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

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Technology-enabled care and support: INNOVAGE seminar

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

Web-based support services for carers

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).
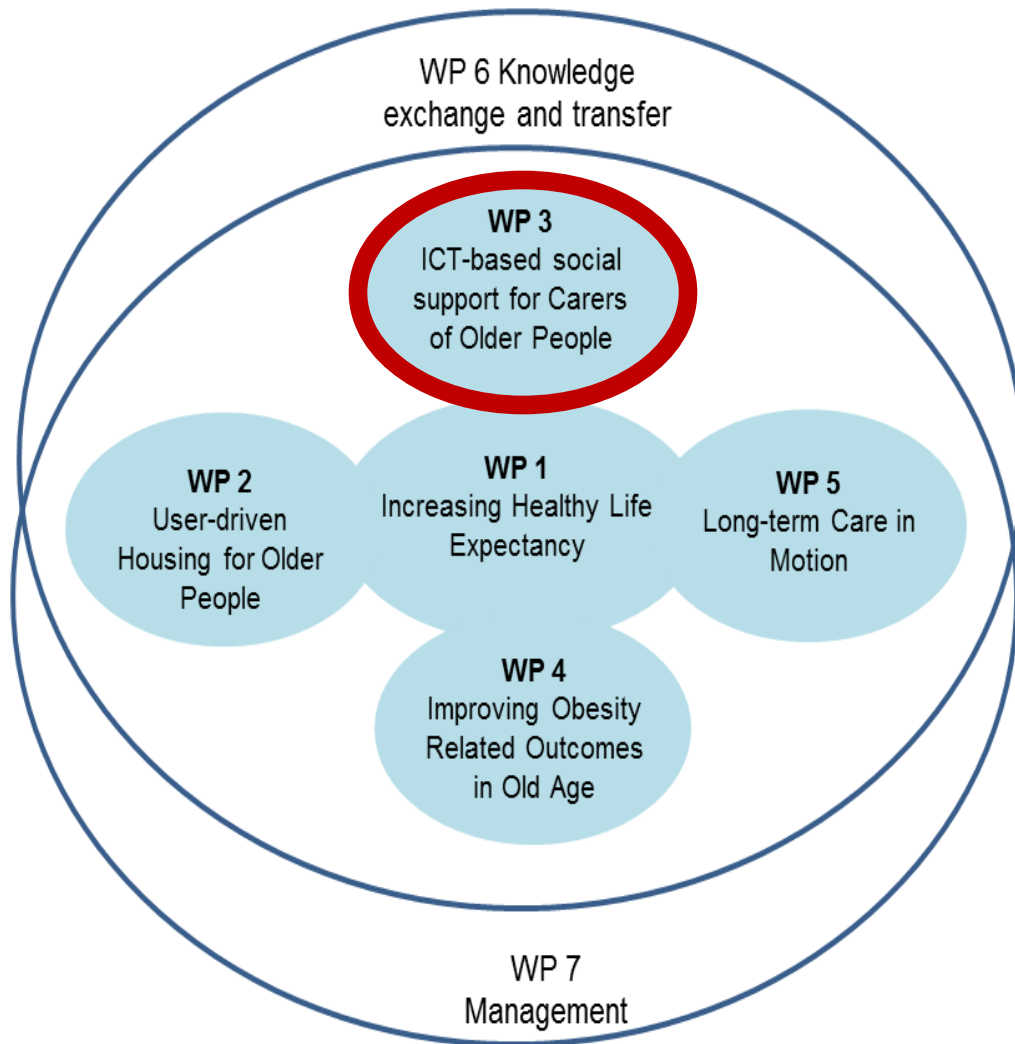
Current gaps in EU context

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).

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Funded by the European Commission's
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5

The INNOVAGE WP3 project

WP 6 Knowledge exchange and transfer

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

WP 2
User-driven Housing for Older People

WP 1
Increasing Healthy Life Expectancy

WP 5
Long-term Care in Motion

WP 4
Improving Obesity Related Outcomes in Old Age

WP 7
Management

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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

A new multilingual platform in EU-27

- 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**

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InformCare: home page

InformCare: internal page on 'Dementia'
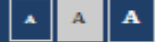
EUROCARERS
EUROPEAN ASSOCIATION WORKING FOR CARERS

Search ...

Caring for older people   Your own needs   Support by the state   Get help

Dementia

Carers

Caring for older people >

Impairments and care management >

Dementia

Parkinson's

Stroke

Arthritis

Osteoporosis

Conditions of the Eyes

Deafness

Diabetes

Hypertension

Bedsores

Urinary Incontinence

Care and support services >

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.

