

Improving Care Quality Through a Patient-Centered Medical Journey – Focusing on Children With Early-Onset Scoliosis

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Abstract

Background: Early Onset Scoliosis (EOS) is a complex and long-term disease requiring a clear treatment journey to meet the needs of patients and improve the quality of care. Constructing a patient-centered medical journey map for EOS patients to provide appropriate medical information is essential.

Aim: Construct a patient-centered medical journey map for EOS patients.

Subject and methods: Data collection was conducted through team formation, expert-guided workshops, literature review, and patient interviews to develop the medical journey map.

Results: The medical journey map covers the entire treatment process, starting from outpatient visits, hospitalization, preoperative examinations, consultations, medical procedures, preoperative explanations, inpatient care, discharge preparation services, and post-discharge follow-up.

Conclusion: Constructing a patient-centered medical journey map provides the necessary information and support to patients and their families, enhancing patient satisfaction and healthcare quality.

Keywords: early onset scoliosis, patient-centered medical journey

1. Introduction

Early Onset Scoliosis (EOS) is a condition that often accompanies rare diseases and involves complex treatment methods, including the use of body casts, traction, or rehabilitation during surgery. The treatment process for this condition is often long and involves repeated hospitalizations, which can be a stressful experience for patients (Jin-Lian, Chun-Mei, Chi-Kuang, & Li-Hwa, 2010). Therefore, providing relevant information to reduce stress is an important consideration. EOS refers to scoliosis that occurs before the age of 10, with Cobb angles exceeding 10 degrees. According to a 2013 survey by the Taipei City Department of Education in Taiwan, the prevalence rates of spinal curvature exceeding 10 degrees among children and adolescents aged 7 and 10 were 2.17% and 3.26%, respectively. The treatment approach varies based on the degree of spinal curvature, with bracing recommended for those with angles greater than 25 degrees but less than 40-45 degrees. Surgery is the primary treatment for those with angles exceeding 40-45 degrees (Ruiz, Torres-Lugo, Marrero-Ortiz, Guzmán, Olivella, Ramírez, 2022). In a study on the emotional experiences of patients during their treatment journey, Delgado-Garcia (Delgado-Garcia, Lapidus, Talero, & Levy, 2022) found that patients with rare autoimmune diseases often experienced anxiety, fear, and depression due to diagnostic and treatment uncertainties. Lauder (Lauder, Sinclair, & Maguire, 2018) interviewed 12 mothers caring for children with EOS and found that they lacked information provided by healthcare institutions or medical professionals and had to seek knowledge from the internet or social media platforms like Google. They felt isolated and unsupported by medical professionals and had to be constantly prepared for emergency situations as their child's condition changed, leading to exhaustion. Willson (Willson, Rogers, Gingrich, Shearer, & Hryniuk, 2021) found that family members needed

information about the disease, diagnosis, and treatment and wanted to be involved in medical decision-making. Benson (Benson, Albanese, Bhatia, et al., 2022) interviewed patients with cervical dystonia about their treatment journey and identified five key stages: symptom onset, medical professional diagnosis, nursing process, treatment process, and post-treatment life, all of which required special attention.

In summary, EOS is a group of rare diseases that may require various treatment methods, including body casts, traction, and rehabilitation, and multiple hospitalizations. Patients face stress and anxiety during the treatment process, making a patient-centered care model crucial for reducing patient stress and providing support. Patients and their families need relevant information about EOS treatment, including understanding the disease, treatment options, and surgical procedures. They also want to be involved in medical decision-making. Providing the information and support that patients and their families need can increase their participation and satisfaction in the treatment process.

