

Cornerstones of Support for People with Dementia: Influence on Public Awareness in Rural Slovenian Region

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ABSTRACT

Introduction: Awareness and knowledge of the effectiveness of four supporting cornerstones (SC) (i.e. people, place, network, resources) for people with dementia (PWD) in rural region have not yet been well analysed. The purpose of the research was to collect data about general population's dementia-related knowledge and about the support for PWD according to the SC.

Methods: The research was done using a questionnaire evaluating dementia-related knowledge thereby comparing different groups of respondents, established on the basis of demographical parameters and, respectively, parameters, evaluating SC for PWD in the environment, as expressed by the respondents. For analysing statistically significant differences between groups, we used ANOVA, T-test and Spearman's correlation coefficient.

Results: The test's average estimate of dementia-related knowledge was high (9,23 out of 12). The performed statistical analyses demonstrated no statistically significant differences in dementia-related knowledge among the compared groups, the only two exceptions being between respondents with different degrees of education and between the groups with different evaluations for levels of information support in their environment. While the first

of the two differences was expected (respondents with higher education having higher degrees of knowledge), the result between the second pair of groups wasn't expected: the people judging their informational support as low had statistically higher grades of dementia-related knowledge.

Conclusions: *The high general results of test with mostly no statistically significant differences among the compared groups might indicate either insufficient difficulty of questions or generally high dementia awareness, possibly due to effective measures for its spreading in the past.*

Keywords

People with dementia, Public awareness, Rural Savinja Statistical Region, Supporting cornerstones.

Introduction

In an ageing society, the number of people with Alzheimer's disease and with other forms of dementia (in the following text referred to as: people with dementia – PWD) is rapidly increasing [1,2]. Even though the majority of cases of dementia cannot yet be cured, PWD and their relatives can however be provided with help and support [3,4]. Well-informed society is namely faced with problems of PWD and of their relatives, therefore it provides them with access to information, education and support thereby alleviating their social exclusion [5-9]. In the last years, experts in the field have developed a model of four supporting cornerstones (SC) for PWD which enable improvements in four areas: people, places, network and resources [5,6]. The SC model enables PWD to live a relatively independent and quality life in their home environment and encourages social inclusion, adjusted to their capabilities. It also enables their relatives, who are mostly informal carers of PWD, to remain active at their employment. Using the model, we can achieve the appropriate awareness of lay and expert society in architecturally adapted environment, thereby establishing a dementia-friendly environment, in which PWD and their relatives are understood, respected and enjoy the community's support [3,5,6,10].

PWD-friendly community

PWD-friendly community is an environment where PWD and their caretakers are respected and included into society, on the basis of knowing their rights and capabilities of PWD. Thereby knowledge about dementia is improved and stigmatization of PWD is reduced. In establishing such communities, important roles are played by expert organizations as well by non-government organizations, such as an example of which is represented by the Belgian dementia-friendly city of Bruges [3,11-15]. In the process of its formation, support for PDW can generally be divided into four SC: people, place, network and resources [5].

People in a community should be well informed about dementia and of PWD' rights, This kind of support is provided by carers, families, friends, neighbors, health, and social care professionals, and voluntary associations like Alzheimers' organizations [5]. They demonstrate respect for PWD, support their active role in the society, and also collect PWD responses, so as to encourage their active role in different predicting stages of dementia.

Place means a suitable spatial arrangement, following the needs of

the elderly, enables PWD to live independently according to their needs [10,16]. It helps to improve their orientation, enables them a safe access to means of transport, shops, banks, the post office and other institutions. It also supports their safe movement along circular promenades.

Network is important that those who support PWD communicate, collaborate and plan together sufficiently well to provide the best support. PWD relatives often find themselves in serious distress because the Alzheimer's disease (the most often form of dementia) is a long-lasting disease [17,18]. Thus, alongside with expert support services, they are in great need of general support and understanding in their environment. The network of PWD-friendly spots ensures the transformation of preexisting spaces and services in local environment, where personnel is appropriately informed and educated to understand PWD and to respect them, as well as to properly respond to their needs [19,20]. provide PWD with effective and friendly help and cooperation [19,20]. Such organizations and institutions are labelled with the sign »Dementia-friendly spot«, while in some other places with »Safe spot for the elderly«.

