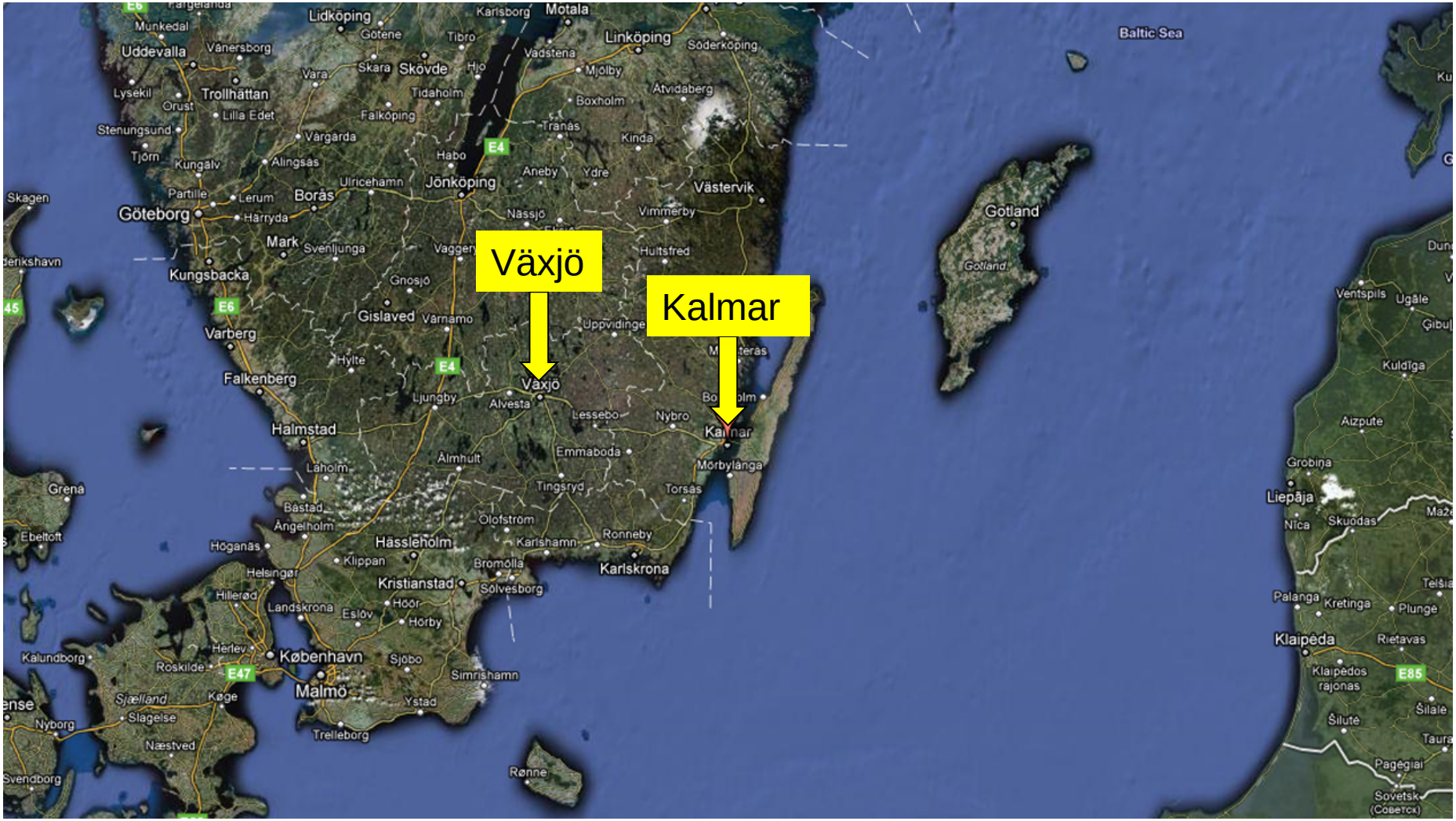
How to support family systems nursing in palliative care in Sweden

