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Prerequisites required for the provision and use of web-based communication for psychosocial support in haematologic care

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A B S T R A C T

Purpose: The purpose of this study was to describe the prerequisites required for the provision and use of web-based communication for psychosocial support within a haematology clinic, from a patient and family perspective.

Method: A qualitative design using content analysis was used. A strategically selected sample of patients ($n = 11$) and family members ($n = 6$) were offered access to a web-based communication capability with a nurse. After four months, individual interviews were conducted with all participants, in order to identify necessary prerequisites.

Results: Preferences and characteristics of the individual patient or family member are crucial as to whether web-based communication for support is perceived as useful. To feel comfortable with writing and to self-identify the need for support are fundamental in getting motivated to use web-based communication. An effective organization around psychosocial support in general is another prerequisite. Goals and responsibilities must be clearly defined for patients and family members to understand their rights and enable the transformation of opportunities into practice. The use of web-based communication must also be a convenient and naturally incorporated part of both individual and organizational use of the web in general.

Conclusions: Prerequisites of taking into account caretakers' different preferences and needs, providing highly structured psychosocial support activities and providing a congruent range of web services, are necessary for successful provision and use of web-based communication for psychosocial support.

Introduction

Blood diseases include many diagnoses, whereof leukemia and lymphoma are the most common diagnostic groups (Schmaier and Lazarus, 2011). More than 3000 individuals in Sweden are diagnosed every year with some type of blood cancer. Some diagnoses occur in people of all ages, while others mainly affect older people, but in general the incidence rate is stable. The prognosis varies between diagnoses, but as the medical treatments develop, more people are cured today (The National Board of Health and Welfare, 2011). Patients are normally affected emotionally and existentially by the diagnosis and the apparent awareness of one's own mortality (Källerwald, 2007). Treatment usually consists of chemotherapy and radiotherapy and in more difficult cases stem cell transplantation (Schmaier and Lazarus, 2011). Stem cell transplantation in particular is considered very physically and psychologically demanding (Stephens, 2004). The need for information and emotional support among patients is therefore indisputable, but not always experienced as sufficient (Sanson-Fisher et al., 2000; Soothill et al., 2001). In line with the increased survival rates and more outpatient care being implemented there is a shift in the management of cancer patients from healthcare professionals to family members. The burden in terms of emotional strain experienced by family members has been identified (Cooke et al., 2011) and the need for information and supportive care, seems to be considerable among family members (Adams et al., 2009; McCarthy, 2011).

To meet patients' and family members' need for support the healthcare system provides different forms of organized supportive care, usually referred to as psychosocial support. Its definition normally includes counselling, information, education and support groups (Adler and Page, 2008). In a Swedish context psychosocial support also includes dieticians and physiotherapists (Swedish Medical Information Center, 2012). Other opportunities for support, albeit less planned, can be given in encounters between

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patients, family members and healthcare professionals. These encounters can provide an opportunity to talk about sensitive topics, such as emotional distress or existential issues. Such dialogues can accommodate a caring or nurturing potential, since they give an opportunity to share one's story, be heard, validated and guided further (Fredriksson and Eriksson, 2001). However, if the meetings are going to be truly caring, a number of conditions have to be fulfilled, primarily on a relational level, but also in terms of surrounding conditions, such as time and space (Radwin, 2000). It is difficult to know the extent to which support should be offered, as high levels of distress do not always imply a desire for support (Merckaert et al., 2010). Nevertheless, studies and national guidelines claim that psychosocial support is occasionally insufficient (Sanson-Fisher et al., 2000; Osse et al., 2006; The Ministry of Health and Social Affairs, 2009).

