

The use of web-based family care support services to support working carers of older family members

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Background

Given the situation of working carers combining employment and caregiving there has been an emphasis on establishing services aimed at supporting their caregiving role.

Aiming for carers information, learning and psychosocial support.

However, a majority of care support services have mainly focused on the caring conditions of older (retired) spousal carers largely overlooking working carers.

Background

Introducing interventions that doesn't match working carers situations and preferences of support?

Web-based information and communication technologies are becoming more widely available as alternative form of support.

Study objective

Two qualitative evaluation studies aimed to explore perceived benefits and challenges with web-based ICTs as a means of supporting working carers' in their caregiving role.

Study objectives

Utilisation of ICTs reflects issues of interaction during support, views of use, clinical obstacles and opportunities (Schulz et al., 2002; Magnusson & Hanson, 2012)

Study objectives

Study1

Explored nursing support staffs' experiences of using web-based ICTs for support of working carers of older people?

(Andersson, Magnusson & Hanson, 2015)

Study2

Explored working carers' experiences of having access to a web-based ICT in connection with providing care for an older family member?

(Andersson et al. submitted for publication)

	Study 1 Study 2	Study 1
Provide access to: (at various degrees depending on municipal set-up)	En bra plats /Gapet (A good place)	Anhörigstödsportalen (The family care support portal)
Information and education via web-pages, lectures, films, radio shows, literature and news	X	X
Communication networks among carers and staff (via E-messages and Telephone services (SMS))	X	X
National online social networks among carers for peer-to-peer support	X	
Personal space, diaries, the older person's life story journal, personal notes and respite care bookings.		X
Tools (at various degrees) for staff to plan and administer carer support in the municipality	x	X

Method

Data was collected from group and individual interviews

Study1

17 staff (specially dedicated in family care support) in two Swedish municipalities

Study 2

9 working carers in one Swedish municipality

Data was analysed using content analysis

Characteristics of participant working carers (N= 9)

Age	34-64
Female	9
Employment	
Full time	8
Temporarily unemployed	1
Relationship to cared-for family member	
Daughter	7
Spouse	1
In-law	3
Niece	1
Duration in years of providing care for older family member	0.5-10
Cohabiting with cared-for family member	1
Living near cared-for family member	8
Condition of cared-for family member*	
Dementia	6
Neurologic disease	1
Stroke	1
Chronic pain	1
Comorbidities	2
Frailty due to advanced age	1
Number of months with access to municipal web-based ICT support network, "Gapet"	4-20

Findings

Study 1 – nursing staff perspective

Based on a mix of ICTs ‘A good place/Gapet’ and ‘The family care support portal’

Three themes

1. Metaphorically a road providing carriageways in both directions for carer access

- Provided an alternative – a complement
- Enabling prompt access
- Lowering distance barriers

2. The ICTs provided nursing and caring instruments in family care support

Pushing (helping) towards the aim of:

- Reinforcing carer competence
- Reinforcing carers personal control and empowerment
- Offering interventions earlier in the caring process

3. Obstacles hindering access to ICT support

Ethical challenge not to infringe on working carers integrity and scare them away due to their technical fears.

Staff also experienced technical challenges of their own due to their levels of digital skill.

Findings

Study 2 – working carer perspective

Based on the ICT 'A good place/Gapet'

Three themes

1. A support hub, connections to peers, personnel and knowledge

Strengthened confidence in caregiving

Improved carers self-experienced ability

Helped carers to feel more prepared in the caregiving role

“I can better influence the situation of my cared-for family member as I get more knowledge. I understand him better and can help him better.”

Helped to channel negativity, to acknowledge social similarities and provide new perspectives

Provided relief through the ability to share feelings and concerns related to balancing work and caregiving

“It’s a relief to be able to get things off your chest, to share anxiety and guilt...To share feelings of guilt about not being there for her every day because you have everything else on top as well ... that others feel the same way.”

2. Experiencing support as relevant in changing life circumstances

A need for correlation between resources located on the web-based support network and one's own situation

Benefits

Flexibility allowed around-the-clock access from remote locations

Provided access at times best suited to one's personal schedule, not bound to office hours, was experienced as a stress relief

“I used it when other support was closed during late evenings, weekends and at night time when I couldn't sleep. It was often when other support was unavailable.”

Challenges

Did not always match carers preferences of support

Disconnecting when the ICT was not timely introduced in the caring process – to late in the carer career

Working carers caring situation, combined with work and family life could be so time consuming that they were unable to prioritize time to use the ICT.

“When life is chaotic and there are a lot of things to deal with, you can’t handle much more, then you can’t cope with searching social media and forums.”

3. Upholding one's personal firewall

Fear of being on display – internet security

Sometimes too much of a technical challenge to chat and network

“I avoid participating in the carer network...I'm not in a group because I'm a bit afraid to write and spell wrong.”

Sometimes an uneasiness about not being able to separate professional health and social care worker role (“double duty carers”) with the caregiver role.

The opportunity to be anonymous using an alias, provided them an alternative to face-to-face groups.

Conclusion

Findings indicate that the web-based ICTs in various degrees are accessible, complementary means enabling working carers to access psychosocial support and learning opportunities.

However, measures needs to be taken to help working carers to improve their digital skills and overcome digital fears.

To better match support to working carers' preferences, web-based support need to be introduced in a timely manner and must more accurately meet each working carer's unique working and caregiving situation.

References

- ANDERSSON S., MAGNUSSON L. & HANSON E. (2015) The use of information and communication technologies to support working carers of older people – a qualitative secondary analysis. International Journal of Older People Nursing doi: 10.1111/opn.12087
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Thank you!

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