The impact of web-based services in supporting family carers of older people: 
*Results from a multicentre pilot study*

Contents

1. The InformCare platform
   A web prototype addressing informal carers

2. Methodology
   Pilot test in three countries

3. General results
   Preliminary findings from the study

4. Discussion
   Main benefits and challenges
1. THE INFORMCARE PLATFORM
Evidence from current practice allows identifying some specific types of effective interactive web-based services:

- **individual support** by health professionals to carers (via e-mail, audio or video communication);
- **structured group support** (via video-conferencing group sessions with a moderator);
- **unstructured group support** (via on-line groups or fora);
- **social participation tools** for interacting with other carers and significant others (via social networks and other tools).
However:

- many initiatives in Europe are small-scale projects and low-funded services, with a limited geographical coverage (Schmidt et al., 2011): availability of and accessibility to web-based services are guaranteed only to few people;

- many countries in Europe experience (a) a low penetration of low-cost broadband internet connection and/or (b) a small (or even no) cultural and social recognition of carers’ role (like in Mediterranean and Eastern European areas).
The INNOVAGE WP3 project

WP 3
ICT-based social support for Carers of Older People

WP 1
Increasing Healthy Life Expectancy

WP 2
User-driven Housing for Older People

WP 4
Improving Obesity Related Outcomes in Old Age

WP 6
Knowledge exchange and transfer

WP 5
Long-term Care in Motion

WP 7
Management

Project Partners
1. University of Sheffield, UK (Coordinator)
2. Lund University, SE
3. Heidelberg University, DE
4. Newcastle University, UK
5. National Institute of Health and Science on Ageing (INRCA), IT
6. Age Platform Europe, BE
7. Eurocarers, LU
8. Sheffield Hallam University, UK
9. Latvian Council of Science, LT

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The overall goal of INNOVAGE WP3 is to contribute to improving the quality of life of informal carers of older people in Europe, by developing an integrated set of web-based, multilingual support services, to address main carers’ needs in an adequate and effective manner.

The specific objectives of WP3 are (1) to develop, (2) test (3) implement and (4) disseminate in the EU-27 the web platform with an integrated package of basic services.

Services: information resources and interactive services
Coping with caregiving

Being a carer sometimes makes it difficult to take care of yourself. Priorities are changing disease condition progresses and looking after yourself takes usually last place on a long list of heavy duties. Caring for a loved one isn’t an easy task, but it is important to understand the value of being a carer and living well...

More »

Family reconciliation

When you are a carer, sometimes you find yourself in a position where you try to combine different family roles: as a parent, as a spouse, as a child and as carer. Reconciliation between family relationships and caregiving is a difficult task...

More »

Work reconciliation

Working while caring isn’t an easy task. Employers and fellow employees might just not get it! Trying to be on time with work tasks and to be a devoted carer generates stress, not always easy to manage. A key factor to reconcile work and care is to raise awareness among your colleagues and employers...

More »

Family reconciliation

Being a carer sometimes makes it difficult to take care of yourself. Priorities are changing disease condition progresses and looking after yourself takes usually last place on a long list of heavy duties. Caring for a loved one isn’t an easy task, but it is important to understand the value of being a carer and living well...

More »
Dementia

This section is devoted to Pathologies of older people and care management.

Information on a number of conditions is provided.

You may visit each page by clicking on boxes below or by clicking on your left side list.

Dementia in numbers

Dementia affects 8% of people over 65 years, a percentage that increases significantly with age, as highlighted by a significant number of surveys. It is estimated that if people lived until the age of 95, then one out of two would suffer from some type of Dementia.

It is estimated that 41 million cases are suffering from dementia worldwide and 10 million in Europe. It is estimated that this percentage will rise to 104 million worldwide, while the proportion of people over 65 years old in Europe accounts for 28% of the general population.

What is Dementia?

The term “Dementia” refers to a group of symptoms that appears to people with conditions which destroy brain cells and cause a gradual deterioration of cognitive abilities. People suffering from types of dementia, actually means that memory, attention, judgment, speech, behaviour are affected.

In order to Dementia to be officially diagnosed, cognitive symptoms should represent a significant loss of previous level of functioning in everyday life.
Ciao Francesco Barbabella!

Cosa c’è di nuovo

Pubblica Qualcosa...

Arianna Poli - Ecco un articolo su Porte Aperte all’INRCA!

