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**Information support system for Alzheimer’s disease patients’ caregivers in Croatia: a phenomenological approach**

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***Introduction****. The paper presents findings from a study that investigated information needs of caregivers of Alzheimer’s disease patients’ in Croatia, a country in which health and social care systems for such persons are insufficiently developed. Special emphasis is put on the barriers caregivers face in obtaining required information or services.****Methods****. Interviews with 11 Alzheimer’s disease patients’ caregivers from the area of Eastern Croatia were conducted. Interpretative phenomenological analysis was chosen as the best method to interpret the caregivers’ experience of information support received from the Croatian system.****Analysis****. Topics were defined for each interview and then superordinate topics were defined for the whole sample.****Results****. Results show that Alzheimer’s disease patients’ caregivers in Croatia are faced with numerous obstacles. No organised information support system was detected.****Conclusions****. A more holistic approach to information support is needed. Authors suggest an Alzheimer’s disease information package to be distributed through the family doctors’ practices.*

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**Introduction**

Alzheimer's disease is a progressive, degenerative neurological disease accounting for an estimated 60 to 80% of all cases of dementia. (World Health Organization, [2017](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wor17)) Clinical symptoms of Alzheimer's disease change over time as a person moves through different stages of the disease and include memory loss, decreased judgement, and behavioural changes. In its late stage, the effects of Alzheimer's disease on the cognitive abilities and physical health of people are immense. They become bed-bound and need to be cared for 24 hours a day. Since none of the pharmacologic treatments for Alzheimer's disease available today can slow or stop the destruction of the neurons, the disease remains fatal. Patients survive an average of 4 to 8 years after diagnosis (Alzheimer's Association, [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Alz19)).

In 2019 Alzheimer Disease International estimated that there were over 50 million people living with dementia in the world. This figure is expected to increase to 152 million by 2050 as the world population aged 65 and older grows (Alzheimer Disease International, [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Alz19)). However, Alzheimer's disease affects not only patients. It is also burdensome for primary (informal) caregivers who care for their family members, relatives and friends diagnosed with Alzheimer's disease. It is estimated that in Croatia a total of 202,164 family members (in most cases women) care for 80,864 persons diagnosed with Alzheimer's disease (Mimica et al., [2015](http://informationr.net/ir/25-4/isic2020/isic2011.html#Mim15)). Recent data for the United States show that in 2019 caregivers of people with Alzheimer's disease and other dementias provided an estimated 18.5 billion hours of informal (unpaid) assistance, a contribution valued at $233.9 billion (Alzheimer's Association, [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Alz19)). This means that Alzheimer's disease and other dementias bring not only substantial human costs, but also an increasingly significant financial burden for families, communities and governments. Having this in mind, the World Health Organization and Alzheimer Disease International called upon governments, policy makers and other stakeholders to recognise dementia as a global public health priority, implement sustained action and coordination across multiple levels and with all stakeholders, and develop national dementia plans and strategies (World Health Organization and Alzheimer’s Disease International, [2012](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wor12)).

This paper deals with information support system for Alzheimer’s disease patients’ caregivers in Croatia and attempts to contribute to understanding of information needs in a specific environment.

