

Family involvement in the context of chronic diseases: The role of social support in treatment decision-making for surgical procedures

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Abstract

If medical decision-making about complex treatment options (such as surgical procedures) is challenging for patients, family members can provide them with advice and health information. Previous research about family involvement in health communication has largely focused on cancer patients. Thus, it lacks an examination of family involvement in surgery decision-making in the context of non-life-threatening chronic diseases like arthrosis. In particular, we focus on the role of social support for family involvement in these situations. Against this background, we conducted semi-structured qualitative interviews with arthrosis patients and their family members (n = 32 patients; n = 8 relatives). To better understand family involvement in surgery decision-making, three research questions were analyzed: (1) What are the perceived characteristics of the arthroplasty decisional process? (2) Which patterns of family involvement exist with regard to social support? (3) What general circumstances are relevant for family involvement? Our results demonstrate that social support plays an important role in the patterns of family decision-making. Instrumental, emotional, and informational support can indirectly enhance family involvement in decision-making. In addition, relatives are also directly involved in decision-making processes and may instigate the decision. The type of family involvement is influenced by characteristics of the decision-making situation. In addition to personal factors and the relationship with the physician, which is perceived as less supportive, the need for familial decisional support intensifies.

Keywords: family members, health communication, information-seeking, decision-making, social support



1. Introduction

Family members, such as partners, adult children, and also friends, neighbors, or colleagues, can play an important role in medical decision-making (Laidsaar-Powell et al. 2016). They can do so by seeking surrogate health information (Cioni et al. 2018; Reifegerste et al. 2017), accompanying patients to medical visits (Laidsaar-Powell et al. 2013), or providing social support in coping with the disease (Rosland et al. 2013). While family involvement in decision-making in the context of cancer treatment (Krok-Schoen et al. 2017; Laidsaar-Powell et al. 2016), intensive care (Nagl-Cupal & Schnepf 2010), or end-of-life situations (Hauke et al. 2011) has undergone intensive research, only a few studies have examined the role of family members in decisional processes that are not life-threatening and allow for longer decision-making time. A systematic review of family roles in treatment decision-making in chronic diseases listed only individual studies not referring to cancer, chronic kidney disease, or multiple diseases (Lamore et al. 2017). As time pressure and emotions are relevant factors in decision-making (Hu et al. 2014), the patterns and functions of family members may vary in medical decisions for such situations. However, due to the growing prevalence of long-term, non-life-threatening chronic conditions, multimorbidity and outpatient care, the role of family members in these situations should receive more attention (Whitehead et al. 2018).

1.1 *Decisions about surgical procedures in the context of chronic diseases*

One example of a long-term surgery decision involves arthroplasty (a surgical replacement of the joints with endoprosthesis). Although the surgical procedure is mostly effective in terms of health outcomes (Sloan et al. 2013), it also includes medical risks, such as pulmonary embolus, wound infection, or dislocation (Saucedo et al. 2014). In addition, the function of the implant gradually diminishes, so that a revision of the hip or knee replacement after 15 to 20 years becomes necessary (Keswani et al. 2016). This causes a great amount of uncertainty about the correct time to perform the surgery, especially for middle-aged and female patients who have a higher life expectancy (Mota 2013). The available treatment options (surgery, delaying surgery, or non-surgical treatment) and their specific advantages and disadvantages require a challenging decision (Stake et al. 2015) that might leave patients overwhelmed and reluctant to make a judgment (Youm et al. 2015). However, in contrast to other types of medical decision-making (e.g., in cancer treatment), the decision can be assessed without pressing time constraints as it relates to a disease with lower severity. Under these circumstances, patients might involve members of their social network more intensively to assist them in their medical decision-making (Youm et al. 2015). It might also be the case, however, that patients feel less need to have their decision confirmed by others because of the lower severity of arthrosis in terms of the burden of the disease compared to diseases like cancer (Prince et al. 2015).

Therefore, we aim to explore the role of family members in decision-making regarding total hip or knee arthroplasty as an example of treatment decisions for surgical procedures in non-life-threatening and less severe chronic diseases. Specifically, we want to gain a better understanding of the role social support plays for the patterns of family in-

volvement, because several studies (Lamore et al. 2017; Lin et al. 2013b; Lin et al. 2017; Nagl-Cupal & Schnepp 2010) have found social support to be an important function of family involvement.

1.2 Patterns of family involvement and the role of social support

The type of family involvement in patient decision-making varies widely on a continuum from complete disengagement to extensive involvement (Laidsaar-Powell et al. 2017b). This also applies for decisions about surgical procedures (Uldry et al. 2013). While some patients make choices independently, others prefer to decide collaboratively with a companion (Clayman & Morris 2013) or even delegate the decision to family members (Krieger 2014). Although attributing responsibility to substitute decision makers might be more relevant for the critically ill or for patients who cannot speak for themselves (Hauke et al. 2011; Hickman et al. 2012), family involvement generally plays an important role in patient decision-making. In general, patients rarely form judgments about important treatment options autonomously (Epstein 2013). Couples often react as a unit when dealing with medical problems (dyadic coping in its supportive or delegated manner) and the supportive reaction of one partner to a stressful event of the other one can contribute significantly to well-being and psychosocial adjustment (Bodenmann 2008; Traa et al. 2015). In decisions on surgery of chronic diseases, family members tend to be even more involved than in decisions on other treatment options (Lamore et al. 2017).

