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Barriers and facilitators to effective communication experienced by patients with malignant lymphoma at all stages after diagnosis

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ABSTRACT

Objective: This study aims to gain insight into patient-perceived communication barriers and facilitators at different stages after the diagnosis of malignant lymphoma. We have detected patterns to explain when these factors influence communication predominantly.

Method: A qualitative approach was applied, derived from the context mapping framework. A total of 28 patients completed a set of assignments about their experiences with provider-patient communication during medical consultations. Subsequently, these patients and nine companions shared their experiences during a semistructured (group) interview, which was recorded on audiotape. The audiotapes and assignments were analysed with MAXQDA software.

Results: From the patients' viewpoint, communicating effectively appears to depend on their own attributes (e.g. emotions), the health care professionals' attributes (e.g. attitude) and external factors (e.g. time pressure). Three patient communication states were identified: (i) overwhelmed, passive; (ii) pro-active, self-motivated; and (iii) proficient, empowered. Patients seem to behave differently in the three communication states.

Conclusions: This study lists patient-perceived communication barriers and facilitators and identifies three different communication states, which indicate when certain barriers and facilitators are encountered.

Practical implications: These findings may support health care professionals to tailor the provision of support and information and remove communication

barriers accordingly. Additionally, they provide input for interventions to support patients in effective communication. Copyright © 2013 John Wiley & Sons, Ltd.

INTRODUCTION

Effective patient-provider communication is essential for optimal cancer care [1] and helps patients to cope with the disease in everyday life. In effective communication, both parties are actively involved in achieving satisfaction as well as better health and psychosocial outcomes [2-5]. The PACE curriculum, designed to teach patients how to communicate effectively and integrated in patient communication interventions [6-9], lists four components necessary for effective patient communication: (i) Presenting detailed information; (ii) Asking questions; (iii) Checking and understanding; and (iv) Expressing concerns. Bylund et al. suggest adding (v) State preferences to this list [10]. These components require a maximum effort of patients.

The often suboptimal quality of communication in cancer care [11] improves when health care professionals (HCPs) tailor information to individual patient needs [12-14]. To provide tailored information, HCPs need to attend to patients' changing needs and adapt the communication accordingly. Patients can contribute to this process by clearly expressing their needs and preferences [15]. Many patients prefer such an active role during consultations [16]. Even at a governmental level, the importance of a participatory role of the patient is underlined [17, 18]. However, the actual contribution of cancer patients in clinical practice is often limited [19-21], suggesting a discrepancy between the patients' preferred and actual role [16, 22] and patients continue to have unmet communication needs [11]. Apparently, patients are hindered by barriers to participate actively.

Recent research reveals the potential benefit of training patients to overcome communication barriers [4, 5, 23, 24]. However, to our knowledge, only a few studies address the nature of communication barriers from a patient's perspective [25-28]. Such knowledge would help to tailor training interventions to patients' needs. In accordance with the communication framework of Feldman-Stewart [29], communication barriers relate to attributes (emotions, skills, values, beliefs and needs) of both patient and HCP and external factors. A recent study of oesophageal cancer patients reveals that patients' perceived communication barriers mostly reflect dysfunctional beliefs (e.g. expecting negative consequences of raising a subject) and skills (remembering questions only afterwards) [25]. These findings also show that barriers might be specific for the type of cancer because of disease-specific issues that patients have to deal with (treatment complications, physiologic alteration and psychosocial problems).

Because of this disease-specificity, the current study focuses on patients with malignant lymphoma, currently the seventh most common cancer diagnosed in Europe [30] with two distinguished groups: Hodgkin's lymphoma (HL) and non-Hodgkin's lymphoma (NHL). Long treatment and control periods for Hodgkin's lymphoma and non-Hodgkin's lymphoma (NHL) patients might result in additional, disease-specific barriers and facilitators. After treatment, the majority of lymphoma patients face a very long period of intense monitoring under specialist care because of the chance of recurrence, the high incidence of second primary cancers, complications of treatment [31] and because many NHL patients never achieve a

complete remission. Also, some patients will not receive treatment immediately after diagnosis and are confronted with regular medical check-ups (wait-and-see policy). Given this long period of monitoring and the knowledge that patients' preferences change over time [21, 22, 32], it is likely that patients' communication preferences change accordingly.