Patient Journey Mapping

Davies (Davies, Bulto, Walsh, et al., 2023) considers patient journey mapping as a patient-centered process aimed at understanding obstacles, facilitating factors, patient experiences, and the outcomes of interactions with healthcare services during the patient's journey. It involves recording elements to create visual or descriptive maps. This patient-centered care model provides patients with information, promotes communication between clinical physicians, patients, and healthcare professionals, and reduces the gap in information perception. Trebble (Trebble, Hansi, Hydes, Smith, & Baker, 2010) believes that managing specific illnesses or treatments as a series of continuous events or steps, represented as a flowchart, allows one to "see" and understand the patient's experience. The sequence of steps between admission and discharge can be seen as the patient's care path or nursing process. According to Sijm-Eeken (Sijm-Eeken, Zheng, & Peute, 2020), patient journey mapping is the trajectory of the complete route followed by a patient during all stages of care, visually presenting emotional experiences during this journey. By analyzing the recorded process of the patient's journey, accurate information can be obtained. The patient's emotional experience during the healthcare process affects satisfaction outcomes. Rodríguez-Fuertes (Rodríguez-Fuertes, Reinares-Lara, & Garcia-Henche, 2023) found that a patient's emotions during the medical journey influenced satisfaction outcomes. Patients had negative emotions related to the healthcare system, such as delayed diagnosis and treatment, anxiety while waiting for test results, and fear and sadness upon receiving diagnosis results. Positive emotions only appeared during recovery or when receiving satisfactory test results. Patient emotions during the medical journey did not affect clinical care satisfaction but did affect organizational satisfaction. Negative emotions had a stronger impact on satisfaction than positive emotions.

Gualandi (Gualandi, Masella, Viglione, & Tartaglioni, 2019) found that the acceptance of information during a patient's medical journey is influenced by many factors. At critical points during events (such as informing the patient of the need for surgery or before transferring to the operating room), it affects the patient's perception and the effectiveness of receiving information. The appropriate timing for each patient to receive information may vary, and choosing the right tools and methods to provide information to the patient is crucial. Patients and professionals perceive different key points for receiving information. From the patient's perspective, the most important time to receive information was before transferring to the operating room. From the professional's perspective, it was the preoperative explanation. Educational needs and preferences of patients varied, so it is important to personalize information delivery to meet patients' needs.

The medical journey map for EOS patients provides comprehensive medical information from outpatient visits to post-discharge follow-up services, focusing on important care processes that can impact patients' emotional experiences and satisfaction. The map can serve as a reference for healthcare providers, patients, and their families to better understand and manage the treatment process. It can also facilitate communication between healthcare providers and patients, allowing for shared decision-making and improved patient-centered care. The purpose of this study was to develop a patient-centered healthcare journey map for patients with EOS.

2. Methods and Subject

This study aimed to construct a patient-centered medical journey map for EOS patients. The map covers the entire treatment process, starting from outpatient visits, hospitalization, preoperative examinations, consultations, medical procedures, preoperative explanations, inpatient care, discharge preparation services, and post-discharge follow-up. The map was developed through the following steps:

Step 1: Formation of a Multidisciplinary Team

A multidisciplinary team was formed. The team consists of 5 members, including 1 director of pediatric

orthopedics, 1 attending physician of orthopedics, 1 chief orthopedic nursing supervisor, 1 chief orthopedic nurse, and 1 orthopedic specialist nurse

Step 2: Expert-Guided Workshops

The multidisciplinary team conducted expert-guided workshops to identify key stages and critical points in the medical journey of EOS patients. These workshops involved discussions and brainstorming sessions to gather insights from different perspectives and identify areas that needed special attention.

Step 3: Literature Review

A comprehensive literature review was conducted to gather information on EOS treatment guidelines, best practices, and patient experiences. This review helped in understanding the existing knowledge and identifying gaps in patient care.

Step 4: Patient Interviews

EOS patients and their families were interviewed to gain insights into their experiences, needs, and preferences throughout the treatment journey. These interviews provided valuable input for the development of the medical journey map from the patient's perspective.

Step 5: Map Development

Based on the information gathered from expert workshops, literature review, and patient interviews, the multidisciplinary team developed the patient-centered medical journey map for EOS patients. The map was designed to be clear, informative, and easy to understand, catering to the specific needs of patients and their families.

3. Results

3.1 This paper presents the results of interviews conducted with six family members of children diagnosed with early-onset scoliosis. Among the interviewed family members, four were mothers and two were fathers. The children's ages ranged from 10 to 16 years, with an equal distribution of three boys and three girls, averaging 11.2 ± 3.1 years old. All children had been diagnosed with early-onset scoliosis and had undergone surgical procedures, with the number of surgeries ranging from 1 to 7. The journey of seeking medical care began when parents observed asymmetrical physical manifestations in their children. They embarked on a quest to find renowned medical experts for their children's treatment. This process involved seeking recommendations from physicians, acquiring information from other families, conducting online searches, and receiving referrals through social media, such as Facebook. Family members emphasized the need to acquire caregiving knowledge and skills during hospitalization, including learning how to administer back braces, caring for postoperative wounds and addressing pain management, engaging in rehabilitation, and providing essential nutritional support in daily life.