Family members' contributions to decision-making of patients can manifest themselves in different forms of behavior. Dyadic coping with the decision can be emotion- or problem-oriented and either be regarded as positive (supportive) or negative (hostile, ambivalent, or superficial) for the patient (Bodenmann 2008; Krieger 2014). In addition, Laidsaar-Powell et al. (2016) distinguish different functions of supportive behaviors (informational, emotional, and instrumental) that are also reflected in social support theory (Holt-Lunstead & Uchino 2015) and family support studies (Song et al. 2018). Whereas informational support includes behaviors such as seeking and remembering information or ensuring patient understanding by providing comprehensive information, emotional support comforts the patient and provides companionship. A systematic review of family involvement in decision-making in chronic diseases identified informational support as the most common form of support provided by family members and emotional support as the second most relevant (Lamore et al. 2017). Two-thirds of all online health information seekers look for materials on behalf of someone else, i. e., surrogate seeking (Cutrona et al. 2015; Sadasivam et al. 2013; Reifegerste et al. 2017).

Families provide an abundance of informational support for the patients, especially in the context of surgeries (Lamore et al. 2017). Family members and friends help the patient by collecting and comparing treatment options. This extends the medical information from health care providers (Lin et al. 2017). By receiving information from family members or other social contacts, patients have more information available (Lin et al. 2017) and can take a more active role in their decision-making (Kahana & Kahana 2007). In addition to this informational support, other types of support might also play an important role for family involvement in decision-making.

Emotional support can consist of providing comfort (when overwhelmed by the options), assisting in the acceptance of the situation, or simply being a companion (Lin et al. 2017; Laidsaar-Powell et al. 2016).

Instrumental support (transportation and physical assistance) might be more common immediately after surgery, but also includes accompanying the patient to the physician. Up to 86% of patients — depending on their specific disease and health status — are accompanied by a family member during medical visits (Laidsaar-Powell et al. 2013; Wolff & Roter 2011).

Although most taxonomies of social support do not name decisional support explicitly (for an overview of taxonomies see Lin et al. 2015), it can be considered a distinctive dimension of social support in health communication (Krieger et al. 2017). Decisional support describes advice and guidance for making choices on treatment options, health care providers, institutions to be involved in treatment, and other health-related questions (Holt-Lunstead & Uchino 2015).

Family involvement in decision-making can also depend on the relationship between physician and patient (Lamore et al. 2017). A strong coalition between patient and physician can restrain family members from decision-making (Boehmer & Clark 2001). In situations where physicians dominate the decision (against the preference of the patient), the support of family members can enhance the patients' autonomy during decision-making (Laidsaar-Powell et al. 2016). By helping them process complex information or express their own preferences, family members can act as patient advocates, who defend the patient's interests (Lin et al. 2013b).

The patient might not necessarily perceive the different types of social support as helpful in meeting their needs. The evaluation of social interactions as supportive can differ between the provider and the receiver (Dunkel-Schetter et al. 1992). The family might provide information and demands to be involved in the decision, while the patient wishes to decide autonomously and perceives the information as non-supportive (Krieger 2014).

1.3 *Circumstances of family involvement*

Several factors seem relevant in the patterns of family involvement in medical decision-making (Lamore et al. 2017). These can be subdivided into circumstances that are related to health situations, to the patient (as a person) or to the relationship between patients and relatives.

Health-related circumstances. The extent of family involvement in medical-decision-making is strongly related to the severity of the patients' illness or the consequences of the decision-making. Family involvement increases if the health status is more serious (Clayman et al. 2005) and if the result of the decision pertains to the family member (Krieger 2014).

Although most studies about family involvement in decision-making focus on cancer treatment, some factors can also be transferred to decisions about surgeries in other health contexts. Greater family involvement typically occurs when decisions are important (beginning, changing, or ceasing treatment) or complex (many treatment options; no clear choice) (Arora et al. 2007; Laidsaar-Powell et al. 2016; Sekimoto et al. 2004). The latter point might be especially relevant for decisions about arthroplasty, due to several treat-

ment options, their accompanying risks, and the long-term effects that create complexity in decision-making (Ballantyne et al. 2007; Stake et al. 2015; Sloan et al. 2013). This could also be interpreted as a higher need for social support in decision-making. Consequently, the perceived risk of the surgical treatment might be a further reason to spread decisional responsibility (Lin et al. 2013a) and ask family members for informational or emotional support.

Patient-related circumstances. The involvement of family members in decision-making might differ according to the patients' demographic characteristics and their general "decision-making capacity" (Hauke et al. 2011: 2667). While younger and older (cancer) patients prefer involvement of others, middle-aged patients decide independently (Laidsaar-Powell et al. 2016; Shin et al. 2013). However, in other studies, age was either not associated with the patients' preferences for family involvement (Sekimoto et al. 2004; Sio et al. 2014) or influence from their social network was less for older patients than younger ones (Krok-Schoen et al. 2017). Male sex and higher education were associated with the patients' preference for less family involvement in decision-making (Hobbs et al. 2015; Shin et al. 2013). In general, more independent patients are less likely to want family members' involvement in medical decision-making (Alden et al. 2018).

Relationship-related circumstances. The most commonly involved third parties are spouses of patients, followed by adult children, while relatively few other relatives and friends are involved in patient decision-making (Krok-Schoen et al. 2017; Laidsaar-Powell et al. 2013; Wolff & Roter 2012; Lamore et al. 2017). Actively involved family members in cancer treatment are typically middle-aged, female, and more highly educated than the patient; they possess professional medical or allied health experience (Laidsaar-Powell et al. 2017a).

1.4 Research questions

As previous research about family involvement in health communication has largely focused on cancer patients or other life-threatening medical situations (e.g. emergency, intensive care), and lacks an examination of family involvement in complex medical decisions about non-life-threatening surgery, the present study seeks answers to the following research questions:

- (RQ1) What are the perceived characteristics of the arthroplasty decisional process?
- (RQ2) Which patterns of family involvement exist with regard to social support?
- (RQ3) What general circumstances are relevant for family involvement?

2. Method

2.1 Design and procedure

The aim of our study is to examine the perception of decision-making situations by patients as well as the role of family involvement with regard to social support in decision-

making processes. The purpose was to provide a profound analysis of patterns of patient-relative interaction in decision-making. Our intent was to identify and better understand the situational dependencies of these complex individual patterns and the specific characteristics of non-life-threatening medical conditions. With the goal of gaining insight into the phenomenon of family involvement in this context, a qualitative approach seemed to be a promising research strategy.

