Spouses Needs for Professional Support: The Spouses' Perspective on Communication

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Spouses' experiences with their partners' hospitalization and the spouses' relationship with nurses and physicians were examined. Health professionals should reflect more on the importance of an ongoing dialogue with the spouses of patients, ensuring they receive correct information to become more involved in supporting patients.

Having a partner with a serious illness has an enormous impact on the lives of spouses, both physically and mentally (Baanders & Heijmans, 2008; Luttik, Blaauwbroek, Dijker, & Jarrsma, 2007). In the past several years, research has focused on spouses and the influences of support on patients' lives. Previous research has shown the emotional status of the spouses played an important role in the patients' adaptation to their illness (Kim, Chopik, & Smith, 2014). For health professionals who provide care to seriously ill patients, the challenge is to find an appropriate way of presenting themselves in a professional manner to patients as well as their spouses. Little research has been done to investigate if spouses believed their needs were fulfilled, and if their situation as spouses was understood and recognized by health professionals. Health professionals may not be aware of what spouses experience during their partners' hospitalization (Altschuler et al., 2009). Typically, no standardized protocol exists for including spouses in care provided by health professionals on a general unit, and great variation is possible in care offered to spouses within hospitals (Kim et al., 2014). In Denmark, satisfaction with health professionals is measured annually in a national survey as a quality improvement initiative at all hospitals. Survey results indicate satisfaction among spouses is poor, and improvements to their needs during their partners' hospitalization must be encouraged (National Survey of Patient Experiences, 2013).

Literature Review

A literature search was performed for the period 2000 to February 2014 in PubMed and CINAHL using the search terms *spouses*, *surgical*, *support*, *needs*, and *communication*. Additional filters were applied to include only studies in English and only articles in full text. An additional manual reference search was completed because not all relevant studies could be found using the search terms. After excluding nonrelevant articles, authors identified 15 articles for inclusion in the literature review. Selected studies were restricted to those that evaluated spouses' experiences regarding their partners' hospitalization.

Published evidence has indicated spouses may be at risk for adverse psychological effects during their partners' illnesses (Houldin, 2007; Röing, Hirsch, & Holmström, 2008). A phenomenologic study of seven spouses of patients with oral cancer found spouses' lives changed dramatically and seemingly were suspended during the long treatment of the patient (Röing et al., 2008). Houldin (2007) interviewed 14 spouses concerning their experiences with patients newly diagnosed with advanced colorectal cancer. While they indicated their whole lives were turned around, they believed they were responsible for balancing family life to main-

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Objectives

To identify the needs of spouses, and develop professional relations and well-planned communication with health professionals.

Background

Having a partner with a serious illness has an enormous impact, both physically and mentally, on the life of the spouse. Emotional status of the spouse plays an important role in the patient's adaptation to illness.

Design

This study was designed as an explorative qualitative study using focus group interviews.

Methods

Focus group interviews with 11 spouses of patients admitted to a general surgical ward were conducted. Data were processed using qualitative content analysis.

Results

Two overall themes were identified: spouses' experiences of professional support, and professional communication. A majority of the spouses did not find health professionals to be adequately present during the hospital admission. Furthermore, spouses felt communication was lacking or incorrect information was unprofessional and created a feeling of uncertainty.

Conclusion

Lack of empathy from health professionals and a lack of well-planned communication toward the spouses could be perceived as a lack of involvement and have a negative effect on the spouses.

Relevance to Clinical Practice

For health professionals, support of spouses should be prioritized to enhance family-centered care. This could be of great benefit to the patient.

tain normalcy despite a feeling of uncertainty and a sense of stress (Houldin, 2007). A qualitative study of 30 female patients regarding psychocial adjustments found withdrawal of a husband's support can have a profound impact on the partner's adjustment (Altschuler et al., 2009). The focus was on the effect a patient's illness has on their joint lives, and how health professionals should be aware of their distress and provide guidance for spouses.

