

INFORMATION AND COMMUNICATION TECHNOLOGY (ICT) FOR CARERS

Demographic ageing in Europe leads to a growing incidence of age-related diseases, a growing demand for care and a real sustainability challenge for our social and health care systems. According to recent EU-funded research, informal carers across the EU provide over 80% of all care, with women providing approximately two thirds of care mainly as daughters (in law) and wives/partners. However, their role is poorly recognised, their needs underexplored, and they have little access to the formal services that are available. Social, psychological and educational interventions are among the best strategies for informal carers to manage the pressure of care. Some European governments have put in place various supports, mainly financial measures and in-kind services, to help informal carers compensate for their economic loss and to allow them to reconcile care and work. Nevertheless, these solutions seem to only partially cover their needs: for example, some 50 % of families caring for older relatives are not satisfied with the public services available for families.

Evidence shows that informal carers and paid assistants have a wide range of social and care needs: psychological support; training and education; information, advice and counselling on caring; self-support; social participation with friends and peer groups; leisure activities; reconciliation of care and work; support in language and culture integration; and protection of their rights. In response, information and communication technologies (ICTs) have been recognised by European policy as proactive measure to be developed in Member States to help in supporting the carers so that care recipients can be cared for at home. ICT-based services for informal carers and paid assistants can be defined as a service provided by any private or public organisation that addresses some carers' and/or care recipients' needs through

technological devices that are integrated or not in a wider intervention programme.

Potential benefits of ICT tools on the quality of life of informal carers

ICT Tools can support the social integration of carers, provide them with social, emotional and peer support, facilitate their participation in aspects of life outside the home and thus supporting carers' quality of life. ICT services for support and integration help the carers to maintain online contact with family and friends, to create online communities and to exchange information, advice and peer-support informally among themselves. The development of electronic networks of informal carers can be a very effective and low-cost way of spreading information on the support services available locally and nationally, and of exchanging ideas on good practice. Electronic networks can also help to alleviate the loneliness experienced by many informal carers, and encourage them to continue their valuable work. For example, a study in the United Kingdom showed that the 42 % of online carers said that the Internet helps them reduce their feeling of isolation.

The vast majority of carers wish to maintain a professional life, not only because it gives them a source of income but also because it

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helps them preserve vital social networks, a sense of purpose and worth. Research has indeed highlighted that the majority of working age carers currently are in employment, some part time but the majority full time. Nevertheless, flexible working arrangements are essential to allow carers to adapt their working patterns to their needs. In this regard, the digital revolution offers opportunities for improving work–life balance that are currently not being harnessed. Technological support for working carers, such as tools to remotely monitor the safety and wellbeing of dependent people during working hours can prove instrumental in helping carers strike a good level of work–care balance. ICT tools for work–care reconciliation can therefore help carers successfully fulfil their caregiving tasks while remaining active and productive.

ICT as a tool to enable and support independent living

Technologies that allow dependent people to stay at home without continual care support allow to relieve pressure on carers and support carers in their caring role. Examples of ICT for independent living include home alarm systems, telecare, tracker devices (GPS), and (gas, temperature, bed) sensors. These technologies can give more independence to older people and their informal carers, as well as easing the constant worry of the latter. Improvements to the quality of life of care recipients could affect the efficiency of social care and health care services. Better quality of life delays the entry of old people into institutional care, and reduces unplanned hospital admissions and the length of hospital stays. These reductions in the use of services could generate savings for the health and social care systems.

ICTs for independent living are probably the best-assessed services, since they have been running for a while, whereas the ones specifically for carers have been developed more recently in the European context.

The area where technology can make the biggest impact – informal care in the home – is the one where there is least knowledge of the technology that is available and what it can do. There is an urgent need to create channels of information to home–based family

carers, via electronic networking, for example.

ICT as a tool to gain information and skills

Carers need adequate preparation for the caring role, in terms of the necessary skills, the provision of timely information and knowledge, assessment and provision of practical and emotional support at different points over the duration of their role. Ultimately, carers need to know that they are doing the right thing and that appropriate help and guidance will be available if they need it.

ICT solutions can provide accessible information, education and support that can help carers directly in their caring situation to increase their preparedness to care (that is, increase their caregiving skills, self–confidence and self–mastery) and in this way can help to improve the quality of informal care provided by the informal carer (e.g. specific aspect of access to patients’ medical records and updates).

ICT services for information and learning allow carers to access online and telephone–based information and advice from peers and professionals. Such ICTs also open up the possibility of online self–training through e–learning platforms for paid assistants to acquire skills or gain recognition for the skills they already have in managing long–term conditions. This can in turn reveal useful to help carers go back to the labour market.

ICT as a tool for coordinated care

Online tools can also prove effective for coordinating care tasks from professional, informal and family–employed carers, respite and information sharing. An example of ICT for care coordination may be seen in online organisational systems with carers’ access. These services sustain communication, coordination and cooperation with all those involved in care, and provide the possibility of arranging services online.