To investigate our research questions, we conducted qualitative, semi-structured, face-to-face interviews with 32 patients. We recruited patients suffering from arthrosis, who were faced with the decision to have a hip or knee replacement or had already undergone such a procedure within two years prior to the study. In addition, we invited their most relevant family member to the interview. To reach a heterogeneous sample of patients with a wide range of experience and knowledge regarding medical decision processes, we used various recruitment strategies, most importantly an advertisement in a regional newspaper. We also disseminated posters and leaflets in various health institutions, such as orthopedic and physiotherapist offices and clinics. In addition, the cooperating clinics sent a letter to arthroplasty patients from their database and invited them to participate in a semi-structured interview. This variety of recruitment strategies was employed to ensure that both active treatment and post-treatment perspectives were captured.

Patients confirmed their participation in the interview by calling the study coordinator. During the call, patients were asked about the role of their family members who contributed to their medical decision-making. If the patient named a specific person, he or she was asked to inform that person about the study. If interested, the family member was instructed to contact the research team and make an individual appointment for a second semi-structured interview. Therefore, the recruitment of the relatives took place through the patients. The aim of the interviews with family members was to supplement the relatives' views as a type of triangulation as well as to validate and evaluate the patient's responses. Approximately one-third of the interviewed patients suggested a family member to recruit for the study ($n = 8$).

Members of the research team who had been previously trained conducted the interviews, which took place at the interviewees' homes or at a place of their choice (e.g., a prepared room at the university). Whenever possible, interviews were conducted in private surroundings. Once the interviews were completed, patients as well as their family members received approximately \$27 (25€) as compensation. Recruitment of patients and family members was conducted over a 10-month period until data saturation, which is defined as the point at which interviews fail to reveal new information or insights about joint decision-making (Francis et al. 2010). Ethical approval to conduct the study was granted by the Institutional Review Board (IRB) at the Hanover University of Music, Drama and Media.

2.2 Interview guide

The guide of the semi-structured interview was developed by the research team, based on a methodical review of (theoretical and empirical) literature on information management, family involvement in medical consultation, and collaborative decision-making (Krieger 2014; Laidsaar-Powell et al. 2017b). Two guidelines, one for patients and one for family

members, were developed. These guides differed only in perspective; otherwise, the same topics were addressed.

All interviews were conducted in German, pretested with members of the target group (patients and family members), and validated by medical experts (specialists in hip and knee replacements) to ensure comprehensibility and medical correctness. Both interview guides were based on open questions. We started with general questions about the current health status and personal experience with the disease and its characteristics. To understand the circumstances of the decision-making situation we wanted to know about the feelings of uncertainty caused by the illness and the required decision-making, the supportive needs, and the patient-physician interaction. With regard to family involvement, if applicable, we asked about the specific person who was involved, the type of interaction and support she or he provided, as well as the reasons for their involvement. Prompts and probes were listed in the interview guidelines and used as necessary.

2.3 *Data analysis*

The aim of our analysis is to better understand and explore the phenomenon of family involvement in surgical decision-making. Therefore it is important to describe the phenomenon itself and to identify the reasons for certain behaviors and attitudes. The focus of our analysis is on the perception of the individual.

To conduct the analyses all interviews were audio recorded. They varied in length between 30 and 90 minutes. The audio files were transcribed word-for-word and then analyzed by one trained member of the research team, using qualitative content analysis based on Mayring (2014), which is extensively used in communication research.

The coding strategy can be described as a combination of inductive and deductive coding; it was conducted in different stages to develop and apply categories (Mayring 2014): (1) In a first step, the major topics and dimensions of analysis (e.g. types of social support) were derived from the interview guide. These categories served as a preliminary thematic framework in the beginning of the analysis helping to identify relevant statements and organize the analysis (deductive basis). (2) During the second step of inductive coding, the framework was differentiated and modified during the course of qualitative content analysis resulting in more specific codes developed from the patients' or relatives' descriptions. Thus, in several stages of iterative category development, complementation, modification and revision of codes, the framework was completed and structured. This framework allowed us to identify reasonable structures and patterns in the data, to reduce the material to statements relevant to the scope of the research, and to answer our research questions. However, the interviewees had only limited ability to reflect on the meaning of personal factors (e.g., age, gender) for their behaviors. Therefore, a comparison between the statements of certain subgroups (e.g., old vs. young, women vs. men) can provide first evidence of such influences.

2.4 Sample

The sample included patients between 42 and 88 years of age (under the age of 50: 4 patients; 50 to 60: 7 patients; 60 to 70: 11 patients; older than 70: 10 patients) and exactly one-half of the participants were female. Four patients were faced with the decision to have a total hip or knee replacement. Twenty-eight patients recalled their experiences and decision-making after the surgery. Participants in the group of family members were between 45 and 70 years old and characterized by a higher proportion of women. The eight family members who gave interviews by themselves included four wives, one husband, one mother, one son, and one male friend of an interviewed patient.

3. Results

3.1 Specific decision-making situation (RQ1)

To understand the context of family involvement in medical decision-making processes, the specific perception of the disease and the surgical decision-making situation are presented from the point of view of the patients and their relatives.

The special characteristic of the disease was described by the patients as “not curable” (e.g. female, 45 years). After the diagnosis the lack of chances for recovery led to a high emotional burden for some of the patients. “The doctor talked to me about it... I was completely shocked and afterwards completely exhausted” (female, 60 years). “Then I went on a pilgrimage from doctor to doctor, because I didn't really want to accept that” (female, 45 years). Whereas the patients experienced the diagnosis as an exceptional emotional state due to the incurability of the disease, none of the family members described this as central in the perception of the situation. Instead, they emphasized that the disease was not “life-threatening” (wife, 65 years). In comparison to other diseases such as cancer, the mentioned characteristics can be described as specifics of chronic diseases such as arthrosis.

