

# INFORMAL CARE IN THE CONTEXT OF LONG-TERM HEALTH CARE FOR THE ELDERLY IN SLOVENIA: A QUALITATIVE STUDY

## NEFORMALNA OSKRBA V OKVIRU DOLGOTRAJNE ZDRAVSTVENE OSKRBE STAREJŠIH V SLOVENIJI: KVALITATIVNA ŠTUDIJA

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### ABSTRACT

**Background:** Slovenia is an aging society. Social security expenditures for the elderly are rising steadily, and the majority of Slovenians are firmly convinced that the state must provide elder care. This situation means that informal caregivers face many challenges and problems in their altruistic mission.

### Keywords:

caregivers, long-term health care, elderly, elder care, Slovenia, qualitative study

**Objectives:** To explore the experiences and feelings of informal caregivers and to provide an understanding of how informal caregivers support the elderly and what challenges and difficulties they face in Slovenian society.

**Methods:** The study is based on qualitative semi-structured interviews with 10 caregivers. In addition to descriptive statistics, we conducted a qualitative study using the qualitative content analysis method.

**Results:** We identified four themes among health caregivers' experiences with challenges and problems in providing long-term health care for the elderly. Caregivers pointed out that they are mostly left to themselves and their altruistic mission of giving informal long-term care to their elderly relatives and friends. Systemic regulation of the national public health care system is the source of many problems.

**Conclusion:** Other social systems determine and limit the position of informal caregivers in Slovenia. This qualitative study should be understood as useful stepping-stone to future research and real improvement in this area.

### IZVLEČEK

**Ozadje:** Slovenija je starajoča se družba. Izdatki za socialno varnost za starejše nenehno naraščajo in večina Slovencev je trdno prepričanih, da mora država zagotoviti oskrbo starejših. To pomeni, da se neformalni oskrbovalci v svojem altruističnem poslanstvu srečujejo s številnimi izzivi in težavami.

### Ključne besede:

oskrbovalci, dolgotrajna zdravstvena oskrba, starejši, oskrba starejših, Slovenija, kvalitativna študija

**Cilji:** Preučiti izkušnje in občutke neformalnih oskrbovalcev in razumeti, kako neformalni oskrbovalci podpirajo starejše ter s katerimi izzivi in težavami se srečujejo v slovenski družbi.

**Metode:** Študija temelji na kvalitativnih polstrukturiranih intervjujih z 10 oskrbovalci. Poleg opisne statistike smo izvedli kvalitativno študijo z uporabo metode kvalitativne analize vsebine.

**Rezultati:** Med izkušnjami neformalnih oskrbovalcev smo izbrali štiri teme z izzivi in težavami pri zagotavljanju dolgoročne zdravstvene oskrbe starejših. Oskrbovalci so izpostavili, da so pri neformalni dolgotrajni oskrbi svojih starejših sorodnikov in prijateljev večinoma prepuščeni sebi in svojemu altruističnemu poslanstvu. Sistemska ureditev nacionalnega sistema javnega zdravstvenega varstva je vir številnih težav.

**Zaključek:** V Sloveniji drugi družbeni sistemi določajo in omejujejo položaj neformalnih oskrbovalcev. To kvalitativno študijo je treba razumeti kot koristno odskočno desko za prihodnje raziskave in resnične izboljšave na tem področju.

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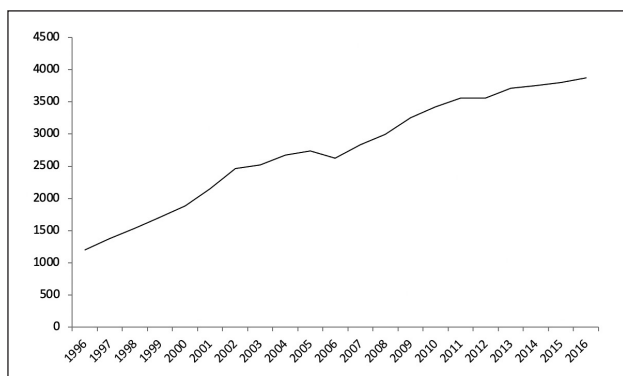
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## 1 INTRODUCTION

Various policy issues regarding population aging and the quandary of how to best serve an aging population that needs long-term care are increasingly urgent in basically all European countries (1-3).

