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The Construction of Care Journey Map for Patients With Adolescent Idiopathic Scoliosis

Man-Ling Lin[1], Pi-Ching Wei[1], Pei-Lin Yang[2] & Hsiao-Hui Chiu[2,3], Kuo-Min Chu[1], Hsiu-Chu Hsu[1] & Ying-Ying Lee Liu[4]

[1] Head Nurse, Department of Nursing, Taipei Veterans General Hospital, Taipei, Taiwan, ROC

[2]Assistant Professor, School of Nursing, National Defense Medical Center, Taipei, Taiwan, ROC

[3] Nurse Supervisor, Department of Nursing, Taipei Veterans General Hospital, Taipei, Taiwan, ROC

[4] Assistant Head Nurse, Department of Nursing, Taipei Veterans General Hospital, Taipei, Taiwan, ROC

Correspondence: Hsiao-hui Chiu, No.201, Sec. 2, Shipai Rd., Beitou District, Taipei City, 11217, Taiwan, R.O.C. Tel: 886-2-2871-2121-2398. E-mail: shchiu2@vghtpe.gov.tw

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Abstract

Background: Idiopathic scoliosis is commonly found in adolescents of 10 to 17 years of age, patients are required to encounter several essential measures and types in treatment. Healthcare team provides patients with complete and continuous treatment, in which a comprehensive care criterion has been a crucial issue.

Aim: This article aims to develop a care criterion tool with reliability and validity.

Subject and methods: By using cross-sectional study, a care criterion is developed with literature review. Moreover, the contents were reviewed by experts which further modified based on nursing personnel's recommendation after actual use among clinical patients.

Results: The "Care Journey Map for Scoliosis Patients" with contents of 72 items had been completed, in which the expert validity was 0.98. After use by nursing personnel, items with 100% completeness achieved 76.2%, the overall satisfaction from nursing personnel was 89.9% and 100% agreed the completeness and significance of this care map.

Conclusion: The "Care Journey Map for Scoliosis Patients" is a care criterion developed based on literature review by nursing experts with years of clinical experience, considering transverse and longitudinal time axes as main parts for the overall process in patient care. The tool is proved to be with reliability and validity, which can be a care criterion provided for clinical nurses' compliance, meriting clinical promotion.

Keywords: adolescent idiopathic scoliosis, patient journey, nursing care map

1. Introduction

Epidemiology for Adolescent Scoliosis

Scoliosis is defined as an abnormal vertebral rotation or curvature forming conditions including lateral curvature and vertebral rotation. The curve is usually "S"- or "C"-shaped over three dimensions. Idiopathic scoliosis is most commonly found in adolescents of 10 to 17 years of age, being known as adolescent idiopathic scoliosis (AIS). In 80% of cases with idiopathic scoliosis the cause is largely unknown. Those possible causes include hormone causes, asymmetric growth, muscular imbalance and genetic factors (Menger & Sin, 2021). Several common appearance characters are found in patients with AIS, including: 1. Uneven height of bilateral shoulders. 2. One shoulder blade is more prominent than the other. 3. Uneven length of bilateral arms. 4. Asymmetric waistline, with uneven height of bilateral hips. 5. More prominent ribs (Burton, 2013; Mesiti, 2021).

In the US (Thomas et al., 2021), the age- and sex-standardized total annual incidence rate of AIS reaches 522.5/100,000 person-year [95% confidence interval (CI): 498.2, 546.8], with female incidence rate doubles that in males ($p < 0.05$). The incidence rate for newly diagnosed cases with a Cobb angle of > 10 ° in X-ray shows 181.7/100,000 person-year (95% CI: 167.5, 196.0). In studies (Dunn et al., 2018; Grossman et al., 2018), it is found that the prevalence rate for a Cobb angle of ≥ 10° among idiopathic scoliosis patients aged 10 to 16 years

is 1% to 3%, ranging from 0.15% to 0.66% in boys and from 0.24% to 3.10% in girls, indicating higher prevalence in females than in males. Cumulative incidence estimates are 1.0% for a Cobb angle ≥ 20° and 0.4% for a Cobb angle ≥ 40°. In the study conducted by Bondar et al. (Bondar, Nguyen, Vatani, & Kessler, 2021) for the adolescent group in Southern California, the incidence rate was 28.6/100,000, with females had a significantly greater initial curve magnitude than boys (18.1 °vs. 16.7 °). In China (Qiu, 2017), the incidence rate of scoliosis varied from 0.6% to 2.0%, with idiopathic scoliosis sharing roughly 90%.