What is Dementia and Alzheimer's Condition?

Symptoms of Alzheimer's

Risk factors of Alzheimer's

Behavioural and Psychological symptoms (BPSD)

Is there a cure for Dementia?

Prevention of Dementia

Caring at a distance

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 44 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 35% 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.

Servizi Interattivi

EUROCARERS
per CAREGIVER

| << Torna alla homepage | Social Network | Messaggi (1) | Chat | Video Chat | Forum |

Ciao Francesco Barbabella!

4 Members Online

💡 Vedi Aggiornamenti 📋 Profilo ✏️ Modifica Profilo 🔍 Cerca Iscritti

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 pioggia 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...
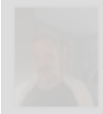
mar alle 11.21 - Mi piace - Commenta - Rimuovi - Condividi

Arianna Poli Buongiorno a tutti! :)

mar alle 11.00 - Mi piace - Commenta - Rimuovi

Frida Andreasson Jag fick ett tips om en dokumentärserie som startar på svt kanal 1 ikväll vid 21.00 om medberoende. Verkar mycket intressant. Ni kan gå in och läsa om den på länken nedan.
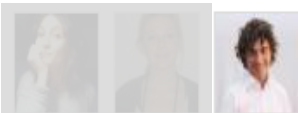
Novità

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 ed emergerà 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 Giuli. Cambia anche la reperibilità della psicologa Arianna Poli, disponibile da oggi tutti i

| ● Cinzia ✖ | ● Cristina ✖ | ● Andrea ✖ | ● Benjamir ✖ | ● Arianna ✖ | 👤 Amici Online (2) |

Servizi Interattivi

EUROCARERS
per CAREGIVER

<< Torna alla homepage | Social Network | Messaggi (1) | Chat | Video Chat | Forum

I Miei Messaggi

Messaggi Ricevuti | **Messaggi Inviati** | **Componi Messaggio**

1 nuovo messaggio ricevuto su un totale di 4   Check All

Cerca

☐ **10 people**
10 settembre
(Nessun Oggetto)
E' stato un piacere, grazie a tutti :) Sono stata felice anche di aver potuto conoscere alcuni ... "colleghi", soprattutto Serenella, con la quale ho avuto il piacere di scambiare messaggi. A presto!

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

☐ Benjamin Salzmann
3 agosto
test
this is just a test message. You can delete it :)

☐ Arianna Poli
15 luglio
risposta di Roberta M
Ciao Arianna. Ho visto solo adesso il messaggio. Per me va benissimo. Se tutto ciò che ho passato, 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 lato "positivo" :) La mia 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 prima o poi riuscirò a parlarne ... A presto, Roberta

Elimina Selezionati

○ Cinzia ✖ | ○ Cristina ✖ | ○ Andrea ✖ | ○ Benjamir ✖ | ○ Arianna ✖ | 👤 Amici Online (2)

Servizi Interattivi

EUROCARERS
per CAREGIVER

<< Torna alla homepage   Social Network   Messaggi (1)   Chat   Video Chat   Forum

Forum

Inserisci Nuovo Topic

Al fianco di una persona con Demenza...	17 RISPOSTE	217 VISITE	Ultimo Post di Roberta Martini 18 settembre
Di positivo oggi c'è che...	10 RISPOSTE	64 VISITE	Ultimo Post di Roberta Martini 4 settembre
Spazio di scrittura – Le vostre storie	19 RISPOSTE	136 VISITE	Ultimo Post di Arianna Poli 31 Luglio
quando l'assistenza del malato diventa troppo stressante...	0 RISPOSTE	7 VISITE	Ultimo Post di Cinzia Giuli 25 Luglio
Assistenti familiari – Badanti	9 RISPOSTE	90 VISITE	Ultimo Post di Arianna Poli 30 giugno

Cinzia   ✕   Cristina   ✕   Andrea   ✕   Benjamir ✕   Arianna   ✕   Amici Online (1)

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?*

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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 <u>older people</u> in need?

	Total	Italy	Germany	Sweden
Older person				
Gender: *woman*	62.0%	**78.6%**	**65.0%**	40.0%
Age	**79.3%**	81.6	76.8	77.5
IADL	3.9 (2.2)	3.7 (2.2)	4.9 (1.9)	3.6 (2.2)
ADL	11.8 (6.6)	13.7 (5.5)	5.3 (6.1)	12.1 (6.6)
Memory problems: *yes*	79.0%	**89.8%**	80.0%	64.4%
Behavioural problems: *yes*	77.4%	**94.9%**	50.0%	66.7%

Who are their <u>carers</u> (in need)?

