Images of suffering depicted in diaries of family caregivers in the acute stage of necrotising soft tissue infection: A content analysis

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Abstract

Objectives: Severe necrotising soft tissue infections (NSTI) are rare life threatening rapidly progressing bacterial infections requiring immediate diagnosis and treatment. The aim of the study was to explore the experience of family caregivers of patients with necrotising soft tissue infection during the acute stage of disease.

Methods: Our study had a qualitative descriptive binational design using qualitative content analysis to explore diaries written by close family members (n = 15). Participants were recruited from university hospitals in Denmark and Sweden.

Findings: Three main categories emerged: Trajectory, Treatment, and Patient & Family. The first helped us construct an overview of the NSTI trajectory showing issues of importance to patient and family caregivers. The following categories were analysed further to describe four themes central to the family caregiver experience: craving information, needing to be near, suffering separation and network taking over.

Conclusions: Necrotising soft tissue infections are uncommon causing shock and concern. Centralised treatment might involve physical separation of patient and family during the acute stage of illness. Family accommodations near the patient and accessibility to adequate communication devices at the bedside are recommended. Health professionals need to keep in mind the importance of information and reassurance on the wellbeing of the family and ultimately of the patient.

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Implications for practice

- Necrotising soft tissue infection (NSTI) is uncommon, unfamiliar, unexpected, and rapid in progresssion.
- Family caregivers experience shock and ignorance during the acute stage of NSTI.
- Family caregivers crave information, wish to be near the patient, suffer separation from the patient and need a social network to take over home responsibilities.
- Health professionals should keep in mind the importance of information and reassurance on the wellbeing of the family during the acute stage of NSTI.

Introduction

Severe necrotising soft tissue infection (NSTI), also known as necrotising fasciitis or flesh-eating bacteria, is a life threatening and rapidly spreading bacterial infection (de Prost et al., 2015; Hansen et al., 2016). The incidence in the Unites States (US) is
about 410,000 person-years with an estimated mortality of 24% (Hua et al., 2015). NSTI progresses in the matter of hours, demanding immediate diagnosis and treatment (Hakkarainen et al., 2014b; Johansson et al., 2010; Ustin and Malangoni, 2011). Diagnosis is challenged by co-morbidities, and independent risk factors such as age, severe peripheral vascular disease, hospital acquired infection and severe sepsis (Hua et al., 2015). Treatment includes antibiotics, debridement surgery, intensive care and hyperbaric oxygen (HBO) therapy. Delay of surgery is an independent risk factor for mortality (Bulger et al., 2015).

The sudden and dramatic manifestations of NSTI can be a harrowing experience affecting quality of life (Hansen et al., 2016). Treatment and prolonged periods in the intensive care unit (ICU) take their toll on patient and family and only few studies have addressed the human cost, particularly for family caregivers. While quality of life is significantly affected, many outcomes of importance to the patient are not easily assessed by traditional methods (Hakkarainen et al., 2014a; Pikturnaitė and Soldin, 2014). Studies are showing that the health related quality of life of the patient and family caregivers are interrelated (Young et al., 2016). More studies are needed that describe how acute illness and hospitalisation affect patient and family. Family-centered critical care has become an integrated part of intensive care and follow-up, where close family members often assume the role of family caregivers or carers (Henneman and Cardin, 2002; Pikturnaitė and Soldin, 2014).

To increase our knowledge of the challenges facing the family and ultimately the patient, we aimed to explore the experience of family caregivers of patients with necrotising soft tissue infections during the acute stage of disease.

Methods

Design

The study had a qualitative explorative binational design analysing diaries written by family caregivers during the acute stage of NSTI. Family was defined in its broadest terms as spouse, common-law partner, blood-relation, neighbor or friend. The carer is usually the person closest to the patient or living with the patient who assumes the role of caring for the patient.

Research questions

We initially asked how family caregivers described 1) early signs and symptoms of infection, 2) encounters with healthcare providers, and 3) the impact on their emotional and social life.

Setting and participants

The study was embedded in a planned series of investigations (P-INFECT), exploring the patient and family perspectives of NSTI (ClinicalTrials.gov NCT02169128). P-INFECT was embedded in the larger INFECT study: Improving Outcome of Necrotising Fasciitis: Elicitation of Complex Host and Pathogen Signatures that Dictate Severity of Tissue Infection (ClinicalTrials.gov NCT01790698).

Patient and public involvement (PPI) helped the construction of our study with continuing collaboration of NSTI survivor Kim Andersson and his family. Andersson experienced a severe course of NSTI in 2009 with bilateral lower limb amputation, right arm paralysis and limitations to left arm and upper torso. Andersson guided the planning of the study and offered us two books he had authored describing his illness trajectory and life after stabilization (Andersson, 2016; Andersson and Sandbacka, 2013).

The main participants of this study were close family of NSTI patients. Patients were recruited in 2015 from the three university hospitals in Denmark (Copenhagen) and Sweden (Gothenburg, and Stockholm), where treatment of NSTI is centralised at the national level and where HBO treatment is available. Participants were selected consecutively from the INFECT-study if a family member volunteered to keep a diary during the first couple of weeks of the patient’s illness.

Ethical approval

The study was approved by the Danish Data Protection Agency and the National Committee on Health Research Ethics in Denmark (No. 48205) and the Regional Ethics Review Board in Gothenburg, Sweden (No. 930–12). Information and consent for P-INFECT and INFECT were obtained simultaneously to reduce the strain on family members acting as proxy for the patient. Consenting family caregivers were informed that participation was voluntary and that all data would be handled confidentially.

Data collection

Diaries providing a narrative account of events in intensive care units (ICU’s) have been kept by nurses since the early 1990s to help patient and family come to terms with critical illness and its aftermath (Egerod et al., 2007; Egerod and Christensen, 2009; Ullman et al., 2015). Studies have demonstrated the importance of ICU diaries to help the patients construct their illness narrative and to support close family in their suffering and upholding their healing process (Egerod et al., 2011). Based on this experience we wished to include 10–15 diaries written by close family to explore their experiences, emotions and events during the acute stage of the patient’s illness. We expected this sample size would ensure informational redundancy without compromising deep case analysis (Sandelowski, 1995). The participating family member was provided with a template for the diary with simple instructions and the option to return a hand-written or computerised version of the diary. All diaries were analysed using computer software NVivo version 11 (QRS International, Melbourne, Australia). The main data were generated from diaries and supplemental demographic data were generated from the hospital chart.

Data analysis

Content analysis was chosen for this study as we assumed our data derived from diaries would be insufficiently rich for a deeper form of interpretation. On a continuum of complexity describing the degree of transformation of data from findings to results, content analysis is closer to the descriptive than the interpretive end of the spectrum (Vainsoradi et al., 2013; Sandelowski and Barroso, 2003). The steps of analysis were: 1) Reading all diaries to get a grasp of data and plan an initial coding scheme, 2) identifying meaning units (quotes from the text) and inductively coding all diaries, 3) identifying tentative categories and transforming latent content into themes (Graneheim and Lundman, 2004; Elo and Kyngäs, 2008). Investigator triangulation during analysis enabled discussion and consensus on the best interpretation of the text (Carter et al., 2014). Investigators from Denmark and Sweden held face-to-face and video conferences, and potential language issues were overcome by coding and writing in English.

Findings

We included 10 diaries from Copenhagen, three from Gothenburg and two from Stockholm (n = 15). Ten diaries were written by wives or partners, the remaining by a husband, sister, daughter, son and close friend. Three were hand-written and 12 were computerised.
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