

Factsheet: Let's start talking about dementia, technology and migrants

The role of Everyday Technologies (ETs) in supporting older people living with and without cognitive impairment and/or dementia in the EU, from migrant and displaced communities.

Older people from migrant backgrounds and older displaced people currently living within the European Union (EU) encounter additional challenges to those older adults born in EU member states. Each experience is unique but the challenges are compounded for older migrants and displaced people living with (diagnosed or undiagnosed) dementia and cognitive impairment. Consideration of the role of ETs as both a facilitator and barrier to engagement in activities of daily life (ADLs) may support increased understanding, in research and clinical practice, of ways to enable participation and access in a person's chosen places, activities and services, within public space.

1. Identifying the needs of migrant & displaced people:

There are approximately 20.7 million (4.7% of the total EU population) citizens of non-member countries living within the EU-28 member states. Such statistics tell us that we live in a "superdiverse" society, with an ageing population, termed an "agequake" and yet little research or policy has effectively focused on preparing for the scale and complexity of caring for people from various cultures as they age.

Barriers: Barriers to identifying and tailoring care include:

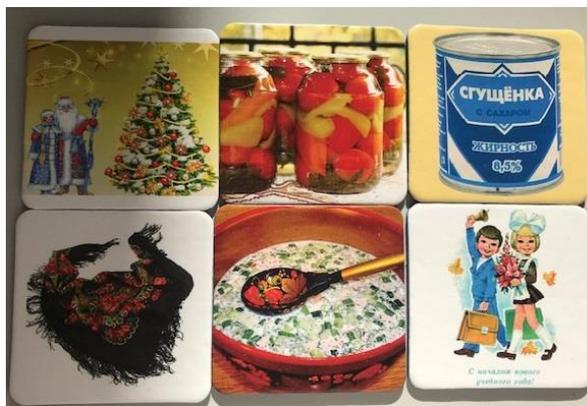
-Insufficient and inconsistent training in culturally sensitive approaches resulting in a reluctance for therapists to directly discuss ethnic, cultural or religious differences (Harper & Iwamasa, 2000).

-A lack of standardised tools that identify and assess the specific needs of migrants and displaced people.

Facilitators: Alternatives to standardised assessments include: adaptable, informal history taking approaches, using interactive storytelling applications (on digital technologies e.g. smartphones, iPads etc.) to promote communications with family and social networks who may be geographically separated.

2. Living with dementia & cognitive impairment:

For migrants and displaced people with dementia or cognitive impairment who have left their homes to travel to the EU, this may mean re-living traumatic experiences. Due to cultural variation, psychological symptoms may manifest in different ways e.g. behaviours deemed as challenging (agitation, disorientation etc).



Barriers: There is a mismatch between growing rates of dementia worldwide and the demanding cognitive processes that are increasingly considered a prerequisite in order to participate in basic activities and places within public space e.g. grocery shopping, public transport. Health professionals should be mindful of significant health inequalities between migrant and national communities within the EU, such inequalities are related to differences in literacy, accessibility to health and technology services and

health status, among other factors (O'Donnell et al., 2016).

Facilitators: Research shows that older adults particularly those with mild cognitive impairment and/or dementia may feel more familiar and comfortable with traditional, non-digital ETs e.g. kettle, radio etc. and such items may be more helpful in tailoring interventions than hi-tech

solutions (CACTUS Research Group: <https://ki.se/en/nvs/the-cactus-research-group>).

3. Cultural v. local adaptations:

Cultural adaptation is defined as the "systematic modification of an evidence-based treatment or intervention protocol to consider language,

culture and context in such a way that is compatible with the client's cultural patterns, meanings and values" (Bernal et al., 2009, p. 362).

Barriers: There is a practical dilemma in implementing evidence-based practice, with generic cultural adaptations, among diverse communities. If originally developed according to European cultural norms, interventions may be perceived as "top-down" with minimal cooperation among the target migrant community (Calzada, 2010; Kessler et al., 2005).

Facilitators: Improved accessibility to culturally relevant evidence-based practice can not only support the positive experience of the person with dementia and their carer but also yield greater efficiency among different services.

-One example referred to as a "Supply Landscape" (*Versorgungslandschaft*) is an interactive map of culturally adapted services to signpost carers and people with dementia to relevant services in the North-Rhine Westphalia region, Germany. It will be available in online and offline formats, and different languages in order to maximise accessibility.

-There are few examples of local "grass-root", active community engagement initiatives. The Turkish Alzheimer's Society, for example, is the only culturally specific dementia organisation founded by the Turkish community of carers, families and people with dementia in Cologne. The Turkish Alzheimer's Society was founded in April 2017 and within a year they amassed over 15,000 Facebook followers. This led to the first Turkish Alzheimer's Society Conference in February 2018 with the aim of connecting people with dementia, families, carers, volunteers,

health and social care professionals and researchers.

4. Technology & Therapist Matching:

Matching clients and therapists is a potential anecdote to several issues.

Barriers: Due to cultural or religious beliefs, migrants or displaced people living with cognitive impairment and/or dementia, and their family may prefer to work with a specific gender of therapist or carer. Language can be another barrier which is exacerbated by insufficient bilingual volunteers or staff to support the community. There are inter-generational and intra-familial aspects of language within migrant and displaced communities, as older relatives living with cognitive impairment may return to communicating exclusively in their native language which may be unfamiliar for subsequent generations living within the EU. Unique challenges identified among migrant and displaced communities pertain to caregiver cultural norms whereby care is viewed as the responsibility of the (extended) family or community. This relates to a trend for migrants and displaced people to seek or access support at a later stage (e.g. late diagnosis due to perceptions of stigma which

results in people accessing aged care or dementia services only after a person reaches crisis or advanced stages of their care needs) (Dibelius, 2016; Okken et al., 2008; Tezcan-Güntekin et al., 2015).

Facilitators: It is important to provide bilingual therapists and interpreters at the earliest opportunity to minimise miscommunication and confusion. Cultural mediation provides an additional layer of support to navigate the complexities of misinterpretation and misrepresentation when communicating with people living with memory or communication difficulties associated with cognitive impairment and/or dementia. There is a need to develop technology including educational materials to support the people with dementia, family and carers about living with dementia. One project in Germany involves the adaptation of online and offline educational and memory aids e.g. flashcards, games, music, books etc. not only through language translation but also by making use of familiar, traditional proverbs, metaphors and imagery which retain the original purpose of brain-training but are delivered in a culturally relevant format.

Recommendations:*

1. Harness participatory research and the interactive nature of technology to involve end-user target groups throughout the process of developing and adapting more user-friendly ETs and personalised assessment tools e.g. life history gathering, connection with relatives from abroad etc.
2. Consider both the challenges and opportunities of an increasingly technological world, for example simpler more familiar ETs may be more effective than hi-tech devices when working with older people living with cognitive impairment/dementia from migrant or displaced communities.
3. Research increasingly demonstrates the benefits of localised adaptations to empower various communities and increase the likelihood of impactful dissemination and implementation of best practices in dementia care.
4. Where possible match technologies, therapists and clients according to language, cultural and gender preferences as early as possible.

*Recommendations based on consultations with multilevel stakeholders from the Turkish migrant community living in the North-Rhine Westphalia region, Germany (October-January 2017/18). The research presented in this report was carried out as part of the Marie Curie Innovative Training Network (ITN) action, H2020-MSCA-ITN-2015, under grant agreement number 676265