3.2 The patient-centered medical journey map for EOS patients consists of key stages and critical points in the treatment journey, with a focus on providing relevant information and support to patients and their families. The map covers the following stages (Figure 1):

(1) Outpatient Visits: Referral to a pediatric orthopedic specialist. Initial diagnosis and evaluation

(2) Medical Procedures:

After admission, we will arrange relevant examinations, including blood tests, urine tests, lung function tests, and neurological assessments. Additionally, consultations with anesthesiology, rehabilitation medicine, and nutritionists will be scheduled to provide a comprehensive treatment plan.

(3) Preoperative Instructions:

Before surgery, the attending physician will conduct a preoperative briefing session. The briefing will include an overview of the preoperative examination results, explanation of the surgical procedure and associated risks, as well as postoperative care instructions. If your relatives are unable to be physically present, we can arrange video conferences to overcome time and space barriers and improve communication efficiency.

(4) Nursing Guidance during Hospitalization:

During your hospital stay, we will provide the following nursing guidance: preoperative nursing instructions, documentation of physical appearance and photographs, skin preparation and back brushing, postoperative care instructions, proper guidance for getting in and out of bed, correct application and removal of braces, and wound care.

(5) Discharge Preparation Services:

Before your discharge, we will provide relevant care instructions, including post-discharge care guidance, wound care, brace usage, maintaining nutritional records, ongoing rehabilitation exercises, and introduce you to information about the Taiwan Scoliosis Care Association.

(6) Follow-up after Discharge:

Depending on your needs, we will provide regular outpatient follow-ups, telephone follow-ups, and dedicated ward hotlines to ensure a smooth recovery process.

The medical journey map provides clear information and guidance at each stage, helping patients and their families understand the process, make informed decisions, and navigate their treatment journey more effectively. It also emphasizes the importance of communication and emotional support throughout the journey.