**Literature review**

Many studies have shown that information and support needs of caregivers for individuals with Alzheimer's disease change over the course of the disease (Wackerbarth and Johnson, [2002](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wac02); Edelman et al., [2006](http://informationr.net/ir/25-4/isic2020/isic2011.html#Ede06); Hirakawa et al., [2011](http://informationr.net/ir/25-4/isic2020/isic2011.html#Hir11); Zwaanswijk et al., [2013](http://informationr.net/ir/25-4/isic2020/isic2011.html#Zwa13); Kucmanski et al., [2016](http://informationr.net/ir/25-4/isic2020/isic2011.html#Kuc16); Whitlatch and Orsulic-Jeras, [2018](http://informationr.net/ir/25-4/isic2020/isic2011.html#Whi18); Erdelez, et al. , [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Erd19)) and that their physical and mental health as well as social relationships and well-being may decline as their caring burden grows (Brodaty and Donkin, [2009](http://informationr.net/ir/25-4/isic2020/isic2011.html#Bro09); Zwaanswijk et al., [2013](http://informationr.net/ir/25-4/isic2020/isic2011.html#Zwa13); Dauphinot et al., [2015](http://informationr.net/ir/25-4/isic2020/isic2011.html#Dau15), [2016](http://informationr.net/ir/25-4/isic2020/isic2011.html#Dau16); Novais et al., [2017](http://informationr.net/ir/25-4/isic2020/isic2011.html#Nov17); Uzun, S. *et at*., [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Uzu19)). For example, Wackerbarth and Johnson ([2002](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wac02)) revealed in their United States study that family caregivers need information concerning diagnosis and treatment of Alzheimer's disease, but also information about legal and financial issues and individual health plans. In addition to those, the study conducted by Wancata et al. ([2005](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wan05)) revealed a number of major problem areas for caregivers in several European countries (Austria, Italy, Germany and Romania), including the lack of information about the services, financial benefits, burnout, emotional support and communication problems and conflicts with the patient. Nevertheless, studies have shown that many caregivers do not know which sources of information are accurate and of good quality, and many lack knowledge of and guidance on how to access them (National Academics of Sciences, Engineering and Medicine, [2016](http://informationr.net/ir/25-4/isic2020/isic2011.html#Nat16)). Lai and Chung ([2007](http://informationr.net/ir/25-4/isic2020/isic2011.html#Lai07)) established that caregivers in Hong Kong lacked knowledge about the services in the community which led to the low level of their utilisation and Whitlatch and Orsulic-Jeras ([2018](http://informationr.net/ir/25-4/isic2020/isic2011.html#Whi18)) concluded that some families and caregivers in the United States have fewer information and support options available to them because of geography or minority status.

Support for dementia carers has been listed as one of seven action areas in the World Health Organization's policy document *Global plan on the public health response to dementia2017-2025.* It has been globally accepted that appropriate interventions should be available to caregivers and that they should have access to support and services tailored to their needs in order to improve knowledge and caregiving skills, and prevent health problems (Alzheimer's Association, [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Alz19); World Health Organization, [2017](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wor17)). However, a number of recent studies which investigated information and support needs of caregivers of individuals with Alzheimer's disease worldwide show that even in high income countries the needs of caregivers remain unmet and that they feel that not enough services are provided for them (Van der Roest et al., [2007](http://informationr.net/ir/25-4/isic2020/isic2011.html#Van07), [2009](http://informationr.net/ir/25-4/isic2020/isic2011.html#Van09); World Health Organization, [2017](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wor17)). The situation is even grimmer in developing countries, such as Croatia, where caregivers do not receive the required information and support although their family members diagnosed with Alzheimer's disease depend upon them almost completely due to fact that health and social care systems are not sufficiently developed (Mimica et al., [2015](http://informationr.net/ir/25-4/isic2020/isic2011.html#Mim15); Rušac, [2016](http://informationr.net/ir/25-4/isic2020/isic2011.html#Rus16)).

