

# BMJ Open Experiences and perspectives related to shared decision-making among outpatients with degenerative joint disease in Taiwan: a qualitative study

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## ABSTRACT

**Objectives** Various treatment options are available for degenerative joint disease (DJD). During clinical visits, patients and clinicians collaboratively make decisions regarding the optimal treatment for DJD; this is the essence of shared decision-making (SDM). Here, we collated and assessed the SDM-related experiences and perspectives of outpatients with DJD in Taiwan.

**Design** In-depth interviews and thematic analysis.

**Setting** Primary care clinics of a regional teaching hospital in Taiwan, October 2021–May 2022.

**Participants** 21 outpatients with at least three visits for DJD and who were aware of SDM.

**Results** Four main themes emerged in this study: first, equipping themselves with knowledge: outpatients obtained disease-related and treatment-related knowledge in various ways—seeking relevant information online, discussing with family and friends, learning from their own experiences or learning from professionals. Second, shared or not shared: physicians had different patterns for communicating with patients, particularly when demonstrating authority, performing mutual discussion, respecting patient preferences or responding perfunctorily. Third, seldom saying no to physician-prescribed treatment plans during clinical visits: most patients respected physicians' professionalism; however, some patients rejected physicians' recommendations indirectly, whereas some responded depending on their disease prognosis. Fourth, whose call?—participants decided to accept or reject a treatment plan independently or by discussing it with their families or by obeying their physicians' recommendations.

**Conclusions** In general, patients with DJD sought reliable medical information from various sources before visiting doctors; however, when having a conversation with patients, physicians dominated the discussion on treatment options. The patient–physician interaction dynamics during the SDM process determined the final medical decision, which was in accordance with either patients' original autonomy or physicians' recommendations. To alleviate medical paternalism and physician dominance, patients should be empowered to engage in medical decision-making and share their opinions or concerns with their physicians. Family members should also be included in SDM.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study explored the experiences and perspectives of shared decision-making (SDM) for outpatients with a chronic joint disease during clinical visits in Taiwan, where the traditional culture emphasises strong family ties and a paternalistic decision-making process.
- ⇒ We investigated patient viewpoints on SDM by using a qualitative research design, which is suitable for gaining an understanding of a relatively unexplored phenomenon.
- ⇒ We recruited outpatients only from the clinics of a single hospital, most of whom had a high education level and lived in a metropolitan area; therefore, additional studies with larger, more diverse samples are warranted.
- ⇒ Because SDM is a newly advocated concept in Taiwan, our interviewed patients may not have been completely aware of the elements of SDM; this may have decreased the accuracy of the study results.
- ⇒ Further research is required regarding the perceptions and experiences of other healthcare providers (eg, physicians, community nurses, home health professionals and physiotherapists) and patients in the SDM process.

## INTRODUCTION

Degenerative joint disease (DJD), also known as osteoarthritis, is an ageing-related condition characterised by the degeneration of the cartilage in joints throughout the body. DJD is a leading cause of disability worldwide.<sup>1</sup> This common disease has several treatment options, including oral medications, local injections, physical therapy, assisted devices and surgical procedures.<sup>2</sup> For some patients, treatment decisions can be predicted on the basis of their baseline characteristics during clinical visits; however, many preference-sensitive factors involving patient values, concerns or expectations influence the final decision.<sup>3 4</sup> Thus, the selection of the optimal treatment for outpatients with DJD

requires the participation of a multidisciplinary care team (including physicians, healthcare nurses, physiotherapists and dietitians) and patients as well as involves effective communication between them.

Shared decision-making (SDM) is a patient-centred approach that involves patient–physician communication for clarifying evidence-based practice and the consideration of patients’ preferences. SDM is valuable when complicated medical decisions involving a tradeoff must be made.<sup>5</sup> According to a recent purposeful SDM framework developed by Ruissen *et al*, SDM can be broadly defined as including the following situations: weighing treatment alternatives, negotiating conflicts, solving problematic situations and gaining insights.<sup>6</sup> The National Institute for Health and Care Excellence<sup>7</sup> has proposed a three-talk model for SDM, which has three key components: *team talk* for introducing decisional responsibility and medical conditions to offer a supportive partnership, *option talk* for comparing treatment options and communicating risks, and *decision talk* for helping patients determine their informed preferences and integrating their preferences into the final medical decision.<sup>5</sup> The imbalanced power and knowledge between patients and physicians have been recognised as the main barrier to SDM.<sup>8</sup> Few qualitative studies have explored the difficulties related to SDM application.<sup>9–11</sup> A study reported patient perceptions regarding SDM when visiting the emergency department.<sup>12</sup> Brembo *et al* explored 26 barriers and facilitators influencing the intention to engage in SDM among patients with hip osteoarthritis.<sup>13</sup> However, research on SDM for common chronic diseases such as DJD remains inadequate.

Patient participation is crucial to ensure effective SDM. A previous systematic review has reported the insufficiency of aligning user-centred design in developing the SDM tool, the patient decision aid.<sup>14</sup> However, SDM is a new concept for the medical and general populations in Taiwan.<sup>15</sup> In general, SDM application tends to be more challenging and complex in compliant Asian cultures than in Western cultures. This is because most Asian cultures adopt a paternalistic model and emphasise that health professionals should take on the decision-making responsibility.<sup>16 17</sup> In Taiwan, the family-centred culture considerably influences patients’ medical decisions; in these situations, patients may play a silent role in decision-making.<sup>18 19</sup> Thus, in Asian countries, paternalistic, empathic and compassionate healthcare providers play an active role in making medical decisions for patients.<sup>20</sup> Understanding the experiences and perspectives of patients with DJD may enhance their compliance.<sup>21</sup> Nevertheless, although several studies have explored patient perspectives and experiences<sup>22</sup> or have assessed methods for improving patient participation,<sup>23</sup> few have included orthopaedic patients with lower back pain.<sup>24</sup> Moreover, the concept of SDM was introduced in 2012 at the Landmark Institute of Medicine to improve the quality of healthcare in the USA.<sup>25</sup> However, knowledge regarding how patients (ie, compliant Asian patients) engage in

medical decision-making, particularly patient–physician communication, during clinical visits remains limited. Therefore, in this study, we aimed at understanding the SDM-related experiences and perspectives of outpatients with DJD in Taiwan.

