Open Access

Decision experiences in joint replacement surgery for patients with haemophilic arthritis: A qualitative study

YaNan Kan¹, YunChun Bao^{1*†} and Fuying Ye^{2*†}

Abstract

Background Patients with end-stage haemophilic arthritis (HA) are often hesitant about joint replacement surgery, yet little is known about the decision experiences faced by these patients. The aim of this study was to better understand the experiences faced by patients with HA when making decisions about joint replacement surgery and to provide a reference for health care professionals in the development of decision-making aids.

Methods Fifteen HA patients who were candidates for joint replacement surgery at a tertiary and first-class hospital in Zhejiang Province were interviewed using a semistructured in-depth interview from January to December 2023. Colaizzi's seven-step method was used to analyse the data and refine the themes.

Results The decision experience for patients with HA regarding joint replacement surgery can be summarized into four themes: decision information conflict, decision support conflict, self-perceived conflict, and self-developmental conflict.

Conclusion Patients with HA face numerous decision conflicts. Health care professionals should develop joint replacement surgery decision-making aids suitable for patients with HA as soon as possible to reduce the decision conflict.

Trial registration The study received approval from the Ethics Committee of Zhejiang Provincial Hospital of Traditional Chinese Medicine, China (registration date: September 22, 2023; registration number: 2023-KLS-294–01).

Keywords Haemophilia, Arthritis, Decision conflict, Qualitative study

[†]Fuying Ye and YunChun Bao should be considered joint corresponding authors.

*Correspondence: YunChun Bao bycrain@163.com Fuying Ye yfy1104@126.com ¹ Orthopaedics Depa

¹ Orthopaedics Department of The First Affiliated Hospital of Zhejiang Chinese Medical University (Zhejiang Provincial Hospital of Chinese Medicine), Hangzhou 310000, Zhejiang, China

² Nursing Department of The First Affiliated Hospital of Zhejiang Chinese Medical University (Zhejiang Provincial Hospital of Chinese Medicine), Hangzhou 310000, Zhejiang, China

Background

Haemophilia is a congenital disorder caused by a deficiency or absence of two coagulation proteins, factor VIII (FVIII) for haemophilia A and factor IX (FIX) for haemophilia B [1, 2]. According to the 2022 annual report of the World Federation of Haemophilia (WFH), 208,957 patients are suffering from haemophilia A and 42,203 are suffering from haemophilia B worldwide [1, 3]. Major symptoms include mucocutaneous bleeding, epistaxis, easy bruising, heavy menstrual bleeding, provoked bleeding in the setting of surgery and other invasive effects [4]. Moreover, repeated bleeding in the joint cavity can occur due to a defect in plasma coagulation FVIII or FIX,



© The Author(s) 2025. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by-nc-nd/4.0/.

causing swelling and stiffness. This swelling and stiffness subsequently leads to haemophilic arthritis (HA), which causes irreversible damage to joints [5]. End-stage HA is characterized by joint pain, deformity, and limited mobility, which severely affects patients' quality of life. For patients with end-stage HA who do not respond well to conservative treatment, joint replacement surgery is a common and effective treatment plan [6, 7].

Although joint replacement surgery is the best option for improving quality of life, patients still face confusion and hesitation [8].Indeed, many appropriate candidates for joint replacement surgery are apprehensive to undergo joint replacement surgery. This confusion and hesitation may stem from a variety of reasons, including fear of surgery, attempting to comprehend the medical situation, associated costs of surgery and hospitalization, concerns about dependency following the procedure, and perceptions of current pain severity [9]. Confusion and hesitation frequently results in decision delays and decision regrets, subsequently impacting patients' treatment processes, nursing experiences, and therapeutic outcomes [9, 10]. Understanding decision experiences in surgical decision-making helps minimize guesswork and uncertainty [11]. However, despite its significant impact, little research has been conducted on the decision experiences experienced by patients with end-stage HA during surgical decision-making.

Previous studies have focused primarily on elucidating the pathophysiological mechanisms involved [6, 16], exploring treatment methodologies [6, 14, 15], and investigating postoperative rehabilitation associated with HA [16-18]. Moreover, exploration of the decision experiences faced by patients during the decision-making process for joint replacement surgery has been limited. Moreover, these studies have failed to delve deeply into the correlative factors that influence patients' decisionmaking processes. Therefore, this study aims to conduct in-depth interviews with patients with end-stage HA to explore their experiences during the decision-making process for joint replacement surgery. This endeavor not only facilitates a better understanding of the decision experiences and needs of patients among health care professionals but also provides a reference for the development of decision-making aids tailored to HA patients. Moreover, it promotes shared decision-making (SDM) between patients and health care providers and enhances patients' treatment satisfaction and quality of life.

