

Article

Identifying Uncertainty-Specific Health Information Seeking Practices in Orthopaedic Implant Patient Journeys

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Findings of a Qualitative Interview Study

Charlotte Schrimppff , **Tanja Fisse**¹ 

Hanover Center for Health Communication, Hanover University of Music, Drama & Media, Germany

Elena Link 

Department of Communication, Johannes Gutenberg University Mainz, Germany

Eva Baumann , **Christoph Klimmt** 

Hanover Center for Health Communication, Hanover University of Music, Drama & Media, Germany

Abstract

Uncertainty is an inherent part of illness that is assumed to vary over time. However, little is known about which kind of uncertainties occur during a chronic illness and how patients manage them at different times. To explore the dimensions of patients' uncertainty perceptions and management strategies, such as health information seeking behaviour, over the course of the disease, we draw on uncertainty management theory and patient journey mapping. We conducted qualitative semi-structured interviews with 19 patients who had received a knee or hip replacement. We found distinct patterns of uncertainty perceptions related to physical, psychological, social/personal, and treatment-related issues in six different phases of the patient journey. Uncertainty perceptions were multi-layered and interconnected. We also found that uncertainty management strategies, such as information seeking, were highly targeted to the uncertainty at hand. Furthermore, our results revealed a high degree of context-specific uncertainty management strategies over the course of a patient journey.

¹Charlotte Schrimppff and Tanja Fisse contributed equally to this article and should be considered co-first authors.

Corresponding author:

Charlotte Schrimppff: charlotte.schrimppff@ijk.hmtm-hannover.de

Keywords

Uncertainty management, health information-seeking behaviour, patient journey, qualitative semi-structured interviews.

For patients, the diagnosis of an acute or chronic disease is associated with uncertainties, for example, concerning the condition, treatment options, or long-term prognosis (Bolz-Johnson et al., 2020; Brashers et al., 2003; Kuang, 2018). As chronic conditions develop over a long period, uncertainty perceptions may arise in different situations and on different issues, and may therefore change over time (Brashers, 2001; Kuang & Wilson, 2017). However, most studies of disease-related uncertainty perceptions and management strategies are not as granular in distinguishing and describing uncertainties during different phases of a disease (Brashers et al., 2003; Kuang & Wilson, 2017). Little is known about when during the disease these uncertainties occur (Martin et al., 2010), and how patients manage them at different points in time (Kuang & Wilson, 2017). However, this knowledge would be crucial to identify critical points in the patient journey where patients' own uncertainty management (UM) is not effective, potentially affecting their emotional well-being and treatment outcomes (Guan et al., 2021; Strout et al., 2018). Therefore, the aim of the current study is to examine situational Health Information Seeking Behaviour (HISB; Lambert & Loisel, 2007) practices for managing uncertainty over the course of an illness. This is important for theory specification as well as for deriving strategic health communication interventions. Information tailored to patients' situation-specific needs is essential to support patients throughout their PJ, which can lead to improved well-being and health-related outcomes (Guan et al., 2021).

To explore the dimensions of patients' uncertainty perceptions and commonly reported UM strategies over the course of the disease, we draw upon Uncertainty Management Theory (UMT; Brashers, 2001) to identify the characteristics and occurrence of uncertainty perceptions and UM strategies, and Patient Journey Mapping (PJM) to assign them to different points in the illness trajectory (Devi et al., 2020; Webb et al., 2022). UMT is a well-established theory in health communication that has often been studied in the context of illness-related information seeking behaviour (Kuang & Wilson, 2017). At the same time, the dynamic, complex, and interconnected nature of the theory requires its detailed exploration in the context of an illness trajectory. PJM enables the focus on perceived uncertainties throughout the treatment process from the patient's perspective. PJM takes into account different stages of treatment - from initial symptoms to completion of treatment (Devi et al., 2020; Webb et al., 2022). It is used to identify potential gaps and areas for improvement in patient care (Webb et al., 2022). Therefore, integrating UMT and PJM is an appropriate way to better understand how treatment progress and uncertainty are related in implant patients (Bolz-Johnson et al., 2020; Brashers et al., 2003).

As a case study of uncertainty-specific HISB, we focus on orthopaedic arthroplasty as it is one of the most common surgeries in Germany (Grimberg et al., 2023). Knee or hip implants are often inserted after years of progressing symptoms such as joint pain and immobility (Drihan et al., 2020). In addition, the patient journey is characterised by well-separated and concise individual diagnostic and treatment-related episodes (Grimberg et al., 2023). Therefore, we believe that this disease context provides valuable insights for studying uncertainty-specific HISB.

Theoretical Background

The Characteristics of Uncertainty in Illness

Uncertainty is an inherent part of illness (Kuang, 2018; Mishel, 1990, 1999). According to Brashers (2001), uncertainty arises when situations are ambiguous, complex, and unpredictable. Uncertainty is a self-perception that can be triggered by a person's experience of a situation or issue and its relevant features (Brashers, 2001). In the case of illness, unavailable and conflicting information, the patients' perceived level of knowledge, the nature of medical evidence, and highly complex expert knowledge, can lead to uncertainty perceptions (Babrow et al., 1998; Brashers, 2001).

Uncertainty perceptions are characterised by their multi-layered, interconnected, and temporal dynamics. Focusing multi-layered uncertainties in chronic illness, medical uncertainties (e.g., symptom patterns, diagnosis, prognosis, treatment options), social uncertainties (e.g., professional, or personal relationships), personal uncertainties (e.g., abilities, beliefs, personal roles, life plans; Brashers et al., 2003; Kuang, 2018), or financial uncertainties (Martin et al., 2010; Romo et al., 2022) are commonly reported by patients. The interconnectedness of uncertainties is demonstrated by the simultaneous and overlapping nature of their occurrence. The temporal dimension is reflected in the fact that uncertainties can be either "short-lived or ongoing" (Brashers, 2001, p. 481) and change over the course of the disease (Martin et al., 2010). Uncertainty perceptions can therefore occur at different points and in different intensities and combinations during a disease (Stone & Olsen, 2022).

