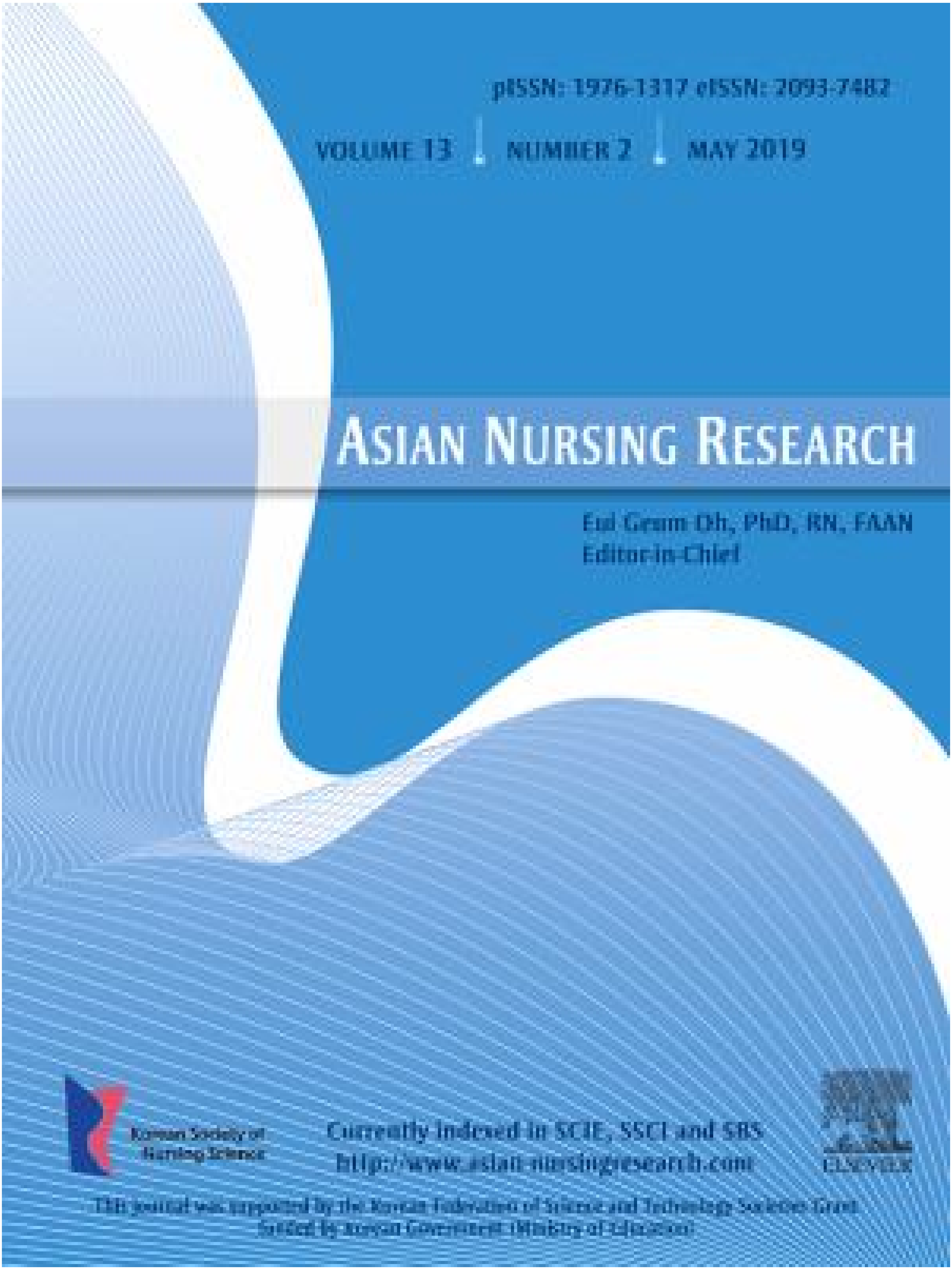

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Research Article

Effectiveness of a home-based exercise program among patients with lower limb spasticity post-stroke: A randomized controlled trial

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ABSTRACT

Purpose: To evaluate the effectiveness of advanced practice nurse–guided home-based rehabilitation exercise program (HREPro) among patients with lower limb spasticity post-stroke.

Methods: This randomized controlled study recruited 121 patients with lower limb spasticity post-stroke. Intervention ($n = 59$) and control ($n = 62$) groups underwent 12-month HREPro and conventional rehabilitation, respectively, after discharge. The Fugl–Meyer assessment of spasticity measurement, modified Ashworth scale of motor function, 10-Meter Walk Test of walking ability, and Barthel index of activities of daily living (ADL) were evaluated at 0, 3, 6, and 12 months after discharge.

Results: Significant differences were found in spasticity degree, motor function, walking ability, and ADL at 6 and 12 months after discharge between the control and intervention groups. Lower limb spasticity and ADL in the intervention group were significantly improved.

Conclusion: HREPro is effective for rehabilitation of patients with lower limb spasticity post-stroke and has favorable home application.

Introduction

Stroke is the third most common cause of death after coronary heart disease and cancer in most Western countries [1,2]. A previous epidemiological survey showed that in China there are 1,596 stroke patients per 100,000 people [3]. Furthermore, almost 70.0% of patients with stroke are reported to suffer from functional disabilities [4]. Lower limb motor function, a prerequisite for performing routine activities of daily life, is often impaired after stroke, causing restrictions in functional mobility [5,6]. Lower limb spasticity is a common consequence of stroke [7], and results from a combination of upper motor neuron syndromes [8]. Spasticity is a velocity-dependent condition that appears to increase during tonic stretch reflexes and hyperexcitability, and is associated with exaggerated tendon jerks [9]. Spastic motor disorder interferes with rehabilitation and leads to joint contractures that cause pain, stiffness, and reduced range of motion of the joint. This restricts the patient's functional mobility and affects activities of daily living (ADL), thereby incurring a large burden on stroke survivors and society [10]. Thus, it is important to seek an effective rehabilitation protocol for stroke patients with lower limb spasticity.

Previous studies have demonstrated the effects of various rehabilitation programs, such as robotic-assisted rehabilitation (a new training technology dependent on robot assistance), neuromuscular electric stimulation (which stimulates the muscles using surface electrodes to excite the peripheral nerve fibers resulting in eventual improvements in the neurophysiological and clinical outcomes), extracorporeal shock wave (pneumatically generated pulsed sound waves are converted into precise ballistic shock waves and transmitted to a target area to achieve rehabilitation), mirror therapy (a rehabilitation method based on the principle of plane mirror imaging to stimulate vision and combine rehabilitation training programs), and bilateral leg exercises in improving motor control among stroke patients [11–13]. However, most patients are unable to complete these treatments because of the prohibitive cost of the equipment, which subsequently limits their recovery [14]. Home-based rehabilitation programs, which are safe,

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inexpensive, and easy-to-implement, have been developed for stroke rehabilitation using different technologies [15]. Randomized trials have evaluated whether nurse-led, home-based rehabilitation programs, such as home-based physical activity incentive and education programs [16], and home-based gaming exercises [17], can positively influence recovery after stroke. Home-based hand rehabilitation has been shown to significantly increase the self-reported function and quality of movement of the impaired hand after chronic stroke [18]. In addition, home-based rehabilitation decreases the level of disability and correspondingly improves functional recovery among patients with motor impairments [19]. Home-based rehabilitation is particularly important for patients who cannot attend supervised training sessions outside their homes [20]. In China, home-based rehabilitation is in its infancy; however, a previous study concluded that home-based traditional Chinese exercise improves the short-term balance ability in patients post-stroke [21]. Exercise training is strongly recommended for patients post-stroke [21,22], and the time spent in hospital may not be sufficient to prepare patients for further rehabilitation. To the best of our knowledge, no study has reported the effects of home-based rehabilitation exercise programs (HREPros) for patients with lower limb spasticity post-stroke.

Therefore, the purpose of the present study was to investigate the effectiveness of an HREPro, led by an advanced practice registered nurse (APRN), to manage patients with lower limb spasticity within 12 months of stroke. This study hypothesized that HREPro would significantly improve recovery of motor function of post-stroke lower limb spasticity.

Methods

Participants

The study participants were post-stroke inpatient who had been admitted to the Department of Neurology at the Second Affiliated Hospital of Wenzhou Medical University, China, from January 2015 to January 2018. The required sample size was calculated using G*Power 3.1. The effect size was estimated from a study on home-based physical activity incentive and education programs in the subacute phase of stroke recovery [16]. Based on the effect size (cohen's $d = 1.66$) and an alpha level set to 0.05, the initial power analysis indicated that 42 participants per group were required to reach 80.0% statistical power. Of a total of 164 patients who expressed interest in participating, 121 completed the study and were subsequently divided into the intervention group (IG; $n = 59$) and control group (CG; $n = 62$) by random allocation. Inclusion criteria were as follows: (1) patients clinically diagnosed with stroke that demonstrate lower limb spasticity, and (2) patients able to comprehend and follow instructions. Exclusion criteria were as follows: (1) patients suffering from cognitive impairment (Mini Mental State Examination <18) [23] and (2) patients with anxiety or depression before the stroke (Hamilton Anxiety Scale and Hamilton Depression Scale $\geq$7) [24,25].

Study Design

This randomized, single-center, patient-blinded study enrolled patients with lower limb spasticity post-stroke who presented to a teaching medical hospital from January 2015 to January 2018. Every patient who met the eligibility criteria was allotted a serial number by the computer with those having an odd number designated as the IG and those having an even number as the CG. The IG underwent HREPro, whereas CG underwent the conventional rehabilitation protocol. This randomized group intervention study was structured using a quasi-experimental, pre-post, CG design. All patients were assessed before (at 0 month) and at 3, 6, and 12 months after initiation of rehabilitation to compare the effectiveness of both programs.

Control Group

Patients in the CG were provided conventional rehabilitation after discharge from the hospital. This included issuing a rehabilitation manual for stroke (standard health education, consisting of information on physical activity, drugs, diet, follow-up time, etc.), performing telephonic follow-up (within 1 month), and completing follow-up medical appointments for assessment of recovery at 3, 6, and 12 months.

Intervention Group

Patients in the IG were provided with an HREPro in addition to the conventional rehabilitation regimen. The HREPro was an individually tailored, year-long rehabilitation intervention program, conducted at the participants' homes by an ARPN who had received professional physiotherapy training. The HREPro consisted of familiarizing the patient with navigating their home environment, as well as psychological preparation, and an exercise component. A nurse, during their first visit, evaluated the home environment, modified any environmental hazards, and guided the patient regarding how to walk safely in their home. The program involved fostering meaningful communication between the nurse and the patient. This helped the nurse understand each patient's specific concerns, including the fear of falling and satisfaction with particular walking aids. This, in turn, enabled them to motivate the patient on the basis of their own self-sufficiency. It was hoped that this would improve the patients' confidence in their own recovery and also help optimize program adherence. A comprehensive exercise program was used, which mainly included strengthening the lower limb muscle groups with exercises, such as joint training, sit-ups, balance training while standing, standing, bending to pick things up, straight leg-lifting, and climbing stairs. The exercise regimen was formulated with a view to reducing lower limb spasticity and improving mobility after stroke (Table 1). Patients underwent three exercise sessions per week during the first 3 months, supervised by an APRN, with each session lasting 30 minutes. This was followed by one supervised session per week, during the next 3 months. Thereafter, the frequency of the supervised exercise dropped to once a month, and once every other month, up to 12 months. HREPro was guided by the APRN with the assistance of family members who participated in all training sessions. If the patient encountered any difficulty during the whole training period, they could communicate with the nurse via e-mail or phone at any time.

Outcome assessments

The outcome assessment for both groups were performed by one trained and certified nurse practitioner before, and at 3, 6, and 12 months after initiation of the respective rehabilitation programs.

Fugl–Meyer assessment of motor function

The Fugle-Meyer assessment (FMA) was applied to assess the motor function of the lower limbs of each patient, which has been shown to have acceptable test-eretest and inter-rater reliability, and construct validity [26,27]. This test consisted of Hip/knee/ankle movement and coordination, achilles /genicular tendon reflex. Fifty items were included in the FMA. A three-point ordinal scale (0, cannot perform; 1, perform partially; 2, perform completely) was

Table 1 *Exercise Sets for the Intervention Group.*

Exercise	Performance	Repetitions
Ankle back extension training	Keep patient with supine position, hold the upper end of the ankle by one hand and press down, hold the upper of the foot by another hand and move up. The extension angle shall not exceed 20°	Hold 5–15 s at end range, repeat 15 times or more per day
Ankle plantar flexion training	Keep patient with supine position, hold the upper end of the ankle by one hand and press down, hold the upper of the foot in one hand and move down. The flexion extension angle shall not exceed 50°	Hold 5–15 s at end range, repeat 15 times or more per day
Ankle varus and valgus training	Keep patient with supine position, hold the upper end of the ankle by one hand and press down, hold the upper of the foot by another hand and move inside/outside. The angle shall not exceed 30°	Hold 5–15 s at end range, repeat 15 times or more per day
Hamstring stretch training	Keep patient with supine position, press knee joint by one hand and another hand hold the heel, then move the lower limb upward. The angle shall not exceed 80°	Hold 5–15 s at end range, repeat 15 times or more per day
Hip and knee flexion training	Keep patient with supine position, press knee joint by one hand and another hand holds the heel, make the hip and knee flex	Hold 5–15 s at end range, repeat 15 times or more per day
Hip abduction and adduction training	Keep patient with supine position, press knee joint by one hand and straight move the lower limbs inward/outward	Hold 5–15 s at end range, repeat 15 times or more per day
Sit-up and standing balance training	Extend hands forward, stay standing and maintain balance	Maintain 5–10min, repeat 4 times per day
Standing and bending to pick up	Slowly bend over and pick up ground items after standing	Repeat 10 times or more per day
Straight leg lifting	Keep patient with supine position and straighten lower limbs	Hold 5–15 s at end range, repeat 15 times or more per day
Climbing stairs	Slowly climb stairs to improve lower limb coordination	Maintain 10–20min, repeat 2 times per day

adopted for each item. The total score (using 17 parameters: The FMA scale can assess the motor function of the upper and lower limbs. the 17 items selected in this study are used to access the motor function of the lower limbs.) for the affected lower limb was 34 points. Therefore, a higher score indicated greater motor function.

Modified Ashworth scale for spasticity measurement

The Modified Ashworth scale (MAS), an assessment tool with good inter- and intra-rater reliability for measuring spasticity [28], is a five-point rating scale with scores ranging from 0 to 4, where 0 indicates no increase in muscle tone and 4 indicates that the affected limb is rigid during flexion or extension. MAS was measured by calculating the degree and point of resistance when a muscle was manually stretched to assess the tension in the lower limb muscles in stroke patients. A lower score denotes less spasticity.

10-Meter Walk Test for assessment of gait speed and step size

The 10-Meter Walk Test was used as a responsive and functional measure to assess the walking ability, gait, and speed of the patients over short distances (a typical distance of a household setting), which has demonstrated good reliability and validity across multiple patient populations and in individuals with known gait impairments [29]. In this study, patients were asked to walk 10 meters at their own comfortable pace. The average value of the three-step lengths at the central 6 meters mark, of a 10-meter walkway was determined by measuring the distance between the footprints. The time taken to walk 10 meters was also recorded using a stopwatch to calculate the gait speed.

Barthel Index for assessment of ADL

The Barthel Index (BI) was used to evaluate the patient's ability to perform ADL, which has been shown to give good reliability and validity in stroke patients [30]. The index includes three actions associated with mobility (on level surfaces, during transfers, and on stairs), and seven activities associated with self-care (bathing, feeding, dressing, grooming, bladder and bowel evacuation, and toilet use). Among these items, bathing and grooming are scored on an interval scale of 0–5, whereas dressing, feeding, bladder and bowel evacuation, toilet use, and stair climbing are scored on an interval scale of 0–10. The capacity to transfer and ambulate on level surfaces are scored on an interval scale of 0–15. The total score ranges from 0 to 100. A higher score indicates greater level of physical independence of the stroke patient.

Data analysis

Data input was managed using EpiData 3.0 software and the analysis was performed with SPSS 19.0 (IBM Corp., Armonk, NY, USA) statistical software. Measurements are expressed as mean ± standard deviation. Student t test for numerical variables and Pearson Chi-square test for categorical variables were applied to compare clinical and demographic characteristics before intervention. The comparison between two groups was analyzed by Student t test. Generalized estimating equations were used to compare the trend of FMA, MAS score, Gait Speed (m/sec), Step Size(m) and BI between the two groups of stroke patients. A $p < .05$ was considered to be statistically significant.

Ethical considerations

The study was approved by the ethics committee of the Second Affiliated Hospital & Yuying Children's Hospital of Wenzhou Medical University, Wenzhou, Zhejiang, China (Approval no. L-2019-11). An informed consent was obtained from each patient or their respective proxy (due to patient age) before the beginning of the study. The protected healthcare information was only used for this study.

Results

Demographic and clinical features of the stroke patients

Figure 1 shows the flow diagram of this study. Of 164 patients enrolled in the study, 24 declined to participate, 11 were withdrawn after randomization (5 patients from the IG and 6 patients from the CG), five were lost to follow-up (3 patients in the IG and 2 patients in the CG), and three refused to continue (3 patients in the IG and 0 patient in the CG). Thus, a total of 121 stroke patients completed the study and were randomly assigned to the IG ($N = 59$) and CG ($N = 62$). The mean age in the IG and CG was 55.41 ± 6.78 years and 56.41 ± 6.13 years, respectively. No significant differences in baseline demographic parameters and clinical features, including age, gender, level of education, residential location, duration of stroke, type of stroke, and SF-36 physical component score were identified between the groups (Table 2).

Table 2 *Comparison of General Data of Stroke Patients in the Two Groups (N = 121).*

	IG (n = 59) Mean ± SD or *N* (%)	CG (n = 62) Mean ± SD or *N*(%)	t/χ^2	*p*
Age (yrs)	55.41 ± 6.78	56.41 ± 6.13	.85	.391
Men	41 (68.3)	44 (73.3)	.16	.692
Education attainment				
None	4 (6.8)	5 (8.1)		
Low	35 (59.3)	36 (58.1)		
Middle	12 (20.3)	12 (19.3)		
High	8 (13.5)	9 (14.5)	.52	.493
Location of residence				
Urban	35 (59.3)	36 (58.1)		
Rural	24 (40.7)	26 (41.9)	.31	.591
Disease duration (mo)	3.41 ± 0.79	3.23 ± 0.82	.22	.224
Stroke type				
Cerebral infarction	25 (42.4)	27 (43.55)		
Cerebral hemorrhage	34 (57.6)	35 (56.45)	.31	.583
SF-36 Physical Component Scale	57.34 ± 10.23	55.21 ± 11.19	1.09	.284

Note. CG = control group; IG = intervention group; SD = standard deviation; SF-36, 36-Item Shon Form Health Survey; yrs = years.

Comparison of Fugl-Meyer assessment and Modified Ashworth scale scores of the two groups

There were no significant differences observed between the FMA scores in the IG and CG at 0 (the baseline) ($t = 0.57$, $p = .572$) and 3 months after initiation of rehabilitation ($t = 1.43$, $p = .153$). FMA scores of the IG patients were significantly greater than those of the CG patients at the 6- and 12-month follow-ups ($t = 6.14$, $p < .001$; $t = 8.03$, $p < .001$, respectively). MAS scores among IG patients decreased significantly compared with those of CG at 6- and 12-month follow-ups ($t = -2.27$, $p = .031$; $t = -3.66$, $p < .001$, respectively). In addition, we observed a significant within-group effect (MAS: F = 13.23, $p < .001$; FMA: F = 14.51, $p < .001$) and interaction effect (MAS: F = 7.69, $p < .003$; FMA: F = 8.22, $p = .002$),

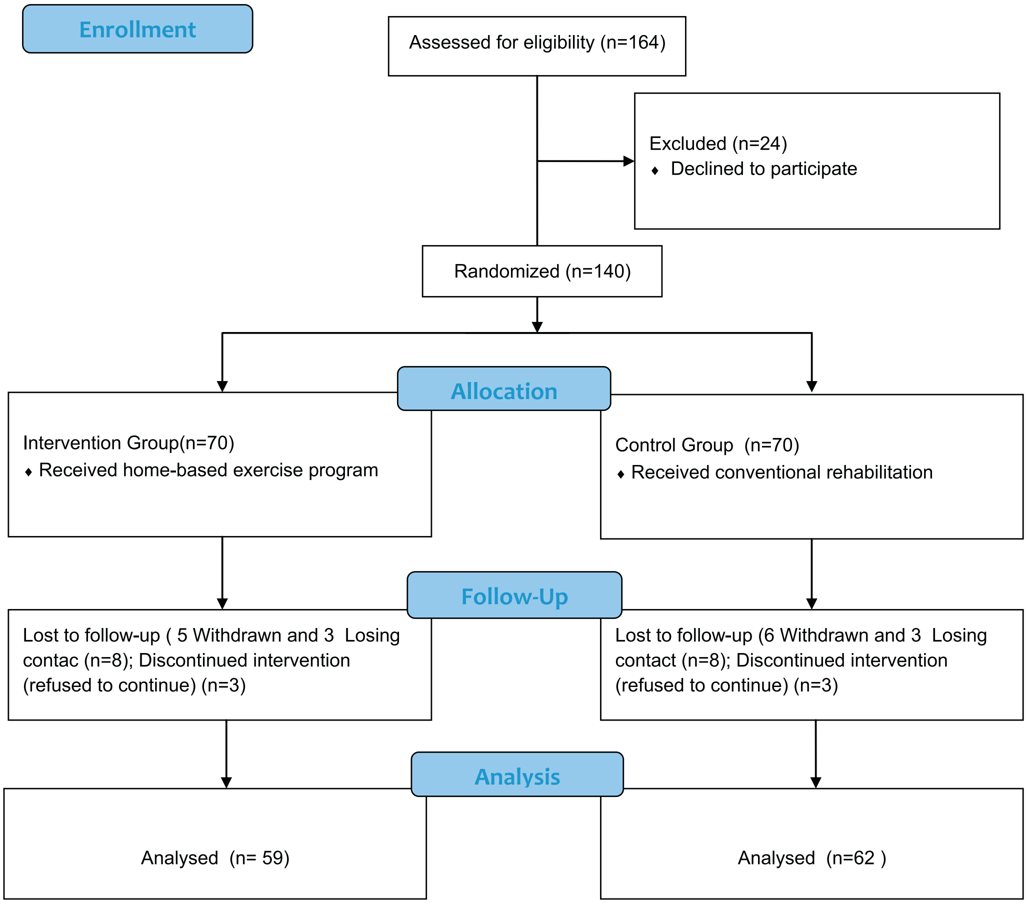

Figure 1. Flow diagram detailing the study design.

Table 3 *Comparison of FMA, MAS, Gait Speed (m/sec), Step Size(m) and BI Between Two Groups of Stroke Patients.*

	Pre-test	Post-test at 3 months	Post-test at 6 months	Post-test at 12 months	Sources	F	P
FMA of spasticity measurement							
IG(Mean ± SD)	12.66 ± 3.01	14.82 ± 3.16	21.23 ± 3.71	24.82 ± 3.31	Group	1.42	.172
CG(Mean ± SD)	12.36 ± 2.78	14.03 ± 2.91	17.19 ± 3.53	20.16 ± 3.07	Time	14.31	<.001
t	0.57	1.43	6.14	8.03	Group*Time	6.91	.007
p	.572	<.001	<.001	<.001			
MAS of motor function							
IG(Mean ± SD)	3.32 ± 0.81	3.19 ± 1.02	1.89 ± 1.08	1.07 ± 0.89	Group	1.03	.199
CG(Mean ± SD)	3.27 ± 0.71	3.04 ± 0.92	2.35 ± 1.15	1.69 ± 0.97	Time	16.32	<.001
t	0.36	0.85	−2.27	−3.66	Group*Time	7.73	.004
p	.721	.393	.031	<.001			
Gait speed							
IG(Mean ± SD)	0.34 ± 0.19	0.45 ± 0.25	0.64 ± 0.31	0.75 ± 0.32	Group	0.83	.263
CG(Mean ± SD)	0.37 ± 0.24	0.42 ± 0.27	0.53 ± 0.29	0.58 ± 0.31	Time	7.41	.003
t	−0.76	0.63	2.02	2.97	Group*Time	5.92	.011
p	.451	.532	.042	<.001			
Step size							
IG(Mean ± SD)	0.31 ± 0.21	0.41 ± 0.26	0.59 ± 0.24	0.71 ± 0.28	Group	0.63	.472
CG(Mean ± SD)	0.34 ± 0.23	0.43 ± 0.29	0.49 ± 0.25	0.54 ± 0.27	Time	8.45	.001
t	−0.75	−0.39	2.24	3.41	Group*Time	7.81	.003
p	.464	.691	.032	<.001			
BI							
IG(Mean ± SD)	36.64 ± 7.85	59.43 ± 10.19	69.64 ± 11.52	85.38 ± 14.53	Group	1.83	.105
CG(Mean ± SD)	35.13 ± 8.17	55.38 ± 9.54	60.45 ± 9.74	71.43 ± 10.61	Time	14.93	<.001
t	1.04	2.26	4.75	6.05	Group*Time	9.98	<.001
p	.311	.033	.002	<.001			

Note. BI = Barthel index; CG = control group; FMA, Fugl–Meyer assessment; IG = intervention group; MAS = Modified Ashworth Scale.

but there was no significant between-group effect (MAS: F = 1.15, $p < .223$; FMA: F = 0.93, $p = .302$). These results indicated that the comparisons of lower limb extremity motor performance and spasticity of IG patients showed great improvement than CG patients. However, no significant difference in MAS scores were identified at 0 or 3 months between the two groups ($t = 0.32$, $p = .721$; $t = 0.85$, $p = .393$, respectively) (Table 3).

Comparison of gait speed and step size of the two groups

At 0 and 3 months, the between-group differences in gait speed ($t = -0.76$, $p = .451$; $t = 0.63$, $p = .532$, respectively) and step size ($t = -0.75$, $p = .464$; $t = -0.39$, $p = .691$, respectively) were not statistically significant. However, the gait speed of the IG patients was significantly higher than the CG patients at 6 months (0.64 ± 0.31 vs. 0.53 ± 0.29, $t = 2.02$, $p = .042$) and 12 months (0.75 ± 0.32 vs. 0.58 ± 0.31, $t = 2.97$, $p < .001$). The increase in step size of the IG patients was also statistically significantly greater at 6 and 12 months compared with that of the CG patients (0.59 ± 0.24 vs. 0.49 ± 0.25, $t = 2.24$, $p = .032$; 0.71 ± 0.28 vs. 0.54 ± 0.27, $t = 3.41$, $p < .001$). In addition, we observed a significant within-group effect (gait speed: F = 7.65, $p = .003$; step-size: F = 8.91, $p = .001$) and interaction effect (gait speed: F = 5.45, $p = .010$; step-size: F = 5.93, $p = .008$), but there was no significant between-group effect (gait speed: F = 0.69, $p = .376$; step-size: F = 0.49, $p = .537$) (Table 3).

Comparison of Barthel Index score of the two groups

We further assessed the ADL of the two groups by assessing the BI score. As shown in Table 3, the BI scores among intervention patients gradually increased over time and were significantly higher than those of the CG patients, especially at the 3, 6, and 12-month follow-ups ($t = 2.26$, $p = .033$; $t = 4.75$, $p = .002$; $t = 6.05$, $p < .001$, respectively). In addition, we observed a significant within-group effect (F = 15.71, $p < .001$) and interaction effect (F = 8.96, $p < .001$), but there was no significant between-group effect (F = 1.78, $p = .122$) (Table 3).

Discussion

This study showed that HREPro led by a trained APRN produced significantly greater improvements in motor performance, spasticity, walking ability, and ability to perform ADL among patients with lower limb spasticity post-stroke than that achieved through conventional rehabilitation. To the best of our knowledge, this is the first study to investigate the possible functional effectiveness of a progressive and semi-supervised HREPro for the rehabilitation of patients with lower limb spasticity post-stroke.

Home-based rehabilitation programs have been demonstrated to be at least as good as hospital-based postoperative rehabilitation programs for patients in terms of achieving functional improvement (including pain relief, walking, balancing, and achieving functionality) [31]. In addition, home-based exercise programs have also been reported to be effective in improving functional mobility and quality of life in sedentary elderly people, even without constant supervision during exercise [32]. Although exercise has been recommended post-stroke, few people exercise after stroke, and even fewer commence long-term exercise [33]; hence, innovative interventions are required to promote and maintain exercise after stroke. Based on these previous studies, this study investigated the possible functional effectiveness of HREPro led by a trained ARPN for patients with lower limb spasticity post-stroke.

The results showed that the FMA scores among patients in the IG were higher than those among patients in the CG at 6 and 12 months after initiation of the respective rehabilitation regimes. Furthermore, the MAS scores among IG patients decreased significantly compared with those of CG patients at 6- and 12-month follow-ups, indicating a significant improvement in lower limb spasticity. This may be attributed to the increased number of motion repetitions along with a larger envelope of motion and multijoint coordination. It is known that lower limb motor recovery correlates significantly with gait speed and step size [34], which can be assessed with the 10-Meter Walk Test. Studies have shown that strengthening exercise of the ankle joint can improve mobility in patients after stroke [35]. The gait speed and step size among patients in the IG were also significantly improved 6 months after initiation of rehabilitation compared with those among patients in the CG, which may be associated with increased joint exercise in IG patients. Overall, the results showed that patients in the IG had a significantly improved lower extremity motor performance with reduced spasticity compared with that of patients in the CG at 6 and 12 months post-stroke, which suggests that the HREPro is not effective in the short-term but can effectively improve lower limb spasticity in the long-term. It has been reported that home-based rehabilitation programs improve the functional capacity of patients with motor impairment, as indicated by the BI [19]. The ADL of the two groups were assessed using the BI, and the scores achieved by the intervention patients were found to be significantly higher than those obtained by the CG patients, which demonstrated that HREPro greatly improved the patients' ability to perform their ADL over time.

The exercises for this study were selected based on their applicability in the home environment, simplicity, no requirement of equipment, and focus on activating the joint and relaxing the muscle. A previous study on home-based exercise led by a nurse was noted to be effective for patients with cardiovascular disease, which increased the participation and adherence rates of the patients [36]. The HREPro in this study was led and followed up by a trained ARPN, which benefited patients with long-term exercise. In addition, the longitudinal design of the study allowed us to assess the effects of HREPro over time (over 3, 6, and 12 months).

However, the present study has a few limitations. Firstly, the study did not evaluate the range of motion of the lower limb joints or adjustment of the muscle tone, which are restricted by lower limb spasticity. Secondly, as this study is a semi-supervised, home-based study, which may affect the frequency of exercise sessions and generate a risk of bias. Lastly, this was a single-center study with a small number of participants, which limits the statistical power of the results derived from the study. Thus, more extensive multicenter studies with larger cohorts are warranted to evaluate and establish the effectiveness of HREPro for stroke patients with lower limb spasticity.

Conclusion

This single-blind, randomized controlled study provides evidence that APRN-guided HREPro is beneficial in the recovery of patients with lower limb spasticity post-stroke by promoting the recovery of motor function, reducing muscle spasticity, improving walking ability, and enhancing ADL. Thus, HREPro, an effective intervention guided by APRN with favorable home application, may be beneficial for improving lower limb spasticity in post-stroke patients at their homes. Rehabilitation nurses can guide patients in continuing their home-based exercise program. Overall, the present study provides evidence for the benefits of an HREPro in the recovery of lower limb spasticity post-stroke. Further longitudinal, large-scale, multicenter, and double-blind randomized controlled studies are required to corroborate the findings of this study.

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Conflict of interest

There are no conflicts of interest.

References

1. Feigin VL, Krishnamurthi RV, Priya P, Bo N, Mensah GA, Bennett DA, et al. Update on the global burden of ischemic and hemorrhagic stroke in 1990-2013: the GBD 2013 study. Neuroepidemiology. 2015;45(3):161–76. https://doi.org/10.1159/000441085
2. Ng M, Fleming T, Robinson M, Thomson B, Graetz N, Margono C, et al. Global, regional, and national prevalence of overweight and obesity in children and adults during 1980-2013: a systematic analysis for the Global Burden of Disease Study 2013. Lancet. 2014;384(9945):766–81. https://doi.org/10.1016/S0140-6736(14)60460-8
3. Wang Z, Hu S, Sang S, Luo L, Yu C. Age-period-cohort analysis of stroke mortality in China: Data from the global burden of disease study 2013. Stroke. 2017;48(2):271–5. https://doi.org/10.1161/STROKEAHA.116.015031
4. Yan R, Zhang Y, Lim J, Yang F, Zhou L, Lyu D, et al. The effect and biomechanical mechanisms of intradermal needle for post-stroke hemiplegia recovery: study protocol for a randomized controlled pilot trial. Medicine. 2018;97(16):e0448. https://doi.org/10.1097/md.0000000000010448
5. Ji SG, Kim MK. The effects of mirror therapy on the gait of subacute stroke patients: a randomized controlled trial. Clin Rehabil. 2015;29(4):348–54. https://doi.org/10.1177/0269215514542356
6. Li Y, Wei Q, Gou W, He C. Effects of mirror therapy on walking ability, balance and lower limb motor recovery after stroke: a systematic review and meta-analysis of randomized controlled trials. Clin Rehabil. 2018;32(8):1007–21. https://doi.org/10.1177/0269215518766642
7. Singer JC, Nishihara K, Mochizuki G. Does poststroke lower-limb spasticity influence the recovery of standing balance control? A 2-year multilevel growth model. Neurorehabilitation Neural Repair. 2016;30(7):626–34. https://doi.org/10.1177/1545968315613862
8. Mayer NH. Clinicophysiologic concepts of spasticity and motor dysfunction in adults with an upper motoneuron lesion. Muscle Nerve Suppl. 1997;6:S1–13.
9. Graham LA. Management of spasticity revisited. Age Ageing. 2013;42(4): 435–41. https://doi.org/10.1093/ageing/aft064
10. Hara T, Abo M, Hara H, Sasaki N, Yamada N, Niimi M, et al. The effect of repeated botulinum toxin A therapy combined with intensive rehabilitation on lower limb spasticity in post-stroke patients. Toxins. 2018;10(9):349. https://doi.org/10.3390/toxins10090349
11. Guo J, Qian S, Wang Y, Xu A. Clinical study of combined mirror and extracorporeal shock wave therapy on upper limb spasticity in poststroke patients. Int J Rehabil Res. 2019;42(1):31–5. https://doi.org/10.1097/mrr.0000000000000316
12. Hong Z, Sui M, Zhuang Z, Liu H, Zheng X, Cai C, et al. Effectiveness of neuromuscular electrical stimulation on lower limbs of patients with hemiplegia after chronic stroke: a systematic review. Arch Phys Med Rehabil. 2018;99(5): 1011–10122 e1. https://doi.org/10.1016/j.apmr.2017.12.019
13. Shakti D, Mathew L, Kumar N, Kataria C. Effectiveness of robo-assisted lower limb rehabilitation for spastic patients: a systematic review. Biosens Bioelectron. 2018;117:403–15. https://doi.org/10.1016/j.bios.2018.06.027
14. Byl NN, Pitsch EA, Abrams GM. Functional outcomes can vary by dose: learning-based sensorimotor training for patients stable poststroke. Neurorehabilitation Neural Repair. 2008;22(5):494–504. https://doi.org/10.1177/1545968308317431
15. Chen Y, Abel KT, Janecek JT, Chen Y, Zheng K, Cramer SC. Home-based technologies for stroke rehabilitation: a systematic review. Int J Med Inf. 2019;123: 11–22. https://doi.org/10.1016/j.ijmedinf.2018.12.001
16. Chaparro D, Daviet JC, Borel B, Kammoun B, Salle JY, Tchalla A, et al. Home-based physical activity incentive and education program in subacute phase of stroke recovery (Ticaa'dom): study protocol for a randomized controlled trial. Trials. 2018;19(1):68. https://doi.org/10.1186/s13063-017-2410-9
17. Kilbride C, Scott DJM, Butcher T, Norris M, Ryan JM, Anokye N, et al. Rehabilitation via HOMe Based gaming exercise for the Upper-limb post Stroke (RHOMBUS): protocol of an intervention feasibility trial. BMJ Open. 2018;8(11):e026620. https://doi.org/10.1136/bmjopen-2018-026620
18. Zondervan DK, Friedman N, Chang E, Zhao X, Augsburger R, Reinkensmeyer DJ, et al. Home-based hand rehabilitation after chronic stroke: randomized, controlled single-blind trial comparing the MusicGlove with a conventional exercise program. J Rehabil Res Dev. 2016;53(4):457–72. https://doi.org/10.1682/jrrd.2015.04.0057
19. Vega-Ramirez FA, Lopez-Liria R, Granados-Gamez G, Aguilar-Parra JM, Padilla-Gongora D. Analysis of home-based rehabilitation in patients with motor impairment in primary care: a prospective observational study. BMC Geriatr. 2017;17(1):145. https://doi.org/10.1186/s12877-017-0526-0
20. Turunen K, Salpakoski A, Edgren J, Tormakangas T, Arkela M, Kallinen M, et al. Physical activity after a hip fracture: effect of a multicomponent home-based rehabilitation program-A secondary analysis of a randomized controlled trial. Arch Phys Med Rehabil. 2017;98(5):981–8. https://doi.org/10.1016/j.apmr.2017.01.004
21. Chen BL, Guo JB, Liu MS, Li X, Zou J, Chen X, et al. Effect of traditional Chinese exercise on gait and balance for stroke: a systematic review and meta-analysis. PloS One. 2015;10(8):e0135932. https://doi.org/10.1371/journal.pone.0135932

22. Chen MD, Rimmer JH. Effects of exercise on quality of life in stroke survivors: a meta-analysis. Stroke. 2011;42(3):832–7. https://doi.org/10.1161/strokeaha.110.607747
23. Folstein MF, Folstein SE, McHugh PR. Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975;12(3):189–98. https://doi.org/10.1016/0022-3956(75)90026-6
24. Hamilton M. The assessment of anxiety states by rating. Br J Med Psychol. 1959;32(1):50–5. https://doi.org/10.1111/j.2044-8341.1959.tb00467.x
25. Hamilton M. A rating scale for depression. J Neurol Neurosurg Psychiatry. 1960;23(1):56–62. https://doi.org/10.1136/jnnp.23.1.56
26. Gladstone DJ, Danells CJ, Black SE. The Fugl-Meyer assessment of motor recovery after stroke: a critical review of its measurement properties. Neurorehabilitation Neural Repair. 2002;16(3):232–40. https://doi.org/10.1177/154596802401105171
27. Sanford J, Moreland J, Swanson LR, Stratford PW, Gowland C. Reliability of the Fugl-Meyer assessment for testing motor performance in patients following stroke. Phys Ther. 1993;73(7):447–54. https://doi.org/10.1093/ptj/73.7.447
28. Gregson JM, Leathley M, Moore AP, Sharma AK, Smith TL, Watkins CL. Reliability of the Tone Assessment Scale and the modified Ashworth scale as clinical tools for assessing poststroke spasticity. Arch Phys Med Rehabil. 1999;80(9):1013–6. https://doi.org/10.1016/s0003-9993(99)90053-9
29. Flansbjer UB, Holmback AM, Downham D, Patten C, Lexell J. Reliability of gait performance tests in men and women with hemiparesis after stroke. J Rehabil Med. 2005;37(2):75–82. https://doi.org/10.1080/16501970410017215
30. Mahoney FI, Barthel DW. Functional evaluation: the Barthel index. Md State Med J. 1965;14:61–5.
31. Lopez-Liria R, Padilla-Gongora D, Catalan-Matamoros D, Rocamora-Perez P, Perez-de la Cruz S, Fernandez-Sanchez M. Home-based versus hospital-based rehabilitation program after total knee replacement. BioMed Res Int. 2015;2015:450421. https://doi.org/10.1155/2015/450421
32. Brandao GS, Oliveira LVF, Brandao GS, Silva AS, Sampaio AAC, Urbano JJ, et al. Effect of a home-based exercise program on functional mobility and quality of life in elderly people: protocol of a single-blind, randomized controlled trial. Trials. 2018;19(1):684. https://doi.org/10.1186/s13063-018-3061-1
33. Simpson D, Callisaya ML, English C, Thrift AG, Gall SL. Self-reported exercise prevalence and determinants in the long term after stroke: the north east melbourne stroke incidence study. J Stroke Cerebrovasc Dis. 2017;26(12):2855–63. https://doi.org/10.1016/j.jstrokecerebrovasdis.2017.07.008
34. Hsu AL, Tang PF, Jan MH. Analysis of impairments influencing gait velocity and asymmetry of hemiplegic patients after mild to moderate stroke. Arch Phys Med Rehabil. 2003;84(8):1185–93. https://doi.org/10.1016/s0003-9993(03)00030-3
35. Lodha N, Patel P, Casamento-Moran A, Gauger K, Christou EA. Endpoint accuracy of goal-directed ankle movements correlates to over-ground walking in stroke. Clin Neurophysiol. 2019;130(6):1008–16. https://doi.org/10.1016/j.clinph.2019.03.030
36. Li X, Xu S, Zhou L, Li R, Wang J. Home-based exercise in older adults recently discharged from the hospital for cardiovascular disease in China: randomized clinical trial. Nurs Res. 2015;64(4):246–55. https://doi.org/10.1097/nnr.0000000000000102

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Research Article

Symptom Experience and Related Predictors in Liver Transplantation Recipients

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SUMMARY

Purpose: Symptom experience after liver transplantation (LT) provides healthcare professionals with important information about the benefits and limitations of LT from patients' perspective. This study aims to explore the multidimensional symptom experience and analyze related predictive factors in LT recipients.