This study is the first to explore decision experiences among Chinese patients with HA undergoing joint replacement surgery. The research question in this study focused on the experiences and journeys of Chinese HA patients during the decision-making process for undergoing joint replacement surgery.

Methods

Research design

Qualitative thematic analysis based on phenomenology [23, 24] is a method that observes specific phenomena, analyses their internal and external components, extracts key elements, and explores the relationships between the elements and the relationships between the elements and the surrounding context. It is often used to focus on subjective experiences and understand life experiences, making it suitable for answering many questions related to the research topic. We used this approach to reveal the conflicts of HA patients with joint replacement surgery selection. Semistructured interviews were conducted with end-stage HA patients to explore their decision conflict during joint replacement surgery. The purpose of this study was to provide a basis for making decisions about patient decision aids (PDAs) and promoting SDM.

Sampling and recruitment

The research team recruited subjects using purposeful sampling methods. Anyone 18 years of age or older with a diagnosis of Haemophilia A or B was eligible for the study.

The study received approval from the Ethics Committee of Zhejiang Provincial Hospital of Traditional Chinese Medicine, China (2023-KLS-294–01), and complied with the requirements of the 1975 Declaration of Helsinki and its amendment in 2008. The first author (YN) introduced the purpose and content of this study to HA patients to obtain the consent of the interviewees. All participants voluntarily participated in the study and signed a written informed consent form, and the research data were kept anonymous and confidential. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) standards [21].

Participants

Using purposive sampling, this study selected patients with HA from Zhejiang Provincial Hospital of Traditional Chinese Medicine, China, who visited the hospital from January to December 2023. The inclusion criteria were as follows: (1) patients with a clear diagnosis of HA; (2) patients with joint lesions that met the indications for joint replacement surgery; and (3) patients with good language expression and communication skills. The exclusion criteria were as follows: (1) patients with severe infections or heart or kidney function damage and (2) patients with severe mental illnesses. The sample size was determined by the saturation point where no new themes emerged from the data provided by the HA patients.

Interview guide development

Based on the research purpose, expert opinions in the field of HA nursing, and literature review results, an initial interview guide was drafted. After three subjects were interviewed, the guide was revised to form the final version (Supplementary Material 1).

Data collection

The authors (YN, YC and FY) are all female, have at least a bachelor's degree, and have received systematic training in qualitative research. Two authors (YN and YC) are clinical nurses responsible for the care of HA patients and have established a stable trusting relationship with the patients. The authors (YN and YC) used face-to-face semistructured interviews to collect data. Before the formal interviews, the purpose and content of the study were explained to the interviewees, who were promised that the collected information would only be used for this research. To protect privacy, codes were used to replace real names, and recordings were made after consent was obtained. When the conditions allowed, the interviewees were invited to the demonstration classroom in the ward to conduct the interviews in a quiet and bright environment. During the interview process, the interviewees were encouraged to express their true thoughts, and their facial expressions and body language were recorded. Additionally, we asked some questions, such as "Could you please tell me more about...", to obtain more information related to our topic. Only interviewers and interviewees participated in the data collection.

Data analysis

The interview results of this study were analysed by Microsoft Word and Excel. Data analysis was based on Colaizzi's 7-step analysis method of phenomenological data [22]. First, within 24 h after the interview, three researchers (YN, YC and FY) sorted the interview materials. The researcher repeatedly listened to the recordings and meticulously transcribed them into text sentence by sentence. Additionally, the researcher recognized facial expressions, body movements, and postures as supplementary information. Second, two researchers (YN and YC) identified statements that were significant and aligned with the research phenomena, documenting them in a Word document. Subsequently, they summarized and distilled the core meanings from these significant statements. These meanings were then categorized and further refined to formulate thematic concepts. Third, the researchers identified common characteristics or meaningful concepts, thereby forming themes, clusters of themes, and categories. They subsequently associated these themes with the research phenomena and presented a comprehensive narrative. Finally, one of the researchers (YN) consolidated the findings and elaborated on the research phenomena, outlining the fundamental structure of the phenomenon in detail. We sent transcripts to participants to verify the data, and their feedback was considered. During the translation phase, following the completion of the analysis phase, we translated the results into English, and all translations were subsequently reviewed by native English speakers.

Quality control

We applied various quality measures to ensure the trustworthiness of the findings.

