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Modest Insight into the Public Level of Knowledge of Dementia-Friendly City in Slovenia

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Abstract: The aim of study was to evaluate knowledge of DFC (dementia-friendly city) in Slovenian population and correlate these findings regarding on status of informal carers of PWD (people with dementia) or noncarers. Questionnaire with 5 demographic and 6 dementia knowledge items, and one DFC knowledge item was sent to first 100 email adult users from first author’s adressess list. During June and October 2013 we managed to obtain 57 filled-out by 17 informal carers (29.8%), and 40 noncarers (70.2%). Categorical data were compared by chi^2 analysis, and *p*-value < 0.05 was considered statistically significant. Differences in responses between informal carers and noncarers are shown in order of significance: (a) in DFC all people know about dementia, understand PWD, and respond with affection and reassurance (64.7% vs. 22.5%; chi^2 7.439; $p < 0.01$); and (b) PWD have opportunity to meet friends and socialize and to take part in singing, walking, and education in DFC (35.3% vs. 7.5%; chi^2 4.932; $p < 0.05$). Efforts to improve public education and to raise awareness on dementia at local and national level should be expanded to boost people in early stages of dementia to be active citizens.

Key words: DFC, PWD, informal carers, noncarers, level of knowledge.

1. Introduction

As populations age, rates of dementia in individuals aged 65 years or older—LOD (late onset dementia) will rise sharply [1-6]. The worldwide dementia prevalence in 2016 is estimated at 46.8 million people, and 32,000 in Slovenia [4, 6]. WHO recognizes dementia as a public health priority. WHO developed the Global Dementia Observatory to support countries in strengthening dementia-relevant policies and evidence-based service planning [3]. Although rising levels of education and more widespread and successful treatment of key cardiovascular risk factors may be the driving factors accounting for the decline in dementia risk, by 2030 the WHO predicts 75.6 million people globally will have the disease [2, 6, 7-9]. In 2008, Japan authors reported the crude prevalence of all types of LOD to be 11.0%, 7.0 for AD (Alzheimer’s disease), 1.7 for vascular dementia, 0.53 for dementia with Lewy bodies, 0.74 for Parkinson’s disease dementia, 0.21 for progressive supranuclear palsy, 0.11 for frontotemporal lobar degeneration and 0.74 for other dementia [10]. In 2010, consistent with the striking increase in the number of elderly individuals, crude prevalence of LOD in Japan was 16.4% [11].

With the striking increase in the number of elderly people, dementia has not only become a medical but also a social issue [1]. In response, cities around the world are creating communities that better help PWD (people with dementia) go about their daily lives. In May 2017, the World Health Assembly endorsed the Global action plan on the public health response to dementia 2017-2025 [3]. It provides a comprehensive blueprint for action for WHO, policy-makers, and

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international, regional and national partners in a number of specified areas, and one is "increasing awareness of dementia and establishing dementia-friendly initiatives" [3].

The concept of dementia-friendly communities originated in central Japan in the 1990s, where cities developed a range of programmes that would allow those living with dementia to continue to engage with the world around them [12]. The concept travelled to Europe and recently landed in Slovenian Ministry of Health [13-15].

The DFC (dementia-friendly city) is a good place to live for PWD and their carers. For example, The Creating a Dementia-friendly York project shows that what is good for PWD is good for everybody [14]. In dementia-friendly cities communities can help to take the barriers for PWD down. For example, a four-cornerstone model suggests that a dementia-friendly community need improve four key areas or cornerstores for PWD [14]. The four cornerstones are: people, place, resources, and networks. PWD relies on other people, to varying degrees. It is important how carers, families, friends, neighbors, health, and social care professionals, especially general physicians, and the wider community respond to and support PWD. Place covers everything from a PWD home, to the feel of the neighbourhood, to the ability to get in and out of, and around, the city. A good place to live means that the physical environment, housing, neighborhood and transport support PWD. Good resources are good health and social care services, and sufficient other services and facilities that are appropriate and supportive of PWD. PWD benefits from the best of what we all need from local services: good costumer's service, patience, and kindness. Networks optimise that those who support PWD communicate, collaborate and plan together sufficiently well to provide the best support and to use people's own "assets" well. [14].