## METHODS

### Research design, setting and participants

To comprehensively explore our participants’ perspectives and experiences, we performed this interview-based qualitative study approach between October 2021 and May 2022 in the primary care clinics of a regional teaching hospital in Taiwan. We applied purposive sampling with the following inclusion criteria: receiving a clinical diagnosis of DJD, being aged >45 years, having at least three outpatient visits, being aware of SDM and receiving treatment after consulting with a physician during a clinical visit, having normal cognitive function, and being able to communicate in Mandarin Chinese or Taiwanese. Patients with psychiatric disorders were excluded. We continued participant recruitment until data saturation (when new data did not generate new substantial ideas<sup>26</sup>) was achieved according to the consensus reached by all authors.

### Data collection procedures

Participants were recruited at the clinics by one of the authors (W-HH), a psychiatrist trained in qualitative interview skills during her PhD study. After obtaining informed consent, one of the female authors (C-YL), with a bachelor’s degree in psychology and training in qualitative research, conducted face-to-face interviews with each participant alone in a small private conference room located next to the outpatient waiting area.

### Instruments

Our interview guide is presented in [table 1](#); it was developed after discussions between all authors and three experts (ie, one clinician, one expert in SDM and the other in qualitative research) as well as based on the literature review of the SDM process. Participants’ non-verbal behaviours were also observed during the interviews. Reflective field notes were also written during data collection and analysis. The average interview duration was approximately 50 min (SD: 8.8 min). All interviews were audio-recorded, and all audio-recordings were transcribed within 72 hours of collection. In addition, the participants’ sociodemographic information (ie, sex, age and education level) was obtained after interviews.

### Patient and public involvement

This study focused on the outpatients’ perspectives and experiences related to the SDM process, which were obtained using the interview topic guide, participant information sheet and consent form as well as from patient electronic medical records. Patient representatives were involved in study management groups, and they underwent practice interviews. To enhance our study’s credibility through member checks, feedback from patient representatives about

**Table 1** Questions and prompt questions in the interview guide

Interview question	Prompt questions
1. What were your disease symptoms and progression?	1.1 Please share your experiences regarding your degenerative hip/knee/spine joint conditions. 1.2 How did your joint pain progress? 1.3 How long did you suffer from this problem?
2. What did you do before visiting the clinic?	2.1 Approximately how long ago did you start to see a doctor for your degenerative joint condition? 2.2 What were the reasons for visiting this clinic? 2.3 What did you do before visiting your doctor?
3. What were the processes and interactions during your physician visits?	3.1 Did anyone accompany you to the clinics? 3.2 How did the doctor explain your condition or disease to you? 3.3 What treatment choices did your physician provide you with? Did the physician indicate any pros and cons? 3.4 Please elaborate on the entire process of your clinical visits.
4. How did you decide on your medical treatments and why?	4.1 How did you make the decision? 4.2 What were the reasons you received or did not receive the treatment options? 4.3 Before decision-making, did you discuss your decision with anybody? What did they say?

the practice interviews was collated and discussed among the research team (table 2).

### Data analysis

Thematic analysis was performed in the following six phases to identify patterns or themes in the qualitative data: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes and noting the findings.<sup>27</sup> Researchers from diverse backgrounds, including psychiatrists, physical therapists, nursing practitioners, medical educators and clinical psychologists, participated in the data analysis.

In phase 1 of the analysis, three authors (C-CW, C-YH and C-YL) listened to the audio-recordings and read and reread the transcripts. In phase 2, two authors (C-YH and J-CW) independently coded the transcripts; then, these two authors and two other authors (Y-HC and W-HH) jointly discussed all the codes during two regular face-to-face meetings and six conference calls. In phase 3, the codes were discussed (J-CW and W-HH), rearranged

and merged, if necessary, until a consensus was reached, thus yielding the initial themes. In phase 4, four authors reviewed the initial themes and compared them thoroughly with the coded extracts and categories as well as the current research objective. In phase 5, the final themes were defined and named. Finally, in phase 6, we selected compelling quotations to support the identified codes and themes. The rigour of this study was enhanced on the basis of four criteria: credibility, dependability, transferability and confirmability.<sup>28</sup> Table 2 provides the strategies applied to each criterion in detail. To enhance its quality, this study was reported according to the Standards for Reporting Qualitative Research.<sup>29</sup>

### RESULTS

Table 3 provides a summary of the demographic characteristics of the included 21 outpatients with DJD with SDM experiences. Of the participants, 13 were women

**Table 2** Strategies for criteria of rigour

Criterion	Strategies
Credibility	<ul style="list-style-type: none"> <li>▶ The authors involved in data collection and analysis had a qualitative research background.</li> <li>▶ Before the interview, we built a rapport with the participants by having an informal conversation.</li> <li>▶ We performed a member check with each participant to clarify ambiguous responses during the interview. Here, two participants were invited to ensure that the results of the data analysis accurately reflected their experiences.</li> </ul>
Dependability	<ul style="list-style-type: none"> <li>▶ We stored the reflective notes, a detailed description of the data analysis and the original data from all interviews for auditing.</li> </ul>
Transferability	<ul style="list-style-type: none"> <li>▶ We documented detailed descriptions of the study methodology, sample selection criteria and data collection process.</li> </ul>
Confirmability	<ul style="list-style-type: none"> <li>▶ Three authors (C-CW, C-YH and C-YL) with diverse backgrounds performed data analysis.</li> <li>▶ The results were discussed among the authors until a consensus was reached.</li> <li>▶ Peer briefing with all authors was also used.</li> </ul>