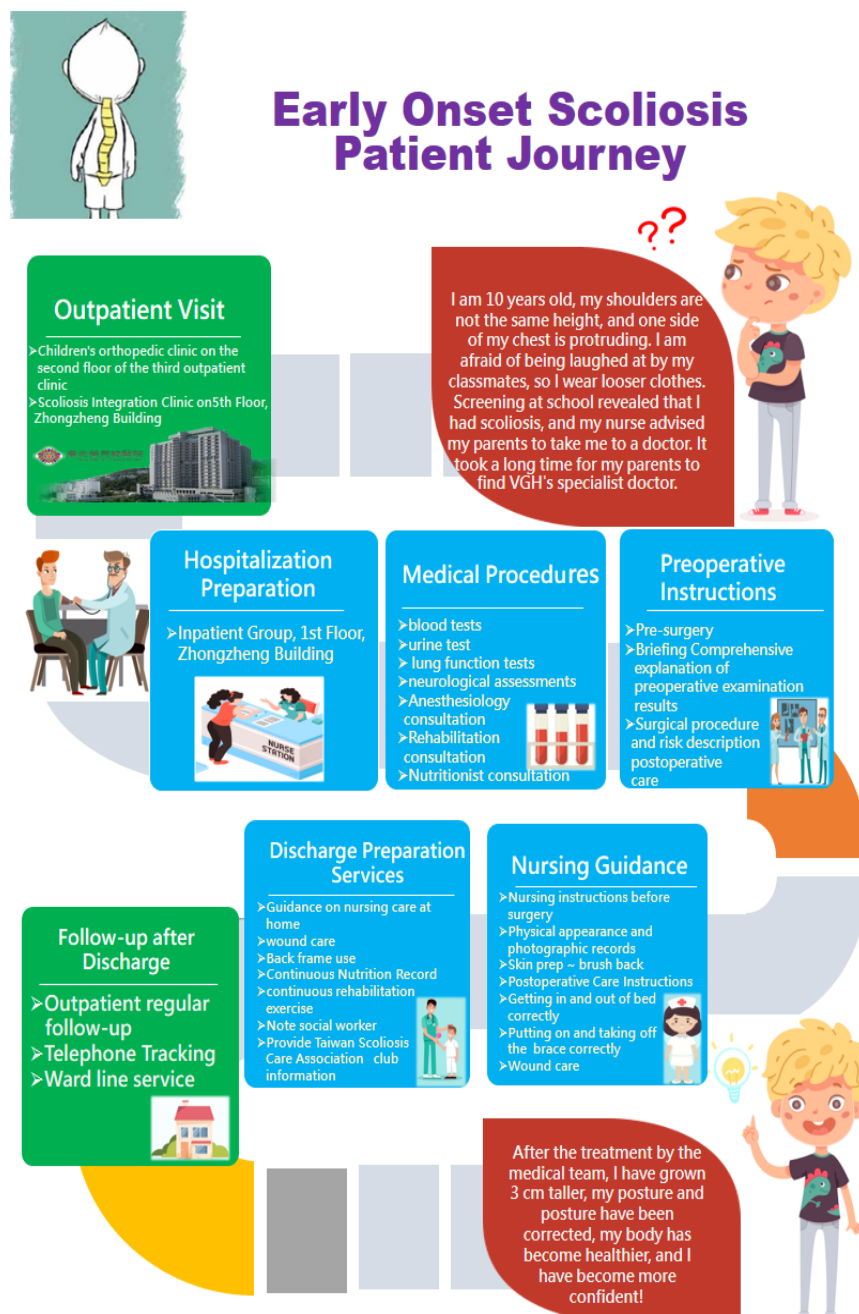


Figure 1. Medical Journey for Early-Onset Scoliosis Patients

3.3 Results of Satisfaction Surveys on Process Diagrams Among Family Members of Children With Early-Onset Scoliosis and Nursing Staff (Tables 1 and 2)

Following the completion of process diagrams, satisfaction surveys were conducted among family members of children with early-onset scoliosis and nursing staff. A total of 6 individuals were surveyed, comprising 3 family members and 3 nursing staff members. Among the respondents, individuals aged 41-50 accounted for 66.7%, and the majority were female (83.3%). Furthermore, the majority held specialized qualifications (83.3%). Overall, all 6 respondents expressed 100% satisfaction with the process diagrams, indicating a high level of satisfaction. Specifically, they reported 100% satisfaction with the information provided, clarity, and aesthetics of each process.

Table 1. The basic information (N=6)

Category		Case number	Percentage (%)
Age	31-40 year-old	2	33.3
	41-50 year-old	4	66.7
Gender	Male	1	16.7
	Female	5	83.3
Education	University	5	83.3
	Master above	1	16.7
Relationship	Mother and child	2	33.3
	Father and child	1	16.7
	Nurse	3	50.0

Table 2. Satisfaction level of early-onset scoliosis patients' medical journey flow chart (N=6)

Item	Very satisfied	
	Case number	Percentage (%)
1. What do you think of the flow chart outpatient information satisfaction	6	100
2. How satisfied are you with the hospitalization information?	6	100
3. How satisfied are you with medical treatment information?	6	100
4. How satisfied are you with the pre-surgery information?	6	100
5. How satisfied are you with the nursing guidance information?	6	100
6. How satisfied do you think the discharge preparation service information is?	6	100
7. How satisfied are you with the discharge tracking information?	6	100
8. What do you think of the clarity of this flow chart?	6	100
9. What do you think of the aesthetics of this flow chart?	6	100
10. How satisfied are you with this flow chart overall?	6	100

4. Discussion

In the study conducted by Benson (2022), it was found that family members are concerned about five stages in the medical journey, including symptom onset, diagnosis by medical professionals, the nursing process, treatment process, and post-treatment life. Consequently, the construction of the process diagram in this case also reveals stages corresponding to disease, diagnosis, treatment and nursing processes, as well as returning home. These stages include outpatient visits, hospitalization, medical procedures, pre-operative briefings, nursing guidance during hospitalization, discharge preparation services, and post-discharge follow-ups, all designed to meet the needs of healthcare seekers. Based on interviews with family members, it was discovered that the initiation of medical care occurs when abnormal physical symptoms are detected. Parents begin their quest for