Eva Benzein

Odense 2014-09-24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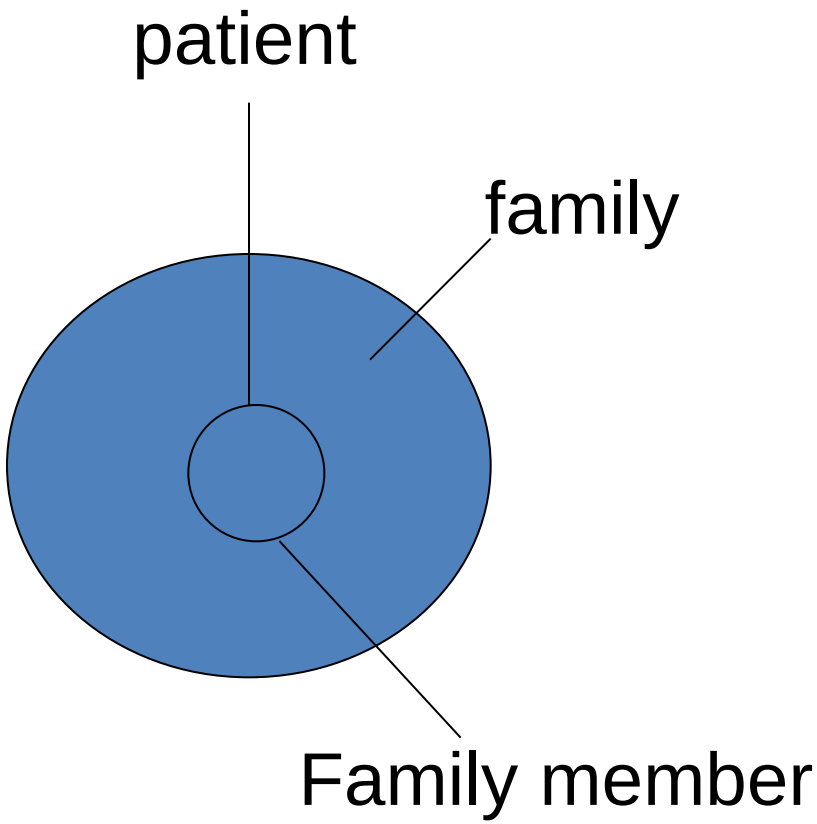
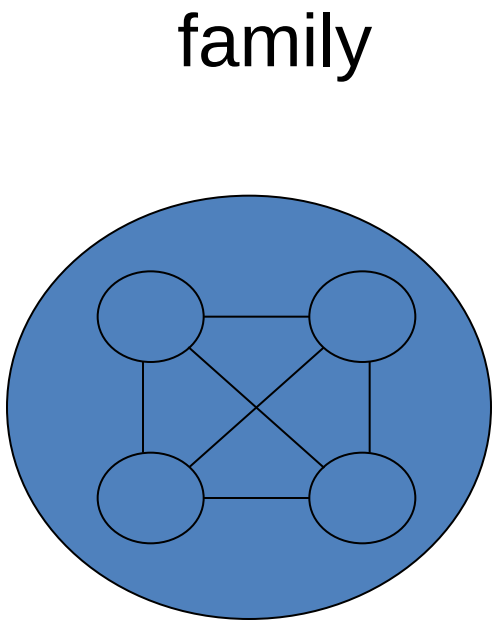




Family-related perspective

Family-centered perspective

The Center for Collaborative Palliative Care

The Kamprad Family Foundation for

Entrepreneurship, Research and Charity

My presentation …..

1. Present the Center for collaborative palliative care

2. Say some words about palliative care and families

3. Highlight some features of a systemic approach

4. Describe the development of and implementation of an educational package to staff in palliative care in Kronoberg based in a systemic approach

Our mission ….

a) to ensure that program and courses in palliative care are offered at the Linnaeus university at all educational levels

b) to develop the clinical palliative practice in terms of educational efforts to the staff

c) to perform research with high quality

Linnæus University

Palliative care and families

Families in palliative care

- Family vulnerability
- Helplessness
- Strain
- Suffering
- A struggle to make sense
- Maintain normality in family living
- Bringing about difficulties in family relationships

Families and palliative care

- Overcome the family's silence about death
- Modifying the family picture
- Making a family plan for death

"We-ness" "me-ness"

Carlander et al (2011) Being Me and Being Us in a Family Living Close to Death at Home. Qualitative Health Research. 21(5), 683–695.

