

LONG-TERM ONGOING STRUCTURED SUPPORT IN EARLY STAGE OF DEMENTIA: PER-MODEL®

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SWEDISH CONTEXT

- Dementia is the third most common cause of death.
- Approx. 160 000 are suffers from dementia in Sweden with 25 000 new cases each year.
- Persons with dementia gradually become aware that something is wrong. They experince loss of short term memory, difficulties communicating, loss of control, autonomy and independence.
- Feelings of insecurity, fear, confusion, humility, and even isolation can occur.

NEED OF SUPPORT

- After diagnosis the need for support is high, but next of kin often feel abandoned and in need of emotional support.
- information and conversation about the coming lifestyle changes and ways to handle the personality changes that the person suffering from dementia may go through.

FAMILY

- Clearly disease and illness in a family member affects the whole family in one way or another and also the family as a whole.
- A Swedish report published in 2014 showed that next of kin often took sick leave, lessened time at work or early retirement to take care of their diseased parent or spouse.

CAREGIVER SUPPORT

- Caregiving next of kin often suffers from different stress related diseases such as anxiety, depression and fatigue syndrom.
- Support have been shown to decrease stress and improve psychological wellbeing.
- Meta analysis show that support should be given for more than 8 weeks for positive effects.

BACKGROUND

- In 2009, the Swedish Parliament passed a new law that states: “Municipalities are obliged to offer support to persons caring for people with chronic illnesses, elderly people, or people with functional disabilities” (Swedish Social Services Act, 2009).
- In the autumn of 2013 the Swedish National Health Board issued guidelines where eight to ten meetings during a three- to six-month period with information and social support were recommended.

THESIS CONTEXT



- Since 2006 a municipality in Northern Sweden have been providing support through support groups to newly diagnosed with dementia and their next of kin.
- The research started in 2010 and resulted in the PER-model® in 2014.

	Study 1	Study 2	Study 3	Study 4
aim	to explore couples' experiences regarding long-term ongoing structured support group with participants in early stages of dementia and their partners.	to explore the meaning of being an adult child to a person with dementia.	to explore family relationships when a family member is affected by dementia.	to explore how participants in support groups score on the Sense-of-Coherence scale and factors to a meaningful, manageable and comprehensible everyday life in the presence of dementia.
Participants	4 couples, 8 participants	9 participants	17 participants	31 participants
Methods	Interviews and non-participant observation	interviews	interviews	interviews and Sense of Coherence scale
Ethical approval	Umeå Dnr 2011-93-31Ö.	Umeå Dnr 2011-376-31M.	Umeå Dnr 2011-376-31M + Dnr 2011-93-31Ö.	Umeå Dnr 2011-93-31Ö + 2011-376-31M.

RESULT STUDY 1

- showed that couples who had been the longest in a support group (4 years) felt great sense of comfort and support. The healthy partners experienced that their knowledge about the disorder was good and that they could prepare for the changes to come.
- However persons with dementia did not want information about their disease.
- International Journal of Older People Nursing (2013).

RESULT STUDY 2

- To be an adult child of a person with dementia disease means being burdened with the responsibility to act on behalf of the diseased parent despite a deep sense of grief and loss, which leads to frustration with the situation.
- Support was needed to handle the crisis.
- International Journal of Qualitative Research on Health and Wellbeing (2013).