renowned medical treatment for their children, often through referrals or online information searches. Therefore, the process diagram in this study provides specific information about hospital outpatient names and locations, enabling family members to obtain accurate healthcare information. Motyer (2018) and others found that family members' information needs include disease information and treatment-related questions. Hence, the process places particular emphasis on pre-operative briefings, providing family meetings, explanations regarding various test results, post-operative care instructions, and even utilizes video conferencing for family meetings when necessary to overcome the challenges of involving distant relatives in clinical practice. Sijm-Eeken (2020) argues that the patient's medical journey is a trajectory that encompasses all stages of nursing care. The emotional state and satisfaction of patients throughout their medical journey can influence their perception of healthcare quality. Therefore, the process diagram includes nursing content during hospitalization, such as pre- and post-operative guidance, instructions for getting in and out of bed, wound care, and more. Building on Benson's (2022) research, which highlighted the importance of family members' concerns about post-treatment life, this process diagram provides the necessary nursing guidance and care information to patients and their families during hospitalization and after discharge. This includes post-discharge preparation services, social resource connections, ensuring the patient's ongoing recovery, and meeting the needs of family members after returning home. This study emphasizes the establishment of a patient-centered medical process, which can provide patients with the information they need, improve communication between patients and healthcare professionals, and reduce gaps in information perception. Gualandi (2019) found that the patient's perspective and the effectiveness of receiving information can affect their medical experience. The appropriate timing for each patient to receive information may vary, and patients and professionals consider different key points for information delivery. From the patient's perspective, the most critical moments are upon entering the hospital and before surgery when their involvement is high. From the professional's perspective, planning for hospitalization and preparing patients for surgery are pivotal moments influencing the patient's experience. Therefore, the process diagram should encompass various perspectives and viewpoints of different roles. In this study, a working group was established, including doctors and nursing staff, to conduct workshops, reference relevant literature, and collect interview data from patient families, encompassing a range of perspectives and angles, to create the process diagram for the medical journey of early-onset scoliosis patients. The study sought feedback from family members and nursing staff regarding the satisfaction level with the information content at each stage of the process diagram. The findings indicated that the content of the completed process diagram, based on expert and family feedback, meets the information needs for scoliosis medical care.

In summary, based on the findings of multiple scholars, family members of early-onset scoliosis patients need information about the disease, treatment, and care aspects during the medical process. Patients need to acquire caregiving knowledge and skills during hospitalization, including wearing back braces, caring for postoperative wounds, managing pain, rehabilitation, and nutrition. A medical journey map aims to provide clear and understandable information, serving as a medium for communication between patients and healthcare providers. A strong patient-caregiver relationship can reduce patient dissatisfaction with organizational inefficiencies and enhance satisfaction with healthcare services.

5. Conclusion and Recommendation

5.1 Conclusion

Constructing a patient-centered medical journey is of paramount importance in improving patient satisfaction and healthcare quality. This paper uses early-onset scoliosis as a case study and establishes a process diagram for the patient's medical journey to provide the necessary information and support to patients and their families.

5.2 Recommendation

When implementing a patient-centered medical journey, several key considerations should be taken into account:

- (1) Ensure that patients and their families receive sufficient information throughout the medical journey, including relevant disease knowledge, treatment options, surgical procedures, and associated risks.
- (2) Provide appropriate nursing guidance and care knowledge to enable patients and their families to adapt to the treatment process and continue their recovery after discharge.
- (3) Emphasize communication and involvement, encouraging patients and their families to participate in medical decision-making and facilitating important communication moments, such as pre-operative briefings and family video conferences.
- (4) Establish strong patient-caregiver relationships to ensure that patients feel cared for and supported throughout the entire medical journey.

(5) Regularly track and assess patients' medical experiences to continuously improve and optimize the patient's medical journey.

By following these recommendations, patient satisfaction can be enhanced, patient confidence in healthcare quality can increase, and overall healthcare service quality can be improved.

(6) The patient-centered approach can be extended to the treatment and care processes of other medical conditions, providing better healthcare services.

(7) This paper establishes the fundamental concepts and related issues of the patient's medical journey. Based on these findings, further research and practical implementation of patient-centered medical journeys can be pursued to enhance the quality of patient care and satisfaction.

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