Valuable is the concept of a dementia friendly community by Kate Swaffer as a person living with younger onset dementia [16, 17]. There are not many PWD capable of expressing their feelings and will. Therefore, a Working Group for Carers of People with Early Onset Dementia was established to exchange experience and socialize. Through this approach, both dementia-friendly and age-friendly initiatives also shift the narrative from deficit and burden to contribution and inclusion, and to mitigation against stigma, prejudice and discrimination [16].

As the workforce ages and the number of people retiring at a later age increases, the number of people living with dementia while they are in work is set to rise. This has implications for employers, who are beginning to recognise that dementia is becoming an increasingly big issue for their organisation and their staff [18].

2. Materials and Methods

2.1 Study Population

Because market researchers have found that participants do not like to take part in written questionnaires or telephone interviews, email invitations with questionnaries were sent out on 20th June 2013. The survey was sent out to 100 coincidentally picted Slovenian adult email users from first author's adressess list. An online survey of adult email users was chosen as the method to administer the questionnaire to ensure as big as possible informal carers of PWD and noncarers could participate in this research. On 28th October 2013 the survey received a total of 57 completed responses, 17 (29.8%) of these were from informal carers and 40 (70.2%) were from noncarers.

2.2 Instrument and Key Measures

This study adopted a questionnaire survey to collect data. The questions were developed by literatures review. The questionnaire was originally written in Slovenian language, as the majority of the public would have difficulties in comprehending the English version. It consisted of three parts. The participants were asked to complete the questionnaire with 5 demographic items, 6 dementia knowledge items, and one knowledge item about DFC. The first part was general information describing the participants demographical determinants which included age, gender, educational level, volunteery status, and family ties with PWD (informal carer). The second part was related to the individual awareness of dementia, this was assessed by 6 mainly open-ended questions. Participants demonstrated their knowledge about AD by descriptive answers regarding to signs, the most frequent age of starting AD, ways of help to patient with AD, and desired additional information. Only for guestion: "Do you want more information about Alzheimer's disease?" the participants indicated their answers on a two-point scale (2 = Yes and 1 = No). The third part of the questionnaire consisted of only one essential question: "Please describe what means dementia-friendly city for you?" All answers were descriptive, and subdivided with respect to four cornerstones of dementia friendly communities: people, place, resources, and networks.

2.3 Data Analysis

Categorical data were compared by chi^2 analysis, and *p*-values of 0.05 or less were considered significant. This pilot study was conducted to test the null hypothese that there is a difference in participant's knowledge about the four cornerstones of DFC: the knowledge of informal carers is better.

3. Results and Analysis

A good essential question is open-ended; that is, it typically will not have a single answer. Ultimately, the answer to the essential question will require that participants craft a response that involves knowledge construction. Listed are answers to the essential question "Please describe what means dementia-friendly city for you?" A higher proportion of informal carers than noncarers say that in DFC (a) "all people know about dementia, understand PWD, and respond with affection and reassurance" (64.7% vs. 22.5%; chi^2 7.439; $p < 0.01$); and (b) "PWD has opportunity to meet friends and socialize and to take part in singing, walking, and education" (35.3% vs. 7.5%; chi^2 4.932; $p < 0.05$). Majority of informal carers and noncarers (60.6% vs. 63.5%; $p > 0.05$) lacked knowledge about early signs of dementia.

4. Discussion

DFCs have been defined as places where PWD and their carers are understood, respected and supported, and confident they can contribute to community life [19]. In a DFC people are aware of and understand dementia, and PWD feel included and involved, and have choice and control over their day-to-day lives [19]. In DFC dementia-friendly communities have more opportunities to support people in early stages of dementia, boosting their role as active citizens [14]. Given the frequent attention and focus on DFC by the mass media over the recent decade, it is assumed that the Slovenian public is fairly well-informed and knowledgeable about the dementia-friendly communities [20].

The present pilot study examined the knowledge of DFC among adult Slovenians. Thus, this study explores the level of overall public knowledge about DFC measured through pilot survey research based on a small sample of 57 persons aged 18 and over. Those who care for PWD are likely to have higher levels of DFC knowledge, others showed limited knowledge about DFC. There are wide gaps of knowledge of early signs of dementia among a significant portion of informal carers and noncarers. Supporting earlier recognition of signs of dementia encompasses public education programmes and good access to information. Our study identified current DFC knowledge level, and areas of misconceptions and knowledge gaps among Slovenian noncarers, calling for urgent needs for educational outreach to improve knowledge about DFC among Slovenians. Additionally, considerable proportion of informal carers and noncarers lacked knowledge about early signs of dementia, especially AD. Raising awareness of dementia, as a component of earlier recognition is, therefore, a challenge among families, friends and communities.