**Context of the study**

According to Mimica and Kušan Jukić ([2015](http://informationr.net/ir/25-4/isic2020/isic2011.html#Mim15))*,*for many years dementia care in Croatia was provided by the family, with no organised support from health and social care systems, and many people with dementia were undiagnosed. Some progress has been made since the early 2000s with the establishment of non-governmental associations which, through their enthusiastic and voluntary work, provide information, support, and education to caregivers and health professionals, raise public awareness of Alzheimer’s disease and fight for changes in Croatia's legislation to ensure better care for people with dementia and protection of their rights. However, a comprehensive and responsive information, healthcare and social system for dementia patients in the country has not been developed yet. A national strategy to address Alzheimer's disease has not been officially adopted yet, a national registry of Alzheimer's disease patients has not been established, and the majority of patients are not treated with anti-dementia drugs (because they are not on the reimbursement list) but with alternative medication like gingko biloba. On a positive side, it could be said that nowadays non-governmental associations are having more and more success in promoting their agendas. A limited number of daily care centres and specialised units in nursing homes for elderly are being opened for persons with dementia. There has been a significant shift in the or­ganisation of palliative care services for people with dementia and health and social care professionals are offered training on Alzheimer's disease though scholarly and educational conferences, lectures and workshops (Bencarić, [2010](http://informationr.net/ir/25-4/isic2020/isic2011.html#Ben10); Mimica and Presečki, [2010](http://informationr.net/ir/25-4/isic2020/isic2011.html#Mim10); Samardžija, [2013](http://informationr.net/ir/25-4/isic2020/isic2011.html#Sam13); Mimica et al., [2015](http://informationr.net/ir/25-4/isic2020/isic2011.html#Mim15); Mimica and Kušan Jukić, [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Mim19); Rušac, [2016](http://informationr.net/ir/25-4/isic2020/isic2011.html#Rus16)).

In order to contribute to better understanding of an information and support system for the caregivers of Alzheimer's disease patients in Croatia, an 18-month research project was funded by the University of Osijek (2018-2020). The project gathered an interdisciplinary team of scholars and practitioners (health professionals, legal experts, information science scholars) who set out to identify information and service needs of caregivers in Eastern Croatia, with special emphasis on the barriers and challenges they face in obtaining the required information or service. The study was designed as a three-phase investigation. In the first phase, a critical analysis of local context, with special emphasis on a legislative framework, available health, social care and support services, and human rights issues was performed (Dološić, et al., [2020](http://informationr.net/ir/25-4/isic2020/isic2011.html#Dol20)). In the second phase, the authors explored information and service needs of caregivers expressed online on the general Croatian discussion list Forum.hr. This study found emerging evidence that caregivers in Croatia have limited access to information and support because they posted on this list not only when they required specific (factual) information or advice but also to describe their situation and experience and to share practical information that they think will help others (e.g., news about the opening of a day centre for Alzheimer's disease patients), and also to seek emotional support (Erdelez, et al., [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Erd19)). In the third phase of the study, which will be presented in this paper, authors build upon the previous findings by exploring the caregivers' experiences of an information support system for Alzheimer's disease patients’ caregivers in Eastern Croatia.

**Methods**

This paper uses a phenomenological approach to interpret the data gathered. This method was used after the failure of the initially planned method (critical incident technique) to provide researchers with meaningful data to complete the study. After the first data were obtained using the critical incident technique method researchers noticed that the interviewee ignored most of the questions from the semi-structured interview and talked mostly about his *experience* of the concepts from the interview. Since it was obvious that the focus of this interviewee was primarily to make sense of his journey as a caretaker of an Alzheimer’s disease patient and convey this experience to the researcher, we realised that a change of methodology was needed. We chose interpretative phenomenological analysis (IPA) because it is best suited to examine how people make sense of major experiences in their lives (Smith, Flower and Larkin, [2009](http://informationr.net/ir/25-4/isic2020/isic2011.html#Smi09); VanScoy and Bright, [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Van19)).

Interpretative phenomenological analysis is a phenomenological approach that involves detailed examination of the participants’ life. This approach is concerned with the person’s experience and perception of an event or object and does not attempt to come up with an objective statement about the event or object (Smith and Osborn, [2007](http://informationr.net/ir/25-4/isic2020/isic2011.html#Smi07)). It is usually conducted on a relatively small-size and reasonably homogeneous sample and the researchers attempt to identify both differences and commonalities of experiences (Smith, Flowers and Larkin, [2009](http://informationr.net/ir/25-4/isic2020/isic2011.html#Smi09), VanScoy and Bright, [2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Van19)). This approach is connected to the *double hermeneutic* because a researcher is trying to make sense of (interpret) the participants who are trying to make sense of (interpret) what is happening to them (Smith, Flowers and Larkin, [2009](http://informationr.net/ir/25-4/isic2020/isic2011.html#Smi09)). In this research study the researchers looked for commonalities among the Alzheimer’s disease patients’ caregivers, but also identified differences in the sample.

