LEE LI MING
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Empowering informal caregivers of people living with dementia through ICT interventions

An analysis of iSupport and UnderstAID[1]

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Challenges experienced by caregivers of people living with dementia

The number of people living with dementia (PLWD) is on a worldwide increase. In 2020, there were over 50 million PLWD across the world. This number is set to double every 20 years, reaching 82 million in 2030 and 152 million in 2050 (Alzheimer's' Disease International, n.d.).

The rise in dementia cases is accompanied with an intensification of informal caregiving responsibilities, with a disproportionate amount of the burden falling on female spouses or adult children. While informal caregiving might be viewed as a cost-effective solution from an economic standpoint, such a view does not acknowledge the negative costs on the emotional, social and economic wellbeing of informal caregivers. Hence, it is important to provide cost-effective

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[1] This is an evolving database. We will be adding more examples and cases over time.

support to sustain the caregiving responsibilities borne by informal caregivers to improve their quality of life. The empowerment of informal caregivers can be defined as *"positive control of one's mind and body, cultivating a positive attitude, proactively attempting to understand one's role as a caregiver to improve caregiving capabilities, focusing on others as well as oneself, supporting the independence of the care receiver, and creating constructive relationships with other people surrounding them"* (Sakanashi and Fujita, 2017, p.1).

Hence, this article will investigate how the Information and Communication Technologies (ICT) can aid in the empowerment of informal caregivers. [2] This will be done through the examples of iSupport and UnderstAID and their evaluations.

Harnessing technology to empower informal caregivers

ICT interventions might be able to improve the subjective wellbeing of informal caregivers. They can do so by offering informal caregivers relevant education, support and training at home at a relatively lower cost, compared to in-person, health professional-led interventions. In addition, ICT interventions allow the possibility of customization of activities and contents informal caregivers wish to engage in, depending on their availability,

preferences, priorities, and emotional states.

iSupport

Developed by the World Health Organization (WHO), iSupport is an online skills training and support program for caregivers of PLWD.

iSupport is organised into five modules (Box 1). Each module is broken down into different lessons and each lesson offers activities, knowledge recap questions and summaries to consolidate the learning of informal caregivers.

Box 1:
iSupport is made up of five modules as follows:
- Introduction to dementia
- Being a carer
- Caring for me
- Providing everyday care
- Dealing with behavioral changes

Source: Training and support manual for carers of people with dementia, World Health Organization, 2019, p.5.

Evaluation of iSupport

A study (Pot et al., 2020) was conducted to understand the perspectives of informal caregivers in Australia on the use of iSupport. Due to the constantly evolving needs of PLWD, caregivers can experience immense amounts of stress while caring for people with dementia. This can adversely affect their motivation to learn

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[2] For an overview of digital resources for caregivers in Singapore, see Siew (n.d.). *Harnessing Digital Resources*

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about dementia care during their caregiving journey. The study revealed that iSupport addresses this challenge by offering "flexible self-directed learning" (Pot et al., 2020, p.1547) which includes elements like "self-learning assessment prior to and after learning activities" (Pot et al., 2020, p.1547).

The study also suggested that a potential challenge that could hinder the adoption of the iSupport program was the availability of time informal caregivers had to use iSupport. Informal caregivers suggested that a possible way to overcome this challenge was for iSupport to "enable quick searching of learning units based on informal caregivers' learning needs" (Pot et al., 2020, p.1546).

In addition, informal caregivers also reflected the need to equip iSupport with a face-to-face caregiver network to achieve positive group interactions amongst informal caregivers. Establishing social bonds and closer relationships with their peers would allow caregivers to have a safe space to discuss their emotional responses to the challenges they encounter and find support and solidarity from other caregivers.

understAID

understAID is an online application that aims to improve the quality of life of caregivers to PLWD by providing accessible information and reliable support. understAID is a project by the Active Assisted Living Programme (AAL), a European funding programme that aims to improve the quality of life for older people and to enhance industrial collaboration in the field of healthy ageing technology and innovation.

understAID consists of five modules with information spanning across fifteen different topics (Box 2). Each topic is organised into four levels of difficulty – quick fixes, simple insights, explanations and more details – allowing informal caregivers to experience a gradual learning curve.

Box 2:
The modules are organized as follows:
- Cognitive declines (Topics: attention, memory and orientation)
- Daily tasks (Topics: bathing, incontinence, massage and touch and physical exercises)
- Behavioural changes (Topics: anxiety and agitated behaviour, depressive mood, maniac symptoms and emotional control and recognition)
- Social activities (Topics: communication and apathy and loss of motivation)
- You as a caregiver (Topics: coping with own stress and motivation)

Source: AAL Programme, (n.d.). *understAID*, http://www.aal-europe.eu/projects/understaid/

Evaluation of understAID

To better personalise the user experience of informal caregivers, understAID allows informal caregivers to fill in an interactive customisation questionnaire on one's specific caregiving situation. Using this information, the system will prompt the

user with information better tailored to their needs.

A study in 2015 (Jajor et al.) surveyed informal caregivers on their user experience of understAID. The study used the most popular keywords searched up by informal caregivers on the Internet as indicators for the scope of content informal caregivers were interested to learn more about. These content areas could be accessed via the understAID application, proving its relevance in terms of helping caregivers to acquire knowledge about the peculiarities of the dementia disease.

However, a pilot randomised control study (Núñez-Naveira et al., 2016) conducted to establish the effectiveness of understAID application among informal caregivers suggested that a limitation of understAID was its lack of time efficiency. Informal caregivers felt that the application was too time consuming because "[it could not] be integrated with their existing medical records" or synchronised with the calendar on their own devices (Núñez-Naveira et al., 2016, p.11).

Conclusion

Informal caregivers assume a crucial role when caring for PLWD. However, they often receive minimal education and training in dementia care and their socio-emotional needs are often overlooked. There is a growing need to improve the access to information and resources for informal caregivers. To fill this gap, the development of ICT tools like iSupport and understAID can enable greater empowerment for informal caregivers by

equipping them with the relevant knowledge and skillsets. While there is still room for improvement in terms of equipping ICT tools with social networking capabilities, these tools have already proven to significantly aid informal caregivers in terms of strengthening their feelings of competence with caring duties and easing the onset of depressive symptoms.

Sources:

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