Dementia communication education should be planning for school curriculum to enhance student nurses' communication abilities, and to increase nurses' patient-centered communication abilities with the ultimate goal of improving quality of care for patients with dementia [21]. Nurses should therefore provide education for elders in nursing homes to improve their AD knowledge and health-promotion lifestyles, and to prevent or ameliorate AD [22].

While dementia is more common in older people, in Slovenian cities like Šentjur, there is a relatively higher older population already, so the number of PWD is set to grow [20]. Active members of the regional Šentjur Alzheimer Association (Forget me not Šentjur) began with activities that are helping to make Šentjur DFC. The activities began in May 2013, with a city round-table discussion that generated ideas and practical ways on how Šentjur could be friendlier for PWD.

In June 2013, the association (Forget me not Šentjur) formally launched the dementia-friendly project, the first of its kind in Slovenia, in cooperation with the mayor of the city Šentjur (Saint George near Celje), a town in the part of the traditional region of Styria in eastern Slovenia [23]. It is the seat of the Municipality of Šentjur with a population of around 20,000 (Fig. 1). The main objective was for Šentjur to be recognised as a DFC as soon as possible, with improvements in the actions of local agencies, businesses and community groups. This includes higher awareness of the needs of PWD and their carers, in order to make socialising, shopping, eating out and using public transport and other amenities a more enjoyable experience for everyone. Finally, in November 2013, the association conducted training sessions for public and private employees as well as social and health workers. These were very popular and the participants returned many positive comments after the sessions. Later on, project was temporary stopped because of disease in project working team. Over the last three years, the city has made good progress, but improving four cornerstones could be done to create a dementia friendly Šentjur [14].

4.1 Improving the People

With continuation of training for staff who provide key services in the wider community, such as in banks, libraries and shops, we will improve customer service and understanding of needs, and remove stigma [24].

4.2 Improving the Place

With making Šentjur as easy as possible to move around and enjoy, with colours, and formats on signs making it easier for people to understand where they need to go, and improving the public transport accessibility [25, 26].

4.3 Improving Resources

Using the "dementia friendly" forget-me-not symbol to denote dementia-friendly services and Alzheimer cafes we will support businesses to become dementia-friendly. We will consider the needs of PWD when developing all services, not just health and care services [27].

4.4 Improving Networks

By encouraging PWD and carers to network and share experience and creating a Šentjur Dementia Action Alliance partners can commit to action within their own organisations and support this movement, building a sense of corporate responsibility across all sectors [19].

5. Strengths and Limitations

The participants in the present study are those people who have a relationship with person with dementia (informal carers) and others who did not have that kind of relationship (noncarers). The disadvantage of the

