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Postoperative health and patients' experiences of efficiency and quality of care after cytoreductive surgery and hyperthermic intraperitoneal chemotherapy, two to six months after surgery

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A B S T R A C T

Purpose: To study post-discharge health after Cytoreductive Surgery (CRS) and Hyperthermic Intraperitoneal Chemotherapy (HIPEC), and to analyse patients' experiences of in-hospital efficiency and quality of care.
Methods: In-depth individual telephone interviews using an interview guide with open-ended questions were performed with 19 patients with peritoneal carcinomatosis between April and October, 2012. Data were analysed with systematic text condensation.
Results: Four themes were identified: 1) Coming home was an essential step in the recovery process and the focus was on getting well physically despite mental stress, uncertainty about the medical rehabilitation plan and the future. 2) Health was affected negatively by postoperative chemotherapy and its side effects. 3) Stoma - a necessary evil affecting the patient's social life. 4) Quality of care and efficiency were defined in patient-centred terms and inter-personal care from the patient's perspectives on micro level. Despite all, 32% of the patients described being fully recovered and had started to study or work two months after surgery.
Conclusions: The study gives insights into some real-life experiences described by patients. The study results can be used to prepare written information, to design a postoperative rehabilitation plan for future patients with Peritoneal Carcinomatosis (PC) and to create a home-page through which patients can receive support from both health care professionals and other fellow patients.

Introduction

Peritoneal carcinomatosis (PC) from different origins is associated with a poor prognosis (van Leeuwen et al., 2008). Treatment with cytoreductive surgery (CRS) and hyperthermic intraperitoneal chemotherapy (HIPEC) is aggressive but improves the prognosis in selected patients with PC (van Leeuwen et al., 2008; Deraco et al., 2004). It requires serious peri-operative preparation of the patients since surgery time is long (mean 10 h, range three to16 h) and the postoperative hospital stay is three weeks (Arakelian et al., 2011a,b).

There are few studies that present patients' own descriptions of their postoperative health experiences and patients' perceptions of the efficiency and quality of care after CRS and HIPEC.

Peritoneal carcinomatosis and postoperative recovery and health

PC may originate from the appendix, small bowels, colon, ovaries, peritoneum and ventricle. Between five to 50% of all cancers with gastrointestinal origins result in PC (Chu et al., 1989; Jayne et al., 2002; Ozolas, 2004) and PC can affect people from different age groups (mean age 50 years) (Hansson, 2009; Mauricio et al., 2010).

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Receiving a cancer diagnosis is a severe shock to any patient (Papadopoulou et al., 2013). The surgical procedure and the recovery process after CRS and HIPEC are felt to be arduous and difficult (Eriksson et al., 2013). In the early period of postoperative recovery after CRS and HIPEC, which extends from discontinuation of anaesthesia after surgery until the patient is ready for discharge (Allvin, 2009; Korttila, 1995; Wolfer, 1973), patients re-established their physical functions and activity within the first postoperative week before discharge (day 1–7 after surgery) (Arakelian et al., 2011a,b). Despite the fact that patients experienced nausea during their hospital stay, oral feeding, bowel function and bowel movement was regained within 7–10 days postoperatively. Sixty-seven per cent of the patients had difficulties sleeping and almost 18% needed psychological support during their hospital stay after CRS and HIPEC (Eriksson et al., 2013).

According to the World Health Organization (WHO, 2013) health is defined as "a state of complete physical, mental and social well-being, and not merely the absence of disease" (WHO, 2013). Kim (2000) describes health as "to reach a state of balance where the goal is stability, it is achieved through processes such as adoption and a subjective interpretation of the meaning of life". However, the sense of being in good health is a subjective feeling that should be studied individually. In one study, patients with PC described themselves being in good mental health before discharge from the hospital despite feeling they were on an emotional roller coaster, having crying attacks one minute and laughing the next (Eriksson et al., 2013). Many talked about getting to know their body functions from the beginning again while they had to deal with nausea, pain, bowel functions, and, to a certain point, altered eating/drinking or sleeping habits. Although all the patients were grateful for having the surgery done, they worried about their uncertain future and death. The surgeon and the staff members were indicated as important support sources in the patient's recovery process (Eriksson et al., 2013).