Methods: This cross-sectional study evaluated the occurrence, frequency, intensity, and level of distress of 40 symptoms in 265 LT recipients. Stepwise multiple regression analysis was performed to analyze the influencing factors of symptom experience.

Results: The analysis of patient-reported data indicated that the ten most common symptoms were fatigue (42.3%), frequent sleep interruptions (38.9%), difficulty falling asleep (35.9%), decreased memory (34.0%), dreaminess (29.8%), itch (28.7%), muscular weakness (26.4%), shortness of breath (25.3%), anxiety (24.5%), and hand tremor (21.9%). Patients were classified into four groups according to survival time (1-month, 2–6-month, 7–12-month, and >1-year groups) after LT, and the most common symptom was fatigue in the one-month and 2–6-month groups, difficulty falling asleep in the 7–12-month group, and decreased memory in the >1-year group. Type of the primary caregiver, complications, concerns about the decreased ability to perform household and outdoor activities, and concerns about being a burden to the family were predictors of symptoms burden.

Conclusion: LT recipients experienced complicated symptoms. In clinical practice, it is critical to integrate physicians, nurses, and social workers as a medical team to help LT recipients develop suitable coping strategies that can potentially address patients' concerns, increase the sense of confidence, and improve symptom outcomes.

Introduction

Orthotopic liver transplantation (LT) is the first-choice therapy for patients with end-stage liver diseases. With advances in surgery and optimization of immunosuppressive regimens, the 1-year and 10-year survival rate can reach 96.0% and 71.0%, respectively [1,2]. Current practice guidelines are primarily focused on clinical outcomes, including postoperative complications, malignancies, and graft survival, as primary treatment endpoints [2]. Moreover, with improvements in the long-term survival of LT recipients, the tendency to use patient-reported outcomes (PROs) to measure the benefits and limitations of treatment has increased [3,4].

PROs are defined as reports of the status of a patient's health condition that come directly from the patient, without interpretation of the patient's response by clinicians or other health professionals [5]. PROs are part of the patient-centered care model and are used by The Food and Drug Administration of the United States to determine the impact of new treatments. PROs are a multidimensional index that includes health-related quality of life (HRQoL), patient compliance and satisfaction, and symptom experience. In this study, we focused on symptom experience and quality of life.

A systematic review involving 23 studies and 5,402 patients indicated that LT significantly increased the HRQoL of patients compared with before surgery. However, the HRQoL of LT recipients was worse than that of the general population [6]. One of the

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reasons for the low HRQoL is the experience of complicated symptoms. However, only a few studies to date investigated the symptom experience of LT recipients [7–10].

Drent et al. [8] evaluated 123 LT recipients and indicated that the median number of symptoms was 16 and the three most frequent symptoms were hair overgrowth, fragile skin, and changes in appearance. Wang et al. [10] reported that 94 LT recipients who survived for more than 3 years after surgery experienced 2 to 43 symptoms, with a median of 7, and the most common symptoms were itching, concentration or memory problems, and fatigue.

Armstrong [11] developed Symptoms Experience Model and defined symptom experience as the perception of the frequency, intensity, distress, and meaning of the occurrence of symptoms, suggesting a multidimensional evaluation of symptoms. Symptoms should be evaluated not only for occurrence characteristics but also perceived frequency, intensity, and distress [11]. Previous studies demonstrated that LT recipients experienced complicated symptoms. However, these studies focused primarily on a single dimension of symptom experience, evaluated some specific post-surgery periods, or had a small sample size. Therefore, previous researches failed to examine all profile of the symptom characters. Moreover, without the guidance of a systematic conceptual framework, the factors influencing symptom experience remain unclear.

Therefore, the objectives of this study are to display the multidimensional symptom experience of LT recipients during the disease courses and analyze the influencing factors to improve symptom management.

Methods

Study design and participants

The study adopted a cross-sectional design. LT recipients were consecutively recruited from March 2018 to December 2018. The inclusion criteria were (1) having undergone LT after January 1, 2015, (2) being aged 18 years or older at the time of LT, (3) being able to communicate normally, and (4) voluntary participation. The exclusion criteria were (1) presence of other serious diseases, including end-stage renal disease and heart failure, and (2) multiple organ transplantation.

The sample size was calculated according to the requirement of factor analysis, which is 5–10 times the number of items in the questionnaire. There were 40 items in the questionnaire; therefore, the required sample size was at least 200 participants. In the study period, 276 liver transplant recipients were eligible to participate in the study, seven recipients (2.5%) refused to participate, and four patients (1.4%) had incomplete questionnaires. Therefore, data from 265 recipients (96.1%) were included in the analysis.

Measurements

Symptom experience

Symptom experience was measured using the Post-Liver Transplant Symptom Experience Questionnaire. This disease-specific questionnaire was self-made according to the conceptual framework of the Symptom Experience Model developed by Armstrong [11]. First, draft items were developed by interviewing LT recipients and combining questionnaires of other studies [7–10,12]. Then, the questionnaire was reviewed by two-round Delphi survey to determine the level of consensus on the development of disease-specific questionnaire. Fifteen experts with more than 10 years of clinical experience in liver transplant were asked about the suitability of the items for the questionnaire, and items would be deleted if the content validity index was less than 0.8. Item content validity index in the second Delphi survey ranged from 0.80 to 1, and the average content validity index was 0.907. Furthermore, the reliability of the questionnaire was assessed by a pilot study on 30 LT recipients; the test showed that Cronbach's α was .84 and split-half reliability was .75.

The final questionnaire contained 40 items. Each item represented one symptom and included three dimensions: frequency, intensity, and distress. If the participant reported the experience of a symptom within the past week, he or she was asked to rate its frequency, severity, and distress. Symptom frequency was rated on a numeric rating scale (NRS) from 0 (none) to 4 (ever-present). Symptom intensity was rated on an NRS from 0 (not at all intense) to 4 (most intense). Symptom distress was rated on an NRS from 0 (not at all distressing) to 4 (most distressing). The burden score of each symptom was calculated by summing the total scores of the three dimensions. Single-symptom burden scores were then summed to create a total symptom burden score of the participant.

Influencing factors of symptom experience

This study was based on the Symptom Experience Model [11], in which symptom experience is affected by demographic, disease-related, and individual characteristics. Using this model combined with literature analysis and clinical experience, we designed a questionnaire of influential factors, including (1) demographic characteristics such as age, gender, marital status, education, family monthly income per capita, employment status, medical insurance, and primary caregiver; (2) disease type and treatment characteristics, including primary diseases, immunosuppressive protocols, chemical therapy protocol, comorbidities, and complications; and (3) individual characteristics, including health knowledge level, routes of acquiring knowledge, and concerns about the effects of LT on the activities of daily living (ADL), including reduced ability to perform household and outdoor activities and being a burden to the family.

Data collection

All LT patients routinely visited the outpatient clinic for regular follow-up according to the postsurgical period. After follow-up in the outpatient service, eligible patients were invited to participate in the study. All data were obtained by interviews and analysis of medical records and were collected by the outpatient specialty nurse.

Statistical analysis

Statistical analyses were conducted using IBM-SPSS software, version 22 (IBM Corp., Armonk, NY, USA). Values were expressed as the mean and standard deviation for continuous variables or percentages for categorical variables. The mean frequency, intensity, distress, and burden scores for each symptom were calculated for the patients who reported the symptom. Therefore, the N for each symptom varied on the basis of the number of participants who reported the presence of the symptom. Mann–Whitney *U* tests were used to determine differences in the number of experienced symptoms between the subgroups, and χ^2 tests were applied to identify differences in the incidence of symptoms between the subgroups.

Stepwise multiple regression analysis was performed to identify the factors that influenced symptom experience. On the univariate analysis, associations between all demographic, disease-related, and individual characteristics and the symptom burden were evaluated. Only those variables with p value $< .10$ on the univariate analysis were selected in the multiple regression analysis. Non-ordinal categorical variables and ordinal categorical variables with nonequidistant data, such as marital status and educational level, were transformed into dummy variables. The probability was considered significant when $p < .05$. Before performing the regression analysis, we examined whether the data satisfied the assumption of the analysis. First, the Durbin–Watson value was 2.04, indicating that the variables were not autocorrelated. The variance inflation factor was <10.0, demonstrating there were no problems associated with multicollinearity. Moreover, the normality and homoscedasticity of residuals were tested using histograms, normal probability plots, and scatter plots, and the results showed that the residuals satisfied the assumptions. No missing data imputation methods were used.

Ethical considerations

Since January 1, 2015, our country has followed the World Health Organization's ethical principles on organ transplantation and completely abolished the use of organs from executed prisoners as a source of donors. Voluntary organ donation after the death of citizens became the only channel for organ transplantation [13]. Therefore, only the participants who underwent LT after January 1, 2015, were enrolled in the study.

The study was approved by the research ethics committee of Zhongshan hospital of Fudan university (Approval no. B2018-021). Before data collection, the participants were informed of the purpose of the research, and written consent was obtained.

Results

Participant characteristics

The demographic, disease-related, and individual characteristics of the participants are shown in Table 1. The median survival time after LT was 9 months (interquartile range, 18 months; range, 1–43 months). The majority of patients (68.7%) used a tacrolimus-based immunosuppressant regimen. A total of 47.5% of participants (126/265) presented complications after surgery, and the five most common complications were diabetes (15.8%, 42/265), infection (12.8%, 34/265), hypertension (10.4%, 28/265), biliary tract stenosis (6.4%, 17/265), and renal impairment (6.4%, 17/265).

Approximately, 50% of patients believed they did not have enough health knowledge, and 89.1% (236/265) of patients acquired health information from the medical staff. With regard to the effects of LT, 64.9% (172/265) of the study population was concerned about the effects of LT on the activities of daily living (Table 1).

Occurrence, intensity, and level of distress of symptoms

The median number of reported symptoms was five (range, 0–40). The ten most common symptoms were fatigue (42.3%), easy wake (38.9%), difficulty falling asleep (35.9%), decreased memory (34.0%), dreaminess (29.8%), itch (28.7%), muscular weakness (26.4%), shortness of breath (25.3%), anxiety (24.5%), and hand tremor (21.9%).

Considering the three dimensions, the results indicated that the five most frequent symptoms were strong appetite (2.29 ± 1.12), easy wake (2.27 ± 1.04), frequent urination (2.26 ± 0.87), difficulty falling asleep (2.23 ± 1.13), and dreaminess (2.20 ± 1.31). The five most intense symptoms were difficulty falling asleep (1.64 ± 0.98), easy wake (1.53 ± 0.81), constipation (1.52 ± 0.76), itch (1.46 ± 0.72), and decreased weight (1.45 ± 0.70). The five most distressing symptoms were difficulty falling asleep (1.35 ± 1.20), easy wake (1.12 ± 1.19), frequent urination (1.12 ± 1.02), constipation (1.05 ± 0.85), and itch (1.01 ± 1.11).

Table 1 *Effect of Risk Factors on Symptom Experience (N = 265).*

Characteristics	%	Symptom burden	
		Median (IQR)	*P*-value
Gender			.293
Men	80.0	21.0 (8.8–40.2)	
Women	20.0	26.0 (9.0–56.0)	
Family residence			.156
Rural areas	17.0	34.0 (18.0–59.0)	
Urban areas	70.5	21.0 (8.0–38.5)	
Rural-urban areas	12.5	20.0 (9.0–45.0)	
Family monthly income (RMB)			.371
<5000	33.2	25.0 (11.0–48.0)	
5000–10000	46.0	21.0 (7.2–40.0)	
>10000	20.8	20.0 (7.0–45.5)	
Educational level			.375
Primary and secondary education	34.0	19.0 (8.0–39.2)	
Tertiary education	31.3	19.0 (7.5–43.0)	
University education	34.7	23.0 (12.8–46.5)	
Source of medical expense			.225
Total medical insurance	17.7	18.0 (6.0–30.5)	
Partial medical insurance	67.6	21.0 (8.0–40.0)	
Personal funds	14.7	23.0 (8.5–45.5)	
Primary caregiver			.067
Spouse	86.0	20.5 (8.0–39.2)	
Offspring	7.2	53.0 (24.0–71.0)	
Parents	6.8	24.0 (10.8–54.8)	
Primary disease			.106
Nonviral hepatitis-related cirrhosis	4.9	22.0 (8.0–37.5)	
Viral hepatitis-related cirrhosis	23.4	18.0 (8.0–37.0)	
Primary liver tumor	63.8	26.0 (11.2–55.0)	
Others	7.9	26.0 (9.0–46.0)	
Complications			.001
No	52.5	17.0 (7.0–34.0)	
Yes	47.5	26.0 (12.0–53.8)	
Readmission			.010
Yes	35.8	25.5 (14.2–54.8)	
No	64.2	18.0 (7.0–40.0)	
Health knowledge level			.064
Poor	8.7	28.0 (13.0–66.5)	
Fair	48.7	23.0 (11.0–43.0)	
Good	42.6	17.0 (6.0–37.0)	
Concern about the decreased ability to perform household activities			<.001
Never	61.5	14.0 (6.0–30.0)	
Occasionally	17.7	25.0 (15.0–43.0)	
Sometimes	11.0	45.0 (21.0–56.0)	
Usually	6.0	34.5 (24.2–44.5)	
Always	3.8	85.0 (65.0–98.0)	
Concern about the decreased ability to perform outdoor activities			<.001
Never	62.6	14.0 (6.0–28.8)	
Occasionally	18.5	33.0 (17.0–43.0)	
Sometimes	8.3	30.0 (14.5–53.8)	
Usually	8.3	42.0 (29.0–57.2)	
Always	2.3	65.5 (45.8–91.5)	
Concern about being a burden to the family			<.001
Never	50.9	12.0 (5.0–26.0)	
Occasionally	21.1	24.5 (17.8–40.0)	
Sometimes	17.4	35.5 (19.0–59.5)	
Usually	5.7	59.0 (41.0–79.0)	
Always	4.9	79.0 (44.0–92.0)	

Note . IQR = interquartile range; RMB = Renminbi (RMB 1000 = €130 as of March 2018).

Symptom progression according to survival time

Symptom experiences vary over time [14]. To assess the dynamic nature of symptom experience after LT, the participants were classified into four groups according to survival time (1-month, 2–6-month, 7–12-month, and >1-year groups) after LT, and symptom progression was identified in each phase. The most common symptom was fatigue in the 1-month and 2–6-month groups, difficulty falling asleep in the 7–12-month group, and decreased memory in the >1-year group. The five most common and burdensome symptoms differed between the four groups (Tables 2 and 3).

Factors influencing symptom experience

The frequency, intensity, and level of distress of symptoms were determined, and the total scores of these three dimensions corresponded to symptom burden. To assess symptom experience comprehensively, symptom burden was used as the dependent variable to analyze the predictive factors of symptoms. The relationship between demographic, clinical, and individual characteristics with symptom burden is shown in Table 1. Seven variables with *p* value < .10 on the univariate analysis, including the primary caregiver, complications, readmission, health knowledge level, concerns about the decreased ability to perform household activities, concerns about the decreased ability to perform outdoor activities, and concerns about being a burden to the family, were selected in the multiple regression analysis to assess the independent predictive factors. In multivariate analysis, five of seven variables showed to be significantly associated with symptom experience.

The results of the regression analysis are shown in Table 4. The predictors of symptom burden in the model were the primary caregiver, complications, concerns about the decreased ability to perform household activities, concerns about the decreased ability to perform outdoor activities, and concerns about being a burden to the family. The five predictors explained 37.5% of the variance in symptom experience.

Primary caregiver

The primary caregiver was an independent influencing factor for symptom burden (Table 4). Patients cared for by their children experienced a higher number of symptoms than patients cared for by spouses and parents (11 vs. 6, $p = .02$), particularly the incidence of psychological symptoms (47.4% vs. 24.8%, $\chi^2 = 6.97$, $p = .008$), including anxiety, depression, and loneliness. Moreover, patients cared for by their children had a statistically higher mean frequency, intensity, and burden of symptoms ($p < .05$).

Complications

Patients with complications experienced more severe symptom burden than patients without complication. The incidence of decreased memory in patients with complications was significantly higher than that in patients without complications (42.9% vs. 25.9%, $\chi^2 = 8.474$, $p = .004$). Moreover, the percentage of psychological symptoms in patients with complications was two-fold higher than that in patients without complications (35.7% vs. 17.9%, $\chi^2 = 10.687$, $p = .001$).

Table 2 *Ranking of Symptoms after Liver Transplantation in the Study Population according to Survival Time.*

Rank	Occurrence rating (%)			
	1 month (n = 57)	2–6 months (n = 62)	7–12 months (n = 47)	>1 year (n = 99)
1	Fatigue (54.4%)	Fatigue (58.1%)	Difficulty falling asleep (46.8%)	Decreased memory (39.4%)
2	Easy wake (52.6%)	Easy wake (45.2%)	Easy wake (40.4%)	Itch (31.3%)
3	Shortness of breath (43.9%)	Muscular weakness (38.7%)	Decreased memory (40.4%)	Fatigue (30.3%)
4	Difficulty falling asleep (40.4%)	Difficulty falling asleep (32.3%)	Itch (36.2%)	Difficulty falling asleep (30.3%)
5	Weight loss (35.1%)	Dreaminess (32.3%)	Frequent urination (36.2%)	Easy wake (27.3%)

Table 3 *Ranking of Symptoms after Liver Transplantation in the Study Sample according to Survival Time.*

Rank	Burden score (mean ± SD)[a]			
	1 month (n = 57)	2–6 months (n = 62)	7–12 months (n = 47)	>1 year (n = 99)
1	Difficulty falling asleep (5.24 ± 3.21)	Anorexia (5.60 ± 3.57)	Jaundice (7.00 ± 3.58)	Jaundice (7.43 ± 3.15)
2	Easy weak (5.04 ± 3.01)	Ankle swelling (5.55 ± 3.56)	Visual loss (5.88 ± 2.42)	Itch (4.96 ± 2.80)
3	Palpitation (4.89 ± 1.52)	Thirst (5.55 ± 1.90)	Hearing loss (5.83 ± 1.17)	Difficulty falling asleep (4.96 ± 2.72)
4	Fatigue (4.67 ± 2.69)	Weight loss (5.43 ± 2.08)	Constipation (5.78 ± 2.64)	Easy wake (4.76 ± 2.81)
5	Dysgeusia (4.50 ± 2.42)	Jaundice (5.17 ± 3.18)	Frequent urination (5.76 ± 2.61)	Muscular weakness (4.75 ± 2.05)

Note. SD = standard deviation

[a] Symptoms that occurred in ≥10% of the sample.

Table 4 *Multivariate Regression Analysis of Influencing Factors of Symptom Experience (N = 265).*

Predictors		β	t	*p* value	R^2	Adjusted R^2	F	*p* value
Primary caregiver[a]	Offspring	18.79	3.31	.001	0.39	0.38	19.87	<.001
	Parents	4.28	0.75	.451				
Concern about being a burden to the family		9.40	6.65	<.001				
Complications		8.31	2.91	.004				
Concern about the decreased ability to perform household activities		4.90	3.23	.001				
Concern about the decreased ability to perform outdoor activities		3.90	2.58	.010				

[a] The primary caregiver is an ordinal categorical variable with nonequidistant data and was transformed into dummy variables, with care provided primarily by spouses as the reference variable.

Concerns about the decreased ability to perform household activities

Among all participants, 38.5% (102/265) had concerns about the decreased ability to perform household activities, and patients with this concern presented a higher number of symptoms than patients without this concern (9 vs. 4, $p < .001$). The incidence of fatigue and muscular weakness in patients with this concern was almost two-fold higher than that in patients with positive belief (64.7% vs. 34.4%, $\chi^2 = 23.3$, $p < .001$).

Concerns about the decreased ability to perform outdoor activities

There were 37.4% (99/265) of participants who worried about the reduced ability to perform outdoor activities. The percentage of psychological symptoms, including anxiety, depression, and loneliness, in patients with negative beliefs was more than two-fold higher than that in patients with positive attitudes (40.4% vs. 18.7%, $\chi^2 = 14.9$, $p < .001$).

Concerns about being a burden to the family

With regard to the effects of LT, concerns about being a burden to the family were most prevalent among LT recipients (49.1%, 130/265) and had the highest regression coefficient in the multivariate regression analysis of influencing factors of symptom experience (Table 4). The incidence of psychological symptoms in patients with negative beliefs was almost four-fold higher than that in patients with positive attitudes (42.3% vs. 11.1%, $\chi 2 = 34.5$, $p < .001$).

Discussion

Symptom experience after LT provides valuable information about the benefits and disadvantages of LT to healthcare professionals from the patients' perspective [15]. This study was the first to investigate three domains of symptom experience of LT recipients, and the results indicated that the most common symptoms among patients in different stages after LT were mainly related to reduced activity tolerance (fatigue and muscular weakness), decreased quality of sleep (difficulty falling asleep, easy wake, and dreaminess), and poor memory. This finding was consistent with previous studies performed by Wang et al. [7,10] but was inconsistent with other studies [8,16] in which body image changes (e.g., hair overgrowth, fragile skin, bruises, and changes in facial features) and itch were the most common or distressing symptoms. This difference in the results may be because of the use of different immunosuppressive protocols. For instance, in the study by Drent et al. [8], all patients adopted prednisolone-based immunosuppressive regimens, and it is well known that hair overgrowth, fragile skin, bruises, and changes in facial features are more common in patients treated with corticosteroid-based regimens. In contrast, 182 patients (68.7%) in our study used a tacrolimus-based immunosuppressive regimen, and the tacrolimus-induced adverse effects are primarily nephrotoxicity, neurotoxicity, infections, hypertension, and diabetes [17,18], which may partly explain why fatigue, frequent sleep interruptions, difficulty falling asleep, dreaminess, decreased memory, muscular weakness, and hand tremor were the most common symptoms among this study participants.

The experienced symptoms were multidimensional, and the present results revealed that the most frequently reported symptoms did not necessarily cause the most perceived distress. The most common symptom was fatigue, and the most intense symptom was enormous appetite. The most distressing symptom was irregular menstruation in women and difficulty falling asleep in men. These findings are consistent with those of McCorkle [19] and McClement et al. [20], wherein the frequency and intensity of symptoms were not always associated with perceived distress. Distressful symptoms are experienced as unpleasantness or discomfort and more likely to cause pain. Therefore, symptom management should consider not only general supportive strategies but also individualized care according to the perceived level of distress.

To investigate symptom characteristics during the disease course, the participants were classified into four groups according to survival time after LT, and the results showed that the most common symptom was fatigue in the one-month and 2–6-month survival groups, difficulty falling asleep in the 7–12-month group, and decreased memory in the >1-year group. Symptom frequency, intensity, and level of distress according to survival time are shown in Table 3. As shown in an previous study [10], the present study revealed that symptom experience changed during the disease course and was supported by theoretical models, including the Symptoms Experience in Time Model developed by Henly et al. [14] and the Dynamic Symptoms Model proposed by Brant et al. [21]. Both Symptoms Experience in Time Model and Dynamic Symptoms Model incorporated the temporal aspects of symptoms and are designed to capture the dynamic nature of symptoms. The joint focus of the theories is on appraisal and management of symptoms over time. Therefore, longitudinal studies are essential to examine symptom progression and further validate our findings so that healthcare professionals can adopt different intervention approaches at different disease stages to improve management effectiveness and efficiency.

The factors influencing symptom experience remain unclear. In this study, influencing factors were systematically analyzed to understand why some patients suffered severe symptoms, whereas others did not. The results of the regression model indicated that demographic, disease-related, and individual factors promoted the development of symptoms, which is consistent with the Symptom Experience Model [11].

One of the most important findings of the regression model is that different caregivers can significantly impact symptom burden. Previous studies suggested the occurrence of complex relationships between caregivers and care recipients [22]. Uncertain prognosis and heavy care burden cause psychological distress (anxiety, helplessness, and depression) and physical problems (fatigue and nausea) in caregivers [23,24]. In turn, caregivers' behaviors affect care recipients' outcomes. This study is the first to assess whether different primary caregivers affect PROs, and the results demonstrated that patients cared by their children had more severe symptoms ($p < .05$) than patients cared by spouses, although there were no significant differences in clinical outcomes between these two patient groups, including the incidence of complications (52.6% vs. 47.2%, $\chi^2 = 0.21$, $p = .65$) and readmission (36.8% vs. 35.7%, $\chi^2 = 0.01$, $p = .93$).

This result may be related to the family context. Some grown children cohabited with their parents and had to perform care if their parents had severe diseases. Moreover, the high social pressure would affect their capacity to provide comprehensive care, including disease management, and physical and emotional care. Patients cared by their children may feel guilty for being a burden and do not want to bother their children, leading to increased psychological stress and poor treatment compliance. As a result, these patients often experience more physical and psychological symptoms. In this respect, semistructured interviews are fundamental to elucidate the reasons behind this phenomenon and improve the role of primary caregivers in symptom management [25].

The unique contribution of this study was that to what extent patients viewed LT′ s interference in ADL, as well as family function would greatly influence their symptom outcome, which agreed with the clinical observation. In clinical practice, definition of situation would have an significant impact on the adaptation to the disease, and it seemed that the recipients who defined themselves as normal and attempted to lead a normal life as much as possible, such as exercising and traveling regularly, tended to experience fewer symptoms. In contrast, the patients focusing on LT's adverse effects on ADL had multiple symptoms. Previous qualitative studies [26,27] also reported the existence of negative beliefs about the effects of LT among recipients, which not only discouraged them and caused psychological problems but also led to nonadherence to medical care. As advances in surgical and medical therapies significantly improve long-term survival, the focus has gradually shifted to ensuring that recipients lead a normal life and achieve social reintegration [28,29]. However, many patients in our study had negative expectations about the effects of LT, which might cause lack of confidence or feelings of being a burden, leading to poor disease management, further impairing normal function at the individual and family level [30].

It is of note that demographic characteristics and disease-related characteristics is objective, whereas the definition of the effects of LT is subjective and amendable and associated with the self-efficacy. Self-efficacy, defined as a person's confidence of his or her ability to execute behaviors necessary to attain a goal, reflects an optimistic self-belief that one can perform new or difficult tasks [31]. Indeed, perceived self-efficacy is an important prerequisite for adopting successful self-care behavior and achieving positive health outcomes [32]. However, the status of self-efficacy in LT recipients was not optimistic [33]. In a previous study, the relationship between the self-efficacy status and symptom experience was found in LT recipients [9]. Therefore, further research studies are necessary to explore efficient and effective interventions that could improve self-efficacy and symptom outcomes of the LT recipients.

The clinical implications of our study are related to healthcare professionals. Healthcare professionals should attach enough importance to the appraisal and management of symptoms, and the focus should shift from which symptoms are the most common to which symptoms are the most important. For example, when one experiences ten distinct symptoms, which causes the patient the most distress? An important responsibility of healthcare professionals is supporting LT recipients to be as confident as possible in adopting appropriate self-care behaviors. Future research studies should further evaluate change in symptoms over time and examine the effect that an intervention has on the symptom experience or on patient outcomes.

Our study has some limitations. First, a cross-sectional design was used. Therefore, the results are descriptive rather than causative. However, to a large extent, the findings agreed with the clinical observation and provided important information on long-term disease management. Notwithstanding, further prospective cohort studies are necessary to confirm these findings. Second, this was a single-center study; consequently, these findings may not be generalized.

Conclusions

LT recipients experienced complicated symptoms, which increased the levels of perceived stress in patients and their families. In clinical practice, it is imperative to assess and manage symptoms periodically. Moreover, recipients' concerns should be addressed to improve self-esteem and disease management. Future studies should evaluate the dynamic nature of symptoms and coping strategies adopted by LT recipients.

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Conflict of interest

The authors have no conflicts of interest to report.

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References

1. European Association for the Study of the Liver. EASL clinical practice guidelines: liver transplantation. J Hepatol. 2016;64(2):433–85. https://doi.org/10.1016/j.jhep.2015.10.006
2. Adam R, Karam V, Delvart V, Mirza D, Klempnauer J, Castaing D, et al. Evolution of indications and results of liver transplantation in Europe. a report from the European Liver Transplant Registry (ELTR). J Hepatol. 2012;57(3):675–88. https://doi.org/10.1016/j.jhep.2012.04.015
3. Bravata DM, Keeffe EB. Quality of life and employment after liver transplantation. Liver Transplant. 2001;7(11B):S119–23. https://doi.org/10.1053/jlts.2001.28520
4. Bravata DM, Olkin I, Barnato AE, Keeffe EB, Owens DK. Health-related quality of life after liver transplantation: a meta-analysis. Liver Transplant Surg. 1999;5(4):318–31. https://doi.org/10.1002/lt.500050404
5. Guidance for Industry FDA. Patient-reported outcome measures: use in medical product development to support labeling claims [Internet]. New Hampshire: U.S. Food and Drug Administration; 2009 [Cited 2019 Oct 10]. Available from: http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf
6. Yang LS, Shan LL, Saxena A, Morris DL. Liver transplantation: a systematic review of long-term quality of life. Liver Int. 2014;34(9):1298–313. https://doi.org/10.1111/liv.12553
7. Lai L, Li X, Luo Y. Relationship between symptom experiences and quality of life in liver transplant recipients. Chin J Nurs. 2010;45:397–400. Chinese.
8. Drent G, Moons P, De Geest S, Kleibeuker JH, Haagsma EB. Symptom experience associated with immunosuppressive drugs after liver transplantation in adults: possible relationship with medication non-compliance? Clin Transplant. 2008;22(6):700–9. https://doi.org/10.1111/j.1399-0012.2008.00864.x
9. Weng LC, Huang HL, Wang YW, Lee WC, Chen KH, Yang TY. The effect of self-efficacy, depression and symptom distress on employment status and leisure activities of liver transplant recipients. J Adv Nurs. 2014;70(7):1573–83. https://doi.org/10.1111/jan.12315
10. Wang C, Wang G, Yi H, Tan J, Xu C, Fang X, et al. Symptom experienced three years after liver transplantation under immunosuppression in adults. PloS One. 2013;8:e80584. https://doi.org/10.1371/journal.pone.0080584
11. Armstrong TS. Symptoms experience: a concept analysis. Oncol Nurs Forum. 2003;30(4):601–6. https://doi.org/10.1188/03.ONF.601-606
12. Cleemput I, Dobbels F. Measuring patient-reported outcomes in solid organ transplant recipients: an overview of instruments developed to date. Pharmacoeconomics. 2007;25:269–86. https://doi.org/10.2165/00019053-200725040-00002
13. Chinese Hospital Association. International organ donation conference held in Hongkong. Peking: Chinese Hospital Association; 2016 Aug 23 [Internet], [Cited 2019 Oct 10] Available from: http://www.cha.org.cn/plus/view.php?aid=15048. Chinese.
14. Henly S, Kallas K, Klatt C. The notion of time in symptom experiences. Nuts Res. 2003;52(6):410–7. https://doi.org/10.1097/00006199-200311000-00009
15. Kugler C, Geyer S, Gottlieb J, Simon A, Haverich A, Dracup K. Symptom experience after solid organ transplantation. J Psychosom Res. 2009;66(2):101–10. https://doi.org/10.1016/j.jpsychores.2008.07.017
16. Hathaway D, Winsett R, Prendergast M, Subaiya I. The first report from the patient outcomes registry for transplant effects on life (PORTEL): differences in side-effects and quality of life by organ type, time since transplant and immunosuppressive regimens. Clin Transplant. 2003;17(3):183–94. https://doi.org/10.1034/j.1399-0012.2003.00024.x

17. Henry ML. Cyclosporine and tacrolimus (FK506): a comparison of efficacy and safety profiles. Clin Transplant. 1999;13(3):209–20. https://doi.org/10.1034/j.1399-0012.1999.130301.x
18. Zahir H, McCaughan G, Gleeson M, Nand RA, McLachlan AJ. Tacrolimus effects and side effects after liver transplantation: is there a difference between immediate and extended release? Transplant Proc. 2013;45(6):2321–5. https://doi.org/10.1016/j.transproceed.2013.03.039
19. McCorkle R. The measurement of symptom distress. Semin Oncol Nurs. 1987;3(4):248–56. https://doi.org/10.1016/s0749-2081(87)80015-3
20. McClement SE, Woodgate RL, Degner L. Symptom distress in adult patients with cancer. Cancer Nurs. 1997;20(4):236–43. https://doi.org/10.1097/00002820-199708000-00002
21. Brant JM, Beck S, Miaskowski C. Building dynamic models and theories to advance the science of symptom management research. J Adv Nurs. 2010;66(1):228–40. https://doi.org/10.1111/j.1365-2648.2009.05179.x
22. Sacher M, Meixensberger J, Krupp W. Interaction of quality of life, mood and depression of patients and their informal caregivers after surgical treatment of high-grade glioma: a prospective study. J Neuro Oncol. 2018;140:367–75. https://doi.org/10.1007/s11060-018-2962-x
23. Athay MM. Caregiver Life Satisfaction: relationship to youth symptom severity through treatment. J Clin Child Adolesc Psychol. 2012;41(4):433–44. https://doi.org/10.1080/15374416.2012.684273
24. Young AL, Rowe IA, Absolom K, Jones RL, Downing A, Meader N, et al. The effect of liver transplantation on the quality of life of the recipient's main caregiver - a systematic review. Liver Int. 2017;37(6):794–801. https://doi.org/10.1111/liv.13333
25. Ullgren H, Tsitsi T, Papastavrou E, Charalambous A. How family caregivers of cancer patients manage symptoms at home: a systematic review. Int J Nurs Stud. 2018;85:68–79. https://doi.org/10.1016/j.ijnurstu.2018.05.004
26. Moayed MS, Khatiban M, Nassiri Toosi M, Khodaveisi M, Soltanian AR, Ebadi A. Barriers to adherence to medical care programs in liver transplant recipients: a qualitative study. Int J Organ Transplant Med. 2019;10(3):115–26.
27. Hochheimer M, Moreland ML, Tuten M, LaMattina J, Connelly M, Sacco P. Insights into the experience of liver transplant recipients with alcoholic liver disease: a descriptive qualitative study. Transplant Direct. 2019;5(12):e506. https://doi.org/10.1097/TXD.0000000000000951
28. Rongey C, Bambha K, Vanness D, Pedersen RA, Malinchoc M, Therneau TM, et al. Employment and health insurance in long-term liver transplant recipients. Am J Transplant. 2005;5(8):1901–8. https://doi.org/10.1111/j.1600-6143.2005.00961.x
29. Åberg F. From prolonging life to prolonging working life: tackling unemployment among liver-transplant recipients. World J Gastroenterol. 2016;22(14):3701–11. https://doi.org/10.3748/wjg.v22.i14.3701
30. Knafl KA, Deatrick JA, Havill NL. Continued development of the family management style framework. J Fam Nurs. 2012;18(1):11–34. https://doi.org/10.1177/1074840711427294
31. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev. 1997;84(2):191–215. https://doi.org/10.1037//0033-295x.84.2.191
32. Clark NM, Dodge JA. Exploring self-efficacy as a predictor of disease management. Health Educ Behav. 1999;26(1):72–89. https://doi.org/10.1177/109019819902600107
33. Xing L, Chen QY, Li JN, Hu ZQ, Zhang Y, Tao R. Self-management and self-efficacy status in liver recipients. Hepatobiliary Pancreat Dis Int. 2015;14(3):253–62. https://doi.org/10.1016/s1499-3872(15)60333-2

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Research Article

The Experience to Implement Palliative Care in Long-term Care Facilities: A Grounded Theory Study of Caregivers

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ABSTRACT

Purpose: The purpose of this study was to explore the experiences of caregivers in long-term care facilities as they implement palliative care. Although palliative care has been available in Taiwan for more than 30 years, it is often provided in hospitals, few models in the long-term care facilities.