As most studies focus on the diagnosis and treatment phase [33], we aim to identify communication barriers and facilitators at all stages after diagnosis. More specifically, we aim to gain insight into patients' ideas about what supports and hinders them to achieve effective communication, and to identify patterns within the perceived barriers and facilitators.

METHOD

A qualitative approach was chosen to learn from the experiential knowledge of the patients. We wanted to know how patients reach their goals in communication or why they do not. Following the Dutch Medical Research Involving Human Subjects Act, this study does not require ethics approval.

Participants

Patients (>18 years old) diagnosed with malignant lymphoma were included. Those who would usually bring a companion to the consultations were encouraged to invite this person to their interview. In general, many patients do bring a companion [34, 35], and they can play an important role in communication [34, 36-38].

Recruitment

In March 2011, the study was introduced at the annual congress and two regional meetings of the Dutch patient association for Lymphoma cancer (LVN) where patients could sign up. Additionally, a nurse in haematology introduced the study to her patients. Interested patients received a letter with information and a questionnaire about their diagnosis. If patients were unable to attend a focus group discussion, for example because of travel distance or health, they were interviewed at home.

Study design

We have followed a two-step approach derived from the context mapping framework [39].

Step 1: sensitizing

One week prior to the (group) interview, participants received a booklet (probe) with questions. The primary aim of these probes was to trigger patients to verbalize experiences, preferences and needs, and to reflect on it. This so-called sensitizing process is supposed to enhance the quality and quantity of the patients' contributions in later (group) interviews [40]. Secondary aim of the probes was to study the patients in their own context, without the presence of researchers or other patients. The leading questions of the probe were checked by a patient expert (HG). To encourage patients to think more freely, we included a set of words and graphics illustrating common feelings.

Step 2: (group) interviews

Participants were asked for permission to audiotape the interview. A semistructured set-up was used to avoid the influence of preconceived notions and to allow patients

to express themselves in their own terms [41]. The facilitator (IB or AA) asked leading questions about experiences, needs and preferences in relation to the time they emerged (before, during or after a consultation), the stage of the disease (diagnosis, treatment or follow-up) and the HCP involved (specialist, nurse or general practitioner). Questions subsequently focused on how the patient behaved in the consultation and how he/she would like to have acted. During the interviews, the facilitator explored topics in further detail while during the group discussions participants were particularly encouraged to react to each other's experiences and to indicate whether they shared experiences.

Data analysis

The data of this study consists of the verbatim transcriptions of all audiotapes and comments from the booklets. The coding, sorting, clustering and comparison of fragments was facilitated by MAXQDA software [42]. Fragments about factors that influence the communication were coded as well as perceptions, values, needs and wishes. 'Open coding' (initial codes given to fragments of text) was gradually replaced by 'axial coding' (describing codes and integration in broader related concepts) to find patterns. Due to the overlap with the communication framework of Feldman-Stewart [29], the coding scheme was organized according to the main domains of this framework.

After having double coded several transcripts and having compared reliability (IB/EW/AA), IB coded all transcripts and discussed new codes and unclear fragments with the other authors. To further improve the quality of the analyses, EW and AA double coded a transcript again at different points. This 'peer debriefing' [43] prevents one-sided interpretations of the data. We have coded four topics for each selected fragment: (i) the factor that influenced the communication; (ii) whether this factor was experienced as a facilitator, barrier or neutral; (iv) when the situation took place; and (iv) the HCP involved (Figure 1). Finally, IB and AA double coded a transcript to determine the interrater reliability. There was agreement on 95% of the text fragments to be coded. Within these text fragments, the coders agreed in 74% on the factor that influenced the communication, in 76% on whether this factor was experienced as a facilitator, barrier or neutral, in 91% on the time phase and in 88% on who was involved. Since the last interviews provided no new themes related to the research questions, data saturation appears to have been reached.