Elderly people often have more chronic diseases, that's why they frequently attend family medicine practices and need help with care. Up to 99% of women and 97% of men over 65 years old have more than one chronic disease. They often have more social and psychiatric problems, medically unexplained conditions and are prescribed more psychotropic drugs and analgesics. Of the almost 17 million prescriptions written in Slovenia in year 2011, more than 9 million were prescribed to people older than 60, which is 52,94 %. 20 % of people over 70 years of age are being treated with more than five drugs at once. This is associated with adverse drug effects, drug-drug interactions, more hospitalizations, longer hospitalizations and re-admissions (4, 5). They often need help with organizing their medication intake, transport to hospitals, collecting referrals and medications from pharmacies.

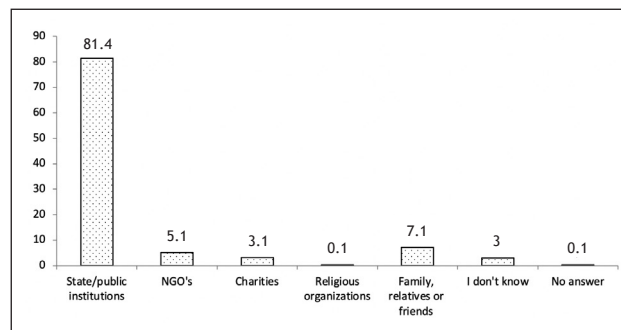
Slovenia is also a markedly aging society. In the last ten years the aging index has risen from 116.3 in 2008 to 131.7 in 2019 (6). Accordingly, age-related social benefits have increased linearly, especially in the last twenty years. From 1996 to 2016 Slovenia increased its social security expenditure for the elderly by 31%. Twenty years ago Slovenian expenditure for elder care was 1.20 billion euros, but today it is much more: 3.87 billion euros in 2016 (Figure 1).



**Figure 1.** Age-related benefits in Slovenia, 1996-2016 (euro million) (6).

The data in Figure 1 are consistent with Slovenian expectations. Slovenians are firmly convinced that the state is the main institution responsible for elder care. This situation is probably the result a strong welfare state system in the past. For instance, only 7.1% of the population think family, relatives or friends should have

to care for the elderly. Slovenians also do not think that elder care is the responsibility of religious and/or non-profit organisations (Figure 2).



**Figure 2.** Who should take care of the elderly? (N=1.204) (7).

The belief that the state is the main institution responsible for various populations and their needs (this opinion is also held regarding health care for the sick, education and schooling, etc.), is a negative assumption for informal caregivers, or at least a negative starting point on their path to success (7). Such a finding is crucial for the interpretation of qualitative data. It offers us a framework that clearly shows that caregivers in Slovenia are more or less left to themselves and their altruistic mission of giving informal long-term care to help their loved ones.

Regardless of the economic and social welfare situation in the country, the family is recognized as one of the core welfare institutions and a positive source of support for dependent older people. The family-based care model, in which a very high level of long-term care demand is traditionally met, is seen as a form of informal care (8). Slovenia is currently seeing a trend whereby increasing numbers of working-age people are reducing their working hours, resigning from their jobs, or simply curtailing their leisure activities in order to informally care for relatives or friends (9).

In their altruistic mission, informal caregivers face many challenges and problem above and beyond the fact that they are usually not health care professionals. This means they face challenges of varying complexity (e.g., feeding, toileting, mobility assistance, bed-making, bed-bathing, monitoring intravenous infusions, repositioning bedridden patients, etc.). Informal caregivers are familiar with the daily conflict between working and caring. They occasionally have to take short-duration leaves of absence in order to deal with health-related emergencies or unexpected elder care needs. In some informal caregiving is a paid activity in different percentages and amount of time. For example, in Hungary and Romania informal care givers receive an allowance for an unlimited time, on the other hand in France, Finland, Denmark for a limited

period. Employers (in the public and private sectors) offer caregivers the option of reducing their working time or guarantee the right to switch to flexible working time (9, 10). However, longer leaves are often unpaid and are often subject to approval by the employer, especially within the private sector. In Slovenia elderly (and other people that require special assistance) are legally entitled to a home care assistant who can be their family member. They can receive a partial payment for their lost income (751,77 EUR gross profit) (11).