Methods: Semi-structured interviews using grounded theory methodology and purposive sampling. Two small long-term care facilities that had performed well in palliative care were selected from eastern Taiwan. A total of 12 caregivers participated in in-depth semi-structured face-to-face interviews.

Results: Four major stages in the implementation of palliative care were identified: (1) feeling insecure, (2) clarifying challenges, (3) adapting to and overcoming the challenges, and (4) comprehending the meaning of palliative care. The core category of these caregivers as "the guardians at the end of life" reflects the spirit of palliative care.

Conclusion: This study demonstrates that successful palliative care implementation would benefit from three conditions. First, the institution requires a manager who is enthusiastic about nursing care and who sincerely promotes a palliative care model. Second, the institution should own caregivers who possess personality traits reflective of enthusiasm for excellence, unusual ambition, and a true sense of mission. Third, early in the implementation phase of the hospice program, the institution must have the consistent support of a high-quality hospice team.

Introduction

In 1980, a rapidly developing economy in Taiwan, a related increase in the number of women entering the workforce, and a lower birth rate combined have contributed to an increase in long-term residential care for older Taiwanese [1–3]. The 1980s saw the rise of many illegal long-term care institutions to address the rising need for long-term residential care. This resulted in a lowering quality of care and an increase in public safety accidents [4]. In 1998, the Taiwanese government responded by increasing the number of beds in long-term care facilities and actively counseled the legalization of smaller institutions with the proviso that they should not exceed 49 beds per facility [4,5]. By 2013, these smaller institutions accounted for 86% of all long-term care facilities in Taiwan [5].

The delivery of good-quality palliative care is dependent on the willingness of institutional managers to give it proper attention and the necessary resources [4,6]. Traditionally, where managers do not fully understand the concept of palliative care, have insufficient staffing, and lack hospice team support, there has been a reluctance to offer palliative care [6–8]. In addition, when it has been delivered, it has suffered from a lack of comprehensive service because of overall deficiencies in skills, education, and training related to the care of near-death patients [9,10]. For example, caregivers at general institutions have tended to send residents to hospitals for emergency treatment when they develop acute problems (such as shortness of breath or hypotension) [6,11]. This has resulted in the overuse of both aggressive medical intervention (such as defibrillators and vasopressors) and life-sustaining treatment (such as mechanical ventilation, intubation, and extracorporeal membrane oxygenation). Such treatments are not only often medically futile (leading to wastes of resources and money), but have also meant

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that patients experience lower well-being quotients near the end of life [2,11]. If palliative care were to be implemented within long-term care facilities rather than outsourced to emergency units, many of the problems so far addressed could be lessened and decreased.

At present, palliative care in Taiwan can be divided into two main types: “the hospital care model” and “the community care model” [12]. The “hospital care model” includes medical teams caring for patients in hospice wards or hospice teams assisting a general medical team to jointly care for patients in general wards. In contrast, the “community care model” can include a hospice team or clinics delivering care to long-term care facilities or residents' homes [12].

A hospice team is typically composed of doctors, nurses, social workers, and psychologists, and requires certification of completion, issued by an agency authorized by the government, to conduct palliative care training [12,13]. Depending on the patient's situation or needs (e.g., religious affiliation), a hospice team can also invite other professionals to fulfill an auxiliary role in delivering palliative care (e.g., religious leader) [12,13].

In Taiwan, 85% of palliative care patients receive services from the “hospital care model”,” whereas the remaining 15% involve the “community care model” [12,13]. In contrast, palliative care in both the United Kingdom and the United States is mainly based on the “community care model” [14]. Palliative care is increasingly being offered at a local level, where care homes are embedded in communities and which can provide palliative care independently, without the need for hospital or larger institutional intervention [14–17]. In recent years, the Taiwanese government has become more intent on reducing the concentration of palliative care delivery in hospitals, seeking to shift the delivery of end of life services and hospice care nearer to communities [1,12]. In doing so, the government has actively promoted the “community care model” of palliative care, so that patients can receive comprehensive care within the comforts of their communities, in either care homes or long-term care facilities [6]. The benefit of this model lies principally with the patient. Palliative care patients can, through community level care, receive a level of service and support, which enhances the dignity and comfort they experience toward the end of life [18,19].

The purpose of this study was to explore the experiences of caregivers in long-term care facilities as they implement palliative care. The goals have been to clearly define the palliative care response process and provide suggestions for long-term care institutions when introducing palliative care. This research may also serve as a reference for governmental policy development in their efforts to improve cooperation between long-term care institutions and hospice teams within hospitals.

Methods

Design and setting

This study made use of grounded theory, which is well-suited for use in complex, interacted, and unexplored fields [20] like the interaction process between caregivers and others in palliative care implementation investigated in this article. Initially, the researchers did not have a preconceived theory in mind, but they started from the field of research and allowed the theory to emerge from the data. Through the use of systematic induction, deduction, and analysis, a theory rooted in the real-world context was developed [20]. Based on the information received from the certification of the hospice team, two small long-term care facilities that had 4 years of experience and performed well in the implementation of palliative care were selected from five (<49 beds) of eastern Taiwan. Both the institutions are located within the downtown core and each has between 36 and 49 residents. The caregivers are nursing staff and nursing aides. The nursing staff and nursing aides are certified by law. Each has sufficient support staff for palliative care delivery, and a low turnover rate. The managers of each are university degree holders. Nurses in both facilities are capable of administering Foley tubes, Nasogastric tubes, and tracheotomies on patients.

Recruitment and participants

After meeting with the managers of two long-term facilities, consent was obtained from the institutional managers granting the researcher permission to enter the facility for research and to recruit caregivers. Thereafter, the investigator explained to caregivers about the purpose of this study, interview procedures, risks, benefits, and right of withdrawal. Purposive sampling was used to select qualified caregivers, the inclusion criteria of the study participants were as follows: (1) full-time caregivers (nurses and nursing aides), (2) with experience in caring for residents of palliative care, and (3) ability to communicate in a Chinese or Taiwanese. The exclusion criteria of the study participants were as follows: (1) caregivers with less than 3 months (probation period) of experience, and (2) withdraw the study. A total of 12 caregivers agreed to participate in the study and granted informed written consent, who were numbered (S1–S12) in order of their recruitment. Participant demographics consisted of nine women and three men, aged 20 to 59 years, with a minimum of 3 months' experience in hospice palliative care. All of whom remained involved until the end. All relative recruitment was conducted by author S.W.C. The study was approved on June 4, 2015, by the Research Ethics Committee of Hualien Tzu Chi Hospital, Buddhist Tzu Chi Medical Foundation, Taiwan (Approval no. IRB104-29-B).

Data collection

Data collection was carried out simultaneously at the two institutions according to the following data collection methods: (1) field observations, (2) semi-structured in-depth interviews, and (3) the basic information sheet. The first data collection period was from August 1, 2015, to July 31, 2016. The second data collection period was from August 01, 2017, to November 30, 2017. The research tools included interview participation consent form, basic information sheet, observation note, reflection diary, voice recorder, and qualitative analysis software NVivo-8. Interviews were face-to-face and held in a quiet and independent room by the author S.W.C. (qualified for qualitative research) in the long-term care facility. Participants were interviewed one or two times (each lasted 45 to 90 minutes). If a relevant concept in the paper needs further explication, or the conclusions are inconsistent and do not follow from observations and interviews, then researchers will need to re-interview and recollect data until whatever conceptual gaps present are addressed. The open-ended question interviews were documented with audio recordings, and after reviewing the articles, interview guidelines were developed by all authors. Over the course of the data collection period, the second author (who volunteered in long-term care facilities) performed observation work, keeping a record of his findings. He would then present these observation records to the first author. The data collected via observation was used to generate questions to be asked during the interview process and to verify what the participants meant when being interviewed. For example, it was found that during the dying phase of the residents, health care providers visit more frequently and receive more medical orders, so health care provider was

Table 1 *An Analysis of the Coding Process from Codes to the Category.*

Open coding	Axial coding	
Code	Concept	Category
Worried about inexperience Worried about insufficient communication skills	Worried about not being capable enough	Feeling insecure
Never encountered death Afraid of ghosts	Afraid of facing the death of residents	
Increased emotional burden Increased workload burden	Personal burden increased	Clarifying challenges
Desire to avoid hearing "bad news" Pressure from other relatives	Low acceptance among the families	
Inadequate assistance Insufficient training courses Infrequent supervisory visits	Cooperated with the hospice team	
Spiritual courses to relieve negative emotions Learned positive thinking from managers Learned new concepts and techniques from managers Actions and beliefs were transformed into organizational culture	Leadership of the managers	Adapting to and overcoming the challenges
Trust was developed Caregivers shared ideas with colleagues	Improve communication efficiency with the families	
Instant consultation by technology software Courses about knowledge and skills to improve care and communication Increased the number of visits	Support of the hospice team	
Family to be at the bedside to accompany To see their loved one without pain or struggle	Making the families have no regrets	Comprehending the meaning of palliative care
Outcome is vary greatly based on whether elected the hospice benefit or not Avoiding emergency intervention	Guarding the dignity of the resident	
Truly understood their role Reinforced the perception of nursing value	The meaning and value of life	

asked: "What do you do when the residents exhibit symptoms at the end of life?" and "What do you feel or think at that time?"

Data analysis and rigor

The grounded theory of Corbin and Strauss (2015) was used to analyze and compare the data [20]. The researcher initially transcribed the voice-recorded files into verbatim transcripts and also filled in the reflection log. The transcripts were then verified for consistency by listening to the recordings once again while simultaneously scrutinizing the written narrative. The analysis procedures were as follows: **Open coding:** Important sentences were first noted by underlining and separating meaningful phrases for coding. For example, S2 said that "When long-time residents died, my mood was affected and I felt sad since I had been caring for them for a long time. When they died, I felt terrible." As the researchers regarded this as "meaningful," it was underlined and coded as "increased emotional burden." A second example is taken from comments by S7 who mentioned that "We needed to more frequently assess vital signs in residents who were close to death" and this increased their workload. This comment was underlined and coded as "personal burden increased." Since "increased emotional burden" and "personal burden increased" are a result of the implementation of palliative care, the researchers condensed these two into the concept of "increased personal workload." **Axial coding:** The researchers then advanced to axial coding, a strategy for aggregating similar concepts. For example, "increased personal workload" and "low acceptance among the families" are both difficulties encountered in the palliative care setting, so these are classified as "clarifying challenges." **Selective coding:** From the aggregation of similar concepts completed during the axial coding process, we identified four distinct categories into which the majority of caregiver issues could be classified. The analysis procedures can be accessed in Tables 1 and 2. As part of their work, the researcher was tasked with verifying and ensuring the rigor of the observation records while they analyzed the interview data. Where the interview data and the observation records were inconsistent, the interview had to be conducted again and the observation data needed to be re-analyzed. Data analysis was conducted by the author S.W.C. To enhance the rigor and coherence of the research process, the second author was responsible for explaining the content of the observation records to the first author for clear and cogent data interpretation. The third author was responsible for monitoring the research process and offering advice and consultation.

Results

Four major stages of implementing palliative care were identified in the interviews with the caregivers: (1) feeling insecure, (2) clarifying challenges, (3) adapting to and overcoming the challenges, and (4) comprehending the meaning of palliative care. The core category shared by the participants may be summed up as "the guardians at the end of life". It reflects the spirit of the successful implementation of palliative care by caregivers in long-term care institutions (see Figure 1).

Feeling insecure

Caregivers expressed insecurity about their role before the implementation of the palliative care program. Specific doubts included their self-perception that they are incapable of performing well in the role because of inexperience. Likewise, they voiced the fear of facing the death of residents. The caregivers were worried about not being capable enough to take care of the residents; those worries caused some stresses and psychological discomfort to caregivers: "*I was more worried about how to deal with their symptoms when they were dying*" ***[S10]***. Caregivers were also worried about having insufficient communication skills to explain the strategies for supporting ongoing care:"*I worried that the family*

Table 2 *From Categories to the Core Category.*

Selective coding	
Category	Core category
Feeling insecure	The guardians at the end of life
Clarifying challenges	
Adapting to and overcoming the challenges	
Comprehending the meaning of palliative care	

*members wouldn't accept or understand what I had told them about the way I took care of residents"****[S06]***. Caregivers did mention that they were afraid of facing the death of residents: *"I had never encountered death before. It felt eerie and I was scared"* ***[S03]***.

Clarifying challenges

During the implementation stage of the palliative care program, caregivers initially faced multiple challenges, including low acceptance by residents' families, an increased work burden, and hesitancy about how to build a cooperative relationship with the hospice team. During this stage, the caregivers faced challenges with low acceptance among the families. Reasons given included the desire to avoid hearing "bad news," which might bring bad luck: *"When I tried to bring up palliative care, the family asked, 'How can I give up? How can you talk about such unlucky things? Do you want to curse my dad to die?' And then they refused to listen to me further"* ***[S5]***. Meanwhile, the palliative care concept was too complicated to understand: "*I wasn't sure that the concept was explained clearly. It seems like they didn't understand*" ***[S11]***. There was pressure from other relatives who felt that the palliative care approach represented a failure to carry out their filial duties. "*When I mentioned hospice, they would say: 'Mom and Dad or other relatives will blame us and ask why we were not so filial"* ***[S12]***.

In the past, when residents developed acute problems, they would be sent to the hospital for emergency treatment, so few residents would expire in the institution. However, after the implementation of palliative care, caregivers were faced with the deaths of residents and dealt with symptoms at the end of their lives:*"They struggled to breathe and lost control of bodily functions (urination, defecation). I needed to help them, but it was toilsome," "The doctor's orders and medications would change frequently, so we needed to closely monitor the physiological state when they were dying"* ***[S09, S06, S07]***.These made them feel that their personal burden increased. However, after an extended time, caregivers had developed emotional bonds with residents. Therefore, when residents passed away, caregivers would sometimes feel despondent, an additional emotional burden: "*I felt like my relative was gone; I cried and felt so sad"* ***[S08]***.

Early in the "roll out" of this new program and the development of collaboration between the hospice team and the caregivers, there were numerous adjustment problems. The caregivers thought that the assistance provided by the hospice team A was inadequate, and that there were insufficient training courses about caring for family and infrequent supervisory visits to the institution: "*there were no courses about how to comfort them (families)," "When the hospice team didn't come often, we found ourselves in a panic"* ***[S5, S12]***. Another hospice team B had poor communication with the staff of the institution: "*Hospital B was not so friendly. We simply listened to them, and it was impossible for us to discuss the various approaches with them"* ***[S1]***.

Adapting to and overcoming the challenges

There is the perception that, principally, the leadership role played by management facilitated the team's adaptation to this new model of care and assisted caregivers in overcoming early challenges. The hospice team provided essential support and avenues of communication among the various professionals developed efficiently. The caregivers believe that a large part of the success is attributable to the influence of leadership in management. The caregivers gained actual support from the manager and learned from her profound work experience: *"She was a nursing aid and later became a nurse and then our manager. She had seen many patients neglected as they were dying. And also she understands our hard work and treats us kindly like her own children"* ***[S4]***. The caregivers also learned the spirit and attitude from the manager's story: "*Our manager's grandma used to live in the institution and was taken care of well. So she told us to take care of the residents well as our own family members"* ***[S9]***.

Caregivers have learned the new concepts and techniques from the manager and felt the sincere dedication and warm care from the process of managers taking care of the residents: "*We often heard how our manager attended conferences on palliative care from which she brought back the ideas. When we had difficulties with certain situations, she was able to use this new wisdom to teach us how to care for the residents"* ***[S8]***. Interviewees could feel the sincere dedication and warm care from the process of managers

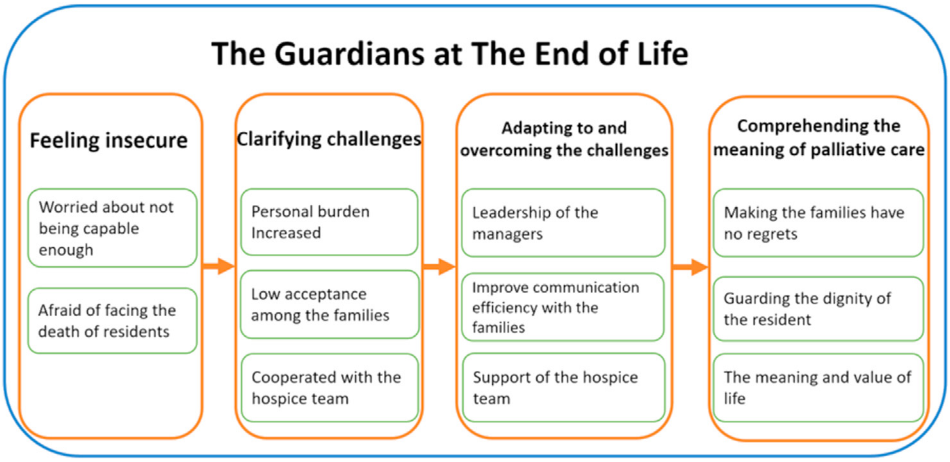

Figure 1. The model of implemented palliative care by the caregivers in long-term care facility.

taking care of the residents: *“Every time I observed our director caring for the residents, the expression on her face and in her eyes was truly a caring expression. It would not be deceiving. We were very touched and wanted to learn from her”* ***[S8]***.

These actual actions and beliefs were transformed into organizational culture, and interviewees were inspired by the managers and willing to follow them: *“Our job is hard work, and the staff still working here must understand the working culture and appreciate the philosophy taught by the manager. We all want to learn from her”* ***[S6]***.

Caregivers commonly learned the positive thinking from managers and knew they were doing something meaningful: “*The manager told us that we are doing the right and meaningful things, so don't be afraid of the death of the residents. We are helping them. She assured us that all the staff would support one another in this job”* ***[S3]***.

In addition, consultant psychologists and religious-spiritual advisors were invited to help the staff discuss their feelings and share their stories and experiences about caring for the dying residents and to give spiritual support to one another: *“During the daily shifts, we shared what had happened that day and how we felt, supporting one another”* ***[S3]***. Meanwhile, caregivers took spiritual courses that the managers arranged to help them facing death and to relieve the negative emotions caused by taking care of hospice residents. One innovative activity found to be therapeutic for the staff and to help them with their own grief was to involve them in caring for plants: *“ We observed the germination of seeds and then understood that death is not the end, it's the beginning of another life”* ***[S7]***.

Initially, the support of the hospice team was very important to the institution as caregiver's implemented palliative care. The hospice team was invited to provide courses about knowledge and skills to improve care and communication. After caregivers gained new knowledge and skills, they worried less about lack of ability: “*After those classes, we had a better knowledge of what residents would be experiencing close to the end of life, how to care for them and how to communicate with their families”* ***[S10]***.Therefore, work efficiency was improved and caregivers gradually adapted to new workloads: *“After repeated practice and caring for residents in the program for a long time, we became more efficient at our work”* ***[S4]***.

In addition to educational training and spiritual courses, the hospice team also used technology software to provide instant consultation: “*We would use the LINE application to communicate with and request advice from the team when residents developed problems. The availability of this technology helped reduce our fear and manage problems quickly”* ***[S11]***. The hospice team also increased the number of visits to the institution until the staff had fully developed the required skill-sets, allowing them to feel secure and to get through the roll-out period as efficiently as possible: *“Once residents enrolled in palliative care, it was rarely necessary to send them to hospital. The hospice nurse would visit and provide necessary medicines. This really relieved the caregivers”* ***[S8]***. In the end, the institution realized that there had been inadequate communication and cooperation with one of the two hospice teams, so caregivers terminated their relationship with that team and continued to work with the one team with which there had consistently been better cooperation: *“We had cooperated with two hospitals, but one of them often couldn't solve the problem immediately, and we needed to send the patient back to the emergency, so we transferred to a more efficient and effective hospice team that addressed issues on a more timely basis”* ***[S12]***.

Initially, acceptance of the palliative care concept was low among the residents' families. The caregivers had a desire improve communication efficiency, and they found that communication became more effective as trust developed: “*Family members were less friendly when they first came in. I preferred to wait for a while, then I slowly brought up the issue (palliative care), and then it would be easier to communicate when we were familiar, one with the other”* ***[S1]***. And caregivers shared ideas with colleagues: “*During our daily shifts, I would often ask colleagues to share with me tips for improving my communication skills”****[S9]***. If caregivers felt that communication remained ineffective, they would require the assistance of hospice team to help them communicate: “*Some families would be unclear about palliative care even after we had discussed it and fully explained. In those cases, we would invite the entire hospice team to sit with the family for a discussion”* ***[S12].***

Comprehending the meaning of palliative care

When the last stage, family members achieved a deep understanding of the role of palliative care as their relationships with caregivers solidified. Without regret, families expressed appreciation for how the institution valued life and guarded the dignity of their loved ones during end-of-life care. Meanwhile, caregivers also truly understood the meaning and value of life. When staff determined that the death of a resident was imminent, caregivers would invite the family to be at the bedside to accompany their loved one through the transition. This provided comfort for the resident in their final moments while it also allowed the family to express their love and thoughts. Staff have reported that family members expressed relief to see their loved one take the last breath without pain or struggle and expressed gratitude to the institution for providing this care environment for which they had no regrets. These experiences validated for the staff that their mission had been meaningful and successful: “*Family members would return to the institution after the funeral to thank us, so grateful that they had been able to accompany their loved one who had died peacefully in our care. There was no regret”* ***[S3]***.

The outcome for the resident and family is likely to vary greatly based on whether or not they had elected the hospice benefit. For example, interviewees described that: *“I have encountered some families who had elected not to choose hospice and their loved one suddenly died in the hospital. The family had no time to prepare, had made no prior arrangements with a funeral home and were, at times, confronted with uncertainty as to where the body would be kept while they made necessary arrangements for burial. Those families who had elected hospice had been able to accompany their loved one in those final moments and were more psychologically prepared”* ***[S10]***. Meanwhile, because of avoiding emergency intervention, the resident could die peacefully: *“I think that hospice can allow for the dying patient to transition with dignity. We observe peaceful facial expressions with little change in appearance. It is like they simply fall asleep”****[S9]***. Therefore, the caregivers expressed that they truly understood that their role is to assist the family to understand what to expect while guarding the dignity of the resident.

One of the more profound effects that hospice work has had on the caregivers is how it has reinforced their perception of the value of nursing and has, very importantly, provided recognition for the staff: “*I feel that others need my care. This is my mission. I am a useful person in this world. I feel I belong here when working in this place”* ***[S2]***. Although the work is full of challenges, it is a unique professional role that has broadened their regard for the meaning and value of life: “*In the process of caring for others, I have come to realize the meaning of life. When people are dying, it is useless to have money. Even the person who can call the wind and summon the rain cannot* *escape death. So treasure our time, doing meaningful things, saying what we wanted to say, having no regrets. So, pursue your dreams now" **[S6]**.*

The caregivers reflected on their own personal and professional growth and how the shared experiences with residents and families had been mutually beneficial. Although the palliative care model, under the compassionate support of the staff, ensured that the residents' physical and emotional needs had been skillfully addressed, that dignity had been preserved in the dying process, the caregivers reported their own developing sense of accomplishment, which affirmed the importance of their role. Recognizing the gratitude of family as they witnessed the true healing effects of palliative care further enhanced the self-confidence of caregivers who affirmed that the process had been personally and professionally transforming.

Discussion

This study indicated that the hospice residents have higher complexity diseases, which create increased workload and pressure for caregivers; furthermore, staff faced the death of residents and sadness because of the loss [21–23]. Education and training in the form of seminars and workshops followed by ongoing mentoring of inexperienced caregivers by more senior staff will promote self-confidence among nursing personnel and likely increase their knowledge base and efficiency [24–26]. Emotional support of hospice staff, who almost daily face the loss of life, is absolutely essential to the success of palliative care programs [27]. Pre-service workshops on grieving should be integrated with palliative care training, and specially trained psychological support personnel should be integral to the hospice team [28]. Ongoing training [29], memorial services for those residents who have died [30], and spiritual care courses can increase working efficiency by addressing the personal grief and loss experienced by caregivers.

This study found that in the initial stage of cooperation between facility and hospital hospice team, there was a gap in expectation between the two parties regarding the content and frequency of hospice team services, and the timeliness of providing consultation and services. The literature mentioned that the hospice team must fully inform and explain in detail the method of care, reasons, impact, and the consistency of communication with the caregivers [22,31,32]. Communication technology can also be used to shorten communication and service timeliness [22,23,32]. Our research found that, in the early stages of the program, facilities would replace the hospice team when communication seemed inadequate. However, one of the hospice team was perfectly willing to maximize frequency of service until the caregivers had enough capacity. Available technology communication tools provided instant communication and support, increasing cooperation [32,33].

In addition, we found that acceptance by family members was low during the initial implementation phase of the program, so delaying sensitive communication until trust has been established may be more effective. Rosemond et al pointed out that it is important to build a family's trust in the caregivers [34]. As long as there is a sense of trust between them, the family will be more willing to listen to the explanation and suggestions of the caregivers [35]. When certain caregivers are less skillful at communicating the principles of the palliative care model, they could benefit from additional training and the opportunity to "shadow" and observe more skillful colleagues as they interact with residents and families [36]. The hospice team has extensive experience and could mentor those care providers who are lacking in the same. If necessary, please ask the members of the hospice team to help communicate [37–39].

Apropos of our concern for family members, the care team timely communicates imminent death to the family to facilitate their participation in the final moments of life leading up to the passing [40]. Likewise, relative to our concern for the dying patient, the providers strictly adhere to the expectations of the resident and family that their wishes for a dignified end-of-life will be honored and that their choice for no last-minute emergency interventions will be respected [40,41]. These two guiding principles are inherent in the hospice concept and have transformed the way people die [42]. The results of this study show that the caregivers do indeed follow this protocol and have consistently involved family in a timely fashion. Allowing for a dignified death with serenity has been integral to the practice, and the caregivers gain self-worth through the care process [43]. Their work becomes a continuing experience of self-growth and the development of their professional expertise, which become direct benefits for future palliative care clients in their care.

Professional knowledge can be enhanced through learning and continuous practice, but the key to success or failure is about "people" The long-term care institution can successfully implement palliative care. In addition to the professional support provided by the hospice team at the outset, the most important over-riding factor is the principled focus and determination of the manager whose enthusiasm and mission inspire and influence the caregivers resulting in an organizational culture imbued with professionalism. The result is high-quality palliative care. In addition, when recruiting employees, the program selects candidates with enthusiasm for service. Then, once candidates are hired, managers can work to foster an environment conducive to enduring enthusiasm through the use of making adjustments, incentivizing learning, and encouraging pride and dynamism in service delivery. In these ways, enthusiasm can be transformed into high-quality palliative care. Some of the employees in the institution are young nurses, and this is their first working experience of palliative care. They are all enthusiastic and having dreams of changing the world, and working here makes them feel proud [17]. In addition, several of the senior employees, who had been helped by others before, were grateful and hoped to give back to society. In short, the characteristics of these employees are either natural or trained, and they are all full of ambition, sense of mission, enthusiasm, and responsibility.

Strengths/limitations

In this study, the subjects are small long-term care facilities in eastern Taiwan, so the results may not be extrapolated to other regions or long-term care facilities of different sizes. In addition, we suggest to include the hospice teams and managers of the long-term care institution as participants in the future study to make the research more comprehensive.

Conclusion

This study shows that a long-term care facility should minimally have three conditions for successful palliative care implementation. First, the institution requires a manager who is enthusiastic about nursing care and sincerely wants to promote palliative care, can stimulate the enthusiasm and sense of mission of the caregivers, and also can provide solid and consistent support for the caregivers. Second, the institution should own a group of employees with full of enthusiasm, ambition, and a sense of mission. Third, early in the implementation phase of the palliative care program, the institution should have the consistent support of a high-quality hospice team to provide requisite training and immediate consultation for staff, while instilling the principles and standards of best practice palliative care in the developing program.

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Conflict of interest

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References

1. Social and Family Affairs Administration Minister of Health and Welfare. Construct long-term care service system [Internet]. Tapei, R.O.C. (Taiwan): Minister of Health and Welfare; 2018 [cited 2020 Jun 14]. Available from https://www.sfaa.gov.tw/SFAA/Pages/List.aspx?nodeid=809. Chinese.
2. Tsai HH, Tsai YF, Huang HL. Nursing home nurses' experiences of resident transfers to the emergency department: no empathy for our work environment difficulties. J Clin Nurs. 2016;25(5-6):610–8. https://doi.org/10.1111/jocn.13084
3. Patomella AH, Sandman PO, Bergland A, Edvardsson D. Characteristics of residents who thrive in nursing home environments: a cross-sectional study. J Adv Nurs. 2016;72(9):2153–61. https://doi.org/10.1111/jan.12991
4. Huang MF. Long-term care institute marketing and management. 2rd rev. New Taipei City: Yang-Chih Book Co., Ltd; 2018. p. 338.
5. Ministry of Health and Welfare, R.O.C. (Taiwan). Statistics of elderly and long term care [Internet]. Tapei, R.O.C. (Taiwan): Ministry of Health and Welfare, Department of Statistics; 2018 [cited 2019 Ma 8]. Available from: https://dep.mohw.gov.tw/DOS/np-1714-113.html. Chinese.
6. Chang JH. Why is it so difficult to good death in long term care facility? Common Health Mag. 2015;204:158–64. Chinese.
7. Lung CH, Lee IJ. Service measures of hospice care in nursing homes in Taiwan. Taiwan J Publ Health. 2018;37(6):638–50. https://doi.org/10.6288/TJPH.201812_37(6).107093. Chinese.
8. Lin LC. The challenges of manpower in long-term care: intergenerational learning approach from ageism to caregiving. J Nurs Res. 2018;26(4):228–30. https://doi.org/10.1097/jnr.0000000000000281
9. Laging B, Ford R, Bauer M, Nay R. A meta-synthesis of factors influencing nursing home staff decisions to transfer residents to hospital. J Adv Nurs. 2015;71(10):2224–36. https://doi.org/10.1111/jan.12652
10. Leclerc BS, Lessard S, Bechennec C, Le Gal E, Benoit S, Bellerose L. Attitudes toward death, dying, end-of-life palliative care, and interdisciplinary practice in long term care workers. J Am Med Dir Assoc. 2014;15(3):207–13. https://doi.org/10.1016/j.jamda.2013.11.017
11. Chang CH, Yeh SH. Realizing the wishes of dying elders-status and trends of hospice in long-term care facilities in Taiwan. J Long-Term Care. 2014;18(2): 175–92. https://doi.org/10.6317/LTC.18.175. Chinese.
12. National Health Insurance Administration Minister of Health and Welfare. Hospice care (ward, home care, shared care) networked information services [Internet]. Tapei, R.O.C. (Taiwan): Minister of Health and Welfare; 2019 [cited 2020 Jun 14]. Available from: https://www.nhi.gov.tw/Content_List.aspx?n=D8386FD9AD1B49D3&topn=5FE8C9FEAE863B46. Chinese.
13. Chen RC. Hospice palliative care policy in Taiwan: past developments and future perspectives. J Nurs. 2015;62(2):13–7. https://doi.org/10.6224/JN.62.2.13. Chinese.
14. Economist Intelligence Unit. The 2015 quality of death index ranking palliative care across the world [Internet]. An Economist Intelligence Unit study, commissioned by the Lien Foundation; 2015 [cited 2020 Jun 14]. Available from: https://eiuperspectives.economist.com/healthcare/2015-quality-death-index
15. Miller SC, Mor VNT. The role of hospice care in the nursing home setting. J Palliat Med. 2004;5(2):271–7. https://doi.org/10.1089/109662102753641269
16. Kamal AH, Currow DC, Ritchie CS, Bull J, Abernethy AP. Community-based palliative care: the natural evolution for palliative care delivery in the U.S. J Pain Symptom Manag. 2013;46(2):254–64. https://doi.org/10.1016/j.jpainsymman.2012.07.018
17. Unroe KT, Stump TE, Effler S, Tu W, Callahan CM. Quality of hospice care at home versus in an assisted living facility or nursing home. J Am Geriatr Soc. 2018;66(4):687–92. https://doi.org/10.1111/jgs.15260
18. Lin HR, Wang JH, Hsieh JG, Wang YW, Kao SL. The Hospice Information System and its association with the congruence between the preferred and actual place of death. J Tzu Chi Med. 2017;29(4):213–7. https://doi.org/10.4103/tcmj.tcmj_125_17
19. Hung YI, Chen CC, Wang YW, Hsieh JG, Chiang SW, Chang CJ, et al. Preliminary study on the effect of hospice and palliative care in long-term care institutions. Taiwan J Hosp Palliat Care. 2016;21(3):245–57. https://doi.org/10.6537/TJHPC.2016.21(3).1. Chinese.
20. Corbin JM, Strauss AL. Basics of qualitative research: techniques and procedures for developing grounded theory. 4th ed. Thousand Oaks, CA: SAGE Publications; 2015. p. 456.
21. Fan SY, Lin IM, Hsieh JG, Chang CJ. Psychosocial care provided by physicians and nurses in palliative care: a mixed methods study. J Pain Symptom Manag. 2017;53(2):216–23. https://doi.org/10.1016/j.jpainsymman.2016.08.019
22. Lester PE, Kawai F, Rodrigues L, Lolis J, Martins-Welch D, Shalshin A, et al. Palliative care in New York state nursing homes: a descriptive study. Am J Hosp Palliat Care. 2018;35(2):203–10. https://doi.org/10.1177/1049909117691229
23. Orellana-Rios CL, Radbruch L, Kern M, Regel YU, Anton A, Sinclair S, et al. Mindfulness and compassion-oriented practices at work reduce distress and enhance self-care of palliative care teams: a mixed-method evaluation of an "on the job" program. BMC Palliat Care. 2017;17(1):3. https://doi.org/10.1186/s12904-017-0219-7
24. Pan HH, Wu LF, Hung YC, Chu CM, Wang KY. Long-term effectiveness of two educational methods on knowledge, attitude, and practice toward palliative care consultation services among nursing staff: a longitudinal follow-up study. Clin Nurs Res. 2018;27(4):483–96. https://doi.org/10.1177/1054773817692082
25. Ten Koppel M, Onwuteaka-Philipsen BD, van der Steen JT, Kylanen M, Van den Block L, Smets T, et al. Care staff's self-efficacy regarding end-of-life communication in the long-term care setting: results of the PACE cross-sectional study in six European countries. Int J Nurs Stud. 2019;92:135–43. https://doi.org/10.1016/j.ijnurstu.2018.09.019
26. Gonella S, Basso I, Dimonte V, Martin B, Berchialla P, Campagna S, et al. Association between end-of-life conversations in nursing homes and end-of-life care outcomes: a systematic review and meta-analysis. J Am Med Dir Assoc. 2019;20(3):249–61. https://doi.org/10.1016/j.jamda.2018.10.001
27. Bukki J, Neuhaus PM, Paal P. End of life care in nursing homes: translating focus group findings into action. Geriatr Nurs. 2016;37(6):440–5.
28. Evenblij K, Ten Koppel M, Smets T, Widdershoven GAM, Onwuteaka-Philipsen BD, Pasman HRW. Are care staff equipped for end-of-life communication? a cross-sectional study in long-term care facilities to identify determinants of self-efficacy. BMC Palliat Care. 2019;18(1):1–11. https://doi.org/10.1186/s12904-018-0388-z
29. Boerner K, Gleason H, Jopp DS. Burnout after patient death: challenges for direct care workers. J Pain Symptom Manag. 2017;54(3):317–25. https://doi.org/10.1016/j.jpainsymman.2017.06.006
30. Hill RC, Dempster M, Donnelly M, McCorry NK. Improving the wellbeing of staff who work in palliative care settings: a systematic review of psychosocial interventions. Palliat Med. 2016;30(9):825–33. https://doi.org/10.1177/0269216316637237
31. Norton SA, Ladwig S, Caprio TV, Quill TE, Temkin-Greener H. Staff experiences forming and sustaining palliative care teams in nursing homes. Gerontologist. 2018;58(4):218–25. https://doi.org/10.1093/geront/gnx201
32. Weng TC, Yang YC, Chen PJ, Kuo WF, Wang WL, Ke YT, et al. Implementing a novel model for hospice and palliative care in the emergency department: an experience from a tertiary medical center in Taiwan. Medicine. 2017;96(19): e6943. https://doi.org/10.1097/md.0000000000006943
33. Pino M, Parry R, Feathers L, Faull C. Is it acceptable to video-record palliative care consultations for research and training purposes? A qualitative interview study exploring the views of hospice patients, carers and clinical staff. Palliat Med. 2017;31(8):707–15. https://doi.org/10.1177/0269216317696419
34. Rosemond C, Hanson LC, Zimmerman S. Goals of care or goals of trust? How family members perceive goals for dying nursing home residents. J Palliat Med. 2017;20(4):360–5. https://doi.org/10.1089/jpm.2016.0271
35. Young A, Froggatt K, Brearley SG. 'Powerlessness' or 'doing the right thing' - moral distress among nursing home staff caring for residents at the end of life: an interpretive descriptive study. Palliat Med. 2017;31(9):853–60. https://doi.org/10.1177/0269216316682894
36. Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the end-of-life: a systematic review of qualitative evidence. Palliat Med. 2019;33(8):926–41. https://doi.org/10.1177/0269216319852007
37. Clayton MF, Hulett J, Kaur K, Reblin M, Wilson A, Ellington L. Nursing support of home hospice caregivers on the day of patient death. Oncol Nurs Forum. 2017;44(4):457–64. https://doi.org/10.1188/17.Onf.457-464
38. Gage LA, Washington K, Oliver DP, Kruse R, Lewis A, Demiris G. Family members' experience with hospice in nursing homes. Am J Hosp Palliat Care. 2016;33(4):354–62. https://doi.org/10.1177/1049909114560213
39. Luckett T, Chenoweth L, Phillips J, Brooks D, Cook J, Mitchell G, et al. A facilitated approach to family case conferencing for people with advanced dementia living in nursing homes: perceptions of palliative care planning

coordinators and other health professionals in the IDEAL study. Int Psychogeriatr. 2017;29(10):1713–22. https://doi.org/10.1017/s1041610217000977

40. Thompson GN, McClement SE. Critical nursing and health care aide behaviors in care of the nursing home resident dying with dementia. BMC Nurs. 2019;18(59):1–13. https://doi.org/10.1186/s12912-019-0384-5
41. Gonella S, Basso I, De Marinis MG, Campagna S, Di Giulio P. Good end-of-life care in nursing home according to the family carers' perspective: a systematic review of qualitative findings. Palliat Med. 2019;33(6):589–606. https://doi.org/10.1177/0269216319840275
42. Vandrevala T, Samsi K, Rose C, Adenrele C, Barnes C, Manthorpe J. Perceived needs for support among care home staff providing end of life care for people with dementia: a qualitative study. Int J Geriatr Psychiatr. 2017;32(2):155–63. https://doi.org/10.1002/gps.4451
43. Ablett JR, Jones RS. Resilience and well-being in palliative care staff: a qualitative study of hospice nurses' experience of work. Psycho Oncol. 2007;16(8):733–40. https://doi.org/10.1002/pon.1130

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Research Article

Development and Validation of a Management of Workplace Violence Competence Scale for Nursing Practicum Students

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SUMMARY

Purpose: The aim of this study was to develop a scale to measure nursing students' competence in managing violence from patients and relatives in the hospital where nursing students perform clinical practicum.

