The potential of ICT for supporting caregivers

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Clara Centeno

Joint Research Centre (JRC)
Institute for Prospective Technological Studies
The European Commission’s Research-Based Policy Support Organisation
IPTS: Part of Joint Research Centre of the EC: 7 Research Institutes across Europe

Mission: “to provide customer-driven support to the EU policy-making process by developing science-based responses to policy challenges that have both a socio-economic as well as a scientific/technological dimension”
Trends in Long Term Care (LTC)

Life expectancy → Ageing ➔ Demand for care

Changing family Structures

Mobility

Labor force

Women at work

Quality of care ➔ Home Care ➔ unattractive working conditions ➔ quality

ICT

IEM
Key research questions

- What is the **role** of informal caregivers in long term care (LTC)?
- What are their **needs**?
- Are there specific supporting **policies**?

- What **ICT** applications are used to support informal carers?
- **Opportunities** and **barriers** for ICT use?
- Potential **policy options**?

... For informal caregivers in general, and in particular for **migrants**
Exploratory research due to scarcity of data

Countries analyzed:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>UK/England</td>
<td>CIRCLE (Centre for International Research on Care, Labour and Equalities) University of Leeds, Prof. Sue Yeandle, Gary Fry</td>
</tr>
<tr>
<td>Germany</td>
<td>Association of Senior Citizens’ Organisations (BAGSO), Dr.Heidrun Mollenkopf</td>
</tr>
<tr>
<td>Italy</td>
<td>Istituto per la Ricerca Sociale (IRS), Sergio Pasquinelli</td>
</tr>
<tr>
<td>Spain</td>
<td>Consultores Euroamericanos Asociados (CEA) and Innovation Institute for Citizen Welfare (i2BC)</td>
</tr>
</tbody>
</table>

1. **Desk-based analysis** of reports and statistics: LTC provision, organization and ICT-related policies & migrant labour in LTC sector

2. **Web searches and interviews with key informants**: ICT-based initiatives and services for LTC at home

3. **Interviews with informal migrant caregivers** about their knowledge and use of ICT (24 in IT, 12 in ES, 4 in DE)
### Family Carers

<table>
<thead>
<tr>
<th>Country</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UK</strong></td>
<td>11% of pop. (=6M) family carers (2001)</td>
</tr>
<tr>
<td><strong>Germany</strong></td>
<td>44% exclusively by informal carers (2007)</td>
</tr>
<tr>
<td><strong>Spain</strong></td>
<td>75% exclusively by informal carers (2004)</td>
</tr>
<tr>
<td><strong>Italy</strong></td>
<td>90% by family members (2003)</td>
</tr>
</tbody>
</table>
Spain
→ **1.3 million people applied** for services provided by SAAD (28% in Andalucía; below 1% in Ceuta y Melilla and Rioja).

→ 1 million 65+; almost 700,000 80+

→ Less than 600,000 benefit from services; in total 680,000 services were granted

→ In 70% of cases of grade II/III dependency the family is the main (and often only) care provider

*Source: SAAD-IMERSO, June 2010*

Main caregiver’s profile (by task)

Main caregiver’s profile (by living arrangement)

Source: INE data: Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia, 2008
### Differences between native and foreign care assistants

<table>
<thead>
<tr>
<th>Metric</th>
<th>Spanish</th>
<th>Foreign</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age</td>
<td>20-30</td>
<td>40-50</td>
</tr>
<tr>
<td>% with secondary education</td>
<td>40-50</td>
<td>60-70</td>
</tr>
<tr>
<td>% living in the same household</td>
<td>60-70</td>
<td>40-50</td>
</tr>
<tr>
<td>% who are the only help received</td>
<td>70-80</td>
<td>50-60</td>
</tr>
<tr>
<td>% employed as main caregivers</td>
<td>80-90</td>
<td>60-70</td>
</tr>
<tr>
<td>% giving daily care</td>
<td>80-90</td>
<td>60-70</td>
</tr>
<tr>
<td>% working 24h/7</td>
<td>60-70</td>
<td>40-50</td>
</tr>
<tr>
<td>% working all day, but not overnight</td>
<td>40-50</td>
<td>20-30</td>
</tr>
<tr>
<td>% working less than 5 h/day</td>
<td>20-30</td>
<td>0-10</td>
</tr>
<tr>
<td>% involved in personal care (ADL)</td>
<td>80-90</td>
<td>60-70</td>
</tr>
<tr>
<td>% assisting in IADL</td>
<td>80-90</td>
<td>60-70</td>
</tr>
<tr>
<td>% performing domestic tasks</td>
<td>80-90</td>
<td>60-70</td>
</tr>
<tr>
<td>% with legal contract (incl social security)</td>
<td>40-50</td>
<td>20-30</td>
</tr>
</tbody>
</table>


Impact of caring on carers’ lives

Impact of caring on carers’ health

Percentage of main carers claiming to suffer from health-related problems caused by the caring activity, by age of care recipient, 2008