Credibility was confirmed by the fact that three researchers held master's degrees, had received pertinent training in qualitative research, and were adept at the skills necessary for conducting interviews, which included questioning, probing, clarifying, and summarizing. Furthermore, we dedicated sufficient time to data collection until saturation was achieved, and the research findings were independently confirmed by three participants. Additionally, to obtain necessary and reliable data, researchers established appropriate trust relationships with the interviewees and strived to include the most diverse participants in the sampling process. To this end, efforts were made to select individuals from different medical specialties, age groups, and educational backgrounds among the eligible candidates to participate in the study. Dependability of the study was ensured through the following approaches: During the interview process, researchers maintained a neutral attitude, refrained from using critical or suggestive language, listened attentively, and encouraged patients to fully express their viewpoints. The data analysis was safeguarded by the participation of three researchers in the same analysis, who provided different perspectives, thereby broadening the understanding of the study phenomenon and leading to multiple conclusions. Conformability was ensured by discussing the codes, subthemes, and themes with the research team and study participants to obtain a consensus. Finally, we observed the transferability of the study by confirming the research findings with three nurses (eligible to participate in the study) who were not part of the original participants. Although these nurses were not original participants, their confirmation results helped to verify the applicability of the study conclusions across different groups.

Results

Participant selection and characteristics

Ultimately, all 15 patients contacted participated in this study, and the average interview time was 35 min, ranging from 30 to 60 min. All participants were male, and

Table 1 Participant demographics (n = 15)

Characteristics		N	%
Age (years)	20–30	3	20.00
	31–40	7	46.67
	41-50	4	26.67
	51-60	1	6.66
Sex	Male	15	100.00
Education level	Primary school	1	6.66
	Secondary school	5	33.33
	High school	6	40.00
	Bachelor's degree	3	20.00
Employment Status	Employed	9	60.00
	Unemployed	6	40.00
Marital Status	Single	8	53.33
	Married	5	33.33
	Divorced	2	13.34
Medical Insurance	Urban Employee	14	93.33
	Rural Cooperative	1	6.67
Affected Joint	Knee Joint	11	73.33
	Hip Joint	4	26.67

their general information is shown in Table 1. Five main themes were extracted: choice dilemma, preference dilemma, information dilemma, treatment dilemma, and conflict.

Decision information conflict

Information vortex

The "information vortex" is defined as a complex environment in the context of the information explosion era, where vast amounts of information converge and swirl, creating a situation that hinders the discernment of truth from falsehood and is difficult to escape. Research indicates that the quality of decision-making information has a significant effect on the formulation of decisions. HA patients often find themselves in an information vortex, struggle to distinguish the scientific and professional nature of the information, and frequently face decision-making dilemmas.

"Is it true that inhibitors of coagulation factors can be produced after surgery, as stated online? It is difficult for me to make an accurate judgement." P1.

"Due to my limited educational background, I have encountered much online content regarding joint replacement surgery. Some praise its effectiveness, whereas others express negative views, some of which are quite alarming. This has left me feeling very confused." P10.

Insufficient sources of professional information

Due to patients' lack of medical background knowledge, they rely primarily on communication with medical professionals to obtain professional information. However, the limited duration and singular channels of communication between patients and health care providers hinder patients from acquiring sufficient professional information to aid in their decision-making processes.

"I do not have sufficient information to determine whether my current decision is the best one, as the doctor does not have ample time to discuss with me in detail about which option is the most suitable." P10.

"I am only able to meet with my doctor during his ward rounds to inquire about surgery-related questions face-to-face. However, due to the brevity of the ward rounds, it is difficult for me to comprehensively ask all these questions." P4.

Decision support conflict

HA patients generally bear psychological burdens from multiple sources, including society, family, and themselves. When deciding whether to undergo joint replacement surgery, patients eagerly seek decision-making support from health care professionals, social organizations, and family members.

Hoping to receive social support

"Both my hip and knee need surgical intervention, and I ideally wish to undergo both procedures simultaneously to avoid two separate instances of discomfort. The surgeon seems to have reservations about this approach, and I sincerely hope to obtain the surgeon's support for my preference." P12.

"The doctor advised me to take medication (coagulation factors) regularly after joint replacement surgery. However, adhering to a regular medication schedule is somewhat impractical for me. I intend to inquire with the 'Haemophilia Home' (a nonprofit organization in China for haemophilia patients) to see if they can provide me with assistance." P15.

