The impact of migrant care work and web-based support services on family carers: opportunities, challenges and policy options

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Outline of presentation

1. Introduction: why these two topics?

2. Migrant work in LTC provision:
   a. Definitions and conceptual framework
   b. Migration as intersection of different policy areas

3. Web-based support services for family carers:
   a. The EU-funded INNOVAGE project
   b. Contents of the InformCare platform
   c. Results of the 3-country pilot study

4. Final remarks
1. Introduction: why these two topics? (1/2)

1. Both increasingly reported in the literature as **essential components** of the debate on carer support (Care Alliance Ireland, 2014; Gallotti, 2016; Hopwood et al, 2018; Luppi et al, 2015; Rostgaard et al, 2011; Sherifali et al, 2018; Versey, 2017);

2. in times of population ageing and care staff shortages, they reflect **two opposite approaches** to address the growing demand for LTC and improve support services for informal carers.
1. Introduction: why these two topics? (2/2)

Two opposite approaches:

a. employment of MCWs: more traditional, labour intensive approach, providing hands-on care services mainly by means of human labour

b. solutions based on ICTs: more innovative, capital intensive strategy

3. No explicit debate on the possibility of substituting technology for labour (or vice versa) in the field of carer support: so far considered as two separate topics.

→ attempt to build a more comprehensive approach
Issues frequently reported as associated to family carers’ health, and mediating factors (1/2)

<table>
<thead>
<tr>
<th>Impact on caregiver’s health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological health</td>
</tr>
<tr>
<td>Physical health</td>
</tr>
</tbody>
</table>

Issues frequently reported as associated to family carers’ health, and mediating factors (2/2)

1. Demographic:
   – gender (women reporting more often psychological costs, men physical ones)
   – age (-)
   – type of kin relationship (spouses being more negatively affected)

2. Care-related:
   – amount of time spent in caring (-)
   – type of care tasks performed (e.g. physically, mentally or emotionally demanding)
     (+/-: some types of care tasks being more demanding than others)
   – difficulty encountered in performing heavy care tasks (→ stress) (-)
   – providing care in a residential care setting (-)

3. Socio-economic:
   – financial restrictions (-)
   – lack of social support (-)

4. Carer’s personal psychological features:
   – coping strategies (+/-: some strategies being more effective than others)
   – tendency to “forget” about oneself (-)
   – experience of negative emotions (e.g. compassion & fear of loss) (-)
   – low quality of care relationship (also based on the past) (-)

Issues frequently reported as associated to family carers’ health, and mediating factors (1/2)

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MIGRANT CARE WORKER:

anybody who moves to another country, and works there in remunerated long-term care activities
Migration in long-term care: a conceptual model

CARE NEEDS

- demographic (number of older people)
- health related (physical, mental and emotional)
- socio-economic (social exclusion & poverty)
- technology (AAL & ICT)

LTC DEMAND

MATCH ?

LTC PROVISION

formal (public & private)
- in-kind (home/residential) services
- cash-for-care schemes

informal
- family volunteers
- friends & neighbours

Migrant care workers

LTC recipients migrate abroad
2. Migrant care work as “intersection” of different policy areas

Governing migrant work in the LTC sector implies a parallel intervention in (at least) three different policy areas:

• migration policies

• LTC (and welfare) policies

• labour market policies.
Managed vs. unmanaged regimes

- **Managed (more regulated/professionalised) regimes:**
  - High-skilled migration is considered as desirable;
  - Labour migration is highly regulated and controlled (no ex-post legalisation);
  - Undeclared migration is uncommon;
  - Migrants are mainly employed by LTC organisations.

Sources: Da Roit & Lebihan 2010; Rostgaard, Chiatti and Lamura 2010; Horvath et al 2017; Simonazzi 2009
Managed vs. unmanaged regimes

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  - High-skilled migration is considered as desirable;
  - Labour migration is highly regulated and controlled (no ex-post legalisation);
  - Undeclared migration is uncommon;
  - Migrants are mainly employed by LTC organisations.