To summarise, ICT-based services for informal carers can positively impact on:

- The quality of life of the informal carers, helping them to reconcile care and work, and improving their social lives and health conditions.
- The quality of life of care recipients, improving their health-related quality of life and their social lives.
- The quality of care provided by informal carers and privately-paid assistants, improving their knowledge of care, skills and competences.
- The cost of care for end-users, generating savings compared with ordinary services.
- The acceptability and accessibility of ICTs, in terms of people's greater willingness to use ICT and their satisfaction with it, their acquisition of digital competences, and their wider use of ICT materials.

Drivers for ICT-based care services

Research has demonstrated that the success of innovative services heavily depends on cooperation between stakeholders, the involvement of the third sector, the empowerment, strong involvement and proactivity of end-users (carers, elderly people and formal care staff) as active players in the design of the services, complemented by training in digital and care services competences, creating new value chains in the delivery of long-term care, under a policy umbrella.

The main drivers that motivate actors to develop and implement these services are:

- The desire of professionals and families to improve the quality of care and quality of life of the dependent person, i.e. the "caree".
- The wish to empower and help carers.
- The search to improve the efficiency and effectiveness in social and health care.

- The need to realise systematic cost savings.

Obstacles to the development of ICT-based solutions to support carers

Despite a growing interest in the potential offered by ICT-based solutions for informal caregiving, obstacles to their development, implementation and transfer still remain. These include:

- Technology-specific issues that refer to the need to demonstrate the value of ICT to provide long-term care, the acquisition of digital competences and skills, access to and use of technological infrastructures, and the fact that ICT supposes new forms of organisation of long-term care services, challenging local care organisations (as the main providers of social care). For example, more efforts could be done to further develop the sometimes limited digital skills of carers – i.e. the skills and knowledge needed to undertake everyday digital activities that could be relevant to support their caregiving role. These can include finding and managing digital information, sharing personal data digitally, using digital technology and making use of e-learning;
- Difficulties associated with the recognition of the role of informal carers in the formal long-term care system as co-providers of care, and also as a group with needs;
- Overcoming the scepticism, negative attitudes and lack of knowledge about the use of these types of services in long-term care;
- Providing convincing scientific evidence that the service actually helped dependent people and their family carers and was cost efficient;
- Creating an efficient business model;
- Deploying the initiatives, due to their small scale; and

- Bridging the digital gap that still exists in some parts or population groups of the European Union. For example, even in Sweden which overall boasts one of the highest rates of Internet access within the general population, there are still over 60% of women and 34% of men aged 65–75 years of age that do not have regular access to the Internet so that there still needs to be targeted initiatives focusing on appropriate comprehensive digital training and education.

ICT-based services for informal carers and paid assistants tend to be beneficial for their end-users, as well as for governments as they can generate a more efficient use of services and more sustainable social protection systems. Some studies report that ICT-enabled services save carers' time and money, increase their wellbeing and self-esteem, help link them with others and with the healthcare

team, and empower them, thus developing their problem solving ability, perceptions of self-efficacy and care skills. This can help convince public authorities on the relevance to recognise the role of informal carers and their paid-assistants in their public long-term care service provision, as well as to deploy these ICT services for their support.

Yet, so far, the analysis of the benefits of ICT-based services has been mainly focused on their impact at the level of users themselves but the effects of ICTs for carers at the organisational and system levels are scarcely documented. Data on impacts at these levels should be collected to complement those at user level and to convince policymakers to promote policy frameworks for the creation of ICT-based services for carers, especially insofar as they provide data on the use of health and social services and savings.

References

Information and communication technologies for informal carers and paid assistants: benefits from micro-, meso-, and macro-levels – S. Carretero, J. Stewart, F. Barbabella, 2015

Adequate social protection for long-term care needs in an ageing society. Social Protection Committee and European Commission, 2014

European citizen's digital health literacy, flash Eurobarometer 404, European Commission, 2014

Can Technology-based Services support Long-term Care Challenges in Home Care? – S. Carretero et al, European Commission (Institute for Prospective Technological Studies/Joint Research Centre), 2012

Final report on the “Methodological Framework”, CARICT Project: Deliverable, Barbabella et al., 2011

Company initiatives for workers with care responsibilities for disabled children or adults, Eurofound, 2011

Health and long-term care in the European Union, Eurobarometer, European Commission, 2007

Coping and the mediation of caregiver stress – Pearlin, L.I., Turner, H.A. and Semple, S.J., 1989

Caregiving and the Stress Process: An Overview of Concepts and Their Measures – Pearlin, L.I., Mullan, J.T., Semple, S.J. and Skaff, M.M., 1990

The careers of caregivers – Pearlin, L.I., 1991

Profiles in caregiving: The unexpected career – Aneshensel, C., Pearlin, L., Mullan, J., Zarit, S.H. and Whitlatch, C.J., 1995

Stressors in adaptation in late life – Pearlin, L.I. and Skaff, M.M., 1995

Caregiving and institutionization: perceptions of family conflict and socioemotional support – Gaugler, J.E., Zarit, S.H. and Pearlin, L.I., 1999



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