Aim of the thesis

To generate knowledge about consequences of informal caregiving for the family members of patients diagnosed with advanced cancer
Aim

- Investigate the type of social support provided, to estimate the consequences of informal caregiving on the family members’ health, and to estimate the economic costs of health service use and informal caregiving (Study I)
- Investigate HRQOL in family members over a 1-year period (Study II)
- Explore management strategies that family members employ when the patient is in the early stage of treatment (Study III)
- Explore the meaning of social support networks for family members of adult persons in the early stage of treatment (Study IV)

Results - Study I

- The family members providing informal caregiving were mostly partners and females. The most common support was emotional, followed by household work.
- The average number of hours spent providing support during one year was estimated at 4 hours per day. If professional caregivers such as home help care assistants had provided this support, it would be equivalent to a cost of 327 000 SEK.
- The medical records indicated increased morbidity with increased health service use (physician consultations), more psychiatric diagnoses and musculoskeletal diseases during the year after the cancer diagnosis than during the year before.
Results - Study II

- The scores on the mental dimensions of HRQOL, as measured with SF-36, were lower than the norm-based ones during the year after the cancer diagnosis.

- The older family members and partners were at higher risk for decreased physical HRQOL the year after the diagnosis.

- Younger family members were at higher risk for decreased mental HRQOL the year after the diagnosis.

Results - Study III

- Family members managed the threatening future by striving to be prepared for the painful.

- Emotion-focused coping strategies were used most, except for the problem-focused coping strategy of making things easier in everyday life both for the sick person and for themselves.

- The partners anticipated that they were going to be left alone as single partners and tried to carry the whole family in their arms.
Results-Study IV

- The family members experienced themselves as being members of their communities.

- Confirmation through togetherness expresses the support they received from their social networks as information, understanding, encouragement, involvement and spiritual community.

- Mostly the family members reported positive experiences in respect of close relatives, nevertheless there were relatives who shied away from the troublesome situation, and the family members desired a deeper relationship with these relatives.

Conclusions

- Family members seem to have adapted management strategies for handling their situation in the early stages after the cancer diagnosis, mostly with support from their social network.

- Despite these management strategies, however, the family members may develop a risk of morbidity, with increased health service use and increased musculoskeletal problems and psychiatric diagnoses during the year following the cancer diagnosis.

- Especially the older family members and partners were at higher risk for decreased physical HRQOL throughout the year following the diagnosis, and younger family members were at higher risk for decreased mental HRQOL.
Conclusions

• The persons diagnosed with cancer had a high mortality rate, which suggests that the family members were living with a mentally stressful situation.

• Family members should be offered support at an early stage to reduce their mental and physical distress.

• Health-care staff needs to pay close attention to each family member both as a person assuming the role of informal caregiver and as a person with particular needs.

• If a person with cancer had not had a family member who gave support and care, this would cost society 327 000 SEK for wage compensation with home help care assistant.

• Costs in terms of loss of productivity in their work and greater healthcare use.

Clinical relevance

• A greater focus on preventive measures will lead to improved treatment and reduced suffering, benefiting both the cancer patients and their caregivers.

• Family members risk of morbidity motivates developing guidelines for preventing both physical and mental morbidity for family members.

• Develop methods that can provide new knowledge about how health professionals can provide individualized support in the best way for family members and their families as a way to strengthen their mental health. Ex. Structured questionnaires (instruments) can help nurses and care planning team to make the right efforts.
Advice

1. Provide family members a conversation with physician and follow-up contact with the nurse.

2. Ask the family members if they want information about society support efforts.

3. Give family members contact information to the municipal family services or refer to contact with social worker in health care.

Is it an investment for the society in preventing illness for informal caregivers?

- Drug costs are increasing, health care experience financial cutbacks and billion deficit.
- There may be a danger to both the health care and community wishes the family members to do more in the future.
- It is unclear whether the families want, or will hurricane to be caregivers in the future. There is a risk that the costs for the caregivers own morbidity increases.
- Will the society be able to put the responsibility on the family or is it society’s responsibility?
- Caring for love or duty?