After study procedures were approved by the University of Osijek ethics board, participants were recruited by the help of Memorija, a non-profit association whose aim is to help and support Alzheimer’s disease patients and their caregivers in Osijek-Baranya County (Eastern Croatia). Similarly to Clare ([2003](http://informationr.net/ir/25-4/isic2020/isic2011.html#Cla03)) the study sample consisted initially of twelve participants, but one interview had to be eliminated because the caregiver gave opportunity to the Alzheimer’s disease patient to take part in the interview and no coherent answers were obtained. All the other caregivers from the sample cared for Alzheimer’s disease patients from Eastern Croatia in a medium or late stage of a disease. Five participants were from the town of Osijek (coded ABOS1-5), and six were from various other places in Eastern Croatia. Four participants came from Đakovo (ABDJ1, ABDJ2, ABDJ3, ABDJ4), one from Valpovo (ABVA1), and one from Belišće (ABBE1). Nine female and three male caregivers cared for five male and six female Alzheimer’s disease patients. In one case (ABDJ2) two people (a married couple) were interviewed as the primary caregivers. The age of Alzheimer’s disease patients ranged from 55 to 87 and of caregivers from 25 to 78 years. Table 1 provides further information about the sample.

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| **Table 1. Demographic data about the sample** |
| **Participant** | **Sex / ADP\*** | **Sex / CG\*** | **Age / ADP** | **Age / CG** | **Education / ADP** | **Education / CG** | **CG Relation** |
| ABOS1 | M | F | 1938 (81) | 1945 (74) | Higher ed. | Higher ed. | Spouse |
| ABOS3 | M | F | 1941 (78) | 1946 (73) | Secondary ed. | Higher ed. | Spouse |
| ABOS4 | M | F | 1950 (69) | 1956 (63) | Primary school | Primary school | Spouse |
| ABOS5 | F | F | 1932 (87) | 1958 (61) | Primary school | Secondary ed. | Daughter |
| ABOS6 | F | M | 1940 (79) | 1969 (50) | / | Secondary ed. | Son |
| ABBE1 | M | F | 1941 (78) | 1941 (78) | Higher ed. | Higher ed. | Spouse |
| ABDJ1 | M | F | 1949 (79) | 1966 (53) | Secondary ed. | Secondary ed. | Daughter |
| ABDJ2 | F | M/F | 1938 (80) | M:1965 (54)/ F:1968 (51) | Primary school | M: PhD, F: Higher ed. | Son and daughter-in-law |
| ABDJ3 | F | F | 1964 (55) | 1994 (25) | Secondary ed. | Higher ed. | Daughter-in-law |
| ABDJ4 | F | M | 1940 (79) | 1964 (55) | Primary school | Secondary ed. | Son |
| ABVA1 | F | F | 1938 (81) | 1959 (60) | Secondary ed. | Higher ed. | Daughter |
| \*ADP – Alzheimer’s disease patient; \*CG – caregiver |

The research was conducted in the period between April and July 2019. The interviews were conducted by two members of the project, the president of the *Memoria* association, and one of the authors of this paper. Both interviewers have had a close relationship with the disease having a close family member affected with Alzheimer’s. According to Smith, et al. (2009) the aims set by interpretative phenomenological analysis researchers tend to focus on people’s *experience* and *understandings* of particular phenomena, or on their *perceptions* and *views*. Following interpretative phenomenological analysis procedures, the research question focused on Alzheimer’s disease caregivers’ *experience* with and *perceptions* of the Croatian information support system for Alzheimer’s disease patients and their caregivers. Since the interpretative phenomenological analysis essentially offers researcher’s interpretation of the participants’ interpretation of their experience, no other data (e.g., field notes) were used. Each participant’s interview was transcribed and analysed to identify themes. The analysis was carried out by two other authors of this paper who did not have a close relationship with the disease as was the case with two colleagues who conducted the interviews. This task division was intentional and was made in order to preserve neutrality and objectivity of the analysis process (bracketing) (Groenewald, [2004](http://informationr.net/ir/25-4/isic2020/isic2011.html#Gro04)).

