



## Finding a wider horizon: Experiences of being a next-of-kin of a person suffering from colorectal cancer as told after having participated in a psychoeducational program

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### A B S T R A C T

#### Keywords:

Colorectal cancer

Patient

Next-of-kin

Psychoeducational program

Content analysis

Caregiver

**Aim:** The aim of this study was twofold: first, to describe the experience of being the next-of-kin of a person suffering from colorectal cancer (CRC), and second, to describe how a psychoeducational program (PEP) might contribute to the next-of-kin's life experience. Psychosocial interventions for next-of-kin to cancer patients are effective in improving quality of life issues, although there are conflicting results in previous studies. Most studies have evaluated the effects of PEP for mixed cancer groups but there is little knowledge about how next-of-kin to a person treated for CRC describe their experience of life and their experience of participating in a PEP.

**Methods:** The study used a qualitative descriptive design. Individual, open-ended interviews with each of the 18 next-of-kin, of persons receiving treatment for CRC, who participated in a PEP. Data were analyzed using content analysis.

**Results:** Based on the experiences described by the next-of-kin to a person treated for CRC, the subtheme; *Facing a personal challenge was developed*. From their described experiences of participating in a PEP, the subtheme *Obtaining New Insights and Perspectives* emerged. One main theme was finally identified; *Finding a Wider Horizon*. The study illuminates the importance of integrating the next-of-kin/family in the colorectal cancer care.

**Conclusion:** The findings from this study can be used to plan future interventions for next-of-kin to patients with CRC as it offers possibilities to understand the next-of-kin's situation and experience from participating in a PEP.

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### Introduction

Colorectal cancer (CRC) is the second most common cancer diagnosis in women and third most common in men worldwide (Ferlay et al., 2010). In Sweden, 6000 persons per year receive this diagnosis (The National Board of Health and Welfare, 2009). The primary treatment is surgical removal of the tumour followed by chemotherapy and radiation treatments.

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The treatment and its side effects impact both the person treated for CRC and their partner because it affects everyday life as well as psychological wellbeing (Houldin, 2007). Partners of CRC patients report a higher level of psychological distress than the treated person (Northouse et al., 2000). The impact of the patient's disease can cause exhaustion and occasionally force a partner into early retirement (Ohlsson-Nevo et al., 2011). A Swedish study found partners of CRC patients to be especially vulnerable. They are more likely to suffer from additional health problems, have higher health care costs, require more frequent psychiatric diagnoses, and incur in-patient care more often, as well as utilizing a higher level of sick leave compared to the general population (Sjovall et al., 2009, 2010). Partners and relatives of cancer patients describe facing an uncertain future and being in need of information (Adams et al., 2009).

Northouse et al. (2010) have classified interventions for caregivers of cancer patients into three major types: psychoeducational group, therapeutic counselling, and skills training (Northouse et al., 2010). The focus in psychoeducational intervention is to provide information about the physical, emotional, and psychosocial needs of patients and caregivers, and about family relations. The therapeutic counselling is mainly a means to develop a therapeutic relationship and address concerns related to cancer or care giving. Intervention, including skills training, provides coping, communication, and problem-solving solutions that can be useful for the next-of-kin (Northouse et al., 2010).

A literature review revealed that partners of cancer patients who participated in a psychoeducational group reported less mood disturbance (Bultz et al., 2000), less negative appraisal of care giving, reduced distress, hopelessness, and uncertainty (Northouse et al., 2007). Following an intervention, the next of kin reported improved problem solving abilities (Caress et al., 2009), improved knowledge, as well as an improved sense of emotional support and belonging (Docherty et al., 2008). On the other hand, recent reviews (Carey et al., 2012; Glasdam et al., 2010; Ussher et al., 2009) conclude the lack of evidence for the efficacy of psycho-social interventions in reducing distress and improving coping in informal cancer careers due to methodological limitations. Nevertheless, a meta analysis of Northouse et al. (2010) reported significant positive effects on multiple outcomes after three months, such as appraising the burden of care giving, informational needs, coping strategies, self-efficacy, mental distress, anxiety, and marital–family relationships.

Previous interventions for next-of-kin were mainly designed for mixed groups of cancer patients, although interventions for next-of-kin to patients with the same cancer type have been found more effective (Ussher et al., 2009). We have not identified any studies focussing on psycho-educational interventions designed for next-of-kin to persons treated for CRC.

It has been suggested that qualitative evaluations of subjective experiences in psycho-social interventions might give other valuable information that standardized instruments in quantitative studies cannot offer. It offers possibilities to detect new variables that are overlooked or neglected in standardized instruments (Hagedoorn et al., 2008).

A deeper understanding of the next-of-kin's life experience and of the experiences of participating in a psychoeducational support group could guide the design of future interventions that are aimed to support the next-of-kin to CRC patients. The above-mentioned benefits as well as the gap in research of next-of-kin of persons treated for CRC participating in psycho-educational interventions, motivate this type of study.

The aim of this study was twofold: first, to describe the experience of being the next-of-kin of a person suffering from colorectal cancer, and second, to describe how a psychoeducational program might contribute to the next-of-kin's life experience.

## Method

### Design

A qualitative design with interviews was chosen for this study in order to capture the subjective experience and to better understand the perspective of the next-of-kin to a person suffering from CRC who had participated in a psychoeducational program (PEP).

### Participants

The definition of “next-of-kin” in this study is a person chosen and defined by the patient as a “significant other”. The 18

participants in this study were recruited from a group of 31 next-of-kins who participated in a PEP. The sampling was based on a maximum of variety in gender, age, and relationship to the patient. All men, siblings, and children participating in the PEP were invited to participate in the study. The remaining invitees were female partners ( $n = 11$ ). While all participants agreed to be interviewed, one was unavailable due to illness. Therefore a total of 13 women and 5 men were distributed as follows: partners ( $n = 14$ ), siblings ( $n = 2$ ) and children ( $n = 2$ ). Their ages ranged between 38 and 82 years (mean 58). Ten were employed; eight were retired.

### The psychoeducational program

The PEP was offered to persons recently treated for CRC (referred to as “patients”) and to the next-of-kin of patients recently treated for CRC. The overall aim of the research project was to determine if a PEP had an effect on mood, anxiety, depression, and quality of life of patients and the next-of-kin (as defined in the above under the paragraph “Participants”). An interview study was chosen in order to capture a thorough picture of the next-of-kin's life experiences, including their participation in the PEP.

The setting for the program was the outpatient ward at the surgical clinic. The program consisted of seven meetings; each meeting featured a 60-min lecture, followed by a 60-min discussion and reflection on the Topic of the Day (Table 1). The meetings were scheduled in the evening and were held once a week over a seven-week period. Two registered nurses introduced the speakers and were present for the entire program.

The patients and next-of-kin attended the lectures together, but moved to separate rooms for the subsequent discussion. A maximum of eight persons were assigned to each group. A registered nurse was in each room to guide and facilitate the discussion.

The PEP was not a part of the ordinary activities of the surgical clinic. It was held twice a year during the research period. The time between a patient's discharge from the hospital and the beginning of the PEP varied between six weeks and six months. The program was repeated on five occasions between 2008 and 2010. A total of 40 patients and 31 next-of-kin participated during this period.

### Data collection

Qualitative face-to-face interviews focussing on the experience of being a next of kin to a person treated for CRC and of participating in the PEP were conducted two weeks after conclusion of the program. One of the authors (EON) who has experienced CRC care as a registered nurse, but who was not present during the PEP, interviewed the participants. A conversational strategy was used for the interviews (Patton, 2002). The researcher gently guided the conversation based on an interview guide covering the areas of interest. The opening question “Can you please tell me what it has been like since you learned that “X” was diagnosed with CRC?” was followed by “Can you please tell me about your experience in the PEP?”. The questions were open-ended to encourage the participants to express themselves freely in their own words (Patton, 2002). Probing questions, such as “What do you mean?”; “How would you describe that?”, or “How did you feel?” were posed. The respondents were encouraged to speak freely about the positive and negative aspects of participating in the PEP, and how it affected their life. The interviews lasted between 22 and 55 min (median 33 min). The participants selected the location of the interview: their home ( $n = 7$ ), research centre ( $n = 4$ ), surgical outpatient clinic ( $n = 4$ ), or their place of work ( $n = 3$ ).

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