Una folla di visitatori per conoscere l’Inrca
ANCONA - La peggio notturna non ha fermato l’iniziativa ‘Porte aperte all’Inrca’ - oggi entrata nel vivo - tesa a far conoscere e visitare le tre sedi di Ancona della storica...

mar alle 11:21 - Mi piace - Commenta - Rimuovi - Condividi

Arianna Poli - Buongiorno a tutti! :)

mar alle 11:00 - Mi piace - Commenta - Rimuovi


Novità

Il 31/07 si è conclusa la fase di sperimentazione della piattaforma INNOVAGE. Da oggi saremo impegnati a migliorarla alla luce di ciò che è emerso edemergerà grazie al tuo contributo. A questo proposito, ti chiediamo un ultimo aiuto alla nostra ricerca: compilare il Questionario finale. Basta cliccare sul menù principale della pagina iniziale della piattaforma sulla voce ‘Questionario’ (evidenziata in azzurro, in alto a destra). Ti ringraziamo sin d’ora per il tuo contributo. I seguenti Servizi Interattivi, inoltre, non saranno più disponibili da Agosto in poi: il Corso Caregiver e gli spazi di ascolto delle psicologhe Silvia Valenza e Cinzia Giuliani. Cambia anche la reperibilità della psicologa Arianna Poli, disponibile da oggi tutti i
1 nuovo messaggio ricevuto su un totale di 4

- **10 people**
  - 10 settembre
  - (Nessun Oggetto)
  - "E' stato un piacere, grazie a tutti :) Sono stata felice anche di aver potuto conoscerli. "colleghi", soprattutto Serena, con la quale ho avuto il piacere di scrivere e parlare. A presto!"

- **2 people**
  - pochi secondi fa
  - (Nessun Oggetto)

- **Benjamin Salzmann**
  - 3 agosto
  - test
  - "This is just a test message. You can delete it."

- **Ananna Poli**
  - 15 luglio
  - risposta di Roberta M
  - "Ciao Ananna. Ho visto solo accessi al messaggio. Per me va benissimo. 
Sono contenta di aver conosciuto tutti, le difficoltà, le paure e le tantissime incertezze, ma anche quelle che sono state le "conquiste", possono essere di aiuto a qualcuno... benissimo... Ho trovato il tuo "positivo" :) A fortuna è stata che ho potuto sostenere tutto questo con il supporto di mia sorella Daniela, mentre l'altra sorella - di cui non ho mai parlato - ha avuto una reazione a dir poco... sconcertante. Forse piuttosto riuscirà a gaitarna... A presto, Roberta"
<table>
<thead>
<tr>
<th>Titolo</th>
<th>Risposte</th>
<th>Visite</th>
<th>Ultimo Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Al fianco di una persona con Demenza</td>
<td>17</td>
<td>217</td>
<td>Roberta Martini</td>
</tr>
<tr>
<td>Di positivo oggi c’è che</td>
<td>10</td>
<td>64</td>
<td>Roberta Martini</td>
</tr>
<tr>
<td>Spazio di scrittura - Le vostre storie</td>
<td>19</td>
<td>136</td>
<td>Arianna Poli</td>
</tr>
<tr>
<td>quando l’assistenza del malato diventa troppo stressante</td>
<td>0</td>
<td>7</td>
<td>Cinzia</td>
</tr>
<tr>
<td>Assistenti familiari - Badanti</td>
<td>9</td>
<td>90</td>
<td>Arianna Poli</td>
</tr>
</tbody>
</table>
2. METHODS
Study design

- **Research design**: one-group pretest-posttest study
- **Intervention duration**: 17 weeks (Apr-Jul 2014)
- **Country settings**: Italy, Germany, Sweden
- **Sampling design**: convenience sample approach
- **Sample size**: 118 carers
- **Research questions**:
  - *Are these new web-based services* **user-friendly**, *perceived as useful and appropriate* by informal carers?  
  - *Do these new web-based services have a positive impact* on informal carers’ perceived health, quality of life, social support, and their role as carers?
**Measures**

Dimensions related to the cared-for older person (with the carer as a proxy):

1. **Demographic** and **background** characteristics (only T0);
2. Level of **dependency** of the older person: Barthel index (10 items) (ADLs) and Duke OARS (6 items) (IADLs) (only T0);
3. **Health** needs and problems of the older person (T0, partly also at T1).