- **Unmanaged (less regulated/professionalised) regimes:**
  - Low-skilled migration, if not desirable, is tolerated;
  - Labour migrations is regulated, but controls are lacking (reiterated ex-post legalisations);
  - Undeclared, low-skilled migration is common;
  - Migrants are mainly employed by private households.

Sources: Da Roit & Lebihan 2010; Rostgaard, Chiatti and Lamura 2010; Horvath et al 2017; Simonazzi 2009
### Migrant LTC workers’ employment patterns: LTC organisations vs. private households

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Migrant’s employer</th>
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<tbody>
<tr>
<td></td>
<td>LTC organisations</td>
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<td>Prevalent countries</td>
<td>Northern &amp; Western Europe</td>
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<td>Main role of care recipients</td>
<td>Client/service user</td>
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<tr>
<td>Main source of funding</td>
<td>Public LTC funds / out-of-pocket</td>
</tr>
<tr>
<td>Control on care quality mainly performed by:</td>
<td>Care provider or funding body</td>
</tr>
<tr>
<td>Professionalization and training level</td>
<td>higher</td>
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</tbody>
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<tbody>
<tr>
<td></td>
<td><strong>LTC organisations</strong></td>
<td><strong>Care recipients’ families</strong></td>
</tr>
<tr>
<td>Prevalent countries</td>
<td>Northern &amp; Western Europe</td>
<td>Mediterranean &amp; Continental (+ Eastern) Europe</td>
</tr>
<tr>
<td>Main role of care recipients</td>
<td>Client/service user</td>
<td>Employer</td>
</tr>
<tr>
<td>Main source of funding</td>
<td>Public LTC funds / out-of-pocket</td>
<td>Out-of-pocket + cash-for-care schemes</td>
</tr>
<tr>
<td>Control on care quality mainly performed by:</td>
<td>Care provider or funding body</td>
<td>Care recipient</td>
</tr>
<tr>
<td>Professionalization and training level</td>
<td>higher</td>
<td>lower</td>
</tr>
</tbody>
</table>
Share of registered foreign-born home-based long-term workers in the care sector (2012/13)

Source: Rada 2016
**Factors associated with carer's health in a sample of 1000 carers in Italy**