FIGURE 1

RESULTS

Respondent and interview characteristics

In total, 32 patients have been registered. All fulfilled the inclusion criteria. Four patients resigned before the start of the data collection because of a worsening physical condition. The 28 participating patients were on average 59 years old (Table 1). Nine patients brought a companion (all spouses). At the time of the interview, 10 patients were in active treatment, four were facing a wait-and-see policy and 14 were in remission. Prior to their current status, three patients had experienced one or more periods of wait-and-see and 23 had undergone one or more periods of treatment.

TABLE 1

Probes

The probes were completed by 21 patients before the interview, two patients completed the probes afterwards. Five patients did not return the assignments (three men/two women; 4 NH/1 H; mean age 62 (39–73)). Two of them indicated as a reason that they lacked the time, three of them had not received the booklet in time.

Focus group discussions and interviews

Three focus group discussions were conducted with four to nine participants and 10 interviews of which one included two patients. Group discussions and interviews lasted approximately 103 (85–128 min) and 55 min (30–95 min), respectively. Spouses attended four of the 10 interviews and two of the three focus group discussions.

Communication barriers, facilitators and ambiguity

In this section, the expressed barriers, facilitators and ambiguity (when a factor is experienced as a barrier for one patient, but as a facilitator for another) are described and illustrated with quotes. Subsequently, a pattern in the different communication states is described.

Barriers related to the patients' attributes

Frequently mentioned barriers in the domain of patient attributes were emotions experienced before (stress and uncertainty) and during (anxiety, sadness and desperation) the consultations.

‘Then your thoughts start rambling and you don't hear what else the doctor has to say’.

Patients also mentioned their lack of specific knowledge about their disease, lack of communication skills and experience with the consultations.

‘I have the feeling, that man is talking, but I don't understand any of it’.

These barriers were expressed in forgetting to ask (prepared) questions, having difficulties in processing discussed information and not knowing how to ask for clarification.

‘Often when you have asked a question, you get an answer and you have to think it over. And then the consultation is finished before you have thought about it. Then you start to think, oh what are they sending me home with this time’.

Hindering beliefs that patients mentioned were the feeling of being dependent on the physician and the idea that a physician did not appreciate an actively participating patient.

‘I often get the impression that it is not appreciated if you ask too many questions’.

Other hindering beliefs were that (vague) complaints were not worth mentioning and the conviction that patients should not interfere.

‘You do not want to be a nuisance. You understand that she is very busy. You see the entire waiting room full of people’.

Barriers related to the health care professionals' attributes

The majority of the coded fragments related to situations involving hospital physicians. Specific communication behaviours of physicians were frequently mentioned as a barrier, for example keeping the conversation too general, not responding to patient's notice of vague physical or psychological complaints, not apologizing for mistakes and a blunt delivery of bad news. Additionally, a professional's haughty or hasty attitude, the perceived poor cooperation with other HCPs or departments and an overly technical and non-psychosocial communication style, hindered patients in their communication (values, beliefs and emotions).

‘I have to be quick with my questions, because I always feel that the doctor is in a rush to get finished with the consultation’.

Few fragments related to GPs, nurses or nurse practitioners. Most interviewed patients rarely consulted the GP after the diagnosis (N)HL was made and the possible role a GP can play was unclear to them.

Barriers related to external factors

A frequently mentioned organizational barrier was time pressure, that is waiting before a consultation (evoked, e.g. stress, anxiety and related emotions), the amount of time during a consultation (skills) and the length of time until results of medical tests were communicated (evoked frustrations, anxiety and related emotions).

‘I also think that doctors are not aware of how much of a burden waiting is. You can't go anywhere with your feelings. Then you enter the consulting room already very stressed’.

Other barriers are discussed in the paragraph ‘ambiguity’ as they were also experienced as facilitating factors, depending on the setting.

