V rámci stávající indikace domácí péče sestra nemá kompetenci určovat rozsah péče, která vychází z potřeb a problémů pacienta klasifikovaných v ošetřovatelském procesu. Přichází k pacientovi, u kterého je již plán péče stanoven na základě lékařské diagnostiky, která ovšem určuje pouze rozsah onemocnění, na rozdíl od ošetřovatelské diagnostiky, která určuje zásah onemocnění do života pacienta a zohledňuje další faktory, které onemocnění významně ovlivňují.“[162]

ZÁVĚREM

Péče o lidi žijící s demencí je náročná z pohledu času, potřebných znalostí či dovedností, fyzické i emoční zátěže a v neposlední řadě představuje také významnou ekonomickou zátěž. V současné době hovoříme velmi často o ekonomické náročnosti péče v institucích, která je zpravidla zjevná tím, že jsou všeobecně známy náklady institucí, a to jak ve zdravotní, tak sociální sféře, tyto náklady se diskutují, a přestože je financování těchto institucí řízeno různými mechanismy a do značné míry tu existují i místní a regionální rozdíly a diference financování jednotlivých institucí, všeobecně je známo, že za lůžkoden v následné zdravotní péči získává zařízení mezi 1000–2000 Kč. Poněkud nižší (či zdánlivě nižší) jsou úhrady za pobyt v zařízeních sociální péče, kde se obvykle uvádějí poněkud nižší částky za lůžko a den, avšak k tomu je třeba přičíst úhrady za zdravotní péči. Přestože dosud nedospěla ministerstva (MPSV a MZd) k uspokojivé legislativě upravující integrovanou zdravotně-sociální péči či dohodě o úhradách za zdravotně-sociální péči, různé pracovní materiály, které z rozličných jednání vycházejí, kalkulují úhradu nákladů pobytu v ústavní péči velmi obdobně, a to v celkové výši přibližně 1500–2000 Kč za lůžko a den.

V České republice se traduje, že péče v domácím prostředí je efektivnější a levnější. To může platit jen pro některé případy, ale v mnoha případech to neplatí. V naší studii, která zkoumala péči o pacienty s rozvinutým syndromem demence, jsme prokázali, že péče o tyto pacienty v domácím prostředí je obdobně nákladná jako péče v instituci.[163] Kalkulace pomocí RUD zahrnuje náklady na péči, ale nikoli další životní náklady a nikoli sekundární nemocnost a potřebu zdravotní péče

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[162] Kabát J., podklady pro sekci domácí péče České asociace sester

[163] Holmerová, I., et al., Costs of dementia..., *op. cit.*

o rodinné příslušníky, která může být – a zpravidla bývá – také velmi významná a může představovat další význačné náklady. Péče o lidi žijící se syndromem demence je tedy ekonomicky nákladná jak v domácím, tak v ústavním prostředí, pokud je poskytována v kvalitě a rozsahu, který odpovídá potřebám lidí žijících s demencí (ponecháváme stranou „úspory" vzniklé nekvalitní péčí a zanedbáváním). V současné době tedy naše společnost vynakládá na péči o lidi žijící s demencí značné prostředky. Ty jsou do velké míry závislé na progresi syndromu demence (jak je všeobecně známo), ale i na přítomnosti dalších komorbidit včetně frailty (jak jsme ukázali i ve studii z dat SHARE). Náklady na péči se nejvíce odvíjejí z množství času, respektive práce, která byla na péči vynaložena. Vyšší náklady na péči souvisejí samozřejmě s vyšší kvalifikací pracovníků, adekvátní kvalifikace je však podmínkou kvalitní péče. Jak je tedy možné zajistit co nejkvalitnější péči o tuto velmi významnou skupinu lidí, kteří jsou velmi křehcí, jejichž zdravotní stav je proměnlivý a komplexní, a zároveň jak je možné docílit co nejefektivnější využití prostředků, které lze na péči vynaložit? Jak jsme již výše zmínili, odpověď na tuto otázku není jednoduchá a v žádném případě nejsou jednoduchá řešení. Pro někoho může být nejlepší volbou pobyt v instituci poskytující kvalitní péči, pro někoho setrvání v domácím prostředí. Péče musí vycházet z vyhodnocení potřeb a přání daného člověka, ale také z vyhodnocení zdrojů, které jsou k dispozici. Tyto zdroje (ať se jedná o finanční, materiální, či lidské) by měly být vynakládány efektivně, aby sloužily přímo uspokojování potřeb daného člověka (či skupiny lidí v péči) a neměly by být vynakládány zbytečně, ať se již jedná o nadměrnou administrativu, opakované výkony, špatnou koordinaci péče, zbytečné převozy, překládání pacientů/klientů z jednoho místa do druhého, či veškeré duplicity a nedorozumění plynoucí z nedostatečné komunikace. S výše uvedenými a dalšími skutečnostmi jsme se v rámci výzkumnéh projektu setkali. Jednou z cest, jak je lze odstranit a zajistit lepší efektivitu péče, je lepší koordinace služeb a komunikace mezi jednotlivými aktéry jejich poskytování.