**Table 3** Participant characteristics (n=21)

	Sex	Age ranges (years)	Education level
A	Female	71–80	University
B	Female	61–70	Graduate school
C	Female	61–70	High school
D	Male	71–80	Graduate school
E	Female	71–70	High school
F	Male	61–70	University
G	Male	71–80	Graduate school
H	Female	71–80	High school
I	Female	71–80	High school
J	Male	81–90	Graduate school
K	Female	71–80	High school
L	Female	61–70	University
M	Male	41–50	University
N	Female	71–80	University
O	Male	51–60	Graduate school
P	Female	61–70	Elementary school
Q	Female	61–70	Junior high school
R	Male	51–60	Graduate school
S	Female	71–80	Elementary school
T	Male	91–100	High school
U	Female	61–70	University

and the mean age was 69.9 years ( $\pm 10.5$ ; range: 47–98). 12 (57.1%) participants had a university degree or higher qualification. The most common diagnosis was lumbar spondylosis (38.1%), followed by knee osteoarthritis (23.8%) and combined lumbar spondylosis and knee osteoarthritis (19%). Four main themes, including several subthemes, emerged (online supplemental table 1 and figure 1), as follows:

- ▶ Theme 1: patients equipping themselves with knowledge during the treatment journey through various strategies such as seeking relevant information online, discussing with family and friends, learning from their own experiences or learning from professionals.
- ▶ Theme 2: patients are involved in shared or not shared final decision-making because their physicians speak with authority, discuss multiple treatment options with them, respect their preferences or respond to them in a perfunctory manner.
- ▶ Theme 3: patients seldom saying no to physician-prescribed treatment plans during visits because they respect their physicians' professionalism, reject physician-prescribed treatment plans indirectly or respond to the physicians depending on how the discussion goes.
- ▶ Theme 4: patients deciding whose call to accept or reject regarding treatment plans on their own, by discussing with family or by obeying their physicians' recommendations.

### Theme 1: equipping themselves with knowledge

Most participants indicated that they would have liked to equip themselves with abundant knowledge relevant to their treatment journey. They wanted to obtain answers to questions such as 'What happened to me?' and 'What should I do?' Furthermore, they attempted to gather information regarding diagnostic methods, treatment options and disease courses relevant to their conditions. By asking or discussing with their families and friends or using the internet, the participants sought health information before and after visiting their physicians. Moreover, they reflected on past personal experiences to identify any relevance to their current condition.

#### Subtheme 1.1: seeking relevant information online

Many participants sought relevant information online since the initial visit. Before visiting their physician, the participants sought information to understand the effects of DJD on their body, the resulting discomfort and problems in daily living, and the types of specialists they can consult for treatment.

Before my visit, I always search online to find which specialist I should see.... (R)

After consulting their physicians, the participants also sought information regarding the treatment options available for their condition.

I went to the clinic to confirm the cause and rehabilitation with the doctor. (F)

#### Subtheme 1.2: asking or discussing with family and friends

Among the various strategies for gaining disease-related knowledge before visiting their physicians, most participants obtained information or suggestions from their family and friends.

My sister had a bad experience.... (B)

My friend's nephew said.... (E)

In addition, most participants who chose to ask family or friends were female.

#### Subtheme 1.3: learning from their own experiences

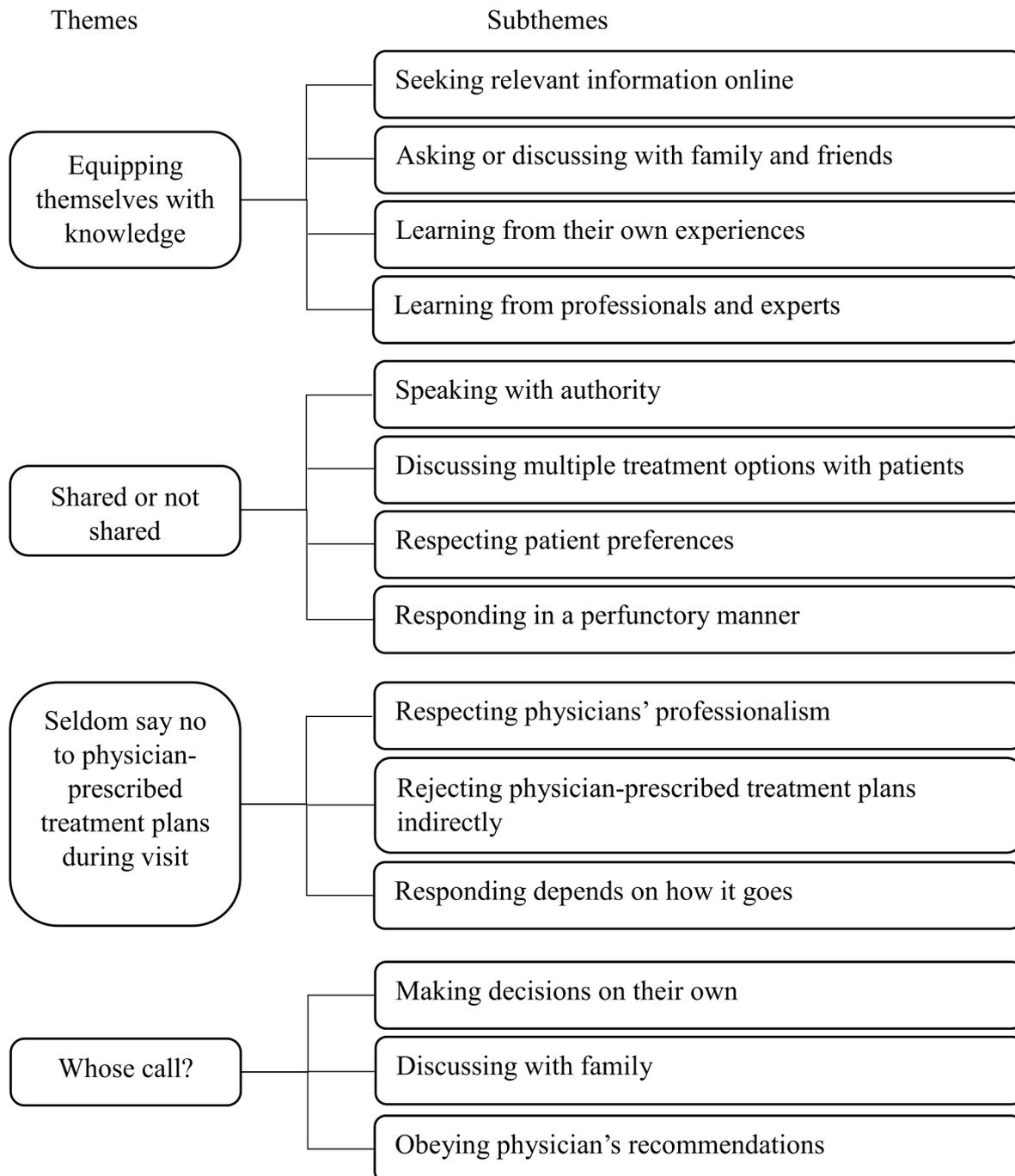
Because of the chronic nature of DJD and the patients' long-term experiences of their condition and associated symptoms, the participants preferred to reflect on their personal experiences and had their own preferences.

