Significant others’ perspectives on person-centered information and communication technology in stroke rehabilitation – a grounded theory study

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Purpose:
To explore significant others’ perspectives on how information and communication technology (ICT) such as mobile phones, tablets or computers may support the rehabilitation process and enable participation in everyday life after stroke.

Method:
To capture the participants’ experiences, two focus groups and five individual interviews were carried out in Sweden and Denmark regarding the use of ICT in everyday life. The participants comprised four men and eight women. They were all significant others e.g. spouses, parents, children, siblings or friends to adult stroke survivors. The interviews were analysed using a grounded theory approach.

Results:
Seven categories were identified from the analysis of the interviews with the participants: 1) ICT providing a sense of security, 2) ICT as a social mediator, 3) ICT as compensator for deficits, 4) lack of connection to the health system, 5) a wish for more rehabilitation without gaps, 6) a need for networking, 7) a need for support to integrate ICT in everyday life after stroke. From these categories two core categories emerged: 1) ICT having new meaning after stroke, and 2) ICT’s potential to minimize the strains that significant others experience.

Conclusions:
Significant others to adult stroke survivors address the need for integrating ICT in the rehabilitation in order to manage, bring meaning, and enable participation in everyday life for both the stroke survivors and the significant others. However, significant others address, concurrently, the need for supporting and assisting the stroke survivors in order to integrate ICT in everyday life after stroke. It is both possible and necessary to start using ICT in rehabilitation, especially since the use of ICT is an integral part of society today.

For people without disabilities, technology makes things easier.
For people with disabilities technology makes things possible”

ibm training manual, 1991

ICT having new meaning after stroke

ICT providing a sense of security
“the mobile phone has become more important now [after the stroke]... I don’t know, because of security I think... we use it more frequently now and phone each other more often than before” (husband)

ICT as a social mediator
“They live out in nowhere. So he was actually trapped out on the farm... he has contact with them [friends and acquaintances] on Facebook... just small messages” (daughter)

ICT as compensator for deficits
“He often takes pictures of things he needs to remember... the intelligent wordbook helps him to write messages” (daughter)

Lack of connection to the health system
“I had to call them [health system] a thousand times” (wife)
“...to stay in contact, to stay informed and to keep track of how things are going at home” (sister)

A wish for more rehabilitation without gaps
“She hadn’t been standing for all those months. So she had to start all over again” (husband)
“The rehabilitation process was too short... I am sure that he could benefit from using ICT to exercise more... the more they can receive, the more their quality of life will increase” (friend)

A need for networking
“It is very difficult to see the person you been living with and love changing to another person. You need help to tackle that... other relatives who has been through the same, can possibly be of support... for example through virtual network groups” (daughter)

A need for support to integrate ICT in everyday life after stroke
“He used to know his way around using the computer and iPad. Then he had a stroke... he didn’t know how to unlock his mobile phone or to write text messages... he optimal solution would have been instructions during the rehabilitation or maybe a course he could attend” (daughter)

“sometimes when you need to update the programs, it goes haywire... and then you are lost... you need to be able to get help [from the health system] to make it work again” (sister)