Given its altruistic character, informal care can definitely be a source of satisfaction. Some qualitative studies of the topic have shown that caregivers frequently emphasize the increased self-worth, closer relationships and sense of meaning gained from their caregiving work (12, 13). However, there is also a darker side (14). In addition to policy frameworks that nominally define the rules, informal caregivers confront numerous other challenges and problems, such as managing the disease and at the same time dealing with inappropriate behaviors, cognitive and psychological state of the elderly, difficulty to balance care with personal life, lack of time, access and support, mental stress and physical burden, unsatisfactory amount of information on how to reach the proper medical services. (13, 15, 16). Informal caregivers deal with the functional and physical impairments of the elderly. Their work frequently depends on the work of the emergency department, hospitals, social services and state administration, especially in times of global economic crisis (17). Sometimes they have to bear unexpected out-of-pocket expenditures, opportunity costs and emotional, physical and social well-being costs (18).

Caring for an older person is a chronic stressor and leads to negative psychological, behavioral, economic and physiological effects (19). The consequences for informal caregivers can be severe: lifestyle disruption, social seclusion and withdrawal from leisure activities. In the worst cases people feel helpless because they are unable to meet the increased physical and mental needs of their elderly relatives and friends, to whom they are emotionally attached (20).

There is little research in Slovenia about caregivers and the challenges and problems they face. National studies focus more on access to and quality of long-term care services provided by the state, the organisational dimension and innovations in formal (institutional) long-term elder care (21-23). These studies are more in the domain of social work, which means they completely neglect caregivers' views on long-term elder care.

The objective of this qualitative study is to fill that gap. It explores the experiences of informal caregivers in Slovenia that care for the elderly. The fundamental goal is to provide an understanding of how informal caregivers support the elderly and what challenges and difficulties they face.

A project called 'Obstacles' was designed to find the answer to this research question. It collected subjective qualitative data about caregivers' experiences. The study findings are applicable for caregivers and policy-makers, who need not only official data, statistics and strategic documents, but also information from caregivers if they want to make overall improvements in the field (24).

## 2 METHODS

### 2.1 Study design

#### 2.1.1 Qualitative component

The study is analogous to other qualitative studies, which seek to describe life-worlds 'from the inside out', from the point of view of people that have actually participated in informal long-term elder care in Slovenia (25). The study relies on qualitative semi-structured interviews with 10 caregivers that were involved in long-term elder care provision in Slovenia. Interviews were conducted at health facilities and at homes of caregivers between March and May 2019.

#### 2.1.2 Quantitative component

Quantitative data from a national public opinion survey and official data from the Statistical Office of the Republic of Slovenia (SORS) focused on long-term the health care for the elderly were also used. Due to the contextualization of the qualitative results, we used already existing demographic databases. We performed frequency statistics using the SPSS statistical tool, version 12.0.

### 2.2 Selection of study subjects

This study is the first qualitative study of informal elder care. We decided to interview caregivers that we believed would offer the most information about their challenges and problems with long-term health care for the elderly. Ten caregivers were included in the study and when their answers began to repeat, saturation was achieved. When selecting the caregivers, we considered the following criteria: they have the knowledge and experience that the investigators need (working with the elderly for the last few years); they are capable of reflection (because of established relationship with them prior to study, interviewers chose them according to their own judgement of being capable of reflection); they had time to be interviewed; and they were willing to voluntarily take part in our study.

In November 2018, the interviewers had training on conducting interviews and on methods of qualitative research. At the training, which was conducted under the guidance of DRP and AM, the interviewers were explained how to provide the most variable sample of interviewees. Table 1 presents the characteristics of interviewers and interviews.