The data analysis was performed with the interpretative phenomenological analysis: first the thematic content of each individual interview was identified, then of the whole group. The researchers compared the themes emerging in the sample and were able to identify similarities and differences in the sample. As already mentioned, data were analysed by two researchers who did not have any prior relationship and/or deeper knowledge about the disease. The motivation for the involvement of two persons in the analysis was not the inter-rater reliability (which would not be appropriate for this method), but to bring the perspectives of both researchers to the interpretation of the data. In the first stage of analysis, researchers read and reread the interview transcripts, noting their comments about the interviews. In the second stage, researchers worked together to identify emerging themes in the data and the commentary. In the last stage, researchers grouped and regrouped the emerging themes to create *superordinate themes* (Smith and Osborn, [2007](http://informationr.net/ir/25-4/isic2020/isic2011.html#Smi07)) for a single participant. This process was repeated for each participant in the sample.

**Results**

This paper presents results of our study related to the Croatian information support system based on the perceptions and experiences of the caregivers of Alzheimer’s disease patients in our sample. The results are grouped into several categories: caregivers’ information sources and finding information about social, financial, legal and medical issues and rights.

**Caregivers’ information sources**

For the majority of caregivers, the process of obtaining information was a solitary one (‘*Alzheimer’s is different for everyone’* ABOS1) – they relied mostly on the Internet, but also on the media (such as documentaries, feature films, journals) and human sources (‘*neighbours’*). Even in cases when they obtained some information from physicians (mostly general practitioners - GPs), they usually did not perceive a physician as a primary source of information (‘*everything that my GP told me, I could find on the Internet’* ABDJ3). One participant even stated that she does not think ‘*that anybody could have informed her better than the sources she found on the Internet’* (ABDJ3). On the other hand, another participant complained that she found many sources online, but that they were mostly in English, not relevant for her situation and therefore not useful. Still another participant noticed that patients in Zagreb, Croatia’s capital, have access to better care and better services than patients in the other parts of Croatia. A few participants relied on their physicians (GPs, neurologists, etc.) as information sources and one participant even described how she was looking for information together with her GP. Those participants were more than pleased with their physicians and the support they provided, trusting them completely. Four participants obtained the necessary information from Alzheimer associations in Croatia and were very satisfied with the usefulness of advice and information they received.

Some participants described their intensive information retrieval using words such as ‘*digging information on the Internet’*, ‘*reading everything they could find’*, or repeating significant words ‘*we read and read’* whereas a few participants were quite passive in obtaining information – the information was mostly *pushed* to them from physicians or family members.

**Information support related to legal issues**

Although a few participants in our study claimed that they had no problems related to legal issues connected with Alzheimer’s disease, for the majority in the sample the prevailing mode of behaviour was – inactivity. In some cases, the reason was overestimation of one’s ability or simply avoidance of the painful truth about the disease:

*Honestly, I didn’t even look for legal assistance because I was confident, I can do everything on my own (ABOS1)*

*His sister is a lawyer, she probably knew everything about legal matters, but the problem was that both of them [brother and sister] for a long, long time didn’t want to know the true nature of their mother’s disease (ABDJ2)*

For some participants dealing with legal practicalities was painful and emotional and they chose not to do anything on that matter.

*I was thinking of depriving my mother of legal capacity, but I just could not go through with it… I was told in the past to obtain the power of attorney for her, but I kept thinking it’s too early. (ABVA1)*

As a consequence, they are presently facing many legal and financial problems because the patients cannot sign their names anymore.