Resources means that organizations, services and facilities are appropriate and supportive of PWD as the ordinary resources of the community. Health and social public services can together serve as support for PWD and their relatives who, in cases of long-term disease, need firm support [4,21,22]. PWD usually live together with those relatives who take care of them. The medical discipline is yet unable to provide cure for most forms of dementia, however health services can help PWD and their relatives by timely taking measures according to the stage of the disease as well as the clinical picture [4,21]. Timely diagnosis of dementia and early treatment of the patient are very important, since PWDs are often misunderstood by their relatives owing to their low familiarity with the disease. Health institutions adapt to PWDs and support a healthy lifestyle in the community. They also inform the wider society (via the media) about the symptoms of the disease, aimed to their timely recognition and proper taking of measures [4]. An important mission of the social service is the prevention of social exclusion, since the environment tends (due to its low awareness and informedness) to rapidly exclude PWD and their relatives. Therefore, social service has to take on an active role, including the exercising of lawful rights [21-24].

A case of support for PWD and their relatives – the role of the local association Spominčica Šentjur

Similar to Alzheimer societies which in many countries cooperate in formation of dementia-friendly environment for PWD and their relatives, in the Statistical region of the Savinja (Savinjska

statistična regija), containing all the municipalities, included in the present research, from year 2008 to present, Spominčica Šentjur (Association of the Western Styrian Region for the Help at Dementia »Forget me not» Šentjur) has been operative [14,24]. Among its founders is the psychiatrist Aleš Kogojč, an honorary Slovenian expert, having the credit for spreading informedness about the Alzheimer disease and other forms of dementia [25]. Spominčica Šentjur, based in the Retirement Home of Šentjur, has the status of an association of public interest in the field of social care. It is a voluntary, independent, non-profit, interdisciplinary expert association whose primary goal and purpose is to provide PWD and their relatives with expert and effective help. The actions of informing and educating the public are performed through a website and through the bulletin Dotik spomina (The touch of the memory), the bulletin of Spominčica Šentjur [14]. The association is cooperating with the central Slovenian Association for help with dementia Spominčica Alzheimer Slovenije, as well as with other similar associations and institutions [13,26]. The yearly programme is designed in the role of informing the public about dementia in a wider area of the Statistical region of the Savinja, in the form of lectures for wider public and workshops for relatives of PWD [14]. The lectures in the relaxed environment of Alzheimer Cafes and workshops are performed by recognised experts from healthcare, social care and other areas, as well as relatives of PWD [27]. Regularly, on a month's basis, a group for self-help is operational, and it yearly commemorates the World day of Alzheimer's disease with a cross-country walk and with informing the public via activities in special information stands [28]. The past and present performance on various projects is aimed primarily at improvement of inter-generational cooperation in the area of help, as well as at shaping a friendly environment for PWD and their relatives [29-32].

Last, but not least, the central activity of Spominčica Šentjur is establishing Safe spot for the elderly (slovenian: Varna točka za starejše), aimed at PWD and their relatives and the general elderly in need. In 2014, Šentjur, as the first town in Slovenia, obtained safe spots for the elderly which primarily serve PWD and their relatives [33,34]. At this moment, the list of institutions in Šentjur which have Safe spots for the elderly includes nine organizations. This is perhaps one of the first cases of practically implementing the SC in Slovenia.

Methods

Awareness and knowledge of the effectiveness of the SC for PWD have not yet been well researched. The purpose of the research was to collect data about general population's dementia-related knowledge and about the support for PWD according to the SC.

Research participants

The research's sample consisted of exclusively voluntary participants who were adult unaffected visitors of four CHCs in rural statistical region of the Savinja: Šentjur pri Celju, Šmarje pri Jelšah, Laško in Žalec. After prior agreement with CHCs' managements, the research data was collected from 31st January 2018 to 15th February 2018. In the meantime, the operating nurse

in CHC's waiting room explained to the respondents the purpose of the research, distributed 60 survey forms in each CHC (together 240 forms) and asked the participants to return the forms to her in person.