Despite the quantity of studies related to spouses experiences of having an ill partner, literature was often limited to including both sexes (Chou, Lee, Sun, Lin, & Chen, 2006; Hoga, Mello, & Dias, 2008; Lin, Lin, Lee, & Lin, 2013). Some research focused on the effect patients' illness have on their joint lives and how the relationship between the spouse and the patient was affected during a hospital admission (Cotrim & Pereira, 2008; Luttik et al., 2007). A cross-sectional study of 153 patients with colorectal cancer and 96 informal caregivers found caregivers to patients with stomas suffered high levels of anxiety and depression (Cotrim & Pereira, 2008). Caregivers often were responsible for most activities at home, leading to a higher level of stress. Authors concluded health professionals must provide assistance and support for caregivers to better understanding. No recent studies were found focusing on spouses and their needs during their partners' hospitalization as seen from spouses' perspectives. Thus, research is needed to explore the different ways spouses experience professional support during a hospital admission and what kinds of guidance are needed.

Purpose

The purpose of this study was to investigate spouses' experiences with their partners' hospitalization and the spouses' relationship with nurses and physicians. In addition, spouses' needs for well-planned communication and the importance of a professional relationship with health professionals were investigated.

Methods

Design

This study was designed as an explorative qualitative study using focus group interviews. The focus group was chosen to secure data collection and retrieve opinions from the spouses. Focus group interviews often are used when informers need to contribute to a deeper understanding or give more nuanced perspectives, as in fields where new intervention is desired (Halkier, 2010). Focus group interviews often help to facilitate a relaxed and nondirective approach, and are valuable in enabling informers to share their experiences (Danielsen & Spanager, 2012). The focus groups encourage participants to talk about issues related to their personal stories (Lakeman & Glasgow, 2009). A semi-structured flexible interview guide was used to ensure informers' responses contributed to a deeper understanding of context-bound events, and themes developed from an overall understanding of the subject were covered. The interview guide was developed through a literature search, and validated by the first and second authors' professional experiences (Danielsen & Spanager , 2012).

Sample

Inclusion criteria were spouses of inpatients with a gastroenterological cancer diagnosis admitted to the general surgical ward at a hospital in the capital of Denmark. Spouses had to be able to participate in a group interview with up to five participants. All informers had to speak and understand Danish, and be able to ask and answer questions and clarify their opinions in a group (Tong, Sainsbury, & Craig, 2007). Participants were recruited by asking inpatients if they had a spouse who would be interested in participating in a focus group interview. This was done by nurses on the surgical ward or by the first author. If a patient agreed, the spouse was contacted by telephone by the first author; a letter describing the purpose of the study also was sent. All contact with patients and spouses was made by the first author.

Of the 55 invited spouses, 17 (31%) agreed to participate and 38 declined. Six withdrew after inclusion; they indicated they did not have the time, or they could not be reached by telephone on the day of the interview (see Figure 1). Seven females and four men were interviewed. All participants were recruited within the first 3 months following their partners' hospitalization. Their median age was 61 (range 37-74), and the majority were active workers. All participants were Danish (see Table 1).