I am familiar with all the procedures. (L)

I have tried everything...so I know about all the options.... (O)

#### Subtheme 1.4: learning from professionals and experts

The participants, mostly male, identified hospital websites, health education materials and social media groups run by professionals as possible sources of medical information.



**Figure 1** Coding tree for thematic analysis: themes and subthemes.

I would read the entire booklet and have a clearer idea of my condition. (E)

I'm very appreciative of my doctor...to answer the questions.... (T)

Although the participants collected information either independently or with the help of family or significant others, they emphasised the necessity of health information on hospitals' official websites, educational materials directly provided by healthcare professionals, and information from various social media groups managed by the hospitals or physicians.

### Theme 2: shared or not shared

During clinical visits, physicians engaged in various patterns of communication with patients when providing diagnoses and treatment plans. Most physicians in Taiwan tended to behave authoritatively. A few friendly physicians discussed different treatment options with their patients or considered the treatment options mentioned by their patients. A few physicians willing to listen to their patients' voice responded in a perfunctory manner. Thus, whether decision-making is shared depends on the attitude of the physician.

**Subtheme 2.1: speaking with authority**

Approximately half of the physicians exhibited authoritative behaviour and selected a particular treatment option, such as injection or surgery, without listening to patients or discussing it with them. These physicians often instructed their older patients arbitrarily without providing them with a second choice.

They always speak fluently and authoritatively, so you have no way to interrupt or ask questions. (D)

He didn't give more details or share precautions regarding the surgery. (E)

**Subtheme 2.2: discussing multiple treatment options with patients**

Nearly a quarter of physicians offered several suitable options to their patients. In this case, the patients and their physicians discussed the treatment options until they reached an agreement.

My rehabilitation physician gave me many options. (B)

He not only prescribed me a painkiller but also asked me to visit a physiatrist for physical therapy, as well as a traditional Chinese physician... (I)

**Subtheme 2.3: respecting patient preferences**

In general, highly educated patients would mention preferred treatment options to their physicians and request specific diagnostic tests or treatment regimens. The physicians agreed with their patients' requests if they were appropriate, were in accordance with clinical practice guidelines or were covered by insurance.

I told the doctor I would like to.... (A)

I asked my rehabilitation physician to arrange...and she agreed. (R)

**Subtheme 2.4: responding in a perfunctory manner**

Few other participants mentioned that physicians were reluctant to listen to their requests, or that they answered their questions superficially. If a physician failed to address the patient's questions directly or provided a vague response, the patient had difficulty in understanding their health condition and participating in medical decision-making. Furthermore, if a physician was unwilling to thoroughly explain a health condition to the patient, the patient potentially consulted with other healthcare professionals or sought health information independently:

The doctor explained it to me again, but he did not ask whether I understood the information. (B)

He did not really want to discuss the treatment options with me. (J)

Extremely few patients indicated that their physicians demonstrated empathy as well as partnership to discuss multiple treatment options with them, and that their physicians tried their best to elicit patients' preferences.

**Theme 3: seldom saying no to physician-prescribed treatment plans during visits**

When the patients and physicians had any disagreement regarding treatment options during clinical visits, the patients refrained from insisting further. Instead, to show respect to their physician, most patients obeyed their physicians' recommendations without any questions. Even when the participants had doubts regarding a treatment option or when they had personal preferences, they said nothing to avoid offending the authority.

**Subtheme 3.1: respecting physicians' professionalism**

Most participants, particularly female participants, refrained from questioning their physicians so as to display respect for their physicians' knowledge and experience. The patients trusted their physicians because of their professionalism; therefore, they tended to accept their physicians' diagnoses and treatment plans.