A few studies (Gustafson et al., 2001; Winzelberg et al., 2003; Owen et al., 2005) have focused on health outcomes from psychosocial support through the use of the Internet. Positive findings regarding social support, informational competence, depression and self-perceived health status have been described. However as the studied support interventions included both discussion forums, chat features and ask-the-nurse-functions, it is hard to say what each one of the functions meant. Research on patients' and family members' use *solely* of online communication with nurses is more limited. Moore and Sherwin (2004) and Cornwall et al. (2008) cautiously highlight the practical advantages of nurse-patient email communication, such as independence of time and more free space for patients to express themselves. A study by Grimsbø et al. (2011) indicates that a web-based communication service can give patients space for unmet information needs and also work as a "place to vent". Information and support seeking through the Internet is an increasingly common coping strategy among disease sufferers (Eysenbach, 2003). Josefsson (2007) stresses that there is a desire that web-based communication should not only be provided by voluntary organizations, but more preferably by the regular healthcare system, as confidence in it is greater. Use of web-based communication between caretakers and healthcare personnel has long been a Swedish vision (The Ministry of Health and Social Affairs, 2006), but implementation has been slow. Little is known about conditions necessary to provide and use web-based communication offering psychosocial support between patients with haematological diseases, family members and nurses within a Swedish healthcare setting. To our knowledge there is no previous study focussing on this. The purpose of this study was therefore to describe the prerequisites required for the provision and use of web-based communication for psychosocial support, from a patient and family perspective.

Methods

Design and setting

In this inductive and explorative study a qualitative design using content analysis, was employed in order to gain a broad picture of the phenomenon in focus (Graneheim and Lundman, 2004). The study was conducted at an adult haematology clinic (i.e., ward and outpatient clinic) in a University Hospital in the western part of Sweden. The geographic catchment area was wide (>1.6 million inhabitants) as the hospital is one of five performing stem cell transplantation in Sweden. The psychosocial support at the present clinic consisted of the possibility for patients and relatives to have access to a counsellor, a chaplain, a dietician and a physiotherapist whenever they wished. Informal support could also be provided in connection to visits to a physician or medical treatments (i.e., meetings that carried a potential of being supportive).

To increase the ability of the participants in the current study to express experiences and comments, they were offered access to a web-based communication channel with a nurse. We took advantage of an existing system for communication between caretakers (i.e., patients and family members) and healthcare personnel, called "My care contacts". The basic function of the system was to change bookings and renew prescriptions. A multi-professional discussion was carried out to integrate a new functionality in an adequate and sustainable manner. In the present study a new function called "Psychosocial support" was then added with the aim of serving as a channel for support. Support was defined as to include information, advice and guidance for conditions where individuals perceive themselves to be in need of some sort of help. It was pointed out to the users that questions of an emotional nature were particularly welcome, but that there was no obligation to accept the offer of communication. Patients and family members needed to log in (i.e., by the use of an e-card or special login and password), select the correct case type (i.e., psychosocial support), write down their issue and then submit. They were informed that they would receive a reply from a nurse via the same system within three days. To avoid the need to monitor if a response had arrived, the user could choose to receive a reminder via a phoned text message or an email. As a family member you accessed the system through the enrolled patients' ID number, which implied that the patient authorized this use.

Participants

Inclusion criteria were being diagnosed with a haematological disease or being a family member, over 15 years of age and being able to master the Swedish language. A nurse at the haematology clinic asked consecutively patients ($n = 11$) and family members ($n = 6$) to participate in the study. The sample was strategically selected (Patton, 1990) in order to achieve variation in characteristics such as age, gender and diagnosis. Demographic and clinical data of the sample are described in Table 1.

Data collection

Data were collected during individual qualitative research interviews (Kvale, 1996) with the enrolled participants four months after recruitment. Fourteen interviews took place in a quiet location at the clinic and three were conducted in the participants' homes. The interviews lasted for ½–1 ½ h and were audio recorded and transcribed verbatim by the first author (KH). The interviews started openly by asking the participants to talk about their experiences of having access to the web-based communication function, related to their illness, or their family member's illness. The interviews made sure to include the question of what prevented or allowed the use of web-based communication for support. The

Table 1
Participants ($n = 17$) included in the study.

	Patients $n = 11$ (P1–P11)	Family members $n = 6$ (Fm1–Fm6)
Gender (m/f)	6/5	2/4
Age (range/m/sd)	22–68/44.7/11.8	38–57/44.5/3.9
Relational status	Husband/wife, 5/3	Husband/wife, 2/2
	Single 2	Friend 1
	Daughter 1	Parent 1
Diagnosis	Lymphoma/Hodgkin's Lymphoma 3/3	Lymphoma/Hodgkin's Lymphoma 2/2
	Myeloma 2	
	Leukemia 3	Leukemia 2