The direct consequence of the perception of uncertainty is its appraisal: In the case of a negative appraisal, uncertainty is perceived as a threat (Brashers, 2001). Events or issues that lead to a negative valence of uncertainty may be perceived as challenging and stressful (Kuang, 2018; Martin et al., 2010). In the case of a positive evaluation of uncertainty, it is perceived as an opportunity that makes one feel hopeful. In the case of a neutral appraisal, the emotional perception of uncertainty has no valence. The different appraisals lead to different goals for UM: reducing, increasing, and maintaining uncertainty (Carciooppolo et al., 2016).

Strengthening the Processual Perspective on Uncertainty in Illness

The conceptualisation of uncertainty as a potentially multi-faceted individual experience of a situation with distinct appraisal is related to the conceptualisation of PJs (Devi et al., 2020; Webb et al., 2022): PJs systematically map the patient's medical, emotional, psychological, and social experiences over the course of a treatment (Webb et al., 2022). Although there is considerable theoretical knowledge about the dynamic characteristics of uncertainty in illness and its consequences for UM, studies that reflect the multifaceted and temporal nature of uncertainty over the course of actual illnesses are scarce.

Most studies only consider the respective disease as a whole but do not look at specific situations within the illness trajectory and their impact on patients' uncertainty perception and management (Kuang & Wilson, 2017; Link, Baumann, & Klimmt, 2022). Studies that provide this level of detail, for instance, in the context of HIV/AIDS (Brashers et al., 1998), cancer (Dauphin et al., 2020; Liao et al., 2008), and transplantation (Martin et al., 2010), all suggest differences in patients' experiences of uncertainty over time. However, the characteristics of the trajectories of life-threatening diseases such as cancer and HIV might differ substantially from the trajectories of serious, common but less fatal diseases such as osteoarthritis (Brashers

et al., 2003). As uncertainty perceptions per se and the (lack of) success in managing them can affect patients' well-being, quality of life, and treatment outcomes (Guan et al., 2021), it seems important to gain a nuanced view of how illness trajectory and uncertainty perceptions are intertwined. Therefore, we believe that PJM is an adequate tool to take a process-oriented perspective and to assess the occurrence of uncertainties at different points of the orthopaedic implant trajectory. Therefore, we derived the following first research question:

RQ1: What type of uncertainties do orthopaedic implant patients experience at which points of their PJ?

Understanding the relationship between uncertainty perceptions and the stage of the patient journey provides the basis for exploring its implications for UM strategies. HISB is one of the main strategies for dealing with uncertainty (Brashers, 2001).

Health Information Seeking as a Strategy to Manage Uncertainty

HISB can be described as an active or purposeful behaviour by individuals (Zimmerman & Shaw, 2020, p. 176) and includes communicative and cognitive activities related to health information such as information seeking and avoidance (Brashers, 2001), as well as more passive forms of information acquisition, such as information scanning (Ruppel, 2016). The concept has often been studied in the context of illness where information can help to cope with health-threatening situations or to participate in medical decision-making (Lambert & Loiselle, 2007; Zimmerman & Shaw, 2020). In the context of UM, HISB is seen as a primary tool for achieving UM objectives, for example, reducing or maintaining uncertainty (Brashers et al., 2000).

The appraisal of uncertainty influences which information behaviour will be applied (Kuang & Wilson, 2017; Yang & Kahlor, 2013). When uncertainty is perceived as negative, information seeking can help to reduce uncertainty as more information can help to resolve ambiguity (Brashers, 2001; Brashers & Hogan, 2013). However, uncertainty can also be perceived as positive. In this case, HISB may serve to maintain or even increase uncertainty. This can be achieved, for example, by patients' seeking for conflicting information or avoiding information altogether (Barbour et al., 2012; Carcioppolo et al., 2016). Information avoidance can be understood as a deliberate attempt to avoid or delay the acquisition of certain content and sources, or to control the flow of a conversation to maintain or increase uncertainty (Barbour et al., 2012).

As perceptions and appraisals of uncertainty may vary at different stages of an illness, HISB strategies (e.g., information seeking or avoidance) and source selection (e.g., physicians, caregivers, friends, family, pharmacists, or online sources) are influenced by the situation and the nature of the uncertainty perceived (Barbour et al., 2012; Johnson & Meischke, 1994; Nanton et al., 2009). According to Johnson and Meischke's Comprehensive Model of Information Seeking (1993), the selection of sources from which to obtain information is of central importance and a key step in the information seeking process. Criteria for source selection include availability, expected outcome, and trustworthiness (Link et al., 2022a). In this sense, a source may be considered helpful at one time and avoided at another.

Looking more closely at purposeful and needs-based information seeking (Hurne & Gutteling, 2008), empirical evidence suggests that there are differences in the selection of information sources. Physicians, one of the most important sources in the context of illness (Wang et al., 2021; Zimmerman & Shaw, 2020), are often reported to be particularly important

in the diagnosis and decision-making phases, as patients discuss symptoms and treatment options with them (Clarke et al., 2016). Media sources, on the other hand, help patients to gather and validate medical information or seek alternative treatment options (Clarke et al., 2016). Other interpersonal sources, such as family and friends or other people with the same condition, are often sought to address uncertainty about the condition and treatment, to improve understanding of medical information, or to cope with emotional distress (Brashers et al., 2004; Kim et al., 2015; Longo et al., 2010). Accordingly, in addition to the knowledge gain, other outcomes of HISB are conceivable, such as receiving social support (e.g., emotional, and instrumental support; Brashers et al., 2004; Lambert & Loiselle, 2007; Stehr, 2021; Zimmerman & Shaw, 2020).

To best achieve their UM goal in a given situation, patients often do not rely on a single source but combine different sources (Ahn & Kahlor, 2020; Rains & Ruppel, 2016). After each HISB episode, patients assess whether their UM goal has been achieved. If not, a subsequent HISB effort may be triggered and the patient will turn to additional sources (Kuang & Wilson, 2017; Link et al., 2022a). The interplay of sources for UM purposes is captured in the concept of multichannel HISB (Link et al., 2022a). In this iterative process of HISB episodes, it is crucial for the success of UM that the outcome of an episode is perceived as helpful (Brashers, 2001; Link et al., 2022a).