**Table 1.** The characteristics of interviewers and interviews.

Interviewers	Gender	Occupation, credentials, experience	Participant knowledge of interviewer, relation between them	Duration of interviews
BP	Female	MD, PhD student	She knew that they are caregivers and asked them in person if they wanted to participate, no one declined her offer	30 min both
JRI	Female	MD, psychiatry resident, PhD student	Chose two people from her surroundings, no one refused	20 min both
ŠT	Female	MD, GP, PhD student, PhD; an Teaching	Chose two caregivers from the clinic where she works, no one refused to participate	60-90 min
ED	Female	Assistant for First Aid, University of Ljubljana, Faculty of Health.	Mother and a neighbour; she chose them according to the instructions from the training; mother used to work at an elderly home and neighbour is actively participating at a club of retired people; no one refused to participate	24 min; 13 min
MKK	Female	MD, GP, PhD	Chose two caregivers from her practice; no one refused to participate	30 min; 1 h

Participants (caregivers) were approached face-to-face or by telephone, they received description of the purpose of the study and reasons for doing the research, and no one refused to participate. All interviews were conducted face-to-face, nine of them at caregivers' homes and one at office, with nobody present besides the caregivers and interviewers. All of the interviews were audio-recorded and transcribed verbatim by a trained transcriber. No audio recordings were returned to participants for comment, but some of the written transcripts were, although none of the caregivers provided any additional comments. Repeated interviews haven't been carried out. Also some field notes were made during and after the interview, later discussed together with supervisors DRP and AM.

### 2.3 Measurements and qualitative methods

Quantitative measurements in the study are based on databases from the public opinion survey and SORS. Some descriptive statistics were used. The qualitative part made use of an 'in-depth' interviewing approach, which sees the interview process as collaboration between the researcher and the caregiver, wherein both partners share reflections and information (27). We used semi-structured interactive interviews. Questions, prompts, guides were provided by the authors. The interview guide questions were designed based on a review of literature and using the comments made by informed advisers. We collected the information with respect to the time period of caring, reasons for the decision of caring, additional support and inclusion of other persons, experiences with health care system, communication with health care staff, their observations of coordination made by health care staff, barriers in the use of health care services, cooperation with district nurses. We also asked caregivers where they acquired the knowledge and skills to care for and what

they would need most to improve care. The interview guide was not pilot tested, but it was presented to the Ethics Committee, which had no comments on the script.

### 2.4 Outcomes and analysis

In addition to descriptive statistics calculated using the software Nesstar (for online analysis), a qualitative study using qualitative content analysis was conducted. This involved inductive content analysis, which includes coding, creating categories and abstraction (framing a general description of the research topic through generating categories) (28). A manual open-coding procedure based on breaking data apart and delineating concepts to represent blocks of raw data was used (29). All researchers independently coded the interviews and supervised the process. We analyzed the answers of the respondents in concordance with the qualitative content analyses. We formed codes and then combined them into categories (higher rank codes), which can be logically connected and methodically described. Two independent encoders did the final coding. The authors agreed on the differences between coders regarding the differently coded segments of the interviews. Contradictions, assumptions were discussed and resolved by discussion with DRP, AM, and the coding scheme was modified several times. With this, we formed the paradigmatic model, which is available in the results section of the study (also known as the 'unitizing process') (30).

## 3 RESULTS

### 3.1 Qualitative content analysis findings

The demography of caregivers interviewed is presented in Table 2, which describes the participants in terms of several demographic variables.

Table 2. Demography of caregivers interviewed.

Interviewer	Caregiver ID	EQF Education level <sup>1</sup> Residence	Age	Gender	Relationship with the elderly person
BP	CG1	Level 4; goriška region, a farmer	58	Male	Son
BP	CG2	Level 4; osrednjeslovenska region, a retired accountant	60	Female	Nephew
AČ	CG3	Level 7; rural area, social worker	56	Female	Daughter
AČ	CG4	Level 8; city area, nurse	47	Female	Daughter
VK	CG5	Level 6; city area	69	Female	Unspecified
VK	CG6	Level 4; city area	59	Female	Daughter
ED	CG7	Level 4; rural area	53	Female	Daughter in-law
ED	CG8	Level 4; rural area	59	Male	Relative (unspecified)
MKK	CG9	Level 4; rural area	65	Male	Nephew
MKK	CG10	Level 5; rural area, an accountant	49	Female	Neighbour

<sup>1</sup>EQF stands for European qualification framework and is a common European reference framework which is linking the qualifications system of different countries. Level 1- basic education with lower educational criteria or incomplete basic education, level 2- basic school education, level 3 - short upper secondary vocational education, level 4- upper secondary vocational education, upper technical education, secondary education or secondary technical education, level 5- short-cycle vocational education, level 6- Professional bachelor's degree or Academic bachelor's degree, level 7 - Master's degree, level 8- Research master's degree or Doctorate (26).