FIGURE 1.
Flowchart

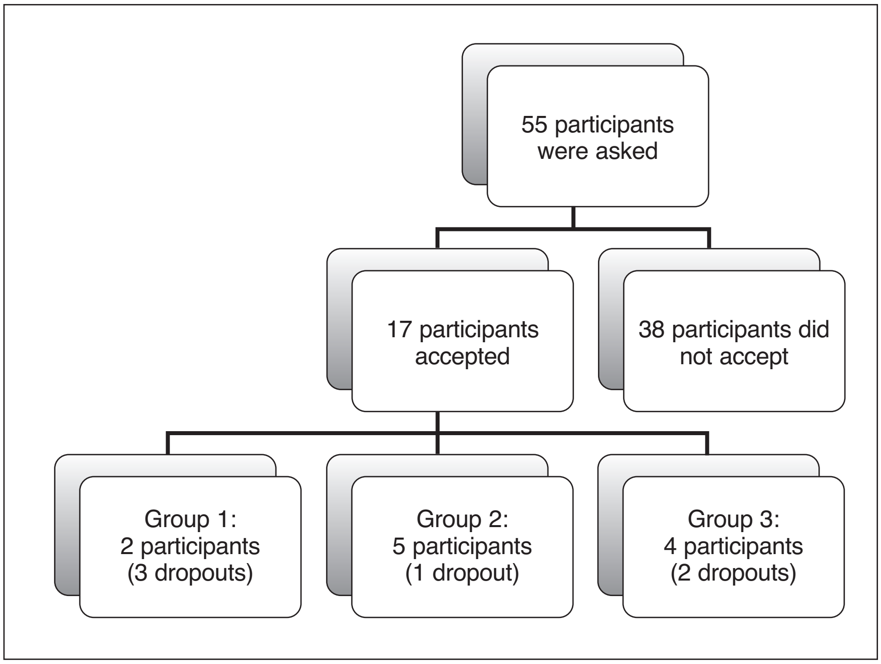

TABLE 1.
Study Participant Demographics

Spouse's Sex	Spouse's Age	Number of Days Patient Hospitalized	Patient's Diagnosis	Spouse's Profession
Female	65	10	Cancer rectum	Active
Female	65	3	Ileus	Active
Female	48	10	Cancer ventriculi	Active
Male	37	8	Appendicitis	Active
Male	74	8	Cancer colon	Active
Female	56	11	Acute pancreatitis	Retired
Female	67	4	Cholangitis	Retired
Female	56	16	Cancer colon	Active
Female	69	5	Hernia	Active
Male	66	17	Cholangitis	Active
Male	69	6	Liver abcess	Retired

Data Collection

The study was reported to the Danish Data Protection Agency. According to law, the study did not need approval from the Ethics Committee. Spouses interested in the study were contacted by the first author, who discussed the study and provided them with a study information sheet. They were asked to sign and return the consent form before the interview. Before each interview was started, consent was re-established and participants were reassured the confidentiality of their interview data would be maintained.

Two interviewers carried out all the interviews, with the second author as interviewer and the first author as an observant. All interviews were audiotaped and lasted approximately 1 hour. Interviews were transcribed into full text for analysis. Data collection continued until all authors were assured saturation was achieved (no new themes emerged from participants' narratives and data were repeating). After three interviews, saturation was reached and data collection was stopped. The translation of the results from Danish to English for this article was conducted by the first author and validated by the second author.

Data Analysis

To capture spouses' personal experiences, a qualitative content analysis was used to examine the interviews (Halkier, 2010; Hsieh & Shannon, 2005). The first phase involved data extraction. This was a repeated process of reading to identify variations and patterns. The text was divided into meaning units, and these meaning units then were condensed. After the text was condensed, it was labeled with a code. Various codes that emerged from the meaning units were compared and, based on differences and similarities, the names of the two overall themes were developed from interpretation of data. Reading and coding were completed by the first author and validated by the second author. Analyses and discussions continued until agreement was reached between first and second author (Lakeman & Glasgow, 2009; Tong et al., 2007).

Results

The two main themes that emerged from data analysis were *negligence of spouses' suffering* and *frustration due to vague or nonexisting communication.*

Negligence of Spouses' Suffering

The relationship with health professionals was given a high priority by spouses. All interviews found strong agreement that health professionals' ability to be present and recognize spouses' needs had a positive effect on the relationship. One spouse indicated, "Courtesy, a smile means so much. That is all you ask for as a spouse."

A majority of spouses did not find health professionals to be present adequately during the hospital admission. They described how few health professionals seemed physically or mentally present to them or the patients, which left them feeling ignored with a lack of empathy that created a great deal of uncertainty. According to one participant, "You need warmth and care as a relative." Another indicated, "Well, if only they were present, it is not much, just the fact that someone came and said 'hi' and talked to you."

Several spouses believed they were met with indifference; health professionals did not take any interest in them, and they felt ignored. This was perceived very negatively by the spouses: "I was met with indifferences among the health professionals. They did not seem very interested in me, which affected me in a bad way. I felt a sense of 'how do you dare to talk to me like that!'"

Health professionals often were described by spouses as being absent. They were left with a feeling of hopelessness, as illustrated by the following comments: "My husband did not always understand the information given to him, and the health professionals did not seem interested in involving me." "You felt powerless. You tried to draw attention to certain things but they did nothing about it. They didn't listen to you."