The questionnaire

For the purpose of the research, the anonymous structured written questionnaire was delivered to 240 randomly selected visitors in CHCs' waiting rooms. The first section consisted of 12 questions about the dementia-related knowledge, the second of 11 questions for evaluating the support for PWD according to the SC in their home environments, and the third of 7 questions about general demographic data. We were primarily interested in the level of participants' dementia-related knowledge, whether there are differences in the dementia-related knowledge among different demographic groups (including relatives and non-relatives of PWD) and whether there are differences in dementia-related knowledge in correlation with different levels of support for PWD. We also analysed which sectors of dementia-related knowledge are best and which worst known to general public and which of SC are, according to respondents' opinions, most successfully provided for in their respective home towns.

Statistical data analysis

The collected data was statistically analysed using SPSS (version 22, for Windows 8.1). The statistical significance limit was set at 5% ($\alpha = 0,05$). Statistically significant differences in degrees of dementia-related informedness were compared among different groups, established upon demographic data and data about different levels of the four cornerstones of support for PWD in respective respondents' places of residence. For statistical analyses, Student T-test, ANOVA and Spearman's correlation coefficient (for range values) were used.

Results

The questionnaire was responded by 166 of 240 included visitors (response being 69%), among who were 37 relatives with PWD and only 3 PWD. The response included: 56 respondents from Health Centre (HC) Šentjur, 51 from HC Laško, 44 from HC Šmarje pri Jelšah and 15 from HC Žalec. The sample included 60,9 % of females and 39,1 % of males with median age in years set at 48. The respondents generally demonstrated relatively high knowledge about dementia (on average the scored 9,23 out of 12 possible points), where relatives of PWD scores showed no statistically significant advantage over other respondents (average 9,24). Differences between the four Health Centres were statistically insignificant (p-value with ANOVA: 0,357). The highest scores related to the knowledge that the frequency of PWD increases steep after reaching age of 65 (99% of correct answers), that early diagnostics of dementia are very important (97,7% of correct answers) and that the consequences of dementia concern not only PWD but also their families (93% of correct answers). On the other hand, the lowest scores were achieved at the following pieces of knowledge: that some forms of dementia are curable (38,75% of correct answers), that dementia is not a normal companion in one's old age (49,2% of correct answers) and

that legislation in Slovenia does not regulate the area of dementia in an integral manner and in detail (63% of correct answers). It is encouraging to note that 83,4% of respondents believe that a dementia-friendly residence is the one where PWD feel safe.

Analysing the second section of the questionnaire, we estimated the degree of support in respondents' hometowns, according to the four cornerstones. On the cornerstone of place: more than 75% of the respondents estimated that significant public institutions are accessible on foot, but only one third (33%) know the circular promenade or are aware of the fact that it is shortly to be built. On the cornerstone of services: 72,6% of respondents are certain that the personnel in public and other social services suitably help PWD; early diagnostics of PWD in Health Centres is estimated as satisfactory by 64,4% respondents. Over a half of respondents (51,8%) believe that PWD and their relatives are provided with enough information. 57,5% of them believe that dementia is not satisfactorily publicly discussed.

On the cornerstone of network, the safe spot for the elderly is known only by 17,4% of the respondents (most of them in Šentjur: 30,7%). Spominčica Šentjur is known to 46,4% of the respondents (most of them in Šentjur: 59,2%). On the cornerstone of people, only 8,3% of the respondents have participated in dementia-related lectures (most of them in Laško (10,7%) and none in Žalec). And only 18,5% of the respondents are aware of the social events, named the Alzheimer café (most in Laško: 23,5%). Comparing levels of knowledge of groups of respondents, formed on the basis of different estimated levels of development of different cornerstones of support for PWD, no statistically significant differences between the groups were found, with two exceptions. People with higher education (expressed in levels, treated as ranks) have scored significantly higher at answering the questions about dementia-related knowledge (p-value with ANOVA: 0,041). The analysis also demonstrated a weak positive correlation between the levels of education (expressed in ranks) and knowledge test scores (p = 0,000; Spearman's correlation coefficient = 0,288). Comparing the two groups of respondents, according to their estimation of accessibility of dementia-related information in their environment, in a seemingly paradoxical manner, the respondents who estimated dementia-related information as non-satisfactory have generally scored significantly higher at knowledge tests (p = 0,0165).