Studies that consider HISB as a means of managing uncertainty often look at the disease or health threat as a whole (e.g., Kuang & Wilson, 2017; Link et al., 2022a; Link et al., 2022b) rather than distinguishing between different uncertainties or situations. However, the multichannel HISB patterns of orthopaedic implant patients found by Link et al. (2022a) suggest a situational basis for UM efforts. Another study by Fisse et al. (2023), which looked at different types of HISB in patients with implants, showed an association between certain goals of HISB and the actual HISB, which could be transferred to the relationship between UP and UM strategies. Depending on the type of HISB, the motives for seeking information differed. For example, action planning was the main motive for implant patients who mainly used physicians as a source. Patients who sought information mainly from their social environment and from affected others were mostly looking for hope. The different motives associated with HISB types may also reflect different perceptions of uncertainty and UM strategies.

To further explore the interplay between uncertainty perceptions at a particular stage of the patient journey and HISB, we derived the following second research question:

RQ2: How do orthopaedic implant patients manage their uncertainties using HISB in different situations across their PJ?

Method

To answer our research questions about implant patients' uncertainty perceptions and UM strategies across their PJs, we conducted qualitative semi-structured interviews.

Participants, Recruitment and Procedures

A total of 19 interviews were conducted with 14 female and five male orthopaedic implant patients aged between 42 and 83 years ($M = 64.6$; see Table 1 for patient characteristics). The relatively high age and gender imbalance of the study participants reflects the clinical reality

of orthopaedic implant patients in Germany (Grimberg et al., 2023; Hawker et al., 2000). Patients reported having had at least one orthopaedic implant (artificial knee or hip joint) implanted, explanted, or reimplanted with within two years prior to the interview. Most of them lived in Germany, one participant lived in Austria.

The patients were recruited in a variety of ways, including leafleting orthopaedic and physiotherapy practices, postings in online communities such as Facebook groups, and direct recruitment from the researchers' social network. We used purposive sampling (Nyimbili & Nyimbili, 2024) to obtain a sample that covered the characteristics of the target patient group in terms of age and gender (Grimberg et al., 2023). In addition, the aim was to reach patients with different levels of education and a wide range of experiences in the PJ. Prior to the interview, the participants were informed about the purpose of the study, their rights as participants, data protection measures in accordance with the General Data Protection Regulation (GDPR), such as the pseudonymisation of their responses and the strict separation of any type of personal data, and were asked for their verbal consent to participate. Recruitment was stopped when theoretical saturation was reached, meaning that no new significant information could be obtained through additional interviews (Francis et al., 2010).

Table 1. Sample Characteristics

Code	Gender	Type of Implant	Age	Area of Residence	Education	General Health Status
P1	Female	Hip (1)	63	Rural	High	Good
P2	Female	Hip (1)	60	Rural	Low	Less good
P3	Female	Hip (1)	56	Rural	High	Average
P4	Female	Hip (1)	55	Urban	High	Very good
P5	Female	Hip (1), knee (1)	64	Rural	High	Good
P6	Female	Hip (2)	63	Rural	Medium	Good
P7	Female	Knee (1)	63	Urban	High	Good
P8	Male	Knee (1)	78	Rural	Low	Very good
P9	Female	Knee (1)	60	Urban	Medium	Good
P10	Female	Hip (1)	55	Urban	High	Average
P11	Male	Hip (1)	67	Rural	Low	Good
P12	Female	Knee (1)	42	Urban	Medium	Less good
P13	Female	Hip (1)	58	Rural	High	Good
P14	Female	Hip (1)	83	Rural	Medium	Average
P15	Male	Hip (1), knee (2)	77	Urban	Medium	Average
P16	Male	Knee (1)	71	Rural	High	Very good
P17	Male	Knee (1)	71	Rural	High	Good
P18	Female	Knee (1)	58	Rural	Medium	Good
P19	Female	Hip (2)	74	Urban	High	Good

Note. The numbers in brackets indicate how many implants of that type the respondent had. The area of residence was divided into *rural* (residence with less than 50,000 inhabitants) and *urban* (residence with 50,000 inhabitants or more). The level of education of the participants was divided into three categories: *low* (lower secondary school or no secondary school diploma), *medium* (middle school diploma), and *high* (at least high school diploma). For the general health status according to the patients' self-report, the five categories *poor*, *less good*, *average*, *good*, and *very good* were considered. None of the participants reported being in poor state of health.

Interviews were conducted by the first authors of the paper between April and November 2022, either by telephone, video call, or face-to-face. Audio-recorded interviews lasted between 30 and 90 minutes and were conducted in German. The transcripts were treated confidentially, with personal information being removed and replaced with pseudonyms. A compensation of €25 was paid to the participants. The study was approved by the Institutional Review Board of the first authors' university (approval number EV LUH 03/2021). The work was funded by the Deutsche Forschungsgemeinschaft (DFG, German Research Foundation) – SFB/TRR-298-SIIRI – Project-ID 426335750.

Interview Guide

Based on the outlined theoretical background of UMT and PJ, open-ended questions were used for the interview guide (see Appendix, Table 2). Patients were asked to describe their disease and treatment history from the time they first noticed symptoms. We asked about perceived uncertainties in specific situations, their information needs, HISB, and HISB outcomes with a focus on source evaluation.

We used a situational approach to help subjects recall their experiences. For each situation (e.g., onset of symptoms, diagnosis, status quo), patients were asked to recall significant situations such as challenges, how they felt, and what sources of information (e.g., physicians, family, media) they turned to manage the uncertainty at hand.

Analysis

For analysis, we transcribed each interview verbatim and conducted qualitative content analysis (Mayring, 2015) using a mixture of inductive and deductive coding to reduce the material to relevant units. The deductive coding scheme (see Appendix, Table 3) was derived from the theory that has also informed our interview guide. Through several rounds of coding, the deductive coding scheme was differentiated and modified during the analysis, resulting in more specific inductive codes from the participants' statements. For example, when a patient mentioned decision making, the main coding of this stage was supplemented with the coding of more detailed uncertainty issues to cover the choice of treating physician or clinic. In addition, information sources such as the physiotherapist were added and the results of HISB efforts (e.g., emotional support) were differentiated. After the iterative category development, evaluation and feedback loops, the detailed codes were summarised into code groups that allowed the discovery of meaningful structures in the data. Coding and analysis were performed by the two first authors of the study using ATLAS.ti version 9. Interim results and ambiguities were discussed and resolved by the team throughout the analysis. We used comparative dimensions (Kelle & Kluge, 2010) to identify uncertainty-specific HISB practices, including the stage of the PJ, uncertainty perception, appraisal of uncertainty, and HISB strategy, focusing on the sources and their evaluation (e.g., their trustworthiness). This approach enabled a comprehensive description of implant PJs and associated HISB episodes (Bengtsson, 2016).

