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Role and perspectives of informal care: a qualitative study of informal caregivers in the Republic of Croatia

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ABSTRACT

Objectives Population ageing and the prevalence of multimorbidity represent major challenges for healthcare systems. People who need long-term care have complex conditions requiring both health and social services. Informal caregivers are emerging as an important part of the long-term care ecosystem. This paper aims to explore the position and capacities of informal caregivers in Croatia.

Design Health and social care legislative documents were analysed using a structured set of keywords. In addition, focus groups were conducted with informal caregivers who cared for a family member. The qualitative method of thematic analysis was used.

Setting and participants Two focus groups were conducted with 15 caregivers (13 women and 2 men). Geographically, participants came from all four NUTS2 Croatian regions. All participants cared for a close family member. The length of care provision ranged from 3 to 35 years. Focus groups were conducted using the Zoom platform.

Results The analysis of the documents indicates the fragmentation of national policy into health and social policy. Long-term care as a term is recognised only in health policy. However, some components related to long-term care are part of social policy. Caregivers are recognised in social policy, although not in healthcare. In focus groups, three main themes were identified as follows: (1) position and role of the caregivers in the system and society; (2) types of care based on the recipient's need and (3) support for the caregivers.

Conclusion The research showed that the process of exercising certain rights and services for caregivers is not sufficiently clear and feasible in practice. There is a lack of a clearly defined role of caregivers and relationships towards professional care providers in the system. The key to improving long-term care is connecting community services, including health and social services, both formal and informal, with the process of providing care.

INTRODUCTION

Community involvement in health development (CIH) has traditionally been present for many years, but only in the last few years has the concept of CIH emerged as a systematic approach to improving health and developing healthcare.[1] The formal healthcare system was created to respond to the needs of people who can care for themselves independently. However, the increased life expectancy of the population, and the growing prevalence of non-communicable diseases with all the advances in technology and the availability of resources, leave the care of sick and vulnerable people with complex needs outside the boundaries of the healthcare system, most often left to informal care, family members and the local community. Therefore, the community and its stakeholders who provide professional care are considered key predictors of meeting overall care needs.[1 2]

Informal care is part of the long-term care system.[3] An informal caregiver is a person who assists family members, friends and people in their social network who need long-term care, living inside or outside their household. Most of the care takes place in the user's home or his primary community, and is characterised by the provision of assistance in performing daily activities.[4 5] In recent years, there have

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The paper is designed to support decision-makers in the development of efficient and sustainable informal care, in the context of healthcare workforce shortage.
- ⇒ The paper explores the position and capacities of informal caregivers in the system and the available community resources aimed at providing sustainable informal care.
- ⇒ Participants were recruited through non-governmental organisations representing informal family caregivers from all Croatian regions.
- ⇒ Due to the relatively small number of focus group participants, it is not possible to know to what extent the results apply to the entire population of informal caregivers.
- ⇒ Considering the COVID-19 pandemic, the focus groups were conducted online. This facilitated access to participants from different regions, especially reinforced by the fact that caregivers cannot leave their residents for long periods of time.

been changes in the demographic and morbidity structure of the population, which has led to greater demands for resources within the informal care system. According to Eurostat data for 2021, 21% of the EU population is aged 65 and over, which is more than one-fifth of the total population. Looking specifically at the age of 80 and over, the number has more than doubled in the last twenty years, from 2% in 2001 to 6% in 2021,[6] and a further increase is predicted in the coming years.[7] According to the results of the population census from 2021, there are 22.45% people over the age of 65 in Croatia, of which 5.55% are 80 and over.[8] According to a systematic review and meta-analysis conducted in 2022, 10.4% of the elderly population has unmet needs for healthcare, while every fourth elderly person has unmet needs for long-term care with a higher prevalence of unmet needs in residents of rural areas.[9] Long-term care needs are complex, multidimensional and very specific, depending on the population group, health status, as well as related social and environmental factors.[10]

Today, healthcare and social care systems are facing numerous challenges in meeting the complex needs of the population, which requires a change in the paradigm of European health systems towards person-centred care, followed by the integration of healthcare and social care services.[11]

Changes affecting the structure and dynamics of the family, society and system have strong implications for the development of informal care and the ability of the family to provide support to individuals in need. The role of informal caregivers is still dominated by women of working age, but the increase in the share of women in the labour market has also affected the dynamics of providing care at home.[12] This has influenced the changing of roles and tasks and, to a significant extent, family relationships, especially between the informal caregiver and the person being cared for, as well as the dynamics of the entire family.[13 14] The overall state and position of informal caregivers is largely determined by the circumstances in the healthcare and social care system.[15] The combination of health status and socioeconomic factors of the person being cared for, together determine the overall complexity of needs and care provided.[16] The diversity of approaches in the provision of care and the professional designation imposed by the system cause a high level of fragmentation and care of reduced quality, which makes the work of an informal caregiver even more difficult.[17 18] Meeting the needs of informal caregivers is one of the tasks of public services today, aiming to ensure not only smooth care, but also a good life for informal caregivers.[19] The result is the increase in care programmes for informal caregivers that include financial benefits, special legal or work statuses, and respite care programmes. Non-governmental organisations (NGOs) are the most common form of organisations that provide support and advocate for the rights of informal caregivers.[20–22]

European and national health policy launched an initiative directed towards person-centred care and the development of non-institutional models of care in the home and community with a special focus on informal care.[23] By investing in informal care and support to informal caregivers, European policies aim to ensure the sustainability of the long-term care system.

The challenge of the long-term care system in assessing the real scale and scope of the need for informal care is real, because informal care occurs in different forms and duration. In addition, in most countries, existing definitions and measures for informal caregivers are dispersed within different systems (healthcare system, social care system, ministry of labour, etc). The meaning of informal care is not unique and harmonised across countries.[24]

The healthcare and social care system in the Republic of Croatia is divided into two Ministries: the Ministry of Health and the Ministry of Labour, Pension System, Family and Social Policy. Healthcare is decentralised at the primary level, where counties are responsible for the organisation of healthcare, while the hospital system is owned by the state, where hospitals are distributed throughout the Republic of Croatia. Healthcare is dominantly reliant on hospitals, which current health policy is trying to shift towards home and community care. Social care is centralised and is realised primarily through financial compensation for various services, with the existence of some other forms of social assistance services.[25] The field of long-term care and specifically informal care, which includes both health and social care, are still underdeveloped. There is a lack of data or any research insights into informal care and the challenges that families and relatives face during the caregiving period.[26] However, the need for long-term care increases over time. According to data from 2021, there were 19 923 children with developmental disabilities and 106 487 adults with disabilities in the treatment of social care centres, and only 44 094 initiated procedures for exercising rights (personal disability allowance, assistance and care allowance, status of a parent caregiver or adult caregiver).[27] Insufficient organisation of the system to respond to the provision of complex care results in a burden of care on the caregiver, especially on women who are dominant in that role.

This paper aims to explore the position and capacities of informal caregivers in Croatia. The paper is designed to support decision-makers in the development of efficient and sustainable informal care, especially in context of the overburden of the healthcare system and the healthcare workforce shortages.

METHODS

Approach and sampling strategy

The research was carried out as a continuation of research activities in the field of integration of care, long-term care and informal care.[28 29] It was conducted within the project ‘Health Observatory’ (project code/grant number: UP.04.2.1.06.0045), and the project ‘Improving care for complex patients’ (REG. NO: 380-59-10106-23-1272, Class: 641-01/23-08/1) within which a doctoral research ‘Specificities of the integration of informal care into healthcare in the Republic of Croatia’ is being conducted. The research team consisted of research assistant MB, two junior researchers DV and ILL and two senior researchers KL and AD.

Document analysis was used as a form of qualitative research in which documents are interpreted by the researcher to give voice and meaning around an assessment topic.[30] It was used for the purpose of providing a conceptual framework for assessing the overall state of development of informal care in Croatia, and the official legal position and role of informal caregivers. The search of the relevant documents was performed using the following keywords: long-term care, informal care, informal caregiver, home care, community care. The analysis included: (1) national legislative documents—strategies, acts, regulations[31–36]; (2) policy documents, projects’, state agencies and public administration’s reports[37–40] and annual national statistical reports.[27 41]

Focus groups were conducted in the second phase of the research. The participants were caregivers who were caring for a close family member who, due to reduced functional ability and impaired health, needed help in performing daily activities. The criteria for the inclusion of participants were (1) the person is an informal caregiver and not a health professional; (2) the length of care is at least 3 months. By introducing these criteria, we focused on lay people providing care, and those who are more experienced in providing long-term care for a person in need and who are more familiar with the possibilities, but also the obstacles within the healthcare and social care system. Sampling was done using the snowball sampling method.[42]

The research was conducted in accordance with the ethical principles of conducting scientific research which include confidentiality, secrecy and anonymity of the data on the participants. The participants were informed about the purpose of the research, benefits, and risks, and voluntarily agreed to participate by signing the informed consent.

Participant and public involvement

The development of this research was inspired by previous research findings as well as expert insights from the field, which pointed to the important role of informal caregivers in providing care.

We included informal caregivers as research participants. The research team contacted members of partnering NGOs in the Health Observatory project which further identified and recruited participants in the research. The invitation to participate in the research was sent via email. Before participating in the research, the participants were informed about the objectives of the research and the choice of outcome measures. Through the conducted focus groups, participants were interviewed about their personal care experiences, the activities they carry out, the available resources in the community and the everyday problems they face.

Participants and or the public were not directly involved in the design, or conduct, or reporting or dissemination plans of this research.

Data collection

Participants were sent a written informed consent via email prior to participation. Focus groups were conducted using the Zoom platform, both lasting 120 min. The moderator led and facilitated the conversation through semi-structured questions (online supplemental file 1). The protocol and questions were formulated according to an analytical framework that consisted of the following domains: (a) activities of caregivers in providing care; (b) use of resources in informal care; (c) the relationship between the informal and formal systems shown on the model of informal care; (d) problems and opportunities for the development of informal care.

The authors (MB, ILL and DV) participated by taking notes. Both focus groups were audiovisually recorded. Conversations were later transcribed and used for the analysis. Data on the participants were anonymised so each participant was assigned with his own number.

Fifteen participants (13 women and 2 men) answered affirmatively, of which 8 participated in the first and 7 in the second focus group. Out of 15 participants, 8 participants were employed, of which 5 worked part-time, 6 participants had the status of a parent caregiver for a child or an adult caregiver, while 1 participant was retired. The caregivers’ ages ranged from 40 to 68 years. Geographically, participants came from all four NUTS2 Croatian regions. All participants cared for a family member, whether it was a spouse, child, parent or grandparent. The length of care provision ranged from 3 to 35 years. In the second focus group, we reached data saturation when participants’ answers started repeating and we no longer gained new insights.[43]

Data analysis

The qualitative method of thematic analysis was used in the analysis of the transcripts. It is applicable and appropriate for problems and models which in reality exist as a complex system consisting of a large number of components, interconnected and dependent in various ways, which are difficult to measure individually. Thematic analysis was performed according to the Braun and Clarke protocol.[44] The transcripts of both focus groups were coded in parallel. First, the authors carefully read the transcripts to familiarise themselves with the data set and identify coding patterns. They created initial codes and connected them with the corresponding text statements. After completing the initial coding, the authors discussed the obtained results to get a clearer picture of the collected findings, aligned with the research questions. This was followed by the axial coding into different themes and subthemes. Final coding scheme was agreed between all authors. In the presentation of the results, themes and their subthemes were matched to the selected quotes that best describe them.

For reporting, we used the Standards for Reporting Qualitative Research checklist,[45] thereby increasing trustworthiness and transferability of the findings (online supplemental file 2).

RESULTS

Document analysis

By using document analysis, we identified the following determinants that provided a conceptual framework relevant to the topic of informal care and caregivers.

National policy is fragmented into health and social policy. Long-term care as a term is recognised only in health policy. However, some components related to long-term care are part of social policy.

The national health policy follows European priorities aimed at strengthening home and community-based services and primary care in accordance with the specific needs and capabilities of local communities. It strives to develop an available and coordinated community long-term care model responding to both health and social needs within the 24/7/365 time frame. However, current health policy does not recognise informal caregivers and their role in providing care.[31–33]

On the other hand, social policy is focused on deinstitutionalisation and development of services in order to further improve the quality of life of users and ensure regional equality and availability of social services.[34] The social system recognises the role of parent caregivers taking care for a child and caregivers taking care for an adult. By providing care to a child with developmental difficulties or to an adult with a disability, the caregiver can obtain the status of a parent caregiver or adult caregiver. The status includes financial compensation, pension insurance rights, mandatory health insurance and rights as an employed person during unemployment. In addition to the caregiver and care recipient, the Social Care Act also recognises the entire family involvement in providing care. A package of social services such as help at home, psychosocial support, counselling, half-day stay or organised housing is defined for the purposes of improving the individual's and family's quality of life in the community.[35] In addition to the Social Welfare Act, as the basic law governing the social welfare system, the Family Act, which regulates the family legal protection of children and families, is also important.[36] In the conducted research and analysis of the current state of distribution of social services in Croatia, the problem of regional inequalities in the availability of social services was highlighted, especially for some vulnerable groups such as health-impaired children, people with disabilities or the elderly, as well as families with impaired health.[27 37–41] For this reason, the National Development Plan for Social Services for the period from 2021 to 2027 emphasises the importance of expanding the scope of social services, and their development directed to the needs of users.

Focus groups

Through the thematic analysis of focus groups' transcripts, the codes were identified and grouped into three themes: (1) position and role of the caregivers in the system and society; (2) types of care based on the recipient's need and (3) support for the caregivers and their related subthemes (figure 1).

Theme 1: position and role of the caregivers in the system and society

From the statements of the participants, we recognised and identified elements explaining the position and role of caregivers in the system and society. Out of a total of 15 participants in the research, 13 participants were women which indicates that women are the predominant providers of informal care for family members. The caregivers' position in the system is determined by their legal status regulated under the Social Care Act—whether or not they have the status of parent caregiver for a child or adult caregiver. Their position is also determined by their work status defined through the relationship with the employer, and by their family status, determined by family relationships and the perception of caregivers in the family.

Legal status

In the situation of providing long-term care to a family member, caregivers have a right to the status of a parent caregiver or an adult caregiver. Caregivers seek the status based on the complexity of the health condition of the person in care, on which the person's level of independent functioning depends. However,

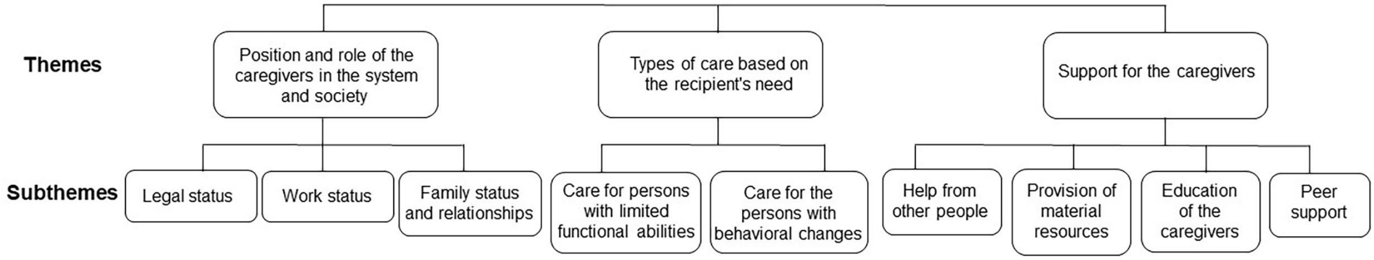

Figure 1 Coding tree for thematic analysis: themes and subthemes.

the majority of participants expressed dissatisfaction with the status, stating that they encountered difficulties in exercising rights, such as the right to physical therapy, an assistant, the acquisition of equipment…

> I've had the status of a parent caregiver for the last 12 years and a few months. I didn't manage to exercise all my rights at the start. (Participant 3)

Some of them state that the financial benefits provided through the social welfare system are not sufficient for their comprehensive needs.

Work status

Participants who are employed or were employed at some point in their lives and now have the status of caregivers, state that they have developed a specific relationship with their employer in order to be able to balance business and private obligations. Out of a total of 8 employed caregivers, 5 of them work part time with the possibility of adapted working conditions from home.

> It was some kind of agreement with the employer. They were very interested in me returning to work and were ready to offer me conditions that actually suit me, just to return. So I've been working from home since 2011. (Participant 8)

Some caregivers decided to become self-employed to have the flexibility of working hours and to coordinate work obligations with caregiving more easily.

> I don't have the status of a parent caregiver, I have my own company, I've been working from home for the past few years, for 4 hours. I'm managing somehow, I'm trotting, I'm finding some kind of work, I'm being resourceful. (Participant 7)

The participants say that they adapt their work to the needs of care recipients as much as possible, which is a big challenge and the slalom of life.

Family status and relationships

According to the findings of the focus groups, women were dominantly in the role of primary caregivers, while men as well as other family members were involved as support in providing care.

> Days with her are extremely stressful. Maybe up until a few years ago, one person could manage alone with her, but not anymore. Now me and my husband must be together with her, if she falls into these conditions so that we can have some control over her. (Participant 4)

The family situations were different, from the parents taking care of the child together (whether they were married or divorced) to the complete absence of the spouse's help in care. Equally, other family members' interest in providing care varied.

> I don't have any support from my husband, in fact, I have to defend him so that they don't meet because my husband constantly thinks that he is an actor. (Participant 10)

> I feed him, sometimes the children too, the children like this when we agree, when someone will feed him, it is also their time for companionship, that is what connected us. (Participant 2)

Due to the specific health condition of the person in care and their complex needs, caregivers and their families often become alienated from the environment and isolated from other people.

> It's a big, big problem with her, for example, going out among people. Her diagnosis also has something from the autism spectrum. In any case, we are very, very isolated. (Participant 4)

The relationship between the caregiver and the person in care reflects on the functioning and dynamics of the entire family. With disease progression, the burden of care increases and the need to involve more family members in care becomes greater.

Theme 2: types of care based on the recipient's need

The needs of elderly people, people with disabilities or people with certain chronic conditions are recognised as complex needs, and such patients are included in the 'high utiliser' group of patients. Besides health needs, they also have needs for home and community social services. Among our participants, different types of care were identified, related to the care recipient's condition.

Care for persons with limited functional abilities

People with limited functional abilities have an increased need for physical assistance. The need depends on the degree of progression of the health condition, that is, on the mobility of a person to carry out their daily activities. The participants point out that the care they provide includes help in performing activities of daily living, from getting up, dressing, feeding, using the toilet, washing, but also in some nursing activities such as aspiration, stoma care, changing diapers…

> In the morning, we have plenty of personal hygiene, you have to bring her to the table, give her breakfast, therapy, see if she has taken the pill or not since her motor skills are a little slower, of course from psychotics. Then we already have the second part of inhalations for the lungs, lunch, a pill every now and then, the time when she rests, walks, has dinner, so there is plenty of that. (Participant 11)

Care for persons with behavioural changes

Changes in behaviour are common and characteristic of people with disorders within the autism spectrum, people suffering from schizophrenia and dementia. Caregivers who care for a person with behavioural changes provide 24-hour care that includes monitoring the person for specific patterns of behaviour that can be potentially dangerous for themselves, the caregiver or the environment. Caregivers fear unexpected changes in behaviour that may occur and affect the dynamics of caregiving.

> He eats by himself, bathes by himself. For a while he refused medication. When there are crises, I have to call the police and the ER because he does not know what he is doing because it is the psyche in question. (Participant 10)
>
> So it's constant, you just finish one part, you go to the second part, from the second to the third, and in the meantime, you pray to God that there will be no explosion, i.e. unwanted behaviour and that's it. (Participant 4)

People with limited functional abilities need help with performing daily activities such as feeding and hygiene. On the other hand, people who have behavioural changes need supervision to timely prevent some potentially threatening situations for themselves, or the environment. Informal care is especially challenging when there is a combination of types of care needed.

Theme 3: support for the caregivers

Support services are crucial for the development of effective informal care. Part of the support services for the development of informal care is directed towards caregivers and family members, and part towards the patients themselves. Some services are being provided outside the basic insurance rights, as a super-standard financed by the local self-government. They are being provided either by professionals in the healthcare and social care system, or NGOs. An important form of support is peer support, facilitated by NGOs.

Help from other people

In addition to the care they receive in the (hospital) healthcare system, complex patients need continued care at home. To meet the overall care needs, caregivers most often rely on the available services and resources in the local community, such as personal assistant services. In a situation of increased need for help in providing care, caregivers use their social network of family members and acquaintances. To compensate for some shortcomings of the system, caregivers take on the burden of organising care and usually finance it from their own pocket, such as hiring health professionals outside the time of care provision.

> We have a personal assistant. The assistant helps us not so much with him as she is important for the whole family. (Participant 2)
>
> When I'm working, I have 2 women who are 4 hours each, one of them can't last 8 hours with her, she's getting nervous and even aggressive. (Participant 11)
>
> Except for those two hours a day during the week when the medical technician comes, with the fact that I have an agreement with them. If I want to do something on the weekend or in the afternoon or go out or hang out with someone, then I call them and additionally pay them. (Participant 5)

Provision of material resources

Part of the resources for providing care is provided through the Croatian Health Insurance Fund, part is covered by NGOs through their sources of funding, while part is covered by caregivers and families out of their own pocket.

> As far as aids are concerned, some 50% is covered by the Croatian Health Insurance Fund. The rest is financed either through the NGOs or with private funds, that is, by some private donors and foundations that exist in Croatia, when, for example, a larger expenditure is needed. (Participant 5)

Education of the caregivers

The hospital healthcare system and NGOs are recognised as stakeholders that provide education for informal caregivers. The education is aimed at the primary caregiver, but also at other family members who participate in care. Some hospitals provide education for parent caregivers during the child's hospital treatment. At the time of the transition to home care, the organisation of care is left to the family. There are NGOs that provide different types of services, including education and psychosocial support.

> He was in the hospital, while I was going through education about taking care of him. His father, who does not live with us, went through the same education. (Participant 8)

Due to the increased need for education both for themselves and for other persons participating in care (whether family members or professionals), caregivers manage to re-educate themselves and educate other persons in the provision of care in different ways.

> So, I educated my mother and, among other things, I educated about 12 nurses that we tried to have through home care. (Participant 3)

The availability of education for caregivers is determined by the place of residence of the caregiver and family and the engagement of NGOs in a particular community. Families living in smaller, rural areas have limited access to education, as well as other social services.

Peer support

Participants recognised the importance of connecting with other caregivers with similar experiences in providing care. NGOs that bring together users and providers of care play a major role in this. The participants highlight the problem of insufficient information about treatment options as well as the rights they can exercise through the system, leaving them to wander through the system to find adequate solutions. That is why they most often rely on peer support, that is, the lay help of other caregivers with similar caregiving experiences.

> The system is, let's say, very harsh and when you find yourself at the beginning of it, no one can guide you, only the parents, they will give you some guidelines. At the centre for social welfare, they will tell you something curt, but mostly about your rights, and other guidelines you will hear from the parents. (Participant 7)
>
> As for those purchases, I used to come, I wandered a lot. You come here, no, you have to go there, so I connected with some people, similar, and somehow we went through it together. (Participant 2)

Caregivers who live in smaller, rural areas usually do not have a developed network of caregivers and therefore find it much more difficult to get information.

> People in the city probably get information much more easily and are probably more grouped and information spreads more, but when you are on the outskirts and if you are living somewhere in the countryside, situations happen that are strange for the 21st century. (Participant 1)

The existing support services are fragmented within the healthcare system and between the healthcare and social care systems, and often insufficient in quantity and scope, as confirmed by the participants' statements.

DISCUSSION

Our results show that informal caregivers in Croatia are recognised to an extent within the social care system, which defines the status of a parent caregiver for providing care for a child and the status of caregiver for providing care for an adult through a package of rights and services such as the right to financial compensation or respite care services.[35] However, the Croatian healthcare system recognises caregivers at the level of practice, but not in legal documents. Our results show caregivers' dissatisfaction with the scope of the rights provided in the system and the lack of regulation of their role towards other stakeholders in the system. This indicates that rights and services for caregivers are not harmonised between healthcare and the social care system.

Furthermore, the results show that the reasons for caregivers' dissatisfaction are the problems in exercising existing rights. Another cause of dissatisfaction is the burden of organising the care by themselves. The problem stems from the lack of recognition of the caregiver's role, and undefined relationships between caregivers and stakeholders in the healthcare and social care system. The results of the focus groups showed that due to the insufficient cooperation and coordination of care providers, caregivers wander through the system in search of information of their rights and the options for care. The caregivers seek answers directly from health professionals, but in most cases, they rely on informal information from their acquaintances within the community, mostly lay help from other caregivers with similar care experiences. The most important role in the community is played by NGOs that provide resources directly aimed at the caregiver or the person in need of care.

Closing the gap between policy and implementation

Fragmentation of health and social care services is a characteristic of most European countries since there is no single definition of informal care nor of the informal caregiver. In this regard, the position of informal caregivers is not clearly defined, which is why there is a mismatch in the recognition of the role and position of informal caregivers within the healthcare and social care system (except for England, Malta and Sweden).[46] Rights and services in the Republic of Croatia are comparable to those in other EU countries, for example, Sweden[47] and Finland.[48] The levels of exercise of the rights differ between countries, which depends on the design and scope of the service, the specifics of the caregiver and the coverage of the service on a national, regional and local level.[49] The most common form of support for informal caregivers among EU countries is financial support, however, European countries differ significantly in its implementation.[46] Some of the services for caregivers are provided indirectly through the mediation of the care user himself, such as financial benefits intended for people who need help and care. In this regard, Twigg and Atkin differentiate the levels of support for informal carers by taking into account the wider policy context.[50] The provision of care requires the engagement and cooperation of various institutions that participate in providing care for the patient, especially professionals within the healthcare and social care system that provide care at the home and community level.[51] To meet the overall needs at the level of home care, coordination and integration of health and social care services are important, as well as the involvement of other relevant stakeholders who provide supportive home care services.[28 52] Although there are some foundations of the role of caregivers in the system, what is missing is a clear procedure for involving caregivers in care. A good model of government investment in local communities to provide support to caregivers was implemented in Sweden.[47] Slovenia is an example of a country that implements community-based programmes through the initiative of the Anton Trstenjak Institute of Gerontology and Intergenerational Relations.[53] However, there are some specific programmes for community caregivers aimed at providing care for certain complex health conditions such as dementia, which is why the Dementia Care Program in America was developed[54] or the national programme 'Learn to thank yourself every day as a relative' implemented in Denmark.[14]

Meeting the informal caregivers' needs

In defining the role of the caregiver, it is necessary to take into account the specific characteristics of the caregivers (eg, place of residence, socioeconomic status, level of education), which affect the possibility of consuming the provided rights and services and the provision of care itself. Similar findings were confirmed by Naiditch *et al*, who point out that the background of informal caregivers, their personal situation, family dynamics and the relationship they have with the person they care for define the set of needs and the dynamics of care provision.[55] Additional determinants that stand out are the institutional, political and cultural context, which is highly specific for a particular environment, and which has a strong influence on the provision of care.[14] It is unknown to what extent legally defined measures correspond to the real needs of informal caregivers.[24] Courtin *et al* question the lack of identification and assessment of caregivers' needs within the existence of a national policy directed towards caregivers.[46] In order to achieve a timely recognition of the real needs of caregivers, and thus the planning of services in the community, some countries have already started conducting national research on examining the comprehensive needs of caregivers, such as Serbia[56] and Lithuania.[57]

Strengths and limitations

The strength of this research is that the end users participated in the research, that is, the informal caregivers themselves. The qualitative methodology gives a real insight into their role and needs in a setting that is not clearly defined. Also, participants from various parts of Croatia were included, which allowed us to gain insight into regional differences in opportunities and barriers in informal care. Similar research was based on a quantitative component[56 57] or focused on a specific population, according to the diagnosis of the person they are caring for.[58 59] However, the needs of the person in care and the caregiver depend on the functionality of the person being cared for, which is common to a number of different diagnoses. A limitation related to the study design is that it remains unknown to what extent the findings are applicable to the entire population of caregivers, given that 15 caregivers were included in the research. Also, the participants were mainly women. Although women bear the greatest burden of informal care worldwide (about 60% of caregivers are women),[60] experiences of men as informal caregivers might bring additional insights on the topic. The focus groups were conducted online via Zoom, which is a relatively new way of conducting focus groups. The advantage of using Zoom was that we had participants from different country regions, who might not otherwise participate, especially because caregivers cannot leave their residents for long periods of time. The most common challenges of Zoom are technical difficulties and the participants' familiarity with the technology.

In addition to family members who are most often caregivers, there are also other people who are informal caregivers and do not have a regulated status but are employed on a private basis to provide care. In most European countries, there is an increasingly pronounced trend of ethnicisation of care and the employment of migrants as informal caregivers.[61] This research does not cover such groups of informal caregivers, whose experience is also important for the overall understanding and development of informal care policies.

Future research and development of informal care

Current events in the field of healthcare, social care and especially long-term care, characterised by a lack of labour and other resources, undoubtedly indicate the need for the development and empowerment of informal caregivers. Although they are already very present in long-term care, there are many unknowns in all segments of their definition—from who they are, to what, how and how much they do.[23] In the light of deinstitutionalisation, which is not only a product of a lack of resources, but also of striving for more humane conditions for patients, great emphasis is placed on the development of home care and community care.[11] It is precisely in this segment of care that informal caregivers play the most significant role. France is an example of a country that is moving towards the development of new forms of informal care aimed at supporting informal caregivers.[62] NGOs, having the most experience, are recognised as partners in the development of informal care. International alliances such as International Alliance of Carer Organizations,[63] COFACE Families Europe,[22] Eurocarers,[21] strive towards the standardisation of programmes, policies and legislation aimed at recognising the contribution of informal caregivers to the long-term care system. National and smaller NGOs do the same within their scope. However, there are many informal caregivers who are not members of NGOs, whose needs for support may be even greater, and they are more difficult to reach.

In order for home and community care to really benefit the patient and be sustainable, it is necessary to coordinate providers and develop a clear care process that is based on the needs of the patient, not the system itself. This includes the needs of informal caregivers in order to be able to provide care and not become patients themselves due to the excessive burden of care. Otherwise, the mismatch between existing services and the needs of informal caregivers often increases the pressure on informal caregivers.[52]

CONCLUSION

The informal caregiver is traditionally present in care but is differently recognised in public systems. Within the legal framework, certain rights and services for caregivers are regulated, however, the process of exercising these rights is not clear enough and enforceable in practice.

The role and relationship of informal caregivers towards other care providers are not defined, which is why the cooperation in providing care is uncoordinated. Caregivers often remain an unrecognised resource, left to themselves. This is further contributed to by the general fragmentation of the system and uncoordinated care at the level of professional providers, viewed primarily through the lens of the diagnosis of the patient and the package of available services within the healthcare and social care system, instead of a comprehensive assessment of the needs of the person in care, including the needs of informal caregivers.

Informal care affects not only the caregiver but also the whole family. Due to the demanding nature of the role, the involvement of the local community is necessary to release the burden and ensure sustainability. Informal caregivers are under the negative influence and pressure of various environmental factors. However, they represent one of the most flexible parts of care that can ensure continuity of care, even in times of extraordinary circumstances (COVID-19, earthquake, economic crisis).

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