Physical, emotional and social functioning are central domains of health related quality of life (HRQoL) and are often influenced by disease symptoms and treatment side effects (Høyer et al., 2011). Patients with endocrine tumours of the gastrointestinal tract perceived physical HRQoL aspects as most important for a good quality of life. Patients who reported high levels of anxiety or depression were less satisfied with HRQoL and had more problems with their health (Larsson et al., 1999). Studies reveal that quality of life is still impaired three months after surgery but improves six to 12 months after CRS and HIPEC (Passot et al., 2014; Piso et al., 2009; Tsilimparis et al., 2013). However, there is a knowledge gap about the late post-discharge period of the recovery process (Allvin, 2009; Korttila, 1995; Wolfer, 1973), i.e. the time period following discharge after CRS and HIPEC.

Efficiency and quality of care

To increase in-hospital efficiency and ultimately improve quality of care for PC patients, a multi-professional surgical team was assembled in the operating room. This meant that the same staff members worked with the PC patients and increased collaboration was established between the surgical ward, the operating department and the outpatient clinic at the hospital. The surgical team that worked with PC patients understood efficiency in terms of "doing one's best", "increased quality of care" and "achieving long term benefits for the patients" (Arakelian et al., 2011a).

The concept of efficiency has been defined in several ways in different domains such as in economics and in health care. Sometimes it is set as a synonym to productivity i.e. maximum production with minimal resources (Encyclopedia, 2014; Hussey, 1997; Kielhorn and Graf von der Schulenburg, 2000). Others mean that efficiency is a product of both productivity and of quality (Landor, 1990). Quality of care was analysed by Donabedian in a triad of elements, namely structure, process and outcome of care, in a conceptual framework for evaluation (Donabedian, 1988). Structure referred to facilities and equipment as well as the qualifications and experience of healthcare professionals and the services available to the patients. Process meant how care was provided, under what circumstances and how patients were moved into, through and out of the system. Outcome represented the results of care and included biological, functional, emotional and social dimensions. The care process was based on clinical and inter-personal aspects of care according to Campbell et al. (2000), the latter including communication, trust, understanding and having empathy for the patient. These relate to emphasize the importance of the fundaments of care, i.e. the quality of care being composed by the staffs' ability to be engage and connect with the patient (transactional quality) and the ability to be able to actually perform the fundaments of care (Kitson et al., 2010; Kitson and Muntlin Athlin, 2013).

The concept of Person-Centred Care (PCC), implies a person can only be understood if one also includes their life story, memories and expectations (Ekman et al., 2011). It is important to actively involve patients as partners in decision-making during the hospital stay and outside the hospital (Olsson et al., 2013) and questions of efficiency and quality of care in order to get patient adherence, share decision-making and in order to keep the patient autonomy (Sandman et al., 2012). Inter-personal aspects such as quality of care from patients' perspectives indicated that patients were dissatisfied with how examination results were reported back to them; with the information they received regarding treatment and self-care; with the lack of opportunity to be involved in their own care, and with the lack of empathy and respect shown towards them. (Fröjd et al., 2011; Muntlin et al., 2008). Quality of care and efficiency is defined by the patient's on micro level which refers to the primary process in which health care provision and consumption takes place (WHO). That is, what was important form them here and now on the ward, such as the communication and information between doctor and patient and nurse and patient.

Quality of care and efficiency are not evaluated from the patient's point of view, despite efforts that have been made to increase both the quality of care and efficiency for patients with PC. It is therefore important to study whether the patients have the same understanding and perceptions as their caregivers in order to increase the fundaments of the patients' care and their involvement in their own care.

Aim

The aim was to study post-discharge, postoperative health described by patients after CRS and HIPEC. The second aim was to study the patients' understanding of in-hospital efficiency and quality of care.

Methods

Design

The study had a descriptive design with qualitative methodology.

Context

The study was performed in a 1100-bed university hospital in Sweden. Each week there were two patients scheduled for surgery with CRS and HIPEC. Waiting time for surgery was from four to eight months and during this time no visits were scheduled with the surgeon at the university hospital. Patients were discharged 22