The qualitative content analysis identified 4 themes, 32 categories and 165 codes with a total frequency of 331.

Table 3. Qualitative content analysis findings.

Interviewer	Categories	Number of codes in category	The total frequency of all codes in the category
<b>Health conditions of the elderly and caregiver's work</b>	Chronic conditions of the elderly	10	16
	Physical impairment of the elderly	3	5
	Functional impairments of the elderly	3	3
	Health accessories	10	12
	Other impairments of the elderly	1	1
	Duration of caregiving	1	10
	Reason for taking on caregiving role	9	23
	Frequency of caregiving	1	1
	Areas of caregiver help	20	59
<b>Difficulties of long-term health care and types of help that caregivers receive</b>	Problems with the health care of the elderly	4	4
	Fears and psychological problems	8	10
	Problems with the organisation of elder care	3	5
	Problems with knowledge and information	1	1
	Help from other people	2	2
	Non-professional help	4	14
<b>Experiences with formal health care institutions</b>	Professional help	3	7
	Positive experiences with the primary care doctor	16	29
	Negative experiences with the primary care doctor	4	5
	Positive experiences with home care nurses	5	10
	Receiving help from home care nurses	1	4
Areas of help from home care nurses	6	7	

Interviewer	Categories	Number of codes in category	The total frequency of all codes in the category
	Positive experiences with emergency centres	6	16
	Negative experiences with emergency centres	8	11
	Not using emergency centres	1	3
	Transport to an emergency centre	2	6
	Positive experiences on hospital wards	7	11
	Negative experiences on hospital wards	8	8
	No previous experiences with hospital wards	1	3
<b>The need for training and caregiver proposals</b>	Knowledge of informal caregivers	2	12
	Sources of information about caregiving	8	21
	Suggestions regarding sources of information	3	8
	Other suggestions	4	4
<b>Total</b>		165	331

Four themes involving health caregivers' experiences with challenges and problems in the field of long-term health care for the elderly were formed. These themes were given names that described the content they illustrated. More detailed findings of this analysis are presented below.

### 3.2.1 Health conditions of the elderly and caregiver's work

The first theme encompasses caregivers and the health conditions of the elderly. It includes nine categories focused on caregivers' motivation for informal work. Their informal health care for the elderly mostly includes some day-to-day activities, such as transportation to GPs (emergency or clinic), buying groceries, food preparation, dressing, feeding, procurement of medicines and other medical devices for the elderly, measuring blood pressure and blood sugar, and so on. On the other hand, caregivers have to be aware that the elderly have serious medical problems. They have chronic diseases; sometimes they are confined to a wheelchair; and they are functionally impeded, so they need all-day care. Caregivers are mostly motivated by altruistic levers anchored in high morality. This causes the caregivers to be even more benevolent.

'Well, now I help her, because she's my mother and I want her old age to be quality. I'm just that kind of person. I like to do it, it's not a problem for me.' (CG7)

'I've always had a feeling for older people, and also for my mother.' (CG6)

Caregivers have a particularly important role in the mental stability and support of the elderly. Therefore, caregivers must have a highly developed social sense for the psychological state of an elderly person. Older people often fear for their lives. They are suspicious and do not trust just anyone. For all these reasons it is important

to develop confidence and mutual respect between caregivers and the elderly. Sometimes a little thing is enough to lose confidence.

'Only the [male] doctor can take him, he has problems with [female] nurses or doctors. He trusts men more.' (CG2)

### 3.2.2 Difficulties of long-term health care and types of help that caregivers receive

The second theme includes seven categories related to informal caregivers' work and some of the difficulties they face. The interviewees described two different areas in which they have the most difficulty. The first relates to the elderly person receiving care (mostly fears and psychological problems), and the second is related to systemic disorder in long-term health care provision. Certain elements of the Slovenian public health care system were emphasized, and also their employers' reluctance to offer them the option to switch to flexible working time. This is a real problem because the caregivers, even though they are family members, are also often physically distant from the relatives or friends they care for. As one interviewee stated:

'Well. You can't get sick leave for caregiving. I drove from Krško to Ljubljana [98 km in one direction] to work and then back again.' (CG3)

When it comes to fears and psychological problems of the elderly, it must be emphasized that they are not directly related to the problems faced by the caregivers. In this context, they represent challenges. The elderly simply have common fears, such as fear of blood sampling, loneliness, deterioration or death. Older people are also often impatient and edgy, and they also do not like to go to day-care centres for the elderly.