Care Journey Map for Patients with Adolescent Idiopathic Scoliosis

Treatment for patients with AIS may involve interventions such as brace, plaster cast, traction and surgery. Aspects of care include physiological, spiritual and social facets. Patient's healthcare journey consists of outpatient clinic visit, hospitalization and returning home. During seeking medical attention, maintaining the consistency and completeness of care contents from clinical nursing personnel to ensure the care contents patient received is a very important issue.

The expert consensus for surgical treatment of AIS collected by Arima (Arima et al., 2021) in Japan has shown a roughly 70% of consistency in aspect of postoperative nursing, indicating the variations for AIS management among institutions. Nevertheless, using a unified care tool for identifying variations to develop consensus can enhance care consistency. Ly et al. (Ly, Runacres, & Poon, 2021) suggest that journey map longitudinally describes patient's healthcare process in various settings and time periods. The identified consistent and overall structure enables medical personnel to better understand the disease course patient experienced, facilitating the interaction between patient and healthcare service to identify the model for illness progression, further realizing patient's care needs and experience, which helps nursing providers positively and properly solve these problems. Benson (Benson et al., 2022) developed a cervical dystonia patient journey map (CDPJM) that describes patient's experience from diagnosis through to treatment. It compares medical interventions with the contents that patients want and need, enabling healthcare providers to improve their services, providing services that meet patient's requirement. Flood et al. (Flood et al., 2021) indicate that a journey map presents patient's complete and specific experience from both practical and emotional aspects, which can be used in creating service models, facilitating to enhance the development of new intervention measures for healthcare service, meeting the needs of patients and healthcare professionals. Sundar (Sundar et al., 2022) analyzed the effects on patient care by providing standardized nursing pathway in AIS patients receiving treatment of posterior spinal fusion and found the improved patient mobility (before: 16.7%, after: 53.3%, $P < 0.00001$), a shortened hospital stay (before: 4.14 days, after: 3.36 days, $P = 0.00006$), reduced postoperative infection (before: 5.1%, after: 0.48%, $P = 0.00547$), reduced readmission (before: 6.0%, after: 0.48%, $P = 0.0021$) and reduced re-surgery (before: 5.1%, after: 0.96%, $P = 0.0195$), indicating that nursing care journey enables healthcare personnel to provide comprehensive care, achieving the benefit in enhancing the quality of patient care.

Measures of treatment and care

Patients with different Cobb angles undergo different treatment measures, those with a Cobb angle of 10 °to 25 °receive X-ray follow-ups at 3, 6, or 12 month intervals; patients with a Cobb angle greater than 25 °but less than 40 °- 45 °or with a curve increase of 5 degrees or more during follow-up period are recommended to wear the brace, undergoing a surgery is primarily required for those who are with more than 40 °- 45 °, in which spinal fusion is the most common surgery (Dunn et al., 2018; Menger & Sin, 2021).

2. Aim of the Study

This article aims to create the Care Journey Map for Scoliosis Patients to provide standardized care contents, investigating

(1) The reliability and validity of the "Care Journey Map for Scoliosis Patients"

(2) The completeness rate for clinical use of the "Care Journey Map for Scoliosis Patients" among nursing personnel

(3) The quality of patient care after use of the "Care Journey Map for Scoliosis Patients"

(4) The degree of agreement in clinical use of the "Care Journey Map for Scoliosis Patients" among nursing personnel

Operation Definitions

AIS: AIS patients aged 10 to 17 years old with a Cobb angle of greater than 10° may undergo hospitalization treatment or spinal surgery treatment.

The completeness rate for clinical use of the "Care Journey Map for Scoliosis Patients" among nursing personnel:

With the measure of medical chart review by 2 senior orthopedic nursing experts, the consistency of implementation for care items that clinical nurses are required to conduct is checked. The formula for the completeness rate: The item number nursing personnel implemented/the item number required to be implemented specified by experts x 100%.

3. Methods and Subject

3.1 Design

Cross-sectional study.

3.2 Setting

Venues for data collection include 4 orthopedic wards at a medical center in northern Taiwan.

3.3 Participants

The enrollment period was between September 1 and December 31, 2021, including patients diagnosed as AIS requiring hospitalization treatment or a surgery.