<table>
<thead>
<tr>
<th>Factors</th>
<th>MOD#1</th>
<th>MOD#2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=763 R²=.2536</td>
<td>n=763 R²=.2499</td>
</tr>
<tr>
<td>coeff.</td>
<td>P&gt;</td>
<td>coeff.</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Female gender (ref male)</td>
<td>0.25</td>
<td>0.027</td>
</tr>
<tr>
<td>Carer's age</td>
<td>0.02</td>
<td>0.000</td>
</tr>
<tr>
<td>Relationship (ref. daughter)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>son</td>
<td>0.00</td>
<td>0.984</td>
</tr>
<tr>
<td>daughter in law</td>
<td>-0.01</td>
<td>0.935</td>
</tr>
<tr>
<td>spouse/partner</td>
<td>0.02</td>
<td>0.874</td>
</tr>
<tr>
<td>other</td>
<td>-0.27</td>
<td>0.002</td>
</tr>
<tr>
<td>Average number of hours of care</td>
<td>0.00</td>
<td>0.307</td>
</tr>
<tr>
<td>Care provided for: health needs</td>
<td>0.04</td>
<td>0.576</td>
</tr>
<tr>
<td>physical/personal care</td>
<td>-0.13</td>
<td>0.090</td>
</tr>
<tr>
<td>mobility support</td>
<td>-0.03</td>
<td>0.834</td>
</tr>
<tr>
<td>emotional/psychol./social support</td>
<td>0.41</td>
<td>0.075</td>
</tr>
<tr>
<td>domestic care</td>
<td>0.09</td>
<td>0.255</td>
</tr>
<tr>
<td>financial management</td>
<td>0.06</td>
<td>0.545</td>
</tr>
<tr>
<td>financial support</td>
<td>-0.05</td>
<td>0.458</td>
</tr>
<tr>
<td>organizing support</td>
<td>0.06</td>
<td>0.633</td>
</tr>
<tr>
<td>Caregiving cause financial difficulties</td>
<td>-0.01</td>
<td>0.778</td>
</tr>
<tr>
<td>You feel you cope well as caregiver</td>
<td>-0.04</td>
<td>0.238</td>
</tr>
<tr>
<td>Negative impact scale</td>
<td>0.04</td>
<td>0.000</td>
</tr>
<tr>
<td>Good relationship with elder</td>
<td>-0.04</td>
<td>0.399</td>
</tr>
<tr>
<td>Social support in case of illness</td>
<td>-0.03</td>
<td>0.009</td>
</tr>
<tr>
<td>No or difficult support network</td>
<td>0.04</td>
<td>0.512</td>
</tr>
<tr>
<td>Place where elder lives (ref. at home)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>in a care home</td>
<td>0.03</td>
<td>0.871</td>
</tr>
<tr>
<td>other</td>
<td>-0.19</td>
<td>0.721</td>
</tr>
<tr>
<td>Work (ref. part-time)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>full-time</td>
<td>-0.04</td>
<td>0.711</td>
</tr>
<tr>
<td>not working</td>
<td>-0.02</td>
<td>0.827</td>
</tr>
<tr>
<td>MCW's help (ref. already employed)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would be ready to accept it</td>
<td>0.05</td>
<td>0.604</td>
</tr>
<tr>
<td>only if no alternative is available</td>
<td>0.11</td>
<td>0.311</td>
</tr>
<tr>
<td>never</td>
<td>0.23</td>
<td>0.065</td>
</tr>
<tr>
<td>don't know</td>
<td>0.23</td>
<td>0.063</td>
</tr>
<tr>
<td>Elder's level of dependence</td>
<td>0.04</td>
<td>0.053</td>
</tr>
<tr>
<td>Elder's behavioural problems</td>
<td>1.67</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Source: own elaborations on Eurofamcare data
### Types of support associated with carer’s burden in a sample of approx. 1000 carers in Italy

<table>
<thead>
<tr>
<th>Type of support received</th>
<th>Coefficient</th>
<th>St. Err.</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employing a migrant home care worker in the last year</td>
<td>-1.520</td>
<td>0.542</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Receiving Home checks by the General Practitioner (GP) at T1</td>
<td>1.338</td>
<td>0.761</td>
<td>0.08</td>
</tr>
<tr>
<td>Receiving home nursing care at T1</td>
<td>0.884</td>
<td>0.505</td>
<td>0.08</td>
</tr>
<tr>
<td>Receiving State care allowance at T1</td>
<td>-0.043</td>
<td>0.337</td>
<td>0.90</td>
</tr>
</tbody>
</table>

^: Burden was measured via one of the sub-scales of the Carers of Older People in Europe (COPE) Index, that includes three subsections: ‘Positive Value’ (PV), ‘Quality of Support’ (QS) and ‘Negative Impact’ (NI). Here the one-year change in the COPE-NI score was used as the dependent variable in a multilevel linear regression to estimate the role of the above listed supports in predicting direction and intensity of its change over time.

*: p < 0.05; **: p < 0.01.

Factors correlated with carer burden\(^{\text{^a}}\) in the Up-Tech study

<table>
<thead>
<tr>
<th>Correlates</th>
<th>Coeff. (Rob. SE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Gender (female)</td>
<td>4.67** (1.12)</td>
</tr>
<tr>
<td>Kinship (ref: other relative): child</td>
<td>3.88* (1.71)</td>
</tr>
<tr>
<td>Behavioral disturbances (yes)</td>
<td>3.68** (1.25)</td>
</tr>
<tr>
<td>Impairment in ADL (one point increase)</td>
<td>0.86* (0.43)</td>
</tr>
<tr>
<td>Impairment in IADL (one point increase)</td>
<td>0.32** (0.05)</td>
</tr>
<tr>
<td>Hours of care provided (one hour increase)</td>
<td>0.09** (0.01)</td>
</tr>
<tr>
<td>Physical Health</td>
<td>-0.18** (0.06)</td>
</tr>
<tr>
<td>Mental Health</td>
<td>-0.51** (0.06)</td>
</tr>
<tr>
<td>Perceived social support from family (one point increase in MSPSS)</td>
<td>-0.53** (0.14)</td>
</tr>
<tr>
<td>Private care worker (ref= No): Yes, on a live-in basis</td>
<td>-4.41* (2.04)</td>
</tr>
</tbody>
</table>