A further specific characteristic of the disease is gradual deterioration. During the long course of the disease, the patients test a variety of therapy options. “It had already been more than four years before the surgery took place” (male, 59 years). “About 15 years after the first diagnosis, I decided to have the surgery” (female, 67 years). Thus, there was no pressure to make a decision; rather, the patient had the chance to extensively deliberate about the decision and consider all the advantages and disadvantages.

In general, the individual's freedom of choice in this decision-making situation seems to have been affected by the urgency of the surgery. Although the symptoms develop gradually, they are acute at specific moments. Therefore, patients repeatedly question whether the surgery is necessary. A 65-year-old patient expressed his uncertainty. “These were the wave movements. Sometimes you think it's nothing. It often happened to me that I thought about it: ‘Gee, are you really doing the right thing with the surgery?’ Then the valley came again. I then thought that I should have surgery as quickly as possible. There is an up and down of feelings.”

With regard to the specific decisional process, the surgery is perceived as "optional" (female, 67 years). "Since orthopedic surgeries are optional, it was my own decision. A doctor can only act in an advisory capacity to someone" (female, 67 years). "Of course, the final decision is not made by a doctor. You have to make the decision yourself. The medical profession does not comment on this" (male, 59 years).

Accordingly, many respondents viewed themselves as responsible and accepted the call for patient autonomy. Physicians and their consultation style were perceived as passive and less supportive for decision-making. Patients also perceived this high autonomy as a burden, which led to higher uncertainties. Two younger patients expressed their doubts. "I have often wondered whether it was the right thing to do or have done" (female, 42 years). "I'm a layman. I don't really know if it's good to influence the doctor or this decision" (female, 45 years). The perceived necessity to decide on one's own in combination with the uncertainties seemed to serve as a basis for family involvement in decision-making.

However, not all respondents realized that they were ultimately responsible for making the decision. This seemed to depend on how the health care providers acted and to what extent they gave clear recommendations. It seems striking that physicians predominantly acted rather cautiously. A more active behavior was described by an older female patient and her relative, who reported explicit statements by her physician, which had a significant influence on decision-making. "And in the medical specialist's report, it was clearly stated what the cause was and what had to be done" (son, 58 years).

Patients perceived the context of the decision very differently. On the one hand, the surgery could be viewed as an exceptional situation and risk factor, thus the decision was perceived as stressful. "A TEP [total endoprosthesis] is a thing you don't do every day. If the first one goes wrong, this leads to a lot of other problems" (male, 45 years). On the other hand, some patients described the surgery as a routine procedure. "Hips are installed today like new tires" (male, 66 years).

In addition, characteristics of surgeries (as a special type of therapy option) affected the perception of the situation. Some patients perceived the surgical procedure as a loss of control, which was accompanied by anxiety. "This is the case with all surgeries, because you practically launch yourself in the hands of the surgeons and do not know whether you will be among your fellows again the next day" (male, 59 years). Another characteristic of a surgical procedure is the irreversibility of the changes to the body. This increases the significance of the decision and the perceived risks. "It has worried me that if I really have an artificial hip built in, there is no going back. That is then sawn off and what is new is in it and that is lifelong" (female, 56 years). Such fears are related to a lack of experience with such surgical procedures. "I was very uncertain, because I was lucky enough to have never been in a hospital myself" (female, 60 years).

Further uncertainties, which are salient in the course of decision-making, are related to the result of the surgery. Patients are uncertain about the chances and risks, which can lead to a delay in the decision. "Besides, of course, you always think something can go wrong. It's the fear or at least the concern that something might go wrong" (male, 66 years). In addition, medical uncertainties with regard to the long-term stability of the implant also represent a specific feature of the decisional process. "One does not know how long it [the implant] will last. There is no guarantee" (female, 60 years).

Patients described pain, reduced mobility, and quality of life as the relevant decision factors for surgery. "In my case, limited mobility was the main problem" (female, 67 years). "The pain really did not go away and it could not be overlooked any more...walking was no longer possible. I had tried everything before and at some point there was no way around it" (female, 60 years). The implantation of an artificial hip or knee joint is the last option after many other therapy options.

With regard to family involvement, it has to be taken into account that these decision factors also mean impairment for family life. For some patients, the hope of more actively participating in family activities and regaining their quality of life within their partnership or family is very relevant in the decision-making process and is an argument in favor of the decision. In contrast, if patients reject the surgery, their partner or family must accept the existing restrictions and jointly bear the consequences of the decision. "To my partner, for example, I also said, 'Okay, but that probably means no joint sports in the next few years.' He said, 'Okay, I can live with that.' It was important for me that he stood by my decision" (female, 45 years). "Running became more and more difficult, until later hardly any walks were possible. Of course it's not nice to see the other person suffer after a few steps and you can't really do anything. Walking and riding a bicycle are also things you like to do together" (wife, 43 years).

3.2 Patterns of family involvement and the role of social support (RQ2)

Against the background of the situational context and with special regard to social support, the patterns of family involvement in decision-making are examined. The responses from patients and their family members reveal four main functions of family involvement: instrumental, emotional, informational, and decisional support. These four support functions can be differentiated into two dimensions. The first one refers to whether the support influences decision-making indirectly or directly. The second dimension considers whether the support meets the patients' needs and is regarded as supportive.