Hoping to receive family support

"My intention to undergo joint replacement surgery is to improve my capacity for driving. However, my mother has rejected the surgery, and I find myself in a dilemma due to my concern for her emotional well-being. I eagerly anticipate gaining her support in this matter." P8.

Self-perceived conflict

Perception of surgical safety

After surgery, HA patients often face increased risks of bleeding and infection. Postoperative rehabilitation is needed for patients to achieve the expected surgical outcomes. Various factors increase patients' uncertainty about whether to undergo surgery, with surgical risks being the main source of uncertainty.

"You know, what we HA patients fear the most is inhibitors. The dose of factors needs to be increased before and after surgery, will this increase the risk of inhibitors?" P5.

"I want to consult how the coagulation factors are adjusted, how much is needed during surgery? When can it be reduced?" P6.

"I'm not sure if I must have surgery. You say the surgical risks are high, and I have to replace the joint with an artificial one. Is it not as good as my own?" P14.

Adjusting the amount of coagulation factors according to the individual situation of HA patients is one of the most important preoperative preparations during the perioperative period. Some patients are worried about the increased risk of inhibitors, which leads to a dilemma in surgical decision-making.

"I have heard that there might be severe bleeding after surgery, and I'm still very worried about that." P13.

Perception of rehabilitation effectiveness

Surgery is an effective means to improve the joint function of HA patients, but it also requires patients to actively cooperate with postoperative rehabilitation to achieve the expected results. The uncertainty patients have about rehabilitation outcomes can affect their decision-making.

"A fellow patient shared with me that after surgery, the pain in the joint was severe during each rehabilitation session. Is this situation caused by the surgery?" P12.

"I'm in my 50 s this year, even if I have the surgery, my recovery may not be as good as others, so I have been considering the necessity of the surgery." P9.

"Both hips and both knees are bad. I had surgery on my hip in 2020. I know a bit about surgery. Although the surgery gave me hope to stand up, I could not stick to the rehabilitation, so the surgical outcome was not good. This time, I'm very conflicted about whether to have surgery or not." P7.

Self-developmental conflict Economic pressure

HA patients usually need to use coagulation factors regularly to prevent bleeding. However, the high price of coagulation factors, coupled with the cost of surgical treatment, further increases the financial burden on patients, making economic factors highly likely to prevent patients from actively seeking treatment in a timely manner.

"I did not have money before, and I wanted to consider surgery when I had earned enough money and had security. Unexpectedly, the harder I worked, the more severe the pain in my leg became." P15.

"I should have had surgery three or four years ago, but I have been delaying it because I felt the medical expenses were too high. In the past, there was less reimbursement, and I had to pay a large part of the money myself, which was too much of an economic pressure for me." P9.

Time conflict

Most HA patients eventually develop varying degrees of bone and joint lesions, and a significant portion of HA patients may experience significant joint function impairment during middle and young adulthood. When patients hope to marry, the trajectory of major life events affects the timing of surgery, leading to decision conflict.

"My knee is a bit stiff, and it hurts to walk 100 m. I have a bit of a limp. The doctor said I could wait a bit longer for the replacement surgery. Then, I thought, would my walking look more normal after the joint replacement? I am looking for a girlfriend and hope to marry." P3.

"I haven not yet decided whether to have surgery. If possible, I want to have it later. I'm too busy with work now and want to postpone it until after the New Year." P1.

Role conflict

The HA patients in this study were mainly middle-aged and young. When a patient's role conflicts with family responsibilities, they are more likely to experience decision conflict.

"Can I continue to work after surgery? How long do I need to rest? I have two children, and there must be someone to take care of them. If I can recover quickly, I want to have surgery. Otherwise, I have to think about it." P11.

"I am currently in charge of a highly significant project, and I cannot abandon my responsibilities." P4.

Discussion

This study explored the decision-making conflict faced by patients with HA while deciding on joint replacement surgery. Similar to previous related research findings, patients with HA encounter a lack of information exchange between health care providers and patients, as well as insufficient family and social decision support during the decision-making process [18]. Additionally, this study reveals several novel findings: 1) decision information conflict, 2) self-perceived conflict, and 3) self-developmental conflict. These findings can contribute to the composition of interventions aimed at improving surgical decision-making for patients with HA.

