

**Telephone consultations as a way to find the information needs of a cystectomised patient that are relevant when coping with the convalescence period.**

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**Introduction:**

The Urological Department at Rigshospitalet cystectomises approximately 60 to 70 patients annually mainly due to bladder cancer. One third of these patients are women and two thirds men. The patients' age varies from 40 to 75 but most patients are 60 to 70 years old. The uncomplicated course of a cystectomy consists of pre- and postoperative nursing information before and after the operation regarding the selected urine drainage, nutrition, mobilisation, GI-function, sex life, expected psychological reactions and various issues on the instruments used during the period. Post-operatively the aim is to teach the patient how to look after his urine drainage in the early stages, to effect early mobilisation and to give information about nutrition.

The patient is discharged after eight days. 10 to 14 days later the patient will return for a check-up.

Today patients are discharged after 8.5 days (median), six years ago patients were discharged after 12 days.

Since 1998 the average time for hospitalisation has changed from 23 days to 12 days.

The nurses in the department experience today that these patients are more often rehospitalised due to poor general condition. It has also been found that the patients contact the department after discharge more often because of uncertainty as to their condition. As a consequence of this a follow-up programme was established by the department in 2005. The program is structured as a questionnaire and is made by the discharging nurse by telephone four to six days after the discharge and again after 12 to 14 days. The average time for a conversation including documentation of the conversation is 15 to 20 minutes.

### **Purpose:**

To investigate how the cystectomised patient experiences the period after discharge with focus on the need for information related to the physical and psychological reactions subsequent to the operation. The purpose is also to investigate if the patient's needs are covered by the follow-up programme.

### **Aim:**

The aim of the project is through a systematic follow-up programme to improve the patients' comfort after leaving hospital and to increase the patient's knowledge of his physical and psychological reactions in the convalescence period.

### **Previous studies of telephonic contact to patients in the convalescence period.**

Earlier research<sup>1</sup> has shown that a patient's knowledge of his treatment, complications and activities, is important in order to help manage his everyday life in the convalescence period. Blystad and Kvalvaag showed in their research in 2004 that patients suffering from malignant diseases have the greatest need for information and that the need for information mainly occurs when the patient experiences discomfort or other problems and links these problems with their uncertainty as to their general condition. In our opinion the research indicates that information given prior to discharge is not enough to give the patient a feeling of security in his everyday life after hospitalisation. Furthermore the research showed that patients felt great comfort in receiving an evaluation from the urological staff as to whether a reaction experienced after the operation was normal or not. This requirement can be met by contacting the patient by telephone on a regular basis after discharge.

There is more research that documents a positive effect of a telephonic follow-up programme<sup>2</sup>, because the programme helps the patients to cope with their illness and

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<sup>1</sup> - Blystad, Astrid og Berit Kvalvaag Grønnestad : Pasienters opplevelse av informasjon i forbindelse med en operasjon. – En kvalitativ studie. *Vård i Norden* 4/2004. Publ.No.74 Vol.24 No.4 PP 4-8. (Ref. 5)

- Kvale, Steinar:” InterView. En introduktion til det kvalitative forskningsinterview”. (2 ed.). København: Hans Reitzel.1998. (Ref. 6)

<sup>2</sup> - Cox K.,Wilson E. : Follow-up for people with cancer : nurse-led services and telephone interventions. *Journal of Advanced Nursing*, 43(1), 51-1. London: Blackwell Publishing Ltd;2003. (Ref.1)

- Sørensen, Mette , Nete Hornnes og Charlotte Møller : En randomiseret undersøgelse af effekten af telefonisk opfølgning efter hysterectomi i accelereret regime. *Vård i Norden* 3/2005. Publ. No.77 Vol.25 No. 3 PP 43-48. (Ref. 2)

makes them feel safe and reassured about it. On the other hand it cannot be documented that the follow-up has any effect on the number of complications occurring during the first months after the operation<sup>3</sup>. The fact that the complications do not always occur at the same time as the follow-up call, can be the reason for this.

The fact that information is important in order to further the feeling of security and that the information should be given individually according to each patient's special needs, has been researched. What we do not know is what problems the cystectomised patient experiences in the early days after discharge and if the follow-up calls made by the Urological Department can improve the patient's ability to cope with the consequences of their illness in their everyday life, and hereby further the feeling of security.

### **Method:**

To collect the necessary data for the research we have decided to set up a focus group. A focus group interview is a qualitative data gathering method and will throw light on the subject. The method will also give a varied picture of the patients' experiences in the convalescence period and is appropriate in order to improve the telephonic follow-up programme.

The first fase of the data gathering is the drawing up of an interview guide divided into subjects which can reveal the physical and psychological reactions of the cystectomised patient in the convalescence period, in this case up to three months after discharge.