Results

Identifying Uncertainties in the Phases of the Orthopaedic Patient Journey

RQ1 asked about the types of uncertainties experienced by implant patients at different times during their PJ. By mapping the reported uncertainties to different points in time, we were able to identify six distinct phases, characterised by different constellations and intensities of physical, psychological, personal, social, and treatment-related uncertainties (see Appendix, Table A3). We distinguished between the phase of initial symptoms (1), the diagnosis phase (2), the decision-making phase (3), the pre-implantation phase (4), the post-implantation phase (5), and finally the phase of living with the implant (6). These phases are described in more detail below.

Phase 1: Initial Symptoms. Many orthopaedic patients experienced their initial symptoms long before they entered the actual treatment process. This early phase of their disease was primarily characterised by the experience of physical uncertainty, which in turn affected other areas of their lives and was often accompanied by personal uncertainty.

In terms of physical uncertainties, pain was mentioned as a key issue, as well as more indifferent symptoms such as swelling or grinding of the joints, and a general worsening of the condition. Uncertainty perceptions arose when people did not know what to do about it: “Gosh, if there's not a remedy, how is it supposed to go on if you're in constant pain?” (P8, 78, male). Closely related to these perceptions was limited mobility: “When I walked, there was a stabbing, shooting pain in my hip. And there was also this increasing immobility” (P4, 55, female). After the initial uncertainty perceptions, pain and reduced mobility were often accepted, ignored, or endured for a long time without any action being taken. Only when the uncertainty perceptions increased due to a worsening condition did patients consider other strategies to manage with uncertainty.

These experiences also affected other aspects of the patients' lives, causing social and personal uncertainty. Daily tasks (e.g., gardening, going to the bathroom) and leisure activities (e.g., hiking, walking the dog) were affected and became difficult or impossible. Uncertainty also arose about the patient's occupation, as work performance and ability were impaired:

I was an editor at a daily newspaper, and once there was a big event and I needed a cool photo. Everyone else had it and I limped along behind and then only got one bad photo, where everyone turned away, and I thought, that's it now, I can't do it anymore. (P5, 64, female)

For some patients, experiencing initial symptoms was also associated with psychological uncertainty because they feared a “really bad diagnosis” (P9, 61, female) or hospitalisation. In addition, patients were uncertain about treatment because of lack of or inadequate communication and information about diagnoses and treatment options: “The treatment at the orthopaedist was very frustrating. The orthopaedist made all kinds of suggestions as to what it could be: The position of the legs or the wrong shoes or the wrong walking habits, something like that. But none of that applied.” (P9, 61, female).

Phase 2: Diagnosis. After receiving a diagnosis, patients reported two dominant uncertainties, which were treatment-related and psychological. Occasionally, social, and personal uncertainties were also mentioned.

In terms of treatment, patients reported feeling uncertain about the further course of treatment, e.g., different treatment options, urgency of surgery, etc., and the perceived lack of communication and information was reported as a challenge: “The orthopaedist examined me and that was it. I didn't go to see him again” (P13, 58, female).

Psychological uncertainty about the diagnosis was also reported as a problem. Some patients ignored their diagnosis or reacted with incomprehension and anxiety because they felt “too young to be diagnosed with osteoarthritis - the disease of the elderly” (P3, 56, female). Others reported that they had welcomed the diagnosis as a relief because the cause of their pain had been found.

Phase 3: Decision-Making. When patients had to decide for or against implant treatment, they were faced with psychological, social, personal, and treatment-related uncertainties. On the psychological dimension, some patients described decision making as a difficult, highly uncertain process that was often delayed: “I wasn't immediately delighted that I had to be implanted. I have been struggling with it for quite a long time” (P17, 71, male). Perceived lack of options, severe pain (“it was torture”, P13, 58, female), or fear of a worsening of the condition served as decision facilitators. Other patients reported no difficulty with decision making (“a piece of cake”, P5, 64, female), often associated with a high perceived self-efficacy to cope with the challenge.

Regarding treatment-related uncertainties, patients were particularly concerned about what results they could expect. This also included social and personal uncertainties about patients' work life and whether they would be able to carry out certain tasks again: “What goes again afterward, what can you do, what can you not do?” (P3, 55, female). Some patients feared that they would no longer be able to work.

Phase 4: Pre-Implantation. Prior to surgery, patients expressed mainly treatment-related uncertainties, but also physical and psychological uncertainties. Choosing a surgeon or clinic seemed to be the most prevalent treatment-related uncertainty: “I thought about which hospital I wanted to go to, what is reasonable, where are many implant surgeries performed, who has experience?” (P6, 63, female). The surgery and related issues such as anaesthesia were also sources of uncertainty. Other treatment-related topics include organisational *issues* such as when to schedule the procedure or rehab.

In terms of physical uncertainties, pain, and limited mobility were experienced as particularly challenging before the surgery: “I was so incredibly restricted in everything and therefore I was in a bad mood. I just wanted to have this surgery done, I was counting down the days at the end” (P7, 63, female).

For some patients, the planned surgery was also associated with psychological uncertainties such as fear:

The fear was surreal. It wasn't that I thought, ‘Oh dear, I'll be in a wheelchair afterward or something.’ But it was just this fear that you can't justify because I had the information and I assumed very firmly that it would be okay. (P13, 58, female)

Phase 5: Post-Implantation. After implantation, patients most often described physical and treatment-related uncertainties. Patients described complications or suboptimal results of the surgery as treatment-related uncertainties: “The realisation that your own body is not working properly is shocking” (P9, 61, female). For other patients, uncertainties related to the *healing process*, the course of treatment, the organisation of aftercare and rehabilitation, and training measures to restore mobility arose after the surgery: “Sometimes you get impatient because you think: you've been treading water for a week now with the healing progress” (P7, 63, female). Questions about how to behave with the implant were also mentioned by patients.