I trust the professionalism of doctors and respect their clinical skills...I trust his diagnosis and mostly accept his professional advice. (H)

As a patient, you must respect your doctor's profession. (S)

**Subtheme 3.2: rejecting physician-prescribed treatment plans indirectly**

Few participants stated that when the treatment plan offered by their physician was different from their expectations or preferences, they avoided rejecting the plan directly. Instead, they informed their physician that they needed to discuss the treatment option with their family, or that they required more time to think about it. Then, they may have sought a second opinion from another physician:

I might tell the doctor that I have to think about it and then discuss it with my family. (A)

I agreed in the clinic but did not take the medicine the doctor prescribed me. In addition, I continued to refill the doctor's prescription for pain pills. (K)

**Subtheme 3.3: responding depends on how it goes**

Most patients did not have much autonomy for their own medical decisions because they lacked medical knowledge and experience of their condition. More male patients than female patients improvised and adjusted their prescriptions depending on the disease progression:

I first listened to my orthopedist...but in vain; then, I accepted the doctor's suggestion of surgery... However, I did not expect to suffer from persistent postoperative soreness...so I turned to receiving rehabilitation. (M)

Therefore, in response to the dominance of the physicians in the SDM process during clinical visits, the patients typically preferred to remain silent and respect their doctors' profession. If they disagreed with their physicians' recommendations, they tried to procrastinate

regarding decision-making or rejected the recommendations indirectly.

#### Theme 4: whose call?

Approximately half of the participants decided whether to accept or reject a treatment plan on the basis of their personal judgement and family members' suggestions. By contrast, the remaining participants insisted on accepting the physicians' recommendations and complying with the treatments they provided.

##### Subtheme 4.1: making decisions on their own

Some participants stated that the final decision should be self-determined and should be based on the collected information. They also considered their financial condition and timing when making medical decisions:

My doctor said that I had to rehab every day, but I didn't have time. Another physician told me to take medicine I didn't accept...Finally, I agreed with the other doctor's recommendation...because I thought it worked. (C)

To accept or reject a surgery recommendation is a personal choice. (M)

##### Subtheme 4.2: discussing with family

Approximately one-fourth of the participants generally consulted their family or significant others before making the final decision, particularly among female patients who encountered life-threatening diseases or invasive treatments.

If the treatment involves surgery, I discuss it with my family...My husband also persuaded me to receive knee replacement surgery.... (L)

My son told me not to undergo the surgery, and I agreed with him because I needed my children's financial support. (N)

##### Subtheme 4.3: obeying physician's recommendations

Approximately half of the participants (regardless of sex or education level but they had a propensity to have spinal DJD) obeyed the orders of their physician without any patient-physician discussion:

I did not need to know the details of the illness clearly, that's the doctors' business...so the doctor told me to undergo lumbar traction, and I did. (G)

I had no choice but to just promise him: yes, I will. (J)

In a compliant Asian culture, such as that in Taiwan, patients expect a paternalistic model in medical visits and assume that physicians are the decision-makers. In addition, because of social tradition and cultural pressure, family involvement is a critical component of the SDM process. This phenomenon is relatively common in older patients with chronic diseases or those with disability.

## DISCUSSION

We identified four main themes in this study. First, outpatients with DJD used various approaches to equip themselves with knowledge: seeking relevant information online, discussing with family and friends, learning from their own experiences or learning from professionals. Second, physicians had different communication patterns with or without SDM. Third, most patients respected the physicians' professionalism and seldom said no to physician-prescribed treatment plans. Fourth, the patients decided whose call it was to accept or reject a treatment plan. Three patient disease management stages for SDM process,<sup>5 30</sup> corresponding to the four extracted themes and their subthemes, were also identified: seeking reliable information, interacting with physicians and making the final medical decision (figure 2).

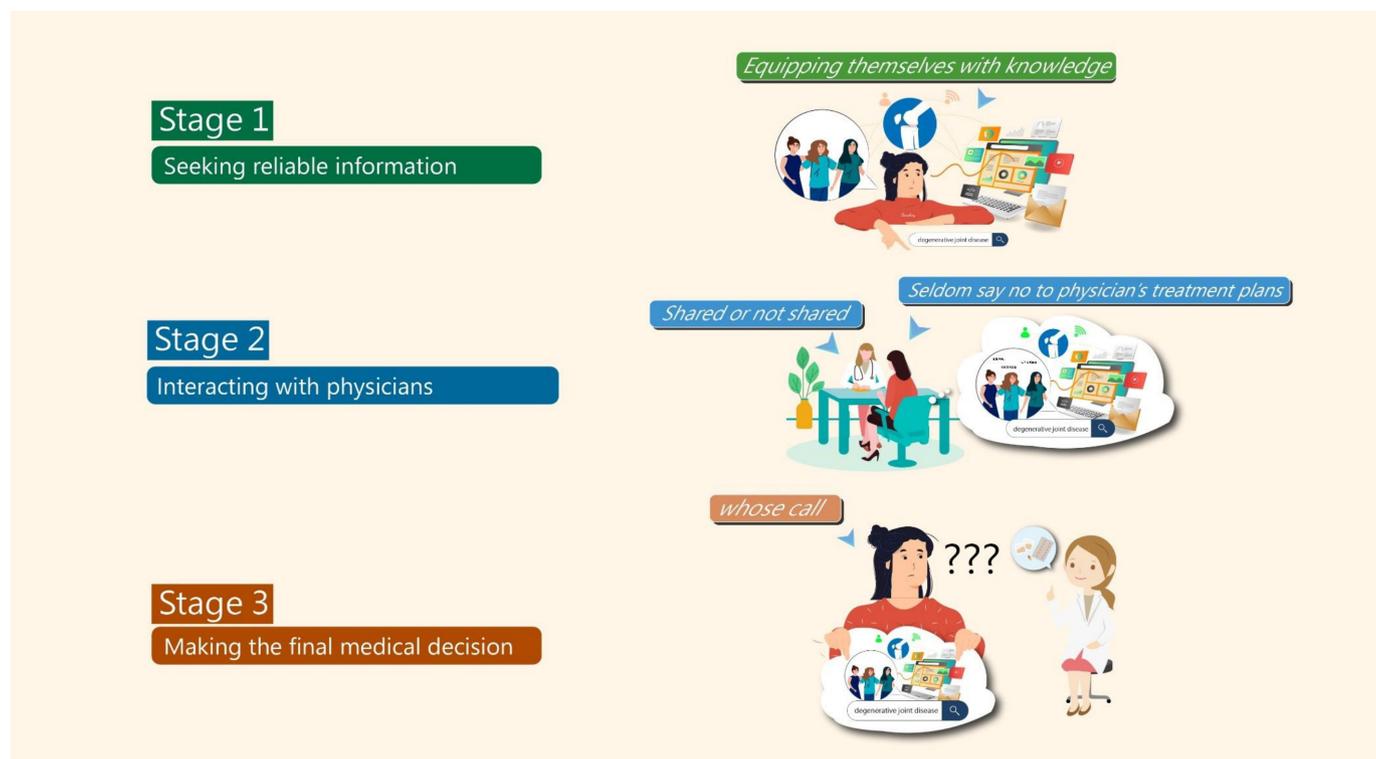
### Patient disease management stages in the SDM process

