

**Research Plan RP09-02**

**How do we support relatives of patients dying of urological cancer, who wish to die at home?**

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**1. Title**

How do we support relatives of patients dying of urological cancer, who wish to die at home?



## 2. Introduction, summary

Since the population is living longer the number of patients who get a urological cancer is increasing. In spite of new treatments being constantly developed, a lot of patients still can't be cured.

Great deals of urological patients are followed in the department of urology for many years after the cancer has been diagnosed.

Therefore some of the patients have several years experience with the hospital. At the urological ward at Odense University Hospital 30 patients had died of a urological cancer from December 1. 2007 until December 1. 2008.

When old patients get bladder or prostate cancer it often is a non-aggressive form of cancer. Because of the rather long progress many patients will accept that there is no cure and they soon have to die.

When the only option is palliative many patients will be considering where they wish to end their life. Some patients want to die in the ward, where they know the staff and have a sense of security. Others hope to die at home surrounded by their family. At the urological ward we often meet relatives who feel inadequate and unable to fulfil the last wish of their dearest ones. They feel insecure to take the responsibility for the dying in the end.

The aim of this study is:

- *How to decrease the insecurity and support the relatives to patients who have a urological cancer and who wish to die at home?*

## 3. Objectives

The following questions have to be clarified.

Which problems occur in the final stage of the life for the dying patients who have a urological cancer?

Which needs for support and information do the relatives have?

How can we assure that the dying and their relatives have the information necessary to solve unexpected difficulties?

How can the staff at the urological ward contribute to ease the course for the dying patient and their relatives?

## 4. Literature review

When a member of the family gets cancer the whole family is affected. They have to cope with a new situation and need new tools. In the last stage a conflict can arise between the dying and their relatives because the dying tries to isolate him selves to spare the family. In a urological ward most of the dying patients are men. The Danish sociologist Simon Simonsen has investigated how men cope with health and illness, and how they sometimes choose to isolate themselves from the family. Primarily a concept of distancing and focussing is developed. By distancing is meant keeping illness, signals of illness, risk of illness and health at arm's length. Distancing and focussing is differentiated into three aspects: social, verbal and mental. These three forms can be interpreted both negatively as isolation/denial and positively as autonomy. The often seen male reaction is also a known phenomenon seen in elephants. A ronkedor is a Dutch word for a lonely male elephant living apart and isolated from the herd. Therefore this PhD is called the ronkedor phenomenon (1).

In 2001 a study focusing on terminal courses in a Danish urological ward showed that anaemia, fatigue, nausea and vomiting, obstipation, diarrhoea, pain, oedema, hematuria and catheter-problems and fever were the main course for telephonic applications.



In the same study interviews indicated that the relatives were insecure about the unknown – and how the course would end (2).

When a patient is going to die at home it often is a prerequisite that the relatives are willing to participate to a certain extent. It is burdensome for the relatives to care for the dying. In Denmark relatives have the option of leaving their job for a period to take care of a dying member of the family. The local homecare will support and relieve the relatives. The general practitioner plays an important role in relation to the homecare and the palliative team at the hospital when a patient wishes to die at home. Just as calling a doctor on call can be necessary. Information about the patient's condition and certain treatment and needs must be accessible to the doctor on call who visits the patient (3).

## **5. Relevance to urology nursing**

In spite of the differences between what is offered in each country related to caring for a dying member of the family, this study will be an eye opener to everybody who deals with treatment and care for terminal urologic patient's and support for their relatives. Even though relatives will be met with different local options in each country.

The hospice movement began in Britain in the 1960's. Its purpose was to provide a service that would enable the terminally ill to die with dignity, sensitive care, and minimum pain (4). Now hospice services have become very widespread in Europe, but in Denmark the number of hospice rooms is limited. Most people agree that when ever it is possible, a person should be able to die in the comfort and familiarity of his or her own home. Hospice services often can make that possible with minimum stress for the family. It is unknown how many of the patients with a urological cancer die in a hospice.

Regarding culture there can be quite a difference how clarified people are with death and how to handle grief. In some places it is a tradition to take care of the dying at home.

In those countries where religion plays an important role the relatives in a higher degree find solace in their faith, but it doesn't change the fact that they often will have need for support from health staff to cope with the problems that occur when they are taking care of a dying member of the family.

## **6. Methodology**

This study will use a qualitative approach to analyse what kind of support the relatives of patients dying of urological cancer need. The methods will be a semi-structured interview with the spouses or the nearest relatives to terminal patients with bladder, prostate or kidney-cancer. The interviews will take place before and after the patient has passed away. The contact will be established while the patient is hospitalized, when he has an expected life span of 3 months left. The interviews will take place at the urological ward or at the patient's home. The goal is to get an insight when problems occur and know why the relatives feel insecure and powerlessness. By looking for certain patterns and commonalities it will become clear how we can contribute to support the family.

Further focus group interviews with staff from the primary healthcare and nurses from the urological ward are considered.

### **6.1 Inclusion criteria**

Relatives of patients with incurable urological cancer with a life expectancy of maximum 3 months who wish to die at home.



The patient must be known to the urological ward.  
 The patient has to live in Region Southern Denmark.  
 The gender, age and social class are irrelevant.

## 6.2 Exclusion criteria

The relatives must understand and be able to express themselves in Danish.  
 The relatives must have a close relationship to the patient e.g. a spouse, partner or a child.

## 6.3 Sample size

Relatives to 5-6 patients.

## 7. Feasibility

### 7.1 Time table

Year	2008												2009	
Month	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb
Literature review	X	X	X											
Data collection Interview with relatives				X	X	X	X	X	X	X				
Data analyses											X	X		
Results												X	X	
Conclusion												X	X	
Publication of guidelines													X	X
Implementation													X	X

### 7.2 Budget

	Costs €
Interviews, transcription and analyses (120 hours)	2100 €
Focus group interviews (40 hours)	700 €
Transport to the patient's home	100 €
Support to the programmes RefMan and Invivo	200 €
Implementation	100 €
<b>Total costs</b>	<b>3200 €</b>

## 8. Conclusions / Relevance

In every urological ward the care of terminal patients and the support to their relatives is an essential part of the nursing. To prevent unnecessary hospitalization the relatives and the primary care nurses have to be able to get advice and counselling from the urological ward. A collaborative agreement between the urological ward, the palliative team at the hospital and the primary sector must be established concerning how to comply with the terminal patients who wish to die at home, and concurrently being considerate to their relatives.

In the end we will be able to:

- Identify why relatives sometimes feel unable to take care of their dearest ones in their final days



- Prepare a clinical guideline for when ever a patient needs to be hospitalized
- Publish an information folder describing where the relatives can apply for help, when they have a specific problem
- Publish a collaborative agreement between the urological ward, the palliative team and the primary sector (home care nurses and general practitioners)

and hereby provide a better support to the relatives.

## 9. References

1. Simonsen S. *The ronkedor phenomenon – constructions of masculinity, illness and health.* Dan Med Bull 2004; 51:454.
2. Bavnhøj HB, Sommer B. *Terminale forløb. Project at Urology Department at County Hospital Glostrup* 2001.
3. Amtsrådsforeningen, Sundhedsministeriet og kommunernes Landsforening *Hjælp til at leve til man dør* 2001
4. <http://en.wikipedia.org/wiki/Hospice>

*A further literature review has to be done in PUB MED and international nurse-related databases e.g. Cinahl.*

## 10. Any possible conflicts of interest

There are no conflicts of interest.

This study will be reported to the Danish ethics committee, and both the patients and their relatives will be asked to give their informed consent. In case any of them regret their participation, they can decide to leave the study immediately.