Dimensions related to the carer:

1. **Demographic** and **background** characteristics (only T0);
2. **Health status** of the carer: part of Minimum European Health Module (T0 + T1);
3. **Quality of life** of the carer: WHO-5 Well-being index (5 items) (T0 + T1);
4. Self-perception of **carer’s role**: COPE index (15 items) (T0 + T1);
5. **Social support** perceived by the carer: MSPSS (12 items) (T0 + T1);
6. **Virtual social support** perceived by the carer: Perceived Virtual Social Support Scale (22 items) (only T1);
7. **Usability** of web services: WAMMI (20 items) (only T1);
8. **Usefulness** and **appropriateness** of the services (only T1);
9. **Navigation patterns** through the platform: Google Analytics (T0-T1).

**Focus groups** were organised with 6-7 users in each country at the end of the intervention.
3. GENERAL RESULTS

preliminary analysis
### Who are the older people in need?

<table>
<thead>
<tr>
<th>Older person</th>
<th>Total</th>
<th>Italy</th>
<th>Germany</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: <em>woman</em></td>
<td>62.0%</td>
<td>78.6%</td>
<td>65.0%</td>
<td>40.0%</td>
</tr>
<tr>
<td>Age</td>
<td>79.3%</td>
<td>81.6</td>
<td>76.8</td>
<td>77.5</td>
</tr>
<tr>
<td>IADL</td>
<td>3.9 (2.2)</td>
<td>3.7 (2.2)</td>
<td>4.9 (1.9)</td>
<td>3.6 (2.2)</td>
</tr>
<tr>
<td>ADL</td>
<td>11.8 (6.6)</td>
<td>13.7 (5.5)</td>
<td>5.3 (6.1)</td>
<td>12.1 (6.6)</td>
</tr>
<tr>
<td>Memory problems: yes</td>
<td>79.0%</td>
<td>89.8%</td>
<td>80.0%</td>
<td>64.4%</td>
</tr>
<tr>
<td>Behavioural problems: yes</td>
<td>77.4%</td>
<td>94.9%</td>
<td>50.0%</td>
<td>66.7%</td>
</tr>
</tbody>
</table>
Who are their **carers** (in need)?

<table>
<thead>
<tr>
<th>Carer</th>
<th>Total</th>
<th>Italy</th>
<th>Germany</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: <em>woman</em></td>
<td>70.8%</td>
<td>69.6%</td>
<td>60.0%</td>
<td>77.3%</td>
</tr>
<tr>
<td>Age</td>
<td>58.5 (11.5)</td>
<td>53.1 (10.2)</td>
<td>60.6 (9.0)</td>
<td>64.7 (10.8)</td>
</tr>
<tr>
<td>Relationship with elderly:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Spouse/Partner</em></td>
<td>30.6%</td>
<td>3.5%</td>
<td>26.3%</td>
<td>66.7%</td>
</tr>
<tr>
<td><em>Children/Children-in-law</em></td>
<td>61.2%</td>
<td>84.2%</td>
<td>57.9%</td>
<td>33.3%</td>
</tr>
<tr>
<td><em>Other</em></td>
<td>8.3%</td>
<td>12.3%</td>
<td>15.8%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Children: yes</td>
<td>77.5%</td>
<td>78.6%</td>
<td>65.0%</td>
<td>81.8%</td>
</tr>
<tr>
<td>Grandchildren: yes</td>
<td>35.5%</td>
<td>22.8%</td>
<td>20.0%</td>
<td>59.1%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Low (up to lower secondary school)</em></td>
<td>18.3%</td>
<td>28.1%</td>
<td>15.8%</td>
<td>6.8%</td>
</tr>
<tr>
<td><em>Medium (upper secondary school)</em></td>
<td>37.5%</td>
<td>56.1%</td>
<td>26.3%</td>
<td>18.2%</td>
</tr>
<tr>
<td><em>High (post-secondary, tertiary education)</em></td>
<td>44.2%</td>
<td>15.8%</td>
<td>57.9%</td>
<td>75.0%</td>
</tr>
<tr>
<td>Employment: yes</td>
<td>52.1%</td>
<td>62.5%</td>
<td>31.6%</td>
<td>47.7%</td>
</tr>
</tbody>
</table>
Carers’ confidence with internet

- Not at all
- Little
- Somewhat
- Much

Total: 
- Not at all: 10,00%
- Little: 20,00%
- Somewhat: 30,00%
- Much: 60,00%

Italy: 
- Not at all: 10,00%
- Little: 30,00%
- Somewhat: 60,00%
- Much: 20,00%

Germany: 
- Not at all: 20,00%
- Little: 10,00%
- Somewhat: 30,00%
- Much: 40,00%

Sweden: 
- Not at all: 50,00%
- Little: 10,00%
- Somewhat: 30,00%
- Much: 70,00%
Usage of the platform /1