Families and palliative care

- To let death spread and leave its mark on life
- To catch sight of life

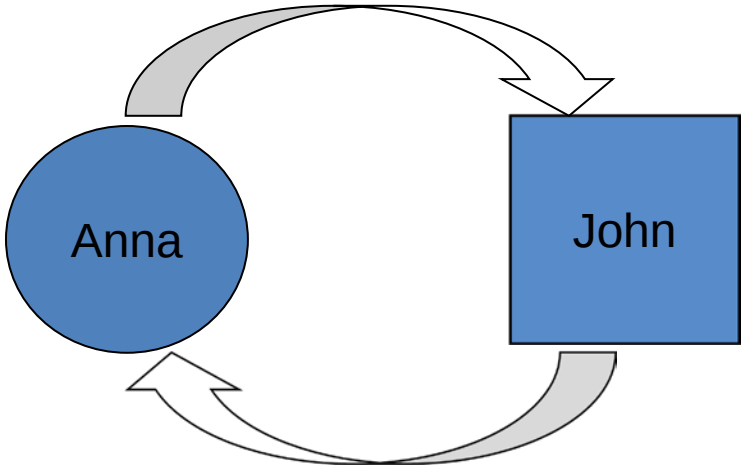
Strang P. & Sand L. (2013) When death is challenging life – about existential crisis and coping in palliative care. Stockholm: Natur & Kultur.

Features of a systemic approach

- Mutual influence

A systemic approach …

- Circularity



A systemic approach …

- Wholeness

… more than …

A systemic approach …

- Multiple perspectives

  multiverse rather than *universe*

  objectivity, objectivity in parenthesis

Maturana (1988)

A systemic approach …

”the difference that makes the difference”

Gregory Bateson (1998)

A systemic approach …

- Co-creation of reality

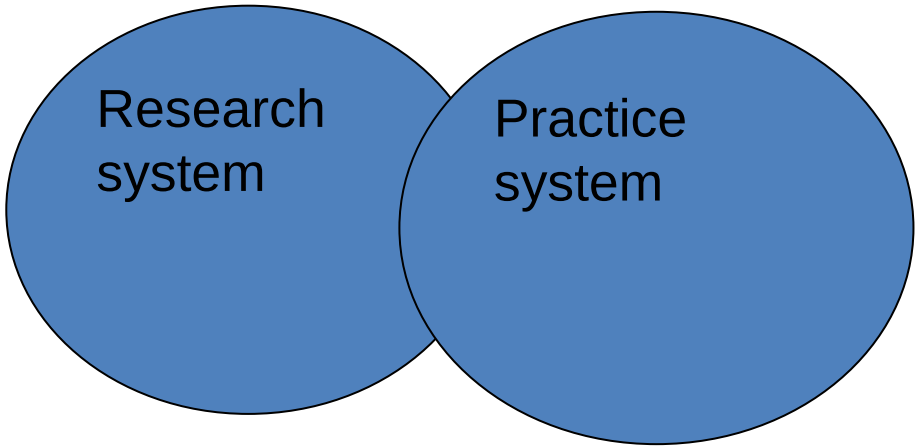
language - narratives

Partnership

- non-hierarchial relationship
- both parts are seen as experts
- knowledge is developed