Facilitators

Many opposites of the barriers were mentioned as facilitators. An additional aspect concerned the patient's belief that one has a responsibility to look after oneself and, therefore, one needs to know what is going on.

‘In this whole process I want to stay in control and nobody else. This is my life’.

Also, preparing questions and entering the consultations with specific goals in mind supported patients to ask questions and engage in discussions.

‘You must come prepared. You have write down everything that crosses your mind in a notebook or on a list’.

The need to keep control (i.e. managing medical records, planning consultations at a preferred time and asking for a one-to-one conversation) was another facilitator as was a good relationship with the HCP.

‘The moment you want to build a relationship with a doctor, and you have certain questions, you have to bring them up yourself, you have to be open-minded... You have to work together on the relationship’.

Patients also mentioned that it helped when a physician showed a reflective communication style and addressed the communication rules between them, that is the meta-communication.

‘The best thing is when someone explains it very thoroughly. And then also checks if you have understood it’

‘Then she asked – without speaking about medical matters –: We are committing to a long term control period, how do you want us to communicate with each other? That completely opened up everything’.

Ambiguity

Several factors, mainly in the external domain, were experienced as both barriers and facilitators. For example, the information patients gathered on the Internet motivated some patients to ask questions and start discussions while it made others feel confused or more stressed. Also, the opinions on the continuity of care varied. Some patients were more at ease seeing the same physician at every hospital visit. Having a familiar physician supported them in asking questions or discussing concerns. Others felt more confident sharing their concerns with several haematologists who cooperated in determining the treatment policy. Most patients had companions to help them raising concerns.

‘My wife always brings a paper with her, so we can write down things if necessary and in case I forget something, she will ask it’. ‘Because you are together, you can have a different sort of conversation. You can complement each other’.

Others mentioned that bringing a companion distracted them or made them feel uncomfortable.

‘You also have things you only dare to ask or say if you are alone with the doctor. If your family is there, you can feel a bit embarrassed’.

Three communication states

The data showed that patients' communication attitudes and skills changed over time and so did the perceived barriers and facilitators. A pattern was observed in when certain barriers and facilitators were experienced, and this pattern could be described as three progressive communication states: (i) overwhelmed, passive; (ii) pro-active, self-motivated; and (iii) proficient, empowered.

Patients who were easily overwhelmed and who contributed little to the conversation characterized the first state. Emotions (fear, uncertainty and sadness), lack of knowledge about the disease (not knowing what to ask) and lack of knowledge about the health care system (not knowing what to expect when and from whom) were important barriers.

‘In the beginning you don't even know what you want to know’. ‘You get blocked and you think: tomorrow I'll die. You do not hear anymore what the specialist is telling you’.

In this first state, patients also mentioned their distrust of health care as a result of the long period of uncertainty until the diagnosis of (N)HL and the feeling of being dependent as communication barriers. A patient seemed to go to the second communication state if the need to understand what was happening resulted in asking questions and learning about the disease.

‘I realized that it was very important to pay attention: be aware of what's happening, remain calm and focussed, so I know what is going on, what is going to happen and why’.

Patients who wanted to understand their situation represented this second state. They started to gather information during and between consultations. These patients tried to go to consultations better prepared and with certain goals in mind. Examples of barriers experienced in this state were lack of communication skills, feeling dependent on the physician (not daring to utter disagreement or ambiguities), conflicting information sources and limited time of the consultation.

‘I always tried to be as clear as possible. But sometimes I wasn't to the point. I did not know exactly what I wanted’.

During this state of learning, the patient became more skilled and experienced and gradually shifted to the third state.

In this third state, patients experienced fewer barriers in communication, had an improved ability to deal with remaining barriers (predominantly external factors), experienced less difficulties reaching their communication goals and asked less, but more specific, questions.

‘My role is to indicate what my questions are and to make sure, that the other really understands my motivations. My experience is that if I indicate what I think is important for me, that they go along in that’.