Instrumental support has an indirect impact on decision-making. Family members provide instrumental support before and particularly after the surgery mostly in the form of tangible assistance in everyday life. Limited mobility and acute pain increase patients' needs for help with everyday duties, such as cleaning or buying food. "You have to do much more, e.g., go shopping for her and do the chores" (husband, 62 years). This form of support is also very relevant in the first days and weeks of recovery. During the preparation for surgery, instrumental support includes accompanying patients to the physician. The doctor's appointments are sometimes even arranged by the family member ("He asked me to make him an appointment" (wife, 65 years)). Although instrumental support is not directly linked to decision-making, it is still relevant to the pattern of family involvement in two ways. First, accompanying patients to medical visits before surgery seems to be associated with offering other types of support and provides a basis to exchange information and deliberate on the physician, the diagnosis, or the medical information. Second, the prospect of needing assistance before as well as after the surgery or existing support without surgery also increases family involvement in general.

A second type of indirect support is the exchange of emotional support. This includes helping to cope with the situation, the disease, and perceived uncertainties in decision-

making. Family members, who are able to listen to the problems and sorrows of the patients, facilitate their coping with the disease and decision-making. An interviewed family member (male friend, 45 years) stated, "Listening is very important and also comforts a person." The exchange with and the encouragement from trusted family members could help to reduce and manage fears and uncertainties related to the outcome of the surgery. "The conversations were very helpful for me and took away my fear a little bit" (female, 53 years). With regard to the second dimension of met or unmet needs of the patients, some family members do not feel able to emotionally support the patient and are themselves emotionally overwhelmed. They reported feeling helpless. "You stand next to them and can't really do anything" (wife, 70 years). Some family members feel that they must deal with their own fears before the surgery: "Of course, we were all afraid, because something can always happen during a surgery" (wife, 67 years). This limits the capacity to assist the partner. In general, it can be assumed that high interpersonal competencies of family members are needed and can increase family involvement, because an open discussion lays the foundation of all types of support. In contrast, high emotional burdens of family members or a lack of empathy of family members inhibit involvement.

The third form of indirect support is informational support. This includes surrogate seeking of health information. Surrogate seeking consists of relatives seeking and sharing basic knowledge and information about the disease and the treatment. The Internet seems to be the most important source of information. For example, a male patient stated, "I talked a lot about it to my wife, and she's the one who searches for information on Google" (male, 69 years). Furthermore, family members also stimulate the patients' information behavior. They recommend special information sources, such as TV shows or newspaper articles about interesting aspects of the medical decision. One male family member (45) remembered, "Sometimes on TV there were programs about the knee, and then I told her, 'You could have a look at this and tell me what they said about it.' Or I recommended visiting a website for more information."

Particularly when relatives themselves sought information, they pointed to the challenge of evaluating which information would be useful to the patient and which might overwhelm the patient. To protect the patient, family members only transmitted part of the information to the patient and acted as curators or gatekeepers. The relevant factor seemed to be the perceived openness of the patient. "My husband? He didn't want to hear anything like that. All I said was, 'It doesn't look so bad.' At least I tried" (wife, 60 years). "On the one hand you always want to tell the truth and not hide anything; on the other hand you don't know, because it influences the person. I told her about the side effects because she asked me about them and wanted to hear my honest opinion" (close friend, 45 years).

In addition, it can also be important how the family member assesses the patient's state of health. For example, the son of an 88-year-old female patient described that he only passed on the information that he considered central for his mother. "So that [the information passed on] is difficult. I think I filtered. I filtered it so that I had the impression that she understood. I didn't give her all the information. I don't think she would have understood anything at all" (son, 58 years).

However, this form of support is challenging not only for family members. Some of the patients mentioned that they rejected the exchange of information. The exchange of

information was partly described as "annoying" and "unnecessary" (female, 60 years). For example, a 42-year-old female patient said, "They also know well that I don't want to talk about my knee forever. I don't do that." A negative attitude toward informational support seemed to be associated with not passing the physician's information on to the relatives. "I don't know what the doctor told him. But I'm sure he also told him which implant would be suitable" (wife, 65 years).

One of the reasons for such a negative attitude is the patient's own information and knowledge base. In the interviews, the patients reported that they did not want to exchange further information because of their comprehensive information basis. "No [exchange with relatives], I think I've already done enough [searching for information] myself. I was already a little doctor" (male, 50 years). "I actually knew everything. If I already know everything, then why should I still talk" (female, 60 years).

Sometimes conflicting needs or interests in information exchange led to disagreements in the family. Nevertheless, often the interviewed family members accepted the patient's preferred interaction styles. For example, one wife (70 years) described that she did not want to interfere because of her husband's level of knowledge. "My husband is the type of guy who keeps himself very well informed. I don't want to be his doctor. He tells me that I say nothing or little about it, but I know that he has been very well informed." Thus, a higher level of knowledge seemed to result in a lower dependency on family members, whereas patients with lower levels of knowledge and unmet needs for information relied more often on their family members for informational support.

Another reason to reject informational support reported by patients and family members refers to the lack of competence and "half-knowledge" (female, 67 years) of relatives. "Why should he [husband] ask me for advice? I could not give him any, because I had no idea either" (wife, 67 years). A prerequisite of informational support seemed to be medical competence of family members based on either (professional) medical knowledge or one's own experience with arthroplasty. A 59-year-old male patient described this stating, "Actually, we have exchanged relatively little. My relatives do not yet have any experience with this topic. I was the first one." In contrast, a male patient (59 years) emphasized, "My wife was a nurse. Especially concerning pills and medicine, I trust her."

However, the exchange of information may not only be inhibited by the patient, but a low level of informational support may also be caused by a lack of interest of relatives. For example, a 60-year-old female patient described that her husband was not interested in searching for and discussing medical information. She depicted her husband in the following statement: "Before he [husband] himself was affected, he was not the most empathetic or the most interested one. We didn't talk about it that much." So, she is forced to cope with the situation "independently" of her husband. Conversely, it can be assumed that higher interest and health orientation of family members can enhance family involvement.