The spouses also described health professionals as unable to understand their situation. They often felt obliged to take responsibility for the care and treatment of their hospitalized spouses. In doing so, they often were met with indifference and sometimes received contradicting statements from health professionals. As one spouse indicated,

> I asked for my husband's blood test results. One nurse said they looked fine without checking them. I asked another nurse and she said they weren't ok. Since then, I have been asking for my husband's file but I can't always get it, don't know why.

Interviews clearly indicated some spouses were given too much responsibility in relation to the care of the patients. Others believed they were given too little. One participant commented, "I felt very insecure that night where my husband didn't get his medicine and that I should remember color and name." Another spouse noted, "One day my husband needed help to get showered. It wasn't me who should do it, but it seemed natural that I helped him."

During the interviews, only a few spouses were pleased and satisfied with their relationship with the health professionals. Two participants described it as follows:

> Health professionals that included me in conversations or asked how I was feeling were seen as sympathetic as well as empathic.
>
> I would like to say something about responsibility. I think we have only been met very kindly by all of the nurses and everyone has been helpful and it has been nice that I have been allowed to participate in the care of my husband and feel a little helpful. It has also been hard. I can see now that I have been very unsure doing all of this.

As another participant described,

> Sometimes they would ask about my family and that I should take care of myself. It has been absolutely fine. It has been the strength of this department. These human qualities counted. Some professionals took 5 minutes to ask about your family but others ran around and did not even see me.

Spouses recalled how health professionals did not show any interest in communicating with them. Spouses needed to do the outreach work in the communication, which one participant described as follows:

> I had to go and inform the nurses, but they were just talking to each other. I asked kindly to speak with one of them, the blonde turned and asked, "Anything wrong?" Yes, but I would not stand here and yield it to you – this was not OK, some of them must immediately say, "Is there anything I can help you with?" or just say, "Just a moment – we will be there."

Mental support had an important impact. It was central for the spouses to feel guided. The health professionals who met these needs were described as the chosen ones. The ones who had the necessary power to act and be available were selected as favorites. Two spouses described support as follows: "We had a good hospitalization, I was actually involved." "Some health professionals offered to help, asked you how things were going, remembered to say good-bye when they left. It mattered when they had good manners."

Spouses felt their time was not important to the health professionals. They were secondary to the patient, and they were not seen as partners with resources to be used. Spouses described it as very hard mentally, indicating the poor communication influenced them in a negative way. One spouse noted,

> When my wife was hospitalized, we had to wait for information, we did not know if she was sick with cancer. At the same time, we also had three children at home that I was responsible for. It was as if they knew something but did not inform me.

The many hours of waiting often increased insecurity among the spouses and seemed peculiar to them. Two participants described their experience: "To sit and wait 2 to 5 hours on rounds – using half my life here – was disrespectful, to wait for something that long." "I would like to have had some feedback. Why was the doctor delayed? I could have done something else – gone home and come back. You just let people wait out here."

Frustration Due to Vague or Nonexisting Communication

Findings indicate spouses were met with an absence of professional and well-planned communication. The communication between spouses and health professionals was described as vague, and spouses were frustrated because they had to take the initiative to get needed information. As one participant described it, "You needed information as a spouse. The health professional did not take the initiative to inform you. They didn't ask you to participate, when information was given. It left you with a feeling of not being welcome." Another spouse commented, "I would ask the health professionals for help, but when I did I got the feeling of being ignored and that I was annoying them."

Some spouses described communication with health professionals as inconsistent. The communication was often ambiguous, or health professionals failed to provide needed information. One spouse noted, "My husband felt he was thrown out – that was what he told me, but the nurse just said, 'No, he is not thrown out.' That was the only response I got from her."

Another participant described the following situation:

> I came to the hospital one day and my husband's bed was gone. Then of course I panicked; I thought he was dead. There was no bed or bed side table, so I asked a nurse, "Where is my husband?' She answered, "I know nothing about this." So I asked another and she said, "It is not me who is taking care of your husband," then she turned and walked away. Then I got angry and said, "You have to tell me right now where my husband is." I was very afraid.

