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Editorial

AI is not allowed to be listed as author or co-author

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Artificial intelligence (AI) tools are technologies and systems that aim to reproduce or mimic human intellectual activities such as learning, reasoning, judgment, and recognition on a computer. Generative AI has the ability to automatically generate a variety of content, including text, images, voice and program code. Several generative AI tools are widely available, such as ChatGPT (OpenAI), Gemini (Google), Copilot (Microsoft), and Apple Intelligence (Apple), and many readers may have already utilized them. Against this backdrop, interest in utilizing AI tools to write papers is growing.

AI tools offer excellent tools to support writing, performing such functions as refining expressions, supporting idea generation and producing summaries of information. However, the sources of the generated text and citations may be unclear, which may border on plagiarism or generate inaccurate citations. In addition, it is necessary to refrain from entering confidential information, because prompts (input contents) may be incorporated for AI learning purposes. As such, it is necessary to be exceptionally cautious when utilizing AI tools, while thoroughly understanding their advantages, challenges and limitations.

Most journals, including the *Journal of International Nursing Research*, prohibit use of AI authorship for to such reasons as the lack of clarity about who is responsible. These would include using images generated by AI and citing AI-generated materials. In addition, to ensure transparency, papers that use AI tools for data collection and analysis must clearly state how they were used in the methods section of the paper. Peer review using AI, moreover, is not permitted owing to confidentiality obligations. However, there is no need to clearly state the use of "AI assisted copy editing," as AI-assisted improvements are acceptable when applied to human-generated texts for purposes of readability and style, as well as to ensure that the texts are free of errors in grammar, spelling, punctuation and tone (Nature Portfolio, n.d.).

AI tools are constantly evolving, and it is important to keep abreast of the latest information. The International Committee of Medical Journal Editors (ICMJE) has developed a set of clearly stated guidelines on the use of AI, which I recommend be used as a point of reference.

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Review Article

Difficulties in daily life among patients who underwent childhood hypospadias surgeries: A scoping review

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Abstract

This study aimed to comprehensively review research on adolescent and adult patients with hypospadias who underwent hypospadias surgery during childhood and clarify the difficulties in daily life experienced by them. The PubMed, CINAHL, and PsycINFO databases were searched for articles published between 1990 and 2023. The retrieved literature was independently reviewed by two investigators, and the studies to be included were determined by three investigators in accordance with the selection criteria. From the target literature, the results related to difficulties in the daily life of adolescent and adult patients who underwent hypospadias surgery during childhood were extracted and analyzed. A total of 23 articles were identified. The analysis revealed the following six core categories: perception of genital appearance, difficulties with sex, social acceptance, difficulty with urination, psychological problems, and immaturity in coping with health conditions. It has become clear that the difficulties experienced by patients in their daily lives are not only physical difficulties caused by symptoms and functional disorders but also psychosocial difficulties that affect their development and quality of life; therefore, the role of nurses in providing long-term medical support must be considered.

Keywords

hypospadias, long term, adolescence, adulthood, difficulties in daily life

JINR 2025, *4*(2), e2024-0038

Introduction

Hypospadias is a congenital disorder in boys that presents with proximal urethral opening, developmental failure of the ventral foreskin, and penile flexion (Hinman & Baskin, 2008); it is one of the most common disorders in Europe and the United States, with a rate of more than 50 cases per 1,000 live births (Springer et al., 2016). The treatment objective is to rectify the position of the urethral opening to facilitate standing urination, rectify the cord deformity to allow sexual intercourse after puberty without hindrance, and mitigate the psychological impact on the affected child by improving the penile appearance (Moriya et al., 2011). Surgical treatment is performed at an early age; however, the technical difficulty of surgery is noteworthy, and surgical techniques have been debated for several years.

The long-term consequences of surgical treatment among children reaching adolescence and adulthood have recently been highlighted. In some cases, after the pediatric medical follow-up is completed, complications, such as urethral stricture and fistula, may occur during adolescence or adulthood (Nuininga et al., 2005; O'Leunbach et al., 2019; Snodgrass & Bush, 2022). Furthermore, cosmetic consequences related to the reconstructed penis, as well as difficulties with sexual and reproductive functions, such as ejaculation, have been reported (Rynja et al., 2011). Psychosocial adaptation has also been identified as a concern. Sandberg et al. (2001) addressed the issue of psychosocial adjustment, whereas

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Schonbucher et al. (2008) focused on the relationship between health-related quality of life (HRQOL) and surgical treatment for hypospadias. Additionally, scattered literature reviews have reported measures for assessing patients' urinary and external genital function, appearance (Sullivan et al., 2017), and psychological effects (Deibert & Hensle, 2011). Although these reviews have partially evaluated the long-term treatment outcomes, none have focused on the actual difficulties faced by post-pubertal patients who have undergone surgery for hypospadias. Furthermore, a review of HRQOL among patients with hypospadias (Bhatia et al., 2021) conceptualized HRQOL and identified five domains. Although outpatient follow-up in childhood is provided to middle and high school students, late complications, such as urethral stricture, can occur in adulthood. Because there is no follow-up system in place after childhood for regular checkups, patients with such complications may not receive the required care. In addition, potential risks to sexual and reproductive function, such as hormone abnormalities and fertility issues, become more apparent with the onset of secondary sexual characteristics and life events. As these problems are recognized as difficulties in daily life after adolescence, nursing support is required to improve patients' HRQOL not only during childhood but also during adulthood. However, there is a lack of existing knowledge focusing on such patient difficulties.

Accordingly, this study comprehensively reviewed the literature on adolescent and adult patients who underwent surgery for hypospadias during childhood. The objective is to determine patients' difficulties in daily life that emerge as remote problems-physical (e.g., issues with urination and sexual function), social (i.e., interpersonal relationships), and psychological-after children with hypospadias have grown up. We believe that a scoping review, which is a method for systematically outlining the primary concepts and knowledge that form the basis of a research area, would be appropriate. This will facilitate an understanding of patient needs, identify gaps in clinical and research work, and enable the formulation of research questions that will contribute to the advancement of nursing research and enhancement of the quality of nursing care for patients with hypospadias.

Research Objectives

This study aimed to determine the physical, social, and psychological difficulties experienced in daily life by adolescents and adults who underwent hypospadias surgery during childhood by comprehensively reviewing related studies.

Definition of the Terms

For the purposes of this study, difficulties were defined as the problems that patients experience, including physical difficulties with urination and sexual function, social difficulties in interpersonal relationships, and psychological difficulties.

Research Methods

Design

A scoping review was conducted to provide an overview of and organize the findings regarding the difficulties faced by adolescent and adult patients who underwent surgery for hypospadias during childhood. This methodology was used following the approach outlined by Arksey and O'Malley (2005). The PRISMA Extension for Scoping Reviews guidelines (Tricco et al., 2020) were followed. The study methods were registered on the Open Science Framework platform (osf.io/2 aud4).

Eligibility Criteria

Participants

The participants in this study were adolescent and adult patients who had undergone surgery for hypospadias during childhood.

Concept

The concept of interest was the difficulties in daily life that occurred after surgery, including physical difficulties, such as urinary and sexual dysfunction, and social and psychological difficulties, such as interpersonal relationships.

Context

This study incorporates literature from all geographical and cultural contexts.

Information Sources and Search

The PubMed, CINAHL, and PsycINFO databases were used to search for literature published from 1990 to 2023. The rationale for focusing on the period after 1990 was that there were notable advancements in surgical instruments and techniques between the 1980s and the 1990s, particularly in surgical techniques, such as the creation of a urethral opening at the tip of the glans.

To search the literature, the following search formula was used: (Hypospadias) and ("adolescents" or "man" or "men" or "adults" or "patients" or "development" or "long term"). The search formula was constructed using the terms "difficult," "problem," "trouble," "matter," "trying," "suffer," "distress," "pain," "agony," "anguish," "worry," "unease," "angst," and "burden." To ensure inclusion of the most relevant and pertinent studies, articles were selected based on the following eligibility criteria: (1) articles on difficulties experienced by adolescent and adult males who underwent hypospadias surgery during childhood, (2) original articles, and (3) articles written in English. The exclusion criteria were as follows: (1) studies focusing on surgical procedures, (2) studies on pain and wound management in the acute postoperative period, (3) cases of other serious diseases, and

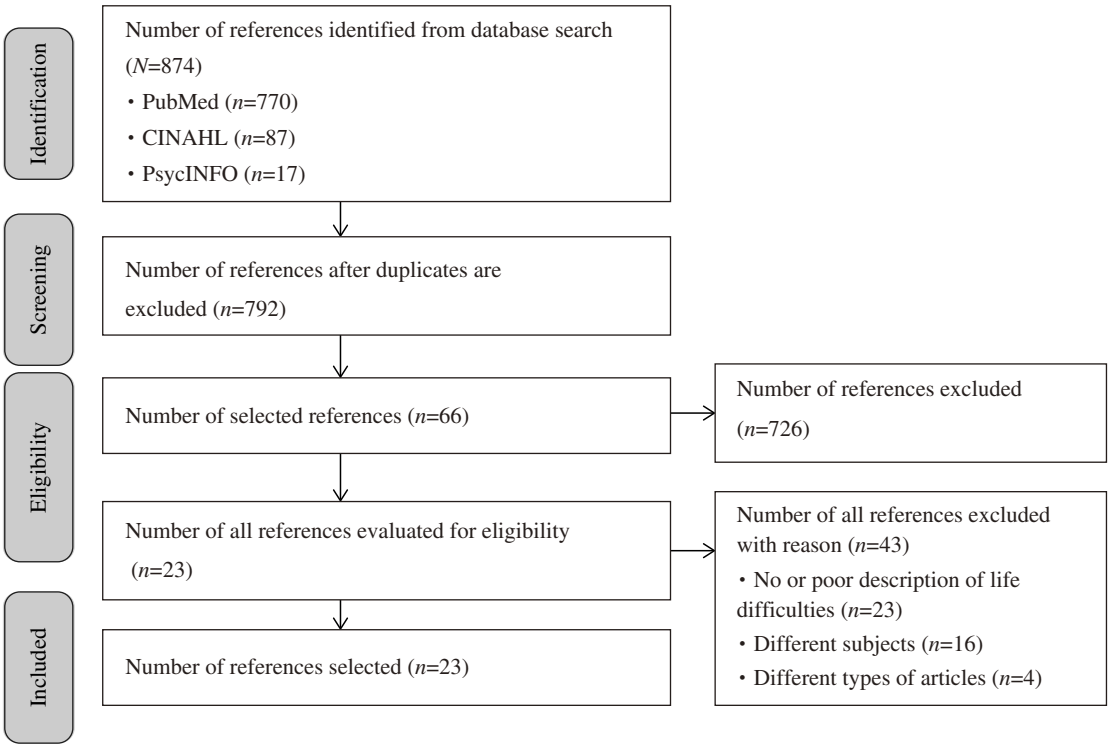

Figure 1. Flowchart of literature adoption based on the PRISMA 2020 flow diagram.

(4) literature review.

Selecting Sources of Evidence

Literature was selected by two researchers who independently reviewed the titles and abstracts in accordance with the established selection criteria. Studies that could not be excluded based on the initial screening of the title and abstract were subjected to a comprehensive review by three researchers after a thorough examination of the full text. Three researchers made final decisions regarding the selected literature.

Data Charting Process and Items

The authors, year of publication, title, purpose of the study, study design, survey content, data collection methods, and main results were organized systematically. The primary findings were derived from the analyzed literature and pertained to the challenges encountered by adolescent and adult patients who underwent surgical treatment for hypospadias during childhood.

Synthesis of the Results

The extracted results were collated and classified based on similarities. The codes were grouped according to their differences and similarities, and subcategories, categories, and core categories were generated. All authors ensured consistency in the generation of categories and reached a consensus on the final structure.

Results

Selection of the Literature

The literature selection process is illustrated in Figure 1. The final analysis included 23 references; a summary of the characteristics of the employed literature is provided in Table 1. A total of 17 studies (73.9%) were quantitative in nature, 5 (21.7%) employed a mixed-methods approach, and 1 (4.3%) was qualitative. All the researchers were physicians. The countries included in this study were Sweden, the United States of America, China (*n*=3), Italy, France, the Netherlands, Belgium (*n*=2), Turkey, Serbia, Canada, and Russia (*n*=1). The age of the participants ranged from 11 to 72 years.

Difficulties in Daily Life of Adolescent and Adult Patients Who Underwent Surgery for Hypospadias during Childhood

A total of 114 codes were grouped into 6 core categories, 25 subcategories, and 13 categories for the topic of "Difficulties in daily life faced by adolescent and adult patients who underwent surgery for hypospadias during childhood," as identified in the target literature (Table 2). In the following sections, categories are indicated by words in quotation marks. The most frequently occurring core category was the perception of genital appearance, which was extracted from 16 references (69.5%).

Perception of Genital Appearance

Patients had difficulty with negative perceptions of genital

Table 1. Summary of life difficulties that patients who underwent surgery for hypospadias during childhood face during adolescence and adulthood.

#	Author, year	Country	Type of study	Population/sample	Main result
1	Can Aydın et al. (2024)	Turkey	Quantitative	Patients who underwent a single surgery for distal hypospadias during their preschool years: *N*=70 (mean age 14.0 ± 0.2 years) The control group consisted of healthy men	·There is an association between penis perception and panic-related symptoms. ·There is an association between the timing of surgery and obsessive-compulsive symptoms.
2	Phillips et al. (2023)	Sweden	Qualitative	Patients with a wide range of phenotypes from small penis and/or penoscrotal hypospadias to glanular hypospadias: *N*=17; aged 20–49 years	·Difficulty urinating: slow urine flow; difficulty voiding: inability to empty the bladder completely; physical (complications) symptoms; and retraction of urethral opening ·Complications and functional and esthetic concerns ·Disappointment with the current situation and the psychological distress of accepting that it may not improve. ·Avoidance of medical care owing to trauma from painful experiences with treatment and medical care, a life of little information and questions about one's body and medical history, parental control, and loss of a sense of patient autonomy
3	Snodgrass et al. (2022)	USA	Quantitative	Patients: *N*=82; aged 28 years (range: 12–66)	Stenosis and meatal stenosis (mature), fistula and stenosis (adolescent), and urinary spraying
4	Gamidov et al. (2022)	Russian Federation	Mixed Methods	Patients with a history of failed hypospadias repair: *N*=112; age was 18–62 years (median age: 29.5 years)	Dissatisfaction with the appearance of the penis and problems with the position of the urethral opening, sexual dysfunction, decreased libido and hypogonadism; effects of hair growth, foreskin, fistulas, and scars on sexual life; ejaculatory weakness; complications of hair growth and hair growth interfering with ejaculation; and ED
5	Belgacem et al. (2020)	France	Quantitative	Patients who underwent MAGPI surgery for hypospadias: *N*=15 (median age: 24.3 years) Circumcised men: *N*=15 & Uncircumcised men: *N*=15	·There was a significant difference in the cosmetic self-perception of the penis compared with the control group and in the erectile function score compared with the control group. ·There were significant differences in self-esteem compared with the controls, and low self-esteem was correlated with low genitalia self-perception.
6	Tack et al. (2020)	Belgium and Austria	Quantitative	Patients who underwent surgery for hypospadias during their preschool years: *N*=193 (Distal 132, Midshaft 38, and Proximal 23); aged 16–21 years The control group comprised healthy men: *N*=50	·There were significant differences in self-esteem compared with the controls, and low self-esteem was correlated with low genital self-perception. ·Those who had not told anyone about their surgery were more likely to be sexually inactive, and those who had difficulty talking about sexual matters were more likely to do so with more frequent treatment. ·Proximal, more frequent surgeries were associated with more concerns about infertility, and more people were pointed out or teased about the appearance of the penis (circumcision appearance and size) in situations where they had to undress in public.
7	Andersson et al. (2018)	Sweden	Quantitative	Patients who underwent surgery for proximal hypospadias: *N*=33; aged 14–25 years The control group had distal hypospadias: *N*=31 and healthy men: *N*=25	·The hypospadias condition was perceived to have negatively affected their sexual experiences, and the hypospadias condition was perceived to have negatively affected their childhood. ·Proximal patients are discouraged from accessing medical care for genital appearance and function because of embarrassment.
8	Nozohoor Ekmark et al. (2017)	Sweden	Quantitative	Patients who underwent surgery for hypospadias: *N*=39; over 18 years old	·Spraying, dribbling, weak stream, and pain urinary symptoms ·Lack of cosmetic or sexual function improvement in response to surgery, scarring after skin grafting, and dissatisfaction with the penile appearance. ·Excess skin and scarring after surgery were quite noticeable, so that they had to cover themselves in public showers and were teased about their genitals, which was difficult for them. ·Wanted extended follow-up and evaluation of sexual function, psychosocial support and information, help communicating with partners, and support in dealing with day-to-day situations; surgery was an unpleasant experience
9	Ching et al. (2011)	USA	Quantitative	Patients who underwent surgery for hypospadias: *N*=55; Median age was 37 years (range: 18–72)	Dysuria, stream spraying, straining, feeling of incomplete urination, weak streaming, frequent urination, and urgency
10	Jiao et al. (2011)	China	Quantitative	Patients: *N*=43; aged 21.6 years	Dissatisfaction with the genital appearance, difficulty during intercourse owing to penis size or bending, and erection and ejaculation problems
11	Wang et al. (2010)	China	Quantitative	Patients: *N*=130 Of these, patients who coped before age 10; *N*=32 (median aged 25.2 years) The control group of healthy men: *N*=50 (median age 26.0 years)	·Self-rated depression and anxiety scale scores were higher than the controls ·Fear of ridicule from others ·Fear of being ridiculed by others, dissatisfaction with penis size and genital appearance, inhibition of seeking sexual contact, and ejaculation problems
12	Aulagne et al. (2010)	France	Quantitative	Patients who underwent surgery for severe proximal or perineal hypospadias during their preschool years: *N*=27; aged 20–35 years	·Embarrassed by the appearance of the penis, feeling different in appearance ·Urine vigor, spraying, difficulty with standing urination, and dribbling

Table 1. Summary of life difficulties that patients who underwent surgery for hypospadias during childhood face during adolescence and adulthood (continued).

#	Author, year	Country	Type of study	Population/sample	Main result
13	Vandendriessche et al. (2010)	Belgium	Mixed Methods	Patients who underwent surgery for hypospadias before the age of 12: *N*=10; aged 11–18 years The control group without hypospadias or physical complaints: *N*=10; aged 11–18 years	·Patients had significantly lower scores on self-perception and social acceptance, and significantly fewer patients thought their penises were different from others and considered their appearance normal. ·Patients felt unaccepted by their peers and were pointed out and teased about the appearance of their penis (circumcision appearance and size) in situations where they had to undress in public.
14	Wang et al. (2009)	China	Quantitative	Patients who underwent surgery for hypospadias (80 had distal and 50 had proximal surgery) : *N*=130 The control group of healthy adults: *N*=50; aged 24–35 years	·Depression and anxiety were caused by external genitalia; worry about others ridiculing the size and appearance of the penis or the appearance of the penis ·Patients had significantly higher SDS/SAS scores and psychological problems of depression/anxiety; more severe and more frequent surgeries were associated with more impaired sexuality; patients were reluctant to talk about their sex lives owing to penile appearance and surgical experience; patients were inhibited about the opposite sex and sexual contact and had significantly delayed sexual experiences. Patients had significantly delayed sexual experiences owing to inhibitions about the opposite sex and sexual contact.
15	Hoag et al. (2008)	Canada	Quantitative	Patients who had hypospadias: *N*=28 The average patient age was 20 years (range: 16–31 years)	·Fistula or urethral stricture, difficulty in passing urine or urine spray during urination, dissatisfaction with urination, low satisfaction ·Dissatisfaction with sexual life, embarrassment, and pain during sexual intercourse
16	Liu et al. (2006)	China	Quantitative	Patients who underwent surgery for hypospadias: *N*=102; aged 24.5 years (range 19.2–33.9 years)	·Dysuria, proximal patients experience more frequent dysuria ·Penis size, ED ·Penile appearance affects partner search, pain during intercourse, and erectile and ejaculatory dysfunction ·Patients are reluctant to visit public places such as bathrooms, hide genitals for embarrassment, and partners ridicule the appearance of the penis
17	Lam et al. (2005)	USA	Quantitative	Patients who underwent 2-stage hypospadias repair: *N*=27; average age of 15.4 years (range 13–21)	·Urinary spray, straining, or pain during urination ·Penis size, lack of cosmetic or sexual improvement after surgery, scarring after skin grafts, and dissatisfaction with the penile appearance ·Dissatisfaction with penis size, cosmetic aspects of surgery, lack of improvement in sexual function, scarring after skin grafts, and dissatisfaction with the appearance of the penis
18	Bubanj et al. (2004)	Serbia	Quantitative	Patients with hypospadias older than 18 years: *N*=37 Age-matched normal control subjects: *N*=39	·Dissatisfaction with sexual life, difficulty with intercourse owing to lack of intercourse, and ejaculation difficulties
19	Mondaini et al. (2002)	Italy	Quantitative	Patients with hypospadias: *N*=42; aged 18 years The control group randomly selected young males: *N*=500; aged 18 years	·Negative genitalia evaluation and dyspareunia owing to penile flexion ·Negative genital evaluation, dyspareunia owing to penile flexion, psychological disturbance, and more negative answers on mental health tests than controls ·Those with decreased libido had problems exposing their genitals in public and had difficulty with opposite-sex contact.
20	Aho et al. (2000)	Finland	Quantitative	Patients who underwent surgery for hypospadias: *N*=48; aged 29.5 years The control group of patients circumcised for phimosis: *N*=43; aged 29.9 years	·Urine spray, direction, and dripping ·Dissatisfaction with appearance of genitals, surgery was an unpleasant experience, penis size as a result of surgery, dissatisfaction with the quality of sex life, difficulty with intercourse owing to inability to have intercourse, and erection and ejaculation problems.
21	Caione et al. (1997)	Italy	Mixed Methods	Patients who underwent surgery for hypospadias: *N*=19; aged 15–20 years	·Concerned about the appearance of the exposed glans
22	Mureau et al. (1995)	The Netherlands	Mixed Methods	Patients underwent surgery for hypospadias: *N*=116; aged 24.5 years (Mean age was 14.4 ± 2.7 years) Comparison group of boys treated for an inguinal hernia: *N*=88 (Mean age was 13.9 ± 2.5 years)	·Dissatisfaction with penis size and scarring, perceived differences in penis from other children because of lack of foreskin, scars, size, and shape of glans, negative genital evaluation, and inhibition from seeking sexual contact because of the appearance of penis. ·Patients with penile flexure were dissatisfied with the appearance of their penis and were concerned about publicity; they covered their genitals in public restrooms because of embarrassment; they were pointed out and teased for the appearance of their penis (circumcision appearance and size) when they had to undress in public; and they were ridiculed by their partners for the appearance of their penis
23	Mureau et al. (1995)	The Netherlands	Mixed Methods	Patients underwent surgery for hypospadias: *N*=73; aged 18 years and older Comparison group who were treated for an inguinal hernia: *N*=50; aged 18 years and older	·Dissatisfaction with genital appearance, perceiving the appearance of the penis differently because of its lack of foreskin or size ·The subject was more inhibited in sexual contact because of embarrassment over the appearance of the penis and had difficulty during intercourse owing to the flexion of the penis ·The main complaint of those who underwent revision surgery was the lack of proper explanation and guidance during treatment; many did not know exactly why they had surgery.

Table 2. Life difficulties faced by adolescent and adult patients who underwent surgery for hypospadias during childhood.

Core Category (*n*=number of references)	Category	Subcategory (literature number)	
Perception of genital appearance (*n*=16)	Negative perception of genital appearance	Dissatisfaction with the appearance of the penis	(2, 4, 6, 8, 10, 11, 13, 15, 16, 17, 20, 22, and 23)
		Negative evaluation of genitalia/perception of being different from others	(5, 13, 19, 22, and 23)
	Shame, decline in self-esteem, and negative impact on quality of life related to genitalia	Shame or low self-esteem related to genitalia	(5, 6, 12, and 15)
		Negative impact of genital appearance on quality of life	(6)
Difficulties with sex (*n*=13)	Dissatisfaction with sexual life	Dissatisfaction with sexual life	(4, 15, 18, and 20)
	Difficulties with intercourse	Difficulties with sexual intercourse	(10, 15, 16, 18, 19, 20, and 23)
	Difficulties related to sexual function	Sexual dysfunction/decline	(2, 4, 6, 8, 17, and 23)
		Ejaculation disorder	(4, 10, 11, 16, 18, and 20)
		Erectile dysfunction	(4, 5, 10, 16, and 20)
Social acceptance (*n*=13)	Inhibition or delay in sexual contact	Sexual reluctance and difficulty disclosing to others	(6, 10, and 1)
		Inhibition in finding a partner, sexual contact, and delay in sexual experience	(6, 7, 11, 14, 16, 19, 22, and 23)
	Negative involvement by others	Being teased or bullied about genitalia by others	(6, 8, 13, 16, 17, and 22)
		Fear or anxiety about being teased about genitalia by others	(6, 11, 14, 21, and 22)
	Difficulties with excretion and cleaning in public places	Difficulty urinating in public places Difficulty exposing genitals in public places, while showering or changing clothes	(8, 16, 19, and 22)
	Social isolation	Feeling socially unaccepted	(13)
	Lack of support	Lack of support	(8)
Difficulty with urination (*n*=8)	Difficulties with urination	Retraction of the urethral opening, fistula, and urethral stricture	(2, 3, and 15)
		Dysuria	(2, 9, 16, and 17)
		Spraying, direction, weak flow, and dribbling	(2, 3, 8, 9, 12, 15, and 17)
Psychological problem (*n*=6)	Mental disorder/stress	Psychological disturbances and distress	(2, 7, 11, 14, and 19)
		Obsessive-compulsive neurological symptoms and panic	(1)
		Sexual psychological disturbances	
		Sexual psychological disturbances	(14)
Immaturity in coping with own health conditions (*n*=5)	Difficulty with taking ownership of the body and treatment	Painful experience of surgery or avoidance of medical access	(2, 7, 8, 20, and 23)
		Doubts about the body and loss of autonomy	(2)
		Not knowing why they received the treatment	(23)

appearance based on dissatisfaction with penile appearance, such as penile flexion, penile size, and scars, as well as negative evaluations of genitalia and perceptions that they are different from others (Aho et al., 2000; Belgacem et al., 2020; Gamidov et al., 2022; Hoag et al., 2008; Jiao et al., 2011; Lam et al., 2005; Liu et al., 2006; Mondaini et al., 2002; Mureau et al., 1995a, 1995b; Nozohoor Ekmark et al., 2017; Phillips et al., 2023; Tack et al., 2020; Vandendriessche et al., 2010; Wang et al., 2010).

The results also revealed that the participants were embarrassed by the appearance of their penis and had lower self-esteem than the control group, indicating that they had difficulties related to "shame, decline in self-esteem, and negative impact on quality of life related to genitalia" (Aulagne et al., 2010; Belgacem et al., 2020; Hoag et al., 2008; Tack et al., 2020).

Difficulties with Sex

Patients reported experiencing "difficulties with intercourse"

(Aho et al., 2000; Bubanj et al., 2004; Hoag et al., 2008; Jiao et al., 2011; Liu et al., 2006; Mondaini et al., 2002; Mureau et al., 1995b), including "dissatisfaction with sexual life" (Aho et al., 2000; Bubanj et al., 2004; Gamidov et al., 2022; Hoag et al., 2008), concerns about penile size and curvature, and pain during intercourse. Furthermore, patients were found to have sexual dysfunction/decline, ejaculation disorder, and erectile dysfunction, which are "difficulties related to sexual function" (Aho et al., 2000; Belgacem et al., 2020; Bubanj et al., 2004; Gamidov et al., 2022; Jiao et al., 2011; Lam et al., 2005; Liu et al., 2006; Mureau et al., 1995b; Nozohoor Ekmark et al., 2017; Phillips et al., 2023; Tack et al., 2020; Wang et al., 2010).

Social Acceptance

The factors of sexual reluctance and difficulty in disclosing to others because of the appearance of the penis and the fact that it has been operated on, the difficulty in finding a partner, and the inhibition and delay in sexual contact and sexual experience because of the appearance of the penis and the embarrassment caused by it, were found to cause "inhibition and delay in sexual contact" (Andersson et al., 2018; Jiao et al., 2011; Liu et al., 2006; Mondaini et al., 2002; Mureau et al., 1995a, 1995b; Tack et al., 2020; Wang et al., 2009, 2010). Furthermore, they exhibited apprehension and distress regarding potential teasing from others regarding their genitalia, as well as "negative involvement by others" when changing clothes because of the size and appearance of their penis (Caione et al., 1997; Lam et al., 2005; Liu et al., 2006; Mureau et al., 1995a; Nozohoor Ekmark et al., 2017; Tack et al., 2020; Vandendriessche et al., 2010; Wang et al., 2009, 2010). Additionally, patients experienced "difficulties with excretion and cleaning in public places" (Liu et al., 2006; Mondaini et al., 2002; Mureau et al., 1995a; Nozohoor Ekmark et al., 2017); they also reported feelings of "social isolation" owing to a perceived lack of social acceptance (Vandendriessche et al., 2010). Patients also expressed a desire for extended outpatient follow-up and support in managing daily problems; they also identified "lack of support" as a significant challenge (Nozohoor Ekmark et al., 2017).

Difficulty in Urination

Patients experienced "difficulties with urination" such as retraction of the urethral opening, fistula, urethral stricture, residual urine, fussiness, frequency and urgency of urination, and pain during voiding (Ching et al., 2011; Hoag et al., 2008; Lam et al., 2005; Liu et al., 2006; Phillips et al., 2023; Snodgrass & Bush, 2022). They were also observed to have difficulties with spray, direction, weak flow, and dribbling during voiding (Aulagne et al., 2010; Ching et al., 2011; Ching et al., 2011; Hoag et al., 2008; Lam et al., 2005; Phillips et al., 2023; Snodgrass & Bush, 2022).

Psychological Problems

Patients reported that hypospadias had a negative impact on their childhood. Patients reported experiencing depression and anxiety owing to external genitalia, negative outcomes in mental testing, psychological disorders, and distress (Andersson et al., 2018; Mondaini et al., 2002; Phillips et al., 2023; Wang et al., 2009, 2010). Furthermore, patients reported the presence of obsessive-compulsive neurological symptoms and panic-related reactions to the surgical procedure and penile perception as well as the emergence of sexual psychological disturbances in more severe cases (Can Aydın et al., 2024; Wang et al., 2009). The patients also exhibited challenges about "mental disorders and stress."

Immaturity in Coping with One's Own Health Conditions

Patients were observed to have difficulty accessing medical support and care because of their painful experiences with surgery and avoidance of medical care (Aho et al., 2000; Andersson et al., 2018; Mureau et al., 1995b; Nozohoor Ekmark et al., 2017; Phillips et al., 2023). Furthermore, the patients had questions regarding their bodies and possessed minimal information about their bodies or medical history. Moreover, they experienced loss of autonomy because their parents managed their physical care (Phillips et al., 2023). The results also indicated that several patients did not know the reason for their treatment (Mureau et al., 1995b), indicating that they had "difficulties in taking ownership of body and treatment." The patients did not recognize medical care as an effective resource, and they also showed that they were unaware of past surgical procedures. These behaviors indicated that they did not have effective coping strategies for dealing with health issues and were immature in their coping.

Discussion

Physical and Psychosocial Difficulties Patients Face

This review revealed that post-pubertal patients who underwent surgical treatment for hypospadias during childhood experienced significant challenges in their daily life. Patients were found to have problems with the perception of genital appearance, difficulty with sex, and difficulty in urinating, as well as psychosocial difficulties of social acceptance and psychological disability. A study (Kanematsu et al., 2016) investigating the impact of disease and treatment on the male life course revealed that although reoperation for urethral stricture is a risk factor for acquiring paternity, patients' sexual intercourse and age at childbirth were not significantly different from the national average, and many patients were not affected by disease and treatment. In the present study, an examination of the patients' daily difficulties revealed that they experienced issues related to urination, genitalia, and sexual activity, which are challenging to discuss with others in their daily life. Furthermore, patients reported being affected by negative involvement from others, including bullying and teasing, and positive involvement

from others, such as inhibition and delayed sexual contact.

During puberty, children begin to develop concerns about their appearance and can experience feelings of inferiority compared to their peers (Gulseth et al., 2021). However, they also demonstrate the capacity to accept and come to terms with their changing bodies and form a positive self-image (Nakamura et al., 2021). Subsequently, they reveal themselves to others and establish intimacy. The study results suggest that factors affecting patients' difficulties in daily life include the disease severity, perception of their perioperative experience, and ideal body image in relation to their genitals. These factors can have a negative impact on patients' self-perceptions and psychological development, hindering social interaction. Although hypospadias is not a life-threatening condition, it has been reported to have a negative impact on a patient's long-term psychological development, including body image, self-esteem, social skills, and mental health. In severe cases, depression and suicidal tendencies have been reported (Jin et al., 2022); these results suggest that hypospadias significantly reduces patients' quality of life. In this study, we focused on the negative aspects of the disease in patients' lives and provided an overview of these aspects, consistent with previous studies that classified patients' HRQOL into five domains: penile appearance, voiding, social interaction, sexual health, and psychological or behavioral function (Bhatia et al., 2021). Additionally, Bhatia et al. (2021) did not discuss the changing relationships between domains at different stages of development but suggested that they may change.

Urinary function is the only issue encountered during childhood. As children mature, potential risks to sexual and reproductive functions emerge, accompanied by the onset of secondary sexual characteristics and life events. Therefore, it is crucial for affected children to gain an understanding of the disease and its treatment from an early age, accept their disability, and develop a positive body image and identity. Iwami (2010) posited that affirming a child's current appearance and fostering a sense of self-worth are vital, particularly in the context of external surface diseases. The formation of a healthy body image and identity is believed to be influenced by childhood experiences. Thus, nursing support that aims to reduce perioperative pain and foster a healthy body image in patients, while considering the disease severity, is crucial.

Adult Patients' Difficulties with Hypospadias-related Self-care Behavior

Patients experienced difficulties with treatable diseases, such as urinary problems; this is because the lack of support and ignorance regarding treatment made it difficult to recognize these conditions as health problems. Furthermore, they exhibited immaturity in terms of perceiving and coping with health problems by avoiding access to medical care. These factors have not been addressed in other literature reviews, and we believe that they represent new findings that point forward in terms of patient support. The findings of the study indicate that given the fact that hypospadias is treated in infancy, it is difficult for children to comprehend the nature of the disease and its treatment unless they receive instructions from adults. Conversely, parents may find it challenging to elucidate the disease and its treatment for their children. In a study of girls with congenital adrenal hyperplasia presenting with masculinization of the genitalia (Iwami et al., 2018), only 30% of the parents explained the condition and external genitalia to their children, and the content was not accurate.

Establishing medical guidelines that focus on the general long-term problems of congenital urological disorders is a future challenge (Wood et al., 2019), and the same can be said for hypospadias. Phillips et al. (2023) reported that follow-up ended when the age of patients with hypospadias exceeded the target age for pediatric urology and transitional care was not provided. One of the challenges in providing long-term medical support for congenital urological disorders is the shortage of adult urologists who specialize in treating patients with complex congenital disorders, such as hypospadias (Wood et al., 2019).

Therefore, if a problem occurs after a child grows up, the child must have access to a specialized medical facility. Furthermore, while parents and doctors are responsible for deciding whether treatment is required during childhood, patients must make decisions regarding their care as adults. We contend that patients' lack of knowledge about their disease and its treatment, coupled with the fact that their parents oversee their care, can present a challenge to their attainment of autonomy.

These findings illustrate that patients are often unaware of the underlying disease when complications emerge in a distant period spanning years to decades following treatment. This lack of awareness can impede their ability to confide in others or seek medical attention, particularly because of the private nature of their condition. Furthermore, they may lack effective strategies to address these challenges. Phillips et al. (2024) found that the extent of the challenges faced and how they are dealt with, which is, coping, vary as esthetic and functional outcomes, and psychological and social contexts differ from patient to patient. They showed that a combination of impact and coping creates a broad spectrum of how hypospadias is experienced. It is essential to consider the provision of support throughout one's lifespan, from childhood to adulthood. Several patients born with complex congenital anomalies of the genitourinary system require lifelong care to manage their condition and treatment. The aim was to ensure that all patients, regardless of age, could identify what they required (Wood et al., 2019). For patients to enjoy optimal development and quality of life, they must

possess the required skills to understand their disease and body, recognize abnormalities, and access medical care when required.

Future Issues Regarding Patients Who Underwent Surgery for Hypospadias during Childhood

Considering the advancements in medical care, there is a need for a paradigm shift in perspective and implementation, moving from a focus on surgical treatment for sustaining life to a greater emphasis on surgical treatment for improving long-term quality of life. A significant challenge in Japan's medical system for patients with hypospadias is the lack of consultation facilities when problems arise; this is because it is difficult for hospitals specializing in pediatrics to provide long-term follow-up for affected children and treat them after they become adults. Furthermore, there is a severe shortage of physicians who can treat adult patients with hypospadias, including those requiring surgical intervention; this may result in patients being unable to access the required medical care and suffering because of a lack of available solutions to their problems.

In addition to medical system problems, problems with the nursing care system also exist. Nurses provide long-term outpatient follow-up care for pediatric patients with high medical requirements; however, for children who undergo surgery after a short hospital stay (e.g., hypospadias surgery), there is no regular outpatient follow-up, and nurses rarely get involved in providing patient support. Furthermore, because there is almost no transition from pediatric to adult healthcare, healthcare professionals are not fully aware of patients' issues in adulthood. To provide patients with high-quality medical care throughout their life, building a long-term care system that considers the transition from childhood to adulthood and addresses potential future problems is crucial. In addition, intervening before future difficulties become apparent and providing preventative and strategic support from childhood is necessary.

This review illuminates patients' experiences and perceptions of treatment from childhood and the challenges associated with psychological and social development. It is imperative to consider the role of nurses in providing long-term medical support from childhood onward. Despite extensive research and development of surgical procedures by physicians and documentation of favorable outcomes (Shimotakahara et al., 2011), the difficulties faced by patients have not been sufficiently explored from a nursing perspective, and the existing knowledge that can inform nursing support is limited. It is imperative to elucidate comprehensive health issues from a triadic perspective encompassing physical, psychological, and social dimensions, along with an in-depth examination of the actual conditions of patients' lives and experiences; this underscores the need for further nursing research.

Research Limitations and Significance

The literature reviewed in this study was mostly quantitative, and there are limitations to the extent that this study can provide a full picture of the difficulties that patients face in their daily life. This study aimed to provide an overview of the research but did not evaluate the risk of bias in the literature. Furthermore, the content of difficulties could differ depending on the cultural values and norms of the country or region, as well as the medical care level. However, we believe it is significant that we determined the difficulties in daily life that occur after adolescence and not only during childhood.

Conclusion

A scoping review of the difficulties in daily life faced by adolescent and adult patients who underwent childhood hypospadias surgery was conducted; the findings were synthesized into six core categories: perception of genital appearance, difficulties with sex, social acceptance, difficulty in urination, psychological problems, and immaturity in coping with own health conditions. The difficulties patients face in their daily life include not only physical difficulties caused by symptoms and functional disorders but also psychosocial difficulties that affect their development and quality of life. Furthermore, coping with problems that occur several years or decades after childhood surgeries can be difficult; this suggests the need for support that considers the transition from childhood to adulthood. Although several quantitative studies have been conducted by physicians, it is necessary to clarify the actual situation of patients' lives and health problems from a comprehensive perspective of physical, psychological, and social aspects, as well as to consider the role of nursing in long-term medical support.

Author Contributions

Yukie Kaji and Naho Sato contributed to the conception and design of this study, and all authors performed the analysis. Yukie Kaji drafted the manuscript. Naho Sato and Nakazuru Aya revised the manuscript and supervised the entire study process. All authors have read and approved the final version of this manuscript.

Declaration of Conflicting Interests

There are no conflicts of interest to disclose.

Ethical Approval

This research was a literature review, and ethical approval or consent from the subjects was not required.

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Original Research

Annual trends in bed transfer and the relationship between bed transfer and patient dynamics: A time-series study

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Abstract

Objective: Although bed transfers, which represent patient transfers within a ward, are common, we know little about how they should be managed. This study aimed to identify annual trends in bed transfers and evaluate the influence of patient inflow, outflow, and bed occupancy rate on the frequency of bed transfers. **Methods:** Using an exploratory observational design, we analyzed the medical data of four wards in a single hospital. The data were obtained from November 2017 to November 2018 and included the numbers of admissions, discharges, transfers into and from wards, inter-room transfers, intra-room transfers, and inpatient admissions. Admissions and transfers to wards were categorized as patient inflows. Discharges and transfers from the wards were categorized as patient outflows. Inter-room and intra-room transfers were categorized as bed transfers. Descriptive statistics were calculated to confirm the trends in the number of bed transfers. Autocorrelations for each variable and cross-correlations between bed transfers and each variable were examined. Multiple regression analysis based on an autoregressive model of order 1 and a non-time-series model was conducted, with the dependent variable being the number of bed transfers. **Results:** In winter, bed transfer, patient inflow, and beds occupancy were higher. We found that patient inflow had a significant effect on bed transfer. **Conclusions:** Bed transfers could be partially predicted by monitoring trends in patient inflow. When the number of bed transfers is high, appropriate staffing is necessary to assign patients to suitable beds by monitoring changes in their conditions.

Keywords

bed occupancy rate, health services research, hospitalization, intrahospital transfer, nursing

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Introduction

Patient transfers within a hospital are key factors in patient flow management (Blay et al., 2014; Bristol et al., 2020). In Japan, to ensure appropriate medical resource allocation for a super-aging society, hospitals are primarily divided into acute care, chronic care, and rehabilitation hospitals. In addition, a system is being developed to provide care at a prearranged hospital based on the patient's condition in collaboration with home care nursing (Kinoshita, 2015). Accordingly, similar to other countries, Japan's length of stay per facility is also declining (Organization for Economic Co-operation and Development, 2022). Acute care hospitals must provide care focused on an individual's symptoms in a

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timely manner; to ensure that those in need receive timely and quality care, there is a need to reduce the number of unnecessary transfers and optimize transfer management.

In acute care hospitals, highly invasive treatments are administered in intensive care units, and patients are transferred to general wards once their condition improves (Blay et al., 2012). These intrahospital transfers have been linked to an increased risk of various adverse patient outcomes (Blay et al. 2017a; Bristol et al., 2020). However, most previous studies on the topic have focused on patient transfer between wards and units (Blay et al., 2012; Stelfox et al., 2017; Tolentino et al., 2018) and have generally overlooked the topic of bed transfers. The latter refers to nurses moving a patient from one bed to another within the same ward/clinical unit, and researchers have confirmed that it is a type of transfer that remains underexplored by researchers despite it being a routine hospital procedure (Goldberg et al., 2015; Blay et al. 2017b). Performing a single bed transfer requires at least two nurses and lasts more than 30 minutes (Blay et al., 2017b), indicating that a considerable amount of nursing resources is invested in implementing bed transfers. Nurse staffing rarely changes when there is a change in patient status (Musy et al., 2020); thus, when there is a bed transfer in a ward with many critically ill patients, staff resources are directed, potentially lowering the quality of care. Therefore, avoidable bed transfers that are not intended for therapeutic purposes should be reduced. Bed transfers can also be burdensome to patients (Bristol et al., 2020); thus, understanding the reality of bed transfers may be a requirement to help nurses focus on delivering optimal patient care in acute care hospitals.

Most studies have investigated the impact of bed transfers on patients and staff. The factors causing bed transfers include changing patient status (Deines & Stevens, 1987; Kosuge et al., 2013) and a shortage of private and observation rooms in wards (Tanaka et al., 2021). The structure of the ward and changes in a patient's condition influence the admission, discharge, or transfer of patients to another ward. However, it is still unclear how patient dynamics affect bed transfers. Once this effect has been clarified, it will be possible to predict bed transfers to some extent, even without detailed data on the patients' conditions. Wards have several indices for patient dynamics. The first and second indices are the dynamics of patients entering the ward, such as admissions and transfers into the ward, and the dynamics of patients leaving the ward, such as discharge and transfers, respectively (Tolentino et al., 2018; Mueller et al., 2019). These patient dynamics have annual trends; for example, stroke admissions are higher in winter (Chu et al., 2018), and patients reportedly experience multiple bed transfers during the influenza season (Ma et al., 2022). Because hospital admissions and discharges are seasonal, the frequency of bed transfers may also be seasonal. Additionally, the incidence of events such as discharge differs by day of the week (Cloyd et al., 2015). A third factor, bed occupancy rate (i.e., the ratio of the total number of beds in the ward to the number of patients admitted), influences patient flow in terms of emergency admissions, rate of readmission, and ward infection control (Bagust et al., 1999; Jones, 2011; Amato-Vealey et al. 2012; Friebel et al. 2019). Moreover, the bed occupancy rate affects patient mortality (Sharma et al., 2022). Hospital capacity utilization, which is affected by the bed occupancy rate, varies not only by season but also by day of the week (Sharma et al., 2021). Therefore, time trends, such as the day of the week and season, must be considered to understand the relationship between bed transfer and patient dynamics.

Bed transfers are influenced by changes in patient conditions and may be related to the relative severity of the conditions of patients entering (and leaving) the ward. Bed occupancy rate may also be related to bed control. However, we still have little evidence to show how these patient dynamics affect bed transfers considering time trends. Therefore, exploring the relationship between patient dynamics and bed transfers, as well as their time-series patterns, may provide relevant data for well-informed decision-making on bed transfer management and procedure prioritization in a ward.

Materials and Methods

Aim

This study aimed to investigate 1) the annual transition of bed transfers and 2) the effect of the bed occupancy rate and patient dynamics (i.e., patient inflow and outflow) on the bed transfer frequency.

Design

This study used a time-series study design.

Settings and Target Wards

This study was conducted in conjunction with another previous study of ours (Tanaka et al., 2021). Nonprobability convenience sampling was used for four wards at an acute care hospital with 300 beds in a rural area of Tokyo, Japan. An interview with the nursing director confirmed that each ward was a mixed medical-surgical ward, where patient care spans various medical specialties and consists of 50 beds in a mix of private and multi-bed rooms. Wards specializing in psychiatry, pediatrics, obstetrics, and gynecology were excluded. None of the surveyed wards had undergone any construction, department reorganization, or closure in the past year.

Data Collection

Data were collected between October and November 2018.

The first author obtained information from the electronic medical records regarding the daily number of admissions, discharges, transfers into wards, transfers from wards, bed transfers, and inpatient admissions for each ward. The data collection periods for wards 1, 2, 3, and 4 ranged from November 1, 2017, to November 7, 2018 (Ward 1: November 8, 2017, to November 7, 2018; Ward 2: November 1, 2017, to October 31, 2018; Ward 3: November 8, 2017, to November 7, 2018; Ward 4: November 7, 2017, to November 6, 2018).

Data Analysis

Independent and Dependent Variables

- Bed transfer (Dependent variable): total number of inter- and intra-room transfers in the same ward per day.
- Patient inflow (Independent variable): total number of admissions and transfers into the ward per day.
- Patient outflow (Independent variable): total number of discharges and transfers from the ward per day.
- Bed occupancy rate (Independent variable): Calculated by dividing the number of inpatients per day by the number of beds per ward (all wards had 50 beds).

Preprocessing Data for Statistical Analysis

Prior to statistical analysis, two key problems required resolution. Problem 1 pertains to the incidence of events, such as patient discharges, which vary by day of the week, resulting in day of the week trends alongside seasonal variations. To mitigate the impact of these trends, we opted to average the variables related to bed transfers, patient inflow, patient outflow, and bed occupancy rate over each 7-day period. Problem 2 arises from the impracticality of analyzing data by ward owing to the study's single institution setting, where transfers between wards influence each other. To address this issue, we calculated ward averages to minimize the effects of inter-ward transfers, particularly during periods of overlap for each ward. As a result, 53 records were generated, encompassing 1 year; data were averaged for 1 week and for each of the four wards.

Statistical Analysis

A time series analysis was conducted as the time-series data from 1 year were handled. The descriptive statistics for each variable were calculated, and the correlations among the variables were examined. As seasonal and trend decomposition requires at least two cycles, and we only had data for one cycle (1 year), seasonal and trend decomposition could not be performed.

Next, a correlation and autocorrelation analysis of each synthetic variable was performed. Cross-correlations between the independent and dependent variables were also checked. One lag represents 7 days. Finally, a multiple regression analysis and autoregressive model of order 1 were conducted, with bed transfers as the dependent variable and bed occupancy rate, patient inflow, and patient outflow as independent variables. The significance level was set at a $p < .05$. As the data were collected through nonprobability convenience sampling, no power analysis or sample size calculation by post-test was performed (Zhang et al., 2019). RStudio (version 1.3.1093) and SPSS Statistics (version 29.0.1) were used for statistical analysis. The analysis used several software packages, including "car" (v3.1-2; Fox et al., 2023), "psych" (v2.3.12; Revelle, 2023), "nlme" (v3.1-164; Pinheiro et al., 2023), and "MLmetrics" (v1.1.1; Yachen, 2015).

To address the potential loss of information resulting from weekly data aggregation, multiple regression and time series analyses were conducted using only ward-level averages (Appendix).

Ethical Considerations

The study was approved by the Research Ethics Committee of the University of Tokyo, Clinical Research Review Board (No. 12071). Furthermore, the study design conformed to the principles of the Declaration of Helsinki. The authors also obtained approval from the ethics committee of the participating hospital. Although patients' personal information was not directly collected, electronic medical records containing this information were accessed. Therefore, A4-sized posters bearing the following information were posted: the data collected pertained only to the number of patients in the ward and the number of movements within the ward during the day; personally identifiable data such as patients' names or diseases were not collected.

Results

In total, there were 1,460 instances of daily admissions, discharges, transfers into and from the wards, inter- and intra-room transfers, and inpatient admissions across all four wards. There were no missing data.

In February, the peak number of bed transfers per day was 18. The average number of bed transfers per day during the year was 4.43 ± 0.78 times (Table 1). Figure 1 shows the trend of each variable in the surveyed period. The peak number of bed transfers per day was 6.63 in the week beginning on January 17, 2018. The peak patient inflow was 3.75 times in the week beginning on June 27, 2018. In addition, patient inflow always exceeded three in January. The peak patient outflow was 3.56 times in the week beginning on February 14, 2018. The peak bed occupancy rate was 94.38% in the week beginning on January 24, 2018. The tendency toward higher bed transfer numbers was identified during winter (i.e., from December to February in Japan; Japan Meteorological Agency, n. d.). Figure 2 presents the time-series data for each ward.

Table 2 presents the correlation coefficients between the variables. The correlations of bed transfer with patient inflow (r = 0.63), patient outflow (r = 0.55), and bed occu-

Table 1. Basic demographics of variables (N = 53).

Ward	Minimum					1st quartiles					Median					3rd quartiles				
	1	2	3	4	com-posite[1]	1	2	3	4	com-posite[1]	1	2	3	4	com-posite[1]	1	2	3	4	com-posite[1]
Bed transfer	0.86	1.71	2.00	2.14	2.34	2.86	2.93	3.86	4.43	4.13	3.43	4.00	4.64	5.14	4.41	4.00	4.71	5.43	6.57	4.75
Patient inflow	1.57	1.71	1.00	1.57	1.38	2.43	2.29	2.00	3.36	2.84	2.71	2.71	2.43	3.71	3.00	3.00	3.29	2.71	4.14	3.25
Patient outflow	1.71	1.29	0.86	1.00	1.75	2.43	2.43	2.00	3.14	2.69	2.86	2.86	2.43	3.79	2.97	3.07	3.14	2.86	4.21	3.13
Inflow/outflow ratio	0.92	1.33	1.17	1.57	0.69	0.86	0.86	0.84	0.87	0.96	0.95	0.95	1.00	0.98	1.03	1.15	1.11	1.17	1.18	1.11
Bed occupancy rate	0.69	0.69	0.65	0.63	0.70	0.85	0.81	0.79	0.72	0.81	0.88	0.85	0.84	0.78	0.83	0.91	0.91	0.88	0.83	0.87

Table 1. Basic demographics of variables (N = 53) (continued).

Ward	Mean					Standard deviation					Maximum				
	1	2	3	4	composite[1]	1	2	3	4	composite[1]	1	2	3	4	composite[1]
Bed transfer	3.35	3.95	4.60	5.27	4.43	1.01	1.33	1.36	1.57	0.78	6.29	8.57	7.71	8.86	6.63
Patient inflow	2.76	2.80	2.39	3.70	3.01	0.53	0.62	0.56	0.81	0.41	3.86	4.43	3.57	5.71	3.75
Patient outflow	2.74	2.79	2.38	3.65	2.90	0.45	0.56	0.56	0.86	0.36	3.43	3.86	3.43	5.29	3.56
Inflow/outflow ratio	1.01	1.00	1.01	1.01	1.05	1.17	1.11	0.99	0.94	0.17	1.13	1.15	1.04	1.08	1.86
Bed occupancy rate	0.87	0.85	0.83	0.78	0.84	0.06	0.07	0.08	0.08	0.05	0.96	0.95	0.98	0.97	0.94

Note: The dataset comprised 365 days of data from four wards, averaged over 7 days each.

[1]Mean of the four wards.

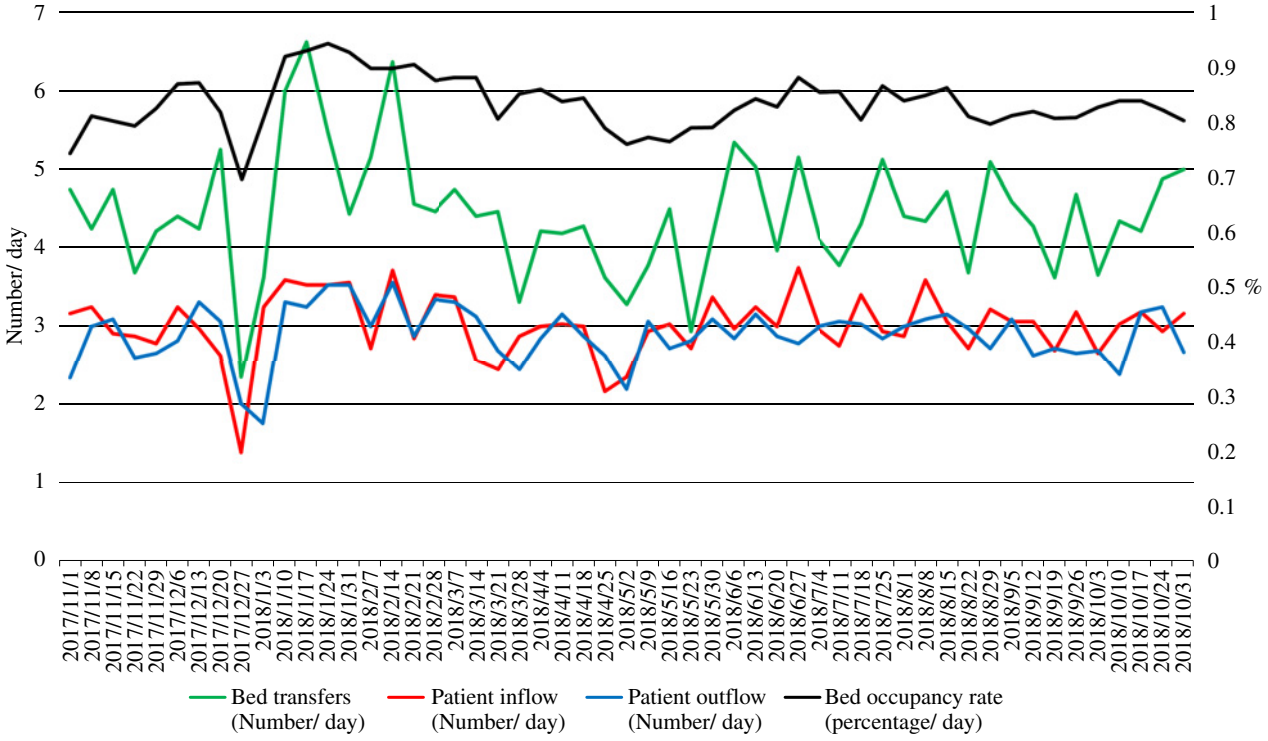

Figure 1. Annual changes in bed transfers and patient dynamics.

Note: The left vertical axis shows the bed transfer, patient inflow, and patient outflow (number/day), and the right vertical axis shows the bed occupancy rate (%). The data for the four wards from November 2017 to November 2018 were summed, and the average number of cases per day was calculated for each week. Bed occupancy is calculated as a rate. Each line graph has a non-zero starting point to emphasize the monthly variation. In Japan, winter occurs from December to February.

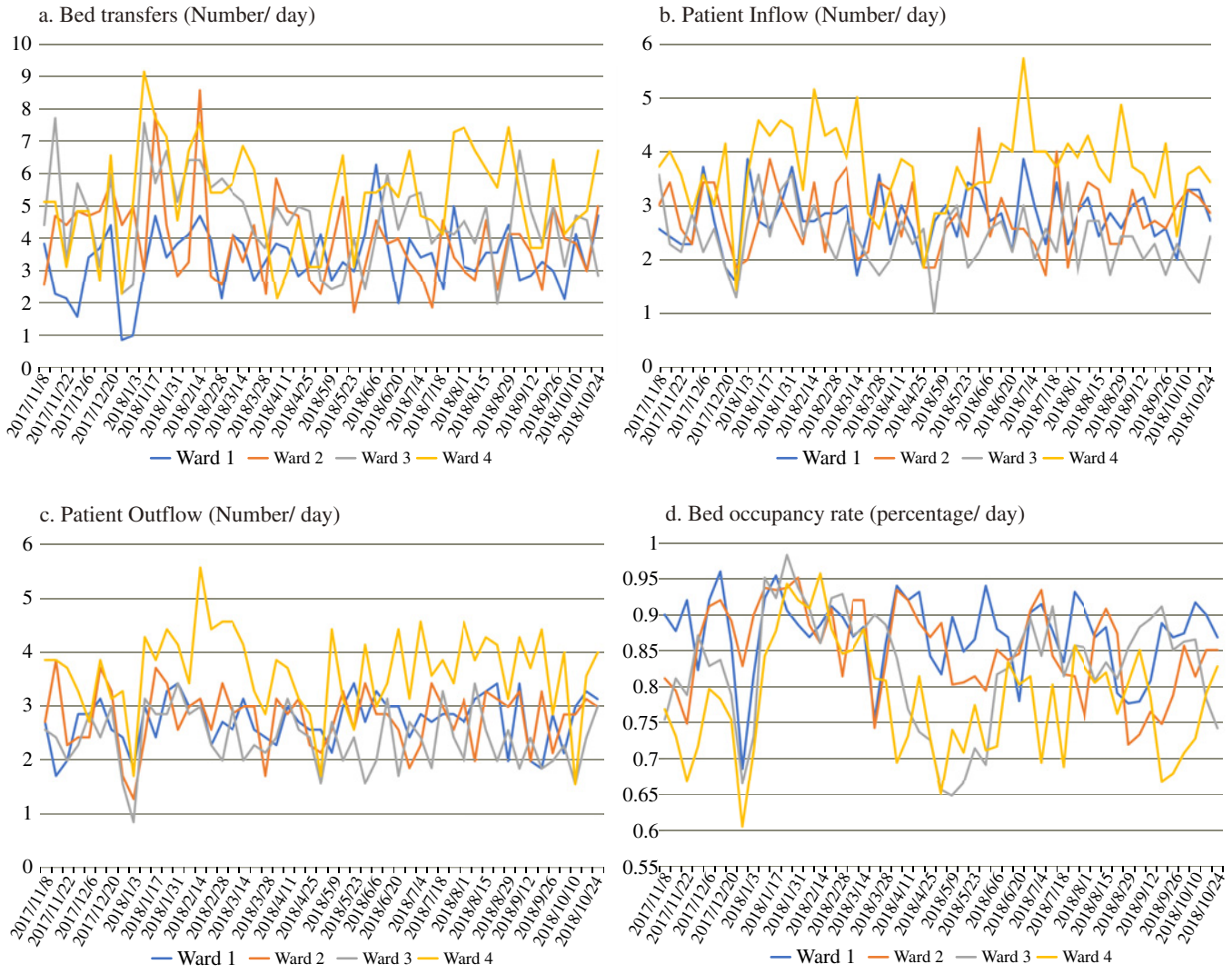

Figure 2. Time trend for each variable by ward.

Note: Bed transfers, patient inflows, and patient outflows are presented in units/day. The bed occupancy rate is expressed as a percentage.

The data for the four wards from November 2017 to November 2018 were summed, and the average number of cases per day was calculated for each week. Only the portions where the periods of all wards overlapped during the survey period of each ward are shown (November 8, 2017 to October 31, 2018).

Table 2. Correlation coefficients of variables of interest (N = 53).

	Bed transfer	Patient inflow	Patient outflow	Bed occupancy rate
Bed transfer	1.00	0.63**	0.55**	0.60**
Patient inflow		1.00	0.51**	0.56**
Patient outflow			1.00	0.65**
Bed occupancy rate				1.00

Note: The dataset comprised 365 days of data from four wards, averaged over 7 days each; then, the ward average was calculated.

**: $p < .01$.

pancy rate (r = 0.60) were statistically significant. Only bed occupancy rate had a significant autocorrelation (Table 3); in the cross-correlation between bed transfer and independent variables, all independent variables had the highest value at Lag 0 (Table 4).

The results of the multiple regression analysis revealed that patient inflow had a statistically significant effect on bed transfer (β = 0.40, $p < .00$; Table 5, Model 1). In the autoregressive model, patient inflow had a statistically significant effect on bed transfer (β = 0.40, $p < .00$; Table 5, Model 2).

Discussion

In our sample, bed transfers occurred multiple times a day in the hospital ward; the number of occurrences were par-

Table 3. Autocorrelation of each variable (N = 53).

Lag	Bed transfer	Patient inflow	Patient outflow	Bed occupancy rate
1	0.225	0.122	0.259	0.627**
2	−0.072	−0.029	−0.091	0.328**
3	0.053	−0.030	−0.090	0.186**
4	0.232	−0.036	0.016	0.116**
5	0.084	−0.057	0.177	0.128**
6	−0.130	0.179	−0.080	0.093**
7	−0.149	−0.184	−0.151	−0.003**
8	−0.038	−0.236	−0.107	−0.060**
9	−0.089	−0.210	−0.107	−0.184**
10	−0.174	−0.102	−0.198	−0.307**
11	−0.212	−0.051	−0.126	−0.311**
12	−0.108	0.052	0.037	−0.273**
13	0.071	0.011	−0.073	−0.331**
14	−0.249	−0.250	−0.165	−0.346**
15	−0.159	−0.130	−0.195	−0.305**
16	−0.017	−0.043	−0.041	−0.223**

Note: One Lag indicates 7 days.

**: $p < .01$.

Table 4. Cross-correlations between bed transfers and variables (N = 53).

Lag	Patient inflow	Patient outflow	Bed occupancy rate
−7	−0.137	−0.010	0.079
−6	0.073	0.006	0.107
−5	−0.059	0.090	0.128
−4	−0.039	0.077	0.248
−3	0.128	0.154	0.216
−2	0.128	0.069	0.256
−1	0.001	0.387	0.400
0	0.634	0.550	0.596
1	0.399	0.223	0.392
2	0.067	−0.202	0.061
3	−0.159	−0.056	−0.016
4	0.078	0.104	0.018
5	0.054	0.130	0.101
6	−0.050	−0.332	−0.059
7	−0.181	−0.292	−0.266

Note: One Lag refers to 7 days.

Table 5. Multiple regression analysis and primary autoregressive model with bed transfer as the dependent variable (N = 53).

	Model 1								Model 2							
	B[a]	β	SE[b]	t	p	95% confidence interval		VIF[c]	B[a]	β	SE[b]	t	p	95% confidence interval		VIF[c]
Intercept	−2.32		1.38	−1.68	.10	−5.10	0.45		−2.38		1.31	−1.82	.07	−4.94	0.18	
Patient inflow	0.75	0.40	0.12	3.20	.00**	0.28	1.23	1.54	0.75	0.40	0.24	3.17	.00**	0.29	1.21	1.60
Patient outflow	0.38	0.18	0.14	1.34	.19	−0.19	0.97	1.82	0.41	0.19	0.29	1.41	.16	−0.16	0.94	1.91
Bed occupancy rate	4.02	0.25	0.14	1.79	.08	−0.48	8.53	1.98	4.03	0.25	2.16	1.87	.07	−0.20	8.27	2.06
MAPE													.10			
R^2					.50								.70			
adjusted R^2					.47								.68			
AIC					95.40								97.06			

Note: Model 1 is a multiple regression analysis with intra-room bed transfers as the dependent variable. Model 2 is a multiple regression analysis of the autoregressive model of order 1, with intra-room bed transfers one-time point prior as the independent variable. The Mean Absolute Percentage Error (MAPE) was calculated in Model 2. The Akaike information criterion (AIC) values were calculated from the unstandardized dataset.

a: Unstandardized coefficient.

b: Standard error.

c: Variance inflation factor.

**: $p<.01$.

ticularly high during the winter months. In addition, bed transfer was affected by patient inflow.

Basic Dynamics of Yearly Bed Transfers

The average number of bed transfers per day during the year was 4.43. Previous studies have reported that acute care hospitals with an average length of stay of 7.8-11.6 days experience an average of 1.89-2.67 bed transfers per patient (Goldberg et al., 2015; Blay et al. 2017b). However, the current results cannot be directly compared with those of previous studies reporting the average number of patient transfers in a single admission. Although this study did not collect data on the average length of stay, it was reported to be approximately 16 days for general hospitals (average value including all clinical departments) in Japan in 2018 (Ministry of Health, Labor and Welfare, 2019). Considering this number and our results with 50 beds in each ward, approximately 1.69 bed transfers occurred.

The average bed transfer and bed occupancy rates peaked from January to February, and patient inflow tended to be higher in January. Furthermore, patient inflow and bed occupancy rates were highly correlated with bed transfer. These results are consistent with those of studies indicating that illnesses that tend to lead to hospitalization, such as influenza and stroke, are likely to occur during winter (Wang et al., 2003; Lenglet et al., 2007; Chu et al., 2018). However, no previous studies have identified seasonal patterns for daily bed transfers. Our results demonstrate that diseases that tend to prevail in winter may increase patient inflows and bed occupancy rates, which, in turn, may increase bed transfers.

Relationships between Bed Transfer and Other Patient Dynamics

The result of the autocorrelation showed that the bed transfer at a certain point of time did not affect the occurrence of bed transfer after the next week, and the result of the cross-correlation showed that the independent variable of that week had the most effect on the bed transfer. The results of the multiple regression analysis and autoregressive models indicated that patient inflow rates had a statistically significant positive effect on bed transfer. Patients entering a ward may be either in stable (e.g., admitted for routine laboratory tests) or unstable conditions (e.g., postoperative cases, transfers from the intensive care unit, or emergency admissions; Kibler & Lee, 2011; Blay et al., 2012; McCairn & Jones, 2014). Patients in unstable conditions are often assigned to specific beds in a ward, such as those located near staff stations (Bristol, 2019; Tanaka et al., 2021). When an unstable patient is admitted, a bed transfer must free up the critically ill patient. Existing patients using critical care beds were initially moved to beds slightly further away from the staff station rather than beds that were the farthest away. A single bed transfer can trigger a chain reaction of other bed transfers, resulting in a domino effect (Kosuge et al., 2013). Although the sample size is too small to confirm the interaction in this case, we may still hypothesize that this cascade of bed transfers may occur, especially when the bed occupancy rate is higher; this is because, during such situations, fewer candidate beds are available for bed transfers for critically ill patients. Considering the high numbers of bed transfers, patient inflows, and bed occupancy rates in winter in our sample, it can be implied that many patients with severe diseases (e.g., cerebrovascular and respiratory diseases) are hospitalized during this season. These high numbers make patient flows, especially bed transfers, more challenging to manage.

Therefore, it may be better to have patient rooms that can accommodate a wide range of patient changes (Hendrich et al., 2004), or a "cushion" ward to place patients before moving them from the intensive care unit to the general ward, such as the step-down unit (Laws et al., 2020). Hospital design could reduce cascading bed transfers by potentially minimizing condition-related differences among patients in the general ward. If a patient has specific characteristics, such as old age, predicting patient flow during hospitalization may help in assigning an appropriate patient room to minimize bed transfer from admission (Bruzzi et al., 2018). Performing predictive simulations may reduce the number of bed transfers due to management issues rather than patient conditions. In this way, if the characteristics of avoidable bed transfers can be clarified by management and hospital design, it may be possible to perform only essential bed transfers, such as responding to changing patient conditions, as well as reducing the burden on patients and staff.

Our results also showed a positive association between the bed occupancy rate and the number of bed transfers. Simulation studies have indicated that emergency admissions are less likely to be accepted when bed occupancy rates exceed 85% (Bagust et al., 1999). This result may indicate an inverse U-shaped association, in which a certain bed occupancy threshold indicates that bed transfer is impossible. This phenomenon shares similarities with bed blocking, where a patient cannot be discharged because there are no vacant beds in the facility where the patient is being discharged (Manzano-Santaella, 2010). As reported in previous studies, this may be because the specific beds used for critically ill patients and the beds for patients who have been weaned from critical care are all occupied. Therefore, further research is needed to accurately determine the relationship between the bed occupancy rate and bed transfer.

Additionally, the average length of hospital stays in Japan is approximately 16 days, more than twice as long as those in other countries (Organization for Economic Co-operation and Development, 2022). Considering the aforementioned cascade effect, the results suggest that the longer the hospital stay, the greater the likelihood that patients will experience additional bed transfers. Nurses will need to devote more resources to bed transfers.

Importance of Considering Human Resource Inputs in Frequent Bed Transfers

Improvements in ward architecture can enhance care efficiency and result in fewer bed transfers (Hendrich et al., 2004). Ideally, wards should be built to incorporate the necessary elements of care and ward management (Hendrich et al., 2004; Fay et al., 2017). However, rebuilding a ward only to reduce bed transfer is often not practical. Therefore, bed transfers can be managed using personnel resource management software. Specifically, one way to reduce bed transfers is by predicting changes in the condition of patients admitted to the hospital or transferred from other wards and then allocating appropriate beds to them. Furthermore, by examining the patient dynamics within the ward (e.g., as was done in this study), hospital stakeholders may have more

relevant data to make well-informed decisions about bed management according to their specific situations.

The results revealed that multiple bed transfers occurred on the same day and that the number of bed transfers varied throughout the year, with most transfers occurring in winter. Each bed transfer is 30-60 minutes and requires two or more nurses (Blay et al., 2017b; Hendrich & Lee, 2005). Due to the potential for a significant loss of time among nursing staff in bed transfers, hospitals should consider deploying more staff than usual to handle bed transfers during periods when they occur at a high frequency. Generally, this study underpins that patient inflow and bed occupancy rate are critical indicators in predicting the number of bed transfers and should be considered when performing staff management and planning.

Limitations

Although the present study revealed important findings, it is not without limitations. This study was conducted at a single hospital, and each of the four wards had 50 beds. The results may differ among wards with different numbers of beds. Furthermore, the study period was limited to a 1-year duration, with data aggregated at weekly and ward levels. Had the sample spanned multiple years and included data from multiple hospitals, biases in the findings would have been minimized. Previous studies have indicated that patient status and the function and number of rooms in each ward influence bed transfer (Tanaka, 2021). However, this study did not collect data on patient status or on ward structure. Thus, future studies should consider these two variables in their examinations.

Considering the recent changes in bed control management in wards to cope with the COVID-19 pandemic (Perondi et al., 2020), these changes may have influenced the number of bed transfers. However, this dataset excluded information on the bed control management method; therefore, its impact on bed transfers could not be examined. Future studies should analyze data on management methods. Consequently, the results of this study cannot be overgeneralized.

The current study focused only on patient dynamics and did not account for the effects of disease severity and staffing. Therefore, future studies should examine how these variables interact with the patient dynamics that impact bed transfer.

Conclusions and Clinical Implications

The current study examined the impact of admissions, transfers into and from wards, discharges, and bed occupancy rates on daily bed transfers using annual data from four wards in a single hospital. Bed transfer numbers varied throughout the year and were more frequent during winter in Japan. The results indicated that patient inflow (the combined number of admissions and transfers into the ward) and bed occupancy rate had a statistically significant positive effect on bed transfers.

In summary, the focus of this study on the annual trends in daily bed transfers, patient inflows, and bed occupancy rates highlights the importance of appropriate staffing to manage high bed transfer rates. Monitoring changes in patients' conditions and ensuring appropriate bed allocation to minimize bed transfers.

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Author Contributions

Shingo Tanaka developed the initial concept, obtained ethical approval, collected data, performed statistical analyses, drafted the first version of the manuscript, and revised the final manuscript. Keiko Kunie, Yusuke Saigusa, and Yukie Takemura participated significantly in the analysis. Keiko Kunie and Yukie Takemura significantly participated in the interpretation of the findings. All authors have agreed on the content of the final manuscript.

Declaration of Conflicting Interests

The authors declare no conflicts of interest.

Ethical Approval

This study was approved by the Research Ethics Committee of the University of Tokyo, Clinical Research Review Board (No. 12071).

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Original Research

Association between personality traits and self-care behaviors in patients with gastrointestinal cancer undergoing outpatient chemotherapy: A cross-sectional study

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Abstract

Objective: To improve the side effects of chemotherapy, practicing self-care behaviors is important for patients with cancer to continue treatment and maintain their quality of life. Herein, we aimed to assess the association between personality traits and self-care behaviors among patients with gastrointestinal cancer undergoing outpatient chemotherapy. **Methods:** This study included patients who received intravenous chemotherapy at a designated regional cancer hospital in Japan between June 2020 and October 2020. A self-administered survey was conducted using the Japanese version of the Ten-Item Personality Inventory and a unique 29-item questionnaire to assess self-care behaviors. The correlation of each item was analyzed using Spearman's rank correlation coefficient. **Results:** In total, 53 (93.0%) responses were obtained from 57 participants, of which 52 (91.2%) complete responses on personality traits were valid. The mean personality trait scores ranged from 6.7 ± 2.8 for neuroticism to 11.0 ± 1.9 for agreeableness. A high degree of openness had a moderately significant positive correlation with adjustment of exercise ($\rho = .49$, $p < .01$) and adaptation to changes in appearance ($\rho = .41$, $p < .01$). Additionally, a high degree of conscientiousness had a significant positive correlation with the acquisition of information on disease and treatment ($\rho = .30$, $p = .03$) and confirmation of inspection results ($\rho = .39$, $p < .01$). **Conclusions:** Openness and conscientiousness were significantly associated with patients' self-care behaviors. Assessing these personality traits before initiating chemotherapy can predict self-care behaviors and provide individualized support, considering the limited involvement at outpatient visits.

Keywords

chemotherapy, personality traits, self-care behaviors, cancer

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Introduction

Cancer incidences are increasing annually; gastrointestinal cancer accounts for approximately 26% of all cancer cases worldwide (Sung et al., 2021) and 41% of all cases in Japan (Cancer and Disease Control Division Ministry of Health, Labour and Welfare, 2022). Additionally, the 5-year relative survival rate of patients with gastrointestinal cancer has increased because of the early detection of cancer and advanced treatment methods, ranging from 8.5% for pancreatic

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cancer to 71.8% for rectal cancer in Japan (Center for Cancer Control and Information Services, National Cancer Center, 2020). However, owing to the characteristics of the cancer site, the initial symptoms are poor; in some cases, the disease is diagnosed at an advanced stage. Therefore, improving the survival rate of patients with gastrointestinal cancer remains a challenge. Even today, disease recurrence and progression are a concern for many patients with gastrointestinal cancer, and chemotherapy is the predominant treatment for preventing recurrence or progression.

Chemotherapy for gastrointestinal cancer involves the use of cytotoxic agents, such as antimetabolites (e.g., fluoropyrimidine anticancer drugs), platinum-containing preparations, and topoisomerase inhibitors. These drugs have a narrow therapeutic range; they act on cancer and healthy cells. Hence, side effects depending on the mechanism of action of anticancer drugs, such as myelosuppression, hair loss, and gastrointestinal symptoms, are unavoidable (Hassett et al., 2006). As patients with cancer undergoing outpatient chemotherapy do not have a medical attendant to assist them in daily life, they must develop self-care habits and behaviors, such as monitoring, preventing, and coping with side effects. Insufficient self-care for side effects may lead to serious consequences, such as the occurrence of prolonged, chronic, or severe side effects, eventually resulting in treatment interruption or discontinuation (Beijers et al., 2014; Quasthoff & Hartung, 2002). Moreover, side effects influence the physical, psychological, and social well-being of patients, potentially influencing their quality of life negatively (Han et al., 2020).

In patients with gastrointestinal cancer, side effects that cause peripheral neuropathy and changes in appearance may restrict in activities, change interpersonal relationships, and narrow down the range of their activities, further resulting in anxiety and distress (Driessen et al., 2012; Han et al., 2020; Morrow & Greenwald, 2021; Mols et al., 2013; Tofthagen et al., 2013). Individualized self-care support aims to understand patients' diverse living backgrounds and assist them in practicing and strengthening their self-care behaviors. However, providing individualized support is challenging, given the short-term involvement of outpatients with healthcare professionals and short treatment durations (Nakaguchi et al., 2013).

Personality comprises a set of traits indicating individual behavioral tendencies. Unique personality traits characterize individuality (Allport, 1937). Therefore, personality traits can be useful in explaining and predicting individual behaviors (Allport, 1937; Cattell, 1946). Previous studies have investigated the association between personality traits and health-maintaining behaviors, such as alcohol consumption, smoking, and undergoing medical examinations (Bogg & Roberts, 2004; Iwasa et al., 2009; Lemos-Giráldez & Fidalgo-Aliste, 1997; Strathman et al., 1994; Vollrath et al., 1999). In addition, studies on patients with cancer and chronic diseases have investigated the association of personality traits with treatment compliance and behaviors required for managing the disease, including medication, diet, and exercise (Christensen & Smith, 1995; Lima et al., 2018; Skinner et al., 2002). Reportedly, conscientiousness, agreeableness, and openness are associated with health-maintaining behaviors and therapeutic compliance. Although studies focusing on patients with cancer are limited, one study demonstrated that conscientiousness and agreeableness among outpatients with cancer were associated with treatment adherence (Lima et al., 2018). However, the association between personality traits and self-care behaviors, including psychological and social aspects, remains unclear. Meanwhile, the acquisition of effective information, assurance, and encouragement from others, in addition to the existence of trustworthy individuals, promotes self-care behaviors in patients with cancer undergoing chemotherapy (Iino & Komatsu, 2002). Another study on patients with gastrointestinal cancer reported that sex, chemotherapy interval, and presence of counselors were associated with self-care behaviors among patients undergoing outpatient chemotherapy (Saito & Sato, 2010). Individual self-care support is possible when these factors are considered; personality traits can be one such factor. Chemotherapy for patients with gastrointestinal cancer requires self-care behaviors, including psychological and social aspects, because of its characteristic side effects. Therefore, investigating the association between self-care behavior, including psychological and social aspects, and personality traits is important.

At present, self-care support that considers personality traits is limited to practice based on nurses' insights and assessment abilities. Personality reflects an individual's emotional and volitional behavior, as well as intellectual aspects such as intelligence, attitudes, and values (Allport, 1937). Therefore, if the associations are observed between personality traits and self-care behaviors, it may explain or predict individual unique behaviors based on the characteristics of the associated personality traits. If we can empirically demonstrate the association between personality traits and self-care behaviors, including managing daily life, in patients with gastrointestinal cancer undergoing outpatient chemotherapy, it will potentially be useful for individual and optimal self-care support, given the limited involvement at outpatient visits. Therefore, this study aimed to clarify the association between personality traits and self-care behaviors in patients with gastrointestinal cancer undergoing outpatient chemotherapy.

Materials and Methods

This cross-sectional study investigated the quantitative association between personality traits and self-care behaviors in

patients with gastrointestinal cancer undergoing outpatient chemotherapy using a self-administered questionnaire. This study was approved by the Observation Research Ethics Review Committee of Osaka University Hospital (approval number: 20001-3).

Patients

Patients registered in the gastrointestinal surgery department of the designated regional cancer hospital, who received intravenous chemotherapy, were enrolled. The survey was conducted in Osaka prefecture, Japan, between June 2020 and October 2020. Patients who were ≥20 years old [the adult age in Japan], received one or more courses of outpatient chemotherapy, received chemotherapy with a regimen comprising one or more cytotoxic anticancer drugs, were aware of their cancer diagnosis, and could complete the questionnaire themselves. Patients who were treated with antibody-drug conjugates were included in the study. In addition, patients who experienced cognitive decline and were considered ineligible by the attending physician were excluded from the study. Using an effect size similar to previous studies (ES = .4; Lima et al., 2018), an a priori power analysis (G*Power 3.1.9.4; Faul et al., 2009) indicated that at least 44 individuals (total sample size) were required for a power level of .8.

Procedure

For patients fulfilling the inclusion criteria, the attending physician verbally requested their cooperation using a leaflet that described the study outline during the examination. After confirming their willingness to participate, the details of the study procedures were explained in writing and verbally before treatment initiation. All patients who provided written informed consent were included in the study. Questionnaire and reply envelopes were provided to the participants, and the completed questionnaire was submitted via mail. Information related to age, sex, disease, and treatment status was obtained from their medical records.

Measurements

Personality traits

Personality traits are the units that comprise personality. This study was based on the Big Five theory, which captures five personality traits-extraversion, agreeableness, conscientiousness, neuroticism, and openness. This theory analytically quantifies each of these five personality traits as high or low (Goldberg, 1990, 1992). Personality traits were assessed using the Japanese version of the Ten-Item Personality Inventory (TIPI-J), measuring the five personality traits using 10 questions (Gosling et al., 2003; Oshio et al., 2012). The participants responded to each question on a seven-point Likert scale, with 1 being "strongly disagree" and 7 being "strongly agree." After scoring the reversed items, the scores were evaluated as 2-14 points. Each personality trait can be understood as follows (Gosling et al., 2003; Oshio et al., 2012):

1. Extraversion: extraverted and enthusiastic
2. Agreeableness: sympathetic and warm
3. Conscientiousness: dependable and self-disciplined
4. Neuroticism: anxious and easily upset
5. Openness: open to new experiences and complex

The higher the score, the greater the strength of the personality trait. The test-retest reliability and convergent and discriminant validity of the TIPI-J were established based on previous studies (Oshio et al., 2012). Considering the burden on patients undergoing treatment, we used the TIPI-J, which has fewer questions than other scales relating to personality traits.

Self-care Behaviors

Herein, to investigate the association between specific self-care behaviors, the concept of self-care behaviors included direct behaviors for addressing side effects and coping behaviors in daily life that were affected by side effects. Therefore, we created a questionnaire regarding self-care behaviors that were essential for patients with cancer undergoing outpatient chemotherapy and included information search/utilization, self-monitoring, selection/adjustment of behavior in daily life, utilization of support resources, prevention of/coping with side effects, and psychological care. Two physicians, one pharmacist, and five nurses specializing in cancer care evaluated the validity of each question. In total, 30 candidate questions were prepared based on a literature review, and their appropriateness was rated on a three-point scale: "appropriate," "do not know," or "not appropriate." For questions rated "do not know" or "not appropriate," they were asked to provide reasons. A total of 27 questions were rated as valid by six or more evaluators. Questions regarding self-care behaviors were revised based on the suggestions about their wording and content; a question was deleted because three experts recommended it as not a self-care behavior; finally, 29 questions were included. Participants answered each question using a four-point scale, with 1 point indicating "not at all" and 4 points "frequently" meaning.

Patients' Characteristics

The questionnaire was used to obtain demographic data. Demographic data included age, sex and marital, cohabitation (living with someone/family or alone), educational, employment, and performance statuses based on the scale created by the Eastern Cooperative Oncology Group. Disease- and treatment-related data obtained from the medical records included the primary tumor site, tumor stage, treatment history for the current disease, chemotherapy history, and treatment status for the current regimen (cytotoxic anticancer drugs used and cycles). In addition, we obtained information on physical symptoms (stomatitis, fatigue, nausea/vomiting,

loss of appetite, dysgeusia, constipation, diarrhea, peripheral neuropathy, and hair loss) and the presence or absence of anxiety using the questionnaire. Regarding the status of self-care support, we asked about the content of the information and support provided by the healthcare professionals.

Statistical Analyses

Convenience sampling was used to recruit participants. All patients satisfying the inclusion criteria were included. Descriptive statistics were used to assess each item in the questionnaire. The association between the scores for each of the five personality traits and the frequency of each self-care behavior was analyzed using Spearman's rank correlation coefficient. The significance level was set at 5% for both sides. All analyses were performed using the statistical software JMP Pro 15.1.0 (SAS Institute Inc., Cary, NC, USA).

Results

Questionnaires were distributed after obtaining consent from all 57 participants, and responses were obtained from 53 (response rate: 93.0%). The responses of 52 participants were included in the final analysis after excluding 1 because of inadequacies in the responses to the TIPI-J items and difficulty in analyzing the association between personality traits and self-care behaviors (valid response rate: 91.2%).

Patients' Characteristics

The mean age ± standard deviation (*SD*) of the participants was 66.1 ± 9.1 years; there were 35 (67.3%) men. The colon/rectum was the most common primary tumor site in 24 (46.2%) participants. The most frequently used cytotoxic anticancer drugs in the current regimen were 5-fluorouracil and irinotecan in 17 (32.7%) and 16 (30.8%) participants. Oxaliplatin was used in the current regimen in 13 (25.0%) participants, whereas 7 (13.5%) had it removed from their regimen owing to side effects, such as peripheral neuropathy (Table 1).

The mean (± *SD*) number of symptoms reported by the participants was 3.4 (±2.2) of 9 physical symptoms. The most commonly reported physical symptoms were peripheral neuropathy in 37 (71.2%) participants, fatigue in 27 (51.9%), hair loss in 22 (42.3%), and constipation in 22 (42.3%). Additionally, 28 (53.8%) participants reported experiencing anxiety (Table 2).

All participants reported that one or more counselors were available during chemotherapy. In total, 50 (96.2%) participants reported that they consulted physicians regarding chemotherapy, whereas 28 (53.8%), 21 (40.4%), 3 (5.8%), and 0 (.0%) consulted nurses, family members, acquaintances, and people with the same disease. The information and support provided by healthcare professionals pertained to observation/recording of side effects in 44 (84.6%) participants, information acquisition about cancer and its treatment in 34 (65.4%), life adjustment in 33 (63.5%), psychological care in 11 (21.2%), and utilization of support resources in 6 (11.5%); only 4 (7.7%) participants reported that no information and support were received pertaining to the above-mentioned aspects.

The mean score ± *SD* was 8.9 ± 2.7 for extraversion, 11.0 ± 1.9 for agreeableness, 8.8 ± 2.7 for conscientiousness, 6.7 ± 2.8 for neuroticism, and 8.9 ± 2.5 for openness.

Self-care Behaviors

Figure 1 shows the implementation status of self-care behaviors among patients with gastrointestinal cancer undergoing outpatient chemotherapy in the order of the percentage of participants who answered "frequently" in each category. The most frequently practiced self-care behaviors among the participants were following the therapeutic and symptom-based medicine usage instructions provided by their healthcare professionals in the "prevention of/coping with side effects" category, as reported by 45 (86.5%) and 42 (80.8%) participants, respectively. Frequently practiced self-care behaviors reported in <30% of the participants included the following:

1. Selection/adjustment of behavior in daily life asking nearby people to help with work and housework in 12 (23.1%) participants
2. Utilization of support resources: communicating the status of the disease and treatment to people other than healthcare professionals in 11 (21.2%) participants, asking for help from someone other than healthcare professionals in 9 (17.3%), contacting the hospital when they cannot handle the situation in 4 (7.7%), and exchanging information with people who have experienced the same disease or treatment in 3 (5.8%)
3. Prevention of/coping with side effects: applying ingenuity to adapt to changes in appearance in 15 (28.8%) and exercising moderately according to the physical condition in 14 (26.9%)
4. Psychological care: expressing thoughts and emotions to someone in 14 (26.9%).

Association between Personality Traits and Self-care Behaviors

Table 3 presents the correlation coefficient (ρ) between personality traits and self-care behaviors of patients with gastrointestinal cancer undergoing outpatient chemotherapy. Openness and conscientiousness were significantly correlated with multiple self-care behaviors.

Openness had a significant positive correlation with the following self-care behaviors:

1. Selection/adjustment of behavior in daily life: trying to adjust the amount of work and housework according to the physical condition (ρ = .29, p = .036) and trying to

Table 1. Demographic characteristics of the participants.

		n	% [a]
Demographic data			
Age (*N* = 52)	Mean age in years±standard deviation (SD)	66.1 ± 9.1	
Sex (*N* = 52)	Men	35	67.3
	Women	17	32.7
Marital status (*N* = 52)	Married	40	76.9
	Single	5	9.6
	Divorced/widowed	7	13.5
Cohabitants (*n* = 47)	Yes	40	76.9
	No	7	13.5
Educational status (*n* = 51)	Junior high school	3	5.8
	Senior high school	17	32.7
	Technical school or junior college	10	19.2
	College and above	21	40.4
Employment status (*n* = 50)	Employed	28	53.8
	Unemployed	19	36.5
	Medical leave from the job	2	3.8
	Other	1	1.9
Performance Status (PS) (*n* = 50) [b]	0	14	26.9
	1	31	59.6
	2	3	5.8
	3	2	3.8
Disease- and treatment-related data			
Primary tumor site (*N* = 52)	Colon/rectum	24	46.2
	Stomach	10	19.2
	Pancreas	8	15.4
	Bile duct/gallbladder	6	11.5
	Esophagus	2	3.8
	Other	2	3.8
Tumor stage (*N* = 52)	Stage I	1	1.9
	Stage II	9	17.3
	Stage III	14	26.9
	Stage IV	22	42.3
	Missing	6	11.5
Treatment history for the current disease (*N* = 52) [c]	Chemotherapy alone	11	21.2
	Surgery [d]	39	75.0
	Radiotherapy	5	9.6
Past chemotherapy history (*N* = 52) [e]	Yes	30	57.7
	No	22	42.3
Treatment status for the current regimen (*N* = 52)			
Cytotoxic anticancer drug [c]	5-Fluorouracil	17	32.7
	Irinotecan	16	30.8
	Oxaliplatin	13	25.0
	Gemcitabine	10	19.2
	Tegafur/gimeracil/oteracil	9	17.3
	Capecitabine	9	17.3
	Paclitaxel	5	9.6
	Trastuzumab deruxtecan [f]	4	7.7
	Cisplatin	3	5.8
	Nab-paclitaxel	3	5.8
	Dacarbazine	1	1.9
Cycle (*N* = 52) [g]	Median	5.5 (1–57)	

Note: [a] If missing values are excluded, the total may not be 100%.
[b] Eastern Cooperative Oncology Group classification
PS0: fully active and able to perform all predisease activities without restrictions
PS1: restricted in physically strenuous activity but ambulatory and able to carry out the work of a light or sedentary nature, e.g., light house office work
PS2: ambulatory and capable of all self-care activities, but unable to perform any work activities; up and about >50% of waking hours
PS3: capable of limited self-care; confined to bed or chair for >50% of the waking hours
[c] Multiple answers
[d] Excludes bypass surgery for passage obstruction and proctostomy
[e] Presence or absence of chemotherapy other than the current regimen
[f] This study included patients who received the antibody-drug conjugate
[g] The number of chemotherapy courses administered as part of the current regimen during the survey

Table 2. Physical symptoms and anxiety scores among the participants (N = 52).

	Currently have symptoms	Degree			Had symptoms during chemotherapy, but not now	Had no symptoms during chemotherapy
		Strong	Moderate	Weak		
	n (% [a])	*n* (% [b])	*n* (% [b])	*n* (% [b])	*n* (% [a])	*n* (% [a])
Physical symptoms						
Peripheral neuropathy	37 (71.2)	7 (18.9)	17 (45.9)	12 (32.4)	7 (13.5)	8 (15.4)
Fatigue (n = 50)	27 (51.9)	3 (11.1)	13 (48.1)	11 (40.7)	16 (30.8)	7 (13.5)
Hair loss	22 (42.3)	3 (13.6)	7 (31.8)	12 (54.5)	11 (21.2)	19 (36.5)
Constipation (n = 49)	22 (42.3)	3 (13.6)	8 (36.4)	10 (45.5)	15 (28.8)	12 (23.1)
Loss of appetite (n = 50)	20 (38.5)	2 (10.0)	6 (30.0)	11 (55.0)	12 (23.1)	18 (34.6)
Diarrhea (n = 49)	14 (26.9)	2 (14.3)	6 (42.9)	6 (42.9)	19 (36.5)	16 (30.8)
Dysgeusia (n = 51)	14 (26.9)	2 (14.3)	4 (28.6)	8 (57.1)	10 (19.2)	27 (51.9)
Nausea/vomiting (n = 49)	13 (25.0)	1 (7.7)	1 (7.7)	11 (84.6)	15 (28.8)	21 (40.4)
Stomatitis (n = 50)	10 (19.2)	0 (.0)	3 (30.0)	7 (70.0)	16 (30.8)	24 (46.2)
Anxiety	28 (53.8)	3 (10.7)	10 (35.7)	15 (53.6)	11 (21.2)	13 (25.0)

Note: [a] If missing values are excluded, the total may not be 100%.
[b] Proportion of patients who currently have symptoms

adjust the level of daily living activities according to the physical condition (ρ = .28, p = .046)
2. Prevention of/coping with side effects: exercising moderately according to the physical condition (ρ = .49, p < .001), applying ingenuity to adapt to changes in appearance (ρ = .41, p = .002), managing life such that fatigue does not increase (ρ = .32, p = .023), taking preventive action against infection (ρ = .29, p = .039), and observing the stool (ρ = .29, p = .040)
3. Psychological care: performing activities for a change of mood (ρ = .40, p = .003)

Conscientiousness had a significant positive correlation with the following self-care behaviors:

1. Information search/utilization: getting information about their disease and treatment (ρ = .30, p = .032)
2. Self-monitoring: checking the results of clinical examinations performed (ρ = .39, p = .005)
3. Utilization of support resources: informing the healthcare professional about their physical and mental condition during the examination (ρ = .31, p = .024)
4. Prevention of/coping with side effects: applying ingenuity to adapt to changes in appearance (ρ = .49, p < .001) and managing life such that fatigue does not increase (ρ = .32, p = .022)
5. Psychological care: expressing thoughts and emotions to someone (ρ = .31, p = .024)

Furthermore, there was a significant correlation between "extraversion" and "trying to keep my mouth clean" (ρ = −.29, p = .040) and between "neuroticism" and "applying ingenuity to adapt to changes in appearance" (ρ = −.28, p = .042); however, no correlation was found between "agreeableness" and any of the self-care behaviors.

Discussion

This study examined self-care behaviors rooted in the daily lives of patients with gastrointestinal cancer and assessed the association between personality traits and self-care behaviors in patients with gastrointestinal cancer undergoing outpatient chemotherapy. The personality traits of openness and conscientiousness were significantly associated with multiple self-care behaviors. A high degree of openness was associated with adjustment of exercise as prevention of/coping with side effects and activities of daily living, whereas a high degree of conscientiousness was associated with an acquisition of information on disease and treatment and confirmation of inspection results as self-monitoring.

Notably, openness was significantly associated with the implementation of exercise, activity adjustments, and ingenuity toward changes in appearance. Reportedly, the intent to exercise is associated with a high degree of openness in patients undergoing chemotherapy (Villaron et al., 2017), which agrees with our results that suggest a moderately significant positive correlation between openness and adjustment of exercise. In other words, openness is associated with an intention to exercise and implement the exercise. Those with a high degree of openness are not bound by existing values and are characterized by active work in new situations (Gosling et al., 2003; Oshio et al., 2012; Shimonaka et al., 1998). Therefore, exercise during outpatient chemotherapy can be a new initiative by patients. Typically, patients with cancer undergoing chemotherapy refrain from physical activity because of concerns about emerging physical symptoms and side effects (Curt et al., 2000; Fisher et al., 2016; Han et al., 2020; Mikkelsen et al., 2019; Moy et al., 2022). Herein, moderate exercise according to physical condition was a frequently practiced self-care behavior re-

Figure 1. shows the implementation status of self-care behaviors among patients with gastrointestinal cancer undergoing outpatient chemotherapy. The implementation status is indicated as "frequently," "sometimes," "not so often," "not at all," and "no answer." The items are arranged in order of the percentage of participants who answered "frequently" in each category.

Table 3. Association between personality traits and self-care behaviors (N = 52).

Self-care behaviors		Personality traits				
		Openness	Conscientiousness	Extraversion	Neuroticism	Agreeableness
		s	ss	n	m	ss
		ρ				
Information search/utilization						
1	Get information about your own disease and treatment	.16	.30*	.19	.04	.15
Self-monitoring						
2	Continue to measure body temperature	−.04	.05	−.10	.09	−.04
3	Check the results of the clinical examination performed (n = 51)	.22	.39**	.12	.00	.04
4	Keep track of your body and treatment status (n = 51)	−.09	.19	−.08	−.14	.06
Selection/adjustment of behaviors in daily life						
5	Try to adjust the level of daily living activities according to your physical condition	.28*	.12	.05	.06	.04
6	Try to adjust the amount of work and housework according to your physical condition	.29*	.21	.15	−.07	.23
7	Ask nearby people to help with work and housework	.10	.06	.07	−.06	.10
8	Choose a method to deal with side effects that you think you can implement and do it in your life	.15	.24	.27	−.01	.02
Utilization of support resources						
9	Exchange information with people who have experienced the same disease or treatment	−.20	−.02	.10	.02	−.11
10	Inform your healthcare professional about your physical and mental condition during the examination	.08	.31*	.24	−.07	−.03
11	Contact the hospital when you cannot handle the situation (n = 51)	.11	.11	.11	−.05	.03
12	Discuss the treatment with your healthcare professional	.25	.19	.05	−.01	−.11
13	Communicate the disease status and treatment to people other than healthcare professionals	.13	.13	−.07	−.09	−.03
14	Ask for help from someone other than healthcare professionals	−.01	.03	−.05	.03	.10
Prevention of/coping with side effects						
15	Take preventive action against infection	.29*	−.06	−.09	.07	.15
16	Try to keep your mouth clean	.11	.21	−.29*	−.05	.01
17	Exercise moderately according to your physical condition	.49***	.16	−.16	−.09	.07
18	Manage your life such that fatigue does not increase	.32*	.32*	−.01	−.12	.03
19	Manage your life such that nausea and vomiting do not increase (n = 51)	.14	.16	.20	−.08	−.11
20	Eat according to your body symptoms	.26	.12	.10	−.06	.21
21	Consciously drinking water	.05	.03	−.13	.12	−.13
22	Observe the stool (n = 50)	.29*	.14	.06	−.16	.21
23	Manage your life such that constipation and diarrhea do not increase (n = 51)	.20	.23	.14	.02	−.05
24	Pay attention to limb numbness	.14	.08	.02	.00	−.16
25	Apply ingenuity to adapt to changes in appearance	.41**	.49***	.12	−.28*	−.02
26	Follow the therapeutic instructions provided by healthcare professionals	.10	.12	−.15	−.07	.14
27	Use medicines according to symptoms based on the instructions provided by healthcare professionals	.06	.10	−.09	.02	.24
Psychological care						
28	Express your thoughts and emotions to someone	.23	.31*	.19	−.15	−.05
29	Perform activities for a change of mood	.40**	.05	.18	−.03	−.06

Note: Spearman's rank correlation coefficient (ρ); *p < .05, **p < .01, *** p < .001

ported by approximately 30% of the participants. Despite the apparent benefits of moderate exercise during chemotherapy, such as reduced fatigue, sleep disturbance, and anxiety; improvement of physical function; and improvement of health-related quality of life (Moy et al., 2022; Oldervoll et al., 2004; Yeun & Jeon, 2020), it is a challenging self-care behavior among patients undergoing chemotherapy. Similarly, for patients with cancer, performing ac-

tivities to change their mood can be considered an activity that helps them cope well with the disease and treatment. Thus, exercise and performing activities for a change of mood have new meanings for patients with cancer concerning their disease and treatment, and these activities were recognized as new potential initiatives by the participants. Therefore, healthcare professionals' attitudes and involvement can play an important role in supporting patients engaged in new self-care behaviors.

Herein, openness was moderately and significantly associated with the application of ingenuity to adapt to changes in appearance. A high degree of openness is also characterized by creativity, imagination, and unique ideas (Gosling et al., 2003; Oshio et al., 2012; Shimonaka et al., 1998). The side effects of regimens may manifest as changes in appearance, such as hair loss, weight loss, and hand-foot syndrome (Fukahori et al., 2021; Morrow & Greenwald, 2021; Shibata et al., 2020). Creativity is essential for patients to respond to these changes in appearance and continue performing activities of daily living. This study suggests that responding to changes in appearance requires support based on the creativity encouraged by openness.

Moreover, our study provides new insights into the association between conscientiousness and self-care behaviors in patients with gastrointestinal cancer undergoing outpatient chemotherapy. Reportedly, conscientiousness was associated with information acquisition about the disease and its treatment, as well as with the expression of thoughts and emotions as part of psychological care. Conscientiousness reflects the will and desire to achieve a goal and defines conducting work in a systematic manner (Gosling et al., 2003; Oshio et al., 2012; Shimonaka et al., 1998; Watson & Hubbard, 1996). Obtaining information about one's disease, treatment, and the examinations performed can be considered an action to understand one's situation and continue treatment and activities of daily life while having a perspective (Iino & Komatsu, 2002); this suggests that highly conscientious individuals comply with the instructions from their healthcare professionals and practice self-care behaviors to manage their disease and treatment. Conversely, healthcare professionals must proactively provide information to patients with low levels of conscientiousness.

Moreover, conscientiousness was significantly associated with the expression of thoughts and emotions. In a previous study investigating the association between personality traits and stress-coping patterns in healthy individuals, extroversion and neuroticism were associated with the ability to cope with emotional stress (Watson & Hubbard, 1996). Herein, the expression of thoughts and emotions was not associated with extroversion or neuroticism; however, there was a significant association with conscientiousness, which is characterized by practicing healthy behaviors. These findings suggest that the expression of thoughts and emotions is a self-care behavior that a patient undertakes hard. Therefore, creating an environment where patients can express their thoughts and emotions honestly to healthcare professionals is necessary. With over half of the participants experiencing anxiety, only 20% received information and psychological support from healthcare professionals and 30% frequently expressed their thoughts and emotions, indicating that support is required to strengthen the psychological self-care behavior. Thus, by predicting the implementation status of psychological self-care behavior in advance based on high and low degrees of conscientiousness, patients can be supported before treatment so that they can perform and improve their psychological self-care behavior.

Furthermore, no association was observed between agreeableness and self-care behavior. Agreeableness indicates a tendency to respond cooperatively to others (Gosling et al., 2003; Oshio et al., 2012; Shimonaka et al., 1998). A previous study reported an association with treatment adherence among cancer outpatients (Lima et al., 2018), and patients may have cooperated with others to adhere to treatment. This study focused on individual patient behaviors, which may explain the absence of an association. Further, there was no sufficient association between neuroticism and extroversion and self-care behaviors, and predicting or supporting self-care behavior from these personality traits in clinical settings is currently difficult.

Finally, this study investigated self-rated personality traits using the TIPI-J, which revealed significant associations between self-evaluation and others' evaluations of openness, conscientiousness, and extraversion, with both evaluations agreeing to some extent (Oshio et al., 2012). Therefore, it is expected that the knowledge regarding openness and conscientiousness obtained in this study can also be utilized by healthcare professionals to observe the characteristics of patients' personality traits. However, self-evaluation and others' evaluation of personality traits do not necessarily match, and there may be cases in which it is necessary to evaluate the personality traits recognized by the patients themselves. It is important for healthcare professionals to assess patients' perceptions of openness and conscientiousness before they begin chemotherapy and to intervene in self-care behavior with predictions.

To our knowledge, this is the first study to conduct a comprehensive examination of the association between personality traits and self-care behaviors practiced by patients with gastrointestinal cancer undergoing outpatient chemotherapy to address the physical, psychological, and social impacts of treatment-related side effects. However, this study has some limitations. First, the questionnaire on self-care behaviors was originally developed. Although the association between personality traits and self-care behaviors was evaluated for each item, considering the constructs of self-care behaviors and summarizing multiple self-care behaviors in

future studies is recommended. Notably, the implementation of self-care behavior was assessed based on the patients' self-evaluation; therefore, the appropriateness of the reported self-care behavior in individual situations cannot be judged. Second, the sample size was small, possibly limiting the generalizability of our findings. Because this was a cross-sectional survey, we could only consider the effects of the treatment history and processes during the survey. Patients must engage in self-care behaviors that can change during treatment. Using more advanced statistical methods, such as considering causal relationships and multiple regression, may lead to more reliable results. Third, colorectal cancer was the most common type of cancer in our sample, and most participants had undergone its surgical treatment. We did not collect surgical data, such as the type of surgery and presence of a colostomy; however, these variables may have impacted the patients' self-care behaviors during chemotherapy. In addition, an investigation into the association between personality traits and self-care behaviors in patients with cancers other than gastrointestinal cancer is needed. Finally, although the purpose of this study was to clarify the association between individual personality traits and self-care behaviors, behavior is reportedly regulated by a combination of personality traits (Allport, 1937). Additionally, the mean agreeableness score was high in this sample. Thus, those who participated in the study tended to be more cooperative, which may have influenced the observed association between openness and conscientiousness. Consequently, large studies are required to assess the association between self-care behaviors and the combination of personality traits. Additionally, although we carefully selected the number of self-care behavior questions to be surveyed, considering the burden on patients to answer, the conceptualization of self-care can be broadened. In the future, self-care behaviors that emphasize the psychological and social aspects of patients undergoing cancer treatment must be studied.

In conclusion, openness and conscientiousness are associated with self-care behaviors in patients with gastrointestinal cancer undergoing outpatient chemotherapy and may be useful in explaining and predicting individual self-care behaviors. It is important for healthcare professionals to assess patients' openness and conscientiousness before beginning chemotherapy and to intervene in self-care behavior with predictions. Conducting large studies in the future to assess the association between self-care behaviors and the combination of personality traits is important.

Author Contributions

Yuri Takei contributed to the study design, development of questionnaire, data collection, analysis, and writing of the manuscript. Sena Yamamoto contributed to the study design, analysis, writing of the manuscript, and critical review of the manuscript for important intellectual content. Taroh Satoh and Masao Mizuki contributed to the study design, data collection, and critical review of the manuscript. Keiko Tazumi contributed to the study design, development of the questionnaire, data collection, and critical review of the manuscript for intellectual content. Harue Arao contributed to the study design, development of the questionnaire, analysis, writing of the manuscript, and critical review of the manuscript for important intellectual content.

All authors have read and approved the final manuscript.

Declaration of Conflicting Interests

The authors declare that there are no conflicts of interest.

Ethical Approval

The study was approved by the Observation Research Ethics Review Committee of Osaka University Hospital (approval number: 20001-3).

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Original Research

Effects of a self-management program for poststroke fatigue: A feasibility study targeting patients with early fatigue

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Abstract

Objective: To examine the effects of a self-management program for poststroke fatigue (PSF). **Methods:** The study participants included were 30 patients with early fatigue within 3 months after a stroke. During hospitalization, a 2-week-long self-management program for PSF was provided, consisting of components on problem-solving support, self-monitoring support, and education. The outcomes included fatigue (Multidimensional Fatigue Inventory [MFI]), motivation (Apathy Evaluation Scale [AES]), and self-management skills (correct answer rate on a knowledge evaluation questionnaire), with higher MFI and AES scores indicating more severe fatigue and reduced motivation. We then performed pre- and post-intervention comparisons to obtain the effect sizes. The ethics review committee approved this study. **Results:** A total of 25 participants completed the program (five dropouts). Regarding the pre- and post-intervention comparisons, MFI scores decreased significantly after the intervention (p = .00, Cohen's d = 1.48), with the proportion of those who exceeded the cutoff decreasing from 60.0% to 36.0%. AES scores also decreased significantly after the intervention (p = .03, Cohen's d = 0.45), with the proportion of those who exceeded the cutoff decreasing from 44.0% to 28.0%. Knowledge also increased significantly (p = .00, r = 0.86), suggesting the acquisition of self-management skills. **Conclusions:** After the intervention, fatigue and motivation improved, and self-management skills were acquired. Although we cannot deny the possibility that fatigue improved naturally, the program was likely effective to some extent. Further studies on the program are necessary, and a randomized controlled trial with an adequate sample size is warranted to examine its effects. Trial registration: UMIN Clinical Trials Registry (UMIN000048681)

Keywords

early fatigue, feasibility study, poststroke fatigue, self-management program

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Introduction

After stroke, 50% of patients experience poststroke fatigue (PSF) (Cumming et al., 2016). According to a previous review of five longitudinal studies (n = 762) (Wu et al., 2015), more than one-third of patients experience early fatigue (referring generally to fatigue within 3 months after a stroke). Although approximately one-third of these patients recover from early fatigue, the remainder transition to late fatigue (referring generally to fatigue at more than 1 year after the stroke) (Wu et al., 2015). Moreover, even for those who do not experience early fatigue, as time progresses, 10%-60% of patients eventually develop late fatigue (Wu et al., 2015). PSF is an independent predictor of a decrease in activities of daily living (Glader et al., 2002), which leads to a reduction in quality of life (Tang et al., 2010) and increases the risks

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of depression (Ormstad & Eilertsen, 2015) and death (Glader et al., 2002). In addition to being a symptom of distress in patients, PSF is an important health issue that must be managed.

With regard to drug therapy for PSF, evidence supporting the efficacy of the psychotropic drug modafinil has been accumulating in recent years (Bajorek et al., 2020; Bivard et al., 2017; Brioschi et al., 2009; Lillicrap et al., 2018; Poulsen et al., 2015; Visser, Goodin, et al., 2019; Visser, Maréchal, et al., 2019). However, currently, no drug therapies for PSF are available.

Nondrug therapies for PSF include transcranial direct current stimulation (De Doncker et al., 2021; Dong et al., 2021; Sun et al., 2022), education (Barker-Collo et al., 2022; Boehm et al., 2015; Clarke et al., 2012), cognitive behavioral therapy (Byun et al., 2021; Gillespie et al., 2020; Mead et al., 2022; Nguyen et al., 2019; Wu et al., 2017), mindfulness (Johansson et al., 2012), exercise therapy (Ghaffari et al., 2022; Wang et al., 2022; Xu et al., 2020; Yoon et al., 2020), a combination of cognitive behavioral therapy and exercise therapy (Zedlitz et al., 2011; Zedlitz et al.,2012), light therapy (Connolly et al., 2021; West et al., 2019), and horticultural therapy (Pálsdóttir et al., 2020). However, in 2017, the American Heart Association reported insufficient evidence regarding the effectiveness of nondrug therapies for PSF and noted that studies on nondrug therapies have a high risk of bias (Hinkle et al., 2017). To our knowledge, no reports on nondrug therapies for PSF supported by a high level of evidence have been published. Clinical and randomized controlled trials with appropriate sample sizes are needed to collect more evidence.

Long-term fatigue is associated with decreased mental and physical function, reduced quality of life, and increased risk of death (Sato & Hyakuta, 2024a). Therefore, fatigue should be managed early after stroke. Although supporting the acquisition of self-management skills at an early stage after disease onset is important to avoid the severe consequences of PSF, efforts to support such self-management programs have yet to be established. The causes of PSF include the stroke event itself, personality traits, and physical, mental, behavioral, social, and environmental factors (Sato & Hyakuta, 2024a). These factors must be managed comprehensively to improve fatigue, which increases the complexity of interventions. To this end, we developed a self-management program for PSF based on the UK Medical Research Council's "A new framework for developing and evaluating complex interventions" and conducted a feasibility study; feasibility studies evaluate the feasibility and acceptability of interventions to guide decisions about progression to the next phase of evaluation (Skivington et al., 2021).

During the development phase of the intervention program, we conducted a literature review (Sato & Hyakuta, 2024a), a conceptual analysis of PSF self-management (Sato & Hyakuta, 2024b), fieldwork, and consultations with specialists and patients with stroke. This program was developed exclusively for patients with normal levels of consciousness and cognitive function. After the program was fully developed, it was tested for safety and validity. In the testing phase, a randomized controlled trial with a small sample size was conducted to assess feasibility and acceptability. The development process of this program has been previously reported (Sato, 2024).

Although the feasibility and acceptability of the program have been verified (Sato, 2024), its effectiveness still needs to be examined. Therefore, the present study aimed to examine the effects of a self-management program for PSF by examining changes in fatigue, motivation, and knowledge of PSF before and after the intervention and to evaluate self-monitoring and problem-solving skills after the intervention. In addition, we aimed to clarify the extent of change in fatigue and motivation before and after the intervention and its relationship to the characteristics of the participants. This feasibility study has implications for randomized controlled trials with appropriate sample sizes.

Definitions

PSF: Referencing the Japanese Society of Fatigue Science's definition of fatigue and sense of fatigue (2011), PSF was defined as a condition characterized by a unique feeling of discomfort and a desire for rest that occurs in patients with stroke due to extreme physical and mental activity, accompanied by a decline in physical activity function and a sense of awareness regarding the existence of fatigue.

Patient with early fatigue: A patient who experiences PSF within 3 months after a stroke.

Materials and Methods

Research Design

This study adopted a one-group pretest/post-test design.

Data Collection Period

Data were collected from September 6, 2022, to March 31, 2023.

Setting

This study was conducted at the general and recovery phase rehabilitation wards of two facilities. Convenience sampling was used to consider ease of access.

Participants

Eligibility Criteria

The inclusion criteria were as follows (all must apply):

- At least 1 week but within 3 months after stroke
- Infarction or cerebral hemorrhage

- Modified Rankin Scale (mRS) score ranging from 0 (no symptoms) to 3 (moderate disability)
- Age ≥20 years
- Expected hospitalization duration of approximately 3 weeks
- Exhibits PSF; i.e., answered "yes" in response to the question "Do you feel tired all the time or get tired very quickly since your stroke?" (Wu et al., 2017)
- Having the decision-making capacity to consent to and refuse participation independently

Exclusion Criteria

The exclusion criteria were as follows (all must apply): stroke recurrence, depression, cognitive dysfunction, and inability to communicate verbally because of severe aphasia.

Sample Size

The sample size was determined using G*Power 3.1.9.7 statistical analysis software (Buchner et al., 2020). Considering potential dropouts, the sample size was set to 30.

Intervention

In addition to standard care, the participants underwent a 2-week (14 days), six-session, self-management program for PSF during hospitalization (Table 1). The program components included education, self-monitoring, and problem-solving support.

In the first session, the participants were given information on PSF and self-monitoring using audiovisual materials. In the second session, we prepared a plan and set goals aimed at improving fatigue using a self-monitoring notebook. From the plans recommended for PSF, we supported the selection of a plan by the participants that they felt could be carried out on a weekly basis. The recommended plans included one or more of the following nine contents: (a) securing strategic rest (17 items), (b) adequate physical activity (nine items), (c) adequate mental activity (16 items), (d) appropriate nutrient intake (three items), (e) flexible schedule adjustment (five items), (f) suppressing energy consumption (nine items), (g) adjusting the living environment (five items), (h) gaining understanding of others (seven items), and (i) gaining support from medical professionals (six items). In the third session, the participants performed self-monitoring and planned to improve their PSF. The items for self-monitoring (observation, measurement, and record-keeping) included fatigue, physical activity, sleep, behavior, and cognition. In the fourth session, goal achievement was evaluated, and a new plan was developed. In the fifth session, the participants conducted self-monitoring and planning again. In the sixth and final session, the entire program was evaluated and a future plan was developed. In the first, second, fourth, and sixth sessions, support was provided by medical professionals (researchers with a nursing license) five times (20 minutes each time). No support was provided in the third and fifth sessions because these involved self-monitoring and planning with the aim of improving the PSF. The audiovisual materials, self-monitoring notebook, details regarding the recommended plans for PSF, and intervention protocol used in these sessions have been previously reported (Sato, 2024).

Program Theory

Program theory describes how an intervention is expected to have effects and under what conditions (Skivington et al., 2021). The program theory for this study is as follows: by providing a self-management program for PSF at a hospital, which is the stage prior to transitioning to home medical care, patients would be able to acquire self-management skills, including knowledge, self-monitoring skills, and problem-solving skills, making the self-management of PSF, i.e., the ability to conduct coping behaviors against PSF, possible.

Survey Content

Participant Characteristics

Sex, age, employment status, number of days since stroke, type of stroke, site of stroke (left- or right-sided cerebral stroke), functional disorder (mRS and National Institutes of Health Stroke Scale [NIHSS] scores), complications, presence/absence of sleep disorders, and rehabilitation duration were obtained from the participants' medical records. A questionnaire survey was also conducted to assess vulnerability to stress (five-point scale ranging from "strongly disagree" to "strongly agree") and the availability of social support (instrumental and emotional support).

Outcomes

PSF

PSF was evaluated using the Japanese version of the 20-item Multidimensional Fatigue Inventory (MFI) (Sugay et al., 2005), which consists of the five subscales (20 items) as follows: general fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue. Scores ranged from 20 to 100 points (score range of each subscale: 4-20 points), with higher scores indicating more severe fatigue. The MFI was tested for reliability and validity (Sugaya et al., 2005). For the PSF, a score of ≥12 for overall fatigue was evaluated as "significant fatigue that interferes with daily life" (Poulsen et al., 2020).

Motivation

Motivation was evaluated using the Japanese version of the Apathy Evaluation Scale (AES) (Okada et al., 1998). Scores on the AES range from 0 to 42 points, with higher scores indicating lower motivation and a cutoff score of 16 points. The AES was tested for reliability and validity (Okada et al., 1998).

Knowledge of the PSF

The knowledge of the PSF was evaluated using the PSF

Table 1. Self-management program for poststroke fatigue.

Session	Theme	Content	Duration	Standard schedule	Support by medical professional
1	Education regarding PSF and self-monitoring	Listen/watch audiovisual materials regarding PSF (about 10 min) and Q&A (5 min)	20 min	Day 1	Yes
		Listen/watch audiovisual materials regarding self-monitoring (about 10 min) and Q&A (5 min)	20 min	Day 2	Yes
2	Preparation of plan and goal setting aimed at improving PSF	1. Clarify challenges/goals during recuperation after stroke 2. Set objectives/goals to improve PSF Set objective as "improving PSF" Set goal as "able to reduce fatigue at the beginning and end of the week or maintain low levels of the fatigue" 3. Associate challenges/goals during recuperation with problems regarding PSF 4. Prepare a plan executable on a weekly basis from among the nine plan contents below: (a) securing strategic rest; (b) adequate physical activity; (c) adequate mental activity; (d) appropriate nutrient intake; (e) flexible schedule adjustment; (f) suppress energy consumption; (g) adjust living environment; (h) gain understanding of others; and (i) gain support from medical professionals	20 min	Day 3	Yes
3	Plan execution and self-monitoring aimed at improving PSF	1. Execute plan 2. Self-monitoring a. measure, record, and observe sense of fatigue, physical activity, and sleep b. record and observe behavior c. record and observe cognitive process	4 days	Days 4-7	No
4	Evaluation of state of goal achievement and preparation of new plan	1. Obtain feedback from medical professionals regarding self-monitoring 2. Evaluate state of goal achievement 3. Clarify challenges in carrying out plan, consider measures to address challenges 4. Prepare a plan for the next week	20 min	Day 8	Yes
5	Plan execution and self-monitoring aimed at improving PSF	1. Execute plan 2. Self-monitoring a. measure, record, and observe sense of fatigue, physical activity, and sleep b. record and observe behavior c. record and observe cognitive process	5 days	Days 9-13	No
6	Evaluation of overall program and preparation of future plan	1. Obtain feedback from medical professionals regarding self-monitoring 2. Evaluate state of goal achievement 3. Clarify challenges in carrying out plan, consider measures to address challenges 4. Clarify skills acquired over the entire program 5. Prepare future plan	20 min	Day 14	Yes

Note: *Program components: education, self-monitoring support, and problem-solving support

*Medical professionals are defined as certified nurses who have passed the national nursing examination. In the present study, this refers to researchers with a nursing license.

PSF = poststroke fatigue

knowledge assessment questionnaire (Sato, 2024). This questionnaire is composed of the following 10 items, with answers consisting of "yes," "no," and "I don't know." The percentage of correct answers on the questionnaire was calculated (range: 0.0%-100%). This questionnaire was tested for content validity by one patient with stroke, two certified nurses, and one certified nurse specialist.

- Fatigue can be caused by stroke onset. (correct answer: yes)
- Poststroke fatigue recovers spontaneously and does not have serious consequences for the body, mind, or life. (correct answer: no)
- To improve poststroke fatigue, it is advisable to spend as much rest time as possible and lead a sedentary lifestyle. (correct answer: no)
- Exercise should be avoided to improve poststroke fatigue. (correct answer: no)
- To improve poststroke fatigue, only temporary high-priority activities should be performed so that daily life is not interfered with and physical fitness is reduced.

(correct answer: yes)
- To improve poststroke fatigue, flexible schedule adjustment is necessary. (correct answer: yes)
- Psychotherapy and stress reduction may improve poststroke fatigue. (correct answer: yes)
- Education and counseling on fatigue-related topics may help improve poststroke fatigue. (correct answer: yes)
- Poststroke fatigue is a sensation that only one can understand, and seeking understanding from those around you are not expected to improve fatigue. (correct answer: no)
- Poststroke fatigue recovers spontaneously and does not require regular assistance from a health-care professional. (correct answer: no)

Self-monitoring Skills

We evaluated the self-monitoring skills based on the record-keeping rate in a self-monitoring notebook (number of days of record-keeping/9 days × 100%). The 9 days correspond to the number of days the participants conducted self-monitoring during the 14-day program.

Problem-solving Skills

Problem-solving skills were evaluated based on the plan selection rate for PSF, self-evaluation score for plan execution, and self-evaluation score for goal achievement. The plan selection rate for PSF refers to the proportion of plan contents selected by participants from among the nine plan contents during the first and second weeks of the program. The self-evaluation score for plan execution refers to the degree to which the selected plan was carried out, scored on a 5-point scale (Could not execute the plan at all [execution rate: 0%] = 1 point; Could not execute the plan to a large extent [execution rate: 25%] = 2 points; Cannot say either way [execution rate: 50%] = 3 points; Executed plan somewhat [execution rate: 75%] = 4 points; and Executed plan very well [execution rate: 100%] = 5 points) over the course of 9 days. The self-evaluation score for goal achievement refers to the self-evaluation score for improving PSF on the last day of the program's first and second weeks on a 5-point scale (Could not achieve goals at all [achievement rate: 0%] = 1 point; Could not achieve goals to a large extent [achievement rate: 25%] = 2 points; Cannot say either way [achievement rate: 50%] = 3 points; Achieved goals somewhat [achievement rate: 75%] = 4 points; and Achieved goals very well [achievement rate: 100%] = 5 points).

Statistical Analysis

Descriptive statistics were used for quantitative data. Differences in the MFI and AES scores and correct answer rate on the knowledge assessment questionnaire before and after the intervention were assessed using a paired *t*-test or Wilcoxon's signed-rank test. The effect sizes were also calculated using Cohen's *d* or *r*. The effect size is the magnitude of the difference between the test results. The larger the effect size, the greater the difference between the groups. In a test of the difference between the meanings of two paired groups, Cohen's $d = .20$ was rated as a small effect size, $d = .50$ as a moderate effect size, and $d = .80$ as a large effect size (Cohen, 1988).

Differences in outcomes according to participant characteristics were assessed using the unpaired *t*-test or the Mann-Whitney *U* test. Correlations between participant characteristics and outcomes were analyzed using Pearson's correlation coefficient or Spearman's rank correlation coefficient.

SPSS Statistics (version 29; Smart Analytics Inc., Tokyo, Japan) was used for all statistical analyses, with the level of statistical significance set at $p<.05$.

Ethical Considerations

This study was approved by the ethics review committee of the Japanese Red Cross Hiroshima College of Nursing (approval No.: D-2201). This study was registered with the University Hospital Medical Information Network Clinical Trials Registry (UMIN000048681). All participants were provided with an explanation of the study and signed informed consent forms. Individual data were anonymized, and all research data were strictly managed according to the documentation management regulations of the researchers' institution.

Results

Eligibility, Participants, and Analysis Population

A total of 35 candidate participants were recruited, four of whom were evaluated as not having PSF during screening and were therefore excluded (Figure 1). One candidate dropped out because of fatigue. After removing excluded candidates and participants who dropped out, 30 participants remained. The consent rate was 96.8%. Among the 30 participants, another withdrew consent because of a sense of fatigue and burden and four dropped out after discharge. Therefore, the final analysis included 25 participants who completed the program (program completion rate: 83.3%).

Participant Characteristics

The study participants consisted of 20 males (80.0%) and five females (20.0%), with a mean age of 70.2±10.8 years and mean time after stroke of 17.0±20.3 days (Table 2). In total, 18 participants (72.0%) had cerebral infarction and 7 (28.0%) had cerebral hemorrhage. None of the participants had mRS0 (no symptoms at all), seven (28.0%) had mRS1 (symptoms but without clear disability), nine (36.0%) had mRS2 (mild disability), and nine (36.0%) had mRS3 (moderate disability). The mean NIHSS score was 2.6±1.9. Some participants had impairments in physical function and higher brain dysfunction, including lower limb motor disorder (*n* =

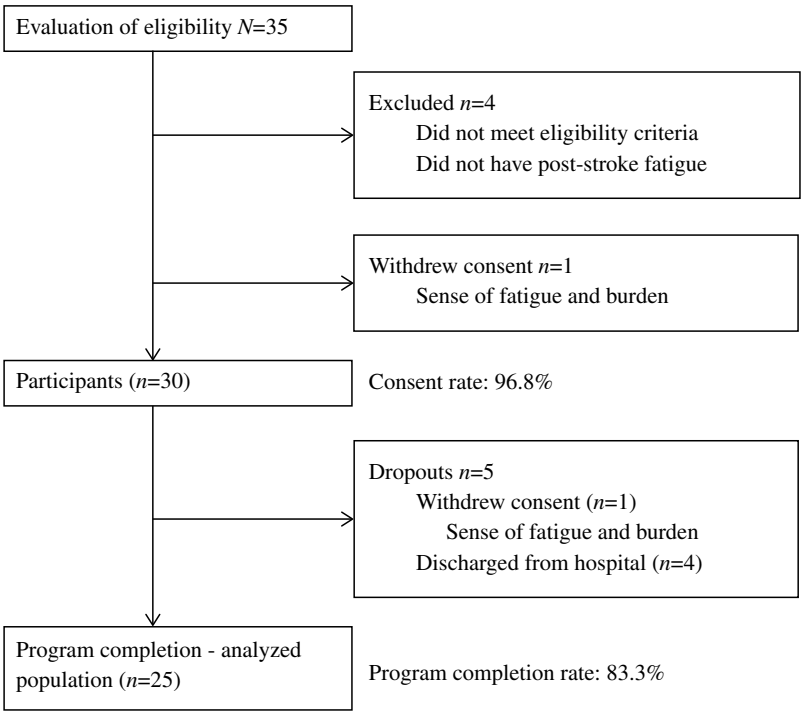


Figure 1. Flowchart of participant selection and the analyzed population.
The number of participants at each step from eligibility assessment to analysis.

13; 52.0%), dysarthria (n = 12; 48.0%), upper limb motor disorder (n = 9; 36.0%), and extinction/attention disorder (n = 8; 32.0%). Complications included hypertension, dyslipidemia, cardiovascular disease (chronic heart failure, myocardial infarction), kidney disease (chronic kidney disease, end-stage kidney disease), sensory organ disease (hearing loss, cataracts), diabetes, and sleep apnea syndrome. Five participants (20.0%) had a sleep disorder requiring sleep medication.

Changes in PSF

The MFI total score, overall fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue significantly decreased after the intervention, suggesting an improvement in fatigue (p = .00; Cohen's d = 1.48; Table 3). Moreover, the proportion of participants with an overall fatigue score ≥12 (significant fatigue that interferes with daily life) decreased from 60.0% before to 36.0% after the intervention.

Changes in Motivation

AES scores significantly decreased after the intervention, suggesting an improvement in motivation (p = .03; Cohen's d = 0.45; Table 3). The proportion of participants with reduced motivation exceeding the cutoff (i.e., ≥16 points) decreased from 44.0% before to 28.0% after the intervention.

Changes in Knowledge about PSF

The correct answer rate on the PSF knowledge assessment questionnaire significantly increased after the intervention, suggesting an increase in knowledge (p = .00; r = 0.86; Table 3).

Self-monitoring Skills

The mean record-keeping rate (number of days of record-keeping/9 days × 100%) was 70.7%±24.3% (range: 33.3%-100%). The reasons for not keeping records were as follows: sense of fatigue, higher brain dysfunction (aphasia, attention disorder), ataxia, motor dysfunction due to previous external injury, and tediousness.

Problem-solving Skills

In the first week of the program, each of the nine plan contents was selected in 14.8%-56.0% of the plans (Table 4). For the second week of the program, each of the nine plan contents was selected in a mean of 15.5%-56.0% of the plans. The mean self-evaluation score for plan execution was 4.1±0.6 (range: 2.3-5.0) (Figure 2). The mean self-evaluation scores for goal achievement were 3.8±1.1 (range: 2.0-5.0) for the first week of the program and 4.5±0.7 (range: 3.0-5.0) for the second week, with scores for the second week being significantly higher than those for the first (p = .01; Figure 3).

Table 2. Participant characteristics.

Characteristics				
Sex	Male	*n* (%)	20	80.0
	Female	*n* (%)	5	20.0
Age	40s	*n* (%)	2	8.0
	50s	*n* (%)	2	8.0
	60s	*n* (%)	8	32.0
	70s	*n* (%)	8	32.0
	80s	*n* (%)	5	20.0
		M ± *SD* (min–max)	70.2 ± 10.8 (44–86)	
Employment status	Unemployed	*n* (%)	14	56.0
	Employed	*n* (%)	11	44.0
Number of days since stroke (days)		*M* ± *SD* (min–max)	17.0 ± 20.3 (7–84)	
Type of stroke	Cerebral infarction	*n* (%)	18	72.0
	Cerebral hemorrhage	*n* (%)	7	28.0
Site of stroke	Right	*n* (%)	14	56.0
	Left	*n* (%)	11	44.0
[1]mRS	0: no symptoms at all	*n* (%)	0	0.0
	1: no significant disability despite symptoms	*n* (%)	7	28.0
	2: slight disability	*n* (%)	9	36.0
	3: moderate disability	*n* (%)	9	36.0
NIHSS		*M* ± *SD* (min–max)	2.6 ± 1.9 (0–8)	
Functional disorder	Visual impairment	*n* (%)	0	0.0
	Facial paralysis	*n* (%)	2	8.0
	Upper limb motor disorder	*n* (%)	9	36.0
	Lower limb motor disorder	*n* (%)	13	52.0
	Ataxia	*n* (%)	2	8.0
	Sensory impairment	*n* (%)	5	20.0
	Language disorder	*n* (%)	4	16.0
	Dysarthria	*n* (%)	12	48.0
	Extinction/attention disorder	*n* (%)	8	32.0
Complications	Hypertension	*n* (%)	21	84.0
	Diabetes	*n* (%)	3	12.0
	Dyslipidemia	*n* (%)	6	24.0
	Atrial fibrillation	*n* (%)	2	8.0
	Cardiovascular disease (chronic heart failure/ myocardial infarction)	*n* (%)	4	16.0
	Neurological disease	*n* (%)	0	0.0
	Respiratory disease	*n* (%)	0	0.0
	Kidney disease (chronic kidney disease/ end-stage kidney disease)	*n* (%)	4	16.0
	Locomotor disease	*n* (%)	0	0.0
	Sensory organ disease (hearing loss/cataracts)	*n* (%)	4	16.0
	Liver disease (chronic hepatitis)	*n* (%)	1	4.0
	Cancer	*n* (%)	1	4.0
	Sleep apnea syndrome	*n* (%)	2	8.0
Sleep disorder (use of sleep medication)	No	*n* (%)	20	80.0
	Yes	*n* (%)	5	20.0
Duration of rehabilitation (min/day)		*M* ± *SD* (min–max)	138.0 ± 42.4 (60–240)	
Vulnerability to stress Do you feel susceptible to stress	1: strongly disagree	*n* (%)	2	8.0
	2: disagree	*n* (%)	12	48.0
	3: neither agree nor disagree	*n* (%)	1	4.0
	4: agree	*n* (%)	8	32.0
	5: strongly agree	*n* (%)	2	8.0
Instrumental support - presence/absence of someone to support activities of daily living and role activities	Absent	*n* (%)	6	24.0
	Present	*n* (%)	19	76.0
Emotional support - presence/absence of someone who understands one's feelings or someone who one can feel at peace with	Absent	*n* (%)	4	16.0
	Present	*n* (%)	21	84.0

Note: NIHSS = National Institutes of Health Stroke Scale. Score range: 0–42 points. The higher the score, the higher the neurological severity.

mRS = modified Rankin Scale. 0: no symptoms at all, 1: no significant disability despite symptoms, 2: slight disability, 3: moderate disability, 4: moderate-severe disability, 5: severe disability, 6: dead

Table 3. Changes in MFI, AES, and correct answer rate on knowledge assessment questionnaire before and after intervention.

	Before intervention		After intervention		*p*	ES Cohen's *d*
	M	*SD*	*M*	*SD*		
MFI total	64.0	11.4	48.4	13.0	.00	1.48
overall fatigue	12.5	3.3	9.2	3.2	.00	0.85
physical fatigue	15.1	3.5	11.1	3.3	.00	1.12
reduced activity	13.1	3.2	9.9	2.7	.00	1.13
reduced motivation	10.4	3.0	8.4	3.5	.00	0.68
mental fatigue	13.0	3.5	9.9	2.9	.00	0.78
AES	14.0	6.7	11.2	6.1	.03	0.45
Knowledge assessment questionnaire correct answer rate (%) *	29.6	26.2	92.8	7.9	.00	0.86

n = 25

Paired t-test

* Wilcoxon's signed-rank test, effect size r

Note: MFI = Multidimensional Fatigue Inventory. Score range: 20–100 points. Score range for each factor: 4–20 points. The higher the score, the more severe the fatigue. Cut-off for overall fatigue: 12 points.

AES = Apathy Evaluation Scale. Score range: 0–42 points. The higher the score, the lower the motivation. Cut-off: 16 points.

Table 4. Plan selection rate for poststroke fatigue.

Plan for poststroke fatigue		Mean selection rate (%)	
Content	Total items	First week of program	Second week of program
① securing strategic rest	17	16.2	21.4
② adequate physical activity	9	29.8	36.0
③ adequate mental activity	16	14.8	15.5
④ appropriate nutrient intake	3	44.0	49.3
⑤ flexible schedule adjustment	5	25.6	36.0
⑥ suppress energy consumption	9	19.1	18.7
⑦ adjust living environment	5	56.0	56.0
⑧ gain understanding of others	7	21.1	21.1
⑨ gain support from medical professionals	6	32.7	36.0

n = 25

Factors Influencing Outcomes

The following significant results were obtained in the analysis of changes in MFI and AES scores according to participant characteristics (Table 5). Changes in MFI scores were significantly larger for participants who were unemployed than for those who were employed (p = .03). Changes in MFI scores were significantly larger for participants without than for those with lower limb motor disorders (p = .03), and changes in AES scores were significantly larger in participants without than in those with dysarthria (p = .02). Furthermore, changes in MFI scores were significantly larger in participants without than in those with sleep disorder (p = .03). Significant differences in MFI subscale scores were also observed for several participant characteristics (Table 5).

The following significant correlations were observed between changes in MFI and AES scores according to participant characteristics (Table 6). Changes in rehabilitation duration and reduced motivation showed a moderate positive correlation (r = .40, p = .049); the longer the rehabilitation duration, the smaller the change in reduced motivation. Moreover, vulnerability to stress and changes in reduced motivation were moderately positively correlated (r = .42, p = .04); the higher the vulnerability to stress, the smaller the change in reduced motivation.

Discussion

Effectiveness of the Program

The effectiveness of the program was demonstrated in the present study based on the observed improvements in fatigue and motivation, as well as increased knowledge about PSF, after the intervention. We are currently in the feasibil-

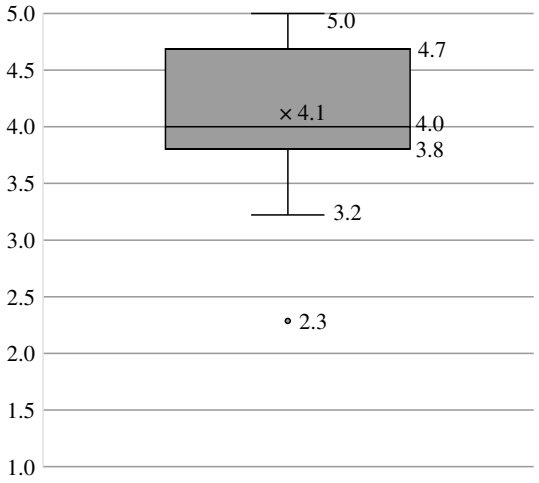
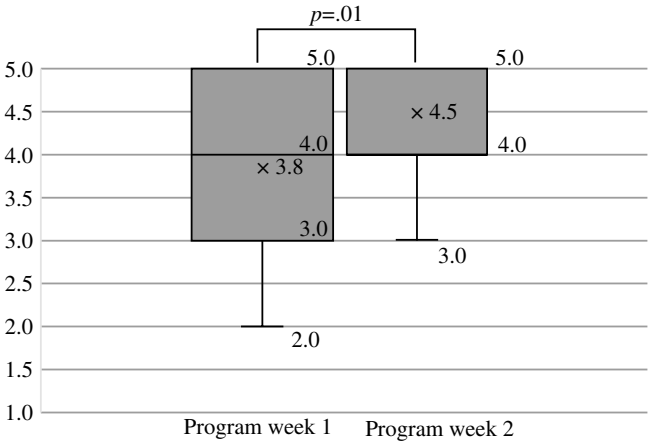


Figure 2. The execution status of plans for post-stroke fatigue.
The self-evaluation of plan execution was based on a 5-point scale and conducted over 9 days.



Wilcoxon's signed-rank test

Figure 3. Self-evaluation of goal achievement.
Whether poststroke fatigue improved was determined through self-evaluation on a 5-point scale on the last day of weeks 1 and 2.

ity testing phase; however, given the lack of a control group, we cannot rule out the possibility that PSF can be improved naturally. However, based on the results of a meta-analysis on the rate of PSF in patients with stroke, regardless of the duration of the stroke, 50% (Cumming et al., 2016) or 47% (Zhan et al., 2023) of patients have been reported to experience PSF. The reduction in the PSF rate to 36.0% in the present study suggests that, in addition to natural recovery, the program also contributed to improving PSF to some extent.

Regarding motivation, a meta-analysis found that in the acute stroke stage, the apathy rate was 36.3%, with no changes in relation to the time that has elapsed since the stroke (Caeiro et al., 2013). Thus, it is likely that motivation did not recover naturally and that the observed improvements were due to the program.

Regarding the increase in knowledge about PSF, standard care does not include self-management interventions for PSF. Instead, patients generally acquire experience over the course of their long recuperation period and develop coping methods over time based on trial and error (Eriksson et al., 2022). This also supports the view that, rather than acquiring knowledge naturally over a short period, the program in this study contributed to increasing the participants' knowledge about PSF.

Various factors are involved in the onset of PSF, including stroke, personality traits, and physical, mental, behavioral, social, and environmental factors. Improvements in fatigue cannot be achieved by managing only one of these factors. Instead, comprehensive management of multiple factors is required. In the proposed program, factors related to PSF can be managed comprehensively by selecting an executable plan from among nine plan contents. Our findings suggest that each of the nine plan contents was selected in a mean of ≥15% of the plans and that the plans were executed and self-evaluated as having led to the achievement of the goal, i.e., improved fatigue. Thus, self-management skills for PSF were acquired, and self-management was successfully implemented via the program. The ability to perform self-management can also be considered one of the program's effects.

Mechanisms Underlying Program Effects

By participating in the program, patients acquired knowledge, self-monitoring, and problem-solving skills. Improvements in fatigue and motivation were also noted after compared with before the intervention. These results support the program theory discussed above. By participating in the program, patients performed self-management for PSF (i.e., taking measures against fatigue, and this likely led to improvements in fatigue. With respect to participant characteristics, unemployed, right-sided lesions, no lower limb motor disorder, no dysarthria, no dyslipidemia, no sleep disorder, short rehabilitation period, and low vulnerability to stress reflected an improved state of fatigue, suggesting that avoiding physical and mental burdens may be effective for improving fatigue.

Program Challenges

The following challenges remain. First, of the 30 initial participants, four dropped out after being discharged. As hospitalization durations decrease, securing patients in a general ward for 2 weeks, 1 week after stroke onset, is expected to become increasingly challenging. To avoid severe outcomes due to chronic fatigue, our program is needed before transitioning to home care during the early stages after stroke.

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Table 5. Factors which influence the outcome: differences in change in MFI and AES by participant characteristics.

		n	Change in MFI total			Change in overall fatigue			Change in physical fatigue			Change in reduced activity			Change in reduced motivation			Change in mental fatigue			Change in AES		
			Change	*SD*	*p*	Change	*SD*	*p*	Change	*SD*	*p*	Change	*SD*	*p*	Change	*SD*	*p*	Change	*SD*	*p*	Change	*SD*	*p*
Sex	Male	20	-15.6	11.4	.97	-3.5	4.2	.67	-4.5	3.6	.17	-3.4	2.6	.71	-1.5	2.9	.06	-2.9	4.1	.66	-2.6	6.1	.62
	Female	5	-15.4	6.3		-2.6	2.1		-2.0	2.6		-2.8	4.1		-4.2	2.2		-3.8	3.3		-4.2	8.1	
Employment status	Unemployed	14	-19.5	10.4	.03 *	-4.1	3.1	.25	-4.4	3.6	.54	-4.4	2.8	.02 *	-2.0	2.8	1.00	-4.6	3.1	.02 *	-3.7	4.4	.47
	Employed	11	-10.6	8.7		-2.3	4.5		-3.5	3.6		-1.7	2.2		-2.0	3.3		-1.1	4.2		-1.8	8.4	
Type of stroke	Cerebral infarction	18	-15.4	10.5	.93	-3.0	3.9	.57	-3.6	3.7	.37	-3.2	2.9	.84	-2.6	2.5	.10	-3.1	3.5	.95	-4.0	5.2	.16
	Cerebral hemorrhage	7	-15.9	11.4		-4.0	3.9		-5.0	3.1		-3.4	2.9		-0.4	3.7		-3.0	5.2		0.0	8.6	
Site of stroke	Right	14	-18.4	10.1	.14	-3.8	3.9	.47	-4.4	4.2	.54	-3.7	2.4	.36	-3.1	3.3	.03 *	-3.4	4.1	.70	-2.9	7.4	.97
	Left	11	-12.0	10.4		-2.6	3.9		-3.5	2.7		-2.6	3.4		-0.6	1.7		-2.7	3.9		-2.8	5.1	
Facial paralysis	No	23	-15.2	10.9	.54	-3.2	3.9	.79	-4.3	3.4	.10	-2.9	2.7	.05	-2.0	2.8	1.00	-2.7	3.9	.15	-3.0	6.6	.76
	Yes	2	-20.0	1.4		-4.0	4.2		0.0	2.8		-7.0	1.4		-2.0	5.7		-7.0	1.4		-1.5	5.0	
Upper limb motor disorder	No	16	-15.6	12.0	.97	-3.1	3.4	.80	-4.4	3.6	.45	-2.8	3.2	.33	-2.2	2.6	.68	-3.1	3.3	.94	-2.6	4.9	.75
	Yes	9	-15.4	7.7		-3.6	4.8		-3.2	3.5		-4.0	2.2		-1.7	3.6		-3.0	5.1		-3.4	8.7	
Lower limb motor disorder	No	12	-20.3	10.5	.03 *	-4.3	3.5	.23	-5.2	4.3	.10	-3.8	3.5	.41	-3.3	2.3	.04 *	-3.9	4.4	.32	-1.0	6.6	.16
	Yes	13	-11.2	8.7		-2.4	4.1		-2.9	2.3		-2.8	2.2		-0.9	3.1		-2.3	3.5		-4.6	5.9	
Ataxia	No	23	-15.3	10.5	.69	-3.2	3.9	.79	-3.7	3.4	.21	-3.3	3.0	.71	-1.8	3.0	.33	-3.3	4.1	.45	-2.7	6.1	.56
	Yes	2	-18.5	13.4		-4.0	4.2		-7.0	5.7		-2.5	0.7		-4.0	1.4		-1.0	1.4		-5.5	12.0	
Sensory impairment	No	20	-16.1	11.0	.62	-3.6	3.8	.42	-4.2	3.5	.51	-3.3	3.0	.84	-2.5	2.7	.09	-2.5	3.8	.15	-3.0	6.2	.92
	Yes	5	-13.4	8.7		-2.0	4.4		-3.0	4.1		-3.0	2.3		0.0	3.2		-5.4	3.8		-2.6	7.7	
Language disorder	No	21	-14.5	9.8	.27	-3.0	3.8	.42	-3.6	3.6	.28	-3.1	2.9	.71	-2.0	3.1	1.00	-2.8	3.9	.37	-2.7	6.6	.71
	Yes	4	-21.0	14.0		-4.8	4.6		-5.8	3.0		-3.8	3.3		-2.0	2.7		-4.8	4.5		-4.0	5.8	
Dysarthria	No	13	-16.0	10.1	.83	-3.2	4.0	.95	-3.5	3.5	.55	-2.7	2.9	.33	-3.2	2.3	.04 *	-3.4	2.8	.70	-5.6	5.8	.02 *
	Yes	12	-15.1	11.3		-3.3	3.8		-4.4	3.7		-3.8	2.9		-0.8	3.2		-2.8	5.0		0.1	5.8	
Extinction/attention disorder	No	17	-14.7	9.9	.54	-3.1	3.2	.77	-3.8	3.4	.79	-3.4	3.2	.67	-1.4	2.8	.11	-2.9	3.4	.80	-2.5	5.8	.65
	Yes	8	-17.5	12.2		-3.6	5.2		-4.3	4.0		-2.9	2.0		-3.4	3.0		-3.4	5.2		-3.8	7.8	
Complications* (dyslipidemia)	No	19	-17.7	10.8	.07	-3.9	3.6	.16	-4.4	3.8	.26	-4.0	2.6	.03 *	-2.3	3.2	.35	-3.1	3.9	.96	-2.8	6.3	.96
	Yes	6	-8.8	6.4		-1.3	4.3		-2.5	2.4		-1.0	2.6		-1.0	2.0		-3.0	4.3		-3.0	7.1	
Sleep disorder (use of sleep medication)	No	20	-17.9	9.8	.03 *	-3.6	4.1	.49	-4.3	3.8	.42	-3.7	2.9	.16	-2.7	2.5	.01 *	-3.7	4.2	.12	-3.9	6.5	.13
	Yes	5	-6.4	8.4		-2.2	2.6		-2.8	1.9		-1.6	2.2		0.8	3.3		-0.6	1.1		1.0	4.7	
Instrumental support	Absent	6	-15.0	10.6	.89	-2.5	5.0	.58	-3.0	4.1	.46	-3.0	2.2	.82	-2.3	3.1	.76	-4.2	5.0	.45	-6.3	3.9	.13
	Present	19	-15.7	10.7		-3.5	3.5		-4.3	3.4		-3.3	3.1		-1.9	3.0		-2.7	3.7		-1.8	6.7	
Emotional support	Absent	4	-13.0	13.1	.61	-1.3	5.7	.26	-3.8	5.1	.90	-2.5	2.1	.59	-2.3	1.5	.86	-3.3	6.1	.93	-6.0	4.8	.30
	Present	21	-16.1	10.2		-3.7	3.5		-4.0	3.3		-3.4	3.0		-2.0	3.2		-3.1	3.6		-2.3	6.6	

Note: *For the presence/absence of complications other than dyslipidemia, there were no significant differences for MFI and AES.

MFI = Multidimensional Fatigue Inventory. Score range: 20–100 points. Score range for each factor: 4–20 points. The higher the score, the more severe the fatigue. Cut-off for overall fatigue: 12 points.

AES = Apathy Evaluation Scale. Score range: 0–42 points. The higher the score, the lower the motivation. Cut-off: 16 points

Table 6. Factors which influence the outcome: correlations between change in MFI/AES and participant characteristics.

		Age	Number of days since stroke	mRS	NIHSS	Duration of rehabilitation	Vulnerability to stress	Change in MFI total	Change in overall fatigue	Change in physical fatigue	Change in reduced activity	Change in reduced motivation	Change in mental fatigue	Change in AES
Age	γ		0.03	0.01	-0.19	-0.14	-0.17	-0.26	-0.02	-0.05	-0.33	-0.11	-0.31	-0.35
	p		0.90	0.97	0.38	0.51	0.43	0.20	0.92	0.82	0.11	0.62	0.13	0.09
Number of days since stroke	γ			-0.26	-0.13	0.37	-0.33	0.14	0.06	0.10	0.18	-0.09	0.18	-0.02
	p			0.21	0.53	0.07	0.11	0.50	0.79	0.64	0.39	0.66	0.40	0.92
mRS	γ				0.63 **	-0.30	0.44 *	0.23	0.22	0.16	0.13	0.26	-0.05	0.04
	p				0.00	0.15	0.03	0.28	0.29	0.45	0.53	0.21	0.81	0.86
NIHSS	γ					0.02	0.45 *	0.17	0.24	0.25	-0.07	0.31	-0.18	-0.07
	p					0.92	0.02	0.41	0.25	0.23	0.75	0.14	0.39	0.73
Duration of rehabilitation	γ						0.13	0.24	0.12	0.13	0.16	0.40 *	-0.02	0.04
	p						0.53	0.25	0.56	0.54	0.45	0.05	0.92	0.84
Vulnerability to stress	γ							0.19	0.09	0.25	-0.01	0.42 *	-0.12	0.18
	p							0.37	0.68	0.22	0.96	0.04	0.58	0.40
Change in MFI total	γ								0.73 **	0.68 **	0.65 **	0.47 *	0.51 **	0.10
	p								0.00	0.00	0.00	0.02	0.01	0.65
Change in overall fatigue	γ									0.71 **	0.40 *	0.08	-0.03	-0.25
	p									0.00	0.05	0.70	0.90	0.24
Change in physical fatigue	γ										0.26	0.03	0.02	-0.24
	p										0.20	0.90	0.94	0.26
Change in reduced activity	γ											0.17	0.24	0.16
	p											0.41	0.25	0.44
Change in reduced motivation	γ												0.26	0.36
	p												0.20	0.08
Change in mental fatigue	γ													0.32
	p													0.12
Change in AES	γ													
	p													

*$p<.05$ **$p<.01$

Note: MFI = Multidimensional Fatigue Inventory. Score range: 20–100 points. Score range for each factor: 4–20 points. The higher the score, the more severe the fatigue. Cut-off for overall fatigue: 12 points.

AES = Apathy Evaluation Scale. Score range: 0–42 points. The higher the score, the lower the motivation. Cut-off: 16 points.

NIHSS = National Institutes of Health Stroke Scale. Score range: 0–42 points. The higher the score, the higher the neurological severity.

mRS = modified Rankin Scale. 0: no symptoms at all, 1: no disability despite symptoms, 2: slight disability, 3: moderate disability, 4: moderate-severe disability

While the current setting and timing of the program are appropriate, the program length should be shortened based on each patient's hospitalization period.

Future Directions

Given that patients exhibited improved fatigue, motivation, and knowledge about PSF in a pre- and post-intervention comparison of the present self-management program, we hope to improve upon the program's remaining issues, advance the research, and assess the effects of the program through a randomized controlled trial with an adequate sample size.

Limitations

This study has several limitations. First, because of the lack of randomization and blinding, the possibility of sampling bias, information bias, or confounding bias cannot be ruled out. Second, because this study did not include a control group, we cannot deny the possibility that fatigue improved naturally. Third, because no method to observe PSF self-management skills has not been established, we used an independently developed scale to assess PSF knowledge.

Conclusions

In the present study, participants with stroke in a self-management program for PSF exhibited a significant decrease in MFI scores (early fatigue) (p = .00; Cohen's d = 1.48). The proportion of patients with significant fatigue who exceeded the MFI cutoff decreased from 60.0% before the intervention to 36.0% afterward. AES scores also significantly decreased following the intervention (p = .03; Cohen's d = 0.45), indicating an improvement in motivation. The proportion of patients with reduced motivation who exceeded the AES cutoff decreased from 44.0% before the intervention to 28.0% afterward. Furthermore, the correct answer rate on the knowledge assessment questionnaire significantly increased after the intervention (p = .00).

The mean record-keeping rate using a self-monitoring notebook was 70.7%. Each of the nine plan contents ((a) securing strategic rest, (b) adequate physical activity, (c) adequate mental activity, (d) appropriate nutrient intake, (e) flexible schedule adjustment, (f) suppress energy consumption, (g) adjust living environment, (h) gain understanding of others, and (i) gain support from medical professionals) to address PSF was selected in a mean of ≥15% of plans. On average, participants self-evaluated the execution of their selected plans as "executed plan somewhat (execution rate: 75%)," and assessed their achievement of the goal of improving PSF in the second week of the program as "achieved goals somewhat (achievement rate: 75%)."

Although we cannot deny the possibility that PSF recovered naturally, a comparison with a previous study that assessed the rate of patients who had PSF suggested that our program had a noticeable effect. Moreover, it is unlikely that the participants' motivation and knowledge improved and were acquired naturally; these were considered to be the result of participating in the program. We speculate that PSF can be improved through self-management and by avoiding physical and mental overload.

Given the program's demonstrated effectiveness, we plan to make improvements, advance the research, secure an appropriate sample size, and further assess the effects in future studies.

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Author Contributions

M.S. carried out the entire research process. T.H. provided suggestions for drafting the manuscript and conducting the research. All authors have read and approved the final manuscript.

Declaration of Conflicting Interests

The authors declare no conflicts of interest associated with this manuscript.

Ethical Approval

This study was approved by the ethics review committee of the Japanese Red Cross Hiroshima College of Nursing (approval No.: D-2201). This study was registered with the University Hospital Medical Information Network Clinical Trials Registry (UMIN000048681).

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Original Research

Continuous clinical assessment: An interpretive description of the experience of mentors and students' preregistration nursing education

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Abstract

Background: In many countries around the world, professional nursing training is provided after completing higher education. In Hong Kong, the syllabus of the accredited program for registered nurses must consist of theory and clinical practice components. While written assessment is used in the theoretical component, continuous clinical assessment (CCA) is deployed in clinical practice to assess the competence of students. Although nurse educators confirm CCA's importance, feedback on clinical assessment process is not uncommon. **Study Aim, Objectives, and Significance:** This study aimed to gain insights from the current practice and complexities inherent in CCA implementation to recommend practice implications and future research directions. The key study objectives are as follows: 1) to describe the outcomes of CCA implementation perceived by students and mentors; 2) to identify commonalities and differences between the concepts and actual practice of CCA for the factors that affect CCA implementation; and 3) to generate the themes that fill the gap existing in the body of literature about success in CCA practice and development for preregistration nursing education. **Methods:** The interpretive descriptive methodology (Thorne, 2016) was adopted to explore in depth the CCA experiences of the mentors and students. Data were transcribed and analyzed through the constant comparative analysis approach based on primary understanding of the text, analysis of the descriptive reflection, and interpretive reflection to unravel participants' CCA experiences. **Results:** Three final themes emerged: 1) *"Relation" without Relationship*, 2) *Stand behind the Yellow Line*, and 3) *The Sound of Silence*. These themes are important structural components in identifying the main theme, *Shades of Gray*, which contextualize and personify the subtleties of the CCA experiences of nursing students and mentors in preregistration nursing education. **Conclusions:** The study findings reveal the phenomenon of mentor practice diversity in CCA. The key to improving CCA is striking a balance in practice decision-making while upholding nurses' competence to ensure patient safety. Effective mentorship seems to provide guidance for achieving such a balance. The importance of developing complete and practical guidance for CCA implementation in preregistration nursing education is also suggested.

Keywords

continuous clinical assessment, interpretive description, pre-registration nursing education, nursing students, mentors

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Introduction

In many countries, the professional registration of nurses is overseen by authorized bodies after the nurses have undergone formal education and assessment. In Hong Kong, the Nursing Council of Hong Kong (NCHK) is the statutory body that oversees the registration, enrolment, training, and licensing examinations related to nursing qualifications (NCHK, 2024). Educational institutions accredited by NCHK provide nursing education programs that cover the theoretical and clinical practice components that nursing students must learn to acquire a general registered nursing license.

Clinical practice plays a crucial role in nursing education because it allows students to apply their theoretical knowledge and skills acquired in the classroom to real-world clinical scenarios. The practical aspect of preregistration nursing training accounts for a significant portion of the overall training duration, encompassing almost half of the time required for students (Saarikoski, 2017). The NCHK requires clinical education as an essential component of nursing training. In Hong Kong, clinical education comprises 50% of the total preregistration nursing education. Therefore, assessment of clinical practice competence is central to undergraduate preregistration nursing programs as a means of determining student achievement and eligibility for professional registration (Vae et al., 2018). Among the various assessment methods in preregistration nursing education, both internationally and in Hong Kong, continuous clinical assessment (CCA) is used as a framework for teaching, learning, and assessment. CCA uses both formative and summative teaching and learning approaches to help nursing students develop essential clinical skills; however, CCA has shifted to focus more on mentors' feedback to students during the clinical practicum (Chiang, 2015). Although there is a general consensus that effective mentoring and robust continuous assessment are needed in CCA practice, studies have found that the specific strategies deployed to achieve these results are limited (Lee & Chiang, 2021). Clinical education in nursing often focuses on mentors and mentorship from the perspective of a supervising relationship that allows students to learn (Lee & Chiang, 2021). Only a few studies have investigated issues arising from the fundamental need for practice supervision and assessment, particularly regarding the experiences of nursing students and mentors involved in CCA.

Background

Competent nursing graduates are fundamental to patient safety; ensuring that nursing graduates have the skills and knowledge to seamlessly transition to their roles as registered nurses is the top priority in nursing education (Usher et al., 2017). Teaching and learning in nursing education must consist of two major components, i.e., theories and clinical practice. Clinical practice, or clinical education, is the process of teaching and learning for nursing students in authentic clinical settings, which aims to help students acquire the competencies needed for safe and effective care delivery to patients (Oermann & Shellenbarger, 2020). Similar to the European Union (European Council, 2013), the NCHK mandates clinical education as a component of nursing training. In Hong Kong, clinical education comprises half of the total preregistration nursing education curriculum. Therefore, assessment of clinical practice competence is central to preregistration nursing programs as a means of determining student achievement and eligibility for professional registration (Cant, McKenna, & Cooper, 2013; O'Driscoll, Allan, & Smith, 2010). Different competence assessments are also used in different countries to comply with the assessment requirements and syllabus mandated by their corresponding nursing authorities, such as the Competency Inventory of Nursing Students (Hsu & Hsieh, 2013) and the Nurse Professional Competence Scale (Nilsson et al, 2014). Among the various assessment methods in preregistration nursing education, both internationally and in Hong Kong, CCA is widely used to deal with common problems arising from teaching, learning, and assessment in clinical practice, such as being over-pragmatic and results-orientated toward summative assessment, rather than formative teaching and learning of the students (Harlen & Deakin-Crick, 2002). In other words, CCA balances the efficacy of a formative and summative teaching and learning approach for nursing students to develop essential clinical skills with a shifted focus on unequivocal teacher feedback to students during their clinical practicum (Chiang, 2015). CCA raises many concerns about the consistency of assessment decisions and the appropriate use of program assessment tools and predetermined competences (Fitzgeraid, Gibson, & Gunn, 2010; Zasadny & Bull, 2015). Subjectivity and variability among assessors are often mentioned as adverse factors in CCA implementation (McMullan et al., 2003; Hanley & Higgins, 2005). The phenomenon of "failed to fail a failed student" where a mentor is reluctant to judge a student as unsatisfactory, is commonly identified (Brown, Douglas, Garrity, & Shepherd, 2012; Duffy, McCallum, & McGuinness, 2016). As a result, the wide interpretations and lack of consensus on the term "competence" in clinical nursing practice make clinical practice assessment a mainly subjective process (Butler et al., 2011; Fahy, Tuohy, McNamara, Butler, Cassidy, & Bradshaw, 2011). Although there is a general consensus that effective mentoring and robust continuous assessment are needed in CCA practice, studies have found that the specific strategies deployed to achieve these results are limited (Lee & Chiang, 2021). In addition, the literature has revealed that the current under-

standing of CCA implementation in preregistration nursing education is underdeveloped (Lee & Chiang, 2021). Given CCA's fundamental importance in nursing clinical education among international communities, examining current CCA practices in preregistration nursing education may generate implications and suggestions to narrow the gap between rhetoric and the reality of its implementation.

Methods

Study Objectives and Design

The current understanding of CCA implementation in preregistration nursing education is limited (Lee & Chiang, 2021). This study aimed to gain insights into the current practices and complexities inherent in CCA through detailed and in-depth conceptual descriptions of the experiences of mentors and students going through the CCA process. The study objectives were 1) to describe the CCA implementation outcomes perceived by students and mentors, 2) to identify commonalities and differences between the concepts and actual practice of CCA, and 3) to generate themes that fill the literature gap pertaining to the efficacy of CCA practice and development. Given these aims, this study used a qualitative approach that solicits and explains subjective human experiences of particular situations or phenomena (Grbich, 2013); this approach is often adopted to explain human experiences (Guest, Namey & Mitchell, 2013). Among the qualitative methodologies, interpretive description (Thorne, 2016) was considered the most appropriate for this study as its interpretivistic underpinning could be used to explore the participants' experiences of their naturalistic environment. In this study, an interpretive description was used to understand the mentors' and nursing students' experiences of CCA by applying description and interpretation.

Setting

This study was conducted in the naturalistic context of a school of general nursing in a public hospital in Hong Kong, where the researcher had established a thorough understanding of the Higher Diploma in Nursing preregistration education program over 7 years as a teacher. The baccalaureate nursing program at a university in Hong Kong was selected as another setting for the study. School mentors and final-year nursing students who have substantially undergone long consolidation clinical placement (i.e., 3 months of continuous clinical practice) and completed the CCA of their program during this placement period are the target participants of the study.

Sampling Strategy and Participants

For this study to be credible, convenience sampling, purposive sampling, and theoretical sampling were employed to ensure that the selected participants were representative and the desired rich research data could be generated (Thorne, 2016). The inclusion criteria for the participants were as follows:

1. Mentors who had worked as qualified registered nurses for at least 3 years, taught in a nursing program, and had implemented CCA for at least 6 months;
2. Students in the final year of the nursing program and had completed at least 80% of the required clinical practice hours for qualification as a registered nurse;
3. Mentors and students who can provide information-rich experiences on CCA implementation during clinical placement.

This study had no predetermined participant numbers. Interviews were conducted until no new themes were generated during the iterative process between data collection and analysis. Recruitment ended when the participants repeated the themes and a sound framework of the themes was verified. Thematic saturation was achieved in 22 participants. All 11 mentors included in the study were women and ranged in age from 25 to 54 years old. Six male and six female students were recruited, all between the ages of 21 and 24. Once all interviews were completed, each participant was assigned a pseudonym to de-identify the participant.

Ethical Approval and Data Collection

Ethical approval was obtained from the Ethical Review Committee of one university in Hong Kong (Ref. No.: HSEARS20171101005) and from the Clinical and Research Ethics Committee of the Hospital Authority (Ref. No: NTWC/CREC/17108). Participation in the study was voluntary after a full explanation of the study was provided. Informed consent was obtained from all eligible participants. The data were collected through in-depth individual interviews and were concurrently analyzed during the data collection process. The data were analyzed using constant comparative analysis, with each analysis iteratively informing the subsequent data collection (Fram, 2013; Glaser & Strauss, 1967). Figure 1 describes the data collection process.

Data Analysis and Trustworthiness

This study was guided by an interpretive description methodology and consisted of "constant comparison, iterative analysis, and reciprocal approaches to data making and analysis" (Hunt, 2009, p. 1288). The data analysis process was based on the method outlined by Thorne (2008) in which researchers apply inductive analytical approaches that allow structure and meaning to be given to data so that new understandings and insights can be developed (Thorne et al., 2004). Figure 2 describes the cyclic process of the constant comparative analysis. Upon completion of the data analysis, the relevance and appropriateness of the themes generated were verified in member checking by the participants who

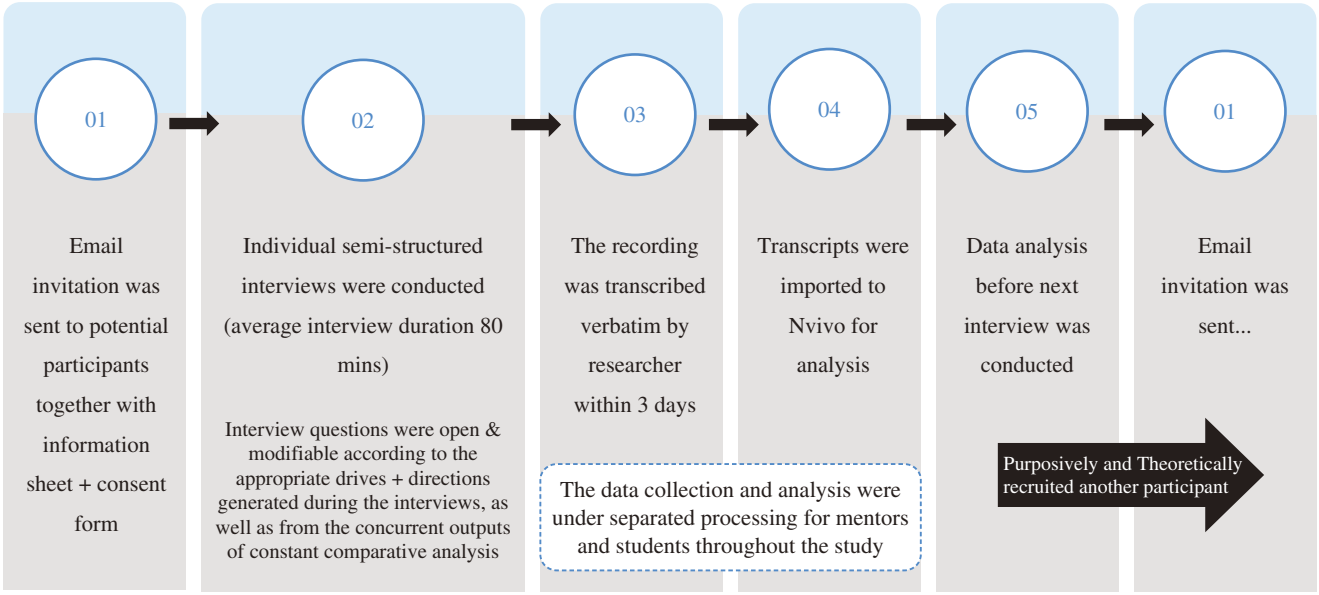

Figure 1. Data collection process.

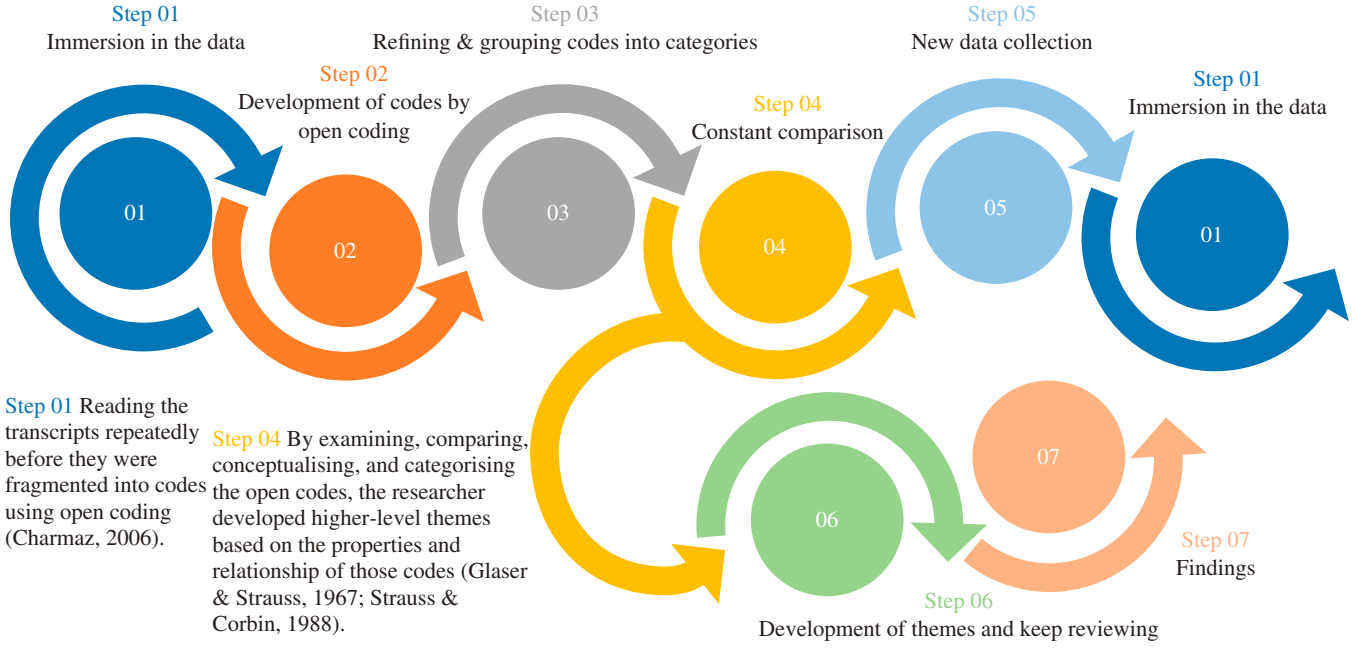

Figure 2. Cyclic process of constant comparative analysis.

provided positive comments and affirmed the results.

Several strategies were used to promote the study's rigor, as outlined by Thorne (2016), namely, epistemological integrity, representative credibility, and interpretive authority. For the meaning to be constructed effectively in terms of epistemological integrity, the researcher actively made herself aware of her own experience and preconceptions by reflective journaling (Thorne, 2008), which was maintained from the conception of the study until the end of this study. Representative credibility was achieved by ensuring that the selected participants were representative of those intended in the study design (Thorne, 2008); this was achieved through careful consideration of participant recruitment via purposive sampling. In addition, the same interview process was maintained for each interview throughout the data collection process to enhance the analytic consistency and improve the study's credibility. In terms of interpretive authority, the researcher recognized her own experiences and preconceptions by writing in her journal for reflection and references. All interview questions were presented as open, non-specific, and non-leading questions. Clarifying questions were developed from the transcripts of previous participants rather than

from the curiosity of the researcher to minimize bias. In addition, the guidelines for conducting qualitative studies established by the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) were adopted.

Results

The themes that captured the essence of the CCA experience in terms of the mentoring relationship, assessment practice, and feedback emerged through thematic process in the data analysis: 1) *"Relation" without Relationship*, 2) *Stand behind the Yellow Line*, and 3) *The Sound of Silence*. The interpretive understanding of the ideas in these themes yielded the building blocks that enabled the researcher to identify the main theme, *Shades of Gray*; this main theme contained contextualized and personified subtleties of CCA mentor and student experiences in preregistration nursing education.

Relation without Relationship

Relation often refers to the formal context of the ways in which matters or people are connected, whereas relationship refers to the informal context of the connection itself (Cambridge Dictionary, 2024). In the literature, assessment refers to the reporting of students' achievement through grading while supporting students' learning, and it cannot be isolated from learning (Gibbs, 2019). Thus, the elements that constitute CCA practice are the formative function of learning and the summative function of competence assessment. The roles of mentors, assessors, and clinical teachers are also central to CCA practice. Accordingly, two types of relationships affecting CCA implementation were identified: (1) the functional relationship between mentors and students in formative learning and summative assessment, and b) the mentoring relationship; these relationships were interrelated and interactive. There was constraint and ambiguity in the relationships, and the absence of a relationship in some cases created diversity in CCA practice.

Mentors often expressed that they encountered difficulties in the functional relationship in terms of continuation in teaching (formative) and assessment (summative) in CCA; for example, because their workload was too large or having an unmatched roster, leaving no time for the students. This also affected the mentoring relationship in the CCA. Mentor Flora stated,

> *... it's really difficult to do continuous assessment. First, it might be the working in a busy ward. There is a high chance that you may be unable to match your roster with the same student. When the roster is not matched, in fact, there is a small chance of achieving CCA.*

Apart from the constraints on the establishment of functional relationships, which resulted in improper assessment in CCA practice, there was a fundamental problem related to the commitment of mentors to the mentoring relationship in the teaching and assessment of students. Mentor Elsa reflected that some of their colleagues were inclined to avoid or ignore their relationship and duty to perform CCA.

> *I think most of the clinical mentor's problems belong to... a few categories. The first category is that they are reluctant to take up the responsibility of conducting CCA because they think that it is the task of the school only... So they will simply pass the student in order to save themselves troubles... A further type is that they don't know the importance of providing continuous feedback... if the student is not OK, they will go ahead to give a fail without providing any feedback for improvement. In fact, there is no formative essence in the process.*

Student Queenie echoed that the duties of the mentors in the CCA were not performed effectively. In some situations, CCA practice was formal and did not achieve its intended purposes.

> *In fact, it's called continuous, but it's not effective... As there is actually no time and no chance to evaluate and comment by the mentors... they will tend to pass us* [students] *in order to save effort in explaining the reasons for failure.*

Mentor Elsa and Student Queenie explained that when the mentors failed to perform their duties in CCA practice, they broke not only the functional relationship but also the mentoring relationship with students. In addition, students reaffirmed the difficulty of establishing mentor-student relationships in the CCA. Owen revealed that

> *All of the mentors...are very busy...it is very hard to find the opportunity to ask them questions and get feedback...*

Regardless of whether external constraints, personal situations, or personal attitudes were involved, the desirable mentoring relationship that enables authentic and continuous learning in the CCA context cannot be clearly established if mentors perform their duties improperly or only when convenient (hence the *"Relation" without Relationship*). Therefore, the formative (learning) and summative (assessment) functions of the CCA were separated from one another.

Stand Behind the Yellow Line

The *Yellow Line* is a commonly used safety warning in public transport systems, which indicates that people should be alert because they are in proximity to danger. Crossing beyond the yellow line carries a risk of danger not only to oneself but also others. Regarding the core values of the nursing profession, the yellow line refers to the potential risk of endangerment to patient safety (Levett-Jones et al., 2020). In CCA, it is the mentor's responsibility to assess the clinical competence of nursing students by evaluating the students' performance against predetermined learning outcomes. Ensuring patient safety is considered the most im-

portant assessment standard for nursing students because patient safety is always the first priority in clinical practice and is fundamental to nursing care. The data generated from the study were consistent with this understanding; no other important assessment criteria were mentioned. This priority is relatively simple to understand and is crucial for patient care. Thus, it has become the gold standard that one must "stand behind" during student assessment in CCA practice. Nevertheless, different experiences and perceptions, and inconsistencies in the practices of the assessments and tools might affect mentors' judgment and CCA practice. As a result, different mentors may conduct student assessments differently; however, all of the mentors in this study claimed that the concept of standing behind the yellow line had been observed. The experience below reveals how conventional this golden rule was. Mentor Dorothy stressed that

> *...Mentor tends to fail the student if the act* [of the student] *causes potential harm to a patient, no matter how well the student has performed before.*

Another mentor, Anna, expressed her interpretation of the standard that needed to be upheld in the CCA:

> *It is not easy to...dispel the fact that the student is used to be good based on a single incident* [of failure]. *Actually, you have to do everything correct in ward since it is all about life and death matters... It is normal that you may encounter something you don't know how to handle; but at least you should understand their severity and ask for help instead of handling it randomly. This is the clinical judgement that you should always maintain.*

The above mentor perspectives on the clear CCA standard of assessment were common; the student experiences of CCA assessment were somewhat similar to that perspective.

> *...unless* [the student] *does harm to a patient or the action is so serious that it endangers patient safety, the mentors will not easily fail the student.* (Student Steve)

In the above statement, Student Steve explicitly agreed with the mentors' views that ensuring patient safety is the golden rule (i.e. a rigid yellow line) for assessment. Students who cross this line at any time should fail. However, this view is somewhat radical and does not consider other possibilities, nor does it allow for the formative learning function in CCA.

Regarding patient safety, the understanding of this standard may be affected by different experiences and perceptions. For example, the experience of Mentor Helen demonstrated subjectivity while observing the gold standard for patient safety assessment:

> *CCA is an ongoing* [continuous] *assessment involving the elements of teaching, demonstration, practice, reflection, evaluation, and finally assessment...there is a student who forgets to raise the bedside rail... the patient does not end up falling out of the bed. I give her a pass, since she is performed well all along, and I simply don't think that she will commit this error again...Yes, of course I will fail the student* [if the patient did fall out of bed] *... I have no choice though...*

The data revealed that it was common for mentors and students to uphold the gold standard of assessment, which ensures patient safety. This standard was conventional in that standing behind the yellow line became a generalized assessment standard for mentors and students in CCA practice. This gold standard appeared to be absolute; however, when incorporated with the mentors' personal priorities, experiences, perceptions, and judgments, its actual practice was diverse, as reflected in the statement from Mentor Helen. Theoretically, standing behind the yellow line was also true when mentors were not committed to performing their roles and duties in the CCA. These mentors might have been inclined to not fail any students to avoid extra work and trouble so long as the yellow line was not crossed. Standing behind the yellow line was considered to be upheld; however, the diversity in practice showed that there was discretion and variation in the assessment of CCA.

The Sound of Silence

"Sound and silence" is a powerful oxymoron that can be used to express the meaning of contradictory situations. The meaning of "silence" is "the absence of sound" (Merriam-Webster, 2024). The "sound" that might be heard in "silence" can be an abstract illustration of intense emotion pertinent to a specific situation. In CCA's formative function, mentors are responsible for continuously facilitating students' learning and guiding them to improve their performance over a period of time (Stanja et al., 2023). Providing ongoing feedback to students about their learning is essential for CCA (Isaksson, 2008). However, the theme "*The Sound of Silence*" refers to the situation (sound) where feedback in CCA practice was absent (silence). This section describes the mentors' practices and demonstrates the importance of continuous and timely feedback for the students' formative learning in CCA. The occurrence of silence in CCA implementation creates diversity and problems in its practice.

The mentors had different experiences with and perceptions of providing feedback in the CCA.

> *In fact, I think the student must have the initiative to ask... Sometime I ask the student: What do you want me to show you? If the reply is nothing, then I will just let it...* (Mentor Dorothy)

Mentor Dorothy adopted a passive perspective when providing feedback to the students. The silence that emerged was thus related to students' lack of initiative in asking questions and seeking assistance from their mentors. Furthermore, mentors may have little opportunity to provide timely and continuous feedback to students because of their

heavy workload or unmatched roster. Mentor Dorothy further highlighted the meaning of silence for students during the placement:

> *...before the summative assessment, suddenly their* [other nurses in the ward] *comments will change... In a way, the student must have had some problems during the formative observations. Since the issue is not fatal, they will not care to say it or give feedback* [the silence]. *The result is that a student may have a pass in formative while receiving a fail in summative assessment.*

Providing timely feedback is important; however, the mentors might miss the right time to provide feedback (i.e., at the beginning of placement instead of the end), or they might wait too long for the students to approach them for help. Therefore, silence occurs as time elapses. Regarding the students' perceptions of silence from their mentors, Student Owen considered silence to be the result of ineffective communication:

> *So many unanswered questions in the placement... in times when you have troubles and want to get help from your mentor but receive no reply, then it is normal that you won't dare to ask again, right?*

In the students' experiences, continuous and timely feedback was clearly absent from formative learning. Furthermore, in one situation, the mentor deliberately avoided providing feedback in formative learning:

> *...actually I want to learn how to deal with the chest drainage system... but she* [mentor] *asked me to stay away from the patient and... she screened the patient and blocked my view. Actually, I can't see what she has done to the patient... I was just like an idiot... standing outside...* (Student Queenie)

Communication, especially timely feedback, was often absent or had broken down in CCA. An important point observed was that mentors expected students to take the initiative to approach them, whereas for students, this expectation was reversed. The students were often expecting and were concerned about timely feedback from their mentors. Unfortunately, the sound of silence was common during CCA in the clinical context.

Main Theme: Shades of Gray

The color gray is created by mixing white and black. Slight changes in gray result in many shades of the achromatic gray scale between white and black. The gray scale idea is embedded in the main theme and is a metaphor that captures the phenomenon of uncertainty in a situation in which right and wrong cannot be judged absolutely. "Shades of gray" is the main theme that captured the essence of the CCA experience. It was clear from the findings that CCA was implemented as a spectrum of practices whereby the clinical mentors, nursing staff in wards, and nursing students were often uncertain about their decisions and judgments. In other words, a distinctive black or white path was seldom followed in the complex clinical context of CCA. CCA practice varies among individuals in different settings under diverse constraints. The participants' experiences, represented by the themes garnered from thematic coding, support shades of gray as their main theme. In the theme of relation without relationship, the mentors were sometimes unable to meet the students' needs due to their large workloads or unmatched roster; in these instances, the students could be observed by their colleagues to continue the formative CCA process. In addition, the perspectives of the different mentors revealed different CCA practices. Therefore, the practice of mentoring in the CCA varied; it may have aimed to follow predetermined rules; however, there were different degrees of variation in execution by the stakeholders.

Regarding CCA assessment practices and standards, diversity emerged regarding the theme of *stand behind the yellow line.* In the same clinical setting, different mentors and students used different assessment methods and perceptions. In this regard, assessment can be placed on a spectrum between highly stringent and loose/arbitrary.

The elaboration of the theme of the sound of silence indicated that the practice of providing timely feedback was not standardized, resulting in the silence of various parties due to uncertainty about who should take the first step to communicate. Silence from students was a common consequence of the mentors not answering the students' questions. This observation was interesting when taking an integrative view of the participants' experiences. Timely feedback is extremely important in CCA practice, yet the mentors and students expect each other to be responsible for initiating communication. Were these expectations correct or not? This question has no clear black or white answer.

CCA practices were found to be diverse and filled with issues about the mentoring relationship, assessment practice, and feedback, as indicated in the three themes. CCA implementation often occurred in the context of a spectrum of perceptions and judgments rather than according to strict adherence to a set of defined protocols and standards. The appropriateness of the CCA practice was often unclear among the stakeholders due to the various settings and constraints.

Discussion

By incorporating the unique experiences of mentors in CCA implementation, this study revealed a spectrum of perceptions and judgments of mentors who attempted to sustain continuity and impartiality in CCA practice. The practice of nursing care, as in CCA, is inherently diverse, and nurses must manage and intervene under a variety of conditions, requirements, and ever-changing clinical settings (Thorne, 2013). As such, it is not conceptually the diversity of CCA

practice that matters; what matters are the elements and factors that guide and govern the perceptions, attitudes, and judgments of the mentors that lead to such diversity. Further understanding of the experiences of the current CCA practice in greater detail may help improve its development and implementation.

Mentor Readiness and Capabilities

Theoretically, mentors should understand their role in CCA; however, their perceptions, attitudes, and judgments are largely affected by their readiness and capability to act as a mentor. A mentor's attitude, motivation (Doyle et al., 2017), and work engagement (Tomietto et al., 2016) can affect a student's learning; thus, these are the factors that contribute to a mentor's CCA practice. Mentors who were not ready for their role, regardless of the reason, were often inclined to avoid their duties in CCA practice, as revealed in the final theme "*Relation without Relationship.*"

Capability refers to a positive attitude, individual mentoring competency, sufficient interpersonal and communication skills, and relevant competencies in knowledge, teaching, and assessment (Jokelainen et al., 2013). The present study found that some mentors did not communicate or provide timely feedback to students because they were unsure about the correct answer or lacked confidence. This finding is consistent with those of Helminen et al. (2016), O'Brien et al. (2014), and Hall-Lord et al. (2013). Mentors often require support when facing challenging students or managing critical evaluations (Hall-Lord et al., 2013); there is a need for more education and support in the mentor role (Griffiths et al., 2022). Consequently, CCA's formative function was often interrupted when students did not receive timely feedback. Regardless of whether it was caused by an avoidance of duties or mentor incapability, CCA implementation was rendered ineffective, as indicated by the theme *"The Sound of Silence*."

Priorities and Preferences of Stakeholders in Practice Settings

Diversity in CCA practice can also be driven by stakeholders' different priorities in the practice setting. Stakeholders other than nursing students in the practice setting, including nursing professionals, hospital management, and healthcare authorities, are crucial entities that play an important role in ensuring successful CCA implementation. For example, the supernumerary status of nursing students perceived by nursing professionals in a practice setting can differ and might contribute to CCA practice diversity. As the daily ward operation is often considered a higher priority than students' learning needs (including CCA practice), ward staff may ignore students' learning needs and perceive students as an essential workforce. This perception can result in compromises in the practice setting, such as placing a student with a mentor who is on leave or occasionally loosening the nursing standard of patient safety. One of the most important factors behind these compromises may be the heavy constraints on or fluctuations in human resources in clinical settings, which is an issue beyond the help of organizational policies and values (Allan et al., 2011).

To effectively implement CCA in practice settings, stakeholders and nursing students involved in CCA must collaborate. Students must be at the center of learning and be supported to learn and practice their skills safely (NMC, 2020). Recognizing the purpose and value of the supernumerary status of students to support learning may help improve the clinical mentoring experience of both mentors and students (Shepherd, 2014), which may result in a better CCA implementation. These ideas are consistent with other studies that have identified deficiencies in communication between stakeholders and nursing students in clinical settings and differences in role perception (Gropelli & Shanty, 2018).

Gold Standard: Ensuring Patient Safety

The ultimate goal of nursing education is to produce registered nurses who are fit for practice to ensure public safety and professionalism in nursing (NMC, 2020). The experiences of the participants in this study revealed that there was diversity in assessment practices related to patient safety. Such CCA practice diversity regarding the standards for assessment may have resulted from the varying experiences and perceptions of the mentors about mentorship. The function of mentorship, which is closely aligned with formative learning in CCA, is fundamentally supported by mentors who facilitate students' learning and guide them to continuously improve their clinical performance through mentoring or clinical supervision. In turn, mentors can gain a better understanding of students' learning needs and performance in clinical practice by conducting effective mentorship (Lee & Chiang, 2021). The varied perceptions and experiences obtained through the effective mentoring of students have created a diversity of CCA assessment practices related to upholding the standard of patient safety.

Conclusion

CCA is the main strategy used in preregistration nursing education to instill professionalism and proficiency in students to achieve a predetermined competence level. Although the concept of CCA is clear, the practice of CCA is so diverse that it has often been criticized as subjective and even ineffective. This study aimed to improve students' understanding of CCA practice by analyzing the experiences of their CCA mentors. The use of interpretative descriptions enabled an in-depth investigation into the current practices and complexities inherent in CCA implementation. This study also identified the importance of developing thorough

and practical guidance for CCA implementation in preregistration nursing education; this guidance should be based on effective mentorship. This study supplements the evolving knowledge of CCA by contextualizing observations and meanings from nursing professionals' current experiences. The findings might aid in the development of better clinical teaching and learning activities to improve the competence and fitness of nursing students in their practice after graduation, thereby more effectively assuring patient safety.

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Author Contributions

NL and VC initiated the conception. NL conducted data collection. NL and VC worked together to analyze and interpret the data. NL drafted the manuscript, and VC critically revised the manuscript for important intellectual content. Both authors have read and approved the final manuscript.

Declaration of Conflicting Interests

There are no conflicts of interest to declare.

Ethical Approval

Ethical approval was obtained from the Ethical Review Committee of Hong Kong Polytechnic University (Ref. No.: HSEARS20171101005) and from the Clinical and Research Ethics Committee of Tuen Mun Hospital, Hospital Authority (Ref. No: NTWC/CREC/17108).

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Original Research

Psychological and physiological effects of warm posterior neck compression in restricted supine position

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Abstract

Objective: This study aimed to investigate the psychological and physiological effects of applying a hot pack to the posterior neck while in a restricted supine position. **Methods:** In the hot pack (HP) method, a hot compress at approximately 41°C was applied to healthy adults for 30 min after 60 min of supine restraint and compared with the control (CR) method. Psychological effects were assessed using the POMS2 Japanese shortened adult version to measure the mood before and after treatment. Physiological parameters, including body temperature, blood pressure, pulse rate, heart rate variability (HRV) as an autonomic index, and skin surface temperature, were also measured. **Results:** The results showed that the HP method significantly decreased fatigue and lethargy, whereas the CR method decreased tension and anxiety and increased friendship scores. HRV analysis revealed that the HP method tended to suppress sympathetic nerve activity more than the CR method, although the difference was not statistically significant. There were no significant differences in the physiological parameters between the two methods; however, the skin surface temperature was significantly higher with the HP method at 70, 80, and 90 min. **Conclusions:** Warm posterior neck compression does not cause changes in the circulatory system and is safe for patients in the supine position for prolonged periods. Although it alleviates negative mood states, it is not strong enough to conclude that it inhibits sympathetic nervous system activity.

Keywords

warm posterior neck compression, thermotherapy, hot packs, nursing techniques, psychological distress

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Introduction

Recent advances in medical equipment and new treatment methods have improved the survival rates of patients with various diseases. However, there is also an increasing number of invasive procedures that approach the femoral artery, such as percutaneous coronary angioplasty and coil embolization for cerebral aneurysms, liver disease, and peripheral arterial occlusive disease, often forcing patients to stay in bed for long periods (Dohi et al., 1994; Sasaki et al., 2003), thereby causing physical and psychological distress (Inoue et al., 2002; Sasaki et al., 2003; Shiraishi & Ohgushi, 1990).

Although pressure relief is commonly used to reduce the distress associated with positional restrictions (Chair et al., 2003; Taguchi et al., 2019), it has limitations and fails to reduce psychological distress (Yamauchi et al., 2018). Although music (Ishii et al., 1993), fragrance inhalation (Teymouri et al., 2019), and time warnings (Sakurai, 2002) have been used, their effectiveness is limited. Therefore, a method that reduces psychological distress in the restricted supine position is required.

This study proposes that warm compression of the poste-

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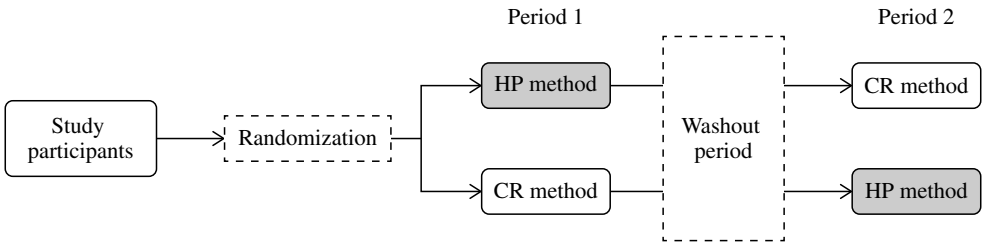


Figure 1-1. Experimental protocol.

rior neck can help reduce psychological distress. Warm compression, which has long been used as a nursing technique, suppresses sympathetic nerve activity and produces pleasant sensations (Egami, 2008). The beneficial effects of warm shoulder compression and massage on psychological fatigue in the prone position were reported (Furushima et al., 2016). However, only few studies have examined the effects of warm compression in patients in the supine position. Owing to the tendency to trigger muscle fatigue in the neck and lumbar regions and distress in the occipital and scapular regions (Akiyama et al., 2009; Hosoda et al., 2017), the physical and mental effects of the supine position must be investigated.

The posterior neck region was selected as the application site for warm compression. The posterior neck area is stimulated more than the lumbar back area because the former has more nerves to detect warmth (Arita et al., 2006); warm compresses in this area have been shown to have a relaxing effect (Kato, 2012; Katsuhashi et al., 2014; Kawahara et al., 2018) and less impact on physiological surfaces (Chuno et al., 2018). In addition, warm compresses on the posterior neck do not require clothing removal and are easier to apply in busy clinical settings.

Study Purpose

This study aimed to determine the psychological and physiological effects of warm compression on the posterior neck while the patient was in a restricted supine position.

Definition of Terms

Hot packs: There are two types of hot packs: (1) wet heat methods using steamed towels and (2) dry heat methods using hot packs or steam heating sheets. In this study, we used gel-based heat therapy products.

Materials and Methods

Study Design

A quasi-experimental randomized crossover design was used (Figure 1-1). The randomized crossover method used computer-generated random numbers; the two groups were randomly and equally allocated to decide which group would be administered the HP method or CR method. The same subject underwent a 90-min supine restricted positioning with a hot pack on the posterior neck (HP method) and without a hot pack (CR method).

Participants

The participants included 24 adults, aged 20 years or older, with no health problems and who had never been diagnosed with arrhythmia. After obtaining permission from the president of University A, a recruitment flyer outlining the study was distributed among the students. Volunteers who met the inclusion criteria and consented to participate were included.

The number of participants was determined by referring to a previous study (Furushima et al., 2006), assuming a one-paired repeated-measures two-way analysis of variance (ANOVA) with a 0.5 effect size, 80% power, and a 5% significance level, and calculating the sample size using G*Power.

Data Collection Period

The data were collected from March to July 2022.

Data Collection Items and Methods

Data collection included Profile of Mood States 2nd Edition (POMS2) as psychological items, vital signs (temperature, blood pressure, and pulse), heart rate variability (HRV) analysis, and skin surface temperature as physiological items.

Psychological Survey Items

Mood Assessment

Mood was assessed using a self-administered questionnaire called the Japanese Abbreviated Adult Version of the POMS2 (Kaneko Shobo). The POMS2 was developed by McNair (1971) and was translated by Yokoyama (2006). Thus, the reliability and validity of the proposed method were confirmed. To assess short-term changes in mood, the questionnaire consists of 35 items divided into seven subscales: "Anger-Hostility" (AH), "Confusion-Bewilderment" (CB), "Depression-Dejection" (DD), "Fatigue-Inertia" (FI), "Tension-Anxiety" (TA), "Vigor-Activity" (VA), and "Friendliness" (F). The seven subscales add up to a "Total Mood State" (TMD).

The prime scores for each scale were rated on a Likert scale ranging from 0 to 4, with TMD scores ranging from

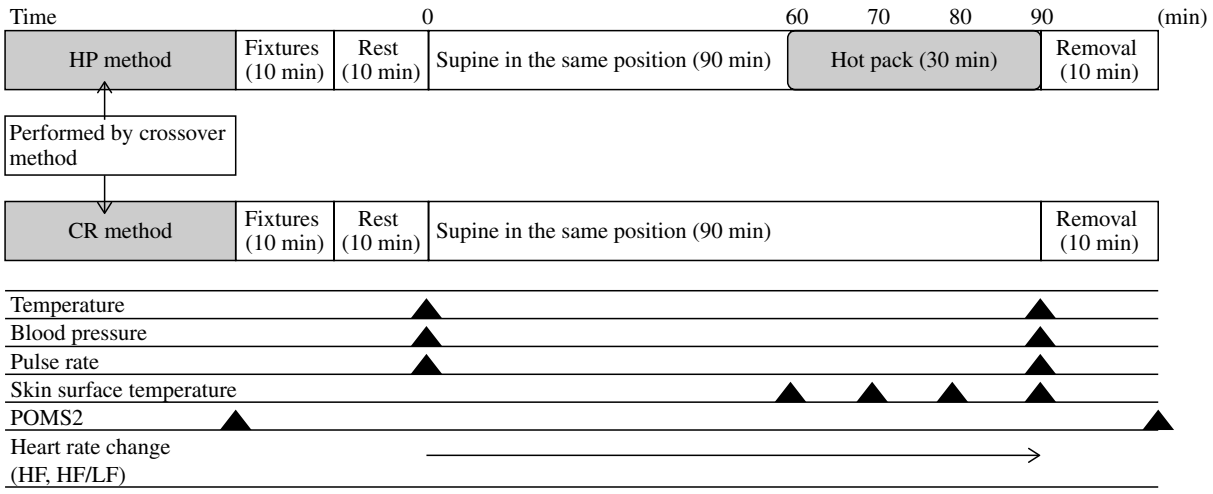


Figure 1-2. Experimental protocol.

−20 to 100 and all other scores ranging from 0 to 20. Higher AH, CB, DD, FI, TA, and TMD scores indicated negative mood states, whereas higher VA and F scores indicated positive mood states.

Physiological Investigation Items

Vital Signs

Body temperature, blood pressure, and pulse rate were measured. Body temperature was measured using an ear thermometer (CTD711, CITIZEN) to determine the tympanic membrane temperature; blood pressure and pulse rate were measured in the upper left arm using a brachial sphygmomanometer (HEM-7120; OMRON). All measurements were performed twice, at the beginning and end of the compression tests.

Autonomic Nervous System Indices

The autonomic nervous system was evaluated by measuring HRV using a wearable heart rate sensor (WHS-1; UNION TOOL, Inc.). HRV is an indicator of cardiac autonomy that measures the instantaneous beat-by-beat variability of the RR interval (Hayashi, 1999). The frequencies covered were 0.04-0.40 Hz, with a high-frequency (HF) component (0.15-0.40 Hz), a low-frequency (LF) component (0.04-0.15 HZ), and the component ratio of the LF and HF components (LF/HF). The LF component represents the activity of the sympathetic and parasympathetic nervous systems. An increase in the ratio of LF to HF components (LF/HF) indicates increased sympathetic activity, whereas an increase in HF indicates increased parasympathetic activity (Pomeranz & Macaulay, 1985). Frequency analysis based on the maximum entropy method was used for HRV, with the start of the study (0-5 min) as the reference and considering the time of HP implementation. The following LF/HF and HF averages were measured: The mean values of LF/HF and HF were measured at (1) 60 min after positional restriction (55-60 min), (2) 70 min after positional restriction (65-70 min), (3) 80 min after positional restriction (75-80 min), and (4) at the end (85-90 min), using the start (0-5 min) as the baseline and considering the time of HP implementation.

Skin Surface Temperature

The skin surface temperatures were measured to assess safety and thermal effectiveness. The measurement site was 5 cm next to the seventh cervical vertebra and was marked before the start of the procedure. Four measurements were performed using a radiation thermometer (IT-545NH, HORIBA) at 60, 70, 80, and 90 min after supine restriction.

Experimental Procedures

Environmental Setting and Participants' Conditions

The experiment was conducted in the researcher's facility, with the room temperature set at 24 ± 2°C and humidity at 40 ± 5%.

The participants were informed in advance, and they agreed not to engage in strenuous exercise, drink alcohol the day before or on the day of the experiment, or eat two hours before the start of the experiment to adjust for factors that would affect the experimental measures. Considering the diurnal variation in autonomic nervous system activity, the experimental schedule was adjusted for each participant, and the HP and CR methods were conducted simultaneously. The study was designed for prolonged supine rest after cardiac catheterization. The position was supine with weights (approximately 1 kg each) on both ankles and no flexion, rolling, or upper body was performed; minor exercises of the upper limbs were permitted.

Methods

The experiment was conducted as per the protocol (Figure 1-2). The HP and CR methods were randomly selected and were spaced at least 24 h apart to allow sufficient washout time. With reference to previous studies (Konan, 2024; Nawa, 2004) on washout time, we considered that the effect

of the hot pack would not last longer than 24 h and decided to carry out the HP and CR methods at least 24 h apart after confirming this in a pretest before the experiment. The patients were placed in a bed rest position for 10 min with a heart rate sensor on their chest and ankle weights on both ankles. The decision to use 90 min was based on the fact that in previous studies, approximately 70% of subjects were said to be in some distress after 60 min of supine rest; it was also based on pretest results and the subject's burden.

In this study, the HP method used hot packs. There are two methods of applying hot compresses directly to the skin: the wet heat method using a steamed towel and the dry heat method using a HP or steam heating sheet. Steamed towels have the disadvantage of being easily cooled, thereby having a short warming effect. Therefore, the dry heat method (HP) was used in this study, which can be easily performed in busy clinical settings. The participants were placed in the supine position for 90 min, starting with the conditions before implementation. The HP (1570 BT, 3M: 10 cm × 25 cm) was heated in a microwave oven at 600 W for 40 s immediately before use; a radiation thermometer was used to confirm that the surface temperature reached 41°C (±1) and did not exceed 45°C. The center of the HP side was aligned with the center of the posterior cervical region (from the first to the seventh cervical vertebrae). The HP was used for 30 min and 60-90 min after the start of positional restriction. All other items (e.g., beds, pillows, and towels) were standardized. The reason for the 30-min duration was determined with reference to the pretest results, as well as the results of previous studies showing the effectiveness of warm posterior neck compresses (Furushima et al., 2006) and the study results on the treatment time in HP therapy (Matsuzawa et al., 2007).

The experiment used a urethane mattress (stretch glide (KE-7B1T, PARAMOUNT BED)) of approximately 12 cm thickness; all other items used (pillows, towels, etc.) were standardized.

Methods of Analysis

Descriptive statistics were calculated for all measurement items. Survey items related to physiological aspects (temperature, blood pressure, and pulse rate) were subjected to t-tests. For POMS2, the Wilcoxon signed-rank sum test was used to compare scores and changes in scores before and after the start of each method. Autonomic indices (HRV analysis) and comparisons of changes in skin surface temperature in the HP and CR methods were performed using two-way repeated-measures ANOVA for the two factors (method and time), assuming no carryover effects from washout time. Greenhouse-Geise's epsilon was used to adjust for degrees of freedom if the assumption of sphericity was rejected after Mauchly's test. Multiple comparisons were performed using the Bonferroni method if at least one of each factor's main effects or interactions was significant.

All statistical analyses were performed using IBM SPSS Statistics Version 28, with a 5% significance level.

Ethical Considerations

This study was approved by the Tokyo Healthcare University Ethics Committee for Research on Human Subjects (Directorate 33-100). Written consent was obtained from all participants to publish their information, including photographs.

During the experiment, we observed if any disadvantage or physical burden was caused to the participants and if cold burns or other injuries occurred.

Results

Participants

A total of 19 subjects were analyzed: 17 women and 2 men with a mean age (±SD) of 28.57 (±7.91); consent for the study was obtained from 23 subjects, excluding 1 who withdrew during the study and 3 subjects whose HRV analysis was too noisy and difficult to analyze.

POMS2

Table 1 compares the pre- and post-start scores on the mood scale for the HP and CR methods. Item fatigue-lethargy (FI) showed significant differences in the mood scale scores of the HP method (p=.047). In addition, although no statistically significant differences were observed, all items representing negative mood states (AH, CB, DD, FI, TA, and TMD) showed flat or declining scores. In contrast, the items that showed significant differences in the CR method were TA and friendliness (F) (p=.036 and p=.020, respectively). Although no statistically significant differences were observed, all items representing negative mood states (AH, CB, DD, FI, and TMD), except TA, either remained unchanged or increased. Table 2 compares the POMS2 scores using the HP and CR methods. The comparison showed a significant difference in the DD (p=.037) and higher DD scores using the CR method.

Autonomic Indices (HRV Analysis)

Table 3 and Figure 2 compare the sympathetic nerve activity indices of the HP and CR methods (LF/HF). The results of the two-way repeated-measures ANOVA for LF/HF showed no significant differences in the main effect of the method, main effect of time, or interaction effect between the method and time. No significant differences were observed in the time-by-time comparison of the HP method. Still, the LF/HF ratio fell sharply after 70 min (10 min after the HP was applied) and continued to fall after that, not exceeding the start time until the end of the HP. However, the LF/HF ratio increased sharply at 70 min and continued to rise until the end

Table 1. Comparison of POMS scores before and after the start and end of the hot pack and control methods.

N=19

		HP method					CR method				
		Before		After		*p-value*	Before		After		*p-value*
		Mean (±SD)	Median [IQR]	Mean (±SD)	Median [IQR]		Mean (±SD)	Median [IQR]	Mean (±SD)	Median [IQR]	
AH	【Anger–Hostility】	41.5 (±8.07)	37 [7.50]	40.2 (±6.25)	37 [6.50]	.360	41.7 (±7.68)	37 [7.00]	41.7 (±6.90)	39 [9.00]	.570
CB	【Confusion–Bewilderment】	45.3 (±11.2)	40 [18.0]	42.8 (±8.30)	40 [9.00]	.092	44.7 (±9.84)	40 [15.0]	43.2 (±8.49)	40 [12.0]	.250
DD	【Depression–Dejection】	47.1 (±10.3)	41 [16.0]	44.6 (±7.76)	40 [11.0]	.085	45.5 (±9.18)	41 [6.00]	45.2 (±8.09)	41 [12.0]	.510
FI	【Fatigue–Inertia】	39.7 (±11.4)	34 [10.0]	37.5 (±9.52)	32 [16.0]	.047*	39.5 (±10.2)	37 [14.5]	40.2 (±10.3)	37 [16.0]	.750
TA	【Tension–Anxiety】	43.5 (±11.2)	40 [14.5]	39.9 (±8.38)	36 [13.0]	.083	42.6 (±9.23)	42 [13.5]	39.7 (±9.05)	36 [14.5]	.040*
VA	【Vigor–Activity】	50.8 (±11.9)	50 [14.5]	48.2 (±9.80)	48 [10.0]	.280	49.6 (±12.0)	48 [16.0]	46.6 (±10.9)	43 [18.0]	.370
F	【Friendliness】	52.6 (±12.7)	53 [17.5]	50.8 (±12.3)	51 [17.0]	.460	54.2 (±11.2)	56 [9.50]	50.3 (±10.3)	51 [13.0]	.020*
TMD	【Total Mood State】	42.7 (±10.6)	38 [13.5]	40.4 (±7.22)	37 [8.50]	.054	41.7 (±9.47)	39 [10.0]	42.0 (±8.12)	40 [13.0]	.590

Note: *p<.05, * shows the results of the Wilcoxon signed rank sum test.

Table 2. Comparison of POMS changes between hot pack and control methods.

N=19

		HP method		CR method		
		Mean (±SD)	Median [IQR]	Mean (±SD)	Median [IQR]	*p-value*
AH	【Anger–Hostility】	-1.30 (±7.79)	0.00 [2.00]	0.05 (±6.31)	0.00 [2.00]	.173
CB	【Confusion–Bewilderment】	-2.50 (±6.51)	0.00 [3.50]	-1.50 (±5.64)	0.00 [3.50]	.512
DD	【Depression–Dejection】	-2.40 (±5.95)	0.00 [3.00]	-0.30 (±3.90)	0.00 [2.00]	.037*
FI	【Fatigue–Inertia】	-2.20 (±10.5)	-2.00 [4.00]	0.74 (±12.2)	0.00 [4.50]	.244
TA	【Tension–Anxiety】	-3.60 (±8.62)	-2.00 [10.5]	-2.80 (±8.21)	-3.00 [7.00]	.744
VA	【Vigor–Activity】	-2.60 (±7.96)	0.00 [7.00]	-3.00 (±11.2)	0.00 [4.00]	.609
F	【Friendliness】	-1.80 (±6.80)	0.00 [6.50]	-3.90 (±8.50)	-2.00 [3.00]	.132
TMD	【Total Mood State】	-2.40 (±7.80)	-1.00 [6.00]	0.30 (±8.70)	0.00 [5.00]	.052

Note: *p<.05, * shows the results of the Wilcoxon signed rank sum test.

Table 3. Comparison of sympathetic activity index (LF/HF) and parasympathetic activity index (HF) in hot pack and control methods.

N=19

		Mean (±SD)					Main Effects				Reciprocal action	
							Method		Time			
		0 min	60 min	70 min	80 min	90 min	f-value	*p-value*	f-value	*p-value*	f-value	*p-value*
LF/HF	HP method	1.21 (±1.17)	1.28 (±1.70)	1.04 (±0.76)	1.00 (±0.54)	0.97 (±0.52)	0.849	.369	0.035	.953	1.347	.272
	CR method	1.13 (±0.93)	1.12 (±0.57)	1.36 (±1.08)	1.30 (±1.11)	1.37 (±1.00)						
HF	HP method	30930.98 (±86893.87)	22304.68 (±32364.19)	20642.16 (±63728.1)	13882.21 (±34549.14)	25724.89 (±43290.93)	0.150	.749	0.525	.556	0.738	.516
	CR method	20492.06 (±35999.02)	12438.27 (±23834.91)	29400.29 (±69669.48)	21281.61 (±49368.77)	13458.15 (±27641.05)						

Note: *p-value*s indicate the results of two-way repeated measures ANOVA.

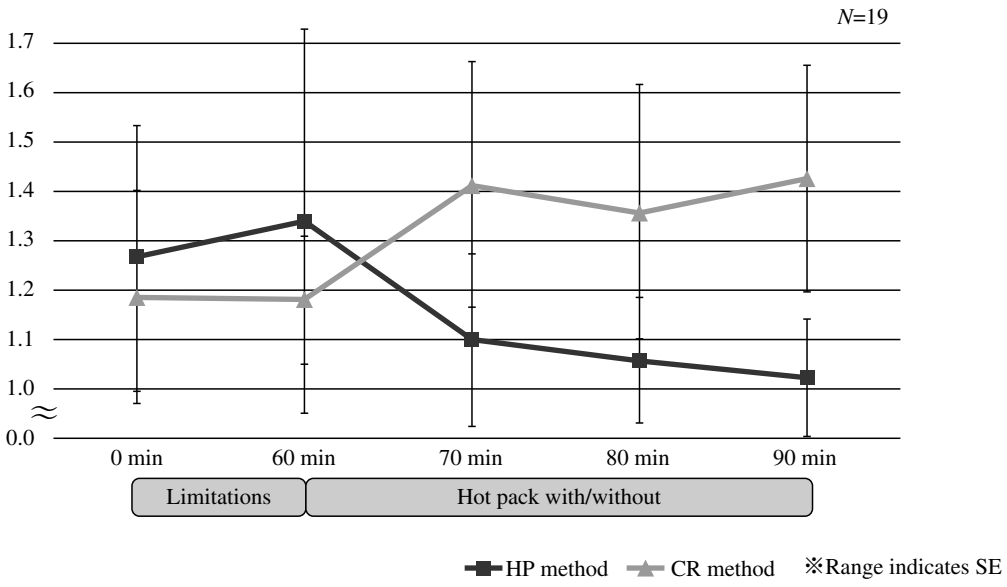


Figure 2. Mean values of the sympathetic activity index (LF/HF) for the HP and CR methods.

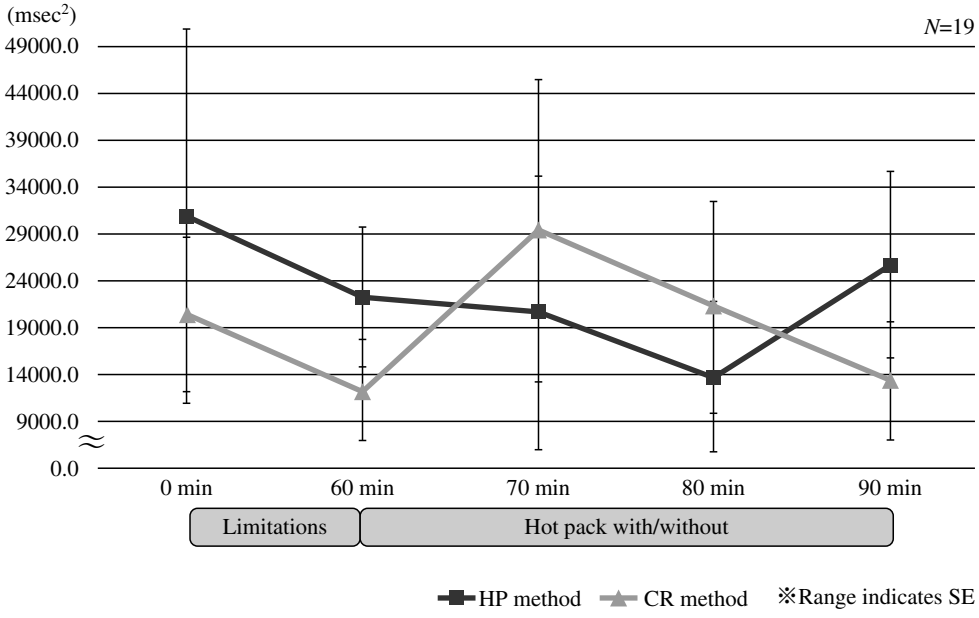


Figure 3. Average parasympathetic nerve activity index (HF) values for the HP and CR methods.

of the study, exceeding that at the start. The parasympathetic activity indices (HF) of the HP and CR methods are compared in Table 3 and Figure 3. The two-way repeated-measures ANOVA results for HF showed no significant differences in the main effect of the method, main effect of time, or interaction effect between the method and time.

Comparisons of the HP method on a time-by-time basis showed no significant differences; however, there was a gradual decline from the start to 80 min (20 min after the HP was applied) and an increase until the end of the HP. A time-by-time comparison of the control method showed no significant differences; however, the HF increased from the start until 70 min and then decreased until the end of the study.

Physiological Aspects

Table 4 compares the survey items (body temperature, blood pressure, and pulse rate) related to the physiological surfaces at the start and end of the study. No significant differences in body temperature, blood pressure, or pulse rate were observed between the start and end of the HP and CR methods.

At the start of the study, the HP and CR methods were compared in terms of body temperature, blood pressure, and

Table 4. Comparison of the physiological survey items (temperature, blood pressure, and pulse) at the beginning and at the end of the survey.

N=19

Measurement item	HP method (mean±SD)			CR method (mean±SD)		
	Before	After	*p-value*	Before	After	*p-value*
Temperature (°C)	36.34±0.35	36.55±0.24	.219	36.49±0.32	36.53±0.25	.662
Systolic blood pressure (mmHg)	108.11±12.71	106.42±12.76	.455	107.68±11.51	107.47±12.95	.909
Diastolic blood pressure (mmHg)	64.79±11.57	62.79±10.17	.233	66.11±10.42	64.63±9.3	.206
Pulse (times/minute)	67.16±10.77	68.53±8.49	.443	67.74±8.47	68.53±9.01	.704

Note: **p-value* indicates the result of a corresponding t-test.

Table 5. Comparison of skin surface temperatures for hot pack and control methods.

unit=°C, *N*=19

	Mean (±SD)				Main effects				Reciprocal action	
					Method		Time			
	60 min	70 min	80 min	90 min	f-value	*p-value*	f-value	*p-value*	f-value	*p-value*
HP method	35.7±0.70	38.1±1.11	37.9±0.88	37.8±0.89	204.999	<.001	27.892	<.001	68.254	<.001
CR method	35.7±0.69	35.5±0.80	35.3±0.79	35.7±0.87						

Note: **p-values* indicate the results of two-way repeated measures ANOVA.

pulse rate, none of which were significantly different (body temperature, p=.786; sBP, p=.797; dBP, p=.522; pulse rate, p =.744).

Skin Surface Temperature

Table 5 and Figure 4 compare the skin surface temperatures obtained using the HP and CR methods.

Two-way repeated-measures ANOVA of the skin surface temperature revealed a significant main effect of method (F [1, 125.85] = 204.999, p < .001), main effect of time (F [3, 10.30] = 27.892, p < .001), and an interaction effect between the method and time (F [3, 14.98] = 68.254, p < .001). In subsequent multiple comparisons, significant differences were observed in the skin surface temperatures between the HP and CR methods after 70, 80, and 90 min, with higher temperatures observed in the HP method (p <.001).

Discussion

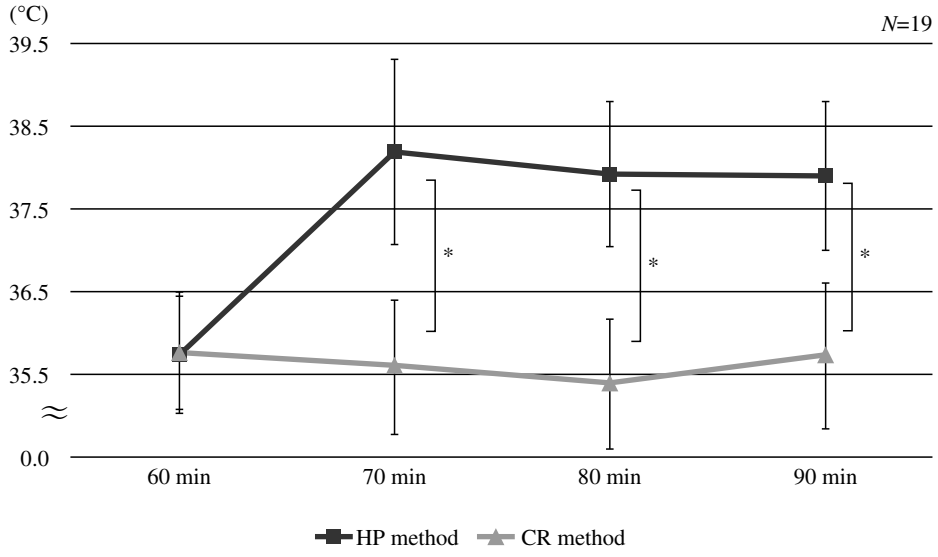
Effects on Psychological Aspects

In the POMS2, FI scores significantly decreased after completion of the HP method compared with before the start, indicating that the degree of fatigue, lethargy, and decreased activity was suppressed. This result is similar to that of a previous study (Furushima et al., 2015), which revealed the positive effect of warm compresses on mood assessment for depressed posture maintenance.

However, the TA and F scores of the CR method used in this study were significantly lower. The TA represents physical tension that is not observable, such as nervous tension, and neuromotor activity that is observable, such as restlessness (Yokoyama, 2006). A study investigating mood changes after applying warm compresses on the back (Nawa et al., 2004) revealed significantly lower TA in both the HP and CR groups at the end of the warm compress treatment than at the beginning. It was concluded that resting and lying in bed stabilized mood. F, an item representing positive affect, was significantly lower in the CR group after 90 min of psychological stress in the same position than in the HP group after 60 min of positional restriction. F is an item that represents positive affect; positive mood decreased in the CR group owing to psychological stress at the same body position for 90 min.

A comparison between the HP and CR methods revealed a significant difference in DD, with higher DD scores obtained using the CR method. Therefore, warm compresses during bed rest effectively alleviate negative mood states. This result is similar to that of a previous study (Nawa et al., 2004) that investigated mood changes induced by hot compresses on the back and concluded that DD significantly improved during stressful situations.

A study on hot compresses with HPs in 10 centers across Europe concluded that relieving physical pain can also reduce psychological distress (Hotfiel et al., 2024). Although the present study did not investigate physical distress, psychological distress may have been reduced, as reported in previous studies.



*p<.01 * is the result of multiple comparisons by repeated measures two-way repeated measures ANOVA and Bonferroni method.

Figure 4. Skin surface temperatures for the HP and CR methods.

Effects on Physiological Aspects

This study showed no significant differences in the physiological aspects of body temperature, pulse rate, and blood pressure between the start and end of the HP or CR methods; this indicates that warm posterior neck compresses in the supine position do not affect the physiological response.

Although no significant difference in body temperature was found in this study, a previous study on the physiological responses to warm posterior neck compresses (Nakano et al., 2009) reported that body temperature was significantly higher after applying warm compresses to the posterior neck. One difference between the present study and that of Nakano et al. (2009) was the type of warm compression used. Nakano et al. (2009) used a wet hot compress with a warm towel set at around 44°C, which had high thermal conductivity, thereby increasing the participant's body temperature. In addition, this study applied dry, hot compresses using a HP at approximately 41°C for safety reasons; thus, the change in body temperature caused by the posterior neck hot compress was minimal. A previous study (Asami & Asakawa, 2018) that applied a 15-minute warm posterior neck compress using a 40°C heat sheet showed no change in body temperature before and after the start of the warm compress, which is similar to the results of the present study.

Regarding pulse rate and blood pressure, previous studies on hot compresses have shown a decrease in pulse rate and blood pressure owing to parasympathetic dominance caused by the relaxation effect (Asami et al., 2018; Nakano et al., 2009). This study was conducted under 90 min restriction in a homotropic posture, implying that homotropic stress occurred and that the parasympathetic nervous system did not change to the extent that circulatory dynamics were affected. Furthermore, research on using warm compresses to maintain a depressed posture (i.e., lying on one's back) (Furushima et al., 2015) reported results similar to those of the present study, showing no changes in pulse rate or blood pressure before or after applying warm compresses.

In the autonomic nervous system index (HRV analysis), LF/HF, representing sympathetic activity, did not differ significantly. However, the HP method showed a sharp drop after 70 min (10 minutes after the hot pack application) and remained within the start time until the end of the study. Similarly, no significant difference was observed in the HF ratio, which represents parasympathetic nerve activity. However, the HP method increased from 80 min (20 min after applying the hot pack) to the end of the study. These results indicated that sympathetic activity tended to be suppressed at 10 min after HP application, whereas parasympathetic activity tended to increase at 20 min after HP application.

In a study by Furushima et al. (2015), hot compresses were applied to hold the supine posture; although LF/HF and HF increased over time in the HP and CR methods, no significant differences were found. Although no statistically significant difference was found in this study, the LF/HF ratio in the HP method remained low from the time of hot pack application until the end of the study. Moreover, this study showed that HPs tended to suppress sympathetic nerve activity, consistent with the results of previous studies. The lack of statistically significant differences in autonomic indices can be because this study was conducted in healthy adults; 90 min of bed rest may not have been enough to affect HRV, and even if the participants experienced pain from

bed rest, they were not wearing devices that could cause stress. The small number of participants may have affected the results.

The HP and CR methods tended to suppress negative mood states and sympathetic nerves in the HP method, even though the supine position was restricted for 90 min under the same conditions; this result could be attributed to the thermal effects of the HP on the posterior neck. In this study, the surface temperature of the HP was set at 41°C. In another study in which warm posterior neck compresses were set at 60°C and 40°C (Kato, 2011), 40°C was shown to reduce stress, suggesting that the temperature of the HP affected the stress level. Furthermore, skin surface temperature is closely related to thermal pleasure or discomfort (Iriki, 2003); when the initial skin surface temperature is 34.4°C, an increase of approximately 0.4°C is reported to produce the sensation of warmth (Schmidt, 1978/1984). This study reported that the average skin surface temperature before and 10 minutes after applying the HP was 35.7°C and 38.1°C, respectively, showing an increase of 2.4°C. In addition, the HP made closer contact with the neck in the supine position than in the prone position, which was assumed to make the sensation of warmth more pleasant.

The posterior neck has the highest number of warm points on the back of the body (Tamura & Lee, 1995). A previous study that compared the effects of warm lumbar back compression with those of warm neck compression based on HRV found that the posterior neck region was more stimulated than the lumbar back region (Arita et al., 2006), indicating that warm posterior neck compression suppresses sympathetic nerve activity and has a relaxing effect.

These findings suggest that warm compression of the posterior neck while in a restricted supine position can alleviate psychological distress.

Implications for Practice

In conclusion, the HP method used in this study had little effect on physiological responses because it did not affect body temperature or circulatory dynamics; this makes it a safe method for alleviating negative mood states in patients in the supine position for prolonged periods. It also tended to suppress sympathetic activity, although not significantly; however, the effect was not strong enough to conclude that it was effective in inhibiting sympathetic activity.

Under the same positional restrictions, pressure relief (Taguchi et al., 2019; Chair et al., 2003), music (Ishii et al., 1993), and time warnings (Sakurai, 2002) have been shown to alleviate psychological distress. However, the results of this study suggest that warm posterior neck compresses are associated with a restricted, supine, negative mood state, which is a simple method for relieving it. Therefore, warm posterior neck compresses may be an option to alleviate negative mood in patients who need to remain in the supine position for extended periods after examination or treatment.

Limitations and Future Challenges

This study was conducted exclusively with healthy adult participants. Future studies should include people of all ages and patients requiring bed rest after cardiovascular treatments or procedures, such as cardiac catheterization, to better capture the real-world implications. Moreover, owing to time constraints and other issues, the duration of the experiment was limited to 90 min; therefore, future research should take into account resting time for catheterization, etc., and extend the experimental time.

The participants' height and weight were not included in the data collection items in this study; however, this is a limitation of this study, as height, weight, and BMI may influence body pressure. Furthermore, because this study investigated the effects of only one type of hot compress, the effects of various methods, such as steamed towels and steam heating sheets, and the combined effects of using pressure relief and other methods simultaneously should be investigated.

Conclusions

In POMS2, the HP method significantly decreased FI scores and suppressed fatigue, lethargy, and decreased activity. Furthermore, comparing the changes in scores between the HP and CR methods revealed a significant difference in DD, with higher DD scores obtained using the CR method.

Although no significant differences in autonomic nervous system indices were observed, the HP method tended to suppress sympathetic nervous system activity 10 min after the application of the hot pack and increase parasympathetic nervous system activity 20 min after the application of the hot pack.

No significant differences in body temperature, blood pressure, or pulse rate were found before and after the HP and CR methods; this suggests that warm posterior neck compression in the restricted supine position is safe.

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Author Contributions

Miho Murano contributed to the study conception and design, data collection, data analysis and interpretation, and manuscript drafting. Tomoko Takahashi and Tomoko Matsuyama contributed to the study conception, data analysis and interpretation, and critical revision of the manuscript for intellectual content. All authors have read and approved the final manuscript.

Declaration of Conflicting Interests

There are no conflicts of interest to declare.

Ethical Approval

This study was approved by the Tokyo Healthcare University Ethics Committee for Research on Human Subjects (Directorate 33-100).

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Original Research

Influence of male spouses of Japanese patients with breast cancer on the decision-making for primary treatment: A qualitative study

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Abstract

Objective: The dynamics of what actually occurs when couples make treatment decisions have not been fully studied. This study aimed to identify the influence of male spouses on the primary treatment decisions of patients with breast cancer in Japan and to obtain ideas for nurses to effectively help patients with breast cancer make primary treatment decisions. **Methods:** This qualitative study included married patients with stage I-III primary breast cancer <6 months after surgery. Semi-structured interviews were recorded and analyzed inductively. **Results:** This study identified three core categories that reflect the influence of spouses of Japanese patients with breast cancer on decision-making regarding primary treatment: the basis, quality, and direction of decision-making. These comprised six categories: "obtaining support that enables me to make my own choices in comfort," "living true to myself became difficult because, contrary to my expectations, I was disrespected," "examining the options together with my spouse will help me recognize values and lead me to a rational choice," "self-determination is disturbed by over-interference and psychological pressure," "rethinking their present state as a couple and exploring the future of their life together," and "not trying to look ahead, just letting things happen." **Conclusions:** It is important to evaluate marital relationships and leverage the strengths of joint decision-making to achieve better-quality decisions.

Keywords

breast cancer treatment, decision-making support, influence of spouse, joint decision-making by couples, marital relationship

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Introduction

Breast cancer is a malignant tumor that has the highest prevalence among Japanese women (National Cancer Center, 2023). In general, breast cancers are treated through a multimodality approach combining surgery, radiation therapy, chemotherapy, endocrine therapy, and anti-human epidermal growth factor receptor 2 (HER2) therapy. Moreover, there has been an increase in the number of treatment strategies available in recent years, including breast reconstruction that considers aesthetic aspects and fertility preservation. In this setting where multiple treatment options are available, patients with breast cancer face difficulties in selecting the best treatment (Ashcroft et al., 1985). This makes it difficult for patients to select and decide on their treatment. Furthermore, patients with breast cancer can expect a long posttreatment survival period, with a survival rate of 80%-90% (National Cancer Center, 2023). However, patients experience treatment-related side effects and complications that affect their lifestyles (Lovelace et al., 2019). The incidence of

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breast cancer is high among Japanese women in their 40s to 60s (National Cancer Center, 2023), when women play a vital role in the family and society with age-specific life events, such as marriage, childbirth, childcare, and careers. Therefore, the everyday family and social lives of patients with breast cancer are greatly affected, requiring complex treatment choices in consideration of the future. The sexual satisfaction of patients with breast cancer and their partners decreases (Martins et al., 2022), which also affects the marital relationship; this suggests that the treatment choice for breast cancer is an issue that must be faced by couples together and not by the cancer-affected patients alone. Furthermore, for the following reasons, deciding which treatment would be best for specific situations among multiple treatment options is not straightforward, as they may affect the lives of those involved (Nakamura, 2010). First, patients with breast cancer generally make primary treatment decisions soon after diagnosis. This makes patients feel rushed and confused because of the need to make decisions in a short period with insufficient information (Kokufu, 2008). Second, when patients are diagnosed with breast cancer, their spouses also experience remarkably similar levels of psychological distress (Segrin & Badger, 2013), which complicates decision-making.

A study that investigated who made health care-related decisions for Nigerian women reported that 33% of such decisions were made jointly as couples, 6% by women alone, and 61% by male spouses alone (Osamor & Grady, 2017). In this manner, there are cases in which a decision is not necessarily made by the patient herself, even if it affects her own medical care. This suggests that decision-making among couples has its own complexities. Furthermore, male spouses of patients with breast cancer are in a special position and are expected to play a central supportive role (Acquati et al., 2023), suggesting that being in this position, by nature, influences decision-making. A recent study by Li et al. (2023) reported that breast cancer is a dyadic stressor that affects spouses. However, the dynamics of what actually occurs when couples make treatment decisions have not been studied holistically. Previous studies on decision-making in marital relationships have focused on identifying the final decision-maker (Dyck & Daly, 2006; Bartley et al., 2005). In addition to these findings, exploring how these decisions are made is important to better understand the complexities of joint treatment decisions by couples.

This study aimed to identify the influence of male spouses on the primary treatment decisions of patients with breast cancer and to obtain ideas for nurses to effectively help patients with breast cancer in making primary treatment decisions given that treatment options are expected to become increasingly diverse in the future.

Patients and Methods

Data Collection

This study was conducted at a single local core hospital in a rural area of Japan between May 25, 2020, and March 31, 2023. Prospective participants were selected by attending physicians of the hospital, and the inclusion criteria were married patients with stage I-III primary breast cancer within 6 months of surgery. We administered semi-structured interviews lasting 30-60 min among participants who signed the informed consent form. The interview guide included questions about the behaviors, actions, and attitudes of male spouses that impressed the participants in the decision-making process and the reasons why they were impressed by these behaviors. As additional reference data, with the participants' consent, we extracted data from their medical records on their age, family structure, course of treatment, and whether the male spouse was present at the medical examinations.

Data Analysis

This study used a qualitative descriptive research design (Sandelowski, 2000). We employed the qualitative content analysis method (Elo & Kyngas, 2008) after transcribing the interviews verbatim. First, the lead author repeatedly read the verbatim records and conducted open coding. Then, subcategories were generated using open coding sheets by multiple researchers, and higher-order categories were generated by focusing on similarities and differences. Furthermore, to gain a deeper understanding of what is happening when couples decide on treatment, core categories were generated and abstracted. When there were no data showing the participants' influencing factors in the analysis process, a second interview was conducted. To enhance reliability and validity, the data were cross-checked under the supervision of a researcher with experience in qualitative oncology nursing research.

Ethical Considerations

The Ethics Committee of Tokushima University Hospital approved this study in compliance with the "Ethical Guidelines for Medical Research Involving Human Subjects."

Definition of Key Terms

- Primary treatment of patients with breast cancer: a series of systemic treatments for patients with breast cancer without distant metastases, aimed at achieving permanent cure.
- Decision-making for the primary treatment of patients with breast cancer: decisions made by patients with breast cancer in selecting primary treatments, including the various choices related to recovering a daily life that may be threatened by cancer.

Table 1. Participant demographics.

Subject	Age	Stage	Surgery	Nonsurgical treatment	Child	Physician consultation with male spouse
A	50s	II	Bt	Adjuvant chemotherapy and endocrine therapy	YES	YES
B	40s	III	Bt	Neoadjuvant chemotherapy	YES	YES
C	50s	I	Bp	Radiation therapy and endocrine therapy	YES	NO
D	40s	I	Bp	Radiation therapy	NO	YES
E	50s	II	Bt	Neoadjuvant chemotherapy and endocrine therapy	YES	NO
F	40s	II	Bp	Neoadjuvant chemotherapy, radiation therapy, anti-HER2 therapy, and endocrine therapy	NO	YES
G	30s	II	Bt	Neoadjuvant chemotherapy, endocrine therapy, and planned breast reconstruction	YES	YES
H	40s	I	Bt	Adjuvant chemotherapy and endocrine therapy	YES	YES
I	20s	I	Bp	Radiation therapy and endocrine therapy	NO	NO
J	40s	II	Bt	Neoadjuvant chemotherapy and anti-HER2 therapy	YES	YES
K	40s	II	Bt	Adjuvant chemotherapy, endocrine therapy	YES	NO
L	50s	I	Bt	Endocrine therapy	NO	NO
M	30s	II	Bt	Neoadjuvant chemotherapy, anti-HER2 therapy, and planned breast reconstruction	NO	YES
N	30s	I	Bt	Endocrine therapy	YES	NO
O	40s	II	Bp	Radiation therapy and endocrine therapy	YES	NO
P	20s	I	Bp	Radiation therapy and endocrine therapy	NO	NO
Q	30s	II	Bp	Neoadjuvant chemotherapy, anti-HER2 therapy, radiation therapy, and endocrine therapy	NO	YES
R	60s	I	Bp	Radiation therapy and endocrine therapy	YES	NO
S	40s	III	Bt	Neoadjuvant chemotherapy, radiation therapy, and endocrine therapy	YES	NO
T	50s	I	Bp	Radiation therapy, adjuvant chemotherapy, and endocrine therapy	NO	YES

Note: Bt = total mastectomy; Bp = partial mastectomy; anti-HER2 = anti-human epidermal growth factor receptor 2

Results

Participant Demographics

Twenty female patients with breast cancer participated in the study, with a mean age of 43.8 years (Standard Deviation= 8.20) and 60% having at least one child. Fifty percent of the male spouses were present at the physician consultations at least once between the time of breast cancer diagnosis and the primary treatment decision. Five participants were interviewed twice. The results are presented in Table 1.

Influence of Male Spouses on Decision-making for the Primary Treatment of Patients with Breast Cancer

Core categories are indicated in **bold**, categories with single quotation marks (‘ ’), subcategories with double quotation marks (“ ”), codes with single angular brackets (< >), and narratives in *italics*. Regarding the influence of male spouses on decision-making in the primary treatment of Japanese patients with breast cancer, the analysis identified the following three core categories: **basis**, **quality**, and **direction of decision-making**. There were 6 categories, 19 subcategories, and 81 codes within these three core categories. We will explain each category and subcategory using particular codes and narratives.

The **basis of decision-making** comprises two categories: ‘obtaining support that enables me to make my own choices in comfort’ versus ‘living true to myself became difficult because contrary to my expectations, I was disrespected.’ The first category, ‘obtaining support that enables me to make my own choices in comfort,’ comprised four subcategories: “recovering from a sense of inferiority arising from the cancer,” “thinking that I can responsibly make my own decisions because I have confidence that my husband will accept my choices,” “having confidence in myself because my husband has thoughtfully encouraged me,” and “feeling less burdened in making choices that may affect my life and the lives of my family.”

Regarding the first subcategory, a participant who had experienced “recovering from a sense of inferiority arising from the cancer,” said, *I thought I will lose my femininity because I will lose my hair due to the chemotherapy and I will not be able to have children in the future. But (my husband) understood how I felt, and this made it easier for me to decide* (H).

Another participant embodied the subcategory (“having confidence in myself because my husband has thoughtfully encouraged me”) when she said, *I do not say that I was unable to make a decision on my own, but I felt uneasy mak-*

ing a life-or-death decision. I was able to have confidence in myself because my husband thoughtfully encouraged me (I). In this manner, 'obtaining support that enables me to make my own choices in comfort' illustrates that participants recovered their mental stability through the involvement of their spouses and felt that they could make their own choices.

The second category, 'living true to myself became difficult because contrary to my expectations I was disrespected' comprised three subcategories: "feeling discouraged and lonely with the indifferent attitude of my husband, contrary to my expectations," "having no peace of mind because I feel I am less respected because I am a woman," and "feeling as if my existence is being denied." One participant said, *I had long thought that married couples are supposed to help each other, but in reality, this is untrue, and I feel lonely* (N). This participant was "feeling discouraged and lonely with the indifferent attitude of my husband, contrary to my expectations." Another participant said, *my husband told me that I could have my breasts removed because it did not matter whether I had breasts or not. I was shocked by his words because I had long thought that I am female and my breasts were important* (P). This participant experienced the situation of "having no peace of mind because I feel I am less respected because I am a woman." In this manner, 'living true to myself became difficult because contrary to my expectations, I was disrespected' illustrates that these participants were hurt because they were not valued by their spouses, who were the very individuals that the participants had most expected would understand them. In other words, the **basis of decision-making** means that spouses' involvement makes it possible for couples to be ready for joint decision-making or, conversely, makes them face difficulties. This suggests that male spouses have a remarkable influence on patients with breast cancer who are preparing to make decisions.

The **quality of decision-making** comprised two categories: 'examining the options together with my spouse will help me recognize values and lead me to a rational choice,' and 'self-determination is disturbed by over-interference and psychological pressure.' The first category further comprised four subcategories: "when various options are presented to me, my perspectives are broadened, enabling me to face myself and make decisions that suit me," "when I was made aware of my role in the family, this gave meaning to my treatment," "my husband helped me control myself when I wished to run away from the difficulties at hand," and "sharing my values and attitudes with my husband enabled me to clarify my wishes, and the answer came automatically."

One participant said, *When I was worried about surgical options and talked with my husband about it, my husband who understands my personality calmly suggested a new option and I felt that that option made sense* (J). Another shared: *Having talked with my husband repeatedly, he helped me to gradually realize what I wished to do* (E). These participants experienced a situation in which "when various options are presented to me, my perspectives are broadened, enabling me to face myself and make decisions that suit me."

Another participant said, *When I needed to make a decision, I immediately felt that I did not want to because it would be too hard. But my husband always emphasized the importance of the outcome. Later, on second thought, I also felt that the outcome of breast cancer treatment was important. In this manner, I was helped by my husband who focused on the outcome from the beginning* (H). This participant experienced a situation in which, "my husband helped me control myself when I wished to run away from the difficulties at hand." In this manner, 'examining the options together with my spouse will help me recognize values and lead me to a rational choice' illustrates that these participants decided on their favored choice themselves after consideration when given an opportunity to thoroughly examine the options with the involvement of their spouses. This type of decision-making is not possible when making decisions alone.

The second category, 'self-determination is disturbed by over-interference and psychological pressure' comprised three subcategories: "my husband forced a treatment on me with an irresponsible attitude without considering my psychological conflicts," "I gave up making decisions by myself and followed my husband's opinion because my husband would not listen to me," and "my husband made me feel guilty for having cancer, and I think I have no choice but to accept his values." One participant stated, *My husband talked as if it were an easy treatment, just saying that anticancer drug treatment would cure me or removing my breast would cure me. He had no concern for me and did not try to understand how I was lost in anxiety* (N). This participant experienced a situation in which "my husband forced a treatment on me with an irresponsible attitude without considering my psychological conflicts." Another participant said, *I reluctantly followed the opinions of my husband although I wanted him to let me do as I wished because it was I who was to undergo the treatment* (A). Meanwhile, another participant stated, *I wanted my husband to respect me as an equal but there was no room for discussion* (K). These participants described their experiences: "I gave up making decisions by myself and followed my husband's opinion because my husband would not listen to me." In this manner, 'self-determination is disturbed by over-interference and psychological pressure,' illustrating that participants were unable to make decisions for themselves because of excessive interference and psychological pressure from their spouses regarding their treatment choices. In other words, the **quality of decision-making** refers to situations in which

the involvement of spouses either increases or decreases the quality of decision-making.

The **direction of decision-making** comprised two categories: 'rethinking their present state as a couple and exploring their future life together' and 'not trying to look ahead, just letting things happen.' The first category comprised three subcategories: "facing the state of the marital relationship and realizing that it will take time to repair it," "confronting treatment with determination from a sense of comfort in being with the husband," and "thinking that we can rebuild our lives as a couple to be able to continue to live together even if we are deprived of the future of having children." One participant said, *I think that falling sick is an awful experience. It reminded me of my marital relationship that I had not cared about before. I feel as if not only the treatment but also all the gears in our life as a couple failed to mesh. To be honest, I still cannot sort out my feelings. I need time to repair my marital relationship* (K). This participant experienced the situation of "facing the state of the marital relationship and realizing that it will take time to repair it." Another participant said, *When I thought about what was most important to us as a couple, I realized that I would like to value a life lived with my husband even if I had to give up hope of having a child, which most married couples hope for* (E). This participant expressed "thinking that we can rebuild our lives as a couple to be able to continue to live together even if we are deprived of the future of having children." In this manner, 'rethinking their present state as a couple and exploring their future life together' illustrates the situation of treating the decision-making process about breast cancer treatment as an opportunity for couples to rethink their present marital relationship, enabling patients to not only choose a treatment but also think about predictions for their future as part of a dyad.

The second category, 'not trying to look ahead, just letting things happen,' comprised two subcategories: "waiting for time to pass without making any predictions about our future together" and "just accepting the recommended choice." One participant said, *I thought I should just go through the treatment period because I would be able to return to my usual life once I finished my treatment. Because I did not try to talk about my disease with my husband very much, I did not think about a bad future* (M). This participant was "waiting for time to pass without making any predictions about our future together." Another participant avoided the burden of making the decision by herself and said, *I was not able to decide about oral hormones on my own and followed the treatment option my husband casually recommended* (D). This participant avoided deciding by herself and preferred "just accepting the recommended choice." This illustrates that the involvement of the spouse in the decision-making process had created emotional dependence and an option for some patients to escape the responsibility of deciding for themselves by 'not trying to look ahead, just letting things happen.' This shows that the **direction of decision-making** can work in two ways depending on the involvement of spouses: to look forward to the future positively or to make passive choices and let things happen without considering the future. The analysis results are presented in Table 2.

Discussion

Influence of Male Spouses on the Treatment Decisions of Patients with Breast Cancer and Joint Decision-making by Couples

To our knowledge, this is the first study to investigate details of the "joint decision-making by couples" in which the wife had breast cancer by identifying the influence of husbands on the decision-making process. Kriston et al. (2010) reported that decision-making begins with disclosure of the need to make a decision. However, joint decision-making among couples may be related to the relationship between the two partners, which serves as the foundation or **basis of decision-making**. Various domains of marital relationships characterize the psychological adaptation to breast cancer (Fergus & Gray, 2009). Specifically, previous studies have described the development of shared coping strategies when multiple parties face problems jointly (Berg et al., 2008; Hagedoorn et al., 2000) and in the use of instrumental and emotional support (Neuling & Winefield, 1988). This aspect of the marital relationship can be observed in the experience of 'obtaining support that enables me to make my own choices in comfort.' In conclusion, marital relationships affect psychological adaptation in patients with breast cancer and form the basis of decision-making.

In terms of the **basis of decision-making**, the participants were ready to make decisions but faced difficulties in doing so because of the influence of their spouses. These difficulties may have led the participants to experience both positive and negative emotions. A recent study suggested that emotions play a vital role in the decision-making process (Barca et al., 2023) and affect rational decision-making. Furthermore, it suggested that positive emotions adjust the framing effect and lead to rational decision-making. This also suggests that the **basis of decision-making** affects the "emotions" that direct rational decision-making and the preparedness for joint decision-making.

Male spouses also affected the **quality of decision-making**. Joint decision-making by couples usually yielded better results than when the decision was made by either party alone. This is because couples may be able to consider more options if both present their individual opinions (Story & Burgard, 2012). This suggests that 'examining the options together with my spouse will help me recognize values and lead me to a rational choice,' which can be considered

Table 2. Influence of male spouses on decision-making in the primary treatment of patients with breast cancer.

Core category	Category	Subcategory
Basis of decision-making	Obtaining support that enables me to make my own choices in comfort	Recovering from a sense of inferiority arising from the cancer
		Thinking that I can responsibly make my own decisions because I have confidence that my husband will accept my choices
		Having confidence in myself because my husband has thoughtfully encouraged me
		Feeling less burdened in making choices that may affect my life and the lives of my family
	Living true to myself became difficult because contrary to my expectations I was disrespected	Feeling discouraged and lonely with the indifferent attitude of my husband, contrary to my expectations
		Having no peace of mind because I feel I am less respected because I am a woman
		Feeling as if my existence is being denied
Quality of decision-making	Examining the options together with my spouse will help me recognize values and lead me to a rational choice	When various options are presented to me, my perspectives are broadened, enabling me to face myself and make decisions that suit me
		When I was made aware of my role in the family, this gave meaning to my treatment
		My husband helped me control myself when I wished to run away from the difficulties at hand
		Sharing my values and attitudes with my husband enabled me to clarify my wishes, and the answer came automatically
	Self-determination is disturbed by over-interference and psychological pressure	My husband forced a treatment on me with an irresponsible attitude without considering my psychological conflicts
		I gave up making decisions by myself and followed my husband's opinion because my husband would not listen to me
		My husband made me feel guilty for having cancer, and I think I have no choice but to accept his values
Direction of decision-making	Rethinking their present state as a couple and exploring their future life together	Facing the state of the marital relationship and realizing that it will take time to repair it
		Confronting treatment with determination from a sense of comfort in being with the husband
		Thinking that we can rebuild our lives as a couple to be able to continue to live together even if we are deprived of the future of having children
	Not trying to look ahead, just letting things happen	Waiting for time to pass without making any predictions about our future together
		Just accepting the recommended choice

higher-quality decision-making that illustrates the positive elements of joint decision-making. However, 'self-determination is disturbed by over-interference and psychological pressure' reflected the behaviors of uncooperative partners in providing one-sided advice (Badr & Taylor, 2009) and exerting excessive control and interference with the patients (Kuijer et al., 2000). Further, some participants in this study felt that "my husband made me feel guilty for having cancer, and I think I have no choice but to accept his values," even when there had been no direct interventions from the male spouses. Osamor and Grady (2018) stated that joint decision-making becomes autonomous when both members of the couple are equal and one is not dominated by the other. This suggests that autonomous decision-making was difficult for patients because of the suppression and control that existed in their usual marital relationships. In other words, the everyday conditions of marital relationships may make individual decision-making difficult because both partners participate in joint decision-making.

Passively, the **direction of decision-making**, as illustrated by 'not trying to look ahead, just letting things happen,' is also a characteristic of joint decision-making. Participants avoided discussing breast cancer treatments by deliberately choosing not to think about it out of their emotional dependence on their spouses. They chose to relieve themselves of the burden of decision-making by entrusting decisions to others. This can arise from mutual avoidance and withdrawal, which are negative aspects of couples coping with

stress (Badr et al., 2010). Regarding the coping strategies of avoidance and withdrawal, Manne et al. (2006) reported that couples who avoided discussing problems experienced higher levels of distress, and Chen et al. (2021) reported that such strategies negatively influenced marital well-being. This suggests that the attitude of 'not trying to look ahead, just letting things happen' is a passive way of decision-making and negatively influences subsequent marital life.

Influence of Male Spouses on Treatment Decisions of Patients with Breast Cancer and Marital Relationships among Japanese Couples

Cultural and psychological factors affect decision-making. Hence, the marital relationship in the specific context of Japanese culture is an essential element when discussing decision-making. The culture of *Sassuru* (to perceive and understand some unvoiced situation) plays a role in Japanese unique cultural aspects. *Sassuru* is a cultural phenomenon of affirming nonverbal communication while estimating and considering the feelings of others based on the situation and atmosphere. Nosue and Hiraki (2008) explained that in this cultural background, couples make the irrational assumption that "if my partner really loves me, my partner should understand my feelings and thoughts without my words." This aspect of the marital relationship can be seen in the participants of this study who experienced a situation where 'living true to myself became difficult because contrary to my expectations, I was disrespected.' This indicates that the participants felt that their male spouses were the person closest to them and hence would understand them; however, they felt disappointed in their husbands because of their attitude. Kashiwagi and Hiraki (2014) pointed out that, at such times, the marital relationship may be negatively affected because one of them feels severely discouraged or develops strong anger and expresses such feelings in an inappropriate manner (Kashiwagi & Hiraki,2014). Furthermore, Trubisky et al. (1991) reported that when such marital conflicts occur, Japanese couples in their collectivistic culture often deal with them in an avoidant manner. Hirayama and Kashiwagi (2001) reported that Japanese couples commonly avoid communication, such as by "saying nothing." In the field of psychology, Syoji (2006) suggested that such coping strategies have positive implications for maintaining long-term relationships through emotional problem-solving and avoiding escalating problems. However, such strategies also pose the risk of negatively affecting the marital relationship (Manne et al., 2006). Therefore, when patients with breast cancer and their spouses encounter such an unknown crisis, Japanese couples may face marital conflicts that do not exist in European countries or the USA because of the Japanese attitude of assuming the adequacy of nonverbal communication. Under such circumstances, it is exceedingly difficult for patients with breast cancer to make decisions by considering their future.

In the experience of 'self-determination is disturbed by over-interference and psychological pressure,' the participants faced a situation where they had to make unfavorable decisions regarding their treatment choices by following the choice of their spouses because of excessive intervention and psychological pressure from the latter. It can be inferred that disharmony was caused by differences in understanding between the husband and wife because the husband was upset and confused by the sudden occurrence of breast cancer in his wife, and his attitude and behavior failed to convey his feelings to his wife. Northouse et al. (1998) reported that, in the first place, couples undergoing malignant cancer treatments face more uncertainty about the nature and course of the disease than those facing benign tumors. A study conducted in Japan reported that male spouses felt upset and had difficulty with this uncertainty, as illustrated by their statements that they did not know what to do to support their wives or understand their feelings (Koga et al., 2014). Furthermore, following their wives' diagnoses of breast cancer, over 70% of husbands are concerned about the disease's effect on the lives of their wives (Akamine, 2001). This suggests that it is a natural reaction for husbands to prioritize treatment and that the husbands in this study made choices to prevent their wives from dying. According to O'Mahoney and Carroll (1997), husbands felt that they must behave appropriately to ensure that their wives can rely on them. Baider et al. (2004) reported that husbands often avoid openly discussing the disease to hide their feelings, although they intend to perform a shielding role to protect the patients, that is, their wives, because they have incorrect perceptions about providing appropriate support. In other countries, it is known that if husbands solve problems with their wives in a positive manner, their wives' mental health and marital satisfaction are better than when husbands hide their concerns or adopt overprotective attitudes toward their wives (Hagedoorn et al., 2000). For these reasons, it can be inferred that the cultural background of Japanese couples may have prevented them from adopting effective coping strategies when faced with the crisis of a breast cancer diagnosis and that this influenced the quality of their decision-making.

Implications for Nursing

This study revealed the advantages and disadvantages of joint decision-making by couples with respect to the primary treatment of wives who have breast cancer. Previous studies reported that joint decision-making by couples improves reproductive health outcomes (Mullany, 2010) and may respect the autonomy of females (Osamor & Grady, 2018). Furthermore, the findings of this study showed that joint decision-making by couples may lessen their psychological distress arising from cancer and enable better-quality decisions. These findings suggest that healthcare professionals

should help patients with breast cancer and their spouses make better decisions by leveraging the strengths of joint decision-making when providing decision-making support.

To further leverage the strengths of joint decision-making, it is important to evaluate the marital relationship, which is the basis of decision-making, in addition to providing support in the decision-making process. An early approach to marital relationships can enable male spouses to become involved in breast cancer treatment and contribute to building a positive decision-making basis. If couples face better treatment decision-making in a relationship than previously in their marital relationship and improve the disharmony between them caused by the Japanese cultural background, the couple may make decisions based on their values. Further studies are needed to develop methods to evaluate the marital relationship that affects the **basis of decision-making** and to develop a joint decision-making support model to effectively allow male spouses to be involved in decision-making.

Limitations

Because this study was conducted at a single institution and the ages of the participants varied widely, the influence of breast cancer treatment on unique lifestyles may not have been duly considered. Further, this study only included female patients with breast cancer; including the perspectives of male spouses in the survey could contribute to a better understanding of aspects of the interactions between husbands and wives in their decision-making.

Conclusions

This study identified three core categories that show the influence of spouses of Japanese patients with breast cancer on decision-making regarding primary treatment: the **basis, quality, and direction of decision-making**. These three core categories comprised six categories: 'obtaining support that enables me to make my own choices in comfort'; 'living true to myself became difficult because contrary to my expectations I was disrespected'; 'examining the options together with the spouse will help me recognize values and lead me to a rational choice'; 'self-determination is disturbed by over-interference and psychological pressure'; 'rethinking their present state as a couple and exploring the future of their life together'; and 'not trying to look ahead, just letting things happen.' In providing decision-making support concerning the treatment of patients with breast cancer, it is important to evaluate the marital relationship by fully considering the influence of the male spouse in consideration of the Japanese cultural background and leveraging the strengths of joint decision-making to realize better-quality decisions.

Author Contributions

Yuki Ichimiya: conception and design of the study, acquisition of data, analysis and interpretation of data, drafting the article, critically revising it for important intellectual content, and final approval of the version to be submitted. Yoshie Imai: conception and design of the study, analysis and interpretation of data, drafting the article, critically revising it for important intellectual content, and final approval of the version to be submitted. Chiemi Onishi: conception and design of the study, analysis and interpretation of data, drafting the article, critically revising it for important intellectual content, and final approval of the version to be submitted. Megumi Kishino: drafting the article, critically revising it for important intellectual content, and final approval of the version to be submitted.

Declaration of Conflicting Interests

The authors declare that there are no conflicts of interest.

Ethical Approval

The Ethics Committee of Tokushima University Hospital approved this study [No. 3702].

Informed Consent

Informed consent was obtained from all participants.

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Original Research

Public health nurses' attitudes in dialogue with parents and families in a qualitative descriptive study: A dialogical childrearing support

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Abstract

Objective: This study aimed to clarify the attitudes of public health nurses (PHNs) endeavor to adopt when engaging in dialogue with parents and families for providing ongoing childrearing support. **Methods:** This was a qualitative descriptive study. We collected data through semi-structured interviews. The data were qualitatively and inductively analyzed. **Results:** The study participants were 10 PHNs with 6-30 years of experience; all of them had work experience in areas such as maternal/child health and child welfare. The PHNs' attitudes in the dialogue were as follows; the attitude of overlaying each other's stories, diversifying the narrative and leaving the conclusion to the future, and returning the story to the other party and being ready to resume the dialogue at any time. **Conclusions:** The PHNs tried to create a story together with the parents and family and continued the dialogue with the aim of letting the parents and family walk the story on their own. We propose a style of support called "dialogical childrearing support" which is the idea of supporting childrearing by continuing dialogue and co-creating the childrearing story.

Keywords

childrearing, attitude, communication, interpersonal relations, qualitative research

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Introduction

The birth of a child or the addition of a family member is a significant event for both the parents and the family. Through their interactions with their children, parents learn the unique signs of their children and accept their growth and development (Friedman, 1986). Each family member assumes a new role and develops a new relationship (Friedman, 1986). Childrearing is a meaningful experience for parents and families, but it can also be a source of distress and anxiety for parents, as it is reported that approximately 15% of mothers suffer from depression (Bauman et al., 2020; Horowitz & Goodman, 2005; O'hara & Swain, 1996); therefore, the birth of a child can also lead to a family crisis (Friedman, 1986). Early care is also essential for families with anxious and stressed parents to prevent child abuse and neglect, which are high-priority problems (WHO, 2006). The ongoing care of children and families can reduce the risk of recurrence of maltreatment and can minimize its consequences (WHO, 2022). In Japan, too, emphasis is being placed on continuity in seamless support from pregnancy to childrearing to respond early to childrearing concerns and worries and to prevent child abuse and neglect (Children and Families Agency, 2015).

PHNs are professionals who can be involved with parents and families from the planning pregnancy stage and have many opportunities to hear from parents and families about childrearing. In childrearing support, dialogue between par-

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ents/families and professionals helps parents and families discover unique meanings and stories (Clement & Kenny, 2019; Huhnen, 2019). Previous research has reported that the role of the PHN in dialogue with parents and families includes being there to listen and understand them (Alstveit et al., 2011; Jack et al., 2005; Rifai et al., 2018; Schaffer & Mbibi, 2014; Vehviläinen-Julkunen, 1992), giving expert advice and providing information (Moody, 1993; Schaffer & Mbibi, 2014; Tammentie et al., 2009; Vehviläinen-Julkunen, 1992), affirming parents and their childrearing (Alstveit et al., 2011; Jack et al., 2021; Vehviläinen-Julkunen,1992), and helping with decision-making (Schaffer & Mbibi, 2014). PHNs were able to develop a working alliance with many families during home visitation for the tertiary prevention of child maltreatment (MacMillan & Thomas, 1993). PHNs continued to build a relationship of consultation in support for parents with mental illness (Kageyama & Yokoyama, 2018). Additionally, it has been reported that PHNs' support for mothers was correlated well with mothers' positive assessments of the mutuality and flexibility of their families (Hakulinen et al, 1999). PHNs have the skills to build good relationships with families during childrearing, and the relationship between PHNs and parents supports healthier childrearing. However, to date, no studies have explored the dialogue between parents/families and PHNs in ongoing childrearing support, and it is not clear what attitudes PHNs have when engaging in dialogue.

The aim of this study was to clarify the attitudes of PHNs toward dialogue when engaging in dialogue with parents and families for providing ongoing childrearing support. Then, based on the clarification of the attitudes of PHNs, a way of providing childrearing support was considered. The significance of undertaking this research is that it makes it possible to examine the attitudes of PHNs keep the dialogue going with parents and families.

Materials and Methods

Theoretical Perspective

This study is based on the epistemology of Bateson (1972) and relies on the social constructivist position. Bateson (1972) proposed an epistemology that considers things in a circular fashion, stating that "a 'bit' of information is definable as a difference that makes a difference. Such a difference, as it travels and undergoes successive transformation in a circuit, is an elementary idea." Based on this epistemology, social constructivism can be understood. "The social construction theorists see ideas, concepts and memories arising from social interchange and mediated thorough language" (Hoffman, 1992). The attitudes of PHNs during dialogue that this study sheds light on is socially created through the relationship between the parent/family and the PHN and the relationship between the PHN and the interviewer. As PHNs become more aware of this, their understanding will deepen.

In this study, dialogue is the effort to seek and understand meaning (Anderson et al., 2013). Attitude is the mindset, feeling, and stance for making sense. The exchange of words is not important. Even if the exchange is nonverbal or takes place in a shared atmosphere, it is important that the participants in the dialogue believe in the possibility of creating new meanings and that they are in a relationship of trying to understand the other party. In this study, a story is "a sequence of events and the plot that connects them" (Morioka, 2009).

Study Design

This is a qualitative descriptive study that offers a comprehensive summary of an event in the everyday terms of those events (Sandelowski, 2000). The attitude of the PHN during dialogue with parents and families, which this study seeks to shed light on, is understood by individual PHNs through their interactions with parents and families and is discussed in a variety of ways in their interactions with the interviewer. Therefore, to accomplish the research objectives, a method was needed to describe the complex experiences and emotions in detail.

Data Collection Method

PHNs with experience in providing childrearing support were recruited as study participants. The first author asked the gatekeeper for help in recruiting. In ethnographical methods, gatekeepers provide access to the culture, facilitate data collection, and increase the legitimacy of the researcher (Gray & Grove, 2021). In this study, we asked the gatekeeper for cooperation, just as we did with the fieldworker, to enable access to fields where PHNs provide child care support work. The gatekeeper was someone who knew the tasks for which each public health nurse was responsible and the hours they worked. The gatekeeper was also a PHN who had discussions with the first author regarding ongoing childrearing support. The gatekeeper informed the PHNs working in maternal health or child health/welfare departments at administrative agencies about this study and introduced interested PHNs to the first author. At their own request, the gatekeeper also participated in the study. The first author also performed snowball sampling.

Semi-structured interviews were conducted to collect data. The attitudes of PHNs are not verbalized on a day-to-day basis. Therefore, a method that would allow the PHN and the interviewer to explore and verbalize the PHN's attitude together while gradually gaining an understanding of the PHN's experience was appropriate. The interviewer is the first author. Interviews were conducted in Japanese, which is the native language of the participants. Interview times ranged from 54 to 151 minutes. During the interviews, the

first author asked the study participants about the stance they endeavor to adopt in dialogue for ongoing childrearing support, as well as how they view their own roles, conflicts, and techniques. During the interview, the interviewer listened to what the interviewee had to say while showing an interest in their experience, thereby adopting a "the not-knowing position" (Anderson & Goolishian, 1992).

Interviews were conducted in a room at the participant's place of employment or in a public facility, where privacy was ensured. The interviews were recorded using a voice recorder and transcribed verbatim with the permission of the participants.

Data Analysis Method

The data were qualitatively and inductively analyzed, and thematic analysis (Gray & Grove, 2021) was employed. The attitude of a PHN is intrinsic and transcends differences in cases and events. Therefore, the interview emphasized careful listening and in-depth interpretation of the PHN experiences. Data analysis began in parallel with recruitment and data collection. The data were analyzed from the perspective of how attitudes are discussed during dialogue with parents, how such attitudes are created, and why PHNs talk about their own attitudes in the way they do. In this study, we focused on PHNs' experiences in dialogues with parents/families and created categories from multiple PHNs' narratives. The verbatim transcripts and audio recordings were referred to repeatedly during the analysis.

Thematic analysis develops themes by exploring the relationships between codes and grouping them using interpretive statements (Gray & Grove, 2021). Frequently, the analysis progresses from smaller meaning units, and the researcher proceeds through coding to find themes and patterns (Gray & Grove, 2021). In this study, as well, each transcript was coded, and each code was synthesized into categories by exploring relationships and interpretations. The analysis was performed according to the following procedure. First, from the verbatim transcripts of each study participant, the attitudes and efforts of PHNs in their dialogue with parents/family were extracted in the form of sentences based on semantic clauses. The extracted sentences were coded to reflect the PHN's attitude toward dialogue and their beliefs. When creating the codes, we used descriptive coding (Gray & Grove, 2021), which classifies the elements of the data using terms that are close to the participant's words. After the descriptive coding of some participants' sentences, we used interpretive coding (Gray & Grove, 2021), which involved labeling the coded data with more abstract terms that represent the merged codes, in parallel with the descriptive coding. The codes were grouped by examining similarities and differences among the codes, and subcategories were generated. Finally, the relationships among these subcategories were examined to generate categories. Subcategories and categories were named using expressions that summarized their content.

The analysis was conducted by the first author. The reason for this is that in this study, it was necessary to carefully and deeply understand the meaning of the participants' narratives while considering the support of PHNs. After the analysis, the second and third authors were asked to comment on the appropriateness of the codes and subcategories/categories.

All analytical processes were conducted in Japanese. After the analysis was completed, it was translated into English by a native English speaker familiar with Japanese.

Saturation of data occurs when additional sampling provides no new information, only redundancy of previously collected data (Gray & Grove, 2021). With this study, too, data sufficiency was also determined to have been reached when no new codes and subcategories were generated to add new data. The commonly used methods of ensuring rigor are member checking, triangulation, and researcher debriefing (Gray & Grove, 2021). In this study, member checking was performed to ensure the rigor of the analysis. Study participants who consented to participate in the examination participated in the study.

Research Team and Reflexivity

In this social constructivist study, ideas were socially created between the researcher and the participants, and the researcher's experiences influenced the interpretation of the findings. The first author was a researcher with previous experience of providing childcare support as a public health nurse and experience in some types of qualitative research with a nursing doctoral degree. The first author had previously worked as a PHN in the same city as some of the study participants, so some of the study participants knew the first author before participating in the study. The first author was committed to reflexivity and strove to put own beliefs into bracketing. Reflexivity is defined as researchers' self-awareness, understanding, and acknowledgment of their personal biases and influence on the topic and the participant (Gray & Grove, 2021). All study participants were informed by the first author that she had experience as a public health nurse and the reasons for the study design.

The second and third authors were researchers with a nursing doctoral degree who conducted qualitative research on childrearing support. The second author had experience as a public health nurse, and the third author had experience as a pediatric nurse. All the researchers were women.

Ethical Considerations

The study was explained to each potential participant orally along with a written document that described. Those who agreed to participate in the study through written and oral communication were designated as study participants. All

Table 1. Participant information.

Name (Pseudonym)	Workplace	Time in working years as a PHN	Interview time	Interview date
Ichikawa	X city	20	114 min	Sep. 2020
Futagawa	X city	30	106 min	Sep. 2020
Mimura	X city	22	84 min	Sep. 2020
Shinjyo	X city	7	72 min	Sep. 2020
Goto	X city	19	82 min	Sep. 2020
Mukai	X city	22	151 min	Sep. 2020
Nanase	X city	9	73 min	Oct. 2020
Hachiya	Y town	11	63 min	Mar. 2021
Kubota	Y town	20	65 min	Mar. 2021
Tokazu	Y town	6	54 min	Apr. 2021

Table 2. Categories and subcategories.

Categories	Subcategories
Attitude 1: Overlapping Each Other's Stories	Be recognized as a listener of the story and strive to be a storyteller yourself
	Aiming for a "you and me" relationship
	Feel that dialogue will continue through work with parents and family members and should reflect on one's own attitude
Attitude 2: Diversifying the Narrative and Leaving the Conclusion to the Future	Strive to assign equal value to various ideas to make the choice free
	Acknowledge that there is a blank space and be prepared to continue creating the story together
	Recognize the diversity of PHNs themselves
Attitude 3: Return the Story to the Other Party and be Ready to Resume the Dialogue at any Time	End the dialogue in a "to be continued" manner
	Let go so that the parents and families can walk through their stories on their own

participants provided written consent for data collection and the publication of anonymized results. Participants were allowed to withdraw from the study at any time. To protect participants' confidentiality, all study participants were assigned pseudonyms in the transcription of audio recordings. The study was first explained to the gatekeeper from the first author. The study was then explained to those who were introduced by the gatekeeper, from the first author. The study was approved by the ethics committee of Hamamatsu University School of Medicine (No. 20-031) and was conducted in accordance with the Declaration of Helsinki.

Results

Summary of the Study Participants

The study participants were 10 PHNs with 6-30 years of experience who had work experience in areas such as maternal/child health and child welfare (Table 1). In Japan, a PHN is a national qualification and has a nursing license, and most PHNs are employed by administrative agencies. The participants in this study were government employees working full-time in city X (with a population of approximately 130,000) or town Y (with a population of approximately 40,000. When data from the tenth participant were added to the analysis, no new codes and subcategories were generated.

Eight participants participated in member checking. They strongly identified with all subcategories and categories and responded that these categories represented what themselves valued.

PHN Attitudes in the Dialogue

Three categories and eight subcategories were generated as attitudes of the PHNs in the dialogue (Table 2). Moreover, several categories were accompanied by conflicts about relationships in dialogue and one's role in this dialogue now.

The *italics* in the text represents excerpts from the narratives of the participants and the first author. In addition, parentheses ( ) denote narrative outlines and words supplemented to make the meaning of the dialogue easier to understand.

Attitude 1: Overlaying Each Other's Stories

This was the attitude of the PHNs in trying to understand the parents' values, beliefs, and ways of thinking about childrearing and to create a way of thinking about childrearing that overlays the ideas of the PHN and the parents. The three subcategories constructed this attitude.

Be Recognized as a Listener of the Story and Strive to be a Storyteller Yourself

The PHNs strived to acknowledge the parent/family's story and recognize the parent/family as listening to the story. When the PHNs themselves felt that they wanted to tell their own stories, they tried to be storytellers as well. However, with this attitude, the PHNs were conflicted about what kind of relationship they should adopt in their conversations with the parents and what opinions they should convey as professionals.

Mimura: I felt like I was saying the same thing all the time and giving guidance from the top, which was kind of... (uncomfortable). There were times when I felt like, "If this person is happy, then why not?" (But) I thought I shouldn't say such things (as a professional), so I tried my best to hold back. (Omitted) At that time, I decided to stop providing guidance. When I started talking about how to be there for them, like, "It's okay if you're happy," "It's okay if you want to see a doctor when you want to see a doctor," "If I were to send my child to a doctor, I would send them here," and so on, the mothers surprisingly accepted my advice. ... I felt that the conversation went much more smoothly if it were a place where they could ask for advice when they wanted to.

Aiming for a "You and Me" Relationship

To create this future story with the parents, the PHNs aimed to transcend the relationship between the PHNs and residents and establish "you and me" as the only relationship. To achieve this, the emphasis was on becoming people who shared a situation or atmosphere and who could tell each other their stories.

Mukai: Yes, I want to find out about you. I said if you are having any problems right now with the children you are raising, I can't think about how to solve them with you if I don't know you. I can't help you if I don't know what your values are and how you want to raise this child. ...

Yamamoto: Okay, so it's not a stance of "I'm here because I'm worried about your child."

Mukai: Right. It's not.

Kubota: When the IV an hour or two while was finished and she (the mother) came out, I was in the waiting area, so she (the mother) said to me, "You didn't go back?" (Then I said to the mother) "You say that you have no relatives around, and that you're not feeling well, right? You're inconsolable, aren't you? You almost want to die, don't you? There was no way I could leave you alone like that." That's when she started pouring all her feelings out." When the mothers opened their hearts, the children began to open (their hearts) as well.

Feel that Dialogue will Continue through Work with Parents and Family Members and Should Reflect on One's Own Attitude

The PHNs felt that the dialogue had continued partly because of the support from their parents and family members. Furthermore, the PHNs were concerned about their ability to offer more effective suggestions after listening to the stories of the parents/family and whether they could have offered a different story.

Goto: (When they were worrying about when to tell the mother that the child had developmental delays and that putting the child in a developmental support center would promote the child's growth and development) After the child entered the developmental support center, she (the mother) was kind enough to say, "You (PHN Goto) really wanted to tell me, but you just couldn't bring yourself to, right?" She said, "The truth is that when you first interviewed me here, you thought that my child should go to a developmental support center, didn't you?" "At that time (during the first interview), I wasn't ready to accept it. But now we can even talk about things like this," she said.

Tokazu told the following story:

One day, during a heavy rainfall, a mother was compelled to leave her home with her newborn second child. The mother had lost custody of her first child to a child welfare facility, so she repeatedly expressed her determination to never be separated from her child again. She stated that she intended to take the child to the home of a man she had just met; however, as a PHN, Tokazu could not approve of this plan. Tokazu understood the mother's feelings about losing her first child and her subsequent loss of confidence in her ability to raise children, but there was no way around it.

Tokazu: "Well, let's just take the child into care, and when you get back on your feet, let's make arrangements so that you can live together again," I said, and we ended up only taking the child into care. I really couldn't forget the look on the mother's face at that moment. Because I wondered whether I'd actually done the right thing. Even now, the mother and child are still living apart.

Attitude 2: Diversifying the Narrative and Leaving the Conclusion to the Future

This was the attitude of PHNs to try to diversify the parent's way of thinking about childrearing, not to rush to choose a way of thinking, and to continue dialogue until the parent found a way of thinking that satisfies them. The three subcategories constructed this attitude.

Strive to Assign Equal Value to Various Ideas to Make the Choice Free

The PHNs strived to make the narrative polysemic (polyphonic). To this end, they presented a variety of stories in their dialogues with parents, including their own professional stories, the stories of parents they had met, and the stories of PHNs and other professionals other than themselves. The parents also tried to talk to people other than the PHNs. The PHNs shared their honest impressions of their parents' stories and the PHN's own difficulties to allow the dialogue to develop from a different perspective than before.

Mimura: It's less me saying that you should do this, and more me saying that I think this. I've seen various cases up to now, and somehow, when I think of this or that child, I feel like this is the right time to make a change. ... But choice is made by mom and dad. I said that in the end, I can't be with that child for the rest of their life, so the decision is yours and your family's. ... I also speak as someone who has been involved in the rehabilitation of various children from a different standpoint (from that of their fathers and mothers), and that's why I think like this.

Acknowledge that There Is a Blank Space and Be Prepared to Continue Creating the Story Together

The PHNs accepted that the future would not be as they had envisioned and that there is unobservable blank space as the child's growth and development, parental attitudes, family situation, and support system change. To provide support in the midst of uncertainty, the PHNs prepared to continue creating the story with the parents. However, the PHNs were conflicted and worried about what to tell the parents at this point in time for the sake of a future that could not be foreseen.

Mimura: At this point in my experience, I felt this was the best thing to do, but you never know how the world will change in the future. There is a possibility that the father and mother will meet someone special as a result of their choices, that a more accepting system will be established, or that things will get better. So it's like I support them (the paths chosen by the parents). ... So, yes, in terms of mental attitude, well, I guess you have to be prepared to some extent.

Yamamoto: Be prepared?

Mimura: Be prepared. Like, even if something happens, you're still willing to engage with them.

Mukai: An ongoing relationship requires, after all ... preparedness, I guess.

Yamamoto: Preparedness? What kind of preparedness?

Mukai: Not to abandon them, ever. ... Preparedness means committing to never abandoning them. It's that sort of attitude. Yep, that's it.

Recognize the Diversity of PHNs Themselves

The PHNs acknowledged their own diversity, feeling that they have their own way of listening and talking that differs from other PHNs and that their own ideas about childrearing change as they gain experience.

Ichikawa: We (each PHN) are totally different as supporters, and each of us has our own character. And I wondered what my own character was. I guess that (the kind of relationship to adopt when talking) is something I've cultivated myself through my interactions with people.

Shinjyo: I would tell parents who did not bring their children (for post-natal checkups) ... that they might be suspected of abusing them. That was the way I looked at them. But now (since giving birth myself), I don't think in that way at all.

Attitude 3: Return the Story to the Other Party and Be Ready to Resume the Dialogue at Any Time

This was the attitude of the PHNs in which the PHNs gradually erased their presence in the dialogue so that the parent could proceed with childrearing proactively, after maintaining a relationship in which the parent could resume dialogue when the parent needed. Two subcategories construct this attitude.

End the Dialogue in a "To Be Continued" Manner

The PHNs understood that worries about childrearing come up repeatedly and should be discussed with parents and families at the time they arise, and they accepted that the dialogue with parents and families would end with a "to be continued."

Futagawa: I always say, "Okay, that's enough for today," indicating that the dialogue is to be continued. Because worries are never ending. ... If they find themselves at a loss again, the grandma will probably come, and that's continuation, I think. They can come to me whenever they need help. It has to end with a relationship with someone who can come back.

Let Go so that the Parents and Families Can Walk through Their Stories on Their Own

The PHNs tried to help the parents and families walk through their stories on their own while returning problems that had arisen to the family as their own problems or stating cold, hard facts. The PHNs hoped that one day, they would return to the background of the story.

Futagawa: You can't get too close to them. Let's see, you have to scold them like a mother would. You can't just be a supporter saying that whatever they do is fine. (Omitted) The goal of ongoing support is independence, so if you want them to be able to stand on their own two feet, I don't think you can just sit there, saying, "Nice, nice."... So mine (goal of support) is to get every parent, whatever kind of parent they are, to stand on their own feet somehow.

Mukai: In my case, how can I put it, I just hope that the person will forget about me someday. In the future, it's enough for them to have just a dim memory of me, along the lines of, "Oh, come to think of it, when I was having

problems many years ago, I talked to someone at city hall."

Discussion

PHN Attitudes in the Dialogue

In the dialogue, the PHNs endeavored to overlap the stories told by the parents and families with the stories that the PHNs themselves had come up with, leaving the conclusions to the future and creating diverse narratives about childrearing. In other words, the attitude of the PHN was to work with parents and families to understand childrearing in multiple ways. Several approaches have been proposed to diversify ways of looking at things, with the goal of "continuing" the dialogue rather than aiming for conclusions or decisions (McNamee & Gergen, 1992; Seikkuka & Arnkil, 2006). The "attitude of tolerating narrative diversity and leaving the conclusion of the story to the future," as described by the PHNs in this study, was similar to the attitudes in these approaches. In contrast, the PHNs clearly positioned the parents/families' ability to walk through their stories, created together with the PHN, on their own as a reason to continue the dialogue. The PHNs then returned the story to the other party and were ready to resume the dialogue at any time. This attitude had not been focused on in previous approaches and was an important dialogue attitude that was verbalized through this study.

Two Characteristics Underlying Attitudes to Dialogue

We believe that the attitudes of PHNs toward dialogue presented in this study are underpinned by two characteristics of their activities. First, there is uncertainty about the support. In this study, the PHNs co-created the childrearing narrative with the parents and families and continued the dialogue with the goal of enabling the parents and families to walk through their stories on their own. The stories beyond the dialogue and the ways in which these stories are told are diverse and variable. Therefore, there are many uncertainties in the support, and it is difficult to make predictions. Uncertainties always arise during support. Open dialogue, which emphasizes democratic conversation with mutual respect (Seikkula & Arnkil, 2006), also exhibits one of the attitudes toward dialogue: "tolerance of uncertainty" (Olson et al., 2014; Buus et al., 2021). We believe that this characteristic of the activity—namely, that uncertainties always arise—will naturally make PHNs conscious of their tendency to overlap each other's stories, to tolerate narrative diversity, and leave the conclusion to the future.

Second, support is accompanied by conflicts. The PHNs were conflicted over how to behave as a PHN in a dialogue relationship and what they could do now to prepare for the future. In a previous study, PHNs reported having a dilemma when a client's decision did not match the nurse's own professional assessment (Suzuki et al., 2015). Conflict is a necessary experience to change one's way of thinking. Learning about diversity in ways of looking at things is said to involve conflict due to contextual inconsistencies (double bind) (Bateson, 1972). In addition, when learning to understand meaning, it is important to question the assumptions on which judgments are based (Mezirow, 1991). In this study, conflict also provided an opportunity for PHNs to question their own thinking about their previous roles in dialogue and approaches to childrearing support. The conflict caused the PHNs to question the roles of PHNs required for dialogue with parents and families and childrearing support. We believe that PHNs will be conscious of their tendency to overlap each other's stories, accept narrative diversity, and leave the conclusion to the future.

Concept of "Dialogical Childrearing Support"

In this study, based on the clarified attitudes of PHNs, we propose a type of support called "dialogical childrearing support." Dialogical childrearing support is the idea of supporting childrearing by continuing dialogue and co-creating a childrearing story. Previous research has identified the role of the PHN in dialogue with parents and families as facilitating interaction (Alstveit et al., 2011; Jack et al., 2005; Jack et al., 2021), and reported that dialogue needs to involve a relationship of trust (Helle et al., 2023; Jack et al., 2005; Jack et al., 2021; Paavilainen & Åstedt, 1997; Rifai et al., 2018; Schaffer & Mbibi, 2014), a collaborative and equal partnership (Phelan, 2014; Sato, 2018; Tammentie et al., 2009), and a relationship of mutual respect between parents and professionals (Sato, 2018). The relationship that underpins childrearing support is the relationship between the PHN and the parents/family. In addition, the participants understood that childrearing support was not based solely on the efforts of PHNs but rather on their collaboration with parents and families. Childcare support is created through collaboration between parents/families and PHNs. This suggests that it is possible to consider "PHNs and parents/families" as a single unit for childrearing support. "Dialogical childrearing support" is a term used to refer to childrearing support as an interaction. We believe that dialogical childrearing support will make it easier to recognize the co-creation by parents/families and PHNs of childrearing stories, thereby making the stories more diverse as one way of supporting childrearing. We believe that each PHN will find a new understanding of the attitudes of PHNs as presented in this study through the provision of childrearing support, personal reflection by PHNs, and discussions with others. They will also reconsider childrearing support, leading to the maintenance of a dialogical attitude and the continuation of childrearing support.

Limitations and Future Outlook

This study shed light on the attitudes of PHNs in ongoing

dialogue with parents and families. In the future, it will be necessary to examine how scaffolding these attitudes can change the attitudes and practices of PHNs in their dialogues. Although the participants in this study were PHNs who provided support with maternal and child health and childrearing, the PHNs' narratives were also influenced by their previous experiences, such as their health-related work with the adults and the elderly. Therefore, the attitudes of PHNs presented in this study may be generalizable to other activities of PHNs in addition to childrearing support.

Conclusion

In the dialogue, the PHNs endeavored to overlap the stories told by the parents and families with the stories that the PHNs themselves had come up with, leaving the conclusions to the future and creating diverse narratives about childrearing. The PHNs tried to create a story together with the parents and family and continued the dialogue with the aim of letting the parents and family walk the story on their own. In this study, we propose a type of support called "dialogical childrearing support." Dialogical childrearing support is the idea of supporting childrearing by continuing dialogue and co-creating a childrearing story.

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Author Contributions
Mami Yamamoto designed the study, analyzed and interpreted the data, and prepared the manuscript. Akiko Kadoma and Midori Asano supervised data analysis and critically reviewed the manuscript.

Declaration of Conflicting Interests
We have no conflicts of interest to disclose.

Ethical Approval
This study was approved by the Ethics Review Committee of Hamamatsu University School of Medicine [No.20-031].

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Informed Consent
Informed consent was obtained from all participants.

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Original Research

Characteristics of difficulties, information acquisition, and needs of working patients undergoing hemodialysis and their relationships with the acceptance of changes in job status: A pilot study

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Abstract

Objective: This study aimed to clarify the difficulties, information acquisition, and needs of working patients undergoing hemodialysis and identify the factors that are important for continuing to work. **Methods:** This survey involved individuals aged >20 years who were working and undergoing outpatient hemodialysis in Ishikawa Prefecture. Descriptive statistics were used to determine the actual situation with regard to three factors: difficulty, information acquisition, and needs. The relationship between the presence of changes in job status and the acceptance of such changes was also analyzed. The Mann-Whitney *U* test and categorical regression analysis were used for the analysis. **Results:** More than 60% of participants experienced difficulty in "fluid management" and "restraints owing to hemodialysis." The mean scores for difficulty in "sleep management," "shunt management," "physical instability," "mental health," and "job content" were significantly higher (from p=.013 to p=.046) in the groups with changes in job status. Results of the categorical regression analysis showed that factors related to "change as desired," "personnel evaluation, promotion, and salary increase," "workplace relationships," and "fluid management" explained 61.9% of the acceptance of changes in job status. **Conclusions:** The present findings indicate the necessity to be mindful of work, sleep, physical condition, shunt management status, and mental health when there are changes in job status as a result of undergoing dialysis. Personnel evaluation, promotion/salary increase, workplace relationships, and fluid management were also identified as factors to be considered when accepting changes in job status.

Keywords

hemodialysis, working, difficulties, information acquisition, needs

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Introduction

There are over 340,000 patients undergoing hemodialysis in Japan (Japanese Society for Dialysis Therapy, 2022a), and approximately 34% of them are working (Japanese Association of Dialysis Physicians, 2021a). When undergoing hemodialysis, patients are required to change their meal content and regulate fluid intake; these changes and limitations are the major stress in their lives (Masaki et al., 1990; Sherriff-tadano & Ohta, 2006; Hong et al., 2017). Their tiredness is more severe on dialysis days than on days without dialysis (Nakahara et al., 2019; Debnath et al., 2021; Bossola et al., 2023). It is difficult to balance dialysis and work (i.e., "continuing to work") while managing their lives and physical

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condition.

In recent years, the proportion of single-person households has been increasing in developed countries, with the percentage exceeding 30% (Ministry of Health, Labor and Welfare, 2023; OECD, 2016); this situation leads to an increase in the number of patients who must continue working for economic independence. We must prevent patients from quitting work because of dialysis. Work is part of self-actualization and is associated with improved mental quality of life (Ikegami et al., 2017; Hao et al., 2024); therefore, continuing to work is spiritually and financially essential.

Difficulties related to continuing to work include self-management of fluid intake, weight, diet, and medication, easy fatigue, commuting, and work restrictions (Nishiyama & Takahashi, 2016; Oyama, 2014; Tsutsui et al., 2017). However, it is unclear which factors they find particularly difficult and what they feel needs to be done to cope with such difficulties.

No previous studies have focused on their needs and examined the actual situation. However, there have been studies conducted from the perspective of whether dietary interventions are associated with improved self-management behaviors (Naseri-Salahshour et al., 2020); it was seen that support related to diet is something that patients require. Regarding social support, a previous study demonstrated whether support from family, friends, and healthcare providers is related to self-management behaviors (Ma et al., 2022); however, this study used the total score of support and did not include the items on social aspects (such as work environment and financial aspects) that are important for working patients undergoing hemodialysis, who are the subjects of this study.

A study of patients with cancer showed that one of the factors for continuing to work is "obtaining information from healthcare providers" (Mukai & Morioka, 2022). Obtaining the necessary information is also an important factor for working patients undergoing hemodialysis; however, there is no specific research on what kind of information they require.

Patients' narratives have reported that starting dialysis forced them to change jobs and departments (Nihonyanagi, 2013; Tsutsui et al., 2017). It is important for patients to accept such changes and continue working after starting dialysis. However, the factors involved in the acceptance of these changes remain unclear.

The purpose of this study was to focus on the difficulties experienced by patients undergoing hemodialysis in continuing to work (i.e., "difficulties"), the state of information acquisition (i.e., "information acquisition"), and what they feel they require (i.e., "needs"), and to identify the factors that are important to support them in continuing to work. The relationship between each factor and acceptance of changes in job description and department (changes in job status) after the start of dialysis was also identified.

This study contributes to providing effective support for patients undergoing hemodialysis who are working and those who wish to work. This report describes a pilot study conducted in Ishikawa Prefecture prior to the full investigation.

Materials and Methods

Research Design

This cross-sectional study used an anonymous self-administered questionnaire.

Participants

The participants were defined as those aged over 20 years who were working (i.e., earning wages from their work) and receiving outpatient hemodialysis at institutions with dialysis facilities in Ishikawa Prefecture. The exclusion criteria included those who had difficulty in answering the questionnaire on their own and those determined by the primary doctor or dialysis unit nurse to be unsuitable for participation in the study.

Data Collection

A research protocol, a letter of request for research cooperation, and a questionnaire were sent to the directors of nursing or hospital directors of all target facilities throughout Ishikawa Prefecture. By sending these documents, the consent to research cooperation and the number of subjects to whom it could be distributed was confirmed. After confirmation, a letter explaining the research and a questionnaire were sent by post to the people who responded, requesting that they be explained to and distributed to the target population.

Questionnaires were collected using an enclosed return envelope. The return of the questionnaire constituted consent to participate in the study. Data were collected between October 2022 and October 2023.

Survey Items

Attributes of Participants

Attribute items included sex, age, family structure, job type, dialysis history, current dialysis details (basic hemodialysis start time, hemodialysis frequency, and average time per hemodialysis session), changes in job status after starting dialysis, and acceptance of this change. The answer format was to select the applicable choice.

Factors Associated with Continuing to Work

The factors considered important to support continued employment (difficulties, obtaining information, and requests) were examined by several researchers familiar with diabetes nursing research, based on previous research and previous experience in nursing and education, and a review of the

questionnaire items. These factors were also used to examine factors related to the presence of changes in job status and the acceptance of such changes. The factors are presented below.

Difficulties

Regarding difficulties, the following points were discussed based on previous studies: patients undergoing dialysis struggle with diet and fluid management (Kugler et al., 2005); are prone to difficulties with medication adherence (Ghimire et al., 2017); have poor sleep quality (Loewen et al., 2009); experience stress owing to shunt management, restrictions from dialysis, and hospital visits (Sherriff-Tadano, 2006); and that support from healthcare professionals at the workplace and home is a factor in continuing employment (Van et al., 2021).

The following 14 items were included: dietary management, medication management, fluid management, sleep management, shunt management, physical instability, mental health, job content, financial aspects such as living and treatment costs, relationships in the workplace, relationships with medical staff, restraints owing to dialysis, hospital visits to the dialysis facility, and relationships with family members. The question was in the form of "How much trouble did you have with the following items in continuing to work while undergoing dialysis?" A four-point Likert scale was used for the responses [1: Very troubled, 2: A little troubled, 3: Not very troubled, and 4: Not troubled at all]; they were used as reversed items in the analysis.

Information Acquisition

Regarding information acquisition, it was considered important to obtain the necessary information regarding the aforementioned difficulties. Therefore, whether they were able to obtain information necessary for physical management while performing dialysis, whether they were able to discuss how to relate to important others, and whether they were able to obtain a contact person to discuss various difficulties were discussed in light of the item "difficulties."

The following 13 items were included: mechanisms and methods of dialysis, dietary management, medication management, fluid management, shunt management, how to relate to supervisors and colleagues, how to relate to family members, how to relate to the medical staff, contact for advice on physical condition, contact for advice on work-related matters, contact for advice on mental health and anxiety, contact for advice on social security and other issues, and balancing work and dialysis. The question was asked in the form of "How much information did you receive on the following items during the preparation period for dialysis?" A four-point Likert scale was used for responses [1: Obtained enough, 2: Obtained a little, 3: Not obtained much, and 4: Obtained nothing].

Needs

Since this study targeted employed patients undergoing hemodialysis, the decision was made to focus on requests related to social aspects. Based on previous studies indicating that factors such as understanding and support from the workplace, support from healthcare professionals, and guarantees related to income contribute to continued employment (Van et al., 2021), discussions were conducted.

The following 12 items were included: understanding of the workplace, ease of taking time off from work, ease of changing working hours and days, ease of adjusting the work content, workplace atmosphere friendly to talk about, presence of counselor, simplicity of access to facility, clear outlook on treatment cost, comfortable atmosphere for consultation with the medical staff, information about consultation places, personnel evaluations, promotions, and salary increases will not be affected, and income guarantee. The question was asked in the form of "What do you feel you need to balance work and dialysis?" A four-point Likert scale was used for responses [1: Very much, 2: Somewhat, 3: Not very much, and 4: Not at all].

Statistical Analysis

The Statistical Package for the Social Sciences version 27.0 was used for the analysis. The Mann-Whitney U test was used to assess differences in means. The presence or absence of a change in job status was used as a grouping variable because such changes may affect stress and satisfaction. Furthermore, the acceptance of changes in job status was considered important and used as another group variable. Categorical regression analysis was also conducted to estimate the relevant factors. The dependent variable was the acceptance of the change in job status. All significance levels were set at $p < .05$.

Ethical Considerations

This study was approved by the Kanazawa University Medical Ethics Review Committee. A written explanation was given that participation in the study was voluntary, that non-participation would not affect future treatment, that data would be strictly managed to prevent leakage, theft, or loss, and that efforts would be made to maintain anonymity in the publication of the study results.

Results

Cooperation for the survey was requested from 42 institutions with hemodialysis facilities in all of Ishikawa Prefecture, and cooperation was received from 18 (42.9%) institutions covering the whole of Ishikawa Prefecture. Questionnaires were distributed to 155 respondents and returned by 103 (response rate: 66.5%). Some responses were lacking; however, there were no non-responses. In this study, all the responses were analyzed for each question item; thus, all the responses were included in the analysis.

Characteristics of the Participants

The characteristics of the participants are presented in Table 1. The majority of respondents were male, and the most common age group was in their 50s (mean age: 55.9±9.2 years). Regarding job type, permanent employment was the most common occupation, followed by part-time employment. The most common dialysis history was more than 10 years. Regarding the start time of hemodialysis, >30% of patients underwent night hemodialysis (starting after 17:00). Almost all participants were on hemodialysis three times a week, in the form of 3-4 hours of hemodialysis.

Table 1. Characteristics of the participants.

N=103

	Survey items	*n* (%)
Sex	Male	75 (72.8)
	Female	28 (27.2)
Age (years)	30 s	5 (4.9)
	40 s	19 (18.4)
	50 s	40 (38.8)
	60 s	32 (31.1)
	70 s	6 (5.8)
	NR	1 (1.0)
Family structure	With dependents	51 (49.5)
	Without dependents	52 (50.5)
Job type	Managers and directors	7 (6.8)
	Full-time employees (including civil servants)	39 (38.2)
	Part-time employees	30 (29.4)
	Temporary, contract, or casual employees	8 (7.8)
	Self-employed (with employer)	1 (1.0)
	Self-employed (without employer)	13 (12.7)
	Internally employed	0 (0.0)
	Not working	0 (0.0)
	Other	4 (3.9)
	Unanswered	1 (1.0)
Dialysis history	Less than 1 year	9 (8.8)
	More than 1 year and less than 3 years	21 (20.4)
	More than 3 years and less than 5 years	20 (19.4)
	More than 5 years and less than 10 years	19 (18.4)
	Over 10 years	34 (33.0)
Basic hemodialysis start time	Until 12:00	33 (32.0)
	12:00–17:00	29 (28.2)
	After 17:00	35 (34.0)
	Not determined	6 (5.8)
Hemodialysis frequency	1 time/week	0 (0.0)
	2 times/week	4 (3.9)
	3 times/week	98 (95.1)
	4 times/week	1 (1.0)
	More than 5 times/week	0 (0.0)
	Not determined	0 (0.0)
Average time per hemodialysis session	1–2 h	0 (0.0)
	3–4 h	97 (94.2)
	5–6 h	6 (5.8)
	More than 7 h	0 (0.0)
	Not determined	0 (0.0)

Difficulties, Information Acquisition, and Needs: Answer Distribution of Each Item

The distribution of responses per item in difficulties, information acquisition, and needs is shown in Table 2. With regard to the sense of difficulty, many items had a high proportion of responses of "not very troubled" or "not troubled at all" as a whole. However, more respondents were "a little troubled" or "very troubled" with regard to "fluid management" and "restraints owing to hemodialysis" ("fluid management": 63.1%, "restraints owing to hemodialysis": 74.7%). In relation to information acquisition, as a whole, a high proportion answered "a little available" or "sufficiently available" for many items. Of these, the proportion of respondents who obtained information on "work-related advice" and "mental health/anxiety-related advice" was equal between the two groups ("work-related advice: 50.5%" and "mental health/anxiety-related advice: 52.5%"). Regarding needs, many items had a high proportion of "fairly agree" and "very agree" responses overall, with more than 60% of the respondents answering "fairly agree" or "very agree" for all items.

Difficulties, Information Acquisition, and Needs: Comparison of Average Values According to whether the Job Status Changed after Dialysis Started

The results regarding the differences in the means of each item, depending on whether there was a change in job status after the start of dialysis, are shown in Table 3. In terms of difficulties, significant differences were found between the two groups for sleep management (p=.033), shunt management (p=.046), physical instability (p=.013), mental health (p=.019), and job content (p=.027). For all items, the group with changes had higher mean values. No significant differences were found for items related to information acquisition and needs.

Difficulties, Information Acquisition, and Needs: Comparison of the Means by the Difference in the Acceptance of Changes in Job Status after Undergoing Dialysis

The results regarding the difference in means based on the acceptance of changes in job status after the start of dialysis are presented in Table 4. Regarding difficulties, significant differences were found between the two groups for financial aspects such as living costs and treatment costs (p=.014), relationships in the workplace (p=.016), relationships with medical staff (p=.033), and hospital visits to the dialysis facility (p=.014). For all items, mean values were higher in the unaccepted group than in the acceptance group. No sig-

Table 2. Difficulties, information acquisition, and needs: answer the distribution of each item.

n=100–103

		Not troubled at all	Not very troubled	A little troubled	Very troubled
Difficulties	Dietary management [d]	7 (6.8)	57 (55.3)	31 (30.1)	8 (7.8)
	Medication management [d]	34 (33.0)	59 (57.3)	9 (8.7)	1 (1.0)
	Fluid management [d]	6 (5.8)	32 (31.1)	55 (53.4)	10 (9.7)
	Sleep management [d]	12 (11.7)	55 (53.4)	32 (31.1)	4 (3.9)
	Shunt management [c]	16 (15.7)	52 (51.0)	32 (31.4)	2 (1.9)
	Physical instability [c]	11 (10.8)	38 (37.3)	49 (48.0)	4 (3.9)
	Mental health [d]	20 (19.4)	46 (44.7)	31 (30.1)	6 (5.8)
	Job content [d]	17 (16.5)	45 (43.7)	35 (34.0)	6 (5.8)
	Financial aspects such as living and treatment costs [c]	16 (15.7)	49 (48.0)	31 (30.4)	6 (5.9)
	Relationships in the workplace [d]	34 (33.0)	53 (51.5)	14 (13.6)	2 (1.9)
	Relationships with medical staff [d]	42 (40.8)	54 (52.4)	6 (5.8)	1 (1.0)
	Restraints owing to dialysis [d]	1 (1.0)	25 (24.3)	56 (54.4)	21 (20.3)
	Hospital visits to the dialysis facility [d]	19 (18.5)	49 (47.6)	33 (32.0)	2 (1.9)
	Relationships with family members [d]	37 (36.0)	50 (48.5)	14 (13.6)	2 (1.9)
		Obtained enough	Obtained a little	Not obtained much	Obtained nothing
Information acquisition	Mechanisms and methods of dialysis [c]	35 (34.3)	40 (39.2)	24 (23.5)	3 (3.0)
	Dietary management [c]	35 (34.3)	46 (45.1)	19 (18.6)	2 (2.0)
	Medication management [c]	42 (41.2)	30 (29.4)	26 (25.5)	4 (3.9)
	Fluid management [c]	30 (29.4)	42 (41.2)	26 (25.5)	4 (3.9)
	Shunt management [c]	36 (35.3)	49 (48.0)	15 (14.7)	2 (2.0)
	How to relate to supervisors and colleagues [b]	27 (26.7)	37 (36.6)	25 (24.8)	12 (11.9)
	How to relate to family members [c]	41 (40.2)	37 (36.3)	19 (18.6)	5 (4.9)
	How to relate to the medical staff [c]	34 (33.3)	42 (41.2)	18 (17.6)	8 (7.8)
	Contact for advice on physical condition [c]	28 (27.5)	40 (39.2)	32 (31.4)	2 (1.9)
	Contact for advice on work-related matters [b]	17 (16.8)	33 (32.7)	36 (35.6)	15 (14.9)
	Contact for advice on mental health and anxiety [b]	16 (15.8)	32 (31.7)	40 (39.6)	13 (12.9)
	Contact for advice on social security and other issues [a]	19 (19.0)	43 (43.0)	26 (26.0)	12 (12.0)
	Balancing work and dialysis [c]	23 (22.5)	44 (43.1)	27 (26.5)	8 (7.8)
		Very much	Somewhat	Not very much	Not at all
Needs	Understanding of the workplace [c]	63 (61.8)	35 (34.3)	4 (3.9)	0 (0.0)
	Ease of taking time off from work [c]	51 (50.0)	40 (39.2)	8 (7.8)	3 (3.0)
	Ease of changing working hours and days [c]	52 (51.0)	40 (39.2)	8 (7.8)	2 (2.0)
	Ease of adjusting the work content [c]	49 (48.0)	40 (39.2)	9 (8.8)	4 (4.0)
	Workplace atmosphere friendly to talk about [c]	44 (43.1)	45 (44.1)	11 (10.8)	2 (2.0)
	Presence of a counselor [c]	30 (29.4)	49 (48.0)	17 (16.7)	6 (5.9)
	Simplicity of access to facility [c]	53 (52.0)	40 (39.2)	9 (8.8)	0 (0.0)
	Clear outlook on treatment cost [c]	37 (36.3)	56 (54.9)	8 (7.8)	1 (1.0)
	Comfortable atmosphere for consultation with the medical staff [c]	39 (38.2)	48 (47.1)	13 (12.7)	2 (2.0)
	Information about consultation places [b]	27 (26.7)	43 (42.6)	24 (23.8)	7 (6.9)
	Personnel evaluations, promotions, and salary increases will not be affected [c]	27 (26.5)	38 (37.3)	25 (24.5)	12 (11.7)
	Income guarantee [c]	33 (32.3)	28 (27.5)	34 (33.3)	7 (6.9)

[a] *n*=100, [b] *n*=101, [c] *n*=102, and [d] *N*=103

nificant differences were found for items related to obtaining information acquisition. Regarding needs, significant differences were found between the two groups for understanding of the workplace (p=.029), ease of taking time off from work (p=.022), ease of adjusting the work content (p=.042), workplace atmosphere friendly to talk about (p=.018), presence of a counselor (p=.044), comfortable atmosphere for consultation with the medical staff (p=.016), information about consultation places (p=.048), personnel evaluations, promotions, and salary increases will not be affected (p

Table 3. Difficulties, information acquisition, and needs: comparison of average values according to whether the job status changed after dialysis started.

n=100–103

		Mean ± standard deviation		Median [interquartile range]		Average rank		*P-value*
		Changed	Unchanged	Changed	Unchanged	Changed	Unchanged	
Difficulties	Dietary management [d]	2.42±0.70	2.35±0.76	2.00 [2.00,3.00]	2.00 [2.00,3.00]	52.77	50.28	.634
	Medication management [d]	1.82±0.60	1.73±0.69	2.00 [1.00,2.00]	2.00 [1.00,2.00]	53.97	49.13	.349
	Fluid management [d]	2.78±0.65	2.56±0.80	3.00 [2.00,3.00]	3.00 [2.00,3.00]	55.42	47.73	.147
	Sleep management [d]	2.42±0.58	2.13±0.82	2.00 [2.00,3.00]	2.00 [2.00,3.00]	57.26	45.96	.033*
	Shunt management [c]	2.33±0.72	2.06±0.70	2.00 [2.00,3.00]	2.00 [2.00,2.00]	56.46	45.86	.046*
	Physical instability [c]	2.65±0.66	2.27±0.77	3.00 [2.00,3.00]	2.00 [2.00,3.00]	57.85	44.55	.013*
	Mental health [d]	2.42±0.81	2.04±0.82	2.00 [2.00,3.00]	2.00 [1.00,3.00]	58.06	45.19	.019*
	Job content [d]	2.48±0.76	2.12±0.83	2.00 [2.00,3.00]	2.00 [1.25,3.00]	57.66	45.58	.027*
	Financial aspects such as living and treatment costs [c]	2.37±0.78	2.15±0.80	2.00 [2.00,3.00]	2.00 [2.00,3.00]	54.47	47.73	.212
	Relationships in the workplace [d]	1.98±0.74	1.71±0.70	2.00 [1.75,2.00]	2.00 [1.00,2.00]	56.44	46.75	.069
	Relationships with the medical staff [d]	1.74±0.69	1.62±0.57	2.00 [1.00,2.00]	2.00 [1.00,2.00]	53.52	49.56	.446
	Restraints owing to dialysis [d]	3.06±0.68	2.83±0.71	3.00 [3.00,4.00]	3.00 [2.00,3.00]	55.88	47.29	.105
	Hospital visits to the dialysis facility [d]	2.24±0.77	2.12±0.73	2.00 [2.00,3.00]	2.00 [2.00,3.00]	54.02	49.08	.362
	Relationships with family members [d]	1.88±0.82	1.75±0.65	1.00 [2.00,2.00]	2.00 [1.00,2.00]	53.14	49.92	.549
Information acquisition	Mechanisms and methods of dialysis [c]	1.88±0.86	2.00±0.82	2.00 [1.00,3.00]	2.00 [1.00,2.75]	48.82	53.06	.439
	Dietary management [c]	1.80±0.79	1.96±0.77	2.00 [1.00,2.00]	2.00 [1.00,2.00]	47.77	54.05	.246
	Medication management [c]	1.92±0.95	1.92±0.88	2.00 [1.00,3.00]	2.00 [1.00,3.00]	50.56	51.41	.877
	Fluid management [c]	2.02±0.85	2.06±0.85	2.00 [1.00,3.00]	2.00 [1.00,3.00]	50.65	51.33	.903
	Shunt management [c]	1.76±0.75	1.92±0.74	2.00 [1.00,2.00]	2.00 [1.00,2.00]	47.60	54.20	.217
	How to relate to supervisors and colleagues [b]	2.40±1.05	2.06±0.90	2.00 [2.00,3.00]	2.00 [1.00,3.00]	55.09	46.26	.112
	How to relate to family members [c]	1.94±0.97	1.83±0.81	2.00 [1.00,3.00]	2.00 [1.00,2.00]	52.06	50.00	.707
	How to relate to medical staff [c]	2.10±0.98	1.90±0.85	2.00 [1.00,3.00]	2.00 [1.00,2.00]	53.54	48.61	.370
	Contact for advice on physical condition [c]	2.04±0.76	2.12±0.88	2.00 [1.50,3.00]	2.00 [1.00,3.00]	49.56	52.36	.611
	Contact for advice on work-related matters [b]	2.65±0.99	2.31±0.88	3.00 [2.00,3.00]	2.00 [2.00,3.00]	55.84	45.37	.059
	Contact for advice on mental health and anxiety [b]	2.65±0.95	2.33±0.86	3.00 [2.00,3.00]	2.00 [2.00,3.00]	55.58	45.62	.071
	Contact for advice on social security and other issues [a]	2.27±1.01	2.35±0.84	2.00 [1.25,3.00]	2.00 [2.00,3.00]	48.40	51.51	.569
	Balancing work and dialysis [c]	2.37±0.91	2.04±0.84	2.00 [2.00,3.00]	2.00 [1.00,2.75]	56.44	45.88	.055
Needs	Understanding of the workplace [c]	1.41±0.57	1.44±0.57	1.00 [1.00,2.00]	1.00 [1.00,2.00]	50.11	51.84	.729
	Ease of taking time off from work [c]	1.53±0.68	1.73±0.82	1.00 [1.00,2.00]	2.00 [1.00,2.00]	47.76	54.06	.231
	Ease of changing working hours and days [c]	1.61±0.70	1.62±0.75	2.00 [1.00,2.00]	1.00 [1.00,2.00]	51.28	50.74	.919
	Ease of adjusting the work content [c]	1.65±0.83	1.71±0.78	1.00 [1.00,2.00]	2.00 [1.00,2.00]	49.35	52.26	.545
	Workplace atmosphere friendly to talk about [c]	1.73±0.73	1.71±0.75	2.00 [1.00,2.00]	2.00 [1.00,2.00]	51.60	50.43	.826
	Presence of a counselor [c]	2.00±0.84	2.00±0.84	2.00 [1.00,3.00]	2.00 [1.00,2.00]	51.29	50.73	.918
	Simplicity of access to facility [c]	1.59±0.64	1.54±0.67	2.00 [1.00,2.00]	1.00 [1.00,2.00]	52.43	49.65	.594
	Clear outlook on treatment cost [c]	1.69±0.62	1.79±0.67	2.00 [1.00,2.00]	2.00 [1.00,2.00]	48.80	53.08	.409
	Comfortable atmosphere for consultation with the medical staff [c]	1.86±0.76	1.69±0.71	2.00 [1.00,2.00]	2.00 [1.00,2.00]	54.25	47.81	.227
	Information about consultation places [b]	2.06±0.90	2.12±0.84	2.00 [1.00,3.00]	2.00 [2.00,3.00]	49.46	51.50	.709
	Personnel evaluations, promotions, and salary increases will not be affected [c]	2.16±1.12	2.25±0.81	2.00 [1.00,3.00]	2.00 [2.00,3.00]	48.86	53.02	.455
	Income guarantee [c]	2.06±0.92	2.23±1.00	2.00 [1.00,3.00]	2.00 [1.00,3.00]	48.63	53.23	.408

[a] *n*=100, [b] *n*=101, [c] *n*=102, and [d] *n*=103

Note: The Mann–Whitney *U* test was used for the statistical analyses.

*$p<.05$

Table 4. Difficulties, information acquisition, and needs: comparison of the means by the difference in the acceptance of changes in job status after undergoing dialysis.

n=47–49

		Mean ± standard deviation		Median [interquartile range]		Average rank		*P-value*
		Accepted	Unaccepted	Accepted	Unaccepted	Accepted	Unaccepted	
Difficulties	Dietary management [c]	2.38±0.66	2.47±0.80	2.00 [2.00,3.00]	2.00 [2.00,3.00]	24.77	26.00	.684
	Medication management [c]	1.72±0.58	2.00±0.61	2.00 [1.00,2.00]	2.00 [2.00,2.00]	23.03	28.71	.126
	Fluid management [c]	2.72±0.68	2.94±0.56	3.00 [2.00,3.00]	3.00 [3.00,3.00]	25.53	27.76	.255
	Sleep management [c]	2.41±0.56	2.47±0.62	2.00 [2.00,3.00]	2.00 [2.00,3.00]	24.84	25.29	.904
	Shunt management [b]	2.19±0.70	2.53±0.72	2.00 [2.00,3.00]	3.00 [2.00,3.00]	22.52	28.12	.148
	Physical instability [b]	2.58±0.67	2.76±0.66	3.00 [2.00,3.00]	3.00 [2.00,3.00]	23.58	26.18	.488
	Mental health [c]	2.28±0.77	2.65±0.86	2.00 [2.00,3.00]	3.00 [2.00,3.00]	23.16	28.47	.184
	Job content [c]	2.31±0.74	2.76±0.75	2.00 [2.00,3.00]	3.00 [2.00,3.00]	22.56	29.59	.076
	Financial aspects such as living and treatment costs [b]	2.16±0.74	2.76±0.75	2.00 [2.00,3.00]	3.00 [2.00,3.00]	21.13	30.65	.014*
	Relationships in the workplace [c]	1.78±0.66	2.35±0.79	2.00 [1.00,2.00]	2.00 [2.00,3.00]	21.81	31.00	.016*
	Relationships with the medical staff [c]	1.56±0.56	2.06±0.83	2.00 [1.00,2.00]	2.00 [1.50,2.50]	22.14	30.38	.033*
	Restraints owing to dialysis [c]	3.03±0.70	3.12±0.70	3.00 [3.00,3.75]	3.00 [3.00,4.00]	24.44	26.06	.677
	Hospital visits to the dialysis facility [c]	2.03±0.70	2.59±0.80	2.00 [2.00,2.75]	3.00 [2.00,3.00]	21.59	31.41	.014*
	Relationships with family members [c]	1.72±0.77	2.18±0.88	2.00 [1.00,2.00]	2.00 [1.50,3.00]	22.44	29.82	.064
Information acquisition	Mechanisms and methods of dialysis [b]	1.77±0.81	2.06±0.97	2.00 [1.00,2.00]	2.00 [1.00,3.00]	23.15	26.97	.335
	Dietary management [b]	1.81±0.79	1.76±0.83	2.00 [1.00,2.00]	2.00 [1.00,2.00]	24.87	23.82	.789
	Medication management [b]	1.97±0.98	1.88±0.93	2.00 [1.00,3.00]	2.00 [1.00,2.50]	24.85	23.85	.802
	Fluid management [b]	2.00±0.78	2.06±1.03	2.00 [1.00,3.00]	2.00 [1.00,3.00]	24.35	24.76	.918
	Shunt management [b]	1.71±0.74	1.82±0.81	2.00 [1.00,2.00]	2.00 [1.00,2.00]	23.92	25.56	.672
	How to relate to supervisors and colleagues [a]	2.27±1.05	2.65±1.06	2.00 [1.00,3.00]	2.00 [2.00,4.00]	22.35	26.91	.256
	How to relate to family members [b]	1.77±0.88	2.24±1.09	2.00 [1.00,2.00]	2.00 [1.00,3.00]	22.45	28.24	.147
	How to relate to the medical staff [b]	1.97±0.98	2.35±1.00	2.00 [1.00,3.00]	2.00 [2.00,3.00]	22.58	28.00	.177
	Contact for advice on physical condition [b]	1.97±0.83	2.18±0.64	2.00 [1.00,3.00]	2.00 [2.00,3.00]	23.08	27.09	.306
	Contact for advice on work-related matters [b]	2.58±1.06	2.82±0.88	3.00 [2.00,3.00]	3.00 [2.00,3.50]	23.56	26.21	.511
	Contact for advice on mental health and anxiety [b]	2.52±1.00	2.94±0.83	3.00 [2.00,3.00]	3.00 [2.50,3.50]	22.45	28.24	.148
	Contact for advice on social security and other issues [b]	2.10±0.94	2.59±1.06	2.00 [1.00,3.00]	3.00 [2.00,3.50]	22.23	28.65	.112
	Balancing work and dialysis [b]	2.26±0.86	2.59±1.00	2.00 [2.00,3.00]	3.00 [2.00,3.00]	22.77	27.65	.225
Needs	Understanding of the workplace [b]	1.29±0.53	1.65±0.61	1.00 [1.00,2.00]	2.00 [1.00,2.00]	21.73	29.56	.029*
	Ease of taking time off from work [b]	1.35±0.49	1.88±0.86	1.00 [1.00,2.00]	2.00 [1.00,2.00]	21.48	30.00	.022*
	Ease of changing working hours and days [b]	1.48±0.63	1.88±0.78	1.00 [1.00,2.00]	2.00 [1.00,2.00]	22.00	29.06	.063
	Ease of adjusting the work content [b]	1.52±0.81	1.94±0.83	1.00 [1.00,2.00]	2.00 [1.00,2.00]	21.74	29.53	.042*
	Workplace atmosphere friendly to talk about [b]	1.58±0.72	2.06±0.66	1.00 [1.00,2.00]	2.00 [2.00,2.00]	21.29	30.35	.018*
	Presence of a counselor [b]	1.81±0.79	2.35±0.86	2.00 [1.00,2.00]	2.00 [2.00,3.00]	21.66	29.68	.044*
	Simplicity of access to facility [b]	1.45±0.57	1.76±0.66	1.00 [1.00,2.00]	2.00 [1.00,2.00]	22.32	28.47	.102
	Clear outlook on treatment cost [b]	1.61±0.67	1.81±0.54	2.00 [1.00,2.00]	2.00 [1.25,2.00]	23.21	26.85	.336
	Comfortable atmosphere for consultation with the medical staff [c]	1.69±0.78	2.18±0.64	2.00 [1.00,2.00]	2.00 [2.00,3.00]	21.70	32.21	.016*
	Information about consultation places [b]	1.87±0.89	2.41±0.87	2.00 [1.00,3.00]	2.00 [2.00,3.00]	21.69	29.62	.048*
	Personnel evaluations, promotions, and salary increases will not be affected [b]	1.91±1.00	2.69±1.25	2.00 [1.00,3.00]	3.00 [1.25,4.00]	21.58	30.34	.032*
	Income guarantee [b]	1.91±0.89	2.38±0.96	2.00 [1.00,3.00]	3.00 [1.25,3.00]	22.27	28.97	.099

[a] *n*=47, [b] *n*=48, and [c] *n*=49

Note: The Mann–Whitney *U* test was used for the statistical analyses.

*$p<.05$

Table 5. Factors influencing acceptance of changes in job status after starting dialysis.

n=94

Variable	Standardization factor (β)	*P-value*
Whether they experienced difficulties with fluid management	0.162	.037*
Whether they experienced difficulties with relationships in the workplace	0.185	.016*
Whether they felt the need for the change to not affect their personnel evaluation, promotion, or salary increase	0.253	.030*
Whether the change in job content or department was in-line with their wishes	0.591	<.001**

Note: Adjusted R^2=0.619, F-value=31.561, and p<.001

**p<.01, *p<.05

=.032). For all items, mean values were higher in the unaccepted group than in the acceptance group.

Factors Influencing Acceptance of Changes in Job Status after Starting Dialysis

The results of the categorical regression analysis are presented in Table 5. The analysis yielded results with a high rate of explanation, with an adjusted R^2=.619 (p=.001). The items that were entered were whether the change in job content or department was in-line with their wishes (β=.591, p <.001), whether they felt the need for the change to not affect their personnel evaluation, promotion, or salary increase (β=.253, p<.030), whether they experienced difficulties with relationships in the workplace (β=.185, p<.016), and whether they experienced difficulties with fluid management (β=.162, p<.037), and they were strongly related, in that order.

Discussion

There are no studies on the factors that make working patients undergoing hemodialysis particularly difficult to continue working. Furthermore, none of the studies focused on whether information was obtained and what was considered necessary to continue the work. The results of the present study indicate which factors are causing difficulties, information acquisition and needs, which information is difficult to acquire, and what is necessary in terms of needs. It was also possible to clarify how the difficulties, information acquisition, and needs are related to whether there have been changes in the job status after starting dialysis and whether there is acceptance of the results of this change. These results are discussed below.

Characteristics of the Study Participants

The male-to-female ratio was similar, taking into account the reported ratios of dialysis patients and the working population in Japan (Japanese Society for Dialysis Medicine, 2022b; Statistics bureau, Ministry of Internal Affairs and Communications, 2024). The mean age was 55.9 years, which was comparable to that of a previous study of working patients undergoing hemodialysis (Yamamoto et al., 2023). Regarding job type, there was a trend toward a smaller proportion of permanent employees and a larger proportion of temporary employees than in the national survey (Japanese Association of Dialysis Physicians, 2021d). In terms of dialysis history, compared with the national survey, there was a tendency for more long-term dialysis patients to have been on dialysis for more than 10 years (Japanese Society for Dialysis Therapy, 2022b). The results of the national survey were similar in terms of nocturnal dialysis users, number of dialysis sessions per week, and dialysis time per session (Japanese Association of Dialysis Physicians, 2021b; 2021c). Although the trends in terms of occupation and dialysis history differed from those in previous studies, they were not significantly biased. Thus, the target population of this study was not significantly different from the Japanese population.

Factors Related to Continued Work and Nursing

A high proportion of working patients undergoing hemodialysis reported that "fluid management" and "restraints owing to dialysis" were troublesome for them to continue working. Previous research has also shown that similar factors, "fluid restriction" and "length of treatment time," can be major stressors for patients undergoing hemodialysis (Sherriff-tadano&Ohta, 2006; Khalil et al., 2011). These factors are likely to be difficult for dialysis patients to control, and their difficulty may lead to increased stress.

Of the factors related to continuing work, patients who had changed their job status due to starting dialysis tended to experience more difficulties with factors related to "sleep management," "shunt management," "physical instability," "mental health," and "job content." In a previous study, "sleep disruption" and "work difficulties" were reported as lower stressors for patients undergoing hemodialysis than factors such as "fluid restriction," "length of treatment time," and "limitation of physical activity" (Sherriff-tadano&Ohta, 2006). In working patients, changes in job status due to shunts or difficulties in managing their condition may cause different stresses than those resulting from dialysis therapy. Sleep disturbances are associated with anxiety and depres-

sion (Shimizu et al., 2011; Martínez-Sanchis et al., 2015). In addition, this study revealed that patients who had a change in their job status felt a greater need for "understanding of workplace," "ease of taking time off from work," "ease of adjusting work content," "workplace atmosphere friendly to talk about," and "personnel evaluations, promotions, and salary increases will not be affected" among the work environment and financial aspects. In patients who have undergone a change in job status, it is important to continuously assess their current job commitment and the impact on their sleep and mental health to help them cope with the stress caused by the change in circumstances.

Regarding factors related to "financial aspects," "personal relationships," and "hospital visits," patients who had not accepted the changes in their job status after starting dialysis tended to experience more difficulties. In the categorical regression analysis, four factors were found to be related to acceptance of the changes in their job status: whether they felt difficulties with "fluid management," "relationships in the workplace," whether there was "no influence on personnel evaluation, promotion and salary increase" and whether the changes in their job status were in line with their wishes. Lack of sleep and fluid management can lead to worsening persistent fatigue and worsening mental health (Parvan et al., 2013; Shimizu et al., 2011; Nakahara et al., 2019; Kumar, S. B. et al., 2021). Social support and high income have been associated with better self-management behavior and mental quality of life in dialysis patients (Ma et al., 2022; Rikos et al., 2023). However, no studies have focused on workplace relationships. In addition, no studies have found an association between these factors and the acceptance of job status. These factors make working patients undergoing hemodialysis important to be aware of and support the factors found to be relevant in this study. In particular, for patients who have changed their job status, it is important to check in detail whether they have sufficiently consulted with their workplaces about their job content and whether they are satisfied with the results of this consultation. It is also important to check whether "fluid management" and "relationships in the workplace" are going well and whether "personnel evaluations and salary increases" are not being judged absurdly so that effective support can be provided.

Regarding information acquisition, patients reported that they had obtained information on most items. The ability of patients to access information is believed to be influenced by factors such as the fact that 67% of the global population uses the Internet (Statista, 2024) and the development of education systems (National Kidney Foundation, 2024). However, the percentage of patients who reported obtaining information about work-related issues and mental health or anxiety support was lower than that for other items.

Work, mental health, and anxiety are personal matters that require individualized responses. In addition, with respect to mental health and anxiety, having consultation resources is crucial, given reports that dialysis patients have higher rates of anxiety and depression (Feroze et al., 2012), as well as findings that their quality of life is significantly lower than that of individuals without the disease (Fletcher et al., 2022). Therefore, nurses must understand what patients may want to discuss regarding their work, mental health, and anxiety and introduce appropriate consultation resources based on their needs.

Limitations of the Study and Future Perspectives

This study was conducted in only one prefecture, and it did not include the causative diseases leading to renal failure, which may not be sufficient for generalization. In addition, specific job descriptions were not investigated. The nature and extent of work requiring restrictions are expected to vary depending on the type of work. In the future, a national survey will also be conducted and analyzed with a focus on the causative diseases and detailed job descriptions so that the results can be generalized.

Conclusion

For patients undergoing hemodialysis, the findings suggest that providing comprehensive care regarding their feelings about their current job, sleep, physical condition, shunt management, and the impact on their mental health when there are changes in job status owing to starting dialysis may contribute to continued employment. Furthermore, "fluid management," "workplace relationships," and "personnel evaluations and promotions/salary increases" were found to be related to the acceptance of changes in job status. Nursing care with these considerations in mind is important in helping patients undergoing dialysis to continue to work.

Author Contributions

All authors participated in the study conception and survey preparation. Asada contributed mainly to data analysis and manuscript writing. Horiguchi contributed mainly to the direction of the data analysis, interpretation of the analysis results, and advice on the content of the manuscript. Inagaki and Tasaki mainly contributed on the content of the manuscript. Yuya Asada and Tomomi Horiguchi contributed equally to this work.

Declaration of Conflicting Interests

The authors declare that they have no conflicts of interest.

Ethical Approval

This study was approved by the Kanazawa University Medical Ethics Committee (No. 913-3).

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Original Research

A qualitative study of the parenting concerns of Japanese mothers with cancer

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Abstract

Objective: Through interviews, this study aimed to clarify the parenting concerns of cancer-affected mothers with children of all ages, from infancy to adolescence. The study also examines how support should be provided to mothers and families according to the children's age. **Methods:** Semi-structured interviews were conducted with 12 mothers with cancer. We asked them the following questions: 1) How has the cancer diagnosis affected your roles and responsibilities as a parent? 2) How have your children influenced your treatment choices and decision-making? 3) What distress did you feel when deciding to tell/not tell your children about your cancer diagnosis? 4) What are your parenting concerns, and what support and resources do you need to address them? The data were transcribed verbatim and classified into categories, subcategories, and codes. **Results:** The parenting concerns were classified into eight broad categories. The features and tendencies of the expressed concerns were characterized differently depending on the children's developmental stage. **Conclusions:** The parenting concerns of patients with cancer differed according to their children's age. Some concerns about social support were adjudged to be trends unique to Japan, as previous research in Europe or North America did not reveal such findings. Furthermore, the mothers desired support from medical personnel for their children and families. According to this study, it will be necessary to provide age-appropriate parenting support to children in the future; this support must include the patients and their families.

Keywords

cancer, mother, parenting, concern, children

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Introduction

The number of patients with cancer in Japan is currently rising, with approximately 56,000 parents of children below the age of 18 newly diagnosed with cancer annually. Additionally, the number of children of patients with cancer was approximately 87,000 (Inoue et al., 2015).

When patients with cancer and who have children receive their cancer diagnoses, the lives of these patients and their families can change dramatically (Lewis et al., 1985). Patients and their families experience changes in their routines, schedules, and household roles; increased financial burdens owing to treatment costs; and impact on the children owing to the physical and emotional changes in their parents (Osborn, 2007; Huizinga et al., 2005; Shah et al., 2017). Patients with cancer and who have children may have to balance treatment and parenting, and their stress levels are usually high (Semple & McCance, 2010; Moore et al., 2015).

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Previous studies in the United States have reported parenting concerns among cancer patients with children, including (1) concerns about the impact of their illness and death on their children, (2) "missing out" and "losing out" on exercising their parental roles and responsibilities, (3) maintaining parental responsibilities despite their life-limiting illness, and (4) the influence of parental identity on decision-making regarding treatment (Park et al., 2017). Furthermore, concerns have been raised about the interactions between the patients and their children, such as communication with children about cancer, the children's reactions to learning of the diagnoses, and dealing with children's reactions (Tavares et al., 2018); these parenting concerns affect the lives of patients with cancer and their children in several ways. Patients with cancer with parenting concerns are at a higher risk of developing depressive symptoms (Hailey et al., 2018); their children could become extremely anxious because of the impact of their parents' cancer on their daily lives and mental health (Beardslee et al., 1998; Schmitt et al., 2008).

It is clear from these findings that medical staff should intervene not only in the treatment of patients' cancers but also in dealing with their parenting concerns.

In Japan, Nakayama et al. (2020) reported that cancer surviving mothers' concerns about childrearing in infancy included "being pressed to balance treatment and childrearing," "difficulty involving children and the family because of cancer," and "lack of resources and information to rely on" (Nakayama et al., 2020). Kojima et al. (2019) also reported "children's understanding and reactions," "feelings as a parent," and "how to communicate about the disease condition" as the main concerns of cancer patients with children. According to these previous studies, the problems faced by parents affected by cancer differ according to their gender (Tamura et al., 2019), their children's developmental stage (Kojima et al., 2019), and the family's social background (Kojima et al., 2019). Therefore, it is necessary to account for these factors when considering patient support.

The purpose of this study was to clarify the parenting concerns of cancer-affected mothers in Japan with children of all ages, from infancy to adolescence, through interviews, and to examine how support should be provided to mothers and families according to the children's age.

Materials and Methods

Research Design

This study has a qualitative descriptive research design.

Participants

The basic demographic characteristics of the participants are presented in Table 1. The participants were 12 mothers with cancer who had children aged below 18. The principal investigator requested the cooperation and participation of representatives of cancer patient associations and received referrals for 12 applicants who agreed to participate in the study. The condition was for the participants to be cancer-afflicted mothers raising children below 18 years of age, or those who had raised children under 18 years of age while previously suffering from cancer. The stage or cancer type was not a qualifying factor; however, the participants were defined as patients who had been diagnosed with cancer for at least 2 weeks, were able to communicate adequately, and were in a stable mental and physical condition to tolerate the interview survey. The participants were limited to 12 residents of northern Japan because of the efficiency of the interviews and limitations of the study's duration.

Data Collection Methods

Semi-structured interviews were conducted. Each interview was conducted in a private setting, such as the participant's home or private room, depending on the participant's preference. The average interview duration was 65 min (56-97 min). The survey was conducted between July and September 2020. All interviews were conducted by the principal investigator to ensure consistency and quality.

The participants were asked to speak freely in accordance with the interview guide, and the interviews were recorded using a digital voice recorder.

Survey Contents

The interview guide was developed on the basis of previous studies by Shands et al. (2000) and Park et al. (2017). Based on the interview guide, we asked the following questions during the interviews: 1) How has your cancer diagnosis affected your roles and responsibilities as a parent? 2) How have your children influenced your treatment choices and decision-making? 3) What was the distress you felt when deciding to tell/not tell your children about your cancer diagnosis? 4) What were your parenting concerns, and what support and resources do you need to address them? We asked the subjects to speak freely and added questions as appropriate to obtain a deeper understanding of their responses.

Analytical Method

The recorded data were transcribed verbatim, and the subjects' narratives that were deemed to express "parenting concerns" were extracted from the data and coded so that their original meaning could be retained. Codes with similarities were designated as one subcategory; multiple subcategories with higher similarity levels were further abstracted into one category. To ensure reliability and validity during the entire analysis process, category concordance for all the codes was discussed with other co-researchers and researchers who were familiar with qualitative research. The principal researcher is a graduate student in the oncology nursing field,

Table 1. Overview of the participants.

Case	Age	Employment status (Before diagnosis → After diagnosis)	Family structure	Cancer type	Stages	Children's age at diagnosis	When diagnosed	Treatment received in the past	Metastasis/ Recurrence	Cancer notification to children
A	30's	Part time → Without an occupation	Partner, 2 children	Breast	IIa	2, 0	1.5 years ago	Surgery, Chemotherapy, Radiation	None	No
B	30's	Full time → Part time	Partner, 1 child	Breast	IIb	Birth one year after diagnosis	6 years ago	Surgery, Radiation, Hormonal therapy	None	Yes
C	40's	Full time → Part time	Partner, 1 child	Breast	IIIa	1	3 years ago	Surgery, Chemotherapy, Radiation, Hormonal therapy	None	Yes
D	40's	Full time → Without an occupation	Partner, 2 children	Breast	IIb	Birth six months after diagnosis, Birth 3 years after diagnosis	7 years ago	Surgery, Hormonal therapy	None	Yes
E	40's	Full time → Full time	3 children	Breast	Ia	19, 16, 13	2 years ago	Surgery, Hormonal therapy	None	Yes
F	40's	Without an occupation → Without an occupation	Partner, 2 children	Breast	Ib	11, 9	2 years ago	Surgery, Chemotherapy, Hormonal therapy	None	Yes
G	40's	Full time → Full time	Partner, 2 children	Cervical	IIb	11, 10	10 years ago	Surgery, Chemotherapy, Hormonal therapy	None	Yes
H	40's	Without an occupation → Without an occupation	Partner, 1 child	Breast	IIIa	3	2.5 years ago	Surgery, Chemotherapy, Radiation, Hormonal therapy	None	Yes
I	50's	Without an occupation → Without an occupation	Partner, 1 child	Breast	IIb	9	3 years ago	Surgery, Chemotherapy, Hormonal therapy	None	Yes
J	50's	Full time → Full time	Partner, 2 children	Breast	IIIa	20, 17	6 years ago	Surgery, Chemotherapy	None	Yes
K	50's	Full time → Full time	Partner, 3 children	Breast	IIb	17, 15, 11	9 years ago	Surgery, Chemotherapy, Hormonal therapy	None	Yes
L	60's	Full time → Part time	Partner, 2 children	Breast	IIa	20, 18	19 years ago	Surgery, Chemotherapy, Radiation	None	Yes

and the co-researchers are professors and assistant professors in the oncology nursing field; all of them are women. Two certified cancer nursing specialists supervised the study. In consideration of the participants' psychological stress, we did not conduct member checking.

Ethical Considerations

The Ethics Committee of Tohoku University approved this study. The following information about the survey was provided to the participants orally and in writing: the purpose, methods, respect for free will, freedom to withdraw consent, handling of benefits and disadvantages associated with participation in the survey, preservation of anonymity, and personal information protection. Patients provided consent to participate by signing a consent form. Explanations and surveys were conducted in a private room or similar environment in which privacy was ensured. The interviews were recorded using a voice recorder and promptly stored in a secure cabinet. In consideration of the participants' burdens, each interview lasted for approximately an hour. To minimize the psychological burden on the participants, they were assured that the interviews could be terminated at any time.

Results

Summary of the Participants

A summary of the participants is provided in Table 1.

Parental Concerns among Mothers with Cancer

From the interviews with mothers with cancer, the parenting concerns of patients with cancer who have children were broadly classified into eight categories, with 23 additional subcategories; 76 codes were extracted (Table 2). The characteristics and trends of the eight categories of concerns

Table 2. Categories, subcategories, and codes of parenting concerns.

Category	Subcategory	Code
Continuing to raise their children while their lives are restricted	Inability to spend enough time with their children due to treatment or the emergence of physical symptoms	I'm sorry I have cancer and can't take care of my children. Side effects of the treatment have increased the amount of time I am unable to play with my children. Losing time to communicate with my children makes me sad.
	Difficulty in performing childcare (feeding, holding, playing, weaning) during infancy and early childhood due to the treatment or physical symptoms	Unable to breastfeed due to chemotherapy. It's hard to breastfeed from the surgical side of the breast. Difficulty in holding and feeding the baby as desired due to painful side effects of chemotherapy. I can't even take my children to the park during chemotherapy. During chemotherapy, even picking up my children from daycare is difficult, and I barely manage to do it. I can't move on chemotherapy days so I can't make baby food for my children. My surgical shoulder hurts so much that I can't even carry my children or cook. It's hard for me physically and I can't play with or carry my children like I used to. I don't think it's possible to raise a small children alone during chemotherapy. Prenting small children during chemotherapy is the hardest part, both mentally and physically.
	Difficulty in taking care of school-aged children (cooking, participating in school activities and events, etc.) due to treatment or physical symptoms	I cannot do housework and cooking as much as I would like to when my child comes home from school. I feel sorry, and it is hard for me not to be able to participate in my children's events and activities due to the treatment. It is hard to always have to think about my children's school and their lives, even when my health is hard.
Not being a good parent to their children	Becoming more angry, frustrated, or worried about their children than necessary, due to the physical and emotional pain caused by cancer	When I'm not feeling well, I get frustrated and take it out on my children. I get angry at my children more than necessary because I am worried about my own illness. I have emotional instability due to anxiety about my illness and transition, which I turn towards my children. I would worry excessively about what if something happened to my children, or them getting sick.
	Being a "cancer parent" would cause inconvenience and burden to their children	I feel sorry for my children because I have a disease that may not let me live long. After getting cancer, I really feel like I have not done anything for my children. I have a hard time with people around me feeling sorry for my children and thinking that they are in trouble. I worry that my children will be looked at strangely by their school friends.
Possibility of not being able to see their children's future and growth	Anxiety about not being able to see their children's future	I have a fear of not being able to watch my children grow up because they are so young. I may not be able to see my children through to adulthood in a satisfactory manner. There is concern about how old my children will be when I will live.
	Anxiety about whether their children would be able to live independently after they passed away	I may not live long, so I am anxious for my children to be independent. I think I need to raise my children to be able to live on their own after I leave.
Telling the children about cancer	Hesitant to tell their children about cancer because they did not want to cause their children anxiety or worry	I hesitate to tell my children because I just do not want to worry them. I am worried that my children will not accept or understand my illness. I cannot tell them right away because I do not want to see my children grieve and I do not want to worry them.
	Hesitant to tell their children about cancer, a disease that is associated with death	I do not think I can talk to my children about my prognosis or death, so I cannot talk about the specific name of the disease. I don't know what to say back to my children when they ask me, "Mom, are you going to die?". I have my own fears of imminent death and hesitate to tell my children.
	Not know how to communicate appropriately about cancer, according to their child's developmental stage	I have a hard time communicating with my toddler children because they are not old enough to fully understand my illness. I worry about how my children will perceive my illness when they reach puberty. I do not know anyone I can talk to about age-appropriate ways to tell my children about the disease.
The psychosocial, physical, and economic impacts on their children	Changing their children's daily lives and behavior	I do not have as much time to play with my children, and their only playtime is on electronic devices such as video games and iPads. I feel sorry that my illness has changed my children's lives. I am worried that my children have become overly attentive and less selfish. My illness has caused my children to endure a lot. My elementary school daughter is always snuggled up and spoiled and I feel I'm making her anxious.
	Cancer would cause their children too much worry and stress	I overstressed my son as he was preparing to take the college entrance exam. My illness even made my daughter think about quitting college. My high school son had a panic attack. I caused undue worry and stress to my children when they were struggling with their studies and club activities.
	Their children would be overly disturbed by the changes in their appearance due to the treatment	My children were very shocked by the changes in my appearance due to the treatment, such as hair loss and surgical scars. After the surgery, my children saw me in a weakened state and it made them anxious.
	The cost of treatment would place a financial burden on their children's upbringing	My children are in college and high school and it's an expensive time for them, so I am sorry to have to pay for my treatment. I worry about how I will pay for my children's upbringing if I am unable to continue working.
	The risk of cancer transmission to their children	I will be sorry if my daughter inherits cancer. I encourage my daughter to self-examine.

Table 2. Categories, subcategories, and codes of parenting concerns (continued).

Category	Subcategory	Code
Difficulty getting parenting support from surrounding community	Hesitant to leave childcare and housework to their working husband	My husband is very busy at work, so it is difficult to ask him to take care of the children even if I wanted him to. My husband is devoted and supportive, but I do not think I should rely on him fully because he is working.
	Thinking that their husbands could not take care of their children alone	My husband has become easily angry with my children due to the stress of parenting. Considering my husband's work schedule, I also need the cooperation of grandparents to take care of my children. My husband could not take care of my children alone.
	Lack of a safe place to leave their children at any time	I don't have a place where I can leave my little children at any time during my hospitalization or treatment. No place to leave my children when they have a fever, forcing me to postpone my treatment.
	Having no one to help them with child-rearing and housework	With no relatives nearby, I am left alone to carry the burden of parenting and treatment. Lack of parenting support that I can ask for whenever I want to ask for it. There is no babysitter that I can safely hire without adding excessive financial burden.
	Lack of understanding in schools for children with parents afflicted with cancer	I do not feel supported by the school when I tell them about my illness. I feel that the school and society are still unaware of the implications of parent's cancer.
	Lack of people who can support the children's concerns and anxieties	There is no one to provide emotional support for my children and family. I do not think there is a place for my children to vent their anxieties and worries.
Absence of someone in the same situation to consult	Lack of a place to share their concerns about parenting and illness because there were no other people around who were in the same situation	I feel alone because there is no place to vent my worries about parenting and my own feelings of weakness. I cannot get to know people with the same disease who have children of the same age.
	Not being able to get the information and support they needed because there was no one around them in the same situation	Inability to share information on parenting concerns and childcare support. I do not know how to get social support. I feel like there really isn't enough information about people who have cancer while raising a baby.
Difficulty in seeking parenting support from medical personnel	Not knowing how to turn to medical personnel for help with their parenting problems and concerns	I am nervous during medical appointments and therefore unable to discuss my parenting concerns with medical personnel. It is difficult to have the doctors and nurses at the hospital listen to my child-rearing concerns because they are too busy. I don't know what and how to ask for help at the hospital's cancer counseling office or patient groups. I feel uncomfortable participating in patient groups because of the high age range of the groups.

were characterized differently depending on the child's developmental stage: infancy, school age, and adolescence. The results are as follows: categories are indicated by [ ], subcategories by ‘’, codes by “”, and conversations by italics.

Continuing to Raise Children while Their Lives are Restricted

The mothers had various concerns about continuing to care for their children while their lives were restricted by treatment; these concerns were influenced by the children's developmental stage.

First, mothers with children from infancy to early childhood felt the “Inability to spend enough time with their children owing to treatment or the emergence of physical symptoms” and “Difficulty in performing childcare (feeding, holding, playing, and weaning) during infancy and early childhood owing to the treatment or physical symptoms.” They felt “Unable to breastfeed because of chemotherapy,” and “During chemotherapy, even picking up their children from daycare is difficult, and they barely manage to do it.”

I knew that sometimes I could not respond immediately when my child asked me to carry her or play with her in the park. Children are still small, so they do not understand that due to the treatment, their mothers cannot move their bodies as much as they would like to. It is difficult to be with children while undergoing treatment. (A)

Mothers with school age children experienced the “Difficulty in taking care of school-aged children (cooking, participating in school activities and events) because of the treatment or physical symptoms.” They felt that “I cannot do housework and cooking as much as I would like to when my child comes home from school,” and “I feel sorry, and it is hard for me not to be able to participate in my children's events and activities because of the treatment.”

There are children's athletic meets, class visits, and lesson presentations. As a parent, I want to participate in such events. Even though I try to avoid overlaps with my treatments...sometimes it is not possible, depending on my health condition. When I see the sad faces of my children, I feel sorry for them. (F)

Not Being a Good Parent to Their Children

Mothers with children of all ages were concerned about “Becoming more angry, frustrated, or worried about their children than necessary because of the physical and emotional pain caused by cancer.” Some mothers said, “When I am not feeling well, I get frustrated and take it out on my children,” and “I get angry at my children more than necessary because I am worried about my own illness.”

Sometimes I just cannot control my feelings. Is it the effect of hormone therapy? My body is tired, my mind is not

relaxed, and sometimes I get angry and frustrated with my children. Later, I feel guilty and say, "Oh, I got angry." (B)

Some mothers also experienced excessive worry about their children's behavior and lives because of their own illness, saying, "I have emotional instability due to anxiety about my illness and transition, which I turn toward my children," and "I would worry excessively about something happening to my children, or them getting sick."

I feel like my children have become very kind to me since I got cancer. Normally, this would be a pleasant change, but on the contrary, it makes me worry that I am making them endure more because their mother is sick, or I think that they should cry or get angry more. (I)

Furthermore, the mothers were concerned that "Being a 'parent with cancer' would cause inconvenience and burden to their children." Some mothers said, "I feel sorry for my children because I have a disease that may not let me live long," and "After getting cancer, I really feel like I have not done anything for my children."

I do not want my children to see me like that, when I am bedridden because I cannot move due to anticancer drugs, but I have to show them. As a mother, I feel sorry for my children. (H)

Some mothers also said, "I have a hard time with people around me feeling sorry for my children and thinking that they are in trouble," and "I worry that my children will be looked at strangely by their school friends."

Possibility of Not Being Able to See Their Children's Future and Growth

Some mothers had "Anxiety about not being able to see their children's future." In particular, mothers with children from infancy to school age expressed strong concerns: "I have a fear of not being able to watch my children grow up because they are so young," and "I may not be able to see my children through to adulthood in a satisfactory manner."

Because my child is so young, I still want to see them grow up and spend time with them in the future. Sometimes I am filled with anxiety and fear of what I will do in that case. I want to be with my little child all the time, but if I can no longer do that, how will she live? I am always anxious. (C)

Simultaneously, mothers expressed "Anxiety about whether their children would be able to live independently after they passed away." One mother said "I think I need to raise my children to be able to live on their own after I leave."

Telling Their Children about Cancer

Some mothers said that they hesitated to tell their children about cancer because they did not want to cause their children anxiety or worry. They said, "I hesitate to tell my children because I do not want to worry them," and "I cannot tell them right away because I do not want to see my children grieve and I do not want to worry them."

Some also said that they were "Hesitant to tell their children about cancer, a disease that is associated with death." Several mothers said, "I do not think I can talk to my children about my prognosis or death, so I cannot talk about the specific name of the disease."

I could not even bear to see them crying when I told my children about my cancer. When my children asked me, "Mom, are you going to die?" I did not know how to respond. I could not answer anything. All I could do was hug them. (I)

Furthermore, the mothers were concerned that they would "not know how to communicate appropriately about cancer, according to their child's developmental stage." The mothers said, "I have a hard time communicating with my toddler children because they are not old enough to fully understand my illness," "I worry about how my children will perceive my illness when they reach puberty," and "I do not know anyone I can talk to about age-appropriate ways to tell my children about the disease." Two mothers consulted a medical professional on how to inform their children about cancer and referred to some existing pamphlets.

Psychosocial, Physical, and Economic Impacts on Their Children

Some mothers were concerned about "Changing their children's daily lives and behaviors." They said, "I do not have as much time to play with my children, and their only playtime is on electronic devices such as video games and iPads," and, "I feel sorry that my illness has changed my children's lives." The mothers were also concerned that "Cancer would cause their children too much worry and stress."

A few mothers with children from school age to adolescence said, "I overstressed my son as he was preparing to take the college entrance exam," "My illness even made my daughter think about quitting college," and "I caused undue worry and stress to my children when they were struggling with their studies and club activities." One mother said, "My high school son had a panic attack," and said that she observed psychological instability in her son after her cancer announcement.

I think the more the older children are able to understand cancer, the more they worry and fret about their mother's cancer. My daughter, a college student, never expressed any such feelings to me, but I later heard that she was thinking about quitting college. As a mother, I felt sorry for making my daughter think about such things. I wanted my daughter to enjoy her college years to the fullest. (J)

Furthermore, she was concerned that "Her children would be overly disturbed by the changes in her appearance because of the treatment."

Mothers with school age to adolescent children were concerned that "The cost of treatment would place a financial burden on their children's upbringing." They felt sorry about

the financial strain that the high cost of treatment would place on their family's budget. They said, "My children are in college and high school and it is an expensive time for them, so I am sorry to have to pay for my treatment," and "I worry about how I will pay for my children's upbringing if I am unable to continue working."

The mothers were also concerned about "The risk of cancer transmission to their children."

Difficulty in Obtaining Parenting Support from the Surrounding Community

Some mothers were "Hesitant to leave childcare and housework to their working husbands." This was particularly true for mothers with infants. These mothers said, "My husband is busy at work, so it is difficult to ask him to take care of the children even if I wanted him to," and "My husband is devoted and supportive, but I do not think I should rely on him fully because he is working."

Furthermore, when asking their husbands to help with housework and childcare, some mothers "thought that their husbands could not take care of their children alone." They also said, "Considering my husband's work schedule, I also need the cooperation of grandparents to take care of my children."

Mothers with children from infancy to early childhood were concerned about the "Lack of a safe place to leave their children at any time."

Previously, when my son developed a fever, I had to postpone my treatment schedule because there was no one to care for him. Because my children are small, it is difficult to find a place to leave them in such an emergency. I cannot easily receive treatment with peace of mind. (H)

Furthermore, "Having no one to help them with childrearing and housework" was also a major concern for mothers who were simultaneously undertaking treatment and childcare.

The mothers also expressed concern that "There is no babysitter that I can safely hire without incurring excessive financial burden."

I know that childcare support services, such as babysitters and housekeeping services, exist. However, it seems that the more frequently they are used, the more expensive they become. I wish there was more childrearing support in society for mothers with cancer. (B)

In addition to support for childrearing, a major concern regarding support for the children was the "Lack of understanding in schools for children with parents afflicted with cancer." The mothers said, "I do not feel supported by the school when I tell them about my illness," and "I feel that the school and society are still unaware of the implications of parent's cancer." These mothers were also concerned about the "Lack of people who can support the children's concerns and anxieties." They said, "There is no one to provide emotional support for my children and family," and "I do not think there is a place for my children to vent their anxieties and worries."

I needed intervention from a third party, such as a health care provider or the community, to help my husband and children cope with the psychological burden and stress that they were experiencing. (E)

Absence of Someone in the Same Situation to Consult

Mothers were concerned about the "Lack of a place to share their concerns about parenting and illness because there were no other people around who were in the same situation"; thus, they were prone to feeling anxious and lonely. They said, "I cannot get to know people with the same disease who have children of the same age," and "I feel alone because there is no place to vent my worries about parenting and my own feelings of weakness." Simultaneously, mothers were concerned about "Not being able to get the information and support they needed because there was no one around them in the same situation." Mothers felt the "Inability to share information on parenting concerns and childcare support."

It is hard to find people around me who are in the same situation, have small children, and have cancer themselves. I did not want to worry people around me, so I could not talk about my worries about childrearing or my illness, not even to my family. I just kept it all to myself. (G)

Difficulty in Seeking Parental Support from Medical Personnel

Mothers were concerned about "Not knowing how to turn to medical personnel for help with their parenting problems and concerns." Some said, "I am nervous during medical appointments and therefore unable to discuss my parenting concerns with medical personnel," and "It is difficult to get the doctors and nurses at the hospital to listen to my childrearing concerns because they are too busy." In addition, the participants stated, "I do not know what and how to ask for help at the hospital's cancer counseling office or patient groups," and "I feel uncomfortable participating in patient groups because of the high age-range of the groups." However, several mothers stated that "the presence of friends they met at patient groups and salons, and the existence of a place where they could vent their feelings was helpful."

The doctors and nurses appear busy, and it is difficult to talk to them while in the hospital. At such times, it would have been reassuring if the nurses had approached me or asked me about my children. It is difficult to speak to the medical staff on my own. (E)

Discussion

Characteristics of Concerns of Mothers with Children in Infancy and Early Childhood

This study revealed that mothers with children in infancy are particularly vulnerable to difficulties in balancing their

anticancer treatments and childrearing because of the time and effort required for childrearing. Infancy is a crucial time for parents and children when lifelong attachments are formed (Bowlby, 1951); it is also a time when mothers must fulfill their important parental role in building the foundations of their children's lives (Watanabe, 2016). Based on these previous studies and the present results, it is clear that the emotional distress that mothers experience when diagnosed with cancer is severe because they experience a change in their roles and loss of their identity as mothers.

Characteristics of Concerns of Mothers with Children from School Age to Adolescence

Mothers of school age were concerned about the psychosocial, physical, and economic impacts on their children and feared that their own cancers would affect their children's lives. Such a psychosocial impact was extracted as a major concern, especially for mothers whose children grew to an age at which they could understand what cancer was, especially at the sensitive adolescence age.

Concerns about financial impacts were also a characteristic concern of mothers with children in the generation that had to pay for childcare from school age to adolescence; these result from changing their employment status or taking a leave of absence because of their cancer treatment.

Characteristics of Concerns Shared by Mothers with Children of All Ages

Mothers of children of all ages faced the problem of telling their children about their cancer. In the present study, all mothers stated that "they were concerned from the outset about informing their children about their cancer." For example, they were concerned about how much to tell their children, especially those in infancy, how to respond to them during the sensitive adolescent period, and how to tell their children according to their growth stages. Previous studies have considered the difficulty of communicating according to the developmental stage as a challenge in cancer notification (Tamura et al., 2019), which is consistent with the results of this study.

Mothers with cancer faced a lack of resources and information to deal with all these parenting concerns and problems and were concerned about the difficulty in getting parenting support from the surrounding community and difficulty in seeking parenting support from medical personnel. For husbands, who could be the closest supporters of mothers' childcare, they said, "they were hesitant to leave childcare and housework entirely up to their working husbands." In Japan today, as the birthrate declines and the population ages, more women are entering the workforce, and there is a push for men to participate in childcare. However, the rate of fathers' participation in childcare is the lowest in developed countries (Ministry of Health, Labor and Welfare, 2017), and the fathers' role is primarily to financially support their children, with mothers taking on the responsibility of childcare in general, including education, discipline, play, and care (Terazono et al., 2015). This situation in Japan is believed to be one of the factors in the results of this study, "Thinking that their husbands could not take care of their children alone."

Support for Cancer Patients with Children

The concerns of cancer patients with children differed according to the children's age, suggesting that pertinent support is needed according to their developmental stage.

A previous study found that cancer patients with infant children experienced particularly severe difficulties in balancing treatment and childrearing during the period of preparation for hospitalization from the time of consultation to initial treatment and during initial treatment, such as anticancer drug treatment (Nakayama et al., 2020). This study also found that mothers felt that it was difficult to ask for support during childrearing and continue childrearing while their lives were restricted. Early intervention for patients with cancer with young children is important because patients who have concerns about childcare experience a decline in mental health and are at increased risk of developing depression (Schmitt et al., 2008). After the initial treatment, mothers with cancer are forced to fight the disease for a long period because of medical anticancer and hormone treatments, physical symptoms associated with cancer, and emergency hospitalization owing to changes in the disease's condition. Therefore, hospitals, community support, and government agencies need to work together to provide continuous and comprehensive support for mothers to balance the long period of treatment and childcare, such as by establishing 24-hour childcare centers near hospitals and increasing the number of consultation services in hospitals and communities to support childcare for patients with cancer. A novel finding of this study is that mothers seek psychological follow-up for their children and husbands through third parties. Therefore, a system that can provide support to patients and their families through collaborations among doctors, nurses, psychologists, peer supporters, community liaison nurses, public health nurses, government officials, and multidisciplinary professionals is necessary.

For telling children about their parents' cancer, providing step-by-step support from infancy to adolescence is important. In Japan, Hope Tree, which provides support for children of patients with cancer, is currently implementing a program to help school-aged children improve their ability to face situations and their feelings. Many books and pamphlets have been published to assist parents in communicating the disease to their children (Osawa, 2018; Tanaka, 2018). Participation in these programs and the use of picture books have been shown to be effective in deepening com-

munication between parents and children and are useful tools for informing children about their parents' cancer (Kobayashi et al., 2017). However, even now, more than 10 years after these support measures were first introduced, it is clear that they have not reached all mothers with cancer. Medical providers should actively provide information on supporting cancer notifications to mothers and their children. This study found that mothers of adolescent children were concerned about the method of cancer notification. Support and communication tools for cancer notifications targeting adolescents are not yet well developed. It is necessary to expand the scope of support for parents of infants, toddlers, school-aged children, and adolescents and to provide support for parents with cancer-related issues.

Patients with cancer who have children experienced the lack of someone in the same situation to consult and were prone to loneliness given their pain associated with treatment and concerns about raising children alone. Concerns about social support were extracted as trends unique to Japan, which were not found in previous studies in the United States (Park et al., 2017) and Germany (Inhestern L et al., 2016). Several mothers stated that "the presence of friends they met at patient groups and salons, and the existence of a place where they could vent their feelings was helpful." Currently, in Japan, several organizations, such as Cancer Parents, allow cancer patients with children to connect with each other via the Internet and Pink Ring, a community where patients can share their worries and anxieties specific to juvenile breast cancer with other patients in Japan. It is important for communities and hospitals to actively provide information on such communities to patients with cancer and to create networks where patients can support and encourage each other.

Limitations and Future Study Directions

This study is significant because it comprehensively clarifies the parenting concerns of patients with cancer who have children of all ages.

This study aimed to clarify the situation and concerns of Japanese mothers with cancer who have children. However, it cannot be denied that there may be regional differences between the results of this study and the situation in urban areas where nuclear families are common. Initially, we planned to include 20 participants from each region, as in previous studies; however, we were unable to conduct the survey in urban areas because of the effects of COVID-19. There were also two participants who were diagnosed more than 10 years after the diagnosis, and there may have been recall bias in the narratives. Therefore, the findings of this study are difficult to generalize. The reason for limiting the survey to "mothers" in this study is that it is generally the mother who experiences childbirth and is centrally involved in childrearing from the newborn onward and also to eliminate the uncertainty caused by the gender of the father and mother. In the future, we also plan to conduct research on fathers. Currently, digestive cancers for men and breast, uterine, and ovarian cancers for women account for the majority of cancer incidence rates among the parenting generations in Japan (National Cancer Center, 2015). In this study, there was a bias in the types of cancer; therefore, in the future, it will be necessary to expand the scope to include mothers and fathers with diseases other than breast and uterine cancer.

Author Contributions

Fumiko Sato contributed to the study conception and design, data analysis, and supervision of the entire study process. Shiori Yoshida critically reviewed the manuscript and supervised the entire study process. Misa Yanai contributed to the conception and design of this study, data collection, and data analysis and wrote the first draft of the manuscript. All authors have commented on previous versions of the manuscript.

Declaration of Conflicting Interests

The authors have no conflicts of interest to disclose.

Ethical Approval

This study was approved by the Ethics Committee of Tohoku University Graduate School of Medicine (Reception No.: 2020-1-108).

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Informed Consent

Informed consent was obtained from all patients and participants involved in this study.

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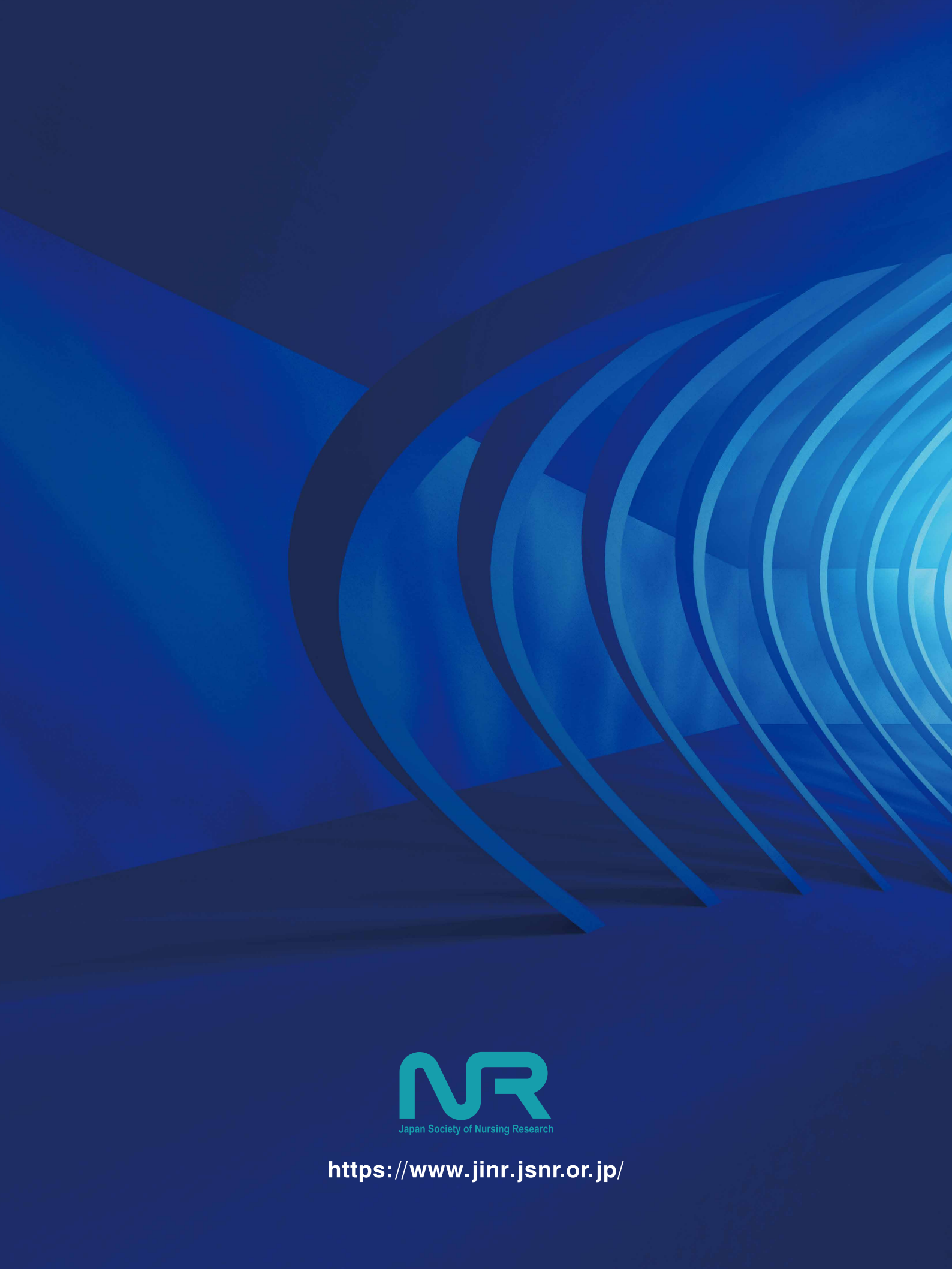
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