The communication states were found to be consecutive, but also fluid, as time since diagnosis or phase of the disease did not predict a certain communication state per se. Some patients started in the second state right away. However, most patients seemed to go from the first to the second state shortly after having been diagnosed. They described this as a process in which they learned that their needs were better fulfilled if they had a more active role in the consultation. For most patients, their state was not a fixed permanent entity as few never seemed to have changed between states. However, some patients never seemed to have moved from the first state because of personal attributes, negative experiences, the inability to understand what is happening or the persisting attitude that there was nothing to say.

DISCUSSION

Barriers and facilitators to effective communication

Most facilitating factors to effective communication experienced by patients with malignant lymphoma seem to concern the patient's need for control over the situation and the emerging need for information. These needs urge the patient to participate actively by asking questions, asking for clarification, addressing new topics and voicing concerns/disagreements and stating preferences. That is components needed for effective communication according to the PACE curriculum and Bylund et al. [10].

Several attributes of HCPs were experienced as facilitator or barrier. An example of a barrier is when physicians keep the conversation too general. This finding concerns physicians' underestimation of patients' desire for information [44]. The ambiguity found in how factors affected communication, such as the enhancing or inhibiting effect of the presence of a companion, indicates the need for tailored support and advice.

Many communication barriers and facilitators did not seem to relate to disease-specific issues, such as the disruptive role of emotions and the facilitating role of previsit preparation, and may therefore be relevant to other cancer patients too. For example, the predominant barriers experienced by oesophageal cancer patients were their dysfunctional beliefs and lack of skills [25], and these were also considered as important barriers by the participants in the current study. However, the importance or prevalence of specific barriers and facilitators may differ across cancer types. For example, the distrust towards HCPs of patients with malignant lymphoma as a result of the long period of uncertainty until the diagnosis might be specific for NHL patients as the disease often starts with vague physical complaints.

Three communication states

Barriers and facilitators in communication with the health care practitioners seemed to differ along three states: (i) overwhelmed, passive; (ii) pro-active, self-motivated; and (iii) proficient, empowered. These three communication states conform to the 'conscious competence learning model', referred to by Maslow, who describes the stages of learning a new skill from unconscious incompetence to unconscious competence. Most patients in the first communication state are unconsciously incompetent as they are unaware of the role they can play. Elements of the first state have been described by Borgers et al. [28] stating that one quarter of the cancer patients are not aware of their own intention. Also, Robinson and Thomson [45]

argue that patients may be unaware of the benefits they can gain by active participation in the consultation. The participants in this study frequently discussed this concept of awareness and it might clarify the transition from the first to the second state. When a patient realizes the importance of understanding what happens, it triggers a change in attitude. Moreover, hindering values and beliefs were found to explain the differences in communication behaviour identified in the first and second state (I am afraid to distract my physician from curing the cancer if I start talking about psychosocial problems). When patients become aware of the role they can play and the skills they need, they start to learn. In this state, conscious competence (e.g. asking prepared questions) alternates with conscious incompetence (e.g. not able to ask for clarification when the answer is not clear). In the third communication state, the patients are unconsciously competent and they have knowledge and skills to fulfil their needs. The transition to this third state appears to evolve more gradually and involves the patient experiencing more control. The increasing emphasis on patient autonomy and participation [45] and the positive outcomes related to participation [2, 46] suggest that it might be worthwhile to support patients with skills facilitating the transition to the third communication state.

Strengths and limitations

We have tried to include a broad range of patients with malignant lymphoma by announcing the study in several different ways. Although the participants represent various regions, various stages of the disease and they attended different hospitals, 78% of the group are member of the LVN. Additionally, patients themselves could take the initiative to sign up for this study. We presume that the participants were more assertive and experienced than the average patient.