\(^{\text{^a}}\): Burden was measured via the Caregiver Burden Inventory (CBI), in which higher scores indicate greater distress. Here only statistically significant variables are reported, used for the model controlled for the largest number of potentially confounding factors.

*: p < 0.05; **: p < 0.01.

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Web-based services for carers: a conceptual model

CARE NEEDS

- demographic (number of older people)
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- socio-economic (social exclusion & poverty)
- technology (AAL & ICT)

LTC DEMAND

MATCH ?

LTC PROVISION

formal (public & private)

in-kind (home/residential) services

cash-for-care schemes

family

Web-based support services

informal

volunteers

friends & neighbours
Web-based services for carers: a conceptual model

- CARE NEEDS
  - demographic (number of older people)
  - health related (physical, mental and emotional)
  - socio-economic (social exclusion & poverty)
  - technology (AAL & ICT)

- LTC DEMAND
  - MATCH?

- LTC PROVISION
  - formal (public & private)
  - informal
  - in-kind (home/residential) services
  - cash-for-care schemes
  - family
  - volunteers
  - friends & neighbours

Web-based support services
Internet-based support services for carers

• effectiveness of web-based supports not yet well-established, best evidence of impact from:
  • multicomponent platforms, tailored to caregivers’ needs & preferences (Aldehaim et al. 2016; Boots et al. 2014; Capurro et al. 2014; Dyer et al. 2012; Hu et al. 2015; Kaltenbaugh et al. 2015);
  • integration of information & educational modules with professional and peer support, e.g. discussion fora, chat rooms & videoconferencing (Griffiths et al. 2015; Marziali & Garcia 2011; Magnusson et al. 2005; McKechnie et al. 2014; Namkoong et al. 2012);
• so far, fragmented & low level of coverage in Europe, with small initiatives with limited scope (Carretero et al., 2012; Schmidt et al., 2011);
CARICT: Mapping of 52 ICT-based initiatives in EU

Objective: Demonstrate the diversity of ICT initiatives for informal carers & privately paid assistants in Europe

Data collection:
- Secondary data (literature review, presentations, project reports, online data bases etc.)
- Primary data (min. 4 expert interviews per care regime)

Inclusion criteria (52 out of 75 chosen):
- Cases beyond pilot status
- Min. 3 per country (if possible)
- Diversity across countries, diseases and dependencies

Analysis:
- Content analysis (quali-quantitative infos)

Website:
http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/carers_pastprojectCARICT.html
ICT for informal care: the CARICT conceptual framework

**Micro Level**
- Carer
- Carer Wellbeing

**Meso Level**
- Families
- Peer groups
- Companies & Organisations

**Macro Level**
- Economic & Social Protection System
- Health & Social Care System

**ICT-supported initiative**

- **Work-life balance**
- **Social participation**
- **Health-related quality of life**

Source: Barbabella et al. 2011
Goals of INNOVAGE (WP3): a multilingual platform for carers in the EU

• Overall goal: contribute to improving quality of life of informal carers of older people in Europe, via an integrated set of web-based, multilingual support services for them.

• Specific objectives: (1) to develop, (2) test, (3) implement and (4) disseminate in the EU-27 the web platform with an integrated package of services.