3.4 Methods and Phase of Data Collection

3.4.1 Study Tools

(1) In the "Care Journey Map for Scoliosis Patients", care contents for patients in the period before hospitalization to discharge returning home were created by the senior head nurse with 30-years clinical experience based on relevant AIS literature. The continuous care contents were completed according to the process involving illness treatment and care. It was organized based on the 3 major fundamentals including outpatient clinic visit, hospitalization and returning home with a total of 71 items of care contents. The measure contents provided include 5 items for outpatient clinic visit (1 week before surgery), 12 items for examination (1 day prior to surgery), 14 items for treatment (the day undergoing surgery), 19 items for the postoperative care during the first 3 days after surgery, 11 items for the postoperative care during the 7 to 14 days after surgery, and 10 items for returning home (discharge preparation and home health care).

(2) Measuring the degree of agreement among nursing personnel: The contents of self-completed structured questionnaire include 2 parts, with the first part involving basic information such as job tenure, orthopedic seniority, and nursing clinical ladder. The second part consists of 7 questions involving the clarity, completeness, significance, feasibility, willingness, capability and overall satisfaction. The 5-point Likert scale was used, scoring from 5 points for "strongly agree" to 1 point for "strongly disagree".

(3) The consistency in use among nursing personnel: The contents and instructions of this tool were introduced through ward morning meetings by the head nurse who organized and developed the tool. Moreover, discussions were conducted to ensure nursing staff understand the procedure and methods in implementation.

3.4.2 Administrative Approach

During the interrogation in outpatient clinic, the orthopedists confirmed the patients who were qualified for enrollment. Nursing personnel then provided scoliosis patients with care contents according to the "Care Journey Map for Scoliosis Patients".

3.4.3 Statistics and Data Analysis

The Excel software was used to calculate the expert validity (content validity index, CVI) in percentage, completeness in use among nursing personnel, the degree of agreement in use among nursing personnel presented in frequency and percentage.

3.4.4 Ethical Considerations

The study complies with research ethics and acquired approval from the institutional review board (IRB, No. 2019-02-006AC). The study commenced with information that was purposed to be impaired by the completion of the study.

4. Results

4.1 Expert Validity for the "Care Journey Map for Scoliosis Patients"

The contents of the "Care Journey Map for Scoliosis Patients" were reviewed based on the opinions from 7 experts, with 5 females (71.4%) among them. In the fields of experts, there were 1 orthopedic specialist, 1 pediatric occupational therapist, 1 orthopedic nurse specialist, 1 assistant professor for the fields of internal medicine and surgery in school, 1 nursing director from long-term care institution, 1 orthopedic head nurse and 1

senior nurse from orthopedic ward. Their job tenure varies from 15 to 35 years, with the orthopedic seniority from 10 to 30 years. For the academic background, master's degree achieves 57.1%, and 28.6% with doctorate degrees. The "clarity", "correlation" and "significance" for each item of the contents were scored by these 7 experts, using a 4-point Likert scale in which 1 point indicates very insignificant, inappropriate and unclear that become unnecessary to be included. Two points indicates insignificant, inappropriate and unclear that requires a major reversion. Three points indicates significant, appropriate and clear that requires a minor reversion. Four points indicates very significant, appropriate and clear that requires to be included. After compiling statistics, the overall expert validity was 0.98, with 0.97 for "clarity", 0.99 for "correlation", and 0.99 for "significance", indicating a good validity. Nevertheless, there were 11 items regarded as with insufficient clarity by experts which required more clear description, respectively including: "Evaluation – 1 week prior to surgery: arranging preparation for surgical treatment", "Treatment – The day undergoing surgery – arriving operation room for confirmation while undergoing surgery", "Care – within the first 3 days after surgery – physiologically-continuous rehabilitation exercises – upper and lower limbs exercise (augmented reality, AR) training", "Care – within the first 3 days after surgery – psychologically – correcting the body image disturbance", "Care – within the first 3 days after surgery – psychologically – increasing the cognition for surgical prognosis", "Care – within the first 3 days after surgery – psychologically – reducing peer isolation (introducing patient groups)", "Care – within the 4-7 days to the 14 days after surgery – continuing relevant care – brace", "Care – within the 4-7 days to the 14 days after surgery– continuing relevant care – wearing the brace for 1 to 3 months", "OPD follow-up – discharge preparation and transportation service – phone calling follow-up", "OPD follow-up – applying a pad using bath towels after returning home – for protection of the back and neck", and "Health promotion/home health care – allowing shopping or visiting, playing games".