The interviewees also underlined some elements of the public health-care system as a real problem. For instance, they have a serious problem with the short duration of medical referrals, and by how overloaded Slovenian physicians are at the primary level of health care. In that context some interviewees responded:

‘The short duration of referrals can be problematic, especially because I’m not able to make the arrangements on such short notice, due to my own obligations.’ (CG1)

‘Our primary care physician is overloaded with too many patients. It’s clear that he’s really busy.’ (CG3)

### 3.2.3 Experiences with formal health care institutions

The third theme includes twelve categories related to caregivers’ experiences with public health care institutions: the local clinic (the selected GP), the home care nursing service, the emergency service and hospitals.

In addition to numerous positive experiences (for example: cooperativeness, kindness of medical staff, being able to participate during medical examination, provided oral and written instructions) regarding health care institutions, basically all of the interviewees emphasized various negative experiences. They pointed out a number of logistical problems such as: access issues, absence of elevators and parking fees. They also pointed out some unpleasant situations with medical staff (hostility; waiting in the hallway; refusal of a home care visit; refusal to participate during a medical examination) and the elements that are the weakest point of the Slovenian public health care system: inaccessibility of GPs, hospital queues and early discharge from hospital due to lack of available beds. Some caregivers highlighted things that really shouldn’t be happening.

‘If I just come for a prescription but end up waiting an hour or more, this really bothers me with all our technology.’ (CG5)

‘There’s a general problem with waiting, which is eternal but also understandable given the situation in Slovenian health care.’ (CG4)

### 3.2.4 The need for training and caregiver proposals

The fourth theme encompasses caregivers’ proposals and their desire to learn more and to receive comprehensive support from public health care institutions. This theme includes four categories related to acquiring information and skills. They also offered some suggestions that would improve their daily work with the elderly.

The interviewees drew attention to the lack of courses and lectures that should be provided by professional health workers (GPs and other medical staff) and patient associations. They emphasized the problem that they mostly just learn by doing, simply copying the practices of their relatives and friends. Some examples are given below.

‘There should be frequent workshops about how to work with them, how to communicate with people with dementia. There should be more awareness.’ (CG7)

‘I would suggest including our caregivers in the training for patient associations for particular diseases that already exist.’ (CG5)

Caregivers also emphasized that they acquire some information from the news media and on the Internet. In short, informal ways of acquiring knowledge predominate, which is probably a consequence of the fact that everyone in Slovenia believes that elder care must be provided by the state. Consequently, these caregiver proposals are more or less focused on potential state provisions and services that could be provided by public health care institutions. The interviewees indicated that they would like to have longer timeframes on medical referrals, morning care in nursing homes (another issue on the systemic level) and more psychological support from GPs and medical staff. Because caregivers are part of the general population, they too are convinced that elder care should be regulated by the state.

## 4 DISCUSSION

### 4.1 Main findings and study impact

The study was conducted to lighten caregivers’ challenges and difficulties in caring for the elderly. Informal caregivers provide care for multimorbid individuals who have functional and mental disorders and often fears and mistrust. In long-term care, caregivers develop psychosocial skills to gain the trust of the elderly. In doing so, they face the need to obtain guidance and instruction from professional health workers. Caregivers learn through media and posts on social networks and the internet. Improvements are possible in terms of information provision. Helping the elderly takes a lot of time, especially to perform complex tasks, and so those who are employed wish to have flexible working time. They believe that it would also be possible to improve logistical procedures, such as making it easier to obtain an appointment or prescriptions.

In the first theme, Health conditions of the elderly and caregiver’s work, informal caregivers describe reasons for taking on caregiving role, among which care for family members, reciprocity and social conscience. This is consistent with some other studies where, regardless of religion and ethnicity, we observe similar motives for long-term care (31).