• Two main types of services: information resources and interactive services
Three target groups

<table>
<thead>
<tr>
<th>COMMON CONTENTS FOR INFORMAL CARERS</th>
<th>NATIONAL CONTENTS FOR INFORMAL CARERS</th>
<th>NATIONAL CONTENTS FOR CARE PROFESSIONALS</th>
<th>NATIONAL CONTENTS FOR EMPLOYERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALL 27 EU MEMBER STATES</td>
<td>ALL 27 EU MEMBER STATES</td>
<td>10 countries: Austria, Belgium, Czech Rep., Finland, Germany, Luxembourg, Malta, Slovakia, Sweden, UK</td>
<td>10 countries: Bulgaria, Germany, Estonia, France, Lithuania, Latvia, Netherlands, Portugal, Sweden, UK</td>
</tr>
</tbody>
</table>

- Common content for informal carers: All 27 EU member states
- National content for informal carers: All 27 EU member states
- National content for care professionals: 10 countries: Austria, Belgium, Czech Rep., Finland, Germany, Luxembourg, Malta, Slovakia, Sweden, UK
- National content for employers: 10 countries: Bulgaria, Germany, Estonia, France, Lithuania, Latvia, Netherlands, Portugal, Sweden, UK
A user-centred approach was adopted to design the platform and develop the services offered through it, based on:

- **a wide mix of user representatives**: almost 200 end-users/experts and 32 stakeholders (mainly user organisations & research centres), including an **Advisory Board** of 15 experts

- **a series of user-centred development activities**:
  - **review** of most successful web-based services tested and implemented in Europe & beyond (≈ 100 services reviewed)
  - **surveys** involving 58 selected experts, users and stakeholders, to get feedback on platform’s main features
  - **preliminary round of user tests** on prototypes of platform
  - **pilot test** with 118 users in 3 countries (Germany, Italy & Sweden)

→ **website**: [http://www.eurocarers.org/InformCare](http://www.eurocarers.org/InformCare)
What can you find in InformCare?

To access the information and services available in your country, please see the related links below:

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>LANGUAGES</th>
<th>CARE PROFESSIONALS</th>
<th>EMPLOYERS</th>
<th>CARERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td></td>
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<td>Belgium</td>
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<td>French</td>
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<td>Belgium</td>
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<td>Dutch</td>
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<td>Sweden</td>
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<td>UK - England</td>
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<td>UK - N. Ireland</td>
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<td>UK - Wales</td>
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</table>
InformCare: section for carers

Making life easier
Different types of equipment or changes to your home could help...
Summary of static information for carers

- Information on illnesses and care management
- Available care and support services
- Psychological support - consultation
- Information on taking care of yourself
- Work and care reconciliation
- Family and care reconciliation
- Legal aspects
- Financial aspects
- Good Practices
- Emergency services

Caring for an older person:

Your own needs as a carer:

Support by the state:

How to get practical help:
InformCare’s interactive services

The Caregiving years: an introduction

When you expect a child, the community (your family, friends, co-workers) rally around you and your spouse. When you expect your first child, you receive gifts, well wishes and the encouragement that you are entering a wonderful, albeit challenging, chapter in your life. As you prepare to welcome your child, you feel pride at the thought of your role as parent: How you will shape the mind of a youngster, impacting him or her with your wisdom, insights and knowledge.

Now think about a similar life experience, just one on the other end of the spectrum. An aging relative, a spouse, a parent, a grandparent, needs your help. And, you want to help—you believe in making the most of the years you have left together. But, when you tell your friends, your colleagues, even other family members, the comments you may hear are a far cry from well-wishes. “I could never do that! Why do you?” Or, the more common response: “Why don't you just put your mother (or your wife, or your grandfather) in a nursing home? That way you won’t...
Evaluation methodology

• **Design**: one-group pre-test/post-test study (pilot)

• **Duration**: 12-17 weeks

• **Countries involved**: Italy, Germany, Sweden

• **Sampling**: convenience sample approach (in Italy: all patients approaching an Alzheimer Assessment Unit)

• **Sample size**: 118 carers

• **Measures**: structured questionnaire (with validated scales & ad-hoc items) & focus groups in each country
## Impact of InformCare use on carers: quantitative data