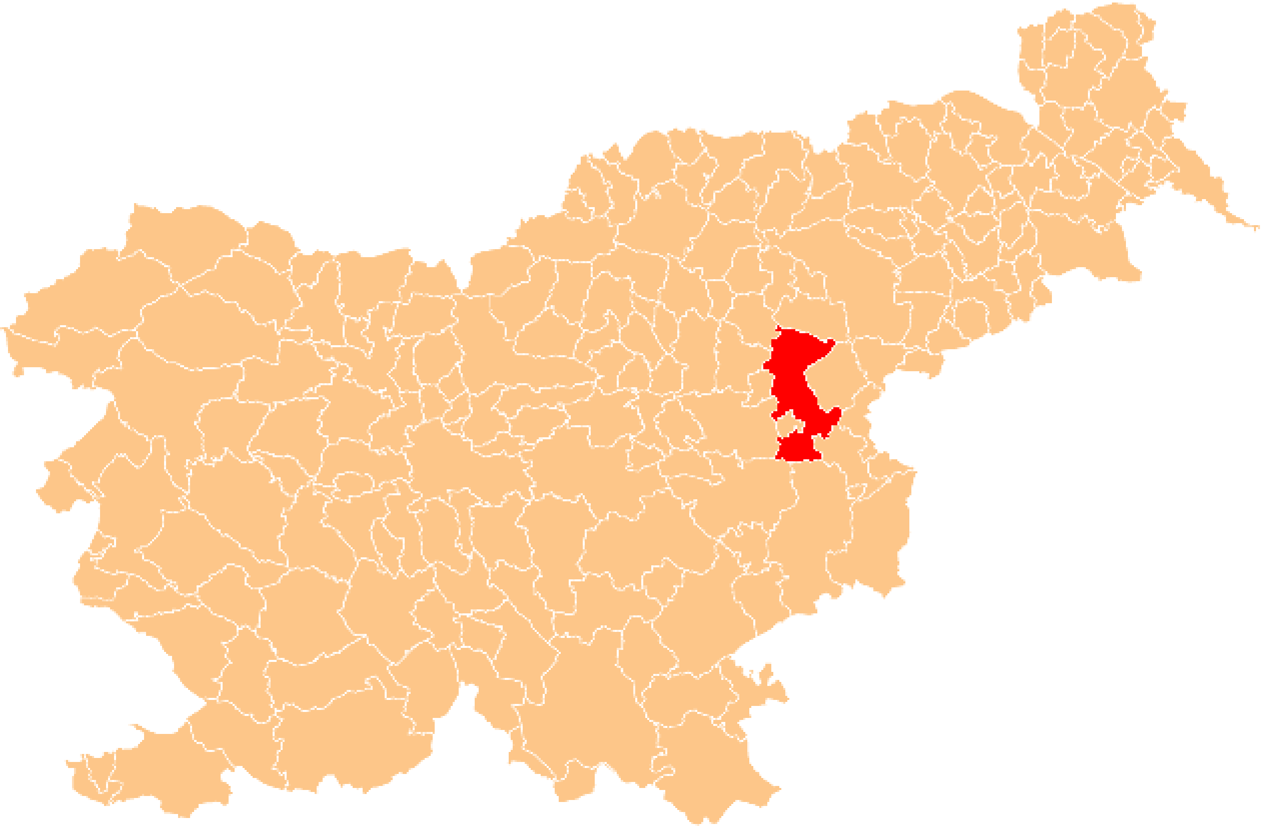

Fig. 1 The location of the Municipality of Šentjur in Slovenia [23].

study is small number of informal carers of person with dementia who completed the survey. Further research is required on this relatively rare subject and should be related to the specific circumstances of having relationship with person with dementia.

6. Conclusions

The aim of present study was to investigate public knowledge about DFC among Slovenian informal carers of person with dementia and noncarers. Although the knowledge is not without gaps, people thought that idea of dementia friendly cities and communities had been well communicated on the whole. The aim of dementia friendly city is to enable PWD to be an active citizen. The dementia friendly city programme offers an opportunity for all citizens to increase their knowledge about dementia and also offers the opportunity for PWD themselves to decide what kind of community they would like Šentjur to be. In dementia-friendly city person with dementia is placed at its heart on the basis that what is good for person with dementia is good for everybody.

7. List of Abbreviations

AD: Alzheimer’s disease; DFC: Dementia-friendly city; PWD: Person with LOD (late onset dementia).

Authors’ Contributions

All authors read and approved the final manuscript and agree with some fee if paper will be published in your journal.

References

[1] Department of Ageing and Life Course. 10 Priorities towards a Decade of Healthy Ageing. WHO Dec. 2017. http://www.who.int/ageing (accessed on January 8, 2018).

[2] WHO Media Centre. Dementia. Fact Sheet 2017. http://www.who.int/mediacentre/factsheets/fs362/en/ (accessed on February 2, 2018).

[3] World Health Organization. Mental Health. 2017. Development of Global Dementia Observatory. http://www.who.int/mental_health/neurology/dementia/GDO/en/ (accessed on February 4, 2018).

[4] Alzheimer's Disease International. World Alzheimer Report 2016. Improving Healthcare for People Living with Dementia: Coverage, Quality and Costs Now and in the Future. https://www.alz.co.uk/research/world-report-2016 (acessed on February 2, 2018).

[5] Alzheimer Europe. 2015. *Dementia in Europe Yearbook 2015: Is Europe Becoming More Dementia Friendly?* http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks (accessed on February 2, 2018).

[6] Alzheimer's Disease International. World Alzheimer Report 2016. Dementia Plans. Slovenia-National Plan 2016-2020. https://www.alz.co.uk/dementia-plans (acessed February 2, 2018).

[7] Devine, P. 2016. "Discussion Paper: Public Attitudes and Knowledge of Dementia: Northern Ireland, Republic of Ireland and Scotland, 2016." http://www.ark.ac.uk/ageing (acessed on February 2, 2018).