In this study, the information conflict was defined as the difficulty patients face in identifying or accessing the decision-making information they require. We revealed that patients are more prone to decision-making dilemmas when they are either overwhelmed by an information vortex or confronted with insufficient sources of professional information. Information seeking is crucial for effective patient-centred decision-making because information from different sources varies in accuracy and quality [23, 24]. In our interviews, half of the participants indicated that they would obtain surgery-related information from the internet but expressed doubts about the quality of such information. Additionally, when the decision content is complex and decision information is limited, patients are prone to decision conflict [23, 25]. Furthermore, a similar proportion of patients expressed a preference for obtaining information from their doctors. However, the gap in medical knowledge between patients and health care professionals is significant, leading to a great imbalance of information [26]. With only a few short conversations, patients cannot easily obtain comprehensive decision-making information [27, 28]. Moreover, during communication with health care professionals, patients cannot easily express their true thoughts and preferences [29, 30]. Furthermore, the mismatch between the decision-making information provided by health care professionals and the information needs of patients is significant, which hinders the ability of patients to make decisions based on the information they have obtained. Health care professionals should not only provide patients with medical professional knowledge but also guide them in making choices [31]. Moreover, social media software or internet + information platforms can be fully utilized to establish more communication media, thereby increasing patients' access to professional information.

The interview results of this study indicate that patients' needs for decision-making support are unmet, leading to phenomena such as delayed decision-making and indecisiveness. Previous research has shown that social support is a factor affecting decision conflict [9]. Patients expressed a desire for support from their family members, decision-making advice from health care professionals, and social assistance support from nonprofit organizations. Therefore, we defined the decision support conflict in the past as the need for support from society, family, etc., during the decision-making process, with a preference for psychological and material support.

In China, a segment of haemophilia patients relies on nonprofit organizations for essential assistance, including facilitating access to coagulation factor concentrates and providing financial support to patients. When these patients decide to undergo joint replacement surgery, physicians adjust the dosage of coagulation factors administered to the patients, typically by increasing the amount. Consequently, patients are required to provide more coagulation factor concentrates. Therefore, the extent of support from nonprofit organizations is a consideration for patients during the decision-making process regarding surgery.

Influenced by traditional Chinese family values and culture, family members and close friends often participate in medical decision-making processes. When multiple parties hold consistent opinions, patients tend to receive additional emotional support from their relatives and friends. In mainland China, confucian philosophy influences societal norms, emphasizing principles such as "the father is kind and the son is filial" and "the husband is righteous and the wife is obedient" as core family ethics [20]. When opinions diverge, patients may experience emotional dilemmas, such as inner conflict, ambiguity, and confusion. Consequently, patients often respect the advice of their families and hope to maintain harmonious relationships. This phenomenon can be attributed to the prevalent family structures and values in Eastern countries. During the surgical decision-making process, family members should be guided to provide appropriate levels of decision support to patients while minimizing negative impacts [32].

Additionally, in this study, some patients reported that despite receiving clear communication from doctors regarding surgical risks, they still harboured significant concerns about these risks, which hindered their ability to accurately assess the benefits and risks associated with different treatment options. Furthermore, some patients expressed hesitation about undergoing surgery because of concerns about postoperative recovery outcomes and adherence to rehabilitation protocols. Subjective perceived uncertainty stems from the values of patients, and studies have indicated that perceived uncertainty originates from both internal and external sources. External sources include factors such as the surgeon's experience and surgical safety indices, whereas internal uncertainty refers to one's confidence in their own knowledge. This uncertainty can exacerbate decision-making dilemmas. Therefore, the sources of patients' subjective perceived uncertainty must be distinguished to provide targeted interventions [33].

In addition, in this study, the self-development conflict referred to the potential constraint that surgical decisionmaking might impose on patients' underlying work and life capabilities. we found that HA patients delay making surgical decisions due to various factors, such as economic pressure, time, and role conflict. These factors are closely related to the patient's self-developmental. Haemophilia is a long-term chronic disease with a heavy disease burden. In China, the cost of coagulation factors during the treatment process is the most significant part of the economic burden of haemophilia, accounting for 45%-93% of the total treatment cost. During surgical treatment, patients must bear not only the cost of surgery but also the large cost associated with increasing the dose of coagulation factors, which further increases the economic burden. Thus, patients often find it difficult to make decisions. In addition, HA patients are mostly middle-aged and young men who often bear more family responsibilities and social roles. Conflicts between time and role can also lead patients to decision conflict.

In recent years, SDM has been recognized as the ideal decision-making model. SDM has been found to improve patient-clinician communication, which improves patients' accuracy of their expectations of intervention benefits and harm, their involvement in decision-making, and their feelings of being informed. Furthermore, SDM increases both patients' and clinicians' satisfaction with care [34]. However, in China, SDM has not yet been fully utilized and is constrained by factors such as inadequate awareness of SDM among health care professionals, limited patient participation, a lack of PDA and the involvement of professionals.