In addition, post-operative pain or other (mis)sensations caused physical uncertainty: “I was just annoyed that I wasn't told beforehand that it was normal for the leg to feel so heavy. I would have liked to know that in advance” (P4, 55, female).

Phase 6: Living with the Implant. After completing rehab, most patients returned to their daily lives, and treatment was considered complete. This is also reflected in the rather low number of reported uncertainties, especially when the treatment had produced satisfactory results.

Uncertainties mostly related to treatment-related therapeutic measures such as physiotherapy. For patients with suboptimal treatment outcomes, these complications continue to be an issue: Physical uncertainties, such as *pain* in the implanted part of the body, pain due to preoperative posture, or sensitivities were mentioned: “Basically, not one day goes by that you don't notice you have a new knee” (P16, 71, male). In addition, there were social and personal uncertainties, e.g., about reintegration into work or everyday life: “You are not prepared for the fact that knee replacement implantation will mean a big change in your life. You will no longer be able to do everything you want” (P16, 71, male).

Summary: Uncertainties in the Orthopaedic Implant Patient Journey. In summary, characteristic patterns emerged regarding the types of uncertainties per treatment phase, showing the temporal nature of uncertainty: in the phase of first symptoms, physical and social/personal uncertainties predominated, whereas in the diagnosis phase, uncertainties were mainly related to the upcoming treatment and the psychological coping with the diagnosis. In the decision-making phase, there were psychological uncertainties, social uncertainties related to work and social life, and uncertainties related to the treatment. In contrast, in the pre-implantation phase, uncertainties were mainly related to the treatment, as well as physical and psychological uncertainties were experienced. Post-implantation, treatment-related uncertainties were most prevalent, accompanied by few physical and psychological uncertainties. After returning to everyday life, the patients rarely reported any uncertainties. When they did, the uncertainties could be categorised as physical, personal/social as well as treatment-related. The fact that several uncertainties occurred in one phase illustrates the multi-faceted and interconnected nature. For example, experiencing pain also affected patients' social and personal lives, or having to decide for or against implant treatment caused psychological uncertainty but also led to questions about one's work life.

Uncertainty-Specific Health Information Seeking Behaviour

In RQ2, we asked how orthopaedic implant patients manage their uncertainty using HISB. We found that information seeking was a regular strategy for orthopaedic implant patients to deal with different types of uncertainty. All participants used HISB to manage at least one

uncertainty. Different HISB practices were identified for different types of uncertainty and at different points in the PJ. The interviewed patients referred to various sources that could be grouped into five types: First, we found three types of interpersonal information sources, namely sources with medical expertise such as physicians or medical staff such as physiotherapists, as well as sources with experiential expertise such as (former) patients. Interaction with affected others took place both offline and online through self-help groups. We also found that people in the patients' social environment, such as partners, family members, or colleagues, were important interpersonal sources. In addition, media sources such as print and online media were reported as a fourth type of source. The fifth type of source was institutional sources such as insurance companies or implant manufacturers. In Table 2, we have summarised the occurrence of HISB by type of uncertainty and phase in the PJ. We also qualified whether a source was considered helpful or not.

Overall, orthopaedic implant patients showed a preference for interpersonal sources and often turned to their physician first. In the following, we will describe the most characteristic HISB practices for each type of uncertainty regarding the respective phase of the PJ.

Physical Uncertainties. Physical uncertainty was reported when patients first noticed symptoms, before and after the implantation, and during rehabilitation. When faced with physical uncertainty, patients focused on interpersonal sources with medical expertise, such as physicians and medical staff. Looking more closely at the most common physical challenge, pain, physicians were the first source patients turned to. UM was perceived as successful when physicians provided information, instrumental as well as emotional support, when they offered treatment that relieved pain, when they informed the patient about previous inadequate treatment, when they encouraged the patient, or when they gave the patient confidence to make decisions about the further treatment: "I finally went to the orthopaedist. He encouraged me and said he wouldn't wait another year with the condition. He told me to be courageous and to trust him" (P14, 83, female).

Conversely, consultation with physicians was perceived as less helpful in managing uncertainty when physicians did not seem to take the patient's suffering seriously, when they did not make a diagnosis, when they gave incorrect or unpromising advice, or when patients felt that they were recommending implant surgery mindlessly. During rehabilitation, the physiotherapist became a second important source with medical expertise to discuss pain and its resolution. Patients also used media, such as search engines, to obtain information about their health status and healing process, or they turned to sources with experiential expertise, such as other patients, for information and emotional support:

What I learned from this Facebook group: It takes time. If I hadn't read that so often, I might have been running to the doctor all the time, whining 'this doesn't fit and that doesn't fit.' That's the biggest benefit, that you're reassured, but that you also know when something might be an issue. (P5, 64, female)

Table 2. Patient Journey of Orthopaedic Implant Patients According to Reported Uncertainty Perceptions And HISB-Practices

Category	Uncertainty/Issue	Source	Patient Journey					
			Initial Symptoms	Diagnosis	Decision Making	Pre-Implantation	Post-Implantation	Living with the Implant
Physical	Pain	ME	++/--			++	++	+/-
		EE	+					
		SE	+			+		
	Mobility	MS				+		
		ME	++/--					
		EE	+					
		SE	+					
	Other physical issues (e.g., discomfort)	MS	+/-					
		ME	+/-				+	+/-
		EE					+	
SE								
Psychological	Stress (e.g., fears, anxiety)	MS						
		ME		++	++	+		
		EE		+	+	++		
		SE			++	+		
		IS			++/--	+/-		
Social and personal	Work	ME	+		+/-			
		EE			+			+/-
		SE	+		+			+
		MS			+/-			+/-
	Personal life (e.g., leisure activities; relationships)	ME	+/-					+
		EE						
		SE	+					+
		MS	-					+/-
		ME	++/--	++/--	+/-		++/--	

