

The INNOVAGE-Eurocarers web platform supporting family carers of older people with dementia: Results from Italian pilot study



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INTRODUCTION

Informal care in Italy

- Informal care is relevant in **complementing** and sometimes **substituting** formal care services for older people
- Nevertheless, what can be observed is:
 - No legal regulation,
 - No financial insurance or benefit,
 - Very limited dedicated support services,
 - No awareness of the role

METHODOLOGY

Italian pilot test

The INNOVAGE web platform provided **59 end-users** with a **set of different web-based support services** for a period ranged, for each user, between 12 and 17 weeks (April – July 2014).

Users could access the **following services**:

- a) Information resources,
- b) E-learning resources,
- c) Individual support via private messages, chat, videochat,
- d) Group support via social network and forum

Italian sample

Only carers of older people affected by **Alzheimer's disease or other dementias** were recruited for Italian pilot test.

Carer	Total	Italy
Gender: <i>woman</i>	71.4%	69.6%
Age	58.5 (11.5)	53.1 (10.2)
Relationship with the older person:		
<i>Spouse/Partner</i>	30.6%	3.5%
<i>Children/Children-in-law</i>	61.2%	84.2%
<i>Other</i>	8.3%	12.3%
Children: <i>yes</i>	77.3%	78.6%
Grandchildren: <i>yes</i>	35.8%	22.8%
Care setting		
Presence of a paid care assistant: <i>yes</i>	42.4%	44.6%
Home care services: <i>yes</i>	25.2%	5.6%
Public financial support for older person: <i>yes</i>	40.3%	50.9%
Public financial support for carer: <i>yes</i>	10.1%	10.3%

Education	Total	Italy
<i>Low (up to lower secondary school)</i>	18,3%	28,1%
<i>Medium (upper secondary school)</i>	37,5%	56,1%
<i>High (post-secondary, tertiary education)</i>	44,2%	15,8%
Employment: <i>yes</i>	52.1%	62.5%
If employed, working hours per week		34.7 (9.7)

Confidence with internet	Total	Italy
<i>Not at all</i>	2.5%	5.2%
<i>Little / Somewhat</i>	54.1%	77.6%
<i>Much</i>	43.4%	17.2%
Need for support from others to surf internet		
<i>I always need somebody helping me</i>	2.5%	5.3%
<i>Often I ask help / Occasionally I ask help</i>	40.8%	56.1%
<i>I am independent</i>	56.7%	38.6%

Stimulation strategies

In addition to basic moderation activities, **specific stimulation strategies** were carried out. In particular, these were:

- **INCREASING ACCESSES. SMSs were sent twice a week** in order to keep carers informed about platform and its services.
- **DEVELOPING PROFESSIONAL SUPPORT.** 3 psychologists (one was the moderator) were available to provide **professional information, suggestion and support** at different day and time slots during the week and through different communication channels.
- **CONNECTING CARERS EACH OTHERS.** Carers experiencing **similar care situations** were put in contact.
- **MONITORING AND COLLECTING INFORMAL FEEDBACK.** **Intermediate phone-calls** were planned in order to understand pattern of usage and non-usage.

RESULTS

Pattern of usage

- **USAGE.** Over **72% of carers** enrolled accessed the platform. However, around **74% of these users made between 1 and 5 visits.**
- **BEHAVIOUR OF USAGE:**
 - Good number of pages and time spent per visit
 - **95% of carer users** accessed the Interactive Services area:
 - Main **passive usage** of interactive services,
 - **Active usage** referred mostly to moderator rather than other carers,
 - Most **popular services:** a) Social Network, b) Forum, c) Private messages
 - **Typical requests** included basic information on dementia and its symptoms, available care and support services and financial benefits, how managing daily care activities, personal emotional support
 - Main issues concerned **how promoting an active usage and putting in contact users**

Pattern of usage and non-usage / 1

• EFFECTIVENESS.

- Scores for **MSPSS family, friends and social support scales** were significantly lower after the intervention (T1) than before it (T0) (*Paired sample t-test*).
- According to the data collection, carers realised not to be adequately supported by family, friends and community, despite their important and urgent needs.

Outcome (N=39)	Pre-intervention (T0)		Post-intervention (T1)		Sig. (2-tailed) * p < .05
	M	SD	M	SD	
COPE negative	21.99	4.04	21.51	3.92	,194
COPE positive	12.38	2.43	11.89	2.02	,235
COPE quality	10.28	2.80	9.62	2.46	,095
MSPSS family	22.36	4.74	20.97	5.49	,033*
MSPSS friends	17.84	5.30	16.22	5.24	,032*
MSPSS social support	23.48	4.78	22.14	5.18	,007*
WHO 5 percent	44.54	24.11	42.27	20.21	,523
WHO 5 raw	11.13	6.02	10.56	5.05	,523

Pattern of usage and non-usage / 2

- **USEFULNESS.** Around 84% of carers thought web platform is **quite or totally useful** at present. More than 88% of users expressed the same opinion in future perspective.
- **USABILITY.** Users assigned a **good global usability score** (WAMMI tool).
- **BARRIERS.** **Time issues and technical problems** (likely related to low digital skills) seem to be the main barriers in usage.

FEEDBACK FROM USERS

Results from Focus Group

At the end of the pilot test, a focus group was conducted. It involved 7 among the most active users.

- Users agreed that web-based support services can sustain informal carers in their role. Among strengths:
 1. solving **time and logistic issues**,
 2. providing **reliable information in safe virtual environment**,
 3. being in contact with peers
- Across the services used, the **main** mentioned **activities were passive**: getting information, reading stories by others, articles, discussions and posts, watching posted videos.

Inputs for implementation

Furthermore, participants contributed with some suggestions on future implementation:

- **Face-to-face and web-based** support services are both important for carers
- **Moderator plays an essential role** in promoting the engagement and making users comfortable with and informed about services
- The web platform might also contribute to **match supply and demand for basic support services** addressing caring issues
- Especially for some interactive services (e.g. video-chat, chat), a **dedicated training** would be useful

Key quotations from Focus Group

Time and logistic issues:

- *Face to face meeting has beginning and end. While web-based support services are **constantly available**.*

Passive usage of the platform:

- *Also **just knowing that there are this kind of support services** and trustworthy people working behind them is really important and helpful for family carers.*

Need of information:

- *When I started, I was **extremely in need of information**. I had not enough time also for sharing and communication.*
- *I **discovered information** that I had never heard before.*

A safe virtual environment:

- *Reading stories from other carers **helps not to feel lonely**. You can also realize how the future will be.*
- *It is **a safe place** where different people with different stories speak the same “language”. This is **a huge relief**.*

CONCLUSION

Remarks on the pilot

1. Web-based support services can be a good way to reach and provide support services to informal carers of older people affected by Alzheimer's disease or other dementia.
2. The usage of the web platform and its services seems to promote the self-recognition of carers' role and sustain the understanding of their own needs.
3. The passive usage of the web platform is also effective and complementary to active usage, that is the passive usage can lead to different benefits for the users.

Challenges for implementation

1. **Digital skills.** Overcoming low digital skills of many carers
2. **Pattern of usage.** Promoting an active usage of the web platform and, accordingly, the creation of a community of carers
3. **Engagement.** Motivating the usage and the long-term adherence to the web-based services

Thank you for your attention!



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