*I cannot do anything any longer - the notary won’t accept her signature since it’s different now from the one on her ID (ABVA1)*

For some participants taking any legal action was also prevented by the knowledge that they would be responsible for everything the patient did to him/herself or others. The information about this responsibility came from physicians.

*… if anything happens to her, you will be held responsible. Therefore, it is extremely important that you do not let anything happen to her, that she does not wonder off (ABOS4)*

In one particular case, the family situation was extremely complex (second wife was looking after the sick husband, but his children from earlier marriage contested her as a primary caregiver as well as his legal and financial successor) and the caregiver felt completely cheated by the system (The Centre for Social Care).

*...another social care worker came but she did not identify herself as a social worker. She asked me to give her the information about his bank account, but I later learned that that was not legal, that the Centre can obtain those data only through the court order, and not through me (ABOS2)*

Only one participant stressed out that he had a support from the association Memoria from Osijek and was extremely satisfied with information and advice they provided.

*Wherever I went, whatever I needed… everything was finished really fast … I was surprised how quick it all was (ABOS5)*

**Information support related to financial issues**

The initial reaction of almost all participants was that they either did not have any financial problems at all, that they were able to obtain financial aid from the state (in the amount of approximately $90 per month), or/and that they are well off and can financially support the Alzheimer’s disease patient on their own.

*To tell you the truth, we are relatively well off and I thought that there are those who are in much greater need for help (ABOS1)*

However, later in the interview some participants complained that there were some financial problems, after all. They complained that the financial aid is insufficient for all their needs, that the medications are too expensive, and until recently, were not subsidised by the state.

*We bought the medications for him because in Croatia they were not on the ‘list’… either in Serbia or in Bosnia where they are much cheaper than in Croatia. … they made in on the list recently. (ABOS1)*

*… medications are very expensive … our pensions are small (ABOS3)*

Some participants expressed their more pressing problem – finding the adequate person to help them with the care for the patient when they work or have to leave the house. All the participants in our research felt that they were primary and only caregivers of their patients, which was extremely burdensome and exhausting, and sometimes even isolating. They craved the system (physicians, social workers) to help them in this regard, but the system does not provide that kind of help.

*… it’s not finances, I need somebody to take care of her while I am at work. (ABVA1)*

*I asked them [Centre for Social Care] to help him, to find a suitable help for him (ABOS3)*

One participant complained that they had to wait too long to get the summons from the Centre for the hearing to obtain the financial help and when they finally did, it turned out the hearing was on the very day they received the letter. They could not make it in time.

The participants mentioned physicians or associations as the sources of information about their financial rights.

In a few cases there were contradictive responses from several respondents – their answers to direct questions related to any kind of help (financial, social) was mostly ‘*We did not receive any help*’, ‘*Nobody informed us*’, but when they shared their experiences later in the interview, it turned out that they did receive help from the system (information, medical or financial aid).

**Information support related to social problems**

Almost all participants in the study experienced a number of negative feelings related to the Croatian system of social care (dissatisfaction, frustration, disappointment, even bitterness). Only one participant expressed her satisfaction with the help she received from the system (‘*whatever we’ve needed so far has been covered by our health system’* ABDJ1).

The participants expressed the need for quality institutions for Alzheimer’s disease patients. They expected also that institutions of social care have a list of suitable people who could take care of those patients in their homes (‘*first I went there [*Centre of Social Care*] to see whether they have a list of people who could take care of those patients in the morning’* ABVA1). Majority of respondents did not want to put their beloved ones in the institutionalised care (poor conditions, too expensive) (‘*facilities are understaffed … they will overmedicate him and he’ll pass sooner’* ABDJ1), and sometimes did not have a right to obtain help from the system (‘*Her husband is 83 and asked whether they could get somebody to help with his wife’s hygiene … they said no because he was there … How can they expect that somebody at his age*...’ ABOS5).