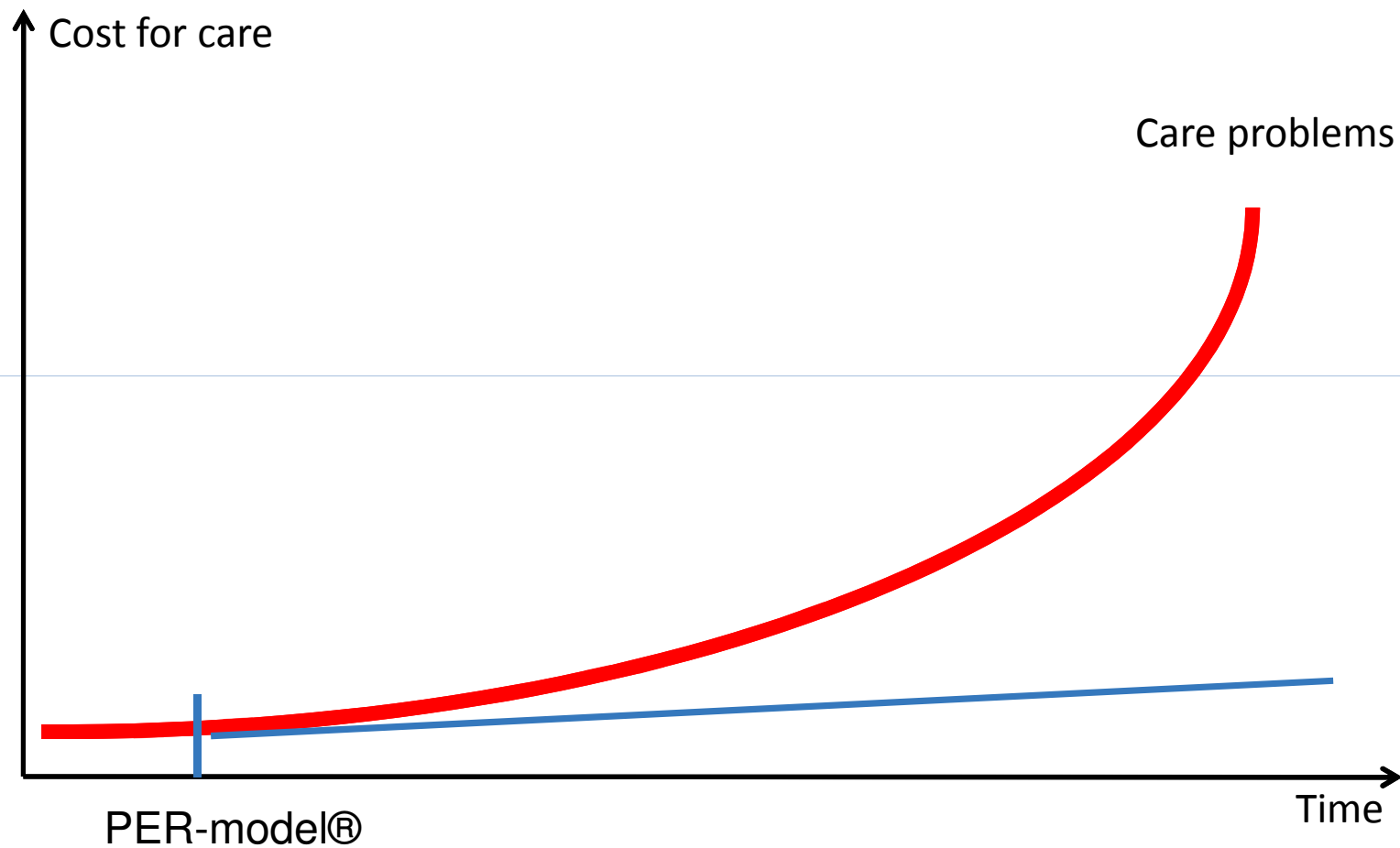
RESULT STUDY 3

- Relationships within the family can sometimes change when a family member is affected by dementia. Sometime for the better; where the family rallied to support the affected member and sometimes for worse; where the relationships were strained when pressure became too much.
- Support from outside is needed for the family members to support each other.
- Open Journal of Nursing (2014).

RESULT STUDY 4

- The persons with dementia who participated in the support groups experienced a great sense of coherence and felt that life was manageable, comprehensible and meaningful. Their healthy partners experienced less comprehensibility and manageability and the adult children more meaningfulness.
- Mixed method; SOC scale and interviews.
- Submitted (2014)

BASIC IDEA OF PER-MODEL®



PER-MODEL®

- Pedagogical – information about the disease is presented in a language and on a level that is adapted to the receiver.
- Emotional – every other meeting is dedicated just to have fun with games, barbecues or bowling; building emotional bonds and memories.
- Relationshipbased- sustaining, creating and building relationships within the group, between members and moderators.

PER-MODEL® OF SUPPORT

Group 1

Group 2

Day Care centre

Shelterd
accomodation

Next of kin group

REFERENCELIST

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