Discussion

Our results demonstrate relatively high knowledge about dementia among inhabitants of the statistical region of the Savinja which may indicate either relative simpleness of the used questionnaire or successful past endeavours for informing and familiarising the wider public with dementia. We could possibly assume that an important role in these efforts was also played by the association Spominčica Šentjur [14]. Our research demonstrates also equal knowledge about dementia between relatives of PWD and the rest of the population, thus we should ask ourselves whether PWD's relatives have in the past really been offered forms of education which were accessible and interesting in a satisfactory manner.

Research around the world namely show that most of caretaking for PWD is carried out by PWD relatives, mostly by their family members [35-37]. Their crucial role is to help PWD remain in home care as long as possible [37]. This often represents for them an extensive burden because PWD should not be left alone and without control [35-38]. When facing these issues, relatives of PWD are significantly assisted by programmes of the associations Spominčica which, in Slovenia, have been importantly contributed to form a friendly environment for PWD and their relatives. Well-informed relatives therefore more often search for support and help in groups for self-help in the association Spominčica [13,14].

The paradoxically higher level of dementia-related knowledge among residents of places where dementia-related information is estimated as being deficient may indicate the fact that those respondents are more critical to the current status compared to other respondents. This should be understood as a warning indicating the fact that the development of the SC should in the future be further improved. Providing constant education for public personnel and personnel in other services can yield higher life quality of PWD, their better social inclusion and their lower social stigmatisation [39,40]. By creating an environment which enables PWD to be better oriented we can also enable PWD to constantly remain mobile is very important for strengthening their health. In this way, we could also help their relatives. According to Zvezdan Pirtošek from Ljubljana University Medical Centre, Department of Neurology the number of relatives of PWD is about 100,000 in Slovenia [41]. In the year 2016, he stated (in an interview for the newspaper Delo; Pirtošek, 2016): "Dementia, the for the time being incurable and progressive disease whose positive diagnostification is expected to rise in the future, has in our place affected more than 130,000 people – not only the patients, but also their relatives. Those tend to fall ill themselves, because of the unimaginable burden which is a consequence of a 20 to 30 year-long period of waning of the beloved person. But there is no help and support which they would need. Or, better, there has not been any."

With assets-based approaches that PWD and their relatives enable a health-promoting and health protecting environment WHO and PWD themselves believe that dementia-friendly community can be accessible and inclusive for people with cognitive disabilities, not only friendly [2,42].

Conclusion and Suggestions for Further Measures

According to the results of our research which demonstrated almost equal knowledge about dementia among relatives of PWD and the rest of the population, we should provide the relatives of PWD with a more accessible form of education. In the future, voluntary associations Spominčica should, among other things, organise as many lectures as possible in relaxed environments of the Alzheimer cafes. In such an environment, PWD and their relatives would encounter and socialise with persons with similar problems, exchanging useful advice and forming valuable bonds. They would also actively meet other locals, actively participate in social life and assist the realization of the FCS of support for PWD.

Another solution may also lie in intensively educating the children and the youth in schools about dementia. Thus, the grandchildren would already be familiar with the importance of the SC for PWD. They would thereby gain respect towards their grandparents and offer additional friendly environment for their relatives.

On the level of the project Safe spot for the elderly, their integration into a pan-Slovenian network of Dementia-friendly spots could be achieved, in order to intensively spread dementia-related knowledge among the employed personnel. In this way, the society in the statistical region of the Savinja would gradually grow more friendly to PWD and their relatives, raising their life quality and enabling their participation in a more creative manner.

Study Limitations

Limitations of our study are that it has been conducted among inhabitants of only one statistical region in Slovenia and that only 3 respondents were PWD. To get more respondents including PWD and consequent yet more objective results it will be useful if similar study will be spread across Slovenia. In that case, needs of PWD could be real taken into consideration. Because, only PWD are the persons who can see if there might be a better way forward. The way, that properly honours the PWD and their right to respectful relationship which does not infringe on their human rights.

List of Abbreviations

CHC: community health centre, PWD: people with dementia, SC: supportive cornerstones

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