Yet another spouse said, "Sometimes you ask for help and they just seem to forget it. It is like, 'Oops, I forgot it.' It is difficult to live with. It leaves you with the feeling of why am I forgotten?" Missing or incorrect information seemed very unprofessional to the spouses and created a feeling of uncertainty. They often found it difficult to contact the health professionals, and they were left feeling unwelcome.

Discussion

Throughout this study, the relationship with health professionals had a high priority among spouses. Spouses preferred professionals who were able to endorse feelings of confidence and see them as individuals. Participants indicated only a few health professionals were able to offer that kind of relationship or give spouses the feeling of being part of a team. Instead, they often were ignored and not accepted as a resource for the patient's hospitalizations. These indifferences made the spouses feel very insecure, stressed, and powerless.

Results of this study were similar to those of a qualitative study by Houldin (2007). The current study also found patients were seeking trust, care, and respect, and health professionals must see them as partners in a safe and caring relationship. Spouses often believed they were neglected by the health professionals and therefore were not able to provide the necessary energy to the patient. A study investigating the influence of husbands' or male partners' support found engagement from the spouse could have a positive effect on patients' quality of life (Altschuler et al., 2009). Houldin (2007) indicated spouses did not know the right approach for the patients, and they admitted to a great deal of uncertainty and a feeling of stress. Findings of the current study indicated spouses were attempting to keep everything as normal as possible and take care of the whole family. This seemed to be difficult to manage due to vague or nonexisting communication.

Spouses discussed how health professionals were unable to understand their situations. They often felt obliged to take responsibility for the care and treatment of the patient. Mental support also had an important impact for the spouses; it was critical for them to feel guided and not left with a feeling of despair. Similar to work by Houldin (2007), spouses were balancing caregiving activities and disruptions while still trying to be positive to daily demands.

A major finding indicated spouses were not satisfied with their communication with health professionals. Spouses did not experience health professionals' empathy or sensitivity to their needs. It could therefore be argued health professionals were not delivering the expected care and were not aware of how their approach affected spouses negatively. Educational and counseling material as well as interventions could be developed to provide support to spouses (Altschuler et al., 2009). Health education could be seen as a relevant model for including spouses' resources in patient care. Health education could help them understand patients' symptoms and needs, but it also could be used to encourage spouses to talk about the burden of being the person who has to keep everything together (Cotrim & Pereira, 2008). Findings suggest health professionals in the surgical unit needed education in how to involve spouses in patient care.

Another important finding concerned poor communication and the absence of communication skills among health professionals. Spouses were vulnerable and depended on trustworthy communication during the patients' hospitalization. They perceived they were not seen by health professionals as individuals with the right to have an opinion. Trust in health professionals was the main concern for spouses, a concern often expressed as, "We were met with indifferences by the health professionals and not given the right information." A study involving inpatients with cancer (Beaver et al., 2010) supported this finding that patients' needs for care are not met by the health professionals. As with the current study, Beaver and co-authors concluded patients need to have trust, a personal relationship with health professionals, and a feeling of being respected as individuals.

Limitations

Interviews were conducted with 11 participants who were prepared to discuss a personal topic in a group with up to five others. The experiences of potential participants may differ from those who did participate. The study also was conducted in one hospital; results may differ in hospitals of different sizes and patient populations.

Future Research

A need exists for continued research regarding spouses' needs for communication and emotional support during their partners' hospitalization. Future studies should focus explicitly on how spouses cope so their needs can be translated into effective interventions for better support. Further focus should be on health professionals and their ability to support and communicate in a professional way.

Nursing Implications

Findings of this study highlight the essential and demanding role of health professionals. Results suggested lack of empathy from health professionals and a lack of well-planned communication toward spouses could be perceived as a lack of involvement. More and better education concerning spouses' resources is needed for health professionals. Health education might teach spouses what to expect during partners' hospitalization and offer assistance with communication skills. Health professionals also need education in how to involve spouses appropriately in patient care. Health professionals should reflect more on the importance of an ongoing dialogue with the spouses, ensuring they receive correct information to become more involved in supporting patients.

Conclusion

This study has helped identify spouses' needs in relation to a hospitalized partner. Further research on their relationship with health professionals may establish appropriate interventions to reduce the psychological burden of spouses. The ultimate goal is to improve patient outcomes through spouse empowerment. MSN

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