The fourth and last form of support is directly related to decision-making. Overall, the patients described their families' involvements in treatment decision-making for surgical procedures ranging along a continuum from patients' autonomous decision-making to collaborative decision-making and to delegation of responsibility to family members. While some patients wished to make an autonomous decision and thus avoid the in-

volvement of their family, others relied on their family members. The described continuum is illustrated by the following comments:

“I didn’t really involve my family in my treatment decision. I just told them that it has something to do with my hip and that I need to go to the hospital” (female, 61 years).

“I talked to friends and, of course, to my wife. In the end, it was my decision or rather our decision” (male, 66 years).

“In order to make a decision, I heavily relied on the judgment of my friends and family” (female, 53 years).

Turning to the factors associated with the amount of decisional support, the patients reported that their level of knowledge made a difference. A higher level of knowledge seemed to be closely linked to self-confidence and self-efficacy as well as related to the wish to make autonomous decisions based on the opinion that the patients know best for themselves. One female patient (67 years) stated, “That’s my personal decision; it’s my character; that’s me. I know what I need and, therefore, I know best what’s good for me.”

In contrast, medical expertise of relatives seemed to increase the delegation of responsibility for decision-making. Thus knowledge asymmetry between the patient and the family member can be understood as another reason for a higher or lower family involvement in decision-making.

When family members provide decisional support, it can refer to various decision-making situations. These include the choice of the physician, the decision for surgery or an alternative treatment, and the timing of the surgery. Family members (including friends) recommended physicians and clinics, which the patient often accepted. In addition, patients and family members often discussed the decision. Family members were a much appreciated discussion partner for decisions about the choice of implants and the weighing of pros and cons regarding the surgery. They acted as advisors who helped to prepare patients for an upcoming medical consultation, accompanied them to the physician, or discussed the explanations and suggestions of the physician after the consultation. “It was more about the information that I got from the doctors. I asked my family and friends, ‘How do you see it or would you do it this way, too?’” (female, 45 years). This type of decisional support helped to increase certainty in decisions, because the assessments received from family members improved the patients’ understanding of the circumstances of their disease. In addition to medical arguments, the quality of life, such as joint physical activities, was also taken into consideration. One female participant (56 years) described her decision-making in this way: “The most important thing was to weigh the two possibilities against one another with the help of my friends. It’s where you ask yourself, ‘Is this the right decision?’”

Apart from the content-based evaluation of information for decision-making, the family members also actively encouraged the patients’ decision-making. In some cases, they motivated the patient to make a decision, sometimes even demanding it. Some patients pointed out that their final decisions were strongly encouraged by adamant family members. Patients and family members described this in the following statements: “In order to decide on a surgery, a conversation in which they [family] tell you that you should do it because it helps can be quite helpful. That means they encouraged me to do it” (female pa-

tient, 56). "And we all kept telling him, 'Go to a doctor. Go and see a doctor.' That means I supported him by telling him that he should do something about it" (wife, 65).

In evaluating decisional support, patients were predominantly in favor of family members' involvement in decision-making and even actively asked for support. The outcomes of family involvement included a higher ability to make decisions, the reduction of uncertainties, and the assurance that the decision would be mastered together with all consequences. However, some of the patients' difficulties in making decisions resulted in a lack of understanding by family and caused conflicts. "Because he is so afraid of surgeries, he kept delaying it. And I don't understand that" (wife, 65 years). The patients sometimes felt misunderstood, patronized, and urged to make a certain decision. "The disputes were rather that my wife wanted to enforce certain things. For example, I should definitely go to a chiropractor before the surgery" (male, 62 years). However, the interviews did not show that these conflicts had a lasting impact on the decision or patients' satisfaction with the decision.

3.3 *General circumstances of family involvement (RQ3)*

To answer the third research question, we explored the general circumstances of family involvement. Based on patients' answers and on the comparison between different patients and their personal characteristics, we distinguished three dimensions of general circumstances: health-related, patient-related and relationship-related factors. These circumstances seem to be generally associated with the patterns of family involvement and the role of social support.

Health-related circumstances. Different stages and states of the disease as well as the behavior of the physician are important factors in the decision process (see RQ1). The patterns of family involvement are related to the perceived burden of the disease and the urgency of the pain. However, the general health conditions of the patients in this sample seemed relatively good. Only one female patient showed poor general health associated with a high age of 88 years. In this case, the patient no longer actively participated in the decision-making process and her son took more responsibility. Nevertheless, on the basis of comparison of different courses of disease, it can be concluded that greater physical and mental impairments increase patients' need for family involvement across all types of support and cause higher dependency. Furthermore, the need for support changes during the course of the disease and the treatment. In an early phase, the need for emotional and informational support is predominant. Caused by increasing physical and mental impairments, attitude formation toward the surgery and decision-making become an important subject of discussion between patients and family members. Following surgery, informational support is still relevant due to the high uncertainty of coping with daily life and temporary physical impairment, but emotional and instrumental support are most needed after surgery.

Patient-related circumstances. Several patient-related circumstances seemed to be relevant for the patients' needs for support by family members. In particular, age and sex of patients seemed to be relevant in their need for informational support. Keeping the small sample in mind, it appeared that especially younger patients were more autonomous in their decision-making, while older patients expected the physician to give them advice.

The latter also tended to delegate the decision to someone else or wanted to involve family members in a collaborative decision-making process. Some men named their wives as important family members for their decision-making, and often stressed that their involvement was very valuable.

In addition, the demand for family support could also be restrained by concerns about the family and the partner. This includes not wanting to bother family members and the wish to protect them from stress. “Actually, I don't want to bother them with my problems. You have to determine how much you can burden your family, especially when they may not be doing so well” (female, 45 years). Such a feeling could be powerful in situations where the need for support is very high, but the patients perceive themselves as a burden to their family. The interviewed family members often had a different perception, as they saw their support as natural and unconditional.

Relationship-related circumstances. Trust and closeness of relationships between patients and their family members affected the pattern of involvement as well as the role of social support. Trust in family members was based on emotional connection and common experience and led to a higher perceived value of support despite their lack of medical expertise. Some participants described the role of family members saying, “That’s just because you trust these people and, therefore, their support plays an essential role” (female, 53 years). “I trust my social environment, because they know me. They know what I’m like, emotionally and so on” (female, 45 years).