[8] Langa, K. M. 2015. "Is the Risk of Alzheimer's Disease and Dementia Declining?" *Alzheimer's Res. Ther.* 7 (1): 34-8.

[9] Larson, E. B., Yaffe, K., and Langa, K. M. 2013. "New Insights into the Dementia Epidemic." *N. Engl. J. Med.* 369 (24): 2275-7.

[10] Wada-Isoe, K., Uemura, Y., Suto, Y., Doi, K., Imamura, K., Hayashi, A., Kitayama, M., Watanabe, Y., Adachi, Y., and Nakashima, K. 2009. "Prevalence of Dementia in the Rural Island Town of Ama-cho, Japan." *Neuroepidemiology* 32 (2): 101-6.

[11] Wada-Isoe, K., Uemura, Y., Nakashita, S., Yamawaki, M., Tanaka, K., Yamamoto, M., Shimokata, H., and Nakashima, K. 2012. "Prevalence of Dementia and Mild Cognitive Impairment in the Rural Island Town of Ama-cho, Japan." *Dement Geriatr Cogn. Disord. Extra.* 2 (1): 190-9.

[12] Dementia Friendly Sanada, Ueda City. https://www.alz.co.uk/dementia-friendly-communities/japan#Sanada (accessed on January 8, 2018).

[13] Hare, P. 2016. "Dementia without Walls: Reflections on the Joseph Rowntree Foundation Programme." *Working with Older People* 20 (3): 134-43.

[14] Crampton, J., Dean, J., and Eley, R. 2012. "Creating a Dementia Friendly York: Joseph Rowntree Foundation, 2012." https://www.jrf.org.uk/report/creating-dementia-friendly-york (accessed January 31, 2018).

[15] Strategija obvladovanja demence v Sloveniji do leta 2020. http://www.mz.gov.si/fileadmin/mz.gov.si/pageuploads/Demenca/92016_strategija_obvladovanja_demence.pdf (accessed on December 2, 2017).

[16] Swaffer, K. 2014. "Dementia: Stigma, Language, and Dementia-friendly." *Dementia* 13 (6): 709-16.

[17] Rahman, S., and Swaffer, K. 2018. "Assets-Based Approaches and Dementia-Friendly Communities." *Dementia* 17 (2): 131-7.

[18] Alzheimer's Society Dementia Friendly Communities Programme Team. Creating a Dementia-Friendly Workplace: A Practical Guide for Employers. Alzheimer's Society 2015. https://www.alzheimers.org.uk/dementiafriendlycommunities (accessed on December 30, 2017).

[19] Hare, P., Dean, J., and Knight, K. 2015. "How Can We Make Our Cities Dementia Friendly? Sharing the Learning from Bradford and York." Joseph Rowentree Foundation 2015. https://www.jrf.org.uk (accessed December 30, 2017).

[20] Slovenia—Dementia Friendly Communities. Dementia Friendly Hospital. Šentjur Dementia Friendly Project. ADI 2013. https://www.alz.co.uk/dementia-friendly-communities/slovenia (accessed on December 30, 2017).

[21] Wang, J. J., Hsieh, P. F., and Wang, C. J. 2013. "Long-Term Care Nurses' Communication Difficulties with People Living with Dementia in Taiwan." *Asian Nursing Research* 7 (3): 99-103.

[22] Du, L., and Hu, J. 2016. "The Effects of Health Education on Knowledge about Alzheimer's Disease and Health-Promoting Behaviours of Older Chinese Adults in a Nursing Home: A Pilot Study." *International Journal of Nursing Practice* 22 (1): 31-42.

[23] Šentjur. https://en.wikipedia.org/wiki/%C5%A0entjur (accessed on February 6, 2018).

[24] Lin, S. Y., and Lewis, F. M. 2015. "Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future." *The Gerontologist* 55 (2): 237-44.

[25] Blackman, T., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S., and Williams, K. 2003. "The Accessibility of Public Spaces for People with Dementia: A New Priority for the 'open city'." *Journal Disability & Society* 18 (3): 357-71.

[26] Fleming, R., Bennett, K., Preece, T., and Philipson, L. 2017. "The Development and Testing of the Dementia Friendly Communities Environment Assessment Tool (DFC EAT)." *International Psychogeriatrics* 29 (2): 303-11.

[27] Lin, S. Y. 2017. "Dementia-Friendly Communities and Being in Healthcare Settings." *Curr. Opin. Psychiatry* 30 (2): 145-50.