Throughout the interviews a shortage of adult day centres was a highly prominent issue for the caregivers:

 *A friend of mine told me that there was a retirement home in Vinkovci where you could bring an Alzheimer’s disease patient, once a week, for an hour or two…not for me, but for her, for socialisation* ABOS5

*I’m afraid to be with him now, especially at night…found a woman, but night is a problem, nobody wants to work at night*… ABBE1

**Information support related to medical problems**

A majority of participants were pleased with the help and advice received from the physicians they came in contact with although it really depended on the physician in question (for example, one was extremely pleased with the GP, but displeased with the neurologist). They usually felt obliged to doctors that went out of their way to help them (‘… *GP, a wonderful person, she helped me immensely*.’ ABOS4; ‘*I can call my GP at any time - she and her nurse are at our disposal … the same goes for the doctor [*neurologist*]’* ABDJ1). The participants reported about the mistreatment by physicians only in a few cases. ‘*Then I called the doctor and she told me ‘by the way, instead of panicking, you could also take one pill and rest a little’* ABOS4; ‘… *and then the doctor turned to me and exclaimed ‘Oh my, she is clean!’ … I don’t understand, why wouldn’t she be clean if she has dementia’*ABVA1)

However, when it comes to the system, the respondents are less positive. They described the system as slow (‘*The problem is you have to wait really long for your turn, to get treatment’* ABOS3; ‘*We couldn’t wait, we obtained the decubitus mattress on our own’* ABDJ2) and inefficient (‘*It’s a shame, all those medications they prescribe to a demented patient, she was a guinea pig for them’* ABOS4). Even when doctors want to help, their time is limited by the number of patients they treat. As a rule, residential facilities do not provide good service, which is pointed out even by physicians (‘*I know that you won’t be able to stand it… don’t do that for your own sake’* [place a father in a facility] ABDJ1)

One participant was troubled with a huge sense of responsibility for the patient and the ethics of if (‘*You make all the decisions in her name in connection to her health and other things’* ABDJ4), while another expressed her insecurity about the progression of the disease.

Only in one case did a caregiver report about the psychological help she as a caregiver received from a neurologist:

*They told me that they [neurologists] re there more for the caregivers, than for the patients… actually, caregivers have much more need for psychological help because of the trauma they constantly battle with. ABVA1*

**Discussion and conclusions**

This paper presents a part of the results from the study on information needs and information behaviour of Alzheimer’s disease patients’ caregivers in the area of Eastern Croatia. Results presented here illustrate the caregivers’ experience with and perceptions of the Croatian information support system for everyone affected with this disease and are analysed through the prism of social, legal, financial and medical issues. Although there are a number of papers on Alzheimer’s disease patients and their caregivers in the area of medicine, this paper is one of the few on this topic in the area of library and information science and contributes to understanding of information needs of a particular socio-economic group in a specific environment (Croatia).

The results show that there is no systematic and organised system of information provision for the Alzheimer’s disease patients and their caregivers in Croatia. The first contact with the disease and the information about it is in the general medical practitioner’s (GP’s) office, but for the majority of the participants this is insufficient and not precise or clear enough. One of the reasons for such a situation may be that the GPs themselves do not have enough knowledge about the disease. The GPs seem to be the only source of information from the *system* that our respondents mention; all the other actors (e.g., Centre for Social Care, Alzheimer’s Associations) are almost invisible. When the caregivers turn to Alzheimer’s Associations for help, they are always extremely satisfied with their informational and emotional support, but only a few caregivers reached for this help. This means that they either did not know about those associations or that contacting them required significant effort which they were not ready to invest.

