Type of Contribution: PAPER

**How Can Libraries Support Dementia Friendly Communities?: The Study into Perceptions and Experiences of Croatian Librarians**

**Keywords:** Alzheimer’s Disease, dementia, public libraries, Croatia

# Introduction

Alzheimer's Disease (AD), the most common cause of dementia, is an incurable neurological disease with an unknown cause. It starts gradually with memory loss but over the course of their disease AD patients experience severe impairment of their cognitive and physical abilities. In the final stage of the disease, persons diagnosed with AD need around-the-clock supervision and care because they have massive problems with speaking, thinking and making decisions (Alzheimer's Disease International, 2018). This complex situation leads ultimately to a number of larger issues, most importantly the questions of human, legal and financial rights of AD patients and the legal status of their caregivers (Dološić 2016).

World Health Organization estimated that in 2017 worldwide around 50 million people had dementia, and approximately 10 million new cases are expected to be reported every year (Alzheimer's Disease International 2015). AD is as much an economic and fiscal burden as it is a social and health challenge and its prevalence is expected to grow. In 2012 the World Health Organization (WHO) and Alzheimer’s Disease International (ADI) recognized dementia as a global public health priority and called upon governments, policymakers and other stakeholders to implement sustained and coordinated action across multiple levels, and develop national dementia plans and strategies (Dementia 2012).

**Theoretical framework and background**

In countries such as Croatia where information, health and social care systems for AD patients and their caregivers (CGs) are not sufficiently developed (Rušac 2016), AD patients in most cases depend fully on their informal CGs. These unpaid non-professionals are in most cases their family members such as spouses, partners, siblings, children, grandchildren, other relatives, and friends, who supervise and support them during all stages of the disease. Caring for elderly family members with AD is an arduous task with immense physical, psychological, emotional, social and financial impact on the CGs (Novais et al. 2017, Dauphinot et al. 2015, 2016). As care needs change as patients move from initial to final stages of the disease, CGs' needs often remain unmet. In order to minimize the CGs' burden and understand how AD patients and their CGs could be better served, scholars from around the world addressed their diverse needs (Edelman et al. 2006; Tatangelo et al. 2018; Lai and Chung 2007; Kucmanski et al. 2016; Arévalo-Flechas et al. 2014; Brodaty and Donkin 2009; Rosa et al. 2009; Vaingankar et al. 2013; Uzun et al. 2019).

 Although librarians have not generally been included in the circle of professionals caring for persons with dementia, recent research indicates that public libraries can contribute to the development of dementia friendly communities by supporting social inclusion, self-efficacy and capacity building of persons with AD (Howarth 2020; IGARD n.d.). Howarth (2020: 20), for example, goes even further and posits that cultural heritage institutions "have a responsibility and a rationale for servicing those who have been marginalized across time by what they have rather than who they are." Libraries can enhance the everyday life experience of AD patients and their CGs through careful space planning (Designing Libraries 2019), storytelling and reading programs (Cayton 2004; Baker, Rimkeit & Claridge 2018), memory cafes (Charbonneau & Rathnam 2020), music and art programs, reminiscence kits, audio-visual materiasl, toys, board games, puzzles, objects, therapy animals, technology etc. (McDermott, Orrell & Ridder 2014; Kelsey 2018; Dickey, 2020) In all of AD related programs it is prerequisite that library staff providing services to persons with AD must be knowledgeable of dementia related diseases and collaborate with professions in the field (Mortenson & Neilsen 2007).

This paper builds upon the emerging information science interest in AD (Erdelez et al. 2015; Harland and Bath 2008) and presents results from a research project titled *Information needs of AD patients and their caregivers* which received a 20-month grant from the University of Osijek, Croatia. In this project, an interdisciplinary team of scholars from different fields (medicine, law, and information science) set out to identify information and service needs of AD patients and their CGs in Croatia with special emphasis on understanding the barriers and challenges they face in obtaining the required information or services. So far, the studies conducted within the project provided critical analysis of the local context with special emphasis on legislative framework, available support services, and human rights issues connected with AD patients and their CGs (Dološić 2019) and explored the information and service needs of AD patients and their CGs (Erdelez et al. 2019; Erdelez et al. 2020, *in print*).

**The Study**

The research reported in this paper builds upon the previously obtained results related to information and service needs of AD patients and their CGs in Eastern Croatia, and aims to contribute to practical implications of the project by examining the role of public libraries in building a dementia friendly community. The study sets of from a premise that people with AD are respected and valuable members of their communities and that they should participate in the community (including libraries) and enjoy meaningful lives. This research will explore how public libraries tailor their spaces, collections, programs and services in order to enhance the everyday experience of persons with AD and their CGs, and in particular their access to education, cultural enrichment (books, art, music etc.), creative recreation etc.

**Research questions**

The aim of the study is to learn how Croatian public libraries serve the needs of this user group, and to provide guidelines on how they could improve these services. The study will try to answer the following research questions:

RQ1: What kind of resources, services and programs for AD patients and their CGs do Croatian public libraries provide?

RQ3: What kind of training do librarians have to respond to the needs of AD patients and their CGs?

RQ4: Are there any differences between the library approaches in relation to their size, community etc.?

RQ5: How could spaces, collections, programs and services of Croatian public libraries be enhanced in order to better meet the needs of persons with AD and their CGs?

**Methodology**

Following the online survey which will be distributed to all public libraries in Croatia, an in-depth interviews with selected respondents (those coming from libraries in which AD related resources, programs and services are provided) will be conducted. Based on the quantitative and qualitative findings from this study, and best practices from international libraries, recommendations on how to enhance local library practice will be outlined.

**Conclusion**

The purpose of this study is to investigate the current services of Croatian public libraries to Alzheimer’s Disease patients and their Care Givers. The findings obtained in this study will help understand how Croatian public libraries serve the needs of these critical categories of users. Practical implications of the study will be evident in the proposed guidelines and recommendations for public libraries in order to contribute significantly to the development of dementia friendly communities.

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