Sources:
INE data: Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia, 2008;
IMSERSO: Cuidados a las personas mayores en los hogares españoles. El entorno familiar, 2005:
Understanding carers’ needs
The needs of informal caregivers

Critical Conditions

- Work load & time schedule (often 24/7)
- Limited knowledge of LTC services
- Lack of information/coordination on care situation
- Limited experiences & skills
- Emotional stress & social isolation

Needs

- Improved working conditions; stress relieve
- Information
- Communication, coordination
- Training
- Social, emotional & peer support
The needs of informal caregivers

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- lack social support network
  - due to work/residence status → invisible
  - intercultural and language barriers
  - lack basic understanding of care context
  - difficult access to training, support etc.
ICT
Usage, Potential, Barriers
The opportunities offered by ICT

**Critical Conditions**
- Work load & time schedule (often 24/7)
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- Limited experiences & skills
- Emotional stress & social isolation

**Needs**
- Improved working conditions; stress relieve
- Communication, coordination
- Training
- Social, emotional & peer support

**eHealth solutions**
- Mobile phones, e-mail, internet, GPS
- Online information, phone helplines
- Online social networks, phones, skype, e-mail
- Online training, phone helplines, online courses & training guides

**Migrants**
- Multilingual information, iconbased devices, translation services

**Home**
- Care worker
- Care organisations
- Doctors & hospitals
- Healthcare professionals

**Informal Caregiver**
- Mobile phones, e-mail, internet, GPS
- Online information, phone helplines
- Online social networks, phones, skype, e-mail
- Online training, phone helplines, online courses & training guides

**Family**
- Friends

**Needs**
- Improved working conditions; stress relieve
- Information
- Communication, coordination
- Training
- Social, emotional & peer support
## State of ICT deployment in LTC

<table>
<thead>
<tr>
<th>Service</th>
<th>IT</th>
<th>ES</th>
<th>DE</th>
<th>UK</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social alarms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Publicly subsidized; 1.8% (IT)-16% (UK) of 65+ population served</td>
</tr>
<tr>
<td>Telecare</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>In ES/DE regional differences; monitoring specific med. profiles</td>
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<tr>
<td>Telehealth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>BUT: in some countries ICT enhanced housing arrangement</td>
</tr>
<tr>
<td>Smart Homes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>By public authorities; associations; forums; wikis</td>
</tr>
<tr>
<td>Online Information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Linked to public administrations, official care providers</td>
</tr>
<tr>
<td>Phone Helplines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Diversity: level of deployment depending on LTC provider &amp; policy recommendations; little involvement of informal caregivers</td>
</tr>
<tr>
<td>PCs, mobile phones, e-mail, GPS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Public “teleassistencia” programme 400,000 users in 2008</td>
</tr>
</tbody>
</table>

**Legend**
- **Mainstream**: Available to certain extend, e.g. in some regions/by some LTC suppliers
- **Pilots being rolled out**: exemplary initiatives
- **Pilots; singular cases**: Research trials/experimental settings
- **Not available**
### Needs - Services

| Planning and organising health and care provision | • LifeSensor (commercial service in DE open to carers) |
| Info and guidance on LTC, | Additional to official websites by public administration, professional associations, etc., |
| • Un cuidador. Dos vidas (Fundación La Caixa) (ES) | • Carers Direct Helpline (UK) – MultiL |
| • SerCuidador (ES) | • SerCuidador (ES) |
| Guide to international recruitment | • Skills for care (UK) |
| Best practice guide to employers | • Social Care Institute of Excellence (UK) |
| Info on assistive technology | • Nottingham City Council’s telecare project (UK) – MultiL |
| Peer support, mutual assistance; information exchange (online forums, blogs, social networks) | • Carers UK |
| • SEKIS (Berlin, DE) – MultiL | • Cuidadoras en Red (ES) - Social network with dedicated online community on “Immigrants in family care” |
| Training with multimedia tools | • Aspasia (IT) – Dedicated to migrant caregivers |
| Training on-line | • City & Guilds – Learning for Living (UK) |
| | • Caring with confidence (UK) explicit BME target |
Más oportunidades para las personas

Un cuidador. Dos vidas
Información y apoyo para el cuidador familiar

Para cuidarse y cuidar mejor

A quién va dirigido

1. Cuidadora familiar de personas en situación de dependencia.
   Actualmente, nuestra sociedad ve incrementarse el número de personas en situación de dependencia. En muchos casos, son las familias las que asumen la responsabilidad de hacer cargo de la situación. Sin embargo, no hemos de olvidar que las personas que tienen a su cargo un familiar en situación de dependencia exponen a un gran desgaste físico y psicológico. A menudo, llevados por la necesidad del momento, descuidan su propia salud.

Qué hacemos

1. Ofrecemos información práctica y de utilidad para la vida diaria del cuidador, de forma que mejore tanto su calidad de vida como el desempeño de su labor.
2. Contribuimos para que pueda conseguir un tiempo de calidad para él mismo, lo que repercute positivamente en la persona cuidada y en su familia.
3. Fomentamos el reconocimiento de la importante labor que desempeña la figura del cuidador familiar en nuestra sociedad.

El objetivo de la guía Un cuidador. Dos vidas es aportar información y soporte a los cuidadores familiares durante el proceso de atención, independientemente de las características y la duración del mismo.

El contenido de la guía ha sido elaborado por distintos autores y se ordena en tres líneas:

1. Un cuidador: Aporta información que permite afrontar y gestionar mejor la situación que asume el cuidador familiar.
2. La persona cuidada: Aporta información en forma de consejos o sistemas de ayuda, como respuesta a las diferentes situaciones o necesidades que se le pueden presentar al cuidador familiar.
3. El entorno: Aporta información y orientación sobre las modificaciones que requiere el entorno y los medios disponibles para incrementar y optimizar las capacidades que permitan efectuar las actividades básicas de la vida diaria y las actividades instrumentales de la vida diaria, así como información relativa a los recursos existentes en las diferentes Comunidades Autónomas en relación a este ámbito.

DVD

El contenido de este DVD ha sido elaborado teniendo en cuenta las demandas expresadas por los cuidadores familiares. Para su elaboración se ha solicitado la colaboración de un equipo de profesionales expertos vinculados a entidades sociales de reconocido prestigio.
Carers Direct Helpline (UK)

Phone Helpline (+ e-mail & mail)
✓ “Language Line”, a conferencing facility for instant translation by a trained interpreter.
✓ Text Relay/Typetalk service for deaf, deafblind, hard of hearing and speech-impaired.

Carers Direct helpline

Call the Carers Direct helpline on 0800 802 0202 if you need help with your caring role and want to talk to someone about what options are available to you. You can also contact us by textphone on 0800 390 8657.

Seven days a week

The helpline is open from 8am to 9pm Monday to Friday, and from 11am to 4pm, at weekends. Calls from UK landlines and Vodafone, T-Mobile and O2 mobile phone networks are free.

Email and postal enquiries

You can also email your questions to us at CarersDirect@nhschoices.nhs.uk, or send them by post to PO Box 4338, Manchester M61 0BY.
Online Training & Courses (UK)

Caring with Confidence National initiative seeking to provide training to 10,000 carers over 3 years
→ Local group sessions
→ Workbooks for self-study
→ Online study sessions
→ Content/courses for BME carers

City & Guilds – Learning for Living
Online Learning Programme for carers:
(1) Learning resource
(2) nationally recognised (level 2) qualification: ‘Certificate in Personal Development & Learning for Unpaid Carers’
since 2004, around 700 participants
Cuidadoras en Red

Social Network for Carers
→ since Nov 2008; connected to Carers of Pizarra (Malaga)
→ 162 users; 13 groups (09/2010)
→ Most frequent activities: Messaging, (micro)blogging, video sharing

Preliminary findings (12/2009)
→ 100% gained or improved basic digital skills
→ 43% have gained more advanced ICT skills
→ social relations between carers and with younger family members improved
Opportunities and barriers
for ICT in support of informal caregivers

Opportunities

ICT can improve

- Information
  - Training

- Quality of Care
  - Communication
  - Coordination
  - Collaboration

- Working conditions
  - health & wellbeing

- Private life
  - social integration

Barriers

ICT in LTC policies

- Carers’ needs overlooked
- Lack of knowledge & awareness
- Few initiatives

Use of ICT

- Lack of awareness
- ICT access and skills
- Privacy/security fears

Use of ICT specific

- ICT access restrictions at work
- Lack of adapted content
- Language barrier
- Residence status -> barrier/incentive

Large migrant communities with ageing members

High ICT use/motivation by migrants

Carers’ needs overlooked

Lack of knowledge & awareness

Few initiatives

Lack of awareness

ICT access and skills

Privacy/security fears

ICT access restrictions at work

Lack of adapted content

Language barrier

Residence status -> barrier/incentive
Potential Policy Options

ICT in LTC policies
- carers’ needs
- knowledge & awareness
- few initiatives

Use of ICT
- awareness
- access and skills
- privacy/security fears

Migrant specific
- ICT access
- Lack of adapted content
- language barriers
- incentive to use ICT

Awareness raising:
- carers’ needs
- ICT opportunities
- ICT impact

Digital inclusion measures: targeted and focused

Privacy & trust-building solutions

Adapt ICT for LTC devices: icon-based/multilingual

Mother tongue/multilingual
- reliable & transparent information
- (vocational) training
- online social networks

ICT for language learning
Follow-Up Study on ICT based solutions for caregivers

Mapping & Analysis of 50 initiatives
which promote the improvement of caring through ICT
(at least 8 European countries)

Development of Impact Assessment Methodology
measuring and assessing in quality terms the outputs and outcomes of ICT initiatives in home care

In depth Analysis of at least 12 initiatives
employing and evaluating the impact assessment methodology
• Redecker et al. (2010). The potential of ICT in supporting Domiciliary Care in Spain.


Thank you very much for your attention!

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http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html
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