The three patient disease management stages for SDM process reflected our four main themes appropriately.

- ▶ Stage 1: seeking reliable information (theme 1).
- ▶ Stage 2: interacting with physicians (various patterns of patient communication with different physicians (theme 2) led to the elicitation of diverse responses and reactions from patients (theme 3)).
- ▶ Stage 3: making the final medical decision (theme 4).

The patients who did not accept physician-prescribed treatment plans were in stage 2 of the patients' disease management for SDM process; occasionally, they sought a second opinion from other physicians (figure 2). The patients proactively managed their DJD by equipping themselves with knowledge from various sources not only before visiting doctors but also throughout their treatment process. During their interaction with a physician, the patients rarely rejected the physician's treatment suggestions directly but showed respect to the physician even when they disagreed with the physician's recommendation because physicians generally dominate the discussion on treatment options. In most cases, physician attitude and communication dynamics influenced the decision-making approach. Half of the patients with DJD made their medical decisions on their own or after discussing them with significant others, and the remaining patients insisted on obeying their physician's recommendation without reflecting on it.

We explored the three aforementioned stages to capture the behaviour of outpatients with DJD involved in SDM before, during and after visiting an outpatient clinic. Several studies have qualitatively investigated patient perceptions regarding participating in SDM among emergent patients,<sup>12</sup> patients with cancer<sup>22</sup> and patients with chronic hip osteoarthritis<sup>31</sup> in Europe. However, only one study explored patients' perspectives in Taiwan's secondary mental healthcare settings; the results revealed that patients were not involved but had a desire to be involved in decision-making.<sup>16</sup> The three SDM stages are embedded in the three-talk model of Elwyn *et al*<sup>5</sup> as well as in other well-known SDM frameworks (eg, those proposed



**Figure 2** Three patient disease management stages for shared decision-making process.

by Charles *et al.*<sup>32</sup> Towle and Godolphin,<sup>33</sup> and Makoul and Clayman<sup>34</sup>). However, they have not examined the components of SDM from the perspective of healthcare professionals. A Norwegian SDM study adopted the six-step MAPPIN'SDM model to analyse SDM barriers and facilitators and found two overlapping decision-making processes (ie, diagnostic and treatment decision-making) in the typical course of an orthopaedic consultation for outpatients with hip osteoarthritis.<sup>13</sup> A systematic review identified that SDM models consistently share key components such as treatment option description, decision-making, patient preferences, tailored information and deliberation, all of which are essential for an effective SDM process.<sup>35</sup> However, the SDM process-related expectations of patients from different cultural and contextual backgrounds remain unclear. Thus, further research on the perceptions and experiences of both patients and interprofessional healthcare personnel in the SDM process is warranted.

### Sufficient health information and patient health literacy regarding SDM

A major theme that emerged from our thematic analysis was that the patients continually improved their disease-related and treatment-related knowledge throughout the treatment process. Most of our patients were not confident regarding the information they received and sought credible health information; these findings are consistent with those reported previously.<sup>8</sup> Moreover, health literacy and communication skills are required for patients' engagement in SDM.<sup>36</sup> The primary information source was the internet. A survey indicated that individuals

with sufficient health literacy exhibit a strong tendency to obtain health information from the internet, books, newspapers and magazines.<sup>37</sup> However, most adults in Taiwan have limited health literacy,<sup>38</sup> which is negatively correlated with the ability to access, understand, evaluate and apply reliable online health information.<sup>39</sup> Therefore, to facilitate patient–physician communication and improve patient health literacy, reliable and comprehensible health information must be made readily accessible.

### Patient–physician interaction in Taiwan

Physician authority affects the dynamics of physicians' communication with patients and patients' decisions. Since the first inclusion of SDM in the hospital accreditation standard by the Joint Commission of Taiwan in 2015, several clinicians have begun rethinking their medical role and professional identity and continuing education for SDM. Taiwan's Ministry of Health and Welfare developed SDM training programmes and published relevant public service announcement-based campaigns to encourage medical and healthcare organisations to practise SDM in 2016<sup>15</sup>; however, some clinicians refused to learn about SDM or change their attitudes.

The profession of physicians is considered prestigious and highly respected in Asia.<sup>40</sup> Most physicians recommend medical prescriptions with the expression of trust and confidence, particularly to older patients. This is because most older patients tend to be more passive and expect physicians to make decisions for them.<sup>41</sup> Our finding also echoed that of a previous review that system-level (ie, health policies, clinical practice guidelines, social norms and resources) and organisational-level

(ie, organisational leadership, organisational culture, infrastructures, teams and workflow) characteristics may impact SDM training and play roles in SDM implementation.<sup>42</sup> Therefore, whether patients make decisions on their own in stage 3 or simply accept their physician's recommendations mainly depends on the dynamics of prior communication.