Category	Uncertainty/Issue	Source	Patient Journey							
			Initial Symptoms	Diagnosis	Decision Making	Pre-Implantation	Post-Implantation	Living with the Implant		
Treatment-related	Information and communication about treatment	EE					+			
		SE	+				+			
		MS		+/-	+/-		++/--			
		IS								
	Outcome expectancies/actual outcomes (e.g., complications)	ME			+			++/--	++/--	
		EE			+/-			++	++	
		SE						+/-		
		MS			+			+/-		
		IS						-		
	Technical and bureaucratic procedures (e.g. Concerning diagnosis, rehab)	ME						++	++/--	
		EE						+	+	
		SE						+	+	
		MS							+/-	
		IS						+	--	
		Choice of treating physician/clinic	ME						++/--	
			EE						++/--	
	SE							+		
	MS							+		
	Training/aftercare/rehabilitation	IS								
		ME							++/--	+
EE								+	+	
SE									+	
MS										
		IS							-	

Note. ME = interpersonal sources with medical expertise (e.g., physicians, medical personnel); EE = interpersonal sources with experiential expertise (e.g., other patients); SE = people from the patient’s social environment (e.g., family, friends, colleagues); MS = media sources (e.g., online and offline media); IS = institutional sources (e.g.,

insurance companies, manufacturer); + = source used & rated helpful; ++ = source often used & rated very helpful; - = source used & rated not helpful; -- = source often used & rated not helpful at all; +/- = source used & rated ambivalently; ++/-- = source often used & rated ambivalently.

Psychological Uncertainties. Psychological uncertainties were reported up particularly in the early phases of the patient journey and were met with very distinct HISB-practices: While perceptions of fear and a desire to ignore symptoms during the initial symptom phase did not trigger any seeking behaviour or source use, the decision for or against implantation involved intensive multichannel HISB. Patients reported using multiple interpersonal and media sources in combination to obtain a nuanced picture:

Because I have many acquaintances with a medical profession, I was able to have conversations with various physicians. I have also obtained many articles from the Internet, especially professional articles. [...] I have read clinic reviews, therapy reviews, surgery reviews, and material reviews. I have tried everything to inform myself beforehand. (P3, 56, female)

Media sources, such as online sources or information material provided by physicians or clinics, were rated as helpful in decision making because they generally provided good and comprehensive information, although patients mentioned the need for some literacy in order to filter relevant information from the plethora of information available online: “Depending on your own background, you can easily run the risk of taking everything you read at face value. You have to question very well” (P3, 56, female).

Experiential expertise was obtained from (former) patients. The exchange took place both offline and online, for example, via Facebook groups, and was predominantly perceived as helpful in reducing uncertainties in the decision-making process: “After everything I knew from the (Facebook) group, I didn't really need much help deciding” (P5, 64, female).

Medical expertise was also frequently sought. Physicians generally enjoyed a high level of trust, especially when they were perceived as experienced, and their communication was encouraging, reassuring, and educational: “Talking to the surgeon was very positive and informative for me and it encouraged me in the decision” (P1, 65, female). On the other hand, patients were sceptical if the physician provided information that they felt was insufficient or if they suspected economic self-interest.

Patients' social environment was consistently perceived as a valuable source of advice. Close relatives such as patients' parents or partners were trusted sources and supported the decision, for example, by acting as surrogate seekers (“My partner has asked some of her friends which doctor treated them and with which they were very satisfied”, P17, 71, male), by participating in the decision making, by discussing possible consequences (“I have consulted with my wife”, P16, 71, male), or by providing general emotional or instrumental support:

I had nightmares beforehand. But I had a very dear colleague who said she would take over for me. She then prayed for me and from that point on I felt better, whether you believe in it or not, from that point on, I was more relaxed. (P13, 58, female)

Some patients also emphasised that they relied on their own experience, (professional) knowledge, and skills (“I was also trained as a PTA 30 years ago, so I understand the medical terminology quite well”, P5, 64, female).

Patients who reported feeling anxious actively avoided information and certain sources: “I didn’t join a Facebook group before the surgery because I know myself and of course there are a lot of horror stories out there” (P4, 55, female).

Social and Personal Uncertainties. Professional and social uncertainties were particularly present at the beginning and end of the PJ. To manage uncertainties related to their personal and professional lives, they rarely sought information to gain additional knowledge. When they did, they turned to their social environment such as their partners or colleagues for emotional or instrumental support:

I have a really great employer and above all I have a new, awesome boss. [...] He always made sure you were okay. And the company did everything to support me.
(P13, 58, female)

Treatment-Related Uncertainties. Treatment-related uncertainties were reported throughout the PJ, but with changing emphasis. Initially, uncertainty was caused by a lack of general information and knowledge about treatment, but as treatment progressed, more specific issues such as technical and bureaucratic procedures or rehabilitation measures became sources of uncertainty.

The choice of treating physician or clinic in the pre-implantation phase was a key treatment-related uncertainty, accompanied by a characteristic pattern of multi-channel HISB. To reach a decision, patients turned to a variety of equally important interpersonal and media sources: “I have a couple of doctors among my friends who gave advice. Then I googled and attended two orthopaedic surgeons in private practice to weigh opinions, and then I visited three or even four clinics” (P4, 55, female). Among these sources, physicians played an important role as interpersonal sources with medical expertise - either because they would perform the surgery themselves or because they recommended a colleague. As it was not easy for patients to determine objective criteria for the suitability of a surgeon or clinic, such as the number of successful surgeries or the surgeon’s expertise in the respective field (“Very experienced surgeons, immediately felt comfortable there”; P6, 63, female), patients often relied on secondary evaluation criteria, such as their communication skills, empathy, and sympathy. Patients referred to the physician’s manner during the interaction, shared interests (“I had a lot of confidence in the surgeon because he is a racing cyclist like me”, P16, 71, male), or general perception of support:

I saw a doctor who is, let's put it this way, a bit of a cold dog. He looks at you and says, ‘Broken. Go to the front, make an appointment’. Done, next. And I think this a bit of a lack of human interaction. (P16, 71, male)

Just as important as the physician’s medical expertise was the patients’ experiential expertise when it came to deciding for or against a surgeon or a clinic: “My acquaintance said: I had good experiences there. She never rushed me to choose the same clinic, but her experiences encouraged me to go to this practice” (P9, 61, female). Patients also reported using the internet to find out about other people’s experiences, but were more ambivalent about the information they received: “On the internet, you always come across people who are totally positive and others who say: it was completely terrible. But everyone has a different impression” (P1, 65, female). Media sources such as the white list of suitable clinics or an

article in the local newspaper about a surgeon in a local clinic were also mentioned as helpful information sources to prepare the decision.