	Total	Italy	Germany	Sweden
Carer				
Gender: *woman*	**70.8%**	69.6%	60.0%	77.3%
Age	58.5 (11.5)	53.1 (10.2)	**60.6 (9.0)**	**64.7 (10.8)**
Relationship with elderly:				
Spouse/Partner	*30.6%*	*3.5%*	*26.3%*	***66.7%***
Children/Children-in-law	*61.2%*	*84.2%*	*57.9%*	*33.3%*
Other	*8.3%*	*12.3%*	*15.8%*	*0.0%*
Children: *yes*	**77.5%**	78.6%	65.0%	81.8%
Grandchildren: *yes*	35.5%	22.8%	20.0%	59.1%
Education				
Low (up to lower secondary school)	18,3%	28,1%	15,8%	6,8%
Medium (upper secondary school)	37,5%	56,1%	26,3%	18,2%
High (post-secondary, tertiary education)	44,2%	15,8%	**57,9%**	**75,0%**
Employment: *yes*	52.1%	**62.5%**	31.6%	47.7%

Care setting
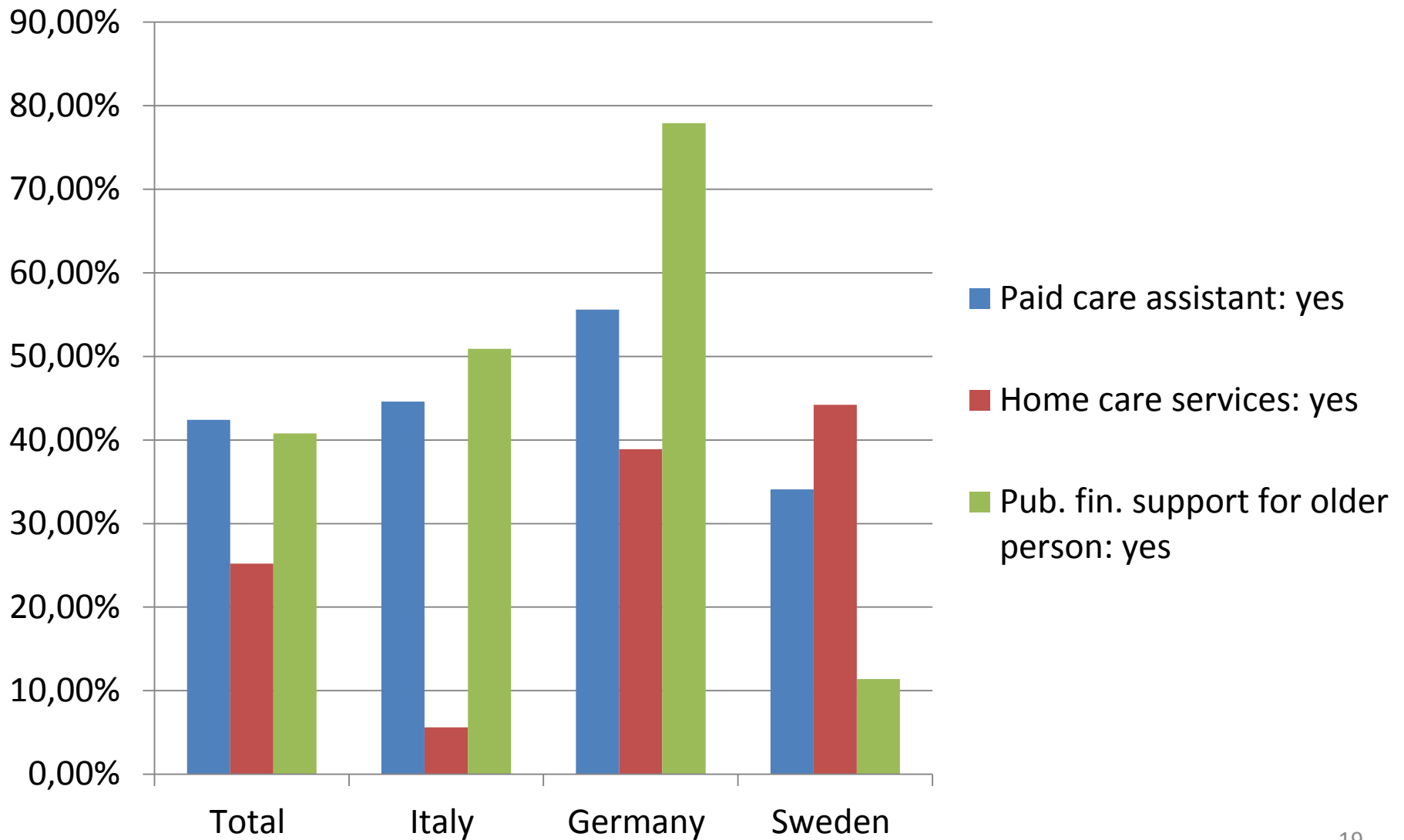
Carers' confidence with internet
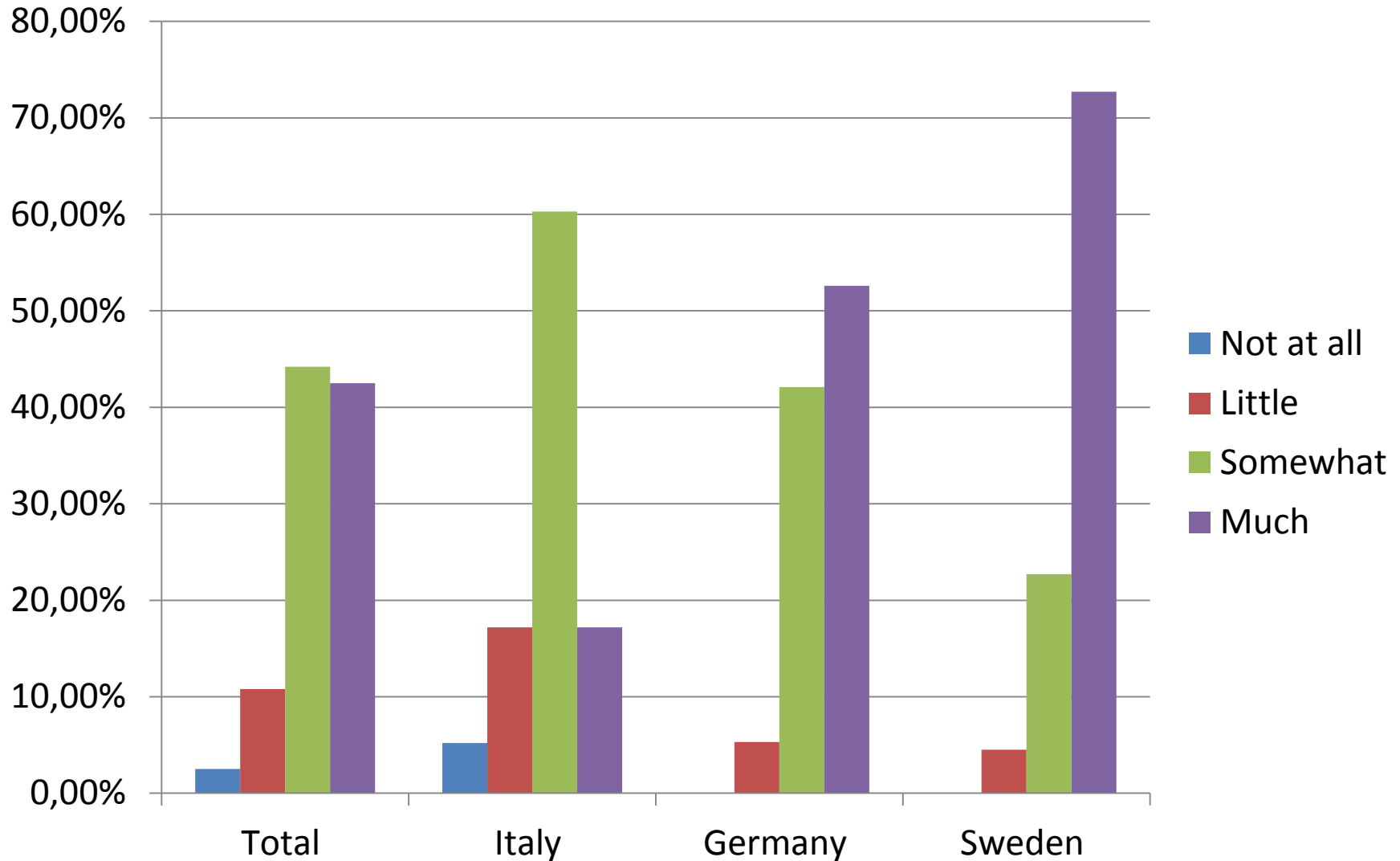
Usage of the platform /1

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

	Total	Italy	Germany	Sweden
Level of access:				
Low (1-5 accesses)	54.9%	**73.8%**	38.9%	42.9%
Medium (6-11 accesses)	18.6%	21.4%	22.2%	14.3%
High (12+ accesses)	26.5%	4.8%	**38.9%**	**42.9%**

- 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

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Usage of the platform /2

- 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).

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

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

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).

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24

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**

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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

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Thank you for your attention!

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