In general, the patient involvement degrees and roles in the SDM process in Taiwan are strongly influenced by the physician's authoritative behaviour toward patients. Patients showing respect to physicians was noted to be a common reaction during the interviews in this study. This characteristic of Taiwanese communication has been described in a relevant study: valuing harmony, avoidance of conflict, and respect for professionals and authority.<sup>43</sup> In Asian culture, physicians warrant respect because of their high socioeconomic status and authority; respect toward physicians may also be extended to the treatment options they recommend. This is the reason that patients and their families do not challenge the decisions of physicians.<sup>44</sup> Here, we found that the SDM and information dispensation statements were distinctively centred on physicians; however, most patients perceived themselves to have a partnership with their physician, but they did not want this relationship to be completely patient dominant. Therefore, of all participants, some never dared to ask their physician any questions, and some directly accepted the physicians' recommendations. By contrast, the remaining patients performed hospital or physician shopping, seeking the opinion of a different specialist and possibly resulting in medical resource abuse and adverse effects on patient health.

### Importance of family involvement

The medical decisions made by patients are often affected by the concerns and opinions of their family, friends and community.<sup>45</sup> In our study, family involvement substantially influenced decision-making from the medical information—seeking step through patient–physician interactions until final decision-making; this indicates the difference in power dynamics of patient–physician engagement in Asian countries from that in Western countries. Although the prominent role of family members in patients' decision-making process has been well documented, the communication style varies across Japan, South Korea and Taiwan.<sup>46</sup> In a cross-cultural study, individuals who valued relational interdependence tended to want their families to be involved in medical decision-making.<sup>47</sup> In the Asian family-centred decision-making culture, older or paediatric patients' family members play the role of primary caregivers who fulfil patients' care needs, including not only financial security and housing needs but also health, personal, psychosocial and emotional care needs. In the current study, family members not only provided health information but also influenced patients' crucial medical decision-making (eg, regarding surgery) directly. A study proposed that in older patients with cancer, high levels of family involvement in

decision-making are associated with their high treatment adherence and good physical and mental health.<sup>48</sup> In the current study, family members and caregivers often served as information brokers or advocators for patients, possibly because they could consider the older patients' past and present circumstances, needs, and attributes and promoted the patients' engagement in decision-making.<sup>49</sup> Thus, family members must be included in SDM.

### Current challenges of SDM and further suggestions

The well-known three-talk model has been used to evaluate the SDM process between patients and physicians in various medical contexts.<sup>5</sup> However, a previous study described that the actual clinical consultations for frail older patients are complex and involve multiple-stage decisions and open-ended treatment planning discussions considering the informed preferences of the patients/families and clinicians.<sup>50</sup> Our study revealed further implementable SDM in clinics should include preparing medical information, engaging discussion partners, facilitating communication, conducting dialogue continuously and collaborating with interprofessional healthcare personnel. However, in this study, we noted that only the second element of the three-talk model, which compares alternative treatment options, existed in our patient–physician communication. The lack of team talk may be attributable to physicians' limited expression of empathy during consultations, whereas the lack of decision talk may be attributable to physicians' authoritative behaviours and medical paternalism.<sup>51</sup>

### Strength and limitations

To the best of our knowledge, this is the first study exploring the SDM-related experiences and perspectives of outpatients with DJD during clinical visits in Taiwan, where the traditional culture promotes strong family ties and a paternalistic decision-making process.<sup>16</sup> However, this study has some limitations. First, participants from the primary care clinics of a single hospital were recruited into this study that aimed to understand patient–physician communication related to treatments for chronic diseases. Further research is warranted that involves interviews to understand both healthcare providers' (eg, physicians, home care nurses, dietitians and physiotherapists) and patients' perceptions and experiences in the SDM process not only in acute care settings but also in community or long-term care settings.<sup>52</sup> However, to understand the medical decision-making process for different specialties in the hospital, we included patients with experiences related to various medical specialists. Moreover, our interview guide was developed based on a literature review and clinical expert discussions. Furthermore, co-design and co-development of an interview guide with patients with DJD may better reflect patient needs. Finally, because SDM is a newly advocated concept in Taiwan, our included patients may not be fully aware of the elements of the SDM process. Therefore, the subthemes or themes we identified from the interviewees, such as what patients



and clinicians did and did not do, might be prone to the respondents' interpretations. More than 50% of our participants had an education level of college or higher and were from a metropolitan area. Therefore, our interviews may adequately capture the perception and experiences related to SDM of patients with DJD with physicians during clinical visits. Future studies recruiting more participants from multiple clinical settings with various demographic backgrounds are required.

## CONCLUSIONS

We qualitatively explored the SDM-related experiences and perspectives of outpatients with DJD visiting clinics in Taiwan. Three key elements of medical decision-making were identified: the need for reliable health information, the authoritative behaviours of physicians, and the involvement of families and friends. We also explored the three stages of patient–physician communication to understand how outpatients proactively manage their DJD.

Our study findings provide researchers and medical educators with important insights regarding the decision-making process of outpatients with DJD. To prevent medical paternalism and physician dominance during consultations, SDM must be promoted not only in the medical education curriculum but also during on-the-job training under the consideration of cultural values. In addition, accessing credible health information, speaking out their concerns or asking questions in the medical decision-making process with their physicians can aid patients in feeling empowered. Furthermore, in SDM, family involvement should be encouraged to promote patient engagement. Our findings may serve as a reference for future studies aimed at developing patient-centred or patient-centred and family-centred treatment plans for the implementation of SDM between patients and physicians.