PDAs can be used to provide information about the risks and benefits of treatments and enable patients to reflect on and communicate their preferences to participate in SDM [35]. It can increase patients' understanding of the risks and benefits of different treatment plans, effectively reduce decision-making conflicts, improve decision-making readiness, and optimize decision-making quality [36]. Research related to PDAs has developed rapidly and has been applied to multiple clinical disciplines [37–39]. Currently, surgical PDAs

for HA patients in clinical practice are lacking, which to some extent hinders effective communication between health care professionals and patients, further affecting the formulation of patients' decisions. Therefore, PDAs for HA patients' surgery are urgently needed to correctly assess patients' decision-making needs, provide decision-making support for patients, and thus reduce patients' decision conflict. PDAs need to encompass sufficient information, such as disease details, surgical procedures, medication information, health care cost information and rehabilitation protocols, while also including the benefits and risks associated with each treatment option. Furthermore, value clarification is equally crucial, enabling patients to make informed decisions by considering their personal circumstances (social, economic, cultural, etc.). Additionally, the practicality, acceptability, and intended users of PDAs in clinical settings need to be considered. The Ottawa Decision Support Framework (ODSF) can provide a theoretical framework for the development of PDAs for patients with HA [40]. This represents an intriguing topic worthy of further investigation.

However, this study, which only used qualitative research methods to obtain the content of the decision conflict faced by HA patients, is subject to limitations. Future research could combine quantitative methods to explore the degree of decision conflict among HA patients and analyse the influencing factors, providing a theoretical basis for the development of PDAs in HA patients.

Conclusion

Patients with HA face dilemmas in the decision-making process for joint replacement surgery. This study identified four themes of decision conflict: decision information conflict, decision support conflict, self-perceived conflict, and self-developmental conflict. These dilemmas can lead to delayed decision-making and regret, which are not conducive to the initiation of treatment. Therefore, medical staff must pay attention to the decision conflict faced by patients with HA. We recommend exploring PDAs for joint replacement surgery that are tailored to the national conditions of China and advocate for increased social attention to the HA patient population.

Abbreviations

- HA Haemophilic arthritis
- COREQ Consolidates Criteria for Reporting Qualitative Research
- FVIII Factor VIII
- FIX Factor IX
- WFH World Federation of Haemophilia
- PDAs Patient Decision Aids
- SMD Shared Decision-making
- ODSF Ottawa Decision Support Framework

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12911-025-02901-3.

Supplementary Material 1.

Acknowledgements

We are grateful to the patients who spent their time and effort to participate in this study and for sharing their personal experiences with us.

Authors' contributions

Yanan Kan and Yunchun Bao interviewed the participants. Yanan Kan and Yunchun Bao conducted the coding and the first analyses. Yanan Kan, Yunchun Bao and Fuying Ye formed the research team and analysed and interpreted the coding together. Yanan Kan prepared the first draft of the article, which was revised by Fuying Ye and Yunchun Bao.

Funding

Zhejiang Province Traditional Chinese Medicine Science and Technology Project, 2023ZR024.

Data availability

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This work was assessed by the Ethics Committee of Zhejiang Provincial Hospital of Traditional Chinese Medicine, China (2023-KLS-294–01). Informed consent was obtained from all the interviewees before the formal start of the interview, and informed consent was approved by Zhejiang Provincial Hospital of Traditional Chinese Medicine. The interviewees participated in the study voluntarily and could withdraw at any time. All research data are confidential and only known to the three authors of this study. For further information, please contact the corresponding author.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 30 August 2024 Accepted: 29 January 2025 Published online: 04 February 2025

References

- Angchaisuksiri P, Amurao-Abiera M, Chou S-C, Chewcharat P, Chozie NA, Gomez R, et al. Haemophilia care in Asia: Learning from clinical practice in some Asian countries. Haemophilia. 2024. https://doi.org/10.1111/hae. 14998.
- Shoukat HMH, Ghous G, Tarar ZI, Shoukat MM, Ajmal N. Skewed Inactivation of X Chromosome: A Cause of Hemophilia Manifestation in Carrier Females. Cureus. 2020;12: e11216.
- Stonebraker JS, Bolton-Maggs PHB, Brooker M, Evatt B, Iorio A, Makris M, et al. The World Federation of Hemophilia Annual Global Survey 1999–2018. Haemophilia. 2020;26:591–600.
- Connell NT, Flood VH, Brignardello-Petersen R, Abdul-Kadir R, Arapshian A, Couper S, et al. ASH ISTH NHF WFH 2021 guidelines on the management of von Willebrand disease. Blood Adv. 2021;5:301–25.
- Terashima A, Ono K, Omata Y, Tanaka S, Saito T. Inflammatory diseases causing joint and bone destruction: rheumatoid arthritis and hemophilic arthropathy. J Bone Miner Metab. 2024;42:455–62.
- 6. Xiang S-C, Shen S-N, Wang R, Wang Z-M, Jin Z-K, Su H, et al. Intra-articular injection of tranexamic acid in patients with haemophilia arthritis:

- Sackstein P, Cooper P, Kessler C. The role of total ankle replacement in patients with haemophilia and end-stage ankle arthropathy: A review. Haemophilia. 2021;27:184–91.
- Wamkpah NS, Gerndt SP, Kallogjeri D, Piccirillo JF, Chi JJ. Patients' Views of Shared Decision-making and Decisional Conflict in Otolaryngologic Surgery During the COVID-19 Pandemic. JAMA Otolaryngol Head Neck Surg. 2021;147:879–86.
- Riffin C, Pillemer K, Reid MC, Tung J, L Ckenhoff CE. Decision Support for Joint Replacement: Implications for Decisional Conflict and Willingness to Undergo Surgery. J Gerontol B Psychol Sci Soc Sci. 2018;73:387–98.
- Ye ZJ, Cheng MH, Zhang XY, Tang Y, Liang J, Sun Z, et al. Treatment Decision Making and Regret in Parents of Children With Incurable Cancer. Cancer Nurs. 2021;44:E131–41.
- 11. Jayakumar P, Moore MG, Furlough KA, Uhler LM, Andrawis JP, Koenig KM, et al. Comparison of an Artificial Intelligence-Enabled Patient Decision Aid vs Educational Material on Decision Quality, Shared Decision-Making, Patient Experience, and Functional Outcomes in Adults With Knee Osteoarthritis: A Randomized Clinical Trial. JAMA Netw Open. 2021;4: e2037107.
- Caliogna L, Berni M, Torriani C, Mancuso ME, Di Minno MND, Brancato AM, et al. Pathogenesis of osteoarthritis, rheumatoid arthritis, and hemophilic arthropathy: The role of angiogenesis. Haemophilia. 2024;30:1256–64.
- 13. Zhu H, Meng Y, Tong P, Zhang S. Pathological mechanism of joint destruction in haemophilic arthropathy. Mol Biol Rep. 2021;48:969–74.
- Rodriguez-Merchan EC, De la Corte-Rodriguez H, Gomez-Cardero P, Alvarez-Roman MT, Jimenez-Yuste V. Arthroscopic ankle surgery in people with haemophilia. Haemophilia. 2024;30:286–94.
- Li Z, Feng B, Du Y, Wang Y, Bian Y, Weng X. Complications of total knee arthroplasty in patients with haemophilia compared with osteoarthritis and rheumatoid arthritis: A 20-year single-surgeon cohort. Haemophilia. 2020;26:861–6.
- Fouasson-Chailloux A, Leboeuf F, Maugars Y, Trossaert M, Menu P, Rannou F, et al. Gait Alteration Due to Haemophilic Arthropathies in Patients with Moderate Haemophilia. Int J Environ Res Public Health. 2022;19:7527.
- Bakeer N, Saied W, Gavrilovski A, Bailey C. Haemophilic arthropathy: Diagnosis, management, and aging patient considerations. Haemophilia. 2024;30(Suppl 3):120–7.
- Liu Y-Q, Guo Y-L, Xu J, Geng W-J, Li Z-Z, Jia M, et al. Shared Decision-Making in Hemophilic Arthropathy Rehabilitation: A Qualitative Study. Patient Prefer Adherence. 2023;17:249–57.
- 19. Sundler AJ, Lindberg E, Nilsson C, Palmér L. Qualitative thematic analysis based on descriptive phenomenology. Nurs Open. 2019;6:733–9.
- Guo Z, Zeng S, Ling K, Chen S, Yao T, Li H, et al. Experiences and needs of older patients with stroke in China involved in rehabilitation decisionmaking: a qualitative study. BMC Med Inform Decis Mak. 2024;24:330.
- Buus N, Perron A. The quality of quality criteria: Replicating the development of the Consolidated Criteria for Reporting Qualitative Research (COREQ). Int J Nurs Stud. 2020;102: 103452.
- 22. Colaizzi P. Psychological research as a phenomenologist views it. In: Valle RS, King M, editors. Existential phenomenological alternatives for psychology. Oxford: Oxford University Press; 1978. p. 6.
- Iyer ES, Weinberg A, Bagot RC. Ambiguity and conflict: Dissecting uncertainty in decision-making. Behav Neurosci. 2022;136:1–12.
- Chhatre S, Wittink MN, Gallo JJ, Jayadevappa R. Sources of Information for Learning and Decision-Making in Men With Localized Prostate Cancer. Am J Mens Health. 2020;14:1557988320945461.
- Lee MK, Bryant-Lukosius D. Information Provision, Decision Self-efficacy, and Decisional Conflict in Adopting Health Behaviors Among Patients Treated for Colorectal Cancer: A Cross-sectional Study. Cancer Nurs. 2023;46:45–56.
- Lin M-L, Chen C-H. Difficulties in Surgical Decision Making and Associated Factors Among Elective Surgical Patients in Taiwan. J Nurs Res. 2017;25:464–70.
- Paul NR, Baker SR, Gibson BJ. Decision Making from the Experience of Orthognathic Surgery Patients: A Grounded Theory Approach. JDR Clin Trans Res. 2022;7:256–66.
- Torrente-Jimenez RS, Feijoo-Cid M, Rivero-Santana AJ, Perestelo-Pérez L, Torres-Castaño A, Ramos-García V, et al. Gender differences in the decision-making process for undergoing total knee replacement. Patient Educ Couns. 2022;105:3459–65.