Summary: Health Information Seeking Practices in the Orthopaedic Implant Patient Journey. In summary, we found that HISB - providing informational, emotional, and instrumental support to the individual - was an important strategy for orthopaedic implant patients to manage uncertainty. Different types of interpersonal and media sources were combined depending on the type of uncertainty. Interpersonal sources with medical expertise or experiential expertise played an important role for most physical and treatment-related uncertainties, whereas interpersonal sources from the patients' social network were more likely used to manage social and personal uncertainties or psychological uncertainties. Some uncertainties, such as the decision whether to have surgery or which surgeon or clinic to choose, triggered rather diverse intensive practices of multichannel HISB, whereas other uncertainties, such as immobility in the initial symptom phase, were not or only weakly associated with any HISB. With regard to the success of UM, the source's helpfulness and trustworthiness of the source were reported as relevant criteria to determine whether further sources had to be accessed or were rather avoided. In addition, emotional and instrumental support from the patient's social network was regularly mentioned as relieving and helpful in managing uncertainty, in addition to the acquisition of useful knowledge.

Discussion

For many patients, chronic illness is associated with the recurrent experience of uncertainty and the need to manage it (Bolz-Johnson et al., 2020; Kuang, 2018; Mishel, 1990, 1999). Uncertainty about different issues, at different intensities, and at different points in time over the course of a treatment is thought to be associated with specific UM strategies.

Building on the UMT (Brashers, 2001), our findings show that this postulate holds true for patients who have undergone orthopaedic implant surgery. To the best of our knowledge, we are the first to trace the patient journey of orthopaedic implant patients based on their perceived uncertainties at different stages of the treatment and to show to what extent these uncertainties are managed with which type of UM strategy. Thus, using the patient journey as a structuring tool, we were able to more comprehensively capture and characterise patients' uncertainty perceptions and the associated HISB as an UM strategy. Three key findings should be highlighted in more detail:

Potentials of Patient Journey Mapping to Locate Patients' Uncertainty Perceptions in Time

By mapping patients' perceptions of uncertainty, we were able to derive six distinct phases of the patient journey of orthopaedic implant patients: the occurrence of initial symptoms (1), the diagnosis phase (2), the decision-making phase (3), the pre-implantation phase (4), the post-implantation phase (5), and finally the phase of patients living with the implant (6). This structure is partly reflected in the treatment guidelines for knee and hip arthroplasty (Deutsche Gesellschaft für Orthopädie und Unfallchirurgie e. V [DGOU], 2021, 2023). However, by taking the patient perspective, the interviews revealed important differences: While the treatment guidelines only consider clinical stages such as the diagnosis and actual implantation, patient perceptions, as proposed by PJM, extend this view by identifying multifaceted

perceptions of uncertainty, especially in the times before and between these care points, such as in the phases of first symptoms, decision making, or treatment preparation. All these identified phases of the patient journey were characterised by different constellations and intensities of uncertainty perceptions. Knowing when which type of uncertainty occurs can enrich healthcare providers understanding of patients' needs, which is a prerequisite for providing adequate informational, emotional, or also instrumental support (Epstein & Street, 2007; Li et al., 2017).

Towards a More Differentiated Understanding of Uncertainty Perceptions

The types of uncertainty perceptions that we identified could be subsumed as treatment-related, physical, psychological, and social or personal uncertainties. This further differentiates Brashers et al.'s (2003) categorisation of medical, personal, and social sources of uncertainty among HIV patients and provides a nuanced understanding of uncertainty in a different disease context. In addition, our findings demonstrate the holistic impact that illness and treatment processes can have on patients' lives, as perceptions of uncertainty extend beyond medical issues and affect patients' psychological well-being and their personal and social lives at multiple points in their PJ. In contrast to the findings of Romo et al. (2022) and Martin et al. (2010), financial uncertainties were not mentioned by the patients in our sample. This may be due to the German healthcare system, in which a large proportion of the population is covered by a statutory or private health insurance, which covers the costs of orthopaedic implants and rehabilitation measures and provides sickness benefits (Blümel et al., 2020).

Furthermore, we saw that patients perceived multiple (sometimes interrelated) uncertainties per phase of their PJ. For example, experiencing *pain* as a physical uncertainty and wondering what to do about it could also lead to uncertainty about one's personal or work life (personal/social uncertainty). This reflects Brashers' (2001) finding that uncertainty can be multi-layered and interconnected. This indicates that patients' uncertainty perceptions should not be considered in isolation, but requires a more holistic understanding.

HISB as a Purposeful Uncertainty Management Strategy Targeted to the Uncertainty at Hand

Through our approach of assigning uncertainties to different time points in the patient journey and simultaneously considering UM strategies, our findings also revealed that the patients' UM strategies were highly targeted and specific to the uncertainty and phase of the PJ. Information seeking was carried out by turning to interpersonal and media sources to manage uncertainties about treatment, physical symptoms, but also psychological challenges such as decision making. We found an overall preference for interpersonal sources and a high importance of sources with medical expertise or experiential expertise, especially for physical or treatment-related uncertainties, which is in line with previous research on health information (Asan et al., 2021; Baumann et al., 2020) and in the context of orthopaedic implants (Fisse et al., 2023; Link, Baumann, & Klimmt, 2022). When physical or treatment-related uncertainties arose, the physician was reported to be the first source patients turned to, as patients placed a high level of trust in health professionals. When unmet needs prevailed after consulting a health professional, the patient turned to other complementary or compensatory sources to meet these needs (Kuang & Wilson, 2017; Link, Baumann, & Klimmt, 2022). Thus, in line with Link,

Baumann, and Klimmt (2022) our findings revealed that multichannel HISB was frequently performed by orthopaedic implant patients.