We intend to gather information using two focus group interviews. Each group will consist of six patients and the duration will be approximately two hours per interview.

The basis of the interview guide is previous experience from telephonic follow-ups made by the department. The structure of the guide will be a few simple questions which participants can use as a basis for discussion and which at the same time give participants

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- Eigø, Jane, Christiansen Conni Biehl : Professionel sygepleje til patienter der tilbydes tonsillektomi i en dagkirurgisk afdeling. (Ref. 3)

<sup>3</sup> - Sørensen, Mette , Nete Hornnes og Charlotte Møller : En randomiseret undersøgelse af effekten af telefonisk opfølgning efter hysterectomi i accelereret regime. Vård i Norden 3/2005. Publ.No.77 Vol.25 No. 3 PP 43-48.

the opportunity to voice their own experiences, and the group dynamics will also make it possible to pick up variations in the patients viewpoints.<sup>4</sup>.

We are aware that it is not possible to make a generalization from the data gathered at the focus group interview, but in relation to the purpose of the project, we find this to be the most appropriate method.

### **Inclusion criteria:**

We will include both women and men who have undergone a cystectomy and who have been discharged to their own homes after maximum three weeks of hospitalisation. All participants are in the age span 60 to 70 years and they have all received a telephonic follow-up from the department. The groups will consist of one third women and two thirds men.

### **Exclusion criteria:**

We will leave out patients who do not speak Danish, patients with abuse problems, patients with dementia or severe mental illness, and finally patients without a telephone.

### **Analysis:**

The data will be analysed through the principles of Grounded Theory:

1. Open coding, where the subject categories or concepts contained in the interview text are identified.
2. Axial coding, where the purpose is to find patterns and connections between concepts and to put concepts from the open coding together
3. Selective coding, where the core of the category is identified and systematically held against and together with the other categories.

When the analysis is concluded we will from its findings create a new interview guide for future telephonic follow-up programmes, with questions as to the physical and

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<sup>4</sup> - Halkier, Bente: " *Fokusgrupper*". Samfundslitteratur & Roskilde Universitetsforlag, Frederiksberg,2002.

- Brødsgaard, Anne og Pia Glerup Hansen : " *Fokusgruppeinterview- et kvalitativt evalueringsværktøj*". Klinisk Sygepleje. Nr.5/2001, pp273- 278.

- Dahler-Larsen, Anne Marie og Peter Dahler-Larsen : " *Fokusgrupper i teori og Praksis* " i Erik Maaløv(red) : " *Internt undervisningsmateriale i kvalitativ metode* ". Handelshøjskolen i Aarhus 1995.

psychological reactions, which we found at the interview occurred most frequently, and at the same time giving the patient the opportunity to ask individual questions.

**Expected result:**

During this project we expect to gain knowledge about the physical and psychological reactions experienced by the cystectomised patient in the convalescence period. With the new knowledge we expect to have enough material on the matter to upgrade the interview guide used previously. We hope the improved interview guide will increase the patient's feeling of security in mastering the convalescence period and thereby decrease rehospitalisation frequency among cystectomised patients.

**Timetable:**

The project will be initiated on 1<sup>st</sup> of April 2008 by working out the interview guide for the focus group sessions. The focus group interviews will be held in May and June 2008 and the data analysis will be done from June until September. When the analysis is complete a project specification will be made. The project specification will contain recommendations regarding the upgraded telephonic follow-up programme. The last part is expected to be completed before 1<sup>st</sup> of April 2009.

**Economy:**

During the 12 months the project is expected to last we will need a nurse for 3 months with full salary. In connection with our focus group interview we will also need an external moderator as this will avoid incapacity and secure qualified data. We expect to hire a skilled and experienced moderator. All put together we assume the project costs to be around 100.000 Dkr.

Transport expenses for the interview participants are expected to be about 2400 Dkr.

(We anticipate to seek financial support from the following companies: "Dansk Sygeplejeråd", Rigshospitalet, FSUIS, Coloplast, Dansac, Astra Tec and COOK.)

**Conclusion:**

Even though it is well documented that telephonic follow-up programmes have a positive effect on cancer patients, it has never been systematically researched whether the cystectomised patient has the same benefit from such a programme. The convalescence period for the cystectomised patient differs significantly from the hysterectomised patients because the cystectomised patients' everyday life changes considerably due to the urine drainage which the operation involves. This means that the cystectomised patients not only have to deal with the physical and psychological reactions in the convalescence period but they will also have to deal with new practical tasks related to their specific urine drainage. With that in mind we are convinced that this is an important issue to research.

**Ethics:**

The focus group interview participants will be informed about the aim of the project and how the interview will be carried out. The participants will also be given a written "consent form" and it is emphasized that they will be given full anonymity and that they at any time can withdraw from the project.