Implementation

A model of knowledge creation through interactive research

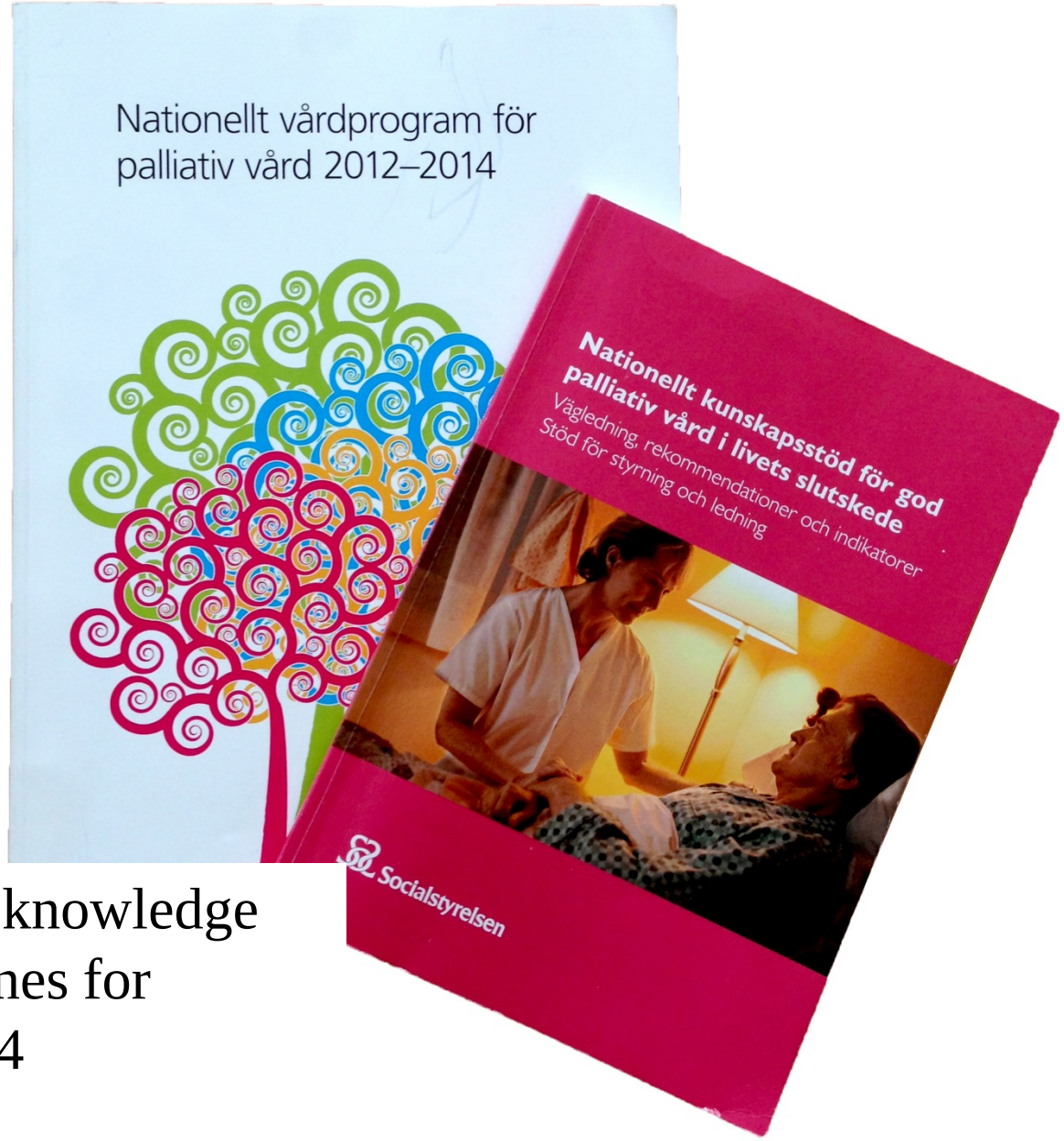


Ellström 1998

Implementation of an educational package to staff in palliative care in Kronoberg

- Meetings with leaders, manager

- Development of a material
    * literature search
    * meetings with staff, patients and family members



The National support of knowledge and the National guidelines for palliative care 2012-2014

Topics

- Palliative philosophy
- Dignified care
- Symptom control
- Existence and dying
- Family members
- Collaborative care
- Own choice

At your working place, what experiences do you have regarding how patients and their family members influence each other? (mutual influence)

Look at the picture of a circular diagram (on page 3)
and share your reflections with your group participants! (circularity)

How can you understand the relationships between individual family members and the family as a unit? What consequences does it have for how to care? (wholeness)

How can you get access to each family members' story? (multiple realities)

In what way are the family members a part of the care for the dying person at your unit?

How do you foster the partnership with families?

How do you use families' knowledge to increase your own competence in palliative care?

Do you offer family members conversations about the care after death? If yes, how? What value do they have, for whom? If no, why not?

Fundings

The Kamprad Family Foundation for Entrepreneurship, Research and Charity

The Linnaeus University

The Kronoberg County council

Lessebo Community

Thank you!