However, their experiences helped them to reflect on consultations where they felt less empowered, which was essential to identify communication barriers at different phases. The context mapping method might also have facilitated participants' ability to reflect on the barriers and facilitators experienced in their communication in consultations. During the following (group) interviews, the participants seemed well prepared. The sensitizing process, thus, seems to have enhanced the participants' contribution as intended. In general, the participants were positive about the applied method, and the probes enriched the data gathered in the interviews. The context mapping method seems appropriate for this type of research. Despite the non-directive formulation of questions, most quotes describe communication with physicians in hospitals. Overall, the results of interviews and group discussions did not differ much. Participating spouses mainly underlined patients' expressions and contributed to the interview when the role of a companion was discussed. Due to the retrospective character of the study, recall bias might have affected the results.

CONCLUSIONS

This study revealed communication barriers, and facilitators experienced by malignant lymphoma patients in their communication with HCPs. A pattern was observed and described as three communication states that indicate when certain barriers and facilitators are encountered.

PRACTICAL IMPLICATIONS

Health care professionals should become aware of the changing, or sometimes persisting aspects that facilitate or hinder the way patients contribute to the consultations. The categorization of three communication states might help HCPs to tailor information and to remove communication barriers. The HCP can also play a role in creating awareness about the patients' role in a consultation. Even though most training programs focus on communication skills for the HCPs, patients may benefit from communication training as well [7, 47]. Results of this study can be used to design training programs for both HCPs and patients.

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Figure 1. Fragments coded: expressed barriers, facilitators experiences, opinions, wishes and visions related to the communication with health care providers

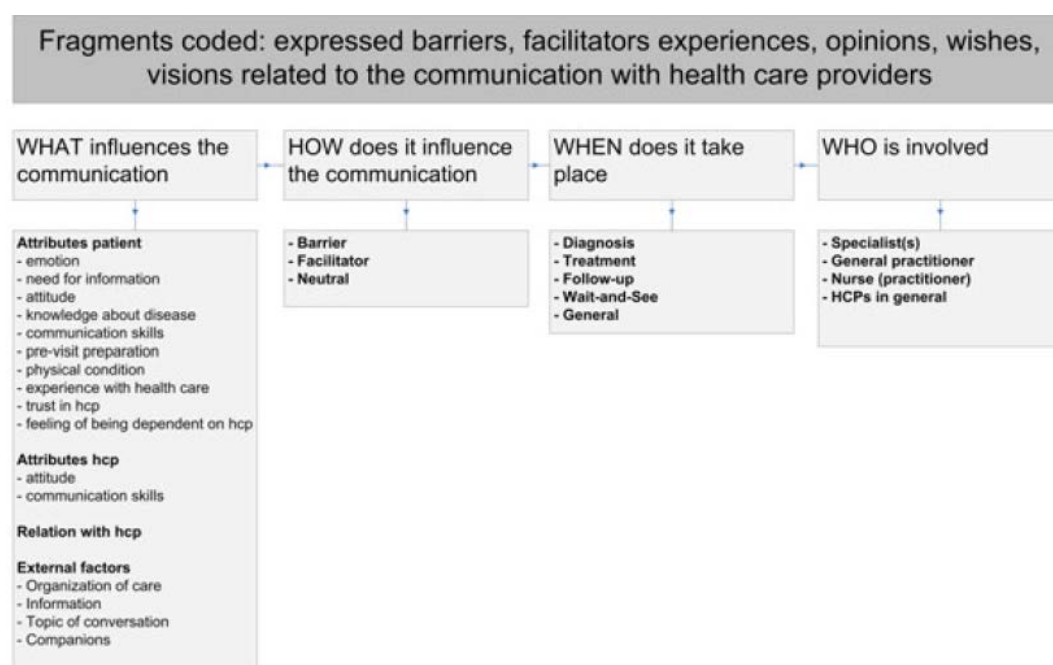


Table 1. Characteristics participants

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	Patients (n = 28)	Spouses (n = 9)
Men	12	4
Women	16	5
Average age(range)	59(39–81)	
Average time since diagnosis(range)	7 years (3 months–29 year)	
Diagnosis	5 Hodgkin 23 Non-Hodgkin	
LVN member	25	