However, in the case of psychological uncertainty, *information avoidance* also played a role, for instance, when patients actively refrained from seeking information from a source because they questioned the quality and reliability of the information provided and feared an increase in the perception of uncertainty. Thus, information acquisition can also be a source of uncertainty. Patients' need for emotional and instrumental support was found to be related to social or personal uncertainties. This finding extends Brashers' (2001) understanding of emotional and instrumental support as an UM strategy, as the patients reported to have received this kind of support did not only through information provision alone. Gathering, evaluating, or buffering from supportive others such partners, family, friends, colleagues, but also through reassurance and practical help ("instrumental support") from their social environment, e.g., in the case of uncertainties about the ability to return to work, were equally important. This should be kept in mind when health professionals address the patients' informational and emotional needs to enable them to access coping mechanisms related to the condition (Epstein & Street, 2007; Li et al., 2017). Especially patients who do not have access to a supportive personal network may be at risk of suboptimal outcomes if important needs are not met by the sources to which they have access (Stewart et al., 2000). For example, these patients could be provided with information about institutionalised support, for instance, through social services or their insurance company.

In summary, our findings suggest that implant patients regularly engaged in HISB using multiple sources and sometimes deliberately avoided information. They sought for informational support as well as emotional and instrumental support.

Limitations and Further Research

Our research aimed to provide in-depth insights into situation-specific triggers of HISB in the context of UM, about which there is still insufficient knowledge. However, our findings are influenced by the conditions of the German health care system, where the majority of the population is covered by a public or private health insurance and that the costs of knee and hip implants are covered (Blümel et al., 2020). Therefore, the results may only partially applicable to other countries. The results are also specific to the implant context. Orthopaedic patients were selected because the course of their diseases is relatively protracted and at the same time associated with a high degree of patient autonomy, as time-critical decisions are rare (Driban et al., 2020). Nevertheless, disease contexts with higher urgency and severity of decision making could result in a different structure of the PJ, affecting the perceived uncertainties and the ability to turn to information sources or combine several sources to manage uncertainties. It should also be noted that our sample includes many female patients and has a rather high average age, which reflects actual patient statistics for endoprostheses: women and older people are more likely to need a knee or hip implant (Grimberg et al., 2023). However, age in particular may also have influenced HISB practices and the preference for interpersonal sources (Barnes et al., 2017; Fisse et al., 2023).

In addition, our results may also have been affected by memory bias. Respondents were asked to recall events and behaviours that may have occurred up to two years previously. Although we have tried to account for any bias by supporting their recall with a situational approach in the interviews, we cannot rule out the possibility that bias may have occurred.

Therefore, other methodological approaches may provide additional insights in future studies. For example, the doctor-patient relationship could be further explored through observations, or the situational nature and specifics of HISB practices could be examined in more detail through diary studies. In addition, we found that interpersonal sources from the patients' social environment and other patients seemed to be rather important in providing them with information or other forms of social support. Therefore, further studies should explore the role of these relevant sources in more detail.

Conclusion

Our results show that orthopaedic implant patients experience a range of uncertainties during their illness and treatment, which they address with specific, targeted UM strategies. These findings are valuable in helping patients to strengthen their UM skills in the spirit of patient-centred care (Epstein & Street, 2007). Physicians continue to play an important role in this regard. Knowing when uncertainty arises and may not be satisfactorily addressed by patients' current UM strategies or available resources will help to develop more targeted interventions (Guan et al., 2021). This may include educating health professionals about cues to patients' uncertainty and their coping strategies at different points in the PJ, as well as providing patients with information about other support options and information services that might support their UM. The knowledge about typical questions at certain stages of the patient journey can also be used to improve general strategies of providing information provision at any type of medical access point for implant patients, such as physicians' offices, physiotherapy practices, or insurance companies.

However, other interpersonal sources are just as important as health professionals. Social support from the patient's personal environment or from fellow patients helps to mitigate the patients' uncertainty level. This can be done either by actively involving the social environment in care or by helping patients who do not have a functioning social network to rely on to find institutionalised alternatives. Overall, these interventions could help patients to better manage their uncertainty during the treatment process and thus improve their well-being.

Ethical Approval

The study has been approved by the joint Ethics Committee of the Hanover University of Music, Drama, and Media and Leibniz University Hanover (approval no. EV LUH 03/2021). All participants provided oral informed consent prior to enrolment in the study.

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Conflict of Interest

The authors declare that there is no conflict of interest.

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Author Contributions

Conceptualisation (main idea, theory): Charlotte Schrimppff, Tanja Fisse, & Elena Link
Funding acquisition: Eva Baumann, Christoph Klimmt, & Elena Link
Project administration: Elena Link, Eva Baumann, & Christoph Klimmt
Methodology (design, operationalisation): Charlotte Schrimppff, Tanja Fisse, & Elena Link
Data collection: Charlotte Schrimppff & Tanja Fisse
Data analysis: Charlotte Schrimppff & Tanja Fisse
Writing – original draft: Charlotte Schrimppff & Tanja Fisse
Writing – review & editing: Charlotte Schrimppff, Tanja Fisse, & Elena Link

Author Biographies

Charlotte Schrimppff is a research associate at the Department of Journalism and Communication Research at the University of Music, Drama and Media Hanover, Germany. Her research interests focus on health and science communication, especially the effects of linguistic framing.

Tanja Fisse is a research associate at the Department of Journalism and Communication Research at the University of Music, Drama and Media Hanover, Germany. Her research interests focus on media reception and health communication, especially on social support through social media use.

Elena Link is an assistant professor at the Department of Communication at the Johannes Gutenberg University Mainz, Germany. Her research interests include health and science communication as well as research methods. She is particularly interested in information-seeking and avoidance behaviours.

Eva Baumann is professor at the Department of Journalism and Communication Research at the University of Music, Drama and Media Hanover, Germany. Her research interests focus on health and risk communication, particularly on target group segmentation, health information seeking, health campaigns, message, and framing strategies.

Christoph Klimmt is professor at the Department of Journalism and Communication Research at the University of Music, Drama and Media Hanover, Germany. His research focuses on Entertaining media use, media reception and media effects as well as new media and communication technologies.