- **76%** of the initial sample **accessed at least once**
- The level of access varies across countries (% on users accessed):

<table>
<thead>
<tr>
<th>Level of access:</th>
<th>Total</th>
<th>Italy</th>
<th>Germany</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low (1-5 accesses)</strong></td>
<td>54.9%</td>
<td><strong>73.8%</strong></td>
<td>38.9%</td>
<td>42.9%</td>
</tr>
<tr>
<td><strong>Medium (6-11 accesses)</strong></td>
<td>18.6%</td>
<td>21.4%</td>
<td>22.2%</td>
<td>14.3%</td>
</tr>
<tr>
<td><strong>High (12+ accesses)</strong></td>
<td>26.5%</td>
<td>4.8%</td>
<td><strong>38.9%</strong></td>
<td><strong>42.9%</strong></td>
</tr>
</tbody>
</table>

- **average number of days of visits**: 5 in Italy - 23 in Germany
- **time spent** in the platform: Italian users staid connected less than 3 hours, German and Swedish more than 7.5 hours
Most success was obtained by the social network, and to a less extent by forum.

Private messages were a major communication channel in Sweden (over 70% of users sent or replied to messages) and used also in Italy and Germany.

Chat and videochat were the least used services.

However, most users preferred a passive use of services.
Effectiveness

- After the intervention, users expressed generally lower values of administrated scales for impact, in particular in COPE quality and MSPSS social support sub-scales.

- We can interpret this result considering that the platform had a role in increasing personal awareness of carers’ role, making them reflect on their actual needs and lack of support (previously unrecognised).

<table>
<thead>
<tr>
<th></th>
<th>Baseline (T0)</th>
<th>After the intervention (T1)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPE negative</td>
<td>21,11 ± 4,1</td>
<td>20,68 ± 4,2</td>
<td>0,143</td>
</tr>
<tr>
<td>COPE positive</td>
<td>12,62 ± 2,2</td>
<td>12,2 ± 2</td>
<td>0,062</td>
</tr>
<tr>
<td>COPE quality</td>
<td>10,4 ± 2,8</td>
<td>9,85 ± 2,6</td>
<td>0,032</td>
</tr>
<tr>
<td>MSPSS family</td>
<td>20,95 ± 5,7</td>
<td>19,99 ± 6</td>
<td>0,057</td>
</tr>
<tr>
<td>MSPSS friends</td>
<td>17,86 ± 6</td>
<td>17,36 ± 6,1</td>
<td>0,363</td>
</tr>
<tr>
<td>MSPSS social support</td>
<td>21,82 ± 5,7</td>
<td>21,06 ± 5,5</td>
<td>0,039</td>
</tr>
<tr>
<td>WHO5 quality of life</td>
<td>11,25 ± 6,1</td>
<td>11 ± 5,8</td>
<td>0,653</td>
</tr>
</tbody>
</table>

Note: N= 80 (subjects that used the platform during the pilot); Mean ± SD; Paired sample T-test

Funded by the European Commission’s Seventh Framework Programme
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Usefulness, adequateness and usability

- Overall, the **majority of carers (over 80%)** thought it is quite or **totally useful** for addressing their needs at present or in the future.
- There was consensus in all the three countries concerning the **adequateness of information and support provided** from project staff for use the platform.
- Generally speaking, scores of **global usability** were satisfactory, even if the Swedish sample was more critic concerning some aspects like helpfulness and efficiency.
- This can be related to the occurrence of some **technical problems** during the intervention, affecting especially Swedish and Italian users (in a quarter and a fifth of cases, respectively).
4. DISCUSSION
Main benefits

• Self-empowerment and awareness concerning carers’ role
• Possibility to receive reliable information, advice and counselling
• Access to a flexible tool available whenever they need
• Sense of solidarity and mutual learning from each other experiences
• Platform felt as a safe virtual environment
• Acceptable level of usability

Funded by the European Commission’s Seventh Framework Programme FP7-HEALTH-2012-INNOVATION-1/No 306058
Main challenges

• **Low digital level of many carers**: need for training and continuous support

• **Passive behaviour in the platform**: need for carrying on adequate stimulation strategies

• **Low (or none) cultural and social recognition of their role**: need to improve self-awareness of what means being a carer and let their needs emerge

• **Technical problems**: need for constant technical support, also in relation to compatibility with different operative systems and devices

• **Limitations of research**: need for further in-depth research beyond a pilot intervention
Thank you for your attention!