<table>
<thead>
<tr>
<th></th>
<th>Effect size (r)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WHO-5 Well-being index</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-0.06</td>
<td>0.410</td>
</tr>
<tr>
<td><strong>COPE index</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative impact</td>
<td>-0.09</td>
<td>0.223</td>
</tr>
<tr>
<td>Positive value</td>
<td>-0.18</td>
<td>0.017**</td>
</tr>
<tr>
<td>Quality of support</td>
<td>-0.18</td>
<td>0.020**</td>
</tr>
<tr>
<td><strong>MSPSS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>-0.15</td>
<td>0.043**</td>
</tr>
<tr>
<td>Friends</td>
<td>-0.03</td>
<td>0.713</td>
</tr>
<tr>
<td>Social support</td>
<td>-0.16</td>
<td>0.035**</td>
</tr>
<tr>
<td>Total score</td>
<td>-0.12</td>
<td>0.113</td>
</tr>
</tbody>
</table>

^: figures refer to comparison of paired data measured before and after the intervention for following outcome variables:
- COPE (=Carers of Older People in Europe) Index: carer’s self-perception of negative & positive aspects of caregiving;
- MSPSS: Multidimensional Scale of Social Support Perceived from significant others and from services.

*: p < 0.05; **: p < 0.01.

Source: Barbabella et al. 2016b
Impact of InformCare use on carers: qualitative data

• Carers in all three countries appreciated the adequateness and usefulness of information provided from project staff through the platform.

• Some passive users reported that even simply to know they could get any time support via the interactive services of the platform was a positive, reassuring feeling.

• Overall scores of global usability were satisfactorily, albeit some Swedish carers were concerned about helpfulness and efficiency of the platform (mainly due to technical problems during the pilot phase, affecting especially Swedish & Italian users, 25% and 20% of cases respectively).
Outline of presentation

1. Introduction: why these two topics?

2. Migrant work in LTC provision:
   a. Definitions and conceptual framework
   b. Migration as intersection of different policy areas

3. Web-based support services for family carers:
   a. The EU-funded INNOVAGE project
   b. Contents of the InformCare platform
   c. Results of the 3-country pilot study

4. Final remarks
Final remarks (1/3)

1. Household-based migrant care work can have a **protective effect** on family carers’ health, thanks to the relief it provides to them from intensive care tasks (especially if other services are lacking)

2. **Web-based services** can facilitate exchange of experiences among carers, information and role awareness, with **ambivalent effects**:

   - reduce isolation, improve knowledge on caring activities
   - stimulate consciousness of own needs and lack of adequate support services: → possible deterioration in perceived wellbeing
## Final remarks (2/3)

### Tailorisation of carer support

*(Schulz & Eden 2016)*

<table>
<thead>
<tr>
<th></th>
<th>Customisation (adaptation to users’ needs)</th>
<th>Integration (within LTC system)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household-based migrant care work</td>
<td>+</td>
<td>Coordination &amp; monitoring</td>
</tr>
<tr>
<td>Web-based supports</td>
<td>Training &amp; user-friendliness</td>
<td></td>
</tr>
</tbody>
</table>
Final remarks (3/3)

Where should future research focus upon?

- **Migrant care work:**

- **Web-based supports (Sherifali 2018):**
  - Ethical implications (e.g. privacy)
  - Health-related outcomes

Marie-Curie Sklodowska PhD-fellowships on informal care (ENTWINE) (deadline 30 November 2018):

- Migrant care work (ESR-5): [https://entwine-itn.eu/research/willingness/](https://entwine-itn.eu/research/willingness/)
- ICT-based support services (ESR-11): [https://entwine-itn.eu/research/implemenion/](https://entwine-itn.eu/research/implemenion/)
Thank you!
Selected references on first section on migrant care work


Care Alliance Ireland (2014) Literature review on the relationship between family carers and home care support workers, Dublin, Care Alliance Ireland.


Selected references on second section on web-based support services for family carers of older people


