Online support for carers
-developing the role of informal caregiving

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The Swedish context

Carer support in Sweden

Carers are increasingly recognised in policy discourse:

- Change in the Social Services Act (2009)

- However, we would argue that carers are still not well-recognised within the health care sector or by the general public yet…

Sweden has a largely devolved government:

- the 290 municipalities decide the range and extent of carer support that is offered

- some municipalities offer an extensive range of support services, whilst others offer mainly traditional respite care services and carer support groups.

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The Swedish pilot study

The users

- Recruitment from all over Sweden (online presentations)
- **heterogenous sample** (different diagnoses, disabilities, former carers, cared for person in a nursing home)
- 53 carers were recruited, **44 carers completed questionnaires and gave full informed consent**, 3 withdrew from the study
- 10 men, 34 women
- Retired carers and working carers (mean age 64,7)
- Caring for spouse or partner
- High educational background (First stage of tertiary education N=21)

The services tested

Static website *– information*

Interactive services *–* ***Social forum****, social network, private messages, chat, videochat*

Writing exercises in the forum every fortnight

How carers used the platform

The general usage

The most frequently used services : Social network, social forum and private messages

Mainly **SHARING** (tips, emotions, thoughts; negative and positive) (**E-mails**)

Not so many requests for information or advice

Confirming users' experiences, asking questions, helping them to **reflect on their situation** (and/or referring relevant sources of literature and media)

The active users had been **caring for a longer period of time** and had already gained extensive 'first-hand´ knowledge and experiences**.**

Feedback from the Swedish users

Results - Swedish focus group interview

Views about web-based support

- Flexibility

- Importance of learning opportunities

- Personal meeting

Why some services were not used so much

- Lack of time

- Time of year- Swedish summer time!

- Insufficient computer training opportunities

- The caring situation

- Technical issues and usability

- Too few participants

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Results – Swedish focus group interview

Changes /improvements

Personal situation
- Acknowledgement *
- Meeting others in a similar situation
- Hope and strength

"I have felt that my experiences are worth something, that I am not an old lady in my 70´s that should just sit and be quiet"

Impact on the cared for person
The carers' wellbeing affects the cared for person's well-being *

Results from questionnaires highlight the following:
Swedish users are less positive about the platform reporting to a higher degree **potential barriers to** usage (like technical problems, web platform was too complex to navigate and interactive services were time consuming)

"I feel less stressed and that can be a result of other people's posts, that now I can allow myself to have negative feelings and thoughts".

Conclusions

Experiences from the pilot study

- **Education/training** in how to use the web platform
- **"Fostering"** how to use different web-based services takes time and perseverance. (it has been challenging to motivate carers to use the services.)
- **To have a moderator** is crucial (more carers active in the evening)
- **A safe setting** with people in similar situations is appreciated
- **Caring is complex** and the variety of carers' needs and preferences represent a challenge. (caring over an extended or shorter period of time, older or younger carers, working carer, former carers etc)
- Positive with **several different services**
- **Technical issues and usabilty** affects motivation
- **It is necessary to have several active members** to create an online community
- An online community **enables development of personal relationships** among carers- preventing feelings of social isolation. *

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Experiences from the pilot study

Annie:

*"I met Eric when I was in a project about care for older people.
I was caring for my husband who was ill and Eric was caring for his father. We were communicating via chat, mostly about how the municipalities helped us in our situations as carers at that time.
Now, a year afterwards, Eric has lost his father and I have lost my husband. /--/The grief is heavy for us both.
Eric has been a support to me and has, with his computer skills, helped me so much. Allready last year he explained a lot of things to me that I didn´t understand. Now it has really helped me. Eric has helped me learn how to blog. I have found a new interest."*

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Developing the role of informal caregiving Ongoing research based on the results from the Swedish pilot study

Bild: smalandsbilder.se

Aim of the article

analyse how informal carers to older people uses ICT such as an online social forum and social network in order to *present themselves as carers* and *how they discuss and socially negotiate their life situation in relation to others* and their *understanding of the Swedish health care system and municipalities.*

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Research design and theoretical framework

Netnography (Kozinets 2010)

"studying the cultures and communities that emerge from online computer-mediated or Internet-based communications".

Constructionist approach

- Usage of ICT as a means of self presentation.

- Identities are seen as something being created over time, in social interaction/communication which can occur both online and away from keyboard

Results

Presentation of self and the responsibility of being a carer

- The invisible self ("Shadowland")

- Gender contract (for better or worse)

- Limited possibility to choose

How does this affect the carer´s role and identity?

"As a carer it is impossible to make plans. Everything is depending on how things are on that exact day, and the weather. How is the caretaker doing? How do the carer feel? You gotta take one day at a time. (...) When I think about it I have been a carer for over 20 years. My mum died and as an only child I took care of my father who wasn´t well. My husband got an illness and I took care of him. When you get married the priest say "in sickness and in health" and now the time had come to sickness."   (Linda)

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Thank you for your attention!

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