4. Discussion

Our study provides new and in-depth insights into the relatively unexplored area of elective surgery decision-making and the role of social support for family involvement in non-life-threatening diseases, which expands the understanding of decision-making within broader social contexts. This is particularly important because previous research about family involvement in decision-making has largely focused on cancer patients (and similar life-threatening diseases) and their family members. Our results demonstrate that perceived characteristics of the disease and elective surgery constitute a special decision-making situation, which is distinct from other decisional contexts. The long-term but unpredictable (nevertheless gradually deteriorating) development of the disease, the uncertainty about the outcomes of the surgery, and a perceived lack of decisional support by the physicians seem to be specific conditions. As long as the pain or the functional limitations are not too acute or too prevalent, there seems to be more time for the deliberation of the chances and risks of the surgery and the involvement of family members. Thus, social support by family members, such as partners, relatives and close friends plays an important role in decision-making of non-life-threatening chronic diseases.

Similar to previous studies about family involvement in cancer treatment (Krieger et al. 2017; Laidsaar-Powell et al. 2016; Lamore et al. 2017), the pattern of family involvement in patient decision-making varies on a continuum from a patient-led to a family-led (Laidsaar-Powell 2015) or from inclusion to exclusion (Lamore et al. 2017). While some

patients decide independently about the surgery, others prefer to decide collaboratively with a companion or even delegate the decision to family members (Krieger 2014).

In our sample we identified all social support functions (informational, emotional, instrumental) of family involvement that were described in the TRIO framework of triadic decision-making (Laidsaar-Powell et al. 2017b), and all supportive (independent, collaborative, delegated) types of family involvement that were described in the DECIDE typology for family communication in cancer care (Krieger 2014). In addition, these functions can be further differentiated. One further dimension distinguishes whether the support influences decision-making indirectly or directly, while another considers whether the patient evaluates the support as supportive.

The rather indirect influence of social support on decision-making might consist of informational, emotional, and instrumental support. Surrogate seeking, sharing knowledge, recommendations about information, and discussion of the information were part of the informational support of family members in health communication. However, compared to surgical decision-making in cancer treatment (Lin et al. 2017), emotional support and instrumental assistance of family members seem to be less relevant for the patient, but they are still relevant to the patterns of family involvement.

A direct form of social support influencing the surgical decisions can be found in the overt sharing of opinions and preferences about arthroplasty. Thus, our findings provide empirical support for the demand by Krieger et al. (2017) to distinguish between communication behaviors of informational, emotional, or instrumental support and those that are directly relevant for treatment decisions. In addition, decisional support also includes demanding a decision, evaluating the physician's information, or simply supporting the decision independent of the outcome.

With regard to the evaluation of the support by the patient, most patients consider the received family involvement as supportive. However, we could also identify a kind of "isolated type" as outlined within the DECIDE typology (Krieger 2014), which describes patients whose need for decisional support have not been satisfied. In contrast to Krieger's (2014) findings, in our study it is the physician who does not fulfill the expectations rather than the family members. Therefore, instead of strengthening the autonomy of the patients against a supposed paternalistic physician, family members are involved to compensate for the lack of decisional support provided by the physician who—from the patients' perspective—merely fulfill an informative role (Emanuel & Emanuel 1992). Family members seem to overtake functions of formal support systems (Künemund & Vogel 2006). In this sense, our findings might be generalized beyond the current case of arthroplasty patients to other complex decisions about medical interventions without an acute life-threatening reason and where the long-term consequences are less clear. This could also imply that medical factors, for example, the specific characteristics of the disease and the patient, such as the burden of the disease, the perceived risk of the surgery, and the patient's age (Lin et al. 2013a), are equally or even more relevant than the communication behavior of a physician.

This argument is supported by the fact that physicians' behavior seems to change in interactions with older patients. Previous findings also report that older patients are regarded as less independent, which means that these patients are offered more support (Nussbaum et al. 2014). As reported in other studies (Xie et al. 2014), older adults tend to

prefer a passive role in treatment decision-making compared to younger adults by delegating the decision either to the physician or to their family. Their higher preference for collaborative decision-making might be explained by their higher need for instrumental and informational support.

The findings also highlight the need to include non-threatening diseases and their therapeutic options in order to gain a more differentiated view on communication dynamics in health decision-making. Due to the long period of time available for the decision, it is possible to include several family members as well as friends in the decision-making process. In contrast to social support in cancer treatment or other more urgent decision-making situations (Arrington 2005; Lamore et al. 2017), weak-tie, i. e. peripheral relations could also provide important support givers, such as distant family members (Tanis et al. 2011). The inclusion of a wider social network might also be caused by the less stigmatized character of a hip or knee surgery. In comparison to cancer patients, patients with arthrosis might be less reluctant to disclose their diagnosis to people in their wider social network (Hay et al. 2009). As arthroplasty is quite prevalent among the elderly (Bawa et al. 2016), it might be easy to gain access to individuals in similar situations. The same applies for other prevalent chronic diseases like diabetes or heart disease. Thus, a wider social network of support resources should also be considered in future research.

In addition to the specifics of the decision process of arthroplasty, we have also determined several general characteristics of health status, the patient, and the family members that are relevant to the patterns of family involvement and the role of support.

Empowerment or independence orientation (Fumagalli et al. 2015; Alden et al. 2018) of the patient or the family member, expressed either as knowledge base, self-confidence, self-efficacy, health orientation, or medical expertise seems to be a key determinant of family involvement in medical decision-making. Patients with high empowerment are less likely to involve those family members with low empowerment. A strong and close relationship as well as the need for instrumental support (before or after the surgery) increase the extent of family involvement. This mirrors results of a recent triadic qualitative study in cancer treatment decision-making (Laidsaar-Powell et al. 2016), where interviewed health professionals proposed that the pre-existing, patient-family relationship dynamics were relevant for family involvement among their patients.