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Supplementary Table 1. Themes, subthemes, and quotations

Theme	Subthemes	Quotations
1: Equipping themselves with knowledge	1.1: Seeking relevant information online	<p>“I searched online to understand what is going and check the details of the rehabilitation; then, I went to the clinic confirming the cause with the doctor and tried rehabilitation for a while.” (F)</p> <p>“Before my visit, I always search online to find which specialist I should see...I also search for information about treatment and then confirm what I find with my doctor. I also search for information to understand my treatment after my doctor told me what to do next.” (R)</p>
	1.2: Asking or discussing with family and friends	<p>“My sister had a bad experience with this treatment. She was in bed for 10 days after the treatment, and she sent me pictures of her leg, which really scared me. So, I am afraid of receiving this treatment.” (B)</p> <p>“My friend’s nephew said that the operation might not go well, so I should try to postpone it if possible.” (E)</p>
	1.3: Learning from their own	<p>“I had a knee operation last year and received injections and physical therapy for a long time, so I am familiar with</p>

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experiences all the procedures.” (L)

“I have tried everything except surgery in the past 6 years,  
so I know about all the options my doctor mentioned.” (O)

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1.4: Learning “If the doctors could give me a health education booklet,  
from even if it contained only two items related to my condition,  
professionals I would read the entire booklet and have a clearer idea of  
and experts my condition.” (E)

“I’m very appreciative of doctors who give me their official  
or private Line account or link me to their Facebook Group  
pages managed by their team, to answer the questions of  
patients and their families.” (T)

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2: Shared or 2.1: Speaking “I’ve been visiting two doctors for a long time. Both are  
not shared with authority very famous and have many patients. They always speak  
fluently and authoritatively such that you have no way to  
interrupt or ask questions.” (D)

“The orthopedist recommended knee replacement surgery.  
He told my daughter and me that it is a simple procedure  
and that I only need to wear a knee brace for 2 weeks after  
the surgery. He didn’t give more details or share

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precautions regarding the surgery.” (E)

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2.2: Discussing “My rehabilitation physician gave me many options. He

multiple asked me which of them I would prefer to try first. I

treatment thought I could start with painkillers. The physician said he

options with would prescribe medication for 2 weeks, and that we would

patients then discuss subsequent treatment during my next visit.”

(B)

“My orthopedist, Dr. Wu, was very patient and enthusiastic.

He not only prescribed me a painkiller but also

[encouraged] me to visit a physiatrist for physical therapy

and a traditional Chinese physician for acupuncture if I

didn’t plan to have the surgery. In addition, he taught me

how to exercise himself. Seldom, physicians provide these

things to patients.” (I)

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2.3: Respecting “I told the doctor I would like to try a long-acting injection

patient on my knee. He said I could have the injection, but I had to

preferences pay for it by myself.” (A)

“I asked my rehabilitation physician to arrange some

machine traction for my back and to refer me to the

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Department of Traditional Medicine for acupuncture, and she agreed.” (R)

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2.4: “I asked questions when I didn’t understand something my Responding in doctor mentioned. The doctor explained it to me again, but a perfunctory he did not ask whether I understood.” (B)

manner “The doctor didn’t respect me. He did not really want to discuss the treatment options with me; he just provided me hints regarding what he wanted to do.” (J)

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3: Seldom 3.1: Respecting “I seek treatment because I trust the professionalism of my saying no to physicians’ doctor and respect his clinical skills. I understand my physician- professionalis doctor’s interpretation of my medical condition and trust prescribed m his diagnosis and mostly accept his professional advice.” treatment plans (H)

during visits “As a patient, you must respect your doctor’s profession... You have to listen to your doctor’s recommendations; yes, to obey and comply with his prescriptions.” (S)

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3.2: Rejecting “I would respond to my doctor’s recommendation after a physician- couple of days; I might tell the doctor that I have to think

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prescribed about it and then discuss it with my family.” (A)

treatment plans “The orthopedist suggested that I should take pain pills; I

indirectly agreed in the clinic but did not take the medicine the doctor prescribed to me. In addition, I continued to refill the doctor’s prescription for pain pills still every 3 months because I thought I would feel embarrassed if I did not return for the appointment according to the doctor’s scheduled.” (K)

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3.3: “I first listened to my orthopedist and received several

Responding injections for the knee but in vain; then, I accepted my

depends on orthopedist’s suggestion of surgery to reassemble my knee

how it goes with a new set of components. However, I did not expect suffer from persistent postoperative soreness and numbness, which disturb my outdoor activity and made me weak thereafter. Although this was not a satisfying surgery, I understood it was not my orthopedist’s fault. So, I turned to receiving rehabilitation.” (M)

“I had job rotation across cities and countries; I couldn’t help but comply with different doctors’ orders and

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therapists' instructions at that time to relieve my pain." (O)

"The orthopedist suggested to arrange surgery. I agreed, and he scheduled surgery in 2 months. So, I went to see a rehabilitation physician, a Chinese medicine specialist, and a physical therapist during those 2 months; then, I decided to not undergo surgery." (F)

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4: Whose call? 4.1: Making decisions on their own

"My doctor said that I have to rehab every day, but I didn't have time. Another physician told me to take medicine I didn't accept because I used to have a stomachache. Finally, I agreed with the other doctor's recommendation to get an injection immediately at clinic because I thought it worked." (C)

"To accept or reject a surgery recommendation is a personal choice. If I believe it's helpful, I accept the treatment options my doctor offered. Yes, that's my philosophy." (M)

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4.2: Discussing with family

"If the treatment involves a surgical procedure, I discuss it with my family. So, my husband accompanied me to visit his classmate, a very reputable orthopedist. My husband

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also persuaded me to receive knee replacement surgery because he knew that I like to travel and that my stamina will become poorer as I get older.” (L)

“My son told me to not undergo surgery, and I agreed with him because I need my children for their financial support for surgery and their care during hospitalization.” (N)

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4.3: Obeying physician’s recommendations

“I didn’t understand my condition completely based on how the doctor explained it to me. I don’t need to clearly know the details of illness; that’s the doctors’ business. The most important thing I need to know is the way to cure my disease; the doctor told me to undergo lumbar traction; thus, I did.” (G)

“Because the doctor asked me to respond to his suggestion, I had no choice but to promise him this: yes, I will.” (J)

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