4.2 Completeness of Care Map Project Selection

Two clinical experts jointly reviewed 22 care maps to check whether the care content of the patient checked by the nursing staff was complete. If the checked items were completely consistent with the patient's needs, it was defined as completeness 100%."Scoliosis Patient Care Journey Map" has 71 care items, of which 54 care items are completely checked by the nursing staff (completeness rate 100%), but 6 of them are often left unchecked, namely "Checkup" - 1 day before surgery - Introduction to postoperative pipeline images (complete rate 36.4%)", "Examination - 1 day before surgery - Introduction to comprehensive care guidance smart link map link (complete rate 36.4%)", "1 day before surgery Care: Rehabilitation exercises - Breathing trainer exercises - Cardiopulmonary movements, upper and lower limb movements (with AR training) (Complete rate 45.4%)", "Treatment - Day of surgery - Infection prevention: Continuous rehabilitation exercises - Breathing trainer exercises - Cardiopulmonary exercises (with AR training) (complete rate 45.4%)", "Care-within 3 days after surgery-continuous rehabilitation exercises-respiratory trainer exercises-cardiopulmonary exercises (with AR training) (complete rate 45.4%)", "Care - 4-7~14 days after surgery: Continuous rehabilitation exercises - upper and lower limb movements (AR training) (complete rate 45.4%)". It shows that rehabilitation exercises are often ignored in the care content.

4.3 The Quality of Patient Care

The analysis for care quality indicators in 22 patients using the "Care Journey Map for Scoliosis Patients" showed the incidence of nerve injury was 0%, incidence of wound infection was 0%, incidence of fall was 0%, incidence of complications was 0%, the rate for 60-day readmission was 0%, incidence of pressure injury was 0.36%, and hospital stay of 3-29 days, with an average hospital stay of 11 days, indicating good care quality.

4.4 The Degree of Agreement in Clinical Use of the "Care Journey Map for Scoliosis Patients" Among Nursing Personnel

In the survey on the degree of agreement in clinical use of the "Care Journey Map for Scoliosis Patients" among 18 nursing personnel, 3 to 10 years of job tenure and orthopedic seniority was in the majority, sharing 44.4%. For nursing clinical ladder, both N3 and N4 achieved 44.4% (Table 1). The range of the degree above agreement was 55.6%-100%, with 2 items achieved 100% for the degree above agreement, which respectively were "You consider this care map is complete", "You consider this care map is significant". There were 3 items achieved 89.9% for the degree above agreement, including "You consider this care map feasible", "You like to use this care map", and "You are satisfied with using this care map". The item with a relatively lower degree above agreement was "You consider this care map clear", sharing 55.6% (Table 2).

Table 1. Basic information for nursing personnel (N=18)

Item		N	%
Job tenure	Less than 2 years	2	11.1
	3-10 years	8	44.4
	11-20 years	3	16.7
	More than 21 years	5	27.8
Orthopedic seniority	Less than 2 years	4	22.2
	3-10 years	8	44.4
	11-20 years	3	16.7
	More than 21 years	3	16.7
Nursing clinical ladder	N2	2	11.1
	N3	8	44.4
	N4	8	44.4

Table 2. The degree of agreement among nursing personnel (N=18)

	Strongly agree		Agree		Fair	
Item	N	%	N	%	N	%
You consider this care map clear	3	16.7	7	38.9	8	44.4
You consider this care map complete	8	44.4	10	55.6	0	0.0
You consider this care map significant	8	44.4	10	55.6	0	0.0
You consider this care map feasible	7	38.9	9	50.0	2	11.1
You like to use this care map	6	33.3	10	55.6	2	11.1
You are capable of using this care map	8	44.4	9	50.0	1	5.6
You are satisfied with using this care map	6	33.3	10	55.6	2	11.1