In the second theme, Difficulties of long-term health care and types of help that caregivers receive, caregivers pointed out that there is a systemic disorder in long-term health care provision. They are bothered by how their employers are often reluctant to offer them the option to switch to flexible working time or to reduce their working time. Apart from this they can only rely on receiving a

partial payment for their lost income. When comparing this issue with the situation in other European countries we realized that most of them face similar problems. In some informal caregiving is a paid activity in different percentages of their salary and amount of time. For example, in Hungary and Romania informal care givers receive an allowance for an unlimited time, while in France, Finland, Denmark for a limited period (9, 10, 14).

Another aspect that troubles them is presented as our third theme, Experiences with formal health care institutions. While they mostly have positive experiences (such as cooperativeness, kindness of medical staff, being able to participate during medical examination) provided oral and written instructions ...) with their GPs, home care nurses, doctors and nurses at hospitals and emergency departments, they have also had some negative experiences in the past; for example inaccessibility of GPs, refusal to participate during a medical examination, hostility, absence of elevators in medical buildings, hospital queues, waiting in the hallways, and early discharge from hospital due to lack of available beds.

The caregivers pointed out that they are mostly left to themselves when it comes to finding information on caregiving. Process of obtaining knowledge can be long and, as our caregivers emphasized, is usually developed through personal experience. In the fourth theme they explained that they find and gather information from media (usually on the internet), ask friends and neighbours but have expressed a wish to gain that knowledge from courses and lectures provided by professional health workers (GPs and other medical staff) and patient associations. Several similar studies from Lithuania and United States have also reported a lack of support and knowledge that informal caregivers face every day and lack of much needed formal training. But there are some positive examples of established support groups and information services in other European countries, such as Finland (with a support center for informal caregivers "Omatori", which provides information and counseling), Germany (with a counseling hotline for informal caregivers) or United Kingdom (with "Digital Resource for Carers" which offers online resources). (15, 32, 33). On the other hand, some community-based training programme for informal caregivers is also provided in Slovenia, one of providers is an Anton Trstenjak Institute of Gerontology and Integrational Relations (15). Training has an important role, because caregivers have to understand the elderly' health conditions, as it makes it easier for them to offer them quality care, but it is just as important to understand their psychological needs. They have common fears, such as fear of blood sampling, loneliness, deterioration or death, are often feeling depressed, can be impatient or edgy. Health care and psychosocial care are in need to be further developed and their importance is still underestimated (34).

Both in Slovenia and in other European countries the mechanism of the welfare state determinates the status of the elderly (1, 2, 9, 18). Within this context caregivers face similar difficulties regarding their elderly relatives' conditions, their semi-professional positions and their ability to liaise with public health care institutions (17, 19, 20). They are enthusiastic about learning more and being trained, and they have similar proposals about how to improve informal elder care in their countries (2, 12, 18,).

#### 4.2 Methodological consideration

In addition to several strengths, such as the implementation of an 'in-depth' interviewing approach in an unexplored area and the rarity of studies about informal caregivers' experiences in Slovenia, this study also has some limitations. A general limitation of the study is related to epistemological criteria and validity in qualitative research (30). Although qualitative studies provide rich detail, large-scale representative quantitative surveys are needed to capture a large amount of data and shed more light on the issue at hand. Although the number of interviewed caregivers seems small, the richness of their testimonies has offered enough information to reach conclusions. However, we are aware that the qualitative content analysis has its limitations and know that an additional study at the population level (or at least a larger sample of caregivers) would be the ideal complement to our findings, putting the importance of the findings in perspective (28).

Our qualitative study draws attention to the problem and provides basic findings about informal caregivers for the elderly in Slovenia. Our study points to the needs of informal caregivers and at the same recalls the need for systemic consideration (and improvements) at the policy level. The study has no potential to directly solve the problem, but it is definitely an important step toward finding ways to improve long-term elder care, which is an increasingly urgent need in Slovenia.

#### 5 CONCLUSION

Our findings are an important step toward filling in the research gap regarding informal caregivers' main problems and challenges, which is a real challenge for decision-makers in Slovenia. In this context the study should be understood as useful stepping-stone to future research and real improvement in this area.

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## CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

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Research was conducted according to ethical principles and was approved by Ethics commission, No. 0120-527/2018/5.

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