Like Clare ([2003](http://informationr.net/ir/25-4/isic2020/isic2011.html#Cla03)), participants made varying judgments about the support system, expressed a range of emotional responses and demonstrated different strategies as they attempted to cope and adjust. The most prominent feeling from the topic related to legal issues was that the caregivers were extremely emotional and almost completely unprepared for the progression of the disease and the deterioration of patient’s faculties. Therefore, almost all caregivers in the sample did not undertake any legal actions to prepare themselves for the time when the patients would not be able to sign their name or decide for themselves. Also, information avoidance was noticed in the cases when caregivers possessed the knowledge about the necessary legal actions but chose not to do anything because it was too painful. Those few who reached out to Alzheimer’s associations were extremely satisfied, but data indicate that the Centre for Social Care was failing to perform a good service. The Centre had an extremely poor image and was perceived as an institution that would take away your rights, that is inefficient and even unethical in its doings.

Similar to VanScoy and Bright ([2019](http://informationr.net/ir/25-4/isic2020/isic2011.html#Van19)), the majority of the respondents initially claimed that they do not have any financial problems, only to change their opinion later during the interviews. Also, many of them contradicted themselves when they first claimed that nobody helped them in anything, that they did not receive any aid – only to share a story later in the interview that they received everything that they had right to by the law (medicine, diapers, etc.).

Social issues are a much bigger problem for our caregivers. First, there is a problem of mistrust of the Centre for Social Care. Second, there are no quality residential facilities dedicated to Alzheimer’s patients and they are mostly placed in regular retirement homes. However, only a few homes will take a late-stage Alzheimer’s disease patients. When they do, those institutions are usually understaffed, and the patients do not receive adequate care. The expressions such as *binding* and *overmedication* are often connected with these institutions. To make things even more difficult for caregivers, day centres for Alzheimer’s patients are even harder to find. In the words of one of the caregivers: ‘*our society is definitely unprepared for Alzheimer’s disease’* ABDJ2.

Our caregivers’ medical problems are related more to the system than to the physicians. They objected to the slowness and inefficiency of the system, physicians with too many patients, as well as the lack of expertise for the disease in general. But they responded well to the humane approach of many general practitioner physicians they come across. There was only one caregiver in the study sample who mentioned that a neurologist addressed her problems as a caregiver. Unfortunately, there is no organised help and/or psychological support for Alzheimer’s disease patients’ caregivers in Croatia.

A sustainable and long-term health and social care system for Alzheimer's disease patients and their caregivers is not provided adequately in Croatia, but also worldwide. The World Health Organization ([2017](http://informationr.net/ir/25-4/isic2020/isic2011.html#Wor17)) proposed that accessible and evidence-based information, training programmes, respite services and other resources tailored to the needs of caregivers should be provided. The Croatian system is currently lacking several important segments: psychological support for the caregivers, day centres, home aid, and specialised residential facilities. Currently, there are several actors in the Croatian system of medical and social care – general practitioners, clinicians, Centre for Social Care, Alzheimer’s associations, visiting nurses, hospice – but they are all highly specialised and working only within their boundaries, not reaching out to patients and caregivers.

A holistic approach is needed that will be compatible with Vygotsky’s Zone of Proximal Development (ZPD), a concept that underpins knowledge development and acquisition (Vygotsky, [1978](http://informationr.net/ir/25-4/isic2020/isic2011.html#Vyg78)). While Zone of Proximal Development is traditionally discussed in a context of children and educational settings, it also has a potential to be applied as a framework for designing information support systems for Alzheimer’s disease patients’ caregivers. With the guidance of this framework the scaffolding of caregivers’ information needs should evolve as their complex caregiving needs change over duration of this disease. Especially critical, in the initial stage of the disease, is a role of an actor who will be proactive and direct caregivers to other actors and credible information sources. It is our view that general practitioners are the best for that role because they are usually the first stop for Alzheimer’s’ disease patients, and they are familiar with and trusted by the patients’ family. However, general practitioners’ broad medical education lacks specialised preparation for complex informational, social and psychological needs of the patients and their caregivers. In the next stage of our project, we plan to develop an informational package with relevant medical, legal, financial, and social care information that will in an approachable way provide current understanding of the disease and its stages but also be customised to local conditions. These informational packages will be provided to general practitioners in Eastern Croatia with instructions to distribute them to newly diagnosed Alzheimer’s disease patients.

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