4.5 Result for the Reversion of Care Journey Map

The “Care Journey Map for Scoliosis Patients” was revised based on the opinions from nursing expert review and suggestion from nursing staff, providing more detailed description about wording according to expert opinions: (1) Revised “OPD-Evaluation-One week before surgery-Integrated OPD guidance-Occupational therapist” by adding physical therapist, thus the reversion was “OPD-Evaluation-One week before surgery-Integrated OPD guidance-Occupational/Physical therapist”. (2) “1 day prior to surgery – briefing on smart link and map link of holistic nursing guidance” was deleted due to the unclear content. (3) “One day prior to surgery – examination item - monitoring spinal cord function” was added. (4) “Bone Health” was added, “Within the first three days after surgery – Nutritional care – fish, meat, protein, vitamin C” was revised as “Within the first three days after surgery – Nutritional care – fish, meat, protein, vitamin C, and Bone Health”. (5) Reversion for descriptive content, “Continuous rehabilitation exercise – upper and lower limbs exercise (AR training)” was revised as “Continuous rehabilitation exercise – upper and lower limbs exercise”. (6) “Returning home – Discharge preparation/Rehabilitation – Wound care – Freshening up (hair and body). (7) The 71 items of care content were revised as 72 items, the measure contents provided including 5 items for OPD visit (1 week prior to surgery), 11 items for examination (1 day prior to surgery), 15 items for treatment (the day undergoing surgery), 19 items for care within the first 3 days after surgery, 11 items for care within the 7 to 14 days after surgery, and 11 items for returning home (discharge preparation and home health care) (originally 10 items). (Figure 1)

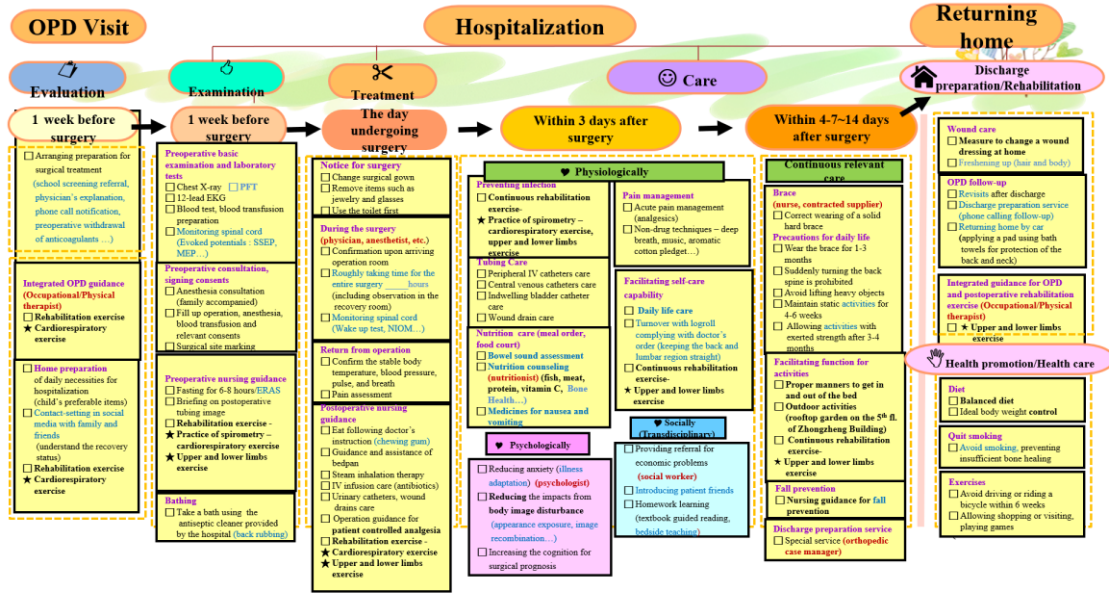

Fig. 1 Care Journey Map for Adolescent Idiopathic Scoliosis Patients

5. Discussion

With literature review and clinical experience, the "Care Journey Map for Scoliosis Patients" was developed by nursing experts with years of orthopedic clinical experience based on the process of patients in seeking medical attention, including OPD visit, examination, treatment, 3 days after surgery to 7-14 days after surgery, and returning home. The overall expert validity for the contents was 0.98, with 0.97 for "clarity", 0.99 for "correlation", and 0.99 for "significance". The tool possesses great entirety and completeness. Nursing personnel 100% agree completeness of this tool. Nevertheless, the degree of agreement for clarity was only 55.6% due to the 71 items of numerous contents. The insufficient clarity probably was resulted from the limited layout space, which makes it impossible for each content to be written in detail. Therefore, the wording was revised to be neat and clear, improving the clarity. In the future, remarks may also be added for content explanation, enhancing the description about in-service education.

In this article, the completeness of use among nursing personnel is 76.2%. Among all 71 items, 54 items were completely implemented. Arima (Arima et al., 2021) indicated that the consistency of postoperative nursing practice for care map was roughly 70%, the rates in completeness and consistency are similar. Therefore, with establishing care criterion to enhance nursing consensus, the incompleteness rate can be reduced. Moreover, in those 6 items with relatively lower completeness rate, there are 4 items involving the implementation of rehabilitation exercise with AR. After analysis, the probable cause may because patients had been instructed to use AR respiratory exercise in OPD visits, AR provides learning effects in the interaction between patient and smartphone which is not required nursing personnel to offer continuous reminders. As a result, it results in omitting during nursing process, and without any records. Therefore, in future implementation orientation for nursing personnel, it should be particularly explained to reach a consistent approach.

Although there was no any comparison with the control group for care quality of the 22 patients, incidence rate for nerve injury was 0%, incidence rate for wound infection was 0%, incidence rate for fall was 0%, incidence rate for complications was 0%, and 60-day readmission rate was 0%, all indicating good care quality. Furthermore, the 0.36% of incidence rate for pressure injury was caused by the longer time of surgery and not occurred during ward care. The average hospital stay for scoliosis surgery in a medical center was 5.5 days but the average hospital stay for these 22 patients was 11 days. The longer length of hospital stay was resulted from the required in-hospital observation due to skull traction in several patients. Sundar et al. (Sundar et al., 2022) suggest that in patients with AIS, providing standardized nursing pathway can reduce postoperative infection, reducing readmission, and enhancing care quality. The result is similar to the findings in this article.

The degree above agreement among nursing personnel for "completeness" and "significance" of this tool achieved 100%, the degree above agreement for all "feasibility", "willingness", and "satisfaction" achieved 89.9%. Scholars such as Ly (Ly et al., 2021), Benson (Benson et al., 2022) and Flood (Flood et al., 2021) all

indicate the benefits of journey map to enhance care capability for nursing personnel.

6. Limitation of the Study

The "Care Journey Map for Scoliosis Patients" provides nursing personnel with a basis for care contents. At this time, the study investigates only for the development of contents. In the future, the comparison can be conducted on patients' prognosis quality and care satisfaction after receiving such a care criterion, ensuring the benefits in clinical application.

7. Conclusion

Past studies on care journey mapping for adolescents with idiopathic scoliosis have the following shortcomings:

(1) Insufficient Assessment of Patient Needs: Many studies focus on clinical treatment outcomes but fail to systematically evaluate the psychological and emotional needs of patients throughout the treatment process.

(2) Lack of Multilevel Participant Perspectives: Most studies primarily rely on the viewpoint of the medical team or the patient alone, lacking input from a variety of stakeholders such as family members, caregivers, and other related healthcare professionals, which limits the comprehensiveness of the care journey map.

(3) Absence of a Dynamic Adjustment Mechanism: Existing care journey maps are often static, failing to accommodate the evolving needs of patients as the disease progresses or as their mental state changes. This limits the ability to optimize the timing and approach of care interventions.

Advantages of This Study Based on Previous Insufficiencies:

(1) Comprehensive, Patient-Centered Needs Assessment: In designing the care journey map, we conducted an in-depth assessment of patient needs, integrating psychological, social, and emotional dimensions to enhance the overall care experience.

(2) Inclusion of Multiple Stakeholder Perspectives: This study engaged participants from various levels, including the medical team, patients, family members, and caregivers, to gather diverse perspectives and design a care process that better aligns with real-world needs.

(3) Dynamic Adjustment and Personalization: We developed a dynamic care journey map that allows for timely adjustments based on individual patient needs and changes throughout the treatment process, ensuring the most suitable and effective care interventions.

The "Care Journey Map for Scoliosis Patients" is a care criterion developed based on literature review by nursing experts with years of clinical experience, considering transverse and longitudinal time axes as main parts for the overall process in patient care. The map content was further reviewed by experts, with further reversion based on the suggestion provided by nursing personnel after actually used in clinical patients. This tool is proved to possess reliability and validity, can be a care criterion provided for clinical nurses' compliance, meriting clinical promotion.

8. Recommendation

(1) Expert validity for the "Care Journey Map for Scoliosis Patients" is 0.98, indicating great validity, which can be used by clinical nursing personnel.

(2) The items 100% completely used in the "Care Journey Map for Scoliosis Patients" achieve 54 items, sharing 76.2%. The contents explanation is required to be strengthened, enhancing the implementation consensus among nursing personnel to increase completeness rate.

(3) The overall satisfaction among nursing personnel for the "Care Journey Map for Scoliosis Patients" achieves 89.9%, moreover, 100% agree that the care map is complete and significant. This tool can be provided as a care criterion for nursing personnel to comply with.

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