Further research is clearly needed to better understand the mechanism between diverse participants (i.e. partners vs. adult children) or cultural differences (Alden et al. 2018) within the family dynamics. The patterns and circumstances of family involvement in medical decision-making models in collective societies, such as Taiwan, might be very different from those in Western societies, which tend to be characterized by individualism and autonomous decision-making (Lin et al. 2017; Lin et al. 2013b).

4.1 Limitations and future research

The generalizability of the present findings may be limited as the recruitment of family members only relied on the patient-centered interviews. As is generally the problem with samples derived from self-selection (Browne & Chan 2012), family members who participated may be more health-conscious or have a closer relationship with the patient than the general population. Thus, we might not have gained a strong insight into non-supportive

forms of dyadic coping (Bodenmann 2008) in our study. Second, we only considered responses by patients and their nominated family member. It is possible that interviews with clinicians or multiadic analyses of different family dyads (Manning & Kunkel 2015) may yield discrepant results. For example, clinicians or other family members may report a perception of the decision-making and their role in it that is incongruent with the patients' perception. Third, the interviews represent self-reports, which may have led to memory biases inherent in retrospective recall. These limitations call for additional studies that follow triadic approaches (Laidsaar-Powell et al. 2016) and attempt to cover the diversity and systemic dynamics of family communication (Manning & Kunkel 2015) longitudinally in order to better account for variations between patients, family members, and stages of disease and treatment.

4.2 Conclusion and practical implications

Our study has revealed that family members play a significant role in identifying, transmitting, and translating health information (Cutrona et al. 2015) and are important resources in health communication. More consideration in theory, empirical research, and medical practice needs to be given to family members' relationships with and the function of their support for the patient. Social network analyses, observation studies (Hauke et al. 2011), and dyadic and triadic interviews (Shin et al. 2013) should be used to explore the social and emotional relations in medical decision-making across different types of chronic diseases and treatments (Schaeffer & Haslbeck 2016).

Our results have two major practical implications. First, due to the differing levels of involvement of family members, clinicians should ascertain the patients' preferences of decisional support and remain open to the varying forms of social support and family involvement in decision-making. If greater family involvement is preferred, then family-inclusive consultation strategies are obviously advantageous (Laidsaar-Powell et al. 2016). Physicians might invite family members for triadic consultations and encourage patients to deliberate decisions with family members.

Second, given the perceived lack of support by the physicians for which patients try to compensate by consulting with family members, the health literacy of these family members should be improved. More information could be provided to those who live with arthritis (Carpenter et al. 2015) or diabetes patients (Reifegerste & Hartleib 2016). With information-seeking as a major factor in health-related decision-making, family members should be informed about their important role. In addition to the triadic consultation, this could also be done by providing health information with content and functions that fulfill the special information needs of family members, which are known to often remain unsatisfied (Washington et al. 2011). Providing family members with such information could improve the empowerment of family members and patients suffering from chronic diseases. However, further studies are needed to confirm these findings for other diseases and to explore information-seeking activities in other decisional circumstances before strategic communication targeting family members can be developed and released.

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Information in German

Deutscher Titel

Die Beteiligung von Familienmitgliedern im Kontext chronischer Erkrankungen: Die Rolle der sozialen Unterstützung in der Entscheidungsfindung bei operativen Eingriffen

Zusammenfassung

Besonders wenn medizinische Entscheidungen zu komplexen Behandlungsmöglichkeiten (wie operativen Eingriffen) von den Patienten als Herausforderung wahrgenommen werden, können Familienmitglieder sie mit Rat und Gesundheitsinformationen unterstützen. Die bisherige Forschung hat sich größtenteils auf die Beteiligung von Familienmitgliedern in der Gesundheitskommunikation bei Krebserkrankungen fokussiert. Daher mangelt es an Untersuchungen, die die Familienbeteiligung bei nicht-lebensbedrohlichen chronischen Krankheiten wie Arthrose betrachten. Wir fokussieren im Besonderen die Rolle der sozialen Unterstützung für die Beteiligung von Familienangehörigen in solchen Situationen. Vor diesem Hintergrund, haben wir qualitative Leitfadeninterviews mit Arthrose-Patienten und ihren Familienmitgliedern durchgeführt (n = 32 Patienten; n = 8 Angehörige). Um die Beteiligung von Angehörigen bei medizinischen Entscheidungen besser zu verstehen, wurden drei Fragestellungen analysiert: (1) Was sind die wahrgenommenen Eigenschaften der Entscheidungssituation für die Implantation einer Endoprothese? (2) Welche Muster der familiären Beteiligung existieren hinsichtlich der sozialen Unterstützungsfunktionen? (3) Welche generellen Rahmenbedingungen sind relevant für die Beteiligung der Familienmitglieder? Unsere Ergebnisse zeigen, dass die soziale Unterstützung eine wichtige Rolle für die Beteiligung der Familienmitglieder an medizinischen Entscheidungen spielt. Instrumentelle, emotionale und informationelle Unterstützung können die Beteiligung indirekt erhöhen. Außerdem sind die Familienmitglieder auch direkt am Entscheidungsprozess beteiligt und initiieren die Entscheidungsfindung. Die Art der Beteiligung wird durch Merkmale der Entscheidungssituation beeinflusst. Neben Eigenschaften der Personen, spielt hierbei die Beziehung zum Arzt eine wichtige Rolle. Diese wird teilweise als wenig unterstützend wahrgenommen, was den Bedarf der Patienten an Unterstützung durch die Familienangehörigen erhöht.

Schlagwörter: Familienmitglieder, Gesundheitskommunikation, Informationssuche, Entscheidungsfindung, soziale Unterstützung

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