- Gardiner TM, Gillespie BM, Latimer S, Hewitt J. Exploring healthcare professionals' perspective of the process of obtaining consent for adult patient's having planned surgery: A scoping review. J Clin Nurs. 2023;32:5779–92.
- Kuosmanen L, Hupli M, Ahtiluoto S, Haavisto E. Patient participation in shared decision-making in palliative care - an integrative review. J Clin Nurs. 2021;30:3415–28.
- Anguzu R, Cusatis R, Fergestrom N, Cooper A, Schoyer KD, Davis JB, et al. Decisional conflict among couples seeking specialty treatment for infertility in the USA: a longitudinal exploratory study. Hum Reprod. 2020;35:573–82.
- Liao Y-L, Wang T-J, Su C-W, Liang S-Y, Liu C-Y, Fan J-Y. Efficacy of a Decision Support Intervention on Decisional Conflict Related to Hepatocellular Cancer Treatment: A Randomized Controlled Trial. Clin Nurs Res. 2023;32:233–43.
- Vives M-L, Heffner J, FeldmanHall O. Conceptual representations of uncertainty predict risky decision-making. Cogn Affect Behav Neurosci. 2023;23:491–502.
- Hoffmann T, Bakhit M, Michaleff Z. Shared decision making and physical therapy: What, when, how, and why? Braz J Phys Ther. 2022;26: 100382.
- Edwards M, Holland-Hart D, Mann M, Seddon K, Buckle P, Longo M, et al. Understanding how shared decision-making approaches and patient aids influence patients with advanced cancer when deciding on palliative treatments and care: A realist review. Health Expect. 2023;26:2109–26.
- Pablos JL, Jover JA, Roman-Ivorra JA, Inciarte-Mundo J, Dilla T, Sacristan JA, et al. Patient Decision Aid (PDA) for Patients with Rheumatoid Arthritis Reduces Decisional Conflict and Improves Readiness for Treatment Decision Making. Patient. 2020;13:57–69.
- Gallegos JV, Edelstein B, Moss AH. Evaluation of a Video Decision Aid to Reduce Decisional Conflict in Physician Orders for Life-Sustaining Treatment (POLST) Decision-Making. J Palliat Care. 2020;35:243–7.
- Wang T-J, Chiu P-P, Chen K-K, Hung L-P. Efficacy of a decision support intervention for reducing decisional conflict in patients with elevated serum prostate-specific antigen: A randomized controlled trial. Eur J Oncol Nurs. 2021;50: 101865.
- Loizeau AJ, Theill N, Cohen SM, Eicher S, Mitchell SL, Meier S, et al. Fact Box decision support tools reduce decisional conflict about antibiotics for pneumonia and artificial hydration in advanced dementia: a randomized controlled trail. Age Ageing. 2019;48:67–74.
- Moghadam ES, Manzari ZS, Ghalenow HR, Sanchooli HN. Ottawa Decision Support Framework to Improve Iranian Nurses' Decision Coaching Skills. Indian J Crit Care Med. 2022;26:199–203.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.