Methods: Literature review and Delphi expert consultation were utilized to develop the content of the management of workplace violence competence scale (MWVCS). A convenience sample of 797 nursing students responded to the questionnaire. Exploratory factor analysis of the scale was performed. Internal consistency and test–retest reliability were examined.

Results: The MWVCS consisted of 40 items with a five-point scale. Seven factors explained 63.2% of the total explained variance. The content validity index for the scale was .99. Cronbach's α of the scale was .96, and test–retest correlations were found to be $\geq$ .76.

Conclusion: The MWVCS is a reliable and valid scale for nursing educators to assess the level of students' competence in violence management and to evaluate the effectiveness of education to enhance their ability to manage workplace violence.

Introduction

Workplace violence (WPV) in the health sector is a significant global public health problem. In particular, recent studies have shown that more than half of nursing students experienced WPV during their clinical placement [1–3]. The extent of WPV toward nursing students includes both physical and psychological violence, such as kicking, pushing, pinching, verbal abuse, and threats, which have negatively impacted on students' attitudes toward nursing profession [4]. In the UK, the most perpetrators in the incidents experienced by nursing students were nurses (19.6%), and a small proportion of perpetrators was patients (4.9%) [4]. On the contrary, a survey in China showed that most perpetrators of WPV toward nursing students were patients or relatives (77.1%) [5]. In another study conducted in Korea, patients or patients' family members were the most frequent offenders of violence (84.8%) followed by nurses (78.6%) or physicians (57.9%) [6]. Although the incidence and perpetrator of workplace violence across China, the UK, and Korea are different because of social and cultural divergence, among all the healthcare professionals, nursing students are the most vulnerable and at-risk group for WPV because of their inexperience in clinical practice, frequent ward rotation, and the challenges of building relationship quickly with patients and nurses [7]. In addition to physical harm, WPV could cause negative impacts on nursing students psychologically. A survey in China showed that 59.1% of nursing students (n = 543) worried about WPV [8], and the majority of students who experienced WPV had the feeling of anxiety and depression [2], which could decrease students' job satisfaction and intensify the deterioration of relationship with nurses in workplace, ultimately affecting the standards of patient care [4]. It was shown that one in five nursing students (n = 657) considered career change, which will affect the nursing team building and workforce in the future [4].

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Because violence prevention is evident to be crucial for nursing students, relevant guidelines and trainings for WPV have been gradually developed [9]. Framework guidelines for addressing workplace violence in the health sector is a well-established joint program of International Labour Office (ILO), International Council of Nurse (ICN), World Health Organization (WHO), and Public Service International (PSI), which clearly illustrates each step of violence management [10]. Apart from the guidelines, some educational programs associated with WPV were designed to be specifically for nursing students. For example, a one-day Management of Aggression Training program, which covered definition, types, legislation, and consequences of WPV as well as the assault cycle and related breakaway skills, was delivered to nursing students in Australia [11]. In addition, there were also some training courses in Germany, Ireland, and America [12–14]. Although the nursing students who participated in these programs have reported a high level of satisfaction with the programs, the level of confidence and improvement of attitude, knowledge, and skills are not comprehensive, and the measurement tools used are not valid. A comprehensive assessment for nursing students' competence in WPV management is required.

Recently, there are some instruments developed to evaluate the skills of violence management. For example, the De-escalating Aggressive Behaviour Scale is a German instrument that assesses nursing students' de-escalation skill of performance in training programs [12]. Although this seven-item, one-dimensional scale has proved to be a practical measure of de-escalation skill with good reliability and validity and has already been modified in English [15], other skills such as breakaway and restraints skills in violence management could not be measured with this tool. There are also other instruments that evaluate healthcare workers' attitudes or confidence associated with WPV. The Management of Aggression and Violence Attitude Scale, which has been mostly used in mental health settings, principally measures nurses' perception of the causes of violence and the approaches to violence management [16]. Although the Management of Aggression and Violence Attitude Scale has been found reliable and valid, it focuses on registered nurses and other registered healthcare professionals. Another one-dimension instrument, the Confidence in Coping with Patient Aggression Instrument, was designed to measure self-confidence of staff in Germany [17]. Although confidence is crucial for performance, it is also underpinned by competence [18]. These existing instruments were developed to measure one single aspect associated with violence management. There is still a lack of instruments directly and specially reflecting nursing students' competence related to WPV management.

The 4R crisis management theory proposed by Heath (1998) has been widely applied into studies in the health field, including violence management [19–21]. In this theory, the four stages of crisis management include reduction, readiness, response, and recovery. The goal of crisis management is to reduce the impact and harmfulness of sudden and uncertain events, which is consistent with WPV management.

The current study aimed to develop and test the MWVCS for nursing students, which is underpinned by the 4R crisis management theory and focused on WPV of the patients or his/her relatives toward students in healthcare facilities. According to the framework guidelines by ILO, ICN, WHO, and PSI, the operational definition of “workplace violence against nursing students” in this study was adapted: incidents where nursing students are abused, threatened, or assaulted by patients and relatives during clinical practicum, involving an explicit or implicit challenge to their safety, well-being, or health.

Methods

The study employed a Delphi method to develop MWVCS among nursing students and psychometric testing of the scale. It consisted of three phases: phase 1, items development; phase 2, Delphi expert consultation; and phase 3, psychometric testing [22].

Phase 1: Items Development

Because 4R crisis management theory was considered as the conceptual foundation [23], the management of WPV was divided into four components: reduction of violence, readiness for violence, response to violence, and recovery from violence. Items were generated from three sources: 1) referring to guidelines, 2) review of literature, and 3) review of items from existing instruments. The framework guidelines of ILO, ICN, WHO, and PSI [10], illustrating the key elements in violence management including violence recognition, workplace risk assessment, intervention to deal with violence, and after-the-event intervention, provided important references for the study. Four domains and 56 items were created to form the initial scale. It consisted of domain 1 (reduction of violence, 18 items), domain 2 (readiness for violence, 16 items), domain 3 (response to violence, 11 items), and domain 4 (recovery from violence, 11 items). A five-point scale was designed for students to rate their level of agreement with each of the items. Each item of MWVCS was rated from 1 (strongly disagree) to 5 (strongly agree). The higher score indicates the better competence in management of WPV.

Phase 2: Delphi Expert Consultation

The Delphi technique was used to establish content validity of the MWVCS in two rounds [24]. The experts were selected based on their professional experience. In total, 18 experts with at least 10 years of professional experience were invited to the Delphi expert consultation (Table 1). Among them, nine experts were nurses in charge of nursing management in hospitals, one expert was a doctor in charge of hospital management, and eight experts were teachers in nursing schools. A four-point scale (1 = irrelevant; 2 = irrelevant unless with major revision; 3 = relevant but minor revision required; 4 = relevant) was used to assess content validity by content validity index (CVI). All items were set up with an open expert comment column to collect expert suggestions. The consultation scales were sent to the experts for completion in 3 weeks. After the collection of the consultation scales in the first round, the research team analyzed the data and discussed revisions. Item-level CVI (I-CVI) was defined as the proportion of experts who gave a score of either 3 or 4. The criterion for inclusion of the item was that the I-CVI was no less than .80 [24]. In the first round, the I-CVI ranged from .83 to 1.00 and the scale-level CVI (S-CVI) was .98. After the first round, eight of the initial 56 items were removed because of overlap with other items (e.g., “I am aware of high-risk areas of hospital violence”), inapplicability in nursing students (e.g., “I will respect others and encourage the team to reach their full potential”), or inappropriate in competence measuring (e.g., “I believe I will benefit from hospital violence related training”). Five additional items were added (e.g., “I will seek support from classmates, teachers and family after the violence”) based on the experts' suggestions. Thirteen items were revised based on the advice such as avoid asking more than two questions in one item, reduce the use of vocabulary indicating the level (e.g., “very”), add explanations of some words (e.g., “disengagement techniques”), add “with the help of teachers” in some items, etc. The revised scale and a detailed list of revisions were sent to the experts in the second round.

In the second round, the I-CVI ranged from .83 to 1.00 and the S-CVI was .99. After the second round, one item was removed because of inconformity with most current hospital conditions: "I understand the staff safe house in the hospital". Three items were revised to make the meaning more appropriate (e.g., "I will verify the vague information with patients or relatives" instead of "I will use clarification techniques to verify the patient's vague information"). A 52-item scale was generated after two rounds of expert consultation.

Phase 3: Psychometric Testing

After the Delphi expert consultation, a pilot test was conducted on 20 final-year nursing students in clinical placement using a convenient sampling method. The pilot test was performed to assess the understandability of the items. The pilot test showed that the participants (n = 20) reported no difficulty in reading and understanding all items. Most participants were women (n = 17), with ages ranging between 19 to 22 years. All of them have attended clinical placement for over 6 months. Through interview, it was found that the items were understood by participants as the research team intended. Further analysis of the MWVCS was conducted then. The methods of analysis included item analysis for item appropriation, exploratory factor analysis (EFA), convergent validity, and discriminant validity for construct validity, Cronbach's α coefficients for internal consistency reliability, and test–retest correlations for indicating stability reliability [25].

Participants

A convenience sampling method was used to recruit nursing students from nine universities/colleges in China. Most nursing students in China take clinical practicum in their final year, at which time they have close contact with patients. The final-year nursing students in clinical placement were eligible for the participation. The sample size should be 5–10 times of the number of items in factor analysis [26]. The sample size was calculated to be 260–520. Considering a dropout rate, the questionnaire was distributed to a total of 1,007 nursing students. For test–retest analysis, a group of 20 to 30 participants is recommended [25]. A convenience sampling of 25 final-year nursing students in local hospital was selected to evaluate test–retest reliability by filling in the MWVCS twice in a two-week interval.

Table 1 *Demographic Characteristics of Experts in the Delphi Expert Consultation (N = 18).*

Characteristics	N	%
Age (years)		
30–39	4	22.2
40–49	8	44.5
50–59	6	33.3
Education level		
Bachelor	3	16.7
Master	9	50.0
PhD	6	33.3
Professional title		
Intermediate	2	11.1
Senior vice	6	33.3
Senior	10	55.6
Working experience (years)		
10–19	7	38.9
20–29	10	55.6
30–39	1	5.5

Note. PhD = Doctor of Philosophy.

Data Collection

Nursing students were approached by the researchers and investigators when they attended courses or meetings in the school. The aim and procedures of the study were explained to the students the survey. Participants were asked to complete and return the questionnaire at the end of the session.

Data Analysis

Data analysis was conducted with the SPSS 24.0 software package (IBM Corp., Armonk, NY, USA). Descriptive analysis was utilized to summarize sample characteristics. An alpha level of .05 was used for all statistical tests. Item analysis was performed by three approaches, including the critical ratio obtained from *t*-test results, item-total correlation coefficient, and Cronbach's α coefficient after item deletion. Items meeting one of the following elimination criteria were removed: (1) the *t*-value of the 27 percentile high-score and low-score groups was insignificant or less than 3.00; (2) the item-total correlation coefficient was insignificant or less than .40; (3) Cronbach's α coefficient after each item deletion was more than that of the entire scale [26]. EFA was performed with principal component analysis and promax rotation. Factors with eigen values greater than 1.00 were extracted. The items with factor loading less than .40 were considered to be eliminated from the scale, and each factor was expected to contain at least three items [22].

Ethical Consideration

The present study was approved by the Ethics Committee of Huzhou University (Approval no. 20190910). The survey was anonymous, and the data collected will be kept confidential. They were assured of the confidentiality and anonymity, as well as that data collected were strictly for study purpose only. The participants were made aware of their right to decline or withdraw their participation at any time without any disadvantage. All respondents participated voluntarily.

Results

Sample Characteristics

In total, 1,007 nursing students were invited to participate in the study, and 797 students completed the survey with 79.1% response rate (Table 2). The majority of students were female (89.6%), with an average age of 21.77 years (standard deviation = 1.10). The majority of the students (99.0%) have attended clinical placement for over 6 months when participating in the study.

Item Analysis

Two extreme groups analysis showed that all 52 items had values of critical ratio at a significant level, ranging from 6.80 to 20.51, indicating that the items had a good discrimination between high and low groups. Apart from the item Q8, item-total correlation coefficients were observed between .41 and .68. After each item deletion, the calculated Cronbach's α coefficient was lower than .96, except for the item Q10. Therefore, these two items were deleted by item analysis.

Validity of the MWVCC

According to the Kaiser-Meyer-Olkin (KMO) and Bartlett's test, the KMO value was .96 and χ^2 was 23557.13, respectively ($p < .001$), which indicated the suitability for factor analysis. The item Q9 and Q14 were firstly removed because its factor loading was lower than .40. Then, because some items cannot be explained by corresponding factors, eight items including Q24, Q28, Q29, Q30, Q13, Q6, Q7, and Q11 were progressively deleted.

Finally, seven factors were extracted from the 40 items, with all item loadings above .40 (Table 3). The names of the factors were determined in accordance with the content of the items contained and by referring to the framework guidelines for addressing workplace violence in the health sector mentioned in Introduction and Methods. The factor 1–7 was named as after-the-event recovery, nurse–patient interaction, response to violence, violence cognition, utilization of protective facilities, knowledge renewal, and risk assessment, respectively. These factors contributed 63.2% of the total variance, indicating good construct validity [22].

The convergent validity of the MWVCS was assessed by examining correlations between the factors and the MWVCS. The convergent correlations ranged from .68 to .88 ($p < .001$) (Table 4). The discriminant validity was assessed by testing the correlations among the seven factors. The correlations ranged from .39 to .60, which were lower than convergent validity, except one correlation between response to violence and after-the-event recovery being .75. The correlations among the MWVCS factors provide evidence for both convergent and discriminant validity (Table 4).

The I-CVI of the final 40 items ranged from .83 to 1.00, and the S-CVI was .99, which indicated good content validity [24].

Reliability of the MWVCC

The Cronbach's α coefficient of the total scale was .96 and that of the seven factors ranged from .80 to .92. The test–retest correlation coefficient of .90 showed that the MWVCC had excellent category of scale stability [27]. Test–retest reliabilities of the MWVCC by subdomains were .76 for violence cognition, .79 for utilization of protective facilities, .81 for risk assessment, .76 for knowledge renewal, .77 for response to violence**,** .83 for after-the-event recovery, and .85 for nurse–patient interaction.

Discussion

It is evident that an exposure to WPV has a long-term negative impact on physical and psychological health of nursing students [28]. Nursing students are a group of inexperienced health workers who are in the transition from students to professionals and challenged by academic and clinical stress [29]. They have been shown to lack social experience, interpersonal skills, coping strategies, and psychological adjustment ability [30,31]. Given the focus of the existing WPV programs on nurses in specific settings and the limited scope of outcome measures in evaluation of programs, nursing students who are in a vulnerable position require special attention. The study attempted to develop an instrument to assist assessing and evaluating competence in WPV management among nursing students, which is one of the main aspects in WPV prevention education.

The MWVCS comprised 40 items with seven factors, which is consistent with conceptual attributes of 4R crisis management theory. In 4R crisis management theory, the first stage, reduction, refers to the reduction of risk, thus reducing the possibility and harm of the crisis. Two factors, violence cognition and nurse–patient interaction, corresponded to “reduction” in the theory. Violence cognition refers to nursing students' understanding of basic theoretical knowledge of workplace violence, including items on causes, current situation, psychological knowledge, and effects of workplace violence. Nurse–patient interaction consists of items on the communication and interaction between nursing students and patients in the process of providing nursing services.

The second stage of the theory, readiness, refers to the preparation made before the occurrence of a crisis, the purpose of which is to enhance the ability to deal with a crisis. Three factors, utilization of protective facilities, risk assessment, and knowledge renewal, corresponded to “readiness”. Utilization of protective facilities includes items on nursing students' understanding and use of violence prevention equipment and safety measures provided by the hospital. Risk assessment consists of items on nursing students' assessment of the risk and the identification of early signs before workplace violence occurs. Knowledge renewal consists of items about actively participating in education and training related to workplace violence and learning related knowledge to enhance their ability to manage violence.

The third stage, response, refers to the response to a crisis situation, that is, what methods or strategies should be adopted to deal with a crisis. One factor, response to violence, was consistent with it. Response to violence consists of items related to reasonably using de-escalation skill to ease the progress of violence and protecting themselves and getting out of dangerous situations as soon as possible.

The fourth stage, recovery, refers to the arrangements for recovery work and the summary and analysis of related experience after the crisis is under control. One factor, after-the-event recovery, including items on performing post-incident treatment, psychological adjustment, and experience reflection after workplace violence, was consistent with the fourth stage.

The MWVCS developed has its strengths in that it was underpinned by 4R crisis management theory [23] and that the framework guidelines had great reference value to the items development [10]. Another strength of the study is that, through the Delphi method, it was possible to identify and reflect international and national, and collective and individual requirements in managing WPV among nursing students into a set of competence for use in China and potentially many other countries across the world. In the phase of Delphi Expert Consultation, several items were revised and added. For example, verification of vague information was suggested by experts, which was considered as an important interaction skill for violence prevention. In particular, experts noted that seeking assistance from the social support system was a considerable way of psychological adjustment after confronting with WPV. Therefore, the final MWVCS includes Q17 and Q47 to address this suggestion.

Relevant instruments have been globally developed, among which the existing instruments aimed at the attitudes [16], self-confidence [17], or a skill [12]. In the current study, the MWVCS placed emphasis on the management competence throughout the violence occurrence and development, covering reduction,

Table 2 *Demographic Characteristics of Participants in the Study (N = 797).*

Characteristics	N	%
Gender		
Men	83	10.4
Women	714	89.6
Age (years)		
18–20	66	8.3
21–23	673	84.4
≥24	58	7.3
Education program		
Junior college study (3 years)	593	74.4
Bachelor's degree study (4 years)	204	25.6
Clinical placement		
< 4 months	5	0.6
4–6 months	3	0.4
> 6 months	789	99.0

Table 3 *The MWVCS Exploratory Factor Analysis.*

Items	M±SD	Factors						
		1	2	3	4	5	6	7
After-the-event recovery	42.61 ± 6.65							
Q51. I can reflect on the inadequacies in the process of addressing the violence after the incident.	3.89 ± 0.74	**.83**	.13	.13	.01	.05	.13	.12
Q43. I can report violence correctly and effectively with the help of teachers after the incident.	3.91 ± 0.83	**.78**	.10	.07	.01	.14	.06	.27
Q50. I can make an analysis of the causes of the incident after the violence.	3.81 ± 0.81	**.78**	−.15	.10	.05	.03	.16	.19
Q44. I can choose an effective legal approach for personal rights protection with the help of teachers after the violence.	3.89 ± 0.78	**.78**	.01	.02	.03	.03	.17	.10
Q45. I can objectively assess my psychological state after experiencing the violence.	3.78 ± 0.83	**.77**	.19	.07	.07	.13	.13	.24
Q52. I will share my experience of hospital violence with other students to avoid the recurrence of such incidents.	3.99 ± 0.79	**.72**	−.03	.05	.01	.11	.22	.09
Q49. I can give psychological comfort to my colleagues after they suffered hospital violence.	3.96 ± 0.76	**.68**	−.03	.07	.06	.10	.26	.04
Q48. I know how to ask for professional psychological help after the violence.	3.70 ± 0.86	**.65**	−.11	.07	.05	.02	.00	.30
Q42. I can choose appropriate ways (such as photos, monitoring, witnesses, etc.) to collect evidence with the help of teachers after the violence.	3.84 ± 0.83	**.63**	.14	.24	.09	.14	.07	.22
Q46. I can use appropriate psychological adjustment methods to adjust the psychological state (such as moderate relaxation, reasonable catharsis, self-suggestion, etc.) after the violence.	3.82 ± 0.82	**.61**	.06	.14	.04	.09	.06	.07
Q47. I will seek support from classmates, teachers and family after the violence.	4.01 ± 0.79	**.54**	.15	.03	.01	.12	.23	.03
Nurse–patient interaction	23.79 ± 3.64							
Q19. I don't use derogatory or threatening language with patients.	4.04 ± 0.85	.09	**.79**	.02	.00	.10	.05	.01
Q18. I respond to patients in appropriate ways (nodding, smiling, encouraging, affirming, etc.).	4.07 ± 0.76	.05	**.77**	.01	.01	.04	.06	.05
Q16. I give attention to the verbal and non-verbal behaviors (such as words, tone, expressions, actions, etc.) of the patients or relatives.	3.89 ± 0.76	.03	**.73**	.00	.09	.08	.06	.19
Q17. I will verify the vague information with patients or relatives.	3.88 ± 0.81	.02	**.68**	.03	.02	.03	.11	.29
Q12. I respect the rights of patients and avoid unintentional infringement or injury.	4.09 ± 0.82	.03	**.63**	.05	.11	.03	.18	.14
Q15. I will adjust the way of communication according to the cognition of patients or relatives.	3.82 ± 0.76	.02	**.63**	.02	.09	.02	-.07	.20
Response to violence	29.90 ± 4.80							
Q35. When the patients or relatives raise the voice or become emotional, I can use appropriate communication skills to ease the tension.	3.79 ± 0.76	.05	.07	**.82**	.04	.07	.02	.10
Q38. When communicating with patients or relatives who have signs of violence, I will try to move to an monitoring area.	3.84 ± 0.82	.07	.13	**.70**	.10	.07	.21	.04
Q34. I can manage my emotions well when facing complaints and misunderstandings from patients or relatives.	3.78 ± 0.77	.03	.16	**.70**	.11	.05	.06	.09
Q37. When facing emotional patients or relatives, I will keep an appropriate distance.	3.98 ± 0.76	.06	.06	**.69**	.04	.18	.30	.02
Q36. I know the ways to control the violence tendencies of special patients (e.g., psychopath, alcoholics, drug user).	3.48 ± 0.90	.05	.18	**.66**	.06	.03	.15	.25
Q39. When encountering hospital violence, I can appropriately turn to teachers for help.	3.98 ± 0.77	.13	.07	**.62**	.01	.14	.24	.16
Q41. If controlled by patients or relatives, I can use disengagement techniques (e.g., protect vital parts, communicate to distract attention, utilize disengagement techniques, and call for help timely).	3.60 ± 0.88	.22	.02	**.54**	.04	.05	.25	.17
Q40. When encountering hospital violence, I can activate the one-button alarm device.	3.45 ± 0.95	.18	.23	**.45**	.11	.35	.11	.02
Violence cognition	17.65 ± 3.46							
Q2. I know the causes of the violence in the health sector.	3.60 ± 0.81	.01	.05	.01	**.83**	.02	.06	.08
Q4. I know the current situation of hospital violence in our country.	3.45 ± 0.89	.03	.04	.05	**.78**	.02	.05	.09
Q1. I know the workplace violence includes physical and psychological violence.	3.57 ± 0.89	.02	.07	.01	**.78**	.02	.10	.09
Q3. I know the psychological knowledge of violence in the health sector.	3.29 ± 0.88	.02	.04	.01	**.77**	.05	.16	.16
Q5. I know the impact of hospital violence.	3.75 ± 0.84	.03	.14	.08	**.77**	.01	.00	.19
Utilization of protective facilities	13.86 ± 3.12							
Q21. I know the location of the one-button alarm device in the hospital.	3.35 ± 0.99	.06	.04	.05	.02	**.92**	.09	.03
Q20. I am familiar with the position of the surveillance camera in my work area.	3.47 ± 0.96	.02	.15	.14	.06	**.79**	.09	.03
Q23. I know the violence contingency plan of the hospital.	3.28 ± 1.00	.02	.12	.05	.13	**.65**	.02	.14
Q22. I know the staff passage in the hospital.	3.75 ± 0.95	.06	.18	.01	.08	**.61**	.31	.05
Knowledge renewal	11.94 ± 2.17							
Q32. I will participate actively in training related to violence organized by the hospital.	4.00 ± 0.84	.06	.01	.04	.00	.14	**.75**	.03
Q33. I will improve my violence management competency by self-directed learning via various approaches.	3.88 ± 0.84	.02	.15	.07	.07	.15	**.72**	.18
Q31. I think the occupational protection education in the health sector should contain violence content.	4.06 ± 0.83	.10	.12	.04	.10	.04	**.67**	.11
Risk assessment	10.89 ± 2.11							
Q26. I can identify the patients or relatives with high risk of violence based on their characteristics (such as personality, expectation of medical treatment, social background, economic conditions, etc.)	3.60 ± 0.83	.03	.13	.12	.11	.06	.07	**.73**
Q25. I can assess the signs of violence using STAMP (Staring and eye contact, Tone and volume of voice, Anxiety, Mumbling and Pacing).	3.64 ± 0.84	.08	.08	.07	.04	.05	.19	**.66**
Q27. I can identify high-risk situations where violence occurs (e.g., working alone, unmet demands of the patients or relatives, misunderstanding, unsatisfying treatment effect, etc.)	3.64 ± 0.82	.13	.16	.03	.04	.01	.07	**.65**
Total score	150.64 ± 20.40							
Eigen value		15.14	2.61	2.30	1.67	1.24	1.18	1.15
Explained variance (%)		37.8	6.5	5.8	4.2	3.1	3.0	2.9
Cumulative variance (%)		37.8	44.4	50.1	54.3	57.4	60.3	63.2

The bold indicates salient load on a factor.

Note. M = mean; SD = standard deviation.

readiness, response, and recovery. It should take 15–20 minutes for students to complete the MWVCS. This instrument could be helpful for nursing educators to obtain a comprehensive understanding of students' violence management competence.

This study has some limitations. First, because no suitable measurement tool was found as a criterion, criterion validity was not performed. Second, two items associated with attitudes were eliminated during item analysis, and the remaining attitude related

Table 4 *Correlations among the MWVCS factors.*

Variable	Violence cognition	Nurse–patient interaction	Utilization of protective facilities	Risk assessment	Knowledge renewal	Response to violence	After-the-event recovery	MWVCS
Violence cognition	1							
Nurse–patient interaction	.50**	1						
Utilization of protective facilities	.46**	.40**	1					
Risk assessment	.48**	.49**	.53**	1				
Knowledge renewal	.39**	.60**	.44**	.50**	1			
Response to violence	.52**	.53**	.53**	.58**	.54**	1		
After-the-event recovery	.49**	.59**	.46**	.57**	.60**	.75**	1	
MWVCS	.70**	.75**	.68**	.73**	.72**	.86**	.88**	1

$^{**}p < .001$.
Note. MWVCS, management of workplace violence competence scale.

items were subsequently removed because of the factor containing less than three items. Attitudes toward violence have an effect on the management of WPV [32]. Thus, it is recommended that the MWVCS collocate with a violence-related attitude scale to obtain an overall understanding of students' competence in violence management and their attitudes.

The instrument has important implications for nursing education in the future. Nursing educators in clinical settings have the great responsibility to cultivate students' coping capacity. The competence level of nursing students in the reduction of violence, readiness for violence, response to violence, and recovery from violence should be observed and assessed by educators. Although a number of training programs have been developed, few of them were specially tailored to student requirements [9]. The instrument can be used for nursing students with the experience of clinical observation or practicum. In addition, it can be used as a pretest or post-test tool in related training. Education courses or training programs could be developed based on the understanding of nursing students' strengths and weaknesses in violence management. The effectiveness of the education intervention could also be evaluated using the instrument. All nurses are expected to have the intention to provide violence prevention education [33]. The instruments could provide guidance for nurses in clinical settings, such as providing alarm device introduction, violence risk patient informing, and psychological care. Therefore, nursing students' awareness of violence prevention could be enhanced, and violence incidents and harmfulness could be reduced. Currently, there is a gap between the student requirements and training in the literature. This instrument would allow nursing academics to analyze the influential factors of students' competence in violence management and design scientific targeted training programs.

Conclusion

The MWVCS in the current study has been demonstrated to have good reliability and validity in a large sample of nursing students. It consists of 40 items in seven factors and could be used to measure competence in WPV management. It is a valuable instrument for nursing educators to understand students' competence, identify their educational needs, develop, and evaluate the effectiveness of educational programs. Further studies are needed to test the scale in different contexts and cultures.

Conflict of interest

The authors declare no conflict of interest.

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References

1. Hopkins M, Fetherston CM, Morrison P. Prevalence and characteristics of aggression and violence experienced by Western Australian nursing students during clinical practice. Contemp Nurse. 2014;49(1):113–21. https://doi.org/10.1080/10376178.2014.11081961
2. Budden LM, Birks M, Cant R, Bagley T, Park T. Australian nursing students' experience of bullying and/or harassment during clinical placement. Collegian. 2015;24(2):125–33. https://doi.org/10.1016/j.colegn.2015.11.004
3. Wang C. Influence of hospital violence on professional identity of practical nursing students. Chin Nurs Res. 2016;30(12):1517–9. https://doi.org/10.3969/j.issn.1009-6493.2016.12.040. Chinese.
4. Tee S, Özçetin YS, Russell-Westhead M. Workplace violence experienced by nursing students: a UK survey. Nurse Educ Today. 2016;41:30–5. https://doi.org/10.1016/j.nedt.2016.03.014
5. Liao YL, Liu TY, Wan GL. Work place violence on the impact of student nurses besides coping strategies. Acta Med Sinica. 2010;23(4):434–6. https://doi.org/10.3969/j.issn.1008-2409.2010.04.031. Chinese.
6. Park JE, Kim DH, Park JH. Violence against nursing students during clinical practice: experiences, perception, responses and coping with violence. J Korea Acad Ind Coop Soc. 2017;18(10):652–62. https://doi.org/10.5762/KAIS.2017.18.10.652. Korean.
7. Magnavita N, Heponiemi T. Workplace violence against nursing students and nurses: an Italian experience. J Nurs Scholarsh. 2011;43(2):203–10. https://doi.org/10.1111/j.1547-5069.2011.01392.x
8. Ye QQ, Li Y, Li JF, Zou JJ, Ni CF, Wang S, et al. Survey of influence of incident of violence between nurses and patients on nursing students in school. Chin Nurs Res. 2016;30(4):1224–7. https://doi.org/10.3969/j.issn.1009-6493.2016.10.021 . Chinese.
9. Heckemann B, Zeller A, Hahn S, Dassen T, Schols JM, Halfens RJ. The effect of aggression management training programmes for nursing staff and students working in an acute hospital setting. A narrative review of current literature. Nurse Educ Today. 2015;35(1):212–9. https://doi.org/10.1016/j.nedt.2014.08.003
10. International Labour Office, International Council of Nurses, World Health Organization, Public Service International. Framework guidelines for addressing workplace violence in the health sector [Internet]. Switzerland: Geneva; 2002 [cited 2020 Jan 1]. Available from: https://apps.who.int/iris/handle/10665/42617
11. Jonas-Dwyer DRD, Gallagher O, Saunders R, Dugmore H, Bulsara C, Metcalfe H. Confronting reality: a case study of a group of student nurses undertaking a management of aggression training (MOAT) program. Nurse Educ Pract. 2017;27:78–88. https://doi.org/10.1016/j.nepr.2017.08.008
12. Nau J, Halfens R, Needham I, Halfens R. The de-escalating aggressive Behaviour scale: development and psychometric testing. J Adv Nurs. 2009;65(9):1956–64. https://doi.org/10.1111/j.1365-2648.2009.05087.x
13. Lyng C, Cocoman A, Ward E, McGrath M. Managing Challenging Situations in Practice: a new program developed to meet the specific needs of nursing students. J Nurs Educ. 2012;51(11):656–9. https://doi.org/10.3928/01484834-20121005-01
14. Brann M, Hartley D. Nursing student evaluation of NIOSH workplace violence prevention for nurses online course. J Saf Res. 2017;60:85–91. https://doi.org/10.1016/j.jsr.2016.12.003
15. Mavandadi V, Bieling PJ, Madsen V. Effective ingredients of verbal de-escalation: validating an English modified version of the 'De-Escalating Aggressive Behaviour Scale'. J Psychiatr Ment Health Nurs. 2016;23(6-7):357–68. https://doi.org/10.1111/jpm.12310

16. Duxbury J. Testing a new tool: the management of aggression and violence attitude scale (MAVAS). Nurse Res. 2003;10(4):39–52. https://doi.org/10.7748/nr2003.07.10.4.39.c5906
17. Thackrey M. Clinician confidence in coping with patient aggression: assessment and enhancement. Prof Psychol Res Pract. 1987;18(1):57–60. https://doi.org/10.1037/0735-7028.18.1.57
18. Bandura A. Perceived self-efficacy in cognitive development and functioning. Educ Psychol. 1993;28(2):117–48. https://doi.org/10.1207/s15326985ep2802_3
19. Hu Y. A research on public hospitals' crisis management against violent conflicts: based on 4R Theory [master's thesis]. China: Beijing Institute of Technology; 2015. Chinese.
20. Ritchie AB. Tourism disaster planning and management: from response and recovery to reduction and readiness. Curr Issues Tourism. 2008;11(4):315–48. https://doi.org/10.1080/13683500802140372
21. Wang FF, Xiang KL, Qu H, Cui Y, Wu QY, Liu L, et al. Construction and implementation of the nursing safety and quality management system based on 4R crisis management theory. Chin Nurs Sci. 2017;32(5):52–5. https://doi.org/10.3870/j.issn.1001-4152.2017.05.052. Chinese.
22. DeVellis RF. Scale development: theory and applications. 3rd ed. Thousand Oaks: Sage Publication; 2011. p. 5–36.
23. Heath R. Crisis management for managers and executives. London: Financial Times Management; 1998. p. 1–20.
24. Lynn MR. Determination and quantification of content validity. Nurs Res. 1986;35(6):382–6. https://doi.org/10.1097/00006199-198611000-00017
25. Ma WJ, Pan B. The reliability and validity of the questionnaire and how to use SAS software to analyze. Chin J Health Statistics. 2000;17(6):45–6. https://doi.org/10.3969/j.issn.1002-3674.2000.06.017. Chinese.
26. Wu ML. Questionnaire statistical analysis practice - operation and application of SPSS. Chongqing, China: Chongqing university press; 2010. p. 140–230. Chinese.
27. Selby-Harrington M, Mehta SM, Jutsum V, Riportella-Muller R, Quade D. Reporting of instrument validity and reliability in selected nursing journals, 1989. J Prof Nurs. 1994;10(1):47–56. https://doi.org/10.1016/s8755-7223(05)80041-9
28. Hopkins M, Fetherston CM, Morrison P. Aggression and violence in healthcare and its impact on nursing students: a narrative review of the literature. Nurse Educ Today. 2018;62:158–63. https://doi.org/10.1016/j.nedt.2017.12.019
29. Evans W, Kelly B. Pre-registration diploma student nurse stress and coping measures. Nurse Educ Today. 2004;24(6):473–82. https://doi.org/10.1016/j.nedt.2004.05.004
30. Nau J, Dassen T, Halfens R, Needham I. Nursing students' experiences in managing patient aggression. Nurse Educ Today. 2007;27(8):933–46. https://doi.org/10.1016/j.nedt.2007.01.007
31. Celebioğlu A, Akpinar RB, Küçükoğlu S, Engin R. Violence experienced by Turkish nursing students in clinical settings: their emotions and behaviors. Nurse Educ Today. 2010;30(7):687–91. https://doi.org/10.1016/j.nedt.2010.01.006
32. Al-Ali NM, Al Faouri I, Al-Niarat TF. The impact of training program on nurses' attitudes toward workplace violence in Jordan. Appl Nurs Res. 2016;30:83–9. https://doi.org/10.1016/j.apnr.2015.11.001
33. Donna GG. The relationship of environmental constraints, self-efficacy, and company risk to occupational health nurses' intentions to provide violence prevention education training [doctor's thesis]. America: University of Kentucky; 1995.

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Research Article

Evaluation of Nurse Practitioners' Professional Competence and Comparison of Assessments Using Multiple Methods: Self-Assessment, Peer Assessment, and Supervisor Assessment

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SUMMARY

Purpose: Nurse practitioners (NPs) are increasingly important in healthcare as they play a key role in leading advanced nursing practices. Assessing their professional competence is essential. The aim of this study was to evaluate NPs' professional competencies based on at a collaborative model around NP self and compare different methods of assessment.
Methods: This is a cross-sectional study, and a purposive sample of 211 participants in the teaching hospital was used. Methods used were self-assessment (nurse practitioners), peer assessment (physicians and nurses) and supervisor assessment (head nurses).
Results: The competence of nurse practitioners was rated as moderate (mean score = 3.45 of a possible 5; SD = 0.59). However, each method resulted in differences in competence for total scores and dimensions. The highest competence was in direct patient care (mean = 3.55, SD = 0.53), and the lowest score was in monitoring the quality of patient care (mean = 3.30, SD = 0.82). *post hoc* analysis shown that supervisor assessment rated professional competence significantly lower than the method of self-assessment and peer assessment ($F = 10.07$, $p < .001$).
Conclusion: NPs require an increased effort to continuous learning for enhancing professional competencies. Moreover, using multiple methods for assessment to obtain a more comprehensive and accurate evaluation of NPs' professional competence.

Introduction

Nurse practitioners (NPs) are expert nurse clinicians leading advanced nursing professional practices [1,2]. In the USA, NPs provided care that was similar to those of a physician's [3]. According to American Association of Nurse Practitioners (AANP) described that NPs focus on health promotion, disease prevention, diagnosis and prescribe treatment and health education [4]. They also play roles as healthcare researchers, interdisciplinary consultants, and patient advocates [4]. In Taiwan, NPs are a result of the shortage of residents in the healthcare system [5]. Therefore, the role of the NP is considered as a new professional role. According to the *Nursing Personnel Act*, Taiwan, one of the scope of practice of NPs is assisting in medical intervention [6]; however, NPs are not allowed to take responsibilities in diagnosing and prescribing treatment. Hence, in Taiwan, NPs' roles focus on health promotion, disease prevention, and health education.

The roles and professional competencies of NPs have becoming more and more important [1]. Regarding "competence" is defined as the specific knowledge and set of skills of an individual [7]. Competence is also defined as the functional adequacy and capacity to integrate knowledge and skills in specific contexts [8]. "Professional competence" is associated with job performance and requirements based on professional expectations [9]. NPs are expected to have expert knowledge, skills, and professional competence to ensure high-quality care in clinical practice [10]. According to the AANP, NPs are licensed, autonomous clinicians focused on managing people's health conditions and preventing disease [11]. NPs are expected to be leaders and able to practice for

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comprehensive assessment and direct/indirect patient care and improve patients care [5]. Satisfactory professional competence for NPs has positive effects in clinical practice, such as increasing patient satisfaction, shortening length of stay, and reducing readmission rates [3,12]. Therefore, ongoing assessment of the professional competence of NPs is very important [13].

The ideal method for competence assessment is controversial because of concerns regarding its objectivity and comprehensiveness with respect to evaluations of competence in clinical practice [14,15]. Evaluation of NPs' professional competence generally uses a self-assessment format. Studies have demonstrated that competencies vary in different nursing environments, which emphasizes the need for different assessments to enhance the accuracy of the measurement [16]. Different methods for competence assessment have been recommended: self-assessment, peer assessment, and supervisor's assessment [17–20]. Self-assessment is the most common and traditional method used in the evaluation of competence. Cowan et al. [21] used self-assessment to determine nurse competence in five European countries and showed that competence varied across countries. However, Meretoja and Leino-Kilpi [22] suggested that when performance is determined by self-assessment subjectivity is limited.

Parker and Hill [1] reviewed evaluation of NP's performance in the United States and stated that peer assessment is gaining interest as the evaluation method, Kenny et al. [23] also stated that peer assessment is the most effective method for evaluating professionalism of NPs and is important for providing feedback and fostering professional growth [17]. John-Mazza [24] used peer assessment to evaluate the clinical practice of NPs and suggested that peer assessment could reflect actual clinical competence.

Regarding supervisor's assessment, Bahreini et al. [16] and Meretoja and Leino-Kilpi [22] indicated that supervisors play a key role in evaluating nurse's competence. To maintain high standards of care, supervisor's assessment of nurse competence should be performed annually. Supervisor's assessment is considered a valuable assessment method [8,16]. Numminen et al. [25] compared the supervisor's assessment and self-assessment of nursing staff competence. The result reported that the supervisor's assessment of nurses' competence was higher than the self-assessment of competence.

Empirical studies regarding the comparison of different assessment methods of NPs' competence are lacking. However, studies have been conducted for nurses. For instance, Meretoja and Leino-Kilpi [22] compared the self-assessment of nurses with managers' assessments of nurse competencies in a university hospital and found the overall score of competence of managers was significantly higher than that determined by nurses' self-assessment. In contrast, when Bahreini et al. [16] compared self-assessment by nurses with supervisor's assessment by head nurses to evaluate nurse competencies, the level of competencies from self-assessment was higher than the supervisor's assessment.

Our literature review suggested that using only two evaluation methods for comparison resulted in inconsistent assessments. Thus, little about NP professional competencies can be gleaned from these different methods of evaluation. We need different methods to more accurately and objectively evaluate NPs' professional competencies. To address this issue, our study used a multi-assessment approach for evaluating NPs professional competence to identify educational needs. In Taiwan, NPs' assessment and management belong to both nursing and medical departments in hospital [26]. However, head nurses are responsible for evaluating NPs' performance [26]. According to the multidisciplinary collaborative model proposed by Chan et al. [27] collaborative pathways connecting interdisciplinary members of health team contribute view and recommendation according to their particular expertise. Based on the multidisciplinary collaborative model, NPs' location could be as a central part in a triangle model. In this triangle collaborative mode, NPs must collaborate with physicians, nurses, and head nurses (Figure 1). For more comprehensive assessment for NPs' professional competencies. Besides NP self, physicians, nurses, and head nurses who really collaborated with NPs should be invited to assess NPs' competencies. Therefore, we adopted three methods to assess NP professional competencies in this study: peer assessment by physicians and nurses, supervisor assessment by head nurses, and self-assessment by the NPs with comparing different evaluation methods examining the differences and similarities of these methods. Our findings could serve as a guide for continuing education courses, a reference for improving competence evaluation methods in general and as a means of gaining a more comprehensive, evaluation for assessing the professional competence for NPs worldwide.

Methods

Aims

The aim of this study was to evaluate NPs' professional competencies in Taiwan. Because of the importance of health team work, we used a triangle collaborative model around NPs to assess NPs' professional competencies. Besides NP's self-assessment, three point assessments from supervisor's assessment (by the head nurse) and two peer assessments (by nurses and physicians) were also examined and then their differences and similarities among these methods were compared.

Study design

A cross-sectional comparative study was adopted in this study.

Participant recruitment and sample size

In health team work, NPs must collaborate and interact with physicians, nurses, and supervise by head nurses [26]. We used a triangle point around NPs to assess NPs' professional competence. Four kind groups (i.e. NPs, physicians, nurses, and hand nurses) participated in this study who were classified three types of assessments including self-assessment, physicians, and nurse colleagues as peer-assessment groups, and supervisor's assessment. All participants were selected from a 400-bed teaching hospital. The sample size was calculated by using G*power analysis with the following parameters: α level = .05, power = .9, and effect size = .3. The minimum estimated sample size was 180 participants. We used a purposive sampling method to select participants. Firstly, we invited all 23 NPs in this hospital to participat in this study. Then we invited nurses, physicians, and head nurses who really collaborated

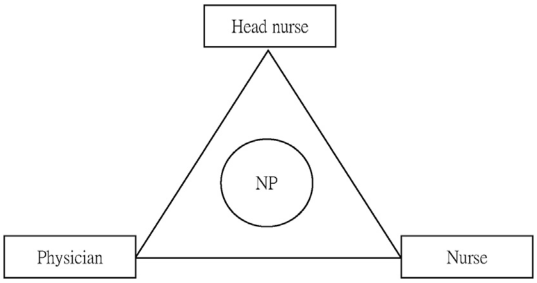

Figure 1. The triangle collaborative model for NPs in health team. *Note.* NPs = nurse practitioners.

and worked together with NPs. The total number was 282. Thirdly, based on a previous study indicating the response rate ranging from 66.0% to 83.0% [28], we distributed 240 questionnaires. Finally, a total of 211 participants (23 NPs, 31 physicians, 143 nurses, and 14 head nurses) completed the questionnaires; the response rate was 88.0%.

Data collection and instrument development

A questionnaire was developed for data collection. The questionnaire was self-administered and consisted of two parts: demographic characteristics and professional competence. After acquiring the list of participants, each participant independently filled out the questionnaire and returned it in an envelope.

Demographic characteristics

Participant characteristics included gender, age, the educational level, the work unit, the number of years, and position on the clinical ladder.

NPs' professional competence

Since 2011, for enhancing NPs' quality of healthcare, the Taiwan Association of Nurses Practitioners has established and continuously revised guideline for NPs’ competence [29] However, the guideline is not concrete and measurable enough. Therefore, we developed a measureable questionnaire with 45-item questionnaire for data collection titled “Nurse Practitioner Professional Competence Questionnaire” (NPPCQ). The NPPCQ was developed based on the Taiwan Association of Nurses Practitioners Guideline for NP's Competence [29], which was reviewed by a panel of experts. The questionnaire incorporated five factors: NP role identity (three items), direct patient care (26 items), nursing and health teaching (six items), communication and collaboration (seven items) and monitoring the quality of patient care (three items). Items were evaluated for level of importance with a five-point Likert scale (1 = very low to 5 = very high). The range of the total score was 45–225, with higher scores indicating that NPs had better competence. The score for each of the five competency dimensions was determined by calculating the mean of the items in each dimension. A value of 3.0 indicated a moderate level of competency.

Validity and reliability

A panel of experts and a convenience sample of 23 NPs participated in testing the validity and reliability. The level of validity and reliability were determined by validity and reliability.

Validity

A panel of three experts established the content validity of the NPPCQ. The experts were certified as NP instructors and included one gastroenterologist, one general surgeon, and one senior NP. The experts were asked to rate the relevance and clarity of each item of the NPPCQ using a four-point Likert scale. Items were to be excluded if the score was less than 3; however, no items received this score. The content validity index was .91.

The construct validity of the NPPCQ was examined by exploratory factor analysis using maximum-likelihood extraction and varimax rotation. This method identified five factors with eigen values greater than 1, accounting for 74.6% of the total variance. The factor loading of each corresponding item ranged from .49 to .95.

Reliability

Internal consistency reliability was examined using a Cronbach's α coefficient. Five dimensions of NPPCQ were as follows: NP role identity was .72, direct patient care was .94, nursing and health teaching was .90, communication and collaboration was .93, and monitoring the quality of patient care was .95. The total of NPPCQ was .93 indicating a good internal consistency.

Ethical considerations

This study was approved by the Institutional Review Board of the National Yang-Ming University Hospital (Approval no. 2013A012). The information packet received by participants included the purpose of the study, the questionnaire, informed consent (including guarantee of anonymity), and a demographic survey. Participants completed the questionnaire and demographic survey anonymously and voluntarily and were free to stop participating at any time.

Data analysis

All data were analyzed using SPSS 15.0 statistical software (IBM Corp., Armonk, NY, USA). Demographic characteristics and professional competencies were analyzed by descriptive statistics including frequency, percentage, mean, and standard deviation. One-way analysis of variance and Scheffe's *post hoc* analysis were used to compare professional competencies assessed by the three different methods for the four types of participants.

Results

Participant characteristics

As shown in Table 1, the disciplines of the 211 participants included 23 NPs (10.9%), 31 physicians (14.7%), 143 nurses (67.8%), and 14 head nurses (6.6%). The participants had a mean age of 31.5 ± 6.9. The NPs, nurses, and head nurses were predominantly women (91.3%, 97.1% and 100%, respectively), and physicians were predominantly men (90.3%). The mean age of NPs was 32.1 years; the mean number of years in the current job was 5.4 years, and a majority (91.3%) of the NPs had college degrees. The mean age of physicians was 38.7 years; the mean number of years in the current job was 5.7 years; most of physicians (71.0%) had bachelor's degree, and 29.0% had a master's degree; a majority (93.5%) of the physicians worked in the medical and surgical ward. The mean age of nurses was 28.83 years, and the mean number of years in the current job was 4.3 years. More than two-thirds (67.1%) of the nurses had college degrees, and 73.4% of the nurses worked in the medical and surgical unit. The mean age of head nurses was 36.7 years, the mean number of years in the current job was 8.0 years, and all of head nurses had bachelor's degrees.

Participants' evaluation of NPs' competencies

As shown in Table 2, the overall score for competency was 3.45 (SD = 0.59). Competencies in the five dimensions were also ranked as moderate, with mean scores ranging from 3.30 to 3.55. Direct patient care scored the highest, and monitoring of quality of patient care was the lowest.

Table 1 *Demographic Characteristics of Participants (N = 211).*

Variable	NP (n = 23)		Physician (n = 31)		Nurse (n = 143)		Head nurse (n = 14)		Total (N = 211)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Gender										
Men	2	8.7%	28	90.3%	4	2.9%	0	0%	34	16.1%
Women	21	91.3%	3	9.7%	139	97.1%	14	100%	177	83.9%
Age (mean ± SD = 31.5 ± 6.9, range 20–60)										
20–25	0	0%	0	0%	25	17.5%	0	0%	25	11.8%
26–30	8	34.8%	7	22.6%	54	37.8%	0	0%	69	32.7%
31–35	12	52.2%	5	16.1%	43	30.0%	4	28.6%	64	30.3%
36–40	3	13.0%	8	25.8%	15	10.5%	10	71.4%	36	17.1%
41–45	0	0%	5	16.1%	4	2.8%	0	0%	9	4.3%
46–50	0	0%	2	6.5%	1	0.7%	0	0%	3	1.4%
≥51	0	0%	4	12.9%	1	0.7%	0	0%	5	2.4%
Education										
College	21	91.3%	0	0%	96	67.1%	0	0%	117	55.5%
Bachelor	2	8.7%	22	71.0%	47	32.9%	14	100%	85	40.3%
Master	0	0%	9	29.0%	0	0%	0	0%	9	4.2%
Work unit										
Medical	10	43.5%	17	54.8%	77	53.8%	8	57.1%	112	53.1%
Surgical	8	34.8%	12	38.7%	28	19.6%	4	28.6%	52	24.6%
GYN & Ped	3	13.0%	2	6.5%	24	16.8%	2	14.3%	31	14.7%
ER	2	8.7%	0	0%	14	9.8%	0	0%	16	7.6%
Current job work experience (mean ± SD = 4.8 ± 4.6, range 0–30)										
≤1 years	2	8.7%	8	25.8%	31	21.7%	0	0%	41	20.8%
2–5 years	13	56.5%	12	38.7%	65	45.4%	4	28.6%	90	45.7%
6–10 years	6	26.1%	7	22.6%	39	27.3%	9	64.3%	51	25.9%
11–15 years	2	8.7%	0	0%	3	2.1%	1	7.1%	6	3.0%
≥16 years	0	0%	4	12.9%	5	3.5%	0	0%	9	4.6%
Clinical ladder										
N1	7	30.4%	N/A	N/A	67	46.9%	0	0%	74	41.1%
N2	9	39.2%	N/A	N/A	67	46.9%	0	0%	76	42.2%
N3	7	30.4%	N/A	N/A	8	5.5%	9	64.3%	24	13.4%
N4	0	0%	N/A	N/A	1	0.7%	5	35.7%	6	3.3%

Note. ER = emergency room; GYN = gynecology; NP = nurse practitioner; Ped = pediatric; SD = standard deviation; N/A = not applicable.

Table 2 *Analysis of variance of different approaches in evaluations of NP competencies (N = 211).*

Competence/evaluations	Total *M* ± SD	1. NP self-assessment *M* ± SD	2. Physician peer assessment *M* ± SD	3. Nurse peer assessment *M* ± SD	4. Head nurse supervisor's assessment M ± SD	*F*	*P*	Scheffe's *post hoc*
NP Role identity	3.34 ± 0.63	3.13 ± 0.57	3.73 ± 0.53	3.31 ± 0.60	2.66 ± 0.86	8.31	<.001***	2 > 1, 3, 4
Direct patient care	3.55 ± 0.53	3.65 ± 0.44	3.86 ± 0.52	3.48 ± 0.48	2.92 ± 0.75	9.43	<.001***	2 > 3, 4
Communication and collaboration	3.54 ± 0.77	3.73 ± 0.54	4.12 ± 0.60	3.37 ± 0.73	2.69 ± 1.09	13.13	<.001***	2 > 3, 4
Nursing and health teaching	3.42 ± 0.69	3.49 ± 0.58	3.73 ± 0.64	3.35 ± 0.67	2.64 ± 1.12	5.71	.001**	1, 2 > 4
Monitoring quality of patient care	3.30 ± 0.82	3.51 ± 0.67	3.59 ± 0.72	3.24 ± 0.72	2.38 ± 1.32	5.33	.002*	1, 2 > 4
Overall score	3.45 ± 0.59	3.51 ± 0.49	3.83 ± 0.49	3.38 ± 0.55	2.64 ± 0.93	10.07	<.001***	1, 2, 3 > 4

Note. M = mean; NP = nurse practitioner; SD = standard deviation; **p* < .05. ***p* < .01. ****p* < .001.

Competency scores and evaluation methods

Comparison of NP competency among groups

The overall competency varied with each of the four groups. The peer assessment by physicians rated the overall competence of NPs the highest (3.83 ± 0.49), followed by NP self-assessment (3.51 ± 0.49), peer assessment by nurse colleagues (3.38 ± 0.55), and the lowest score (2.64 ± 0.93) was from the supervisor's assessment by head nurses. Scheffe's *post hoc* analysis showed that NPs', physicians' and nurses' rankings of overall competency were significantly higher than head nurses.

Comparison of NP self-assessment and peer assessment

Physician and nurse colleagues performed what we defined as peer assessment. The overall of competency of NPs as assessed by physicians was higher than the NPs' self-assessment; however, the differences in scores were not statistically significant. When the five individual dimensions of professional competency were evaluated, only the NP role identity dimension was significantly different, with a higher rating from physicians (3.73 ± 0.53) than NPs (3.13 ± 0.57). The overall score for competency, evaluated by nurse colleague's peer assessment, was not significantly different from NPs self-assessment. In addition, similar to the evaluations by physicians, competency in the dimension of NP role identity was rated higher by peer nurses (3.31 ± 0.60) than by the self-assessment of NPs (3.13 ± 0.57). In contrast, NP self-assessment scores in the four other dimensions of competency were all higher than scores given by peer nurses, although these scores were not significantly different.

Comparison of NP self-assessment and supervisor's assessment

Head nurses performed the supervisor assessment of the NPs. The overall competence rating from head nurses (2.64 ± 0.93) was significantly lower than NP's self-assessment score (3.51 ± 0.49).

The head nurses scored all five dimensions of professional competency lower than NPs' self-assessment. Two of these dimensions, nursing and health teaching and monitoring quality of patient care, were significantly lower than the NPs' self-assessment rating scores.

Comparison of peer assessment and supervisor assessment

The scores for peer assessment by physicians and supervisor assessment by head nurses were significantly different (Table 2). Mean scores from physicians' evaluation were the highest overall, and professional competencies were significantly higher than scores obtained from the head nurses' evaluation. For all five dimensions of competency, the findings revealed significantly higher scores from physicians than head nurses.

With respect to the comparison between peer assessment by nurses and supervisor assessment, regarding the analysis of overall competencies, we found that nurse-evaluated NP professional competencies were significantly different from evaluations by head nurse. However, competency ratings in the five dimensions were not significantly different.

Discussion

NPs' professional competence

The assessment by the medical professional group showed that the NPs in our study had a moderate level of professional competency. This finding is similar to that of Chang et al. [19] but lower than that of Cajulis and Fitzpatrick [30]. The reasons may be related to higher education and more work experience parameters found in the study by Cajulis and Fitzpatrick [30]; all NPs had a master's degree. Several reports have indicated that education positively correlates with personal professional competency [19,22]. In Taiwan, based on the NP national certification requirement, NPs should have at least an associate degree, with three or more years of clinical working experience, and completed the NP training program [31,32]. Indeed, according to the AANP, NPs should be educated at the graduate level [11]. With education as the best way of closing the gap between actual and expected competency, policy maker and nurse educators should consider to improve NPs' education level to master’s degree to fulfill the certification requirement and then to improve quality of patient care. In addition, work experience also differed in these studies. NPs in our study had fewer years of practical work experience (4.83 ± 4.60 years) than the the NPs evaluated by Cajulis and Fitzpatrick [30] (5.98 ± 5.41 years). Less working experience may result in NPs demonstrating lower degrees of professional competence.

Five dimensions of competencies were also revealed a moderate degree. The mean scores were similar (3.30-3.55), and direct patient care rated the highest scores (3.55); next to it was communication and collaboration. The lowest score was in monitoring quality of patient care (3.30). This finding is similar to the study by Chang et al. [19], Copnell et al. [33], Kleinpell [34], and Yao et al. [35]. For instance, Kleinpell [34] found that NPs spend over 80% of their time on direct patient care. The findings of Copnell et al. [33] also supported that NP played a key role in bridging communication and fostering cooperative relationships between patients, healthcare providers, and physicians. Therefore, we concluded NPs are more likely to be the healthcare providers responsible for interacting directly with patients and health team members, relaying important information to patients and acting as a liaison between patients and other team members. As to monitoring the quality of patient care was the dimension with the lowest score for NPs. This result is consistent with those of the studies by Fang and Tung [36] and Kleinpell [34]. The reasons may be because clinical practices are major roles for NPs. NPs have less time for monitoring patient care and quality assurance. Fang and Tung [36] examined daily activities and job competencies of NPs and found that NPs are less frequently involved in practice guidance and quality improvement activities. In a longitudinal study, Kleinpell [34] examined the responsibility of NPs over a five-year period and found that only 17.0–22.0% of NPs reported monitoring patient care for quality assurance in clinical practice. This may account for this dimension having the lowest score. One way to address these shortcomings in professional competence is to encourage NPs to participate in continuing education programs. All the five dimensions of professional competence need to be improved, particularly in monitoring quality of patient care.

Differences among assessment groups

Evaluations of professional competency of NPs differed significantly when the four groups were compared. Physicians rated NPs highest in overall competency and for the five dimensions, followed by NPs, and nurse colleagues; head nurses gave the NPs the lowest scores. The differences between groups within the context of the assessment method are discussed in the following passages.

Differences in self-assessment and peer-assessment methods

Comparison of the self-assessment scores by NPs and peer assessment by physicians and nurses were not significantly different for overall scores of professional competencies. However, the two peer-assessment groups, physicians and nurses, differed in their evaluations of NPs. Physicians rated NPs higher and nurses scored NPs lower, although these scores were not significantly different. One explanation for the higher evaluation by physicians may be that they often work closely with NPs and thus have more opportunities to directly observe NPs' skills. More work experience of NPs, who were formerly registered nurses, and nurses may result in similar expectations of professional competencies. Therefore, nurses apply their own expectations of professional competencies to NPs, and this may also explain the similar ratings between the NPs self-assessment and the nurses peer assessment.

There were also differences between physicians and nurse colleague peer assessment. Physicians rated all five dimensions of competency higher than nurses and three of these dimensions (NP role identity, direct patient care, and communication and collaboration) were significantly different. As stated earlier, NPs in Taiwan have frequent interactions with physicians, and therefore physicians can observe patient care, and communication, and collaboration in the clinical setting, thus leading to the higher rating. However, the lower ratings by nurses may be because nurses do not consider these competencies to be NP roles, and therefore their expectations of NPs may be different. This interpretation is supported by an Australian study [33], which found that NPs had a higher degree of collaboration with physicians than with nurses.

Peer assessment rated all five dimensions of competency higher than the self-assessment of NPs. However, only the dimension of NP role identity was significantly different, and that was from peer assessment by physicians. It is interesting that physicians rated the NPs even higher than the NPs themselves. One explanation may be related to different job descriptions and expectations among the different groups. In most countries, including Taiwan, limitations on the physician's workload and available manpower require a NP to be able to partially perform the role of physician’s assistant and share some of the duties of the physician [36]. This may explain why physicians tended to positively agree with overall of NPs' competencies, which is reflected in the mean of total score of 3.83. The higher score given for the dimension of NP role identity by physicians may be partly explained by the working environment of NPs. In Taiwan, and elsewhere, NPs often work under the instruction of physicians in a collaborative relationship and with a certain degree of autonomy, which may result physicians valuing the role of NPs. This is supported by Hurlock-Chorostecki et al. [37] and Maylone et al. [38] who reported that NPs receive high levels of collaborative relationship and are given a considerable amount of autonomy by physician colleagues.

Differences in self-assessment and supervisor-assessment methods

The most significant differences in the evaluations were seen between the NPs self-assessment and the supervisor assessments. Head nurses rated NPs significantly lower than NPs for overall competency and for two dimensions (nursing and health teaching, monitoring quality of patient care). The overall score of competency (2.64 ± .93) from supervisor assessments was a rating that reflected lower than moderate competency, and this less-than-moderate level was consistent for all five dimensions. These findings are in agreement with studies by Bahreini et al. [16] and O'Connor et al. [14] who also reported that supervisor's assessments of NPs were lower than self-assessment competency ratings. Head nurses, the primary directors of the nursing system, may expect NPs to act as advanced nurses, resulting in a higher standard for the evaluation of NPs' professional competence [13,39]. Head nurses expect NPs to carry out more independent functions such as monitoring quality of patient care, and teaching health, something that NPs do not do on a regular basis. A study by Cheng et al. [26] also confirms these findings and adds an additional explanation. Their study showed that nurse supervisors in Taiwan do not have a clear understanding of how their responsibilities differ from NPs. This confusion could further explain the lower NP competency ratings from nurse supervisors.

Differences in peer-assessment and supervisor-assessment methods

Both nurse and physician peer assessments differed from the supervisor assessments. Although only the overall score was significantly different between peer assessment of nurses and supervisor assessment of head nurses, the nurses evaluated all five of the NP competencies as much higher than did the head nurses. One explanation is that nurse colleagues have a greater recognition of the responsibilities of NPs and provide more support. Several studies [40,41] indicate that nurses are supportive of the role of NPs, recognize the importance of NPs and, in the process of NPs transitioning to advanced practice roles, offer more support to NPs than head nurses.

The high scores of physician peer assessments and significantly low ratings of head nurse supervisor assessments may be explained by Cheng and Chen [42]. Their study, which evaluated “satisfaction with the NP”, found that physicians gave significantly higher ratings for satisfaction with NPs' overall clinical performance than head nurses. This would also explain the high ratings given to NPs by physicians for all five competencies.

To our knowledge, this is the first study to evaluate NPs professional competencies based on a triangle collaborative model around NP self, compare the differences and similarities among NPs, physician, nurses, and head nurse assessment. In Taiwan NPs are a result of the shortage of residents; however, because of regulations placing limits on prescription, medication prescription, this role did not include in this study. For NPs' roles may be verified in different countries. Thus, more studies are expected in different countries in future. In addition, based on our finding, we recommend that policy makers and nurse educators should improve NPs' education level to master’s degree to fulfil certification requirement and then to improve connected international standards to achieve global levels.

The authors acknowledge the present study had some limitations. Additional data will be required to determine if these differences are consistent in different hospital settings and with a larger sample size. The research setting was a teaching hospital, and the sample size of each group was small. These factors limit generalizations of our results to other hospitals. Besides, a larger sample in each group and drawing from different health care facilities are recommended for future research, because it will provide data from a more diverse population and setting. Although the NNPCQ instrument developed for this study had satisfactory validity and reliability, it still need to be modified for use in other countries. Perform confirmatory factor analysis because larger sample sizes are needed. This format of evaluating performance with multiple assessment groups could be applied worldwide by using assessment instruments that are already in place.

Conclusions

Competency evaluation is important for ensuring a high quality of patient care. This study was to evaluate NPs professional competencies and using four different groups and to compare the differences among three assessment methods. However, our study found that NPs revealed a moderate degree of overall professional competencies and even five dimensions. Among five dimensions, the highest score was noted for “direct patient” and the lowest was “monitoring quality of patient care”. Therefore, NPs certain competencies require further development and requires an increased effort to continuous learning for enhancing NPs' professional competencies. In addition, we also found in total dimensions of competency, physician assessment rated the highest score, and then were NP self-assessment and nurse colleague assessment; supervisor assessment rated significantly lower than other three groups. Our findings supported that different assessment methods provide different views of assessing NPs' professional competencies. Therefore, comprehensive assessment through different assessment methods is valuable to improve NPs' competencies, and using multiple methods for evaluating NPs professional competency adds an additional layer that may result in a more accurate assessment of NP's competencies. The 360-degree evaluation method could be used in assessing NPs' competence; therefore, evaluation by patients could be considered as an additional method, adding another perspective to the assessment of professional competencies. More accurate evaluation of NPs can provide information about gaps in education that can be used to develop continuing education programs for monitoring professional competencies to increase the quality of patient care.

Authorship statement confirming

The listed authors meet the criteria for authorship and agree with the content of the manuscript.

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Conflict of interest

The authors declare no conflict of interest.

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SY and HYL were responsible for the study design, developed the instrument. SY, HYL, FIT, and TFW were responsible for the drafting of manuscript and final submission. SY, FIT, and TFW provided statistical expertise and supervision of study.

References

1. Parker JM, Hill MN. A review of advanced practice nursing in the United States, Canada, Australia and Hong Kong Special Administrative Region (SAR), China. Int J Nurs Sci. 2017;4(2):196–204. https://doi.org/10.1016/j.ijnss.2017.01.002
2. Kleinpell R, Scanlon A, Hibbert D, DeKeyser Ganz F, East L, East L, et al. Addressing issues impacting advanced nursing practice worldwide. Online J Issues Nurs. 2014;19(2):4.
3. Naylor MD, Kurtzman ET. The role of nurse practitioners in reinventing primary care. Health Aff. 2010;29(5):893–9. https://doi.org/10.1377/hlthaff.2010.0440
4. American Association of Nurse Practitioners. A scope of practice for nurse practitioners [Internet]. Washington: American Association of Nurse Practitioners; 2019 [cited 2020 August 15]. Available from: https://storage.aanp.org/www/documents/advocacy/position-papers/ScopeOfPractice.pdf
5. Tsay SL, Tsay SF, Ke CY, Chen CM, Tung HH. Analysis of nurse practitioner scope of practice in Taiwan using the Longest policy cycle model. J Am Assoc Nurse Pract. 2019;31(3):198–205. https://doi.org/10.1097/jxx.0000000000000127
6. Ministry of Health and Welfare. Nursing personnel act [Internet]. Taiwan: Law & Regulations Database of The Republic China; 2020 [cited 2020 August 15]. Available from: https://law.moj.gov.tw/LawClass/LawAll.aspx?pcode=L0020166. Chinese.
7. Axley L. Competency: a concept analysis. Nurs Forum. 2008;43(4):214–22. https://doi.org/10.1111/j.1744-6198.2008.00115.x
8. Meretoja R, Koponen L. A systematic model to compare nurses' optimal and actual competencies in the clinical setting. J Adv Nurs. 2012;68(2):414–22. https://doi.org/10.1111/j.1365-2648.211.05754.x
9. National Organization of Nurse Practitioner Faculties. Acute care nurse practitioner competencies [Internet]. Washington: National Organization of Nurse Practitioner Faculties; 2004 [cited 2018 March, 23]. Available from: http://www.nonpf.com/associations/10789/files/ACNPcompsFINAL1104printb.pdf
10. Hughes RG. Patient safety and quality: an evidence-based handbook for nurses. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Chapter 43, Advanced practice registered nurses: the impact on patient safety and quality; p. 601-620.
11. American Association of Nurse Practitioners. Nurse practitioner curriculum [Internet]. Washington: American Association of Nurse Practitioners; 2010 [cited 2020 April, 17]. Available from: https://storage.aanp.org/www/documents/advocacy/position-papers/Curriculum.pdf
12. Kleinpell RM, Ely EW, Grabenkort R. Nurse practitioners and physician assistants in the intensive care unit: an evidence-based review. Crit Care Med. 2008;36(10):2888–97. https://doi.org/10.1097/CCM.0b013e318186ba8c
13. Holley SL. Ongoing professional performance evaluation: advanced practice registered nurse practice competency assessment. J Nurse Pract. 2016;12(2):67–74. https://doi.org/10.1016/j.nurpra.2015.08.037
14. O'Connor SE, Pearce J, Smith RL, Voegeli D, Walton P. An evaluation of the clinical performance of newly qualified nurses: a competency based assessment. Nurse Educ Today. 2001;21(7):559–68. https://doi.org/10.1054/nedt.2001.0594
15. Yanhua C, Watson R. A review of clinical competence assessment in nursing. Nurse Educ Today. 2011;31(8):832–6. https://doi.org/10.1016/j.nedt.2011.05.003
16. Bahreini M, Moattari M, Ahmadi F, Kaveh MH, Hayatdavoudy P, Mirzaei M. Comparison of head nurses and practicing nurses in nurse competence assessment. Iran J Nurs Midwifery Res. 2011;16(3):227–34.
17. Briggs LA, Heath J, Kelley J. Peer review for advanced practice nurses: what does it really mean? AACN Clin Issues. 2005;16(1):3–15. https://doi.org/10.1097/00044067-200501000-00002
18. Robinson DL, Kish CP. Core concepts in advanced practice nursing. St. Louis, MO: Mosby Inc.; 2001. p. 325–43.
19. Chang IW, Shyu YI, Tsay PK, Tang WR. Comparison of nurse practitioners' perceptions of required competencies and self-evaluated competencies in Taiwan. J Clin Nurs. 2012;21(17-18):2679–89. https://doi.org/10.1111/j.1365-2702.2012.04186.x
20. Nieminen AL, Mannevaara B, Fagerstrom L. Advanced practice nurses' scope of practice: a qualitative study of advanced clinical competencies. Scand J Caring Sci. 2011;25(4):661–70. https://doi.org/10.1111/j.1471-6712.2011.00876.x
21. Cowan DT, Wilson-Barnett J, Norman IJ. A European survey of general nurses' self assessment of competence. Nurse Educ Today. 2007;27(5):452–8. https://doi.org/10.1016/j.nedt.2006.08.008
22. Meretoja R, Leino-Kilpi H. Comparison of competence assessments made by nurse managers and practising nurses. J Nurs Manag. 2003;11(6):404–9. https://doi.org/10.1046/j.1365-2834.2003.00413.x
23. Kenny KJ, Baker L, Lanzon M, Stevens LR, Yancy M. An innovative approach to peer review for the advanced practice nurse–a focus on critical incidents. J Am Acad Nurse Pract. 2008;20(7):376–81. https://doi.org/10.1111/j.1745-7599.2008.00335.x
24. John-Mazza L. Advanced practice peer review: setting new standards. J Am Acad Nurse Pract. 1997;9(12):569–73. https://doi.org/10.1111/j.1745-7599.1997.tb00699.x
25. Numminen OL-K,H, Isoaho H, Meretoja R. Congruence between nurse managers' and nurses' competence assessments: a correlation study. J Nurs Educ Pract. 2015;5(1):142–50. https://doi.org/10.5430/jnep.v5n1p142
26. Cheng HL, Tung HH, Guu SM, Tsay SL, Chang CF. Perceptions of NPs and administrators in regard to the governing and supervision of NPs in Taiwan. J Am Acad Nurse Pract. 2012;24(3):132–7. https://doi.org/10.1111/j.1745-7599.2011.00708.x
27. Chan BC, Perkins D, Wan Q, Zwar N, Daniel C, Crookes P, et al. Finding common ground? Evaluating an intervention to improve teamwork among primary health-care professionals. Int J Qual Health Care. 2010;22(6):519–24. https://doi.org/10.1093/intqhc/mzq057
28. Brtnikova M, Crane LA, Allison MA, Hurley LP, Beaty BL, Kempe A. A method for achieving high response rates in national surveys of U.S. primary care physicians. PloS One. 2018;13(8):e0202755. https://doi.org/10.1371/journal.pone.0202755
29. Taiwan Association of Nurse Practitioners. Nurse practitioner professional competencies [Internet]. Taiwan Association of Nurse Practitioners; 2011 [cited 2016 April, 17]. Available from: http://www.tnpa.org.tw/papers/papers_detail2.asp?id=50. Chinese.
30. Cajulis CB, Fitzpatrick JJ. Levels of autonomy of nurse practitioners in an acute care setting. J Am Acad Nurse Pract. 2007;19(10):500–7. https://doi.org/10.1111/j.1745-7599.2007.00257.x
31. Chiu HJ, Tsay SL, Tung HH. Scope of practice and legislation for nurse practitioners in Taiwan. J Am Assoc Nurse Pract. 2015;27(9):497–500. https://doi.org/10.1002/2327-6924.12248
32. Chiu HJ, Tsay SL, Tung HH. A giant leap in the development of nurse practitioners in Taiwan: from statute to regulation. J Am Assoc Nurse Pract. 2016;28(11):622–7. https://doi.org/10.1002/2327-6924.12405
33. Copnell B, Johnston L, Harrison D, Wilson A, Robson A, Mulcahy C, et al. Doctors' and nurses' perceptions of interdisciplinary collaboration in the NICU, and the impact of a neonatal nurse practitioner model of practice. J Clin Nurs. 2004;13(1):105–13. https://doi.org/10.1046/j.1365-2702.2003.00827.x
34. Kleinpell RM. Acute care nurse practitioner practice: results of a 5-year longitudinal study. Am J Crit Care. 2005;14(3):211–9. https://doi.org/14/3/211.
35. Yao FH, Liu WM, Shen HP, Chung SY. A study on the factors influencing nursing competence for nurse practitioner. J Taiwan Nurs Pract. 2016;2(1):22–34. https://doi.org/10.3966/2410325X2016020201004. Chinese.
36. Fang L, Tung H. Comparison of nurse practitioner job core competency expectations of nurse managers, nurse practitioners, and physicians in Taiwan. J Am Acad Nurse Pract. 2010;22(8):409–16. https://doi.org/10.1111/j.1745-7599.2010.00530.x
37. Hurlock-Chorostecki C, van Soeren M, Goodwin S. The acute care nurse practitioner in Ontario: a workforce study. Nurs Leader. 2008;21(4):100–16. https://doi.org/10.12927/cjnl.2008.20291
38. Maylone MM, Ranieri L, Quinn Griffin MT, McNulty R, Fitzpatrick JJ. Collaboration and autonomy: perceptions among nurse practitioners. J Am Acad Nurse Pract. 2011;23(1):51–7. https://doi.org/10.1111/j.1745-7599.2010.00576.x
39. Schoessler MT, Aneshansley P, Baffaro C, Castellano T, Goins L, Largaespada E, et al. The performance appraisal as a developmental tool. J Nurses Staff Dev. 2008;24(3):E12–8. https://doi.org/10.1097/01.NND.0000320654.87802.16
40. Gooden JM, Jackson E. Attitudes of registered nurses toward nurse practitioners. J Am Acad Nurse Pract. 2004;16(8):360–4. https://doi.org/10.1111/j.1745-7599.2004.tb00459.x
41. Sullivan-Bentz M, Humbert J, Cragg B, Legault F, Laflamme C, Bailey PH, et al. Supporting primary health care nurse practitioners' transition to practice. Can Fam Physician. 2010;56(11):1176–82.
42. Cheng H,C, Chen SC. Medical team satisfaction with nurse practitioner clinical performance. J Nurs Res. 2008;16(1):26–36. https://doi.org/10.1097/01.jnr.0000387287.68806.3c

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Research Article

Structural Equation Model of the Quality of Working Life among Cancer Survivors Returning to Work

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SUMMARY

Purpose: This study aimed to construct and validate a model of the quality of working life (QWL) among cancer survivors returning to work.
Methods: A cross-sectional study was developed. Participants included 204 cancer survivors in the extended cancer survivor stage, 6 months after returning to work, who were treated at two tertiary hospital cancer centers. The data were analyzed with SPSS 22.0 and AMOS 20.0 for confirmatory factor analysis to assess the hypothesis fit and verify the hypothesis.
Results: Factors affecting cancer survivors' quality of working liferesulted in cancer stigma and social support (explanatory power was 43.1%) and the model showed acceptable goodness of fit. In the final model, cancer stigma had a significant direct effect on social support and indirect effect on organizational health, employee health, and QWL. Additionally, social support had significant direct effect on organizational health, employee health and QWL.
Conclusion: Based on the results of this study, there is a need to develop strategies and effective intervention programs that can increase the support of supervisors and colleagues for improving overall quality of work life. Furthermore, the development of policies and intervention programs to reduce cancer stigma for the purpose of transforming perceptions through education and public relations which are indirect factors that affect the quality of work life, can contribute to improving the quality of work life for cancer survivors.

Introduction

Cancer is the number one cause of death worldwide, with a global yearly increase of 18.1 million and death rate of 9.6 million. In South Korea, 3.4% of the population has cancer, which means it afflicts one out of every 29 people [1] Due to the recent development of early diagnosis and treatment technologies, cancer survival rates have also been continuously increasing, e.g., from 54.0% in 2005 to 70.6% in 2016, in the case of 5-year relative survival rate. In 2018, worldwide, the total number of people who were still alive within 5 years of a cancer diagnosis, called the 5-year prevalence, was estimated to be 43.8 million. This number is higher than that noticed in Western countries [1,2]. Because of such an increase in the cancer prevalence rate, interest in the importance of cancer survivors' ability to work and return to work is emerging [2]. For cancer survivors, returning to work is a recovery process and an important part of their cure [3]. It is associated with recovery of normalcy and self-esteem, which affect survivors' quality of life, in addition to providing a sense of financial security by securing a source of income.

Despite the importance of employment and work in managing the return to a normal social life and the quality of life of cancer survivors, the rate of South Korean cancer survivors returning to work is only 30.5%, which is lower than that prevailing in overseas countries (63.5%) [4]. The reasons for this include not only an individual's health status but also prejudice and discrimination against the work competence of cancer patients, as well as the lack of resources, information, and emotional support from superiors and colleagues, and the lack of stable management systems in the organizational community [5]. These multiple factors impede survivors' successful return to work, leading to job

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changes and resulting in a reduction in overall quality of life by increasing cancer survivors' job stress [5]. Indeed, the job turnover rate in South Korea in 2014 due to cancer was 47.0–53.0%, and the possible non-retirement rate of cancer survivors was reported to be 47.0% lower than that of the general public [6]. Accordingly, improving quality of working life (QWL) is important for work readjustment and retention of cancer survivors returning to work [7].

There have been studies on the QWL of cancer survivors, such as those designed to develop measurement scales [3,7] and the studies of Jin and Lee [10] who identified job stress, workplace spirituality, and fatigue as influencing factors of the QWL of cancer survivors. The overall quantum of relevant studies, however, is insufficient. QWL refers to the satisfaction and sense of well-being in psychological and emotional dimensions experienced by an individual worker while working to achieve organizational goals, and it can be considered an integral part of overall quality of life [8]. The QWL of cancer survivors is expected to be low because their quality of life overall is lower than that of non-cancer patients. In particular, understanding the characteristics of organizational culture is important for the improvement of the QWL because the QWL of cancer survivors is mainly influenced by job stress caused by the characteristics of organizational culture [9,10]. The reason for this is that the characteristics of organizational culture, such as negative social perception related to cancer survivors returning to work, devaluation [3], prejudice, and discrimination [5] against the work competence of cancer patients, affect not only the quality of life but also the QWL of cancer patients [11]. Consequently, the characteristics of organizational culture should be considered in identifying the level of cancer patients’ quality of life and relationships among the relevant variables.

In the Culture-Work-Health-Model (CWHM), the organizational culture is the main effect factor for the health of organization and employee and priority factor for improving the QWL. In a study on the structural model of QWL based on the CWHM, organizational culture, social support, organizational health, and employee health were found to be factors affecting QWL [12,13]. On the other hand, previous studies that were not based on the CWHM have reported that cancer survivors who returned to work experience cancer stigma, such as social isolation, alienation, criticism, feelings of guilt, a sense of shame, and self-condemnation, because of the negative organizational culture toward cancer patients [14,15] and the experience lowers their quality of life and makes them perceive their health status negatively [16]. On the other hand, social support from superiors and colleagues in an organization helps workers perceive their health positively [13,17] and contributes to the organization's ability to reach stability [13,18].

As discussed above, various factors such as cancer stigma—-which is a feature of negative organizational culture toward cancer survivors—social support, and organizational and personal health status work complexly in the QWL of cancer survivors who have returned to work. Since previous studies, however, are fragmentary toward the QWL of cancer survivors and have limitations in identifying causal relationships among relevant factors [7,10] more research is needed to provide a theoretical basis that can improve QWL. Accordingly, the purpose of the present study was to establish and test a structural model of the QWL of cancer survivors who have returned to work using the main concepts of the CWHM as a theoretical basis and applying influencing factors of the QWL of cancer survivors found in previous studies. The findings of the present study will establish a theoretical basis for future studies on the QWL of cancer survivors and will provide valuable basic data for finding intervention methods and developing programs to improve QWL.

Conceptual framework

The conceptual framework was constructed based on Peterson and Wilson's (2002) CWHM and empirical studies on the effects of the QWL of cancer survivors. The conceptual framework was composed of organizational culture, management system, organizational health, employee health, and QWL, which are key concepts of the CWHM [19]. The paths of main concepts were presented that cancer stigma which were part of organizational culture had direct influence on social support received from supervisors and colleagues [20] and one-way paths in which cancer stigma directly affected the overall quality of working life of cancer survivors [11]. Social support affects the health of employees with cancer and organizations [13,21] because a greater amount of social support means a greater contribution to cancer survivors' job performance which are components of organizational health [18]. This present study also established social support to directly affect organizational and employee's health. In addition, social support had a direct influence path to QWL based on the report that social support for cancer survivors directly affects their quality of life in previous studies [21]. In the case of the concept of employee health and organizational health, the present study presented a direct influence path from employees and organizational health to QWL [22] because the balance through the interactions between employees and organizational health in the CWHM can improve QWL [9]. The subordinate concepts constituting the main concepts presented in the conceptual framework of the present study were selected based on the findings of previous studies. Cancer stigma is composed of negative experiences from surroundings, such as social isolation at work, detachment, discrimination and sense of guilt, attribution of the cancer to oneself, and the experience of insufficient medical support. These are risk factors for returning to work and for job retention [4,15] and they negatively affect cancer survivors' quality of life [11]. Social support includes emotional support that cancer survivors receive from superiors and colleagues, as well as help and informational support for job performance [23]. Organizational health consists of external health, such as productivity and environment and task performance suitability for achieving goals. Organizational health also includes internal health, such as vitality and community oriented [24] while employee health consists of perceived health status [25]. Last, the QWL of cancer survivors who return to work consists of the value of work, meaning of work, work perception, atmosphere of work environment, Understanding and recognition of organization for cancer survivors in the organization, and health-related problems [7].

Hypothesized model

The hypothesized model suggested in this study is depicted in Figure 1. When QWL was used as an endogenous variable; exogenous variables that directly affected QWL included cancer stigma, social support, organizational health, and employee health. Subsequently, organizational health was used as an endogenous variable. The exogenous variables that directly affect organizational health included social support and employee health, and cancer stigma on the other hand, had an indirect influence. When employee health was used as an endogenous variable, the exogenous variable that directly affected employee health was social support, while cancer stigma had an indirect influence. When social

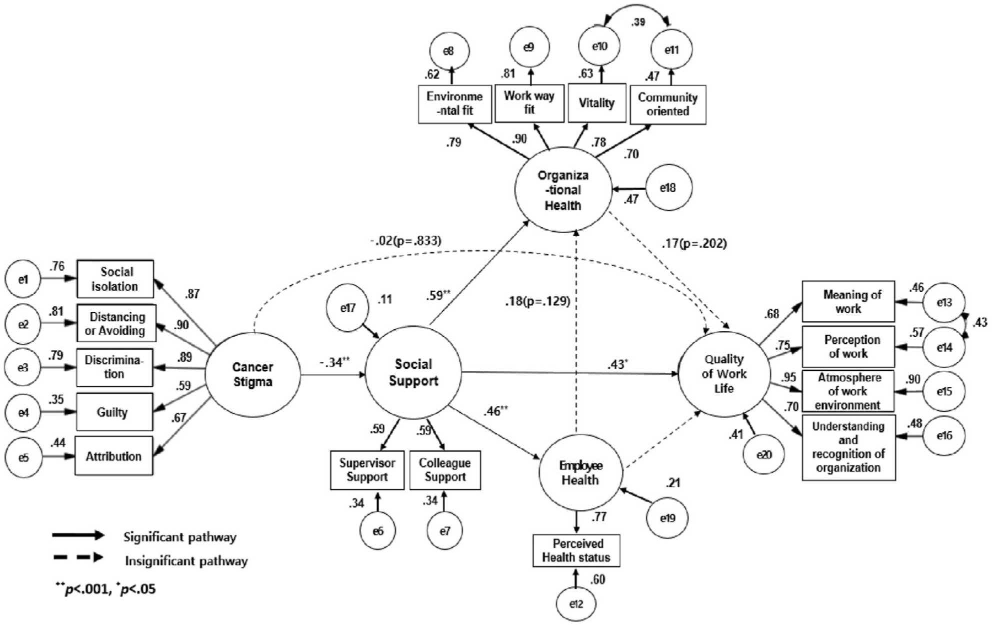

Figure 1. Path diagram of hypothetical model.

support was used as an endogenous variable, cancer stigma was set as an exogenous variable that directly affected social support.

Methods

Study Design

This study employed a cross-sectional design used structured equation modeling. A hypothetical model was constructed based on the relationship between factors related to the QWL of cancer survivors who returned to work. Cross-sectional data were collected, and then the fitness of the model and the hypotheses were tested.

Participants

The sample included is a structural equation modeling (SEM) analysis that needs to be larger than 10 times the number of estimated parameters [26]. The number of free parameters to be estimated in this study was 18. As such, the study sample 204 participants clearly satisfied the minimum sample size of 180. Over 220 questionnaires were distributed and 210 questionnaires were returned. Among the returned questionnaires, 6 were excluded from the analysis due to missing data. Participants were eligible if they were cancer survivors in the extended stage that 2-5 years after being diagnosed with cancer [27] with a period of 6 months passed after returning to work. Because cancer survivors' return rate to work is the highest 12–18 months after cancer treatment [28] and domestic research, which has reported that workers' readjustment after a career break or job rotation takes 3–6 months on average, even if it is the same work or employment [29].

Ethical Consideration

This study was approved by the Institutional Review Board of the Keimyung University (Approval no. 40525-201810-HR-95-03), and the investigation conformed to the principles outlined in the Declaration of Helsinki. Approval from relevant institution directors where data collection took place was obtained. After explaining the purpose and intention of survey, all participants provided written informed consent before completing the questionnaires.

Measurements

There was a total of 23 items for the general characteristics of the participants, including sociodemographic (six items), occupation-related (seven items), cancer-related (seven items), and return-to-work-related (three items) characteristics. For all other instruments, use agreements were obtained from the original authors or authorized agencies of the instruments via email.

Cancer stigma

Cancer stigma was measured using the Korean version of the Cancer Stigma Scale (KCSS) developed by So et al. [5], which has a total of 24 items in six subdomains: social isolation, distancing or avoiding, discrimination, guilt, attribution, and lack of medical support, measured on a 4-point scale. Reliability, as measured by Cronbach's r, was 0.89 in the study of So et al. [5], and Cronbach's r for each subdomain in the present study was social isolation: .92; distancing or avoiding: .92; discrimination: .90; guilt: .77; attribution:.85; and lack of medical support: .49.

Social support

For social support, a total of eight items on a 5-point scale—four items for supervisor support and four items for colleague support—from the Social Support Questionnaires developed by House (1980) were used. In the study of House [30] reliability was not reported separately for supervisor support and colleague support, whereas Korean version scale reported the Cronbach's α for supervisor support and colleague support as .85 and .78 [31]. The Cronbach's α for supervisor support and colleague support in the present study were .85 and .79, respectively.

Organizational health

For organizational health, the Organizational Health Questionnaire (OHQ) developed for Korean employees by Kim and Yu [24] was used. The OHQ is composed of a total of 31 items in four subdomains: environment fit (eight items), work way fit (nine items), vitality (eight items), and community oriented (four items) on a 5-point scale. In the study of Kim and Yu [24], Cronbach's α were environment fit: .88; work way fit: .94; vitality: .94; and community oriented: .91. Cronbach's α in the present study were environment fit: .92; work way fit: .93; vitality: .90; and community oriented: .91.

Employee health

For the health of cancer survivors who have returned to work, perceived health status was measured using the Self-Report Health Scale (SRHS) developed by Lawston et al. [32]. The scale consists of a total of three items (two items on current health status and one item on health status compared to that of others), measured on a 5-point scale. Cronbach's α in the study of Lawston et al. was .76 [32] and Cronbach's α in the present study was .87.

Quality of Working Life

QWL was measured using the Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS) developed by de Jong et al. [7], which has a total of 23 items in five subdomains: meaning of work (four items), perception of work (five items), atmosphere of work environment (five items), understanding and recognition of organization (five items), and problems of health situation (four items), measured on a 6-point scale. Cronbach's α in the study of de Jong et al. [7] was .91. In Korean version of QWLQ-CS, Cronbach's α was .89 [10]. Cronbach's α of each subdomain in the present study was meaning of work:.94; perception of work: .98; atmosphere of work environment: .91; understanding and recognition of organization: .86; and problems of health situation: .91.

Data Collection

Data were collected from February 12 to March 31, 2019. A researcher visited the directors of nursing at each hospital to obtain permission for the data collection. Data were collected from outpatients who met the inclusion criteria. The risks and benefits of taking part in the study, background of the study, and measures taken to preserve confidentiality were explained to each participant. Participants were then asked for their informed consent. Afterward, they were given sufficient time, approximately 30-40 minutes, to answer a questionnaire.

Data Analysis

Data were analyzed using SPSS 22.0 and AMOS 20.0 for Windows (IBM Corp., Armonk, NY, USA). General characteristics of participants and normal distribution of the data were analyzed using descriptive statistics, including frequencies, percentage, means, standard deviations, skewness, and kurtosis. Missing values were estimated using the expectation maximization methods in SPSS, the reliability of the instruments was evaluated using Cronbach's α. A confirmatory factor analysis (CFA) was performed to verify the validity of each variable. Structural equation model (SEM) testing is a two-step approach that was used to perform a measurement model analysis that indicated the relationship between the factors and variables in Step 1, and the structure model linking the factors shown in the hypothetical model set by the researcher was verified in Step 2. To verify the validity of the potential variables in the measurement model, a CFA was performed, and the adequacy of the hypothetical model was evaluated using Amos version 20.0. To evaluate the goodness of fit of the model, the following fit indices and criteria were used: χ^2, normed χ^2, Root mean-Square Residual (RMR), Goodness-of-Fit Index (GFI), Adjusted Goodness-of-Fit Index (AGFI), Root Mean Square Error Approximation (RMSEA), Standardized Root Mean-Square Residual, (SRMR), Comparative Fit Index (CFI), and Tucker–Lewis Index (TLI). The significance of the pathway of the SEM was analyzed using the regression weight standard error (SE), standardized estimated (β), critical ratio (CR), and *p* value, and explanatory power was calculated using Squared Multiple Correlation (SMC). The significance for the structural model path was identified using the regression weight, Standard Error (SE), Standardized estimate (one path was identified), and *p* values, and the explanatory power of the endogenous variable was calculated using Squealed Multiplier Communication (SMC). The significance of the effects of the independent variables on the dependent variables was verified by applying the bootstrapping method.

Results

General characteristics of participants

The demographic, cancer-related, job-related, and return-to-work-related characteristics of the participants are presented in Table 1. Of the 204 participants, the average age was 50.3 ± 7.58 years, 151 (74.0%) were married and 98 (48.1%) were university graduates. With regard to occupational sector, service and sales were 89 (43.6%), followed by health and social work 65 (31.9%) and education and public sector were 29 (14.2%). The average length of working years 11.7 ± 9.39 years, most participants had fixed working type (77.6%) and clerks by work position (54.9%). The cancer diagnosis of participants, breast cancer was the most common (47.5%), followed by thyroid cancer (18.6%) and gastrointestinal cancer (14.2%). The periods of sick leave by cancer treatments, most participants were below 6 months (36.3%), followed by over 1 year (24%) and both treatment and work (22.1%), the majority of participants returned to same workplace (63.7%).

Descriptive statistics of measured variables

The mean, standard deviation, and internal consistency reliability of each of the subscales were calculated in SPSS and are reported in Table 2. Since normality of collected samples are usually tested using SEM for an analysis that uses the Maximum Likelihood Estimate (MLE), the test was performed. The results indicated that normality was ensured because the absolute values of all skewness and kurtosis were 2 or less and 3 or less, respectively.

Confirmatory factor analysis was conducted using maximum likelihood, and variables with a factor loading of 0.5 or less, which were “lack of medical support” of cancer stigma and “problem of health situation” of the quality of work life, were removed. Cronbach's α coefficients values of this study were .77 or higher for all measuring instruments and in the case of the “What is your current state of health?” that is general health condition oneself was selected as a representative item based on the previous study [33].

Analysis of Structural Equation Model

Validity of measurement model

The model was assessed using maximum likelihood to test the normality of the data. The results showed that the data were normally distributed with the absolute values of skewness and kurtosis under one. In addition, the reliability and validity of the measurement model were tested using confirmatory factor analysis. The analysis of the goodness of fit of the measurement model theoretically established showed that $\chi^2(p) = 199.60$ ($p < .001$),

Table 1 *General Characteristics of Participants (N = 204).*

Characteristics		Categories	N (%)
Sociodemographic factors	Gender	Men	35 (17.2)
		Women	169 (82.8)
	Age (years)	≤30	14 (7.0)
		40s	75 (37.0)
		50s	92 (45.0)
		60s	23 (11.0)
	Marital status	Unmarried	42 (20.6)
		Married	151 (74.0)
		Others (divorced, widowed, etc.)	11 (5.4)
	Number of children	None	52 (25.5)
		1	26 (12.7)
		2	107 (52.5)
		≥3	19 (9.3)
	Educational level	≤High school	69 (33.8)
		College	98 (48.1)
		Graduate school	37 (18.1)
	Religion	Yes	152 (74.5)
		No	52 (25.5)
Occupation-related factors	Occupational sector	Education and public sector	29 (14.2)
		Health and social work	65 (31.9)
		Service and sales	89 (43.6)
		Productive work	21 (10.3)
	Working years	≤10	117 (57.4)
		11~20	55 (26.9)
		21~30	23 (11.3)
		≥30	9 (4.4)
	Working type	Shift	48 (23.5)
		Fixed	36 (66.7)
		Others	20 (9.8)
	Work position	Clerks	112 (54.9)
		Managers	62 (30.4)
		Others	30 (14.7)
	Monthly income (10,000 won)	≤150	42 (20.6)
		150~250	68 (33.3)
		250~350	46 (22.5)
	Main source of income in family	Yes	89 (43.6)
		No	115 (56.4)
Cancer-related factors	Types of diagnosed cancers	Breast Cancer	97 (47.5)
		Thyroid Cancer	38 (18.6)
		Gynecological Cancer	15 (7.4)
		Gastrointestinal Cancer	29 (14.2)
		Others	25 (12.3)
	Stage	I	104 (50.9)
		II	71 (34.8)
		Over III	29 (14.3)
	Periods after cancer diagnosis from 2019	1	3 (1.5)
		2	62 (30.4)
		3	30 (14.7)
		4	38 (18.6)
		5	71 (34.8)
	The number of types of cancer treatments (past history)[a]	1	67 (32.8)
		2	61 (30.0)
		3	55 (26.9)
		over 4	21 (10.3)
	The number of types of cancer treatments in progress (at present)	None	99 (48.5)
		1	98 (48.0)
		2	7 (3.5)
Return-to-work-related factors	Periods of sick leave	Both treatment and work	45 (22.1)
		≤6 months	74 (36.3)
		6months~12 months	36 (17.6)
		≥12 months	49 (24.0)
	Return to same workplace	Yes	130 (63.7)
		No	74 (36.3)

[a] The number of types of cancer treatments such as surgery, chemotherapy, radiotherapy, and others (past history).

GFI = .89, AGFI = .84, CFI = .94, TLI = .92, RMR = .03, SRMR = .06, and RMSEA = .06, in which all goodness of fit indices, except for $\chi^2(p)$ and the GFI index, satisfied the criteria, confirming the goodness of fit of the measurement model.

Convergent validity was the level of consistency among the variables when measuring latent variables; each latent variable is greater than recommended cutoff .70 which satisfied the convergent validity. The construct reliability of all latent variables in the present study was .70 or higher, the convergent validity was confirmed. And discriminant validity requires low correlation between the measurement values obtained when different concepts are measured, the AVE values of this study were greater than the square of the correlation coefficients (r) of all factors, discriminant validity between the factors was confirmed in the present study. Nomological validity assesses the consistency between the direction of the hypothetical relationships between the latent variables

Table 2 *Descriptive Statistics and Factor Loading of Confirmatory Factor Analysis (N = 204).*

Latent variables	Measurement variable	Scale Ranges	Mean ± SD	Cronbach's α	Skewness	Kurtosis	Standardized estimate(β)	S. E	C.R. (*p*)	CR	AVE
Cancer Stigma	**Total**	**1–4**	**1.88 ± 0.50**							**0.95**	**.81**
	Social isolation		1.65 ± 0.59	.92	0.32	−1.08	0.87				
	Distancing or avoiding		1.66 ± 0.56	.92	0.19	−0.94	0.90	0.06	17.54*		
	Discrimination		1.98 ± 0.71	.90	0.08	−0.99	0.89	0.07	17.04*		
	Guilty		2.12 ± 0.63	.77	0.03	−0.10	0.59	0.08	9.27*		
	Attribution		1.98 ± 0.65	.85	0.18	−0.62	0.66	0.08	10.78*		
Social support	**Total**	**1–5**	**3.31 ± 0.57**							**0.72**	**.62**
	Supervisor support		3.22 ± 0.74	.85	−0.14	−0.20	0.60				
	Colleague support		3.39 ± 0.66	.79	−0.27	−0.12	0.55	0.15	5.46*		
Organizational health	**Total**	**1–5**	**3.41 ± 0.52**							**0.95**	**.83**
	Environment fit		3.36 ± 0.62	.92	0.06	1.18	0.78				
	Work way fit		3.35 ± 0.62	.93	−0.43	0.72	0.90	0.09	13.07*		
	Vitality		3.35 ± 0.58	.90	−0.48	0.88	0.79	0.08	11.72*		
	Community oriented		3.61 ± 0.56	.91	−0.50	0.77	0.70	0.08	10.05*		
Employee Health	Perceived Health status	**1–5**	**3.31 ± 0.65**	**.87**	**−0.13**	**0.17**	**0.63**			**0.80**	**.80**
Quality of work life	**Total**	**1–6**	**4.27 ± 0.70**							**0.86**	**.62**
	Meaning of work		4.52 ± 1.01	.91	−0.75	0.24	0.68				
	Perception of work		4.52 ± 0.91	.85	−0.75	0.91	0.76	0.08	12.86**		
	Atmosphere of work environment		4.52 ± 0.92	.91	−0.67	0.46	0.95	0.12	10.52**		
	Understanding and recognition of organization		4.14 ± 0.98	.86	−0.25	−0.12	0.69	0.11	9.05**		

* *p* <.05 , ** *p* <.001.
Note. SD = standard deviation.

and the direction obtained from the actual data; nomological validity in the present study was confirmed because the correlation was found to be in the predicted direction.

Validity of path model

The final goodness-of-fit statistics of hypothetical model, the path model was as follows: $\chi^2 = 211.58$ ($p < .001$), $\chi^2/\text{df} = 2.23$, GIF = .89, AGFI = .84, CFI = .93, TLI = .92, RMR = .04, SRMR = .06 RMSEA = .80 (Table 3). Among them, χ^2 and the GFI indices did not fit the criteria; because the χ^2 values are very sensitive to the sample size and the complexity of the model, and the null hypothesis (H_0) is strict, other goodness-of-fit indices, in addition to the χ^2 value, should also be considered. In the present study, the χ^2 index can be supplemented because the Q (χ^2/df) index, which is less sensitive to the sample size, and the TLI, which can complement the limitation of χ^2, fit the criteria. In addition, since the GFI index is highly affected by the sample size and simplicity, the AGFI and CFI are considered together. In the present study, the hypothetical model was confirmed as the final structural model without modification because all goodness-of-fit indices, except for the χ^2 and GFI indices, satisfied the recommended criteria.

The direct influence path from cancer stigma to the QWL in the hypothetical model of which the goodness of fit was confirmed in the present study was rejected (Figure 1). Accordingly, an alternative model was established excluding the direct influence path from cancer stigma to the QWL, and the analysis of the goodness of fit indices of the two models showed that the indices met the criteria. The comparison of goodness of fit between hypothetical and alternative models using the $\chi 2$ test was non-significant. The goodness of fit of the hypothetical model was considered to be good, however, since the SRMR of the hypothetical model was .06, it was slightly lower than that of the alternative model (.07) and closer to zero (Table 3). Therefore, the present study selected the hypothetical model as the final model, and the paths of the measurement variables are presented in Figure 1.

Effect analysis of path model

Influence paths among the concepts in the path model of the quality of work life of cancer survivors returning to work established with the measurement variables such as cancer stigma, social support, organizational health, workers' health, and the quality of work life based on the CWHM are as follows (Figure 1). Cancer stigma had significant influence on social support ($\beta = -0.34$, $p < .001$). Social support was found to have an influence on organizational health ($\beta = 0.59$, $p < .001$), employee health ($\beta = 0.46$, $p < .001$) and QWL ($\beta = 0.43$, $p = .025$).

Next, Table 4 shows the standardized direct, indirect and total effects of variables. Social support was found to have a direct effect on QWL and cancer stigma had an indirect effect on QWL ($\beta = -0.21$, $p = .005$). Furthermore, social support had direct effect on organizational health and employee health. Cancer stigma had an indirect effect on organizational health ($\beta = -0.23$ $p = .005$) and employee health ($\beta = -0.16$, $p = .008$) also. Employee health, however, was found to have no significant influence effect on organizational health and QWL. Organizational health was also found to have no significant effect influence on QWL. Consequently, consequently, the direct effect of social support ($\beta = 0.43$, $p = .025$) and the indirect effect of cancer stigma ($\beta = -0.21$, $p = .005$) were found to have an influence on QWL. The variables that affect QWL, which was the final endogenous variable, explained 41.3% of the variance and seven out of the 10 hypotheses were statistically significant.

Discussion

Main contributions

The QWL score (4.27 out of 6 points) of cancer survivors returning to work in the present study was lower than scores in previous studies, 4.39 points [10] and 4.84 points [7] The reason may be attributable to the fact that the subjects in the present study were in the extended survivorship stage (2-5 years) as described by

Table 3 *Fitness of Hypothetical Model and Slternative Model (N = 204).*

	X^2(p)	X^2/df	GFI	AGFI	CFI	TLI	RMR	SRMR	RMSEA
Hypothetical model	211.58 (<.001)	2.23	.89	.84	.93	.92	.04	.06	.08
Alternative model	211.67 (<.001)	2.20	.89	.84	.93	.92	.04	.07	.08
Acceptable range	p > .05	<3.00	≥.90	≥.80	>.90	>.90	≤.05	<.08	≤.08

Table 4 *Parameter Estimation Results of the Structural Model (N = 204).*

Endogenous Variable	Exogenous Variable	Direct effect(β)	Indirect effect(β)	Total effect(β)	SMC	Hypothesis	
						D	I
Social Support	Cancer Stigma	−.34***		−.34***	.113	A	
Employee Health	Social Support	.46***		.46***	.211	A	
	Cancer Stigma		−.16*	−.16*			A
Organizational Health	Social Support	.59***	.08	.67*	.471	A	R
	Employee Health	.18		.18		R	
	Cancer Stigma		−.23*	−.23*		R	A
Quality of Work Life	Cancer Stigma	−.02	−.21*	−.23*	.413	R	A
	Social Support	.43*	.18	.61*		A	R
	Employee Health	.13	.03	.16		R	R
	Organizational Health	.17		.17		R	

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

Note. A = adoption; D = direct effect; I = indirect effect; R = rejection; SMC = Squared multiple correlation.

Mullan [27], unlike previous studies, and the quality of life in that survivorship stage appears to have been revealed [34]. It appears that the QWL of the cancer survivors in the extended survivorship stage was also lower than the QWL in previous studies as the level of their psychological stress was found to be higher than that of survivors in the acute and permanent stages. Consequently, this finding indicates that cancer survivorship stages should be considered first as disease-related characteristics when conducting research and establishing policies related to the QWL of cancer survivors in the future.

Social support for cancer survivors who returned to work was found to be a key variable that has a direct positive effect on the QWL. The finding is similar to the findings of previous studies [33,35]. That used similar items and reported a direct positive effect of social support on the QWL of non-cancer patients. In addition, the findings of a previous study which emphasized that the support from superiors and colleagues is the actual social support system for cancer survivors, can be considered to support the findings of the present study [18]. Health management of cancer survivors who returned to work, employer's attention and consideration of the work environment [36] and positive perception and support from superiors and colleagues in the direct relationship network are important factors for the improvement of the QWL. Accordingly, mutual support among organizational members to strengthen social support that have positive influence on the work readjustment and improvement in job performance of cancer survivors, and the development of education and programs to increase the sense of fellowship are necessary [37]. In addition, the effect of integrated social support including the support of family, medical staff, and friends, which were identified as valuable social support system for cancer survivors who returned to work, on their health has to be investigated in future studies.

The direct effect of cancer stigma, which is the measurement variable of organizational culture, to the QWL was rejected, but the negative effect of indirect and total effect was similar to the findings of previous studies [13,33,35]. That is, the higher the level of cancer stigma experienced by cancer survivors who returned to work, the lower the support that patients perceive from their superiors and colleagues, and the QWL will eventually decrease. It can be seen as reflecting work-centered culture which is the characteristics of organizational culture in South Korea [15]. There are presenteeism which one cannot be absent from work even for illness [33] and prejudice and stigmatization by organizational members against cancer and cancer survivors [4]. Accordingly, it is necessary to develop and apply integrated palliative care programs that reflect the characteristics of cancer stigma that affect the psychological, physical, and social aspects of cancer survivors [38], include post-traumatic growth [39], resilience [39] and self-efficacy [21] which the influence was proven in previous studies. Furthermore, repeated and extended research is necessary in future studies to compare and analyze stigma experienced by workers with chronic illnesses such as cancer and even healthy workers since stigma is found in organizational culture such as discrimination, prejudice, and isolation that can be experienced even by employees who are not afflicted with cancer, and can be reflected on the over-all organizational health status. In addition, cancer stigma was found to have an indirect influence on the health of the organization and workers with social support acting as a moderator. This finding is partially similar to the results of previous studies which found that workplace discrimination, i.e., stigma, experienced by workers influences turnover intention, which reflects organizational health [12,40]. In addition, the finding is supported by previous studies that reported a significant statistical correlation between cancer stigma and workers' health [16] and workers' health level increases in a healthy and positive organizational culture [9]. Although cancer stigma effects the employee health and organizational health, it can be controlled by perception of social support such as superiors and colleagues. This is because the negative organizational culture, cancer stigma is delivered through the superiors and colleagues to employees and community. Therefore, it is necessary that the development and application of education and promotion programs for improving of perception of cancer survivors who returning work.

Social support is shown to have a positive direct influence on workers' health, which is similar to the findings of previous studies that used similar measurement items [33,35] but different from the findings of LaRocco et al. [41] who reported that the support of family and friends is more related to personal health problems than the support from superiors and colleagues [41]. Accordingly, replication studies using measurement instruments, which include the support of family and friends, are necessary. The direct positive effect of social support on organizational health is similar to the findings of a previous study which reported that organizations with a high level of support from superiors and colleagues positively assess organizational environment and work atmosphere, which can be considered as organizational health [41]. The OHQ used in the present study to measure organizational health is an integrated scale that reflects both external and internal wellbeing, and it can be used to develop intervention programs to build healthy organizational culture by comparing and analyzing internal and external organizational health status according to the support from superiors and colleagues [24].

In summary of these findings, the higher the cancer stigma experienced by cancer survivors who returned to work, the lower the cancer survivors' perception of support from superiors and colleagues. Such low social support can ultimately be considered to decrease the QWL, which is a subjective satisfaction experienced from the physical and human environment at work. In addition, because cancer stigma, which reflects organizational culture, is conveyed to cancer survivors through superiors and colleagues, and it negatively affects organizational and workers' health, the findings of the present study can contribute to the establishment of practical policies for successful return to work and the development of effective intervention strategies and programs to strengthen social support and to alleviate cancer stigma through approaches from various dimensions for the improvement of the QWL of cancer survivors who returned to work.

Discussion on the unsupported hypotheses

A direct effect from cancer stigma to QWL that has not been attempted in previous studies, was attempted and set up for QWL in the present study was based on CWHM. However, it was rejected, which is a different outcome from previous studies that were able to confirm significant causal relationships between cancer stigma and the quality of life. It is a concept in the overall quality of life that includes the QWL, but it is subjective and a specific satisfaction as experienced by the individual employees, it can be different concept from the overall quality of life. In addition, organizational culture is delivered to individual workers through organizational management system according to CWHM, the QWL of cancer survivors also appears to be positively or negatively influenced by supervisors and colleagues who the direct connection network of workers who are cancer survivors rather than the direct effect of organizational culture. Therefore, extended research that includes not only the QWL of cancer survivors but also the overall quality of life is suggested for future studies.

The present study confirmed significant negative indirect effect and total effects of cancer stigma on the QWL with social support acting as a moderator, and the finding is similar to that of previous studies [13,33]. In addition, the hypothetical paths of the positive effects of employee health on organizational health and the QWL were rejected in the present study. This finding is different from that of previous studies [13,33] that confirmed the path in which the employee health measured with one item as the present study influences organizational health and the QWL. The reason may be due to different measurement instruments from previous studies, which determined paths between employee health, organizational health, and the QWL variables. Another reason may be due to Self-Report Health Scale (SRHS) which measured workers' health, used only one item: "What is your current state of health?" [32]. Although SRHS is commonly used for cancer patients [42], it has limitations in reflecting the health status of cancer survivors with diverse and complex health problems for extended survivorship which appears to have affected the results [39]. In addition, it may be due to differences in subjects from previous studies. Since cancer is a chronic disease that continues to be influential in every aspect of life even after treatment is terminated [22,27], the self-rated health level of cancer survivors who returned to work is considered to be different from that of previous studies of non-cancer patients. Therefore, the future studies should apply the measurement instrument that including the health status of cancer survivors in extended survivorship who experience fear, anxiety, fear of recurrence, and the uncertainty of health [39].

Furthermore, the path from organizational health to the QWL was non-significant in the present study, which is different from the results of previous studies, which found that organizational health was the key factor for the QWL in studies on the structural model of the QWL [13,33]. The reason is that the present study used OHQ to measure organizational health instead of single items such as presenteeism [13,33] and turnover intention [12] which were found to be the influencing factors of workers' health and the QWL in previous studies. The OHQ is a general organizational health measurement tool developed for healthy workers, and the tool appears to be limited in reflecting characteristics such as value, meaning, and commitment to the changed organization after cancer diagnosis of cancer survivors who returned to work. That is because cancer survivors who returned to work experience changes in the meaning of work and workplace, and changes in values that put themselves as the top priority over work and workplace [2]. Consequently, replicated and expanded studies that use variables such as presenteeism, absence from work, changing jobs, and increased sick leave that can reflect the interest and support of the organization for the health status of cancer survivors who returned to work are necessary in the future.

Research strength and limitation

The present study is the first study that attempted to build a theoretical framework and model of the QWL of cancer survivors who returned to work based on the Culture-Work-Health-Model (CWHM) and has various significances in the field of nursing.

In terms of nursing theories and research, the significance lies in testing the CWHM, which has previously been tested on healthy workers, but now tested on cancer survivors who returned to work and whose social interest and participation are increasing, and establishing a comprehensive model that includes the characteristics of the work environment and human relationship of cancer survivors such as cancer stigma and support from superiors and colleagues. The present study also has its significance in contributing to the expansion of knowledge in the field of nursing in that it prepared a theoretical foundation that can strengthen the grounds of CWHM theory and is also applicable to the QWL of workers with chronic illness such as cancers, in addition to providing basic data to various studies related to cancer patients in the country who are returning to work, which are still in a nascent stage.

In terms of nursing practice, the results of this study will contribute to developing effective approach strategies and intervention programs for cancer survivors' successful return to work. Furthermore, it would be applied in the management of cancer rehabilitation and the quality of life through the return of cancer survivors to workplace and their work, which tends to increase continuously.

The limitations of the present study are as follows.

In this study, we developed a structural equation model of the quality of working life among cancer survivors returning to work. Contrary to the culture-work-health model (CWHM) proposed by Peterson and Wilson [19] and the model used in this study revealed that cancer stigma indirectly affects the quality of working life of cancer survivors. Social support mediates the relationship between cancer stigma and quality of working life by reducing negative stigma toward cancer survivors. In turn, this improves the survivors' quality of working life. The participants of this study were cancer survivors in an extended survival stage, during which their health conditions began to stabilize. As such, the results cannot be generalized to other cancer patients, such as those in different survival stage. This study also found that employee health did not directly affect quality of working life. However, depending on the survival phase of the individual, employee health may have varying degrees of influence. Future studies must thus compare quality of working life models for cancer survivors in different survival and treatment phases to reveal the factors that directly or indirectly affect quality of working life. Moreover, the employee health assessment tools used in this study have limited efficacy for cancer survivors with complex health conditions. The effects of health on quality of working life must be reevaluated with a tool that can effectively assess the complicated health conditions of cancer survivors. Furthermore, the findings of the present study are difficult to generalize to the entire community of cancer survivors who returned to work because the present study was conducted without taking into account the different types of cancer. The present study was a cross-sectional study that investigated the phenomena of the sample from the population in the same period and has limitations in clearly identifying causal relationships among variables included in the model.

Conclusion

The present study identified cancer stigma and social support as statistically significant variables for the QWL of cancer survivors who have returned to work, of which, social support was found to have greater explanatory power, and these variables explained 43.1% of QWL. On the other hand, paths in which employee health influenced organizational health and organizational and employee health influenced QWL were statistically non-significant, resulting in a rejection of the research hypothesis. Therefore, cancer stigma and support from superiors and colleagues, which were determined to be important factors with direct and indirect influences on the QWL of cancer survivors who have returned to work, may contribute to the exploration and search for measures to improve their QWL. Specifically, they can be used as basic data for preparing promotion and education programs at organizational and social levels, programs to strengthen the sense of a bond with superiors and colleagues—which are social support resources in the organization—and preparation of measures that can increase the self-efficacy and resilience of cancer survivors to reduce cancer stigma and strengthen the support system of superiors and colleagues. Ultimately, not only their QWL but also their overall quality of life will be influenced by this.

Author contributions

All authors participated in designing the study. J.J.H. carried out statistical analysis and wrote the manuscript. L.E.J. supervised the statistical design, interpretation results and wrote the manuscript.

Conflict of interest

All the authors report no conflicts of interest relevant to this article.

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References

1. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA A Cancer J Clin. 2018;68(6):394–424. https://doi.org/10.3322/caac.21492
2. Mehnert A, de Boer A, Feuerstein M. Employment challenges for cancer survivors. Cancer. 2013;119(S11):2151–9. https://doi.org/10.1002/cncr.28067
3. de Jong M, Tamminga SJ, de Boer AG, Frings-Dresen MH. Quality of working life of cancer survivors: development of a cancer-specific questionnaire. J Cancer Surviv. 2016;10(2):394–405. https://doi.org/10.1007/s11764-015-0485-4
4. Shim HY, Lee CW, Yu ES, Park BY, Yang EJ. Cancer survivors and returning to work perspectives from occupational health physicians in Korea. J Korean Med Sci. 2019;34(11):e98. https://doi.org/10.3346/jkms.2019.34.e98
5. So HS, Chae MJ, Kim HY. Reliability and validity of the Korean version of the cancer stigma scale. J Korean Acad Nurs. 2017;47(1):121–32. https://doi.org/10.4040/jkan.2017.47.1.121
6. Park JH. Intervention strategy for cancer survivors' employment. Ann Occup Environ Med. 2014;53:128–30. Korean.
7. de Jong M, Tamminga SJ, van Es RJ, Frings-Dresen MH, de Boer AG. The quality of working life questionnaire for cancer survivors (QWLQ-CS): factorial structure, internal consistency, construct validity and reproducibility. BMC Cancer. 2018;18(1):66–79. https://doi.org/10.1186/s12885-017-3966-1
8. Kanten S, Sadullah O. An empirical research on relationship quality of work life and work engagement. Procedia Soc Behav Sci. 2012;62:360–6. https://doi.org/10.1016/j.sbspro.2012.09.057
9. Peterson M, Wilson JF. A culture-work-health model: a theoretical conceptualization. Am J Health Behav. 1998;22(5):378–90.
10. Jin JH, Lee EJ. Factors Influencing of quality of working life of cancer survivors after returning to the workplace. Korean J Occup Health Nurs. 2018;27(4): 203–14. https://doi.org/10.5807/kjohn.2018.27.4.203. Korean.
11. Brown Johnson CG, Broadsky JL, Cataldo JK. Lung cancer stigma, anxiety, depression, and quality of life. J Psychosoc Oncol. 2014;32(1):59–73. https://doi.org/10.1080/07347332.2013.855963
12. Lee E, Jang I. Nurses' fatigue, job stress, organizational culture, and turnover intention: a culture–work–health model. West J Nurs Res. 2020;42(2): 108–16. https://doi.org/10.1177/0193945919839189
13. Park JH, Cho YS, Lim SR. Analysis of factors affecting the quality of work life of dental hygienists based on the culture-work-health model. J Den Hyg Sci. 2018;18:32–41. https://doi.org/10.17135/jdhs.2018.18.1.32
14. Yang KM, Chae MJ, So HS. Stigma and distress among cancer patients: the mediating effect of self-blame. Korean J Adult Nurs. 2018;30(1):89–97. https://doi.org/10.7475/kjan.2018.30.1.89. Korean.
15. Cho J, Smith K, Choi EK, Kim IR, Chang YJ, Park HY, et al. Public attitudes toward cancer and cancer patients: a national survey in Korea. Psycho Oncol. 2013;22(3):605–13. https://doi.org/10.1002/pon.3041
16. Jang BY, Park JY. Subjective health status, mental health, and cancer stigma in long-term cancer survivors after gastric surgery. Asian Oncol Nurs. 2018;18(2): 86–93. https://doi.org/10.5388/aon.2018.18.2.86. Korean.
17. Taskila T, Lindbohm ML, Martikainen R, Lehto US, Hakanen J, Hietanen P. Cancer survivors received and needed social support from their work place and the occupational health services. Support Care Cancer. 2006;14(5):427–35. https://doi.org/10.1007/s00520-005-0005-6
18. Torp S, Nielsen RA, Gudbergsson SB, Dahl AA. Worksite adjustments and work ability among employed cancer survivors. Support Care Cancer. 2012;20(9): 2149–56. https://doi.org/10.1007/s00520-011-1325-3
19. Peterson M, Wilson JF. The culture-work-health model and work stress. Am J Health Behav. 2002;26(1):16–24. https://doi.org/10.5993/AJHB.26.1.2
20. Earnshaw VA, Quinn DM, Park CL. Anticipated stigma and quality of life among people living with chronic illnesses. Chronic Illn. 2012;8(2):79–88. https://doi.org/10.1177/1742395311429393
21. Kim YS, Tae YS. A Predictive model of quality of life for stomach cancer patients with gastrectomy. Korean J Adult Nurs. 2015;27(6):613–23. https://doi.org/10.7475/kjan.2015.27.6.613. Korean.
22. Duska LR, Dizon DS. Improving quality of life in female cancer survivors: current status and future questions. Future Oncol. 2014;10(6):1015–26. https://doi.org/10.2217/fon.13.249
23. House JS, Umberson D, Landis KR. Structures and processes of social support. Annu Rev Sociol. 1988;14(1):293–318. https://doi.org/10.1146/annurev.so.14.080188.001453
24. Kim JE, Yu GC. A Study on conceptual model of organizational health and development of its measurement (OHQ) and construct validation. Korea Manag Rev. 2014;43(6):1875–904. Korean.
25. Cockerham WC, Ruetten A, Abel T. Conceptualizing contemporary health lifestyles: moving beyond Weber. Sociol Q. 1997;38(2):321–42. https://doi.org/10.1111/j.1533-8525.1997.tb00480.x
26. Raykov T, Marcoulides GA. On multilevel model reliability estimation from the perspective of structural equation modeling. Struct Equ Model. 2006;13(1): 130–41. https://doi.org/10.1207/s15328007sem1301_7
27. Mullan F. Seasons of survival: reflections of a physician with cancer. N Engl J Med. 1985;313(4):270–3. https://doi.org/10.1056/NEJM198507253130421
28. Hedayati E, Johnsson A, Alinaghizadeh H, Schedin A, Nyman H, Albertsson M. Cognitive, psychosocial, somatic and treatment factors predicting return to work after breast cancer treatment. Scand J Caring Sci. 2013;27(2):380–7. https://doi.org/10.1111/j.1471-6712.2012.01046.x
29. Im MS. Employment experience of reemployment nurse in fixed night duty for children's hospital [Unpublished doctoral dissertation]. Busan: Kosin University; 2018 Feb. Korean.
30. House JS. Occupational stress and the mental and physical health of factory workers. Ann Arbor, MI: Institute for Social Research of University of Michigan; 1980. p. 71.
31. Ko JW, Son KA. The moderating effect of social support on the relations between teachers' job stress and job satisfaction, and organizational commitment. J Educ Adm. 2007;25(4):73–94. Korean.
32. Lawston MP, Moss M, Fulcomer M, Kleban MH. A research and service oriented multilevel assessment instrument. J Gerontol. 1982;37(1):91–9. https://doi.org/10.1093/geronj/37.1.91
33. Kim M, Ryu E. Structural equation modeling of quality of work life in clinical nurses based on the culture-work-health model. J Korean Acad Nurs. 2015;45(6):879–89. https://doi.org/10.4040/jkan.2015.45.6.879

34. Im JW, Han IY. Comparison of quality of life on the stage of cancer survivorship for breast and gynecological cancer survivors. Korean J Soc Welf Stud. 2008 Feb;60(1):5–27. Korean.
35. Kim JH, Jang SN. Seafarers' Quality of life: organizational culture, self-Efficacy, and perceived fatigue. Int J Environ Res Public Health. 2018;15(10):2150–60. https://doi.org/10.3390/ijerph15102150
36. Tiedtke CM, de Casterle BD, Frings-Dresen MH, de Boer AG, Greidanus MA, Tamminga SJ, et al. Employers' experience of employees with cancer: trajectories of complex communication. J Cancer Surviv. 2017;11(5):562–77. https://doi.org/10.1007/s11764-017-0626-z
37. Stergiou-Kita M, Pritlove C, Kirsh B. The “Big C”—stigma, cancer, and workplace discrimination. J Cancer Surviv. 2016;10(6):1035–50. https://doi.org/10.1007/s11764-016-0547-2
38. Shen MJ, Hamann HA, Thomas AJ, Ostroff JS. Association between patient-provider communication and lung cancer stigma. Support Care Cancer. 2016;24(5):2093–9. https://doi.org/10.1007/s00520-015-3014-0
39. Lee HJ, Jun SS. Factors related to posttraumatic growth in patients with colorectal cancer. Korean J Adult Nurs. 2016;28(3):247–55. https://doi.org/10.7475/kjan.2016.28.3.247
40. Madera JM, King EB, Hebl MR. Bringing social identity to work: the influence of manifestation and suppression on perceived discrimination, job satisfaction, and turnover intentions. Cult Divers Ethnic Minor Psychol. 2012;18(2):165–70. https://doi.org/10.1037/a0027724
41. LaRocco JM, House JS, French JR. Social support, occupational stress, and health. J Health Soc Behav. 1980;21(3):202–18. https://doi.org/10.2307/2136616
42. Hwang S, Chen N. Health promotion behavior in colorectal cancer patients and general adults. Asian Oncol Nurs. 2016;16(2):94–102. https://doi.org/10.5388/aon.2016.16.2.94

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Research Article

Causal Attributions and Quality of Life of Korean Breast Cancer Survivors

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ABSTRACT

Purpose: The purpose of this study was threefold: to explore the causal attributions of breast cancer, examine underlying factors of the attributes, and determine their relationship to quality of life among Korean breast cancer survivors.

Methods: The study used a descriptive correlational design, which included quantitative survey questionnaires and an open-ended question to complement the study. Three hundred and three breast cancer survivors were recruited from two university hospitals in South Korea, between January and April 2018. The causal attributions were explored using the Illness Perception Questionnaire Revised and an open-ended question. The survivors' quality of life was assessed using the Functional Assessment of Cancer Therapy for Breast Cancer. The quantitative analysis was performed using the SPSS 25.0 software package; the ATLAS.ti 8 software was used for thematic analysis.

Results: Quantitative and qualitative data of 321 and 238 breast cancer survivors, respectively, were analyzed. “Stress and worry” and “diet or eating habits” were believed to be the two most likely causes of breast cancer. Eleven new causal attributes emerged from the analysis. Being diagnosed with breast cancer at an older age ($p < .05$), having received chemotherapy ($p < .05$), and holding nonbehavioral causal attributes ($p < .001$), were significantly related to lower quality of life.

Conclusion: There were differences between the survivors' beliefs on their causes of disease, and causal factors available from the literature. As the survivors' causal attributes were significantly related to their quality of life, healthcare providers should individually assess and incorporate these attributes into their care.

Introduction

Breast cancer is by far the most commonly diagnosed cancer in women [1]. Although the global incidence of breast cancer has declined from 25.1% in 2012 to 11.6% in 2018, it is still ranked second after lung cancer, by a small margin [1,2]. During the same period, the global mortality has declined from 14.7% to 6.6%, raising the number of breast cancer survivors [1,2]. In 2017, similar to global trends, breast cancer ranked second among new cancer cases in Korean women [3]. The average increase rate in yearly new diagnosis of breast cancer is 4.6%, whereas other cancers (e.g., stomach, colon, liver, thyroid, cervical) show decreases in average yearly diagnosis rates [3]. The five-year and 10-year breast cancer survival rates are 93.2% and 87.7%, respectively [3]. This diagnosis rate is higher than other cancers, including stomach cancer (74.6% and 66.8%) and cervical cancer (80.2% and 77.2%) [3]. This trend implies that the population living with breast cancer is increasing and will continue to increase [3]. The management of physical and psychosocial symptoms, caused either by breast cancer or therapy, have therefore gained particular importance [4].

According to Weiner's attribution theory, the understanding of the cause of a phenomenon influences the future expectations,

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related emotions, and behavioral motivation [5]. The theory includes the three properties of locus, stability, and controllability [5,6]. Locus refers to where a person believes the causes are from (internal vs. external) [6]. Stability refers to whether a person believes the causes are changeable (stable vs. unstable) [6]. Lastly, controllability refers to whether a person believes the causes are in their control [6]. Based on these properties, a person perceives causal attributions [6]. The theory propounds that individual's perceived causal attribution is more important in shaping personal experiences of a certain life event than the understanding of the real cause [7]. Therefore, the attribution theory is often used to understand individual attitudes and perceptions related to disease [8], motivation, and compliance to treatments [7,9].

The causal attributes of cancer survivors have been studied among people with childhood cancer [10], lung cancer [11] and breast cancer [12,13]. In particular, causal attribution was found to be associated with the fear of cancer recurrence and psychological well-being in women with breast cancer [12]. Therefore, the understanding of individual causal attributes is believed to be helpful in providing nursing education and psychological support [13]. A study conducted in Australia reported that many of the women in that cohort attributed their breast cancer to stress, chance or bad luck, and aging [12]. Similar findings were found in a study conducted in France, which reported stress, genetic causes, hormones, and poor diet as the four most possible causes of breast cancer [13]. However, relatively few studies have been conducted in Asian countries.

Based on Bernard Weiner's attribution theory and the aforementioned studies, we hypothesized that causal explanations influence individuals' overall emotions and behaviors, which consequently influence overall quality of life (QoL). Considering that Korea is an Asian country with a high incidence of breast cancer [14], it would be meaningful to explore the causal attributes of breast cancer and their associations with QoL. This study aimed to 1) explore causal attributes of breast cancer among Korean breast cancer survivors, 2) examine underlying factors of causal attributes, and 3) determine the relationships between causal attributes and the survivors' QoL. Weiner's attribution theory underpinned our study. The three properties of causal attributes were explored through the first aim. The property of controllability was examined in detail through the second aim. The influence of attributes on a person's disease experience was explored through the third aim.

Methods

Study design

The study used a descriptive correlational design, which included quantitative survey questionnaires and an open-ended question. After answering a list of quantitative survey questionnaires, the participants were asked to describe the three most likely causes of their breast cancer in their own languages. This triangulation was used for the first aim of the study: to achieve comprehensive data of the causal attributes of breast cancer among Korean survivors (i.e., a relatively less frequently studied population) and to identify any new or culturally specific causal attributes that were not included in the quantitative questionnaire [15,16].

Sample and settings

Breast cancer survivors were recruited from the two university hospitals in South Korea between January and April 2018, using a convenience sampling method. The data collection of each participant was done on the day of recruitment. The two university hospitals were chosen as they were major hospitals of the authors' affiliated university. Both hospitals were private university hospitals with over 500- and 800-bed capacities, respectively. The sample size was calculated based on the multiple regression, using the G*Power 3.1.9.2 analysis software [17]. A sample size of 296 was suggested for this study, with a power of .80, alpha level of .05, and an effect size of .30. We recruited 330 participants based on the rate of discontinuation of follow-up among cancer survivors, reported in a previous study [18]. This sample size was adequate for the exploratory factor analysis (EFA), another analytic method used in this study [19]. Female breast cancer survivors who could read, speak, and understand the Korean language, and voluntarily signed the informed consent form, were included in the study. Breast cancer survivors with stage 4 cancer or diagnosed cognitive impairments were excluded from the study.

Data collection

This cross-sectional study was approved by the Institutional Review Board of the authors' affiliated institution (Approval no. XC17QEDI0080S). The research team consisted of the project investigator and two research assistants who visited each of the two hospitals two days a week. The research assistants were graduate-level nursing students who do not work in the participating hospitals. The study was explained to the collaborating physicians of breast cancer outpatient units. They were asked to hand out study advertisement leaflets to the survivors who visit their office and meet the inclusion criteria of the study. Once the survivors complete their physician visits, the research assistants guided them to a separate room. To minimize the response bias, the survivors learned more about the study, signed informed consent, and answered the 10-minute length study questionnaires without the presence of their healthcare providers.

A total of 165 participants were enrolled from the first hospital and 168 from the second hospital. For the validity of the study, the six participants from each hospital who missed over 10% of the total questions were excluded from the study [20]. The missing data of the remaining participants' were assessed for missing at randomness, and all analyses were conducted with full information maximum-likelihood estimation [21]. Data from 159 and 162 participants of each hospital were included in this study.

Study instruments

A total of 12 items were based on demographic (e.g., age and region) and disease-related factors (e.g., breast cancer stage and treatment). The causal attributes of breast cancer were assessed using the “causes” dimension of the Illness Perception Questionnaire Revised (IPQ-R) [22]. The dimension has a list of 18 possible causes of illness (e.g., stress, hereditary, diet or eating habits) and a free text section to state the three most important factors that they believe have caused the illness. The 18 items were rated from “strongly disagree” to “strongly agree.” For the purposes of this study, we scored each item based on an article [23] from the IPQ-R scoring guideline [24] as follows: “strongly disagree” = 1; “disagree” = 2; “neither agree nor disagree” = 3; “agree” = 4; “strongly agree” = 5. The Korean version of IPQ-R [24] demonstrated a Cronbach's α of .87. The “causes” dimension analyzed in this study demonstrated a Cronbach's α of .85. In addition to these quantitative questions, the participants were asked to describe the three most possible causes of their breast cancer in plain language. This open-ended question was asked to explore how participants described the causal attributes in their own language and to identify any new causal attributes that were not included in the IPQ-R.

The participant's QoL was measured using the Functional Assessment of Cancer Therapy for Breast Cancer (FACT-B) [25]. It has 37 items scored on a five-point Likert scale. The FACT-B has five subscales: physical sense of well-being assessed from seven items (score range: 0–28), social well-being from seven items (score range: 0–28), emotional well-being from six items (score range: 0–24), functional well-being from seven items (score range: 0–28), and breast cancer–specific well-being from 10 items (score range: 0–40). The Korean version of the FACT-B was used in this study; it demonstrated a Cronbach's α of .73.

Data analysis

The SPSS 25.0 statistical software package (IBM Corp., Armonk, NY, USA) was used to analyze quantitative data. The ATLAS.ti 8 software package (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to analyze the qualitative data from the IPQ-R "causes" dimension. The participants' demographic and disease-related factors were analyzed using descriptive analyses. For the first aim of the study, the causal attributes of the participants were analyzed using descriptive analyses and were ranked from the most to the least likely cause. The participants' free text data, explaining their belief on the causal attributes, were analyzed using the thematic analysis of elementary contexts methods [26]. This analytic method was chosen over content analysis as it provides flexibility in coding and better explains the relatively new phenomenon [27]. We followed the analytic process by Braun and Clarke [28]. First, the research team repeatedly read the data to get familiarized. Second, the participants' first, second, and third beliefs on the causes of their breast cancer were coded separately. The 18 causes from the IPQ-R were used as initial codes. Third, any new emergent causes were labeled as new codes and clustered into themes. Fourth, the themes were reviewed and ranked by the number of code occurrences.

For the second aim of the study, EFA was performed to further examine the underlying relationships among causes [29]. The detailed eight steps suggested by Henselmans et al. [30] were used for performing EFA. The Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy and the Bartlett's test of sphericity were used for checking factorability of the data [29]. The KMO exceeded .60 in our study, which meant the data are adequate for performing EFA [29]. The number of factors was decided based on the results of the scree plot, parallel analysis, and an Eigen value of over 1.00 [29,31]. A factor loading cutoff of .40 was applied to this analysis [29]. Finally, the identified item clusters were examined for statistical and clinical/theoretical significance.

Table 1 *Characteristics of the Participants (N = 321).*

Characteristics			Mean ± SD or N (%)
Age (years)			55.56 ± 10.21
Age at diagnosis			52.08 ± 10.04
Years since diagnosis			3.47 ± 3.52
Breast cancer	Stage	0 (DCIS)	7 (2.4)
		1	127 (43.6)
		2	109 (37.5)
		3	40 (13.7)
		4	8 (2.7)
	Type	HR (positive)	75 (26.3)
		HER2 (positive)	33 (12.1)
Current treatment	Type	Hormonal therapy	137 (42.7)
		Chemotherapy	80 (24.9)
		Radiation therapy	38 (11.8)
Past treatment	Surgery	Partial mastectomy	137 (43.4)
		Mastectomy	47 (14.9)
	Hormonal therapy		69 (21.5)
	Chemotherapy		129 (40.2)
	Radiation therapy		143 (44.5)
Quality of life			92.28 ± 21.61

Note. Multiple answers were available on "Current treatment" and "Past treatment" questions. DCIS = ductal carcinoma *in situ*; HER2 = human epidermal growth factor receptor 2; HR = hormone receptor; SD = standard deviation.

To determine the relationships between the causal attributes and the survivors' QoL, the third aim of the study, Spearman's rank-order correlation analyses were performed between each causal attribute and the survivors' QoL. Next, univariate and hierarchical regressions were performed using the identified factors from EFA and demographic and disease-related factors. The independent variables included in the regression were based on previous studies [12,13].

Results

Characteristics of the participants

The participants' demographic and disease-related factors are summarized in Table 1. The mean age of the participants was 55.56 years. Their mean age at diagnosis was 52.08 years, and time since diagnosis was 3.47 years. Most of the participants had stage 1 (43.6%) or stage 2 (37.5%) breast cancer. A total of 26.3% and 12.1% of participants reported having hormone receptor–positive and human epidermal growth factor receptor 2–positive breast cancer, respectively. Many participants were receiving adjuvant hormonal therapy (42.7%). In the course of their treatment, 58.3%, 44.5%, and 40.2% of the participants reported having received surgery, radiation therapy, and chemotherapy, respectively. The participants' total QoL scored 92.28 of 148 (62.4%). The subscores or QoL related to physical well-being was the highest (scored 20.33 of 28; 72.6%) and breast cancer–specific QoL was the lowest (scored 22.53 of 40; 56.3%).

Causal attributes of breast cancer (aim #1)

Quantitative data. The causal attributes of breast cancer are presented in Figure 1. The top five most likely causes of breast cancer, as per the participants' beliefs were "stress or worry" (3.95 ± 1.01; mean ± standard deviation), "diet or eating habit" (3.41 ± 1.04), "altered immunity" (3.38 ± 1.06), "over work" (3.38 ± 1.03), and "poor medical care in my past" (3.37 ± 1.13). The least five causes that participants indicated were "accident or injury" (1.87 ± 0.94), "smoking" (1.94 ± 1.06), "alcohol" (2.12 ± 1.14), "a germ or virus" (2.45 ± 0.98), and "hereditary" (2.64 ± 1.27). The variation in participants' responses was highest for "hereditary" and lowest for "accident or injury."

Qualitative data. A total of 238 participants provided answers to the open-ended question on their belief on the causal attributes. A total of 16 of 18 causes from the IPQ-R appeared (i.e., causes "a germ or virus" and "my own behavior" did not appear in qualitative data). The first and second most frequently mentioned causal attributes of breast cancer were similar to that of quantitative data, which were "stress or worries" and "diet or eating habits." "Stress or worries" was mentioned 177 times (29.8% of all codes). "Diet or eating habits" was mentioned 79 times (13.3%). "Poor medical care in my past" was the third most frequently mentioned (8.2%), "hereditary" and "my personality" were the fourth (5.7%), and "overwork" was the fifth (5.0%).

In addition to the causes from the IPQ-R, 11 causes were newly identified from the participants' responses constituting 11.6% of all codes. Some of the participants thought that they had breast cancer because their body was too cold or was born to be weak ("physical constitution"). The use of medication, including hormonal

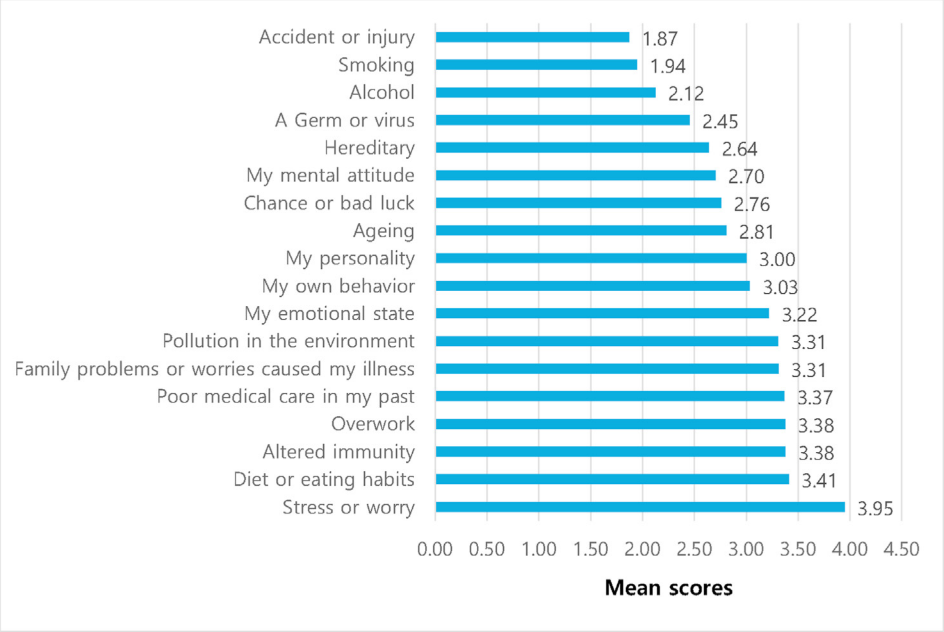

Figure 1. Causal attributes of breast cancer.

Table 2 *Factors of the Top 10 Causal Attributes.*

Rank	Causes	Factor 1: nonbehavioral	Factor 2: behavioral	Communalities
8	My emotional state	**.76**	.11	.59
6	Family problems or worries	**.69**	.19	.51
1	Stress or worry	**.65**	.12	.44
3	Altered immunity	**.62**	.06	.39
4	Overwork	**.58**	.34	.46
10	My personality	**.57**	.23	.38
7	Pollution in the environment	**.46**	.31	.33
5	Poor medical care in my past	.14	**.83**	.72
9	My own behavior	.18	**.79**	.66
2	Diet or eating habits	.18	**.78**	.63
Variance (%)		37.0	13.1	
Cronbach's α		.76	.77	

Note. Bolded values indicate the larger factor loadings.

Table 3 *Bivariate Correlations between Causal Attributes and Quality of Life.*

Variables	Spearman's correlation	Variables	Spearman's correlation
1. Stress or worry	−.156 (.005)	10. Family problems or worries	−.253 (<.001)
2. Hereditary	−.037 (.511)	11. Overwork	−.183 (.001)
3. A germ or virus	−.154 (.006)	12. My emotional state	−.327 (<.001)
4. Diet or eating habit	−.119 (.033)	13. Aging	−.179 (.002)
5. Chance or bad luck	−.167 (.003)	14. Alcohol	−.082 (.142)
6. Poor medical care in my past	−.177 (.001)	15. Smoking	−.089 (.112)
7. Pollution in the environment	−.120 (.032)	16. Accident or injury	−.138 (.013)
8. My own behavior	−.133 (.017)	17. My personality	−.244 (<.001)
9. My mental attitude	−.293 (<.001)	18. Altered immunity	−.084 (.134)

replacement and oral contraceptives, was mentioned as possible causes (“medication”). Some believed that being overweight or obese caused breast cancer (“weight”). The exposure to electromagnetic radiation and chemicals from the working and living environments (“exposure”), not having breastfed their child, or breastfeeding for a short period (“breast feeding”) were believed to cause their breast cancer. “Fatigue” and “anger” were often mentioned as the causes of breast cancer. Some of the survivors attributed their breast cancer to being nulliparous or a past experience of abortion (“pregnancy”). Low-quality sleep from doing night shifts, irregular sleeping hours, and lack of sleep were another causal attributes of breast cancer (“sleep disturbances”). One participant each attributed breast cancer to her doctor not providing adequate screening tests (“screening tests”) and to diabetes (“another illness”), respectively.

Factors of causal attributes (aim #2)

The initial analysis including all 18 causes yielded five factors. The causes “aging” and “chance or bad luck” had very low loading and was excluded from the analysis. Factors 4 and 5 comprised two and one cause, respectively; this was unfavorable for EFA (Each factor is recommended to have at least three items). Moreover, the reliability of factor 4 was .52, which was also unfavorable for EFA. Therefore, we decided to limit the factor analysis to the top 10 causes that the participants indicated as the cause of breast cancer (Table 2).

The KMO Measure of Sampling Adequacy of these 10 causes was .814. The Bartlett's test of sphericity was significant ($X^2 = 818.52$, $p < .001$). The communality of the items ranged between .33 and .72; two factors were determined with Eigen values of 3.70 and 1.31, each. As the value of the component matrix was − .43, orthogonal varimax rotation was performed (Values less than .50 are considered orthogonal) [29].

Factor 1 was labeled “nonbehavioral” causes. Factor 2 was labeled “behavioral” as it included the following causes: “poor medical care in my past,” “my own behavior,” and “diet or eating habits.” The Cronbach's α of factors 1 and 2 were .76 and .77.

Relationships between causal attributes and the QoL (aim #3)

Table 3 demonstrates the correlations between each of the 18 causal attributes and the survivors' QoL. Except for the causal attributes of heredity, alcohol, smoking, and immunity, the other causal attributes showed statistically significant negative correlations to QoL. The relationships between the identified factors from EFA and the survivors' QoL are shown in Table 4. The findings of univariate analysis showed that the survivors' year since diagnosis ($F = 1.58$, $p = .029$), having advanced cancer ($F = 11.37$, $p < .001$), factor 1 (nonbehavioral causal attributes) ($F = 1.84$, $p = .012$), and factor 2 (behavioral causal attributes) ($F = 2.00$, $p = .029$), were significantly related to their QoL.

The first model of hierarchical regression, which included demographic factors, explained 3.1% of the variance in the overall QoL among breast cancer survivors. However, it was statistically insignificant. The entry of identified factors from EFA explained an additional 12.0% of the variance in the overall QoL (R^2 change = .11; $R^2 = .15$, $p < .001$). Having received chemotherapy in the past continued to be significantly related to the overall QoL in both models 1 ($\beta = -.15$, $p = .049$) and 2 ($\beta = -.15$, $p = .040$). In addition, the participants' age at diagnosis ($\beta = -.14$, $p = .013$) and factor 1 (nonbehavioral causal attributes) ($\beta = -.30$, $p < .001$) were significant factors in model 2.

Discussion

In this study, the causal attributes of breast cancer and their relationships to the survivors' QoL were examined among Korean breast cancer survivors. The differences between breast cancer survivors' beliefs on the causes of breast cancer and causal factors available from experts and the literature were noted from the study findings. The causal factors of breast cancer, which are supported by convincing evidence in the literature include both, nonbehavioral (e.g., age and genetics) and behavioral (e.g., physical inactivity, alcohol consumption, and shorter duration of breast feeding) factors [32,33]. In this study, however, the cause “aging” ranked 11th, “hereditary” ranked 14th, and “alcohol” ranked 16th among the 18 causal attributes. The most of the survivors reported “stress or worry” (ranked 1st) or “diet or eating habits” (ranked 2nd) to be the cause of their breast cancer. This finding was consistent with that of a qualitative study that explored causal attributes among Chinese American, Korean American, and Mexican American breast cancer survivors [34]. The three common causal themes were stress, diet, and fatalism [34].

On the contrary, the findings in previous studies with predominantly Caucasian participants were different. In a study on 322 breast cancer survivors in Canada, the most frequently mentioned cause of breast cancer was stress (42.2%), while diet (15.5%) was relatively less mentioned [35]. Similarly, a systematic review on 22 studies, mostly conducted in Western countries, reported stress, family history, and fate as being the most possible causes of cancer, while life style factors (e.g., diet and physical activities) were reported to be less possible [12]. Individual beliefs on health and behaviors are frequently reported to be influenced by culture [34]. Therefore, to provide personalized and effective nursing care, individual cultures and beliefs need to be considered [5,35].

The newly identified causal attributes may be interpreted as unique beliefs of Asian and, particularly, Korean breast cancer survivors. These findings supplement the aforementioned findings from the quantitative analysis by providing causal attributes

Table 4 *Related Factors of Breast Cancer Survivors' Quality of Life.*

Variables	Univariate analysis		Hierarchical regression analysis							
			Model 1				Model 2			
	F	*p*	B	SE (B)	β	*p*	B	SE (B)	β	*P*
(Constant)			102.75	6.98		<.001	144.51	9.43		<.001
Age at diagnosis	1.21	.201	−0.21	0.12	−.10	.084	−0.30	0.12	−.14	.013
Year since diagnosis	1.58	.029	0.46	0.39	.08	.230	0.49	0.36	.08	.178
Advanced cancer (Stage 3,4)	11.37	<.001	1.63	1.54	.06	.288	1.66	1.45	.06	.252
Surgery for breast cancer (Yes)	0.02	.881	0.34	3.52	.01	.924	0.13	3.32	.00	.968
Hormonal therapy for breast cancer (Yes)	0.99	.321	3.17	3.47	.06	.361	2.72	3.27	.05	.406
Chemotherapy for breast cancer (Yes)	2.54	.113	−6.60	3.35	−.15	.049	−6.52	3.15	−.15	.040
Radiation therapy for breast cancer (Yes)	0.27	.605	0.70	3.43	.02	.838	0.38	3.24	.01	.907
Factor 1 (nonbehavioral causal attributes)	1.84	.012					−1.34	0.27	−.30	<.001
Factor 2 (behavioral causal attributes)	2.00	.029					−0.57	0.49	−.07	.246
R^2/R^2 change	.319		.03				.15/0.11			
F	—		1.43			.194	5.86			<.001

Note. B = unstandardized coefficients; β = Standardized coefficients; F = univariate analysis of variance; QoL = quality of life; SE = standard error.

through survivors' own words (rather than choosing from predetermined causal options). The causal attributes of “physical constitution” included concepts of yin-yang imbalance (a belief that their body was too cold, and this caused breast cancer) [36]. This belief may be understood from a body–mind–spirit model in health, which provides a holistic understanding of individual health being influenced by personal and environmental traits [37]. The causal attribute of “anger” may be interpreted from the perspective of Hwabyung, a culture-related anger syndrome, in Korea [38]. This syndrome is listed in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition [39]. A cluster of symptoms generated by chronically, mostly culturally, suppressed anger is called the Hwabyung syndrome [38]. This interpretation needs to be further explored, as no previous studies have explored Hwabyung as a risk factor for cancer. On the other hand, several studies have found suppressed anger as a risk factor for cancer [40,41] or have found no relationship between anger and cancer [42]. Additional studies are needed to explain the causal attribute of anger. Considering these newly emerged factors may help to provide culturally sensitive care to survivors [34].

The findings of the exploratory factor analysis showed that many participants attributed their breast cancer to the nonbehavioral factors (e.g., emotional state, family problems, and stress), rather than the behavioral factors (e.g., poor medical care, diet or eating habits). This finding is consistent to the findings of systematic review on causal attributes, which recommended the increase of awareness of lifestyle/behavioral attributes [32]. Many of the behavioral factors (e.g., overweightness, physical activities) reported to be risk factors for breast cancer are also influential factors in cancer recurrence and prognosis [35,43]. Nurses can support healthier lives among survivors life by providing education on these behavioral factors, which include healthy eating and increasing physical activity [44].

Breast cancer survivors with more of nonbehavioral causal attributes reported a lower overall QoL in this study. In previous studies, causal attributes such as emotional states (e.g., depression or anxiety) or personality traits (e.g., neuroticism) have been shown to have significant relationships with the QoL [45]. It is possible that survivors feel hopeless because they believe that their cancer was caused by factors they had no control over or could not change. For instance, studies on women with hereditary breast cancer have reported high levels of tension and depression, which were not easily relieved despite patient education or help from support groups [46]. Considering the QoL for Korean breast cancer survivors has been emphasized because of their relatively higher survival rate and longer life expectancy than other cancer types. Thus, identifying and addressing factors related to their QoL is important [3].

Study limitations

The present study has several limitations. First, more factors related to breast cancer could have been included in the analysis model. Age at menarche, age at first pregnancy, parity, and length of breast feeding are some of the factors related to breast cancer risk factors and prognosis [43]. Collecting and analyzing these data would allow further exploration of possible influences on the survivors' QoL. Second, the study relied on responses of breast cancer survivors. Many of them did not know their specific cancer type (e.g., hormone receptor positive or negative). Because treatments and disease experience vary by tumor subtypes, collection of reliable data is important [47]. Chart reviews may be included in future studies, in addition to participants' response. Third, the study's internal validity may be lower because it asked open-ended questions to explore the causal attributes of the disease soon after asking about the attributes through multiple choice questions. The participants' answers to the open-ended questions could have been affected by the previous multiple choice questions. Fourth, only 74% of the participants who provided quantitative answers for the causal attributes answered an open-ended question and provided qualitative answers regarding the causal attributes. This lower response rate may be explained by the participants' busy outpatient schedules, because survivors often visit multiple providers or receive follow-up tests during their regular visits. Considering that many of the survivors suffer from peripheral neuropathy as a side effect of their treatment, it is possible that it was uncomfortable for survivors to write phrases and sentences. The research assistants could have asked the participants if they needed additional support to answer this open-ended question. Fifth, the generalizability of the study findings is limited, as it included nonrepresentative Korean breast cancer survivors from a limited number of hospitals.

Implications for nursing

Several suggestions emerged for the nursing practices. First, the differences among breast cancer survivors' beliefs on the causes of breast cancer need to be individually assessed and considered in nursing, as they are significantly related to QoL. In particular, special consideration is needed for survivors who believe their cancer is from nonbehavioral causal factors, as they tend to report a poor QoL. Second, more emphasis needs to be placed on behavioral factors. The survivors can benefit from health educations which provide evidence-based information for healthier lifestyles/behaviors. Third, the new causal attributes that emerged from this study may be considered in health care. As beliefs on health and behaviors are influenced by culture, understanding culturally specific factors would be helpful in clinical practices. In this sense, findings of this study can be useful in designing future interventions for this specific population.

Conclusions

This study explored causal attributes among Korean breast cancer survivors. While ranking the 18 causal attributes of the IPQ-R from the most to the least possible, 11 new causal attributes were identified through this study. As seen in previous studies, the most frequently mentioned causal attributes were stress/worry and diet/eating habits. The newly identified causal attributes need to be further explored in future studies, as they might be specific to Korean breast cancer survivors. Special consideration is needed for survivors who were diagnosed with breast cancer at an older age, received chemotherapy, and hold nonbehavioral causal attributes, as they tend to have a lower QoL. The understanding of causal attributes in breast cancer survivors and their correlation with QoL will allow nurses to deliver more efficient care and education to survivors.

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Conflict of interest

The authors declare that they have no conflict of interest.

References

1. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2018;68(6):394–424. https://doi.org/10.3322/caac.21492
2. Torre LA, Bray F, Siegel RL, Ferlay J, Lortet-Tieulent J, Jemal A. Global cancer statistics, 2012. CA Cancer J Clin. 2015;65(2):87–108. https://doi.org/10.3322/caac.21262
3. National Cancer Information Center. Cancer statistics[Internet]. South Korea: National Cancer Information Center; 2020 [cited 2020 Sep 30]. Available from: http://www.cancer.go.kr
4. Yu XQ, De Angelis R, Luo Q, Kahn C, Houssami N, O'Connell DL. A population-based study of breast cancer prevalence in Australia: predicting the future health care needs of women living with breast cancer. BMC Canc. 2014;14:936. https://doi.org/10.1186/1471-2407-14-936
5. Weiner B. Attribution theory, achievement motivation, and the educational process. Rev Educ Res. 1972;42(2):203–15. https://doi.org/10.3102/00346543042002203
6. Maymon R, Hall NC, Goetz T, Chiarella A, Rahimi S. Technology, attributions, and emotions in post-secondary education: an application of Weiner's attribution theory to academic computing problems. PloS One. 2018;13(3):e0193443. https://doi.org/10.1371/journal.pone.0193443
7. Courneya KS, Friedenreich CM, Sela RA, Quinney HA, Rhodes RE, Jones LW. Exercise motivation and adherence in cancer survivors after participation in a randomized controlled trial: an attribution theory perspective. Int J Behav Med. 2004;11(1):8–17. https://doi.org/10.1207/s15327558ijbm1101_2
8. Switzer B, Boysen GA. The impact of religiosity and attribution theory on attitudes toward addiction and cancer. Ment Health Relig Cult. 2009;12(3):241–5. https://doi.org/10.1080/13674670802428449
9. Fardazar FE, Heidari H, Solhi M. Effect of educational intervention based on locus of control structure of attribution theory on self-care behavior of patients with type II diabetes. Med J Islam Repub Iran. 2017;31(1):774–9. https://doi.org/10.14196/mjiri.31.116
10. Vetsch J, Wakefield CE, Doolan EL, Signorelli C, McGill BM, Moore L, et al. 'Why us?' Causal attributions of childhood cancer survivors, survivors' parents and community comparisons - a mixed methods analysis. Acta Oncol. 2019;58(2):209–17. https://doi.org/10.1080/0284186X.2018.1532600
11. Salander P. Attributions of lung cancer: my own illness is hardly caused by smoking. Psycho Oncol. 2007;16(6):587–92. https://doi.org/10.1002/pon.1121
12. Dumalaon-Canaria JA, Prichard I, Hutchinson AD, Wilson C. Fear of cancer recurrence and psychological well-being in women with breast cancer: the role of causal cancer attributions and optimism. Eur J Canc Care. 2018;27(1). https://doi.org/10.1111/ecc.12579
13. Kadhel P, Schuster C, Grossat N, Janky E, Ghassani A. Causal attribution of breast cancer by survivors in French West Indies. J Canc Educ. 2018;33(2):317–20. https://doi.org/10.1007/s13187-016-1096-0
14. Ghoncheh M, Mahdavifar N, Darvishi E, Salehiniya H. Epidemiology, incidence and mortality of breast cancer in Asia. Asian Pac J Cancer Prev. 2016;17(3):47–52. https://doi.org/10.7314/APJCP.2016.17.S3.47
15. Books C, Coody LC, Kauffman R, Abraham S. Night shift work and its health effects on nurses. Health Care Manag. 2017;36(4):347–53. https://doi.org/10.1097/hcm.0000000000000177
16. Fingren J, Lindholm E, Petersén C, Hallén AM, Carlsson E. A prospective, explorative study to assess adjustment 1 Year after ostomy surgery among Swedish patients. Ostomy Wound Manag. 2018;64(6):12–22.
17. Faul F, Erdfelder E, Lang AG, Buchner A. G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behav Res Methods. 2007;39(2):175–91. https://doi.org/10.3758/bf03193146
18. Mathibe LJ. Drop-out rates of cancer patients participating in longitudinal RCTs. Contemp Clin Trials. 2007;28(4):340–2. https://doi.org/10.1016/j.cct.2007.03.006
19. Sapnas KG, Zeller RA. Minimizing sample size when using exploratory factor analysis for measurement. J Nurs Meas. 2002;10(2):135–54. https://doi.org/10.1891/jnum.10.2.135.52552
20. Dong Y, Peng CYJ. Principled missing data methods for researchers. SpringerPlus. 2013;2(1):1–17. https://doi.org/10.1186/2193-1801-2-222
21. Enders CK, Bandalos DL. The relative performance of full information maximum likelihood estimation for missing data in structural equation models. Struct Equ Model. 2001;8(3):430–57. https://doi.org/10.1207/S15328007SEM0803_5
22. Moss-Morris R, Weinman J, Petrie K, Horne R, Cameron L, Buick D. The revised illness perception questionnaire (IPQ-R). Psychol Health. 2002;17(1):1–16. https://doi.org/10.1080/08870440290001494
23. Weinman J, Petrie KJ, Sharpe N, Walker S. Causal attributions in patients and spouses following first-time myocardial infarction and subsequent lifestyle changes. Br J Health Psychol. 2000;5(3):263–73. https://doi.org/10.1348/135910700168900
24. Moss-Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, Buick D. Using and scoring the IPQ-R [Internet]. Norway: University of Bergen; [date unknown] [cited 2020 May 8]. Available from: https://www.uib.no/ipq/.
25. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, et al. The functional assessment of cancer therapy scale: development and validation of the general measure. J Clin Oncol. 1993;11(3):570–9. https://doi.org/10.1200/JCO.1993.11.3.570
26. Miglioretti M, Meroni C, Baiardo G, Savioli G, Velasco V. The perceptions of the causes of cardiac diseases: a taxonomy. Psychol Health. 2018;33(4):537–54. https://doi.org/10.1080/08870446.2017.1380810
27. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. Nurs Health Sci. 2013;15(3):398–405. https://doi.org/10.1111/nhs.12048
28. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. https://doi.org/10.1191/1478088706qp063oa
29. Howard MC. A review of exploratory factor analysis decisions and overview of current practices: what we are doing and how can we improve? Int J Hum Comput Interact. 2016;32(1):51–62. https://doi.org/10.1080/10447318.2015.1087664
30. Henselmans I, Helgeson VS, Seltman H, de Vries J, Sanderman R, Ranchor AV. Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. Health Psychol. 2010;29(2):160–8. https://doi.org/10.1037/a0017806
31. Vivek PH, Singh SN, Mishra S, Donavan DT. Parallel analysis engine to aid in determining number of factors to retain using R [Internet]. Washington: Gonzaga's School of Business; 2017 [cited 2020 May 8]. Available from: https://analytics.gonzaga.edu/parallelengine/
32. Dumalaon-Canaria JA, Hutchinson AD, Prichard I, Wilson C. What causes breast cancer? A systematic review of causal attributions among breast cancer survivors and how these compare to expert-endorsed risk factors. Cancer Causes Control. 2014;25(7):771–85. https://doi.org/10.1007/s10552-014-0377-3
33. Tan MM, Ho WK, Yoon SY, Mariapun S, Hasan SN, Shin-Chi Lee D, et al. A case-control study of breast cancer risk factors in 7,663 women in Malaysia. PloS One. 2018;13(9). https://doi.org/10.1371/journal.pone.0203469
34. Gonzalez P, Lim JW, Wang-Letzkus M, Flores KF, Allen KM, Castañeda SF, et al. Breast cancer cause beliefs: Chinese, Korean, and Mexican American breast cancer survivors. West J Nurs Res. 2015;37(8):1081–99. https://doi.org/10.1177/0193945914541518
35. Charavel M, Bremond A, Moumjid-Ferdjaoui N, Mignotte H, Carrere MO. Attributions of cause and recurrence in long-term breast cancer survivors. Psycho Oncol. 2001;10(2):179–83. https://doi.org/10.1002/pon.497
36. Chien TJ, Song YL, Lin CP, Hsu CH. The correlation of traditional Chinese medicine deficiency syndromes, cancer related fatigue, and quality of life in breast cancer patients. J Tradit Complement Med. 2012;2(3):204–10. https://doi.org/10.1016/S2225-4110(16)30101-8
37. Chan C, Chow E. A body-mind-spirit model in health: an Eastern approach. Soc Work Health Care. 2001;34(3-4):261–82. https://doi.org/10.1300/J010v34n03_02
38. Min SK, Suh SY, Song KJ. Symptoms to use for diagnostic criteria of Hwa-byung, an anger syndrome. Psychiatr Investig. 2009;6(1):7–12. https://doi.org/10.4306/pi.2009.6.1.7
39. Park SC, Park YC. Korea in the diagnostic and statistical manual of mental Disorders, fifth edition. J Kor Med Sci. 2020;35(2):e6. https://doi.org/10.3346/jkms.2020.35.e6
40. Thomas SP, Groer M, Davis M, Droppleman P, Mozingo J, Pierce M. Anger and cancer: an analysis of the linkages. Canc Nurs. 2000;23(5):344–9. https://doi.org/10.1097/00002820-200010000-00003
41. White VM, English DR, Coates H, Lagerlund M, Borland R, Giles GG. Is cancer risk associated with anger control and negative affect? Findings from a prospective cohort study. Psychosom Med. 2007;69(7):667–74. https://doi.org/10.1097/PSY.0b013e31814d4e6a
42. Bruno A, Pandolfo G, Scimeca G, Leonardi V, Cedro C, Racchiusa S, et al. Anger in health, benign breast disease and breast cancer: a prospective case-control study. In Vivo. 2014;28(5):973–7.
43. Abubakar M, Sung H, Bcr D, Guida J, Tang TS, Pfeiffer RM, et al. Breast cancer risk factors, survival and recurrence, and tumor molecular subtype: analysis of 3012 women from an indigenous Asian population. Breast Cancer Res. 2018;20(1). https://doi.org/10.1186/s13058-018-1033-8
44. Scott E, Daley AJ, Doll H, Woodroofe N, Coleman RE, Mutrie N, et al. Effects of an exercise and hypocaloric healthy eating program on biomarkers associated with long-term prognosis after early-stage breast cancer: a randomized controlled trial. Cancer Causes Control. 2013;24(1):181–91. https://doi.org/10.1007/s10552-012-0104-x
45. Van Der Steeg AFW, De Vries J, Roukema JA. Anxious personality and breast cancer: possible negative impact on quality of life after breast-conserving therapy. World J Surg. 2010;34(7):1453–60. https://doi.org/10.1007/s00268-010-0526-0
46. Landsbergen KM, Brunner EG, Manders P, Hoogerbrugge N, Prins JB. Educational-support groups for BRCA mutation carriers satisfy need for information but do not affect emotional distress. Genet Counsel. 2010;21(4):423–37.
47. Al-Naggar RA, Osman MT, Al-Baghdadi N. Study of quality of life and characteristic factors in women with breast cancer undergoing different types of therapy. J Appl Pharmaceut Sci. 2016;6(9):147–52. https://doi.org/10.7324/JAPS.2016.60922

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Research Article

Factors Influencing Supportive Care Needs of Colorectal Cancer Survivors

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SUMMARY

Purpose: There is an increasing number of colorectal cancer survivors in South Korea. However, no research has identified supportive care needs of survivors of colorectal cancer in South Korea. Thus, the purpose of this study was to determine the level of supportive care needs and effects of emotional state and quality of life (QoL) on supportive care needs of colorectal cancer survivors.
Methods: This cross-sectional study was conducted among 115 survivors of colorectal cancer in South Korean who had primary treatment of surgery for colorectal cancer. Data were collected from April to September 2016. Participants responded to self-reported questionnaires assessing supportive care needs, emotional state (Hospital Anxiety and Depression Scale), and QoL (Functional Assessment of Cancer Therapy-Colorectal scale).
Results: The overall score of supportive care needs for colorectal cancer survivors was 1.22 ± 0.61 (full score: 3 points), with health care staff and social support needs garnering highest scores. Approximately, 20.0% and 21.7% of patients had anxiety and depression, respectively. The mean QoL score was 2.90 ± 0.53, with social and family status having the lowest QoL score. Multiple regression analysis showed that both the period after treatment and anxiety significantly influenced supportive care needs.
Conclusion: Appropriate interventions should be used immediately after completion of treatment to help reduce anxiety and meet supportive care needs of colorectal cancer survivors.

Introduction

Colorectal cancer is the second most common cancer in South Korea with a 5-year survival rate of 75.0%, higher than the overall cancer survival rate of 70.4% in South Korea. Early detection of cases and advancement of cancer treatment technology have led to a rise in the number of survivors [1].

Depending on the stage of colorectal cancer, various treatment modalities may be used. However, these treatments can cause irreversible physical changes and result in several consequent problems [2]. The primary treatment for colorectal cancer is surgery. Chemotherapy and radiation therapy can be added depending on the location and stage. Colorectal cancer surgery can lead to long-term sequela such as intestinal adhesions, bowel disorders, and sexual dysfunction. In fact, 71.3% of patients who underwent rectal cancer surgery experienced excessive bowel movement 6–24 months after surgery [3]. Chemotherapy has general side effects such as nausea, vomiting, and alopecia. These side effects eventually disappear on termination of treatment. However, patients who experience peripheral neuropathy after they receive oxaliplatin as standard colorectal cancer chemotherapy after surgery have reduced quality of life (QoL) [4]. Furthermore, patients who undergo radiation therapy show adverse events such as fecal incontinence and sexual dysfunction [5].

As shown in a previous study [6], colorectal cancer survivors experience diverse problems including decreased QoL, limited social lives, negative emotions such as depression and anxiety, and financial difficulties. Compared with their healthy counterparts, colorectal cancer survivors undergo more challenges related to changes in roles at home and societal and financial problems [7]. Furthermore, survivors continue to worry about recurrence [6]. Thus, there is a great need for emotional support for their fear of recurrence [8]. As the number of colorectal cancer survivors

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increases, demands to address late complications, prevent secondary cancer, and address psychosocial problems after the termination of treatment have increased [3]. Interests in the QoL of survivors have also increased [6]. Nevertheless, most health care staff focus on meeting physical needs such as peripheral neuropathy and changes in patient's bowel movement during the treatment period [3].

Supportive care refers to the provision of necessary services for those who are living with cancer or affected by cancer to meet their informational, emotional, spiritual, social, and physical needs [9]. Information needs of cancer survivors are related to treatment, prognosis, rehabilitation, surveillance, body image, and sexuality [10]. Cancer survivors are relieved when treatment is over. However, they remain uncertain of what comes next. Thus, cancer survivors have at least one unmet emotional, spiritual, or social needs [11]. Cancer survivors who have unmet physical needs due to treatment side effects such as fatigue, tingling sensation, and alopecia often experience decreased QoL [12]. To systematically support potential health issues that cancer survivors may experience throughout their lives, both concerns and needs of patients must be accurately identified. Factors influencing supportive care needs must be identified to ensure adequate care for survivors. Good understanding of supportive care needs of a survivor will help us develop an effective supportive care service [9].

Supportive care needs of cancer survivors are influenced by emotional conditions such as anxiety and depression [13]. Actually, colorectal cancer survivors experience clinical meaningful levels of anxiety and depression [14]. Unmet supportive care needs of colorectal cancer survivors have a significant correlation with QoL [15]. Survivor's QoL also changes over time after cancer treatment [6]. Therefore, supportive care needs of colorectal cancer survivors must be studied according to different emotional state and QoL.

Several studies have investigated supportive care needs of colorectal cancer survivors [2,8,15,16]. Continued efforts have been made to manage survivors by developing and implementing multiple programs [17]. However, there is little research on factors influencing supportive care needs of colorectal cancer survivors. In South Korea, management of cancer survivors is one of the national cancer policies [18]. Several studies have been performed by cancer-related societies. However, most of these studies on cancer survivors have focused only on breast cancer survivors [19,20]. Only a few studies have evaluated colorectal cancer survivors [21,22].

Therefore, the purpose of this study was to identify the level of supportive care needs and effects of emotional state and QoL on supportive care needs of colorectal cancer survivors in South Korea. Findings from this study will help us develop programs that address the management of colorectal cancer survivors in South Korea.

Methods

Design

A descriptive survey was conducted to identify supportive care needs of colorectal cancer survivors and determine factors that could influence supportive care needs of colorectal cancer survivors. This cross-sectional survey was performed among 115 Korean colorectal cancer survivors who had primary colorectal cancer treatment.

Sample

Adult patients aged 19 years or older who were followed-up after completing adjuvant therapy (chemotherapy and radiation therapy) after colorectal cancer surgery at S Hospital in C University were analyzed. Of total patients, 116 patients who had either Stage I, II, or III colorectal cancer without recurrence or metastasis were enrolled. Stage IV patients were excluded as many of them continued to receive treatment. Patients who had been diagnosed with another type of cancer, who had previous mental problems, and those who were taking psychiatric medications were also excluded from this study. There was no limitation of patients' survival periods so that the influence of survival period after treatment on supportive care needs could be determined. A total of 116 patients participated in this study. One of them was excluded from the analysis because of incomplete responses.

Sample size

Sample size was computed using the G*power 3.1 software [23]. With a statistical significance of 0.05, a power of 0.8, a medium effect size of 0.15, and seven predictors in multiple regression, the minimum sample size was found to be 103. Considering potential loss to follow-up, 116 patients were enrolled for this study.

Instruments

General and disease-related characteristics

General characteristics included gender, age, education, religion, occupation, and disease-related characteristics including period since treatment, current tumor stage, and treatment status with radiation and chemotherapy.

Supportive care needs

After adapting it for use with colorectal cancer survivors, a 59-item comprehensive assessment tool for needs of cancer patients [24] was used to measure supportive care needs. Content validity was tested by 10 experts (2 colorectal cancer specialists, 4 nurses with more than 10 years of experience managing colorectal cancer patients, and 4 nurses with PhDs). Nine items related to hospice and hospital facilities and four items related to chemotherapy with a content validity index of <0.8 were removed. Hence, only 46 items were assessed. Finalized items were tested on five patients to check for comprehensibility. The finalized tool consisted of five subcategories (10 items on information and education needs, 10 items on psychological needs, 11 items on physical needs, 11 items on health care staff and social support needs, and 4 items on family, interpersonal relationships, religious, and spiritual needs). Each item was scored on a four-point scale (from 0 to 3), with a higher score indicating a higher need. The overall Cronbach's α was .97. Cronbach's α values for those five subcategories were .90, .93, .85, .82, and .92, respectively.

Factors influencing supportive care needs

Emotional state. Emotional state was measured using the Hospital Anxiety Depression Scale (HADS) originally developed by Zigmond and Snaith [25] and standardized in Korean by Oh et al. [26]. The HADS was purchased from Granada Learning Education Group (www.gl-assessment.co.uk). In this 14-item scale, odd-number items measure anxiety, whereas even-number items measure depression. Each item was rated on a four-point scale from 0 (none) to 3 (severe), with a higher score indicating a higher degree of anxiety and depression. A score of 0–7 indicates a state without depression or anxiety. A score of 8–10 indicates mild depression or anxiety and a score of 11–21 indicates moderate or severe depression and anxiety [25]. Cronbach's α values for anxiety and depression were .89 and .86, respectively, in a study of Oh et al. [26]. In the present study, they were .87 and .71, respectively.

QoL. QoL was measured using the Korean version (FACT-C_KOR) of the Functional Assessment of Cancer Therapy-Colorectal (FACT-C) originally developed by Ward et al.[27] after obtaining approval from the original developer FACIT (www.facit.org). The FACT-C contains colorectal cancer-specific items in addition to the FACT-general scale. It was developed to assess cancer survivors. It was translated into Korean by Kim et al.[28]. This 36-item tool measures physical state (7 items), social/family state (7 items), emotional state (6 items), functional state (7 items), other states, and colorectal-specific items (9 items). Each item was rated on a five-point scale from 0 (not at all) to 4 (strongly true), with a higher score indicating a higher QoL. The Cronbach's α of the FACT-C_KOR was .87. It was .91 for the present study.

Data collection

Data were collected from April to September 2016 after obtaining approval from the institution. Disease-related characteristics were obtained from medical records. We reviewed and approached all patients who had completed treatment for colorectal cancer coming to the outpatient clinic for a surveillance visit during the study period. The purpose of this study was explained to patients who met the inclusion criteria. The questionnaire was distributed to patients if they were willing to participate in this study. Participants responded to self-report questionnaires measuring supportive care needs, emotional state, and QoL.

Ethical considerations

This study was approved by the institutional review board (Approval no. KC16QISI0257) at ST. Mary's Hospital in Catholic University. Questionnaires were completed by those patients who provided informed consent. It took about 15 minutes to complete the survey.

Data analysis

Collected data were analyzed using SPSS software 24.0 (IBM Corp., Armonk, NY, USA). Participants' characteristics, supportive care needs, emotional states, and QoL were presented as frequencies and percentages and as means and standard deviations. Differences in supportive care needs, emotional states, and QoL were analyzed with t-test, analysis of variance, and Scheffé test. Relationships among supportive care needs, emotional state, and QoL were examined with Pearson's correlation coefficients. Factors affecting supportive care needs were identified with multiple regression analysis.

Results

Participants' characteristics

Approximately, of the total participants with a mean age of 57.32 years, 57.4% of participants were men. About 55.7% either completed high school or had a lower educational level and 63.5% had a religion. About 71.3% were employed. The mean period after treatment termination was 24.95 months. About 37.4% had Stage III cancer. Approximately, 21.7% of patients underwent radiation therapy, whereas 62.6% received chemotherapy as adjuvant therapy (Table 1).

Supportive care needs

Table 1 presents scores of supportive care needs for the sample population. The mean score was 1.22 of 3. Among subcategories, health care staff and social support needs had the highest score (1.56), followed by information and education needs, family, interpersonal relationships, religious and spiritual needs, psychological needs, and physical needs. Women had a higher score (1.36) of supportive care needs than men (1.11) ($p = .032$). Women also had higher scores for psychological needs than men ($p = .012$). Patients under the age of 50 years had the highest score for information and education needs ($p = .045$). Those who had a religion had a higher score (1.31) ($p = .024$) for the following items: physical needs ($p = .028$); family, interpersonal relationships, religious, and spiritual needs ($p = .001$). For patients with <6 months since treatment completion ($p = .002$), the following needs had the highest scores: information and education needs ($p = .001$), physical symptoms ($p = .007$), and health care staff and social support needs ($p = .032$). Supportive care needs, information and education needs, and physical symptoms were higher for those under 6 months of treatment than those with 6 to 12 months of treatment and those with 25 months or more treatment. Stage II patients had the highest scores for psychological needs ($p = .024$). Patients who received chemotherapy had higher scores for supportive care needs ($p = .044$) and psychological needs ($p = .030$) (Table 1).

Emotional state and QoL

The mean anxiety score was 0.67 of 3. About 13.9% of participants had mild anxiety and 6.1% had moderate anxiety. The mean depression score was 0.73 of 3. Approximately, 15.6% of participants had mild depression and 6.1% had moderate depression (Table 2). The mean QoL score for all patients was 2.90 of 4. Among QoL subcategories, social/family state (2.29) had the lowest score, followed by functional state, other state, emotional state, and physical state (Table 2).

Factors influencing supportive care needs

Supportive care needs were positively correlated with anxiety ($r = .64$, $p = .001$) and depression ($r = .50$, $p = .001$) but negatively correlated with QoL ($r = -.32$, $p = .001$) (Table 3). A multivariate regression analysis including seven independent variables (anxiety, depression, QoL, gender, religion, period after treatment, and chemotherapy) was performed. Gender, religion, period after treatment, and chemotherapy were selected as covariates because overall supportive care needs differed significantly when stratified by these groups. As a result of checking autocorrelation with Durbin–Watson, the assumption of residual independence was fulfilled as it was close to 2 (2.080). As a result of the test of multicollinearity using the tolerance limit and the variation inflation factor (VIF) value, it was found that all variables did not have a multicollinearity problem because the tolerance limit was 0.1 or higher or the VIF value was not more than 10 (tolerance limit: .37~.96; VIF: 1.04~2.73). Results of multivariate regression analysis showed that only the period after treatment ($p = .013$) and anxiety ($p = .001$) were main factors affecting supportive care needs. Regression analysis revealed that the explanatory power of this regression model was approximately 48.0% ($F = 14.26$, $p < .001$; Table 4).

Discussion

An important step in the development of an intervention plan for colorectal cancer survivors is the process of recognizing supportive care needs of colon cancer survivors whose number is growing globally. Supportive care needs may vary based on cultural and social differences. Thus, this study was conducted to examine

Table 1 *Supportive Care Needs According to General Characteristics (N = 115).*

Characteristics	Mean ± SD/N (%)		Supportive care needs	t/F (*p*)	Information, education	t/F (*p*)	Psychological problems	t/F (*p*)	Physical symptoms	t/F (*p*)	Family, friend, religious	t/F (*p*)	Health care staff, social	t/F (*p*)
Gender														
Men	66	(57.4)	1.11 ± 0.55	−2.17 (.032)	1.28 ± 0.76	−1.91 (.059)	0.98 ± 0.73	−2.55	0.70 ± 0.54	−1.46 (.146)	1.05 ± 0.81	−1.92	1.48 ± 0.69	−1.27
Women	49	(42.6)	1.36 ± 0.66		1.56 ± 0.78		1.36 ± 0.84	(.012)	0.86 ± 0.64		1.35 ± 0.81	(.057)	1.66 ± 0.80	(.208)
Age (yr)	57.32 ± 9.56													
≤50	20	(17.4)	1.36 ± 0.63	2.18 (.118)	1.68 ± 0.77	3.19 (.045)	1.37 ± 0.82	1.93	0.70 ± 0.70	0.67 (.513)	1.25 ± 0.72	2.70	1.75 ± 0.68	1.57
51~60	49	(42.6)	1.29 ± 0.64		1.48 ± 0.79		1.21 ± 0.86	(.150)	0.85 ± 0.59		1.35 ± 0.84	(.072)	1.61 ± 0.77	(.212)
≥61	46	(40.0)	1.08 ± 0.54		1.20 ± 0.73		0.98 ± 0.70		0.72 ± 0.53		0.97 ± 0.81		1.42 ± 0.72	
Education														
≤High school	64	(55.7)	1.28 ± 0.63	1.12 (.265)	1.42 ± 0.88	0.26 (.795)	1.24 ± 0.86	1.38 (.170)	0.83 ± 0.58	1.08 (.281)	1.21 ± 0.80	0.53 (.595)	1.63 ± 0.74	1.10 (.272)
≥College	51	(44.3)	1.15 ± 0.57		1.38 ± 0.62		1.03 ± 0.72		0.71 ± 0.60		1.13 ± 0.85		1.47 ± 0.74	
Religion														
No	42	(36.5)	1.05 ± 0.56	−2.28 (.024)	1.22 ± 0.78	−1.88 (.063)	1.01 ± 0.82	−1.33	0.61 ± 0.50	−2.22 (.028)	0.83 ± 0.64	−3.87	1.42 ± 0.69	−1.51
Yes	73	(63.5)	1.31 ± 0.62		1.50 ± 0.76		1.22 ± 0.79	(.187)	0.86 ± 0.62		1.38 ± 0.85	(.001)	1.64 ± 0.76	(.135)
Occupation														
No	33	(28.7)	1.29 ± 0.69	0.78 (.437)	1.45 ± 0.88	0.39 (.697)	1.31 ± 0.85	1.41	0.86 ± 0.69	1.06 (.293)	1.18 ± 0.93	0.03	1.56 ± 0.79	0.00
Yes	82	(71.3)	1.19 ± 0.57		1.38 ± 0.74		1.08 ± 0.78	(.161)	0.74 ± 0.54		1.18 ± 0.78	(.977)	1.56 ± 0.72	(.997)
Period since treatment (mo)	24.95 ± 25.31													
<6	30	(26.1)	$1.56 \pm 0.62^{a,b}$	5.14 (.002)	$1.85 \pm 0.84^{c,d}$	5.61 (.001)	1.44 ± 0.85	2.25	$1.07 \pm 0.63^{e,f}$	4.26 (.007)	1.52 ± 0.77	2.49	1.88 ± 0.68	3.04
6–12	20	(17.4)	1.03 ± 0.54^{a}		1.11 ± 0.64^{c}		1.09 ± 0.83	(.086)	0.56 ± 0.45^{e}		1.00 ± 0.69	(.064)	1.33 ± 0.67	(.032)
13–24	21	(18.2)	1.21 ± 0.50		1.38 ± 0.65		1.16 ± 0.70		0.79 ± 0.56		1.02 ± 0.68		1.57 ± 0.73	
>24	44	(38.3)	1.08 ± 0.60^{b}		1.24 ± 0.74^{d}		0.96 ± 0.76		0.66 ± 0.56^{f}		1.10 ± 0.92		1.44 ± 0.76	
Current stage														
I	42	(36.5)	1.10 ± 0.60	1.64 (.199)	1.33 ± 0.79	1.06 (.351)	0.90 ± 0.78^{g}	3.84	0.66 ± 0.63	1.36 (.262)	0.98 ± 0.89	1.97	1.52 ± 0.72	0.08
II	30	(26.1)	1.36 ± 0.64		1.58 ± 0.75		1.41 ± 0.82^{g}	(.024)	0.89 ± 0.59		1.24 ± 0.81	(.144)	1.58 ± 0.82	(.923)
III	43	(37.4)	1.24 ± 0.58		1.35 ± 0.78		1.19 ± 0.76		0.80 ± 0.53		1.32 ± 0.74		1.58 ± 0.71	
Radiation														
No	90	(78.3)	1.19 ± 0.59	−1.11 (.269)	1.33 ± 0.75	−1.79 (.077)	1.11 ± 0.80	−0.88	0.76 ± 0.57	−0.40 (.693)	1.18 ± 0.80	−.0.08	1.53 ± 0.74	−0.85
Yes	25	(21.7)	1.34 ± 0.65		1.64 ± 0.83		1.27 ± 0.83	(.379)	0.81 ± 0.65		1.19 ± 0.91	(.936)	1.67 ± 0.75	(.399)
Chemotherapy														
No	43	(37.4)	1.07 ± 0.57	−2.04 (.044)	1.27 ± 0.70	−1.41 (.163)	0.93 ± 0.82	−2.20	0.67 ± 0.60	−1.41 (.163)	0.99 ± 0.84	−1.92	1.41 ± 0.72	−1.68
Yes	72	(62.6)	1.31 ± 0.61		1.48 ± 0.81		1.27 ± 0.77	(.030)	0.83 ± 0.58		1.29 ± 0.79	(.057)	1.65 ± 0.75	(.096)
Total			1.22 ± 0.61		1.40 ± 0.78		1.14 ± 0.80		0.77 ± 0.59		1.18 ± 0.82		1.56 ± 0.74	

a–g: Scheffé test: the same letters indicate significant difference.
Note. SD = standard deviation.

Table 2 *Emotional State and Quality of Life of Study Subjects (N = 115).*

Characteristics (items)	Total number of items	Range	Mean ± SD/N (%)
Anxiety	7	0~3	0.67 ± 0.49
Normal			92 (80.0)
Mild			16 (13.9)
Moderate to severe			7 (6.1)
Depression	7	0~3	0.73 ± 0.46
Normal			90 (78.3)
Mild			18 (15.6)
Moderate to severe			7 (6.1)
Quality of life	36	0~4	2.90 ± 0.53
Body condition	7	0~4	3.46 ± 0.61
Social and family status	7	0~4	2.29 ± 0.86
Emotional state	6	0~4	3.17 ± 0.68
Functional status	7	0~4	2.74 ± 0.96
Other factors related to colorectal cancer	9	0~4	2.86 ± 0.61

Note. SD = standard deviation.

supportive care needs and influence factors of colorectal cancer survivors in South Korea.

In this study, health care staff and social support needs had the highest score for supportive care needs, followed by needs for information and education. This was similar to results of Kotronoulas et al. (2017) [8] on patients undergoing treatment for colorectal cancer. Either during treatment or after treatment, information should be obtained by contacting medical staff [29].

In the present study, findings revealed that colorectal cancer survivors had the greatest supportive care needs for health care staff and social support, particularly within 6 months after treatment completion. A potential explanation for this is that patients suddenly have limited opportunities to meet with health care staff after completing their treatment course. Russell et al. (2015) [2] have found that colorectal cancer survivors still desire to have opportunities to frequently consult medical staff regarding their difficulties even after completing their treatment. Thus, it is important for medical staff to discuss follow-up care with patients immediately after treatment completion and monitor patients' needs.

Colorectal cancer survivors also showed a high need for information and education. This need was particularly high among patients aged <50 years and patients who completed treatment within 6 months. These results were similar to those of previous studies reporting that patients aged <55 years and patients who completed treatment within 2 years showed high information and education needs [30]. Showing needs particularly high for those with age <50 years could come from their higher education level and active social economic activity. Furthermore, patients who completed treatment within 6 months were more pressured to manage their health as they have fewer opportunities to meet with medical staff [2]. Currently in South Korea, education for patients undergoing surgery or receiving chemotherapy is covered under insurance. Thus, it is offered frequently. This same education is not offered to cancer survivors, although cancer survivors also desire to receive education [2]. Hence, it would be important to identify such needs, implement relevant education, and ultimately promote insurance reimbursement for education of cancer survivors.

The third highest need identified in this study was related to family or interpersonal relationships and religious and spiritual problems. Patients particularly showed a high need for spousal support. This finding is similar to findings of a previous study reporting that colorectal cancer survivors with spouse have better QoL [31]. Therefore, it would be necessary to include the spouse or family members when educating colorectal cancer survivors so that they can assist these survivors in dealing with problems.

The fourth highest need was psychological need. Women had a higher psychological need than men, similar to findings of a similar study on cancer patients [30]. Furthermore, patients with Stage II cancer had a higher psychological need than patients with Stage I or III cancer. This might be because Stage I patients have less concern for recurrence than Stage II patients. In addition, Stage III patients probably have frequently met with and received support from medical staff while receiving chemotherapy to lower the possibility of recurrence. Among psychological problems, patients particularly had a deep fear about recurrence. Because cancer survivors find it difficult to express their psychological difficulties [32], medical staff should closely monitor these patients.

Colorectal cancer survivors had the least need for physical symptom management. This result is similar to findings of a previous study [2] reporting that patients' physical needs decline after treatment over time. However, survivors had high supportive care needs for hand and feet tingling and reduced sensation. This might be due to the fact that 37.4% of these patients had Stage III cancer and thus received oxaliplatin.

According to our study, about 20.0% of colorectal cancer survivors had moderate or more severe anxiety or depression. This finding was similar to results of a previous study [33], but lower

Table 3 *Correlations Between Supportive Care Needs, Emotional State and Quality of Life (N = 115).*

Variables	Anxiety	Depression	Quality of life
		r(*p*)	
Supportive care needs	.64 (.001)	.50 (.001)	−.32 (.001)
Anxiety		.73 (.001)	−.58 (.001)
Depression			−.64 (.001)

Table 4 *Factors influencing Supportive Care Needs (N = 115).*

Variables	Supportive care needs				
	B	SE	β	t	*p*
(Constant)	10.37	18.89		0.55	.584
Gender	2.01	4.23	.04	0.47	.636
Religion	8.11	4.19	.14	1.93	.056
Period since treatment	−4.03	1.60	−.18	−2.51	.013
Chemotherapy	7.21	4.16	.13	1.73	.086
Anxiety	4.10	0.90	.51	4.54	.001
Depression	1.511	1.00	.17	1.51	.134
Quality of life	0.17	0.14	.11	1.19	.235

$R^2 = .48$; F = 14.26; $p < .001$.

than what was reported in studies on colorectal cancer patients receiving chemotherapy [34,35]. This might be due to differences in study population. Our sample consisted of Stages I–III colorectal cancer patients who had a high potential for being cured. However, the previous study [33] included patients with more advanced cancer with less potential for being cured. Furthermore, our patients probably had a lower incidence of developing negative emotions as they had fewer treatment-related acute symptoms than those who received chemotherapy and had fewer symptoms than those with a more advanced cancer. However, depression and anxiety are among factors that can increase cancer mortality [36]. Therefore, it is important for medical staff caring for survivors to pay attention and endeavor to resolve survivors' psychological problems.

Our participants had better QoL than colorectal cancer patients who received chemotherapy in another study [35] presumably because our participants had fewer chemotherapy-related symptoms. Meanwhile, patients who received chemotherapy had the lowest functional QoL [35], whereas our participants had the lowest social/family related QoL. This is probably due to the fact that survivors who have completed treatment are given less attention and care from family members and other people than those who are currently undergoing treatment.

Our results on relationships among supportive care needs, anxiety, depression, and QoL of colorectal cancer survivors were similar to those of Sakamoto et al.'s study[37], which examined supportive care needs of colorectal cancer patients receiving chemotherapy. Our results were close to those of Santin et al.'s study[15], which suggested that the inability to meet needs of these patients could reduce their QoL. Our results were also similar to a previous study revealing that survivors of Korean breast cancer with QoL problems reported a higher degree of supportive care needs [38]. Thus, satisfying colorectal cancer survivors' supportive care needs could lower their level of depression and anxiety and increase their QoL.

Although it is difficult to compare factors affecting colorectal cancer survivors' supportive care needs because of the lack of relevant studies, one study that investigated colorectal cancer patients receiving chemotherapy [37] found that gender was a major factor that influenced patients' supportive care needs. In contrast, