



Next of kin of cancer patients – Challenges in the situation and experiences from a next of kin course



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A B S T R A C T

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Purpose: To gain more knowledge about the challenges facing the next of kin of cancer patients and how a cognitive-based course for these next of kin helps them handling the challenges they are facing.

Methods: Focus groups were used to explore the experiences, thoughts, and perceptions of the next of kin about specific challenges and their participation in the course. A thematic content analytical approach was used.

Results: Three focus groups were convened with each group consisting of 4–7 adults. A total of 9 women and 7 men, aged 32 to 78 years, were included in the sample. The following two main themes emerged in the results: *Fighting three battles* and *From distance to acceptance*. This study shows that the difficult situations next of kin experience require the next of kin to gain a new understanding of challenges, which involves a comprehensive learning process.

Conclusion: The results suggest that a cognitively oriented course for the next of kin fill a need for help for them to learn and cope, but further research in this area is recommended.

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Introduction

Cancer affects not only the patient with the disease but also the patient's entire family. Next of kin become involved in dealing with various aspects of the disease, often over a long period of time. They experience new challenges and often act as informal caregivers. The role of the next of kin is both multifaceted and challenging (Blindheim et al., 2013). Through various stages of the disease, the next of kin live with the threat of losing their loved ones. They experience protracted stress, which takes a toll on their own health, having to cope with everyday life while maintaining a sense of coherence (Antonovsky, 1987; Jensen and Johnsen, 2000). Coping is the cognitive and behavioural effort to master own feelings and to accept or minimise external or internal demands (Lazarus and Folkman, 1984). Lazarus (1999) explains that problem-focused coping strategies are those that channel efforts and actions in order to deal with distressing behavioural situations, while emotion-focused coping is a process of cognitively reframing difficult thoughts, with the goal of positive reassessment. Reassessment has a profound connection with embedded values, which become

visible when one considers the limits and conditions for coping (Lazarus, 1999).

Next of kin may dissociate themselves from their own feelings and suffer in silence. They may experience loneliness and stress, along with loss of a sense of safety in daily life. They cannot make plans as they had done before the diagnosis, and therefore their access to an ordinary life is limited. When the health conditions of their loved ones worsen, the next of kin's burden and emotional stress may further increase (Ekholm et al., 2013; Eriksson and Svedlund, 2006; Esbensen et al., 2008; Persson and Sundin, 2008; Sjövall et al., 2011; Sterckx et al., 2013). They may fear that their loved ones not will recover, but what they fear is beyond their control (Gunnarsson and Öhlén, 2006). Next of kin may have higher levels of anxiety, depression, and distress than the patients (Schmid-Büchi et al., 2010).

Johansson et al. (2002) have investigated how relatives or close friends cope when having an adult next of kin or close friend admitted to critical care. They identified coping strategies of alleviating, recycling, mastering or excluding feelings. The next of kin or close friends tried to make the experience easier, and the strategy used differed due to their own inner ability and in accordance with their inner and external resources. There is often the need for next of kin to learn how to cope and adapt oneself to the situation and to traumatic experiences; however, these needs are largely

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unmet (Harding et al., 2011). Next of kin of patients with cancer should be provided with knowledge, support, and guidance in order to help them understand and cope with the situation and reduce the amount of strain (Blindheim et al., 2013). In this long-lasting situation, next of kin need information about treatments, prognosis-related matters, the impact of disease on families, coping mechanisms, and self-care (Adams et al., 2009; Ohlsson-Nevo et al., 2011). Research has found that the next of kin have more unmet needs regarding information about supportive care for the patient than they do regarding medical information (Adams et al., 2009). On the other hand, it is not always easy for next of kin to get emotional support from health care professionals, communication is centred on the patient, the patient's needs, and the treatment plan (Brataas et al., 2010).

There is a lack of formal structure in the care for the next of kin and a need for support from professionals in this regard (Luttik et al., 2007). Development of evidence-based support programs for next of kin of cancer patients is recommended (Harding et al., 2011; Schmid-Büchi et al., 2010; Sterckx et al., 2013). The next of kin may also benefit from sharing experiences with others who are in similar situations. Next of kin's participation in courses, or support groups with other next of kin, may affect their sense of control and emotional coping (Franzén-Dahlin et al., 2008; Harding et al., 2011; Hudson et al., 2008; Madsen and Poulsen, 2011; Stang and Mittelmark, 2009). Sharing emotions and experiences with others in similar situations may lead to helpful knowledge about the universality of reactions and also about how others have improved their coping and mastery over situations (Beverly and Worsley, 2007). Mindfulness-based stress reduction and cognitive theory, as a theoretical foundation, have been used in studies describing cancer patients' experiences with courses and support groups (Cohen and Kuten, 2006; Hoffman et al., 2012; Kieviet-Stijnen et al., 2008; Kvillemo and Bränström, 2011). These studies conclude that mindfulness training can potentially help cancer patients handle the stress of their life-threatening disease and increase their well-being. It is possible that the next of kin might also benefit from such a course.

Therefore, a course for adult next of kin was developed and tried out in a project of the Norwegian Cancer Society (www.kreftforeningen.no). The Norwegian Patient Rights Act (1999), define next of kin to be those that the patients states as kin. The course "Livslyst – når det røyner på" (LNRP) (Promoting joy of life in situations of adversity) (www.kreftforeningen.no) was based on cognitive theory (Beck, 1995) and mindfulness-based stress reduction methodology (Kabat-Zinn, 2003). Within the time-frame of the intervention, the program comprised six three-hour evening classes. Other research has suggested that seven two-hour classes of a psycho-educational program are helpful towards meeting the needs of the next of kin of cancer patients (Ohlsson-Nevo et al., 2013). The target group were adult kin, regardless of age, gender and social status, and kin relation as a parent, child or spouse. They were noted as next of kin in the medical Records. Three courses were held, each with 4–7 participants.

Teaching materials were developed and cancer nurses were educated as course facilitators but they had nothing with the design or the evaluation of the intervention. The course had an initial goal of creating trust and transparency in the course group, and to explore and discuss main challenges and possible similar educational needs of the course participants. The next of kin learnt to use some mental coping strategies and stress reduction techniques. Main topics were stress, mastering, mindfulness, health and how to take care of oneself and the family. The course participants were training on techniques between the course meetings, and had counselling conversations about the training with the course facilitators.

The purpose of the research project was to gain knowledge about the next of kin's experiences of challenges, and their perceptions about course experiences as a help in the kin situation.

Research questions:

How do the next of kin of cancer patients experience and interpret the challenges of being the next of kin during a long lasting cancer situation?

What are their course experiences and potential sense of benefit of the course on handling of challenges in the cancer situation?

Methods

Design

Aiming to shed light on a complex and little explored issue, a qualitative descriptive study was conducted. Focus groups were used to explore the informants' experiences, thoughts, and perceptions regarding the next of kin situation and course participation. Focus groups are considered to be appropriate for the evaluation of programs, and to increase knowledge on a social-psychological level (Kitzinger, 1995; Krueger, 1994; Orvik et al., 2013; Patton, 1990). Focus group interviews were conducted after course completion, and data were collected from March to December 2010.

A thematic interview guide was used. The informants were asked to describe the next of kin situation, everyday life, and course experiences. They were asked to describe their own situations and to discuss each other's experiences, this to gain knowledge and insight about the meaning of different experiences. The moderator introduced the theme, listened to the members, interpreted the responses and key information, and followed up to deepen the discussion within the group. A highly experienced moderator (the first author) led the group interviews, and a co-moderator took notes during the discussions, provided summaries, and ensured that all topics were covered. Audio and video recordings of the focus group interviews were made. The video recordings were used to ensure the quality of transcription.

Sample

A sample of typical cases with respect to being the next of kin of a patient who has had cancer for more than half a year, and to participate in more than half of the LNRP course, was used. Studying typical cases is a way to identify the common issues that individuals usually experience (Morgan, 1997). Adult next of kin who are spouse, parent or child of the patient, and reported as next of kin in the medical Records, were included. Children who are next of kin were excluded because of their special needs (Ensby et al., 2008). From 2010, Norwegian hospitals were imposed by act to meet their needs (Health Personnel Act, 1999). Choosing adult participants with various next of kin experiences increases the possibility to shed light on the research question (Patton, 1990). The sample was not homogenous with respect to cancer diagnosis of the patients.

The sample comprised three focus groups. Each group consisted of four to seven adults. A total of 9 women and 7 men, ages 32–78 years, were included in the sample (see Table 1). There is no information about persons who are not interested in participation. The Ethical committee of medical and health research in Norway, have not given no permission to have any information about persons who were not interested in participation.

Sampling

A lead nurse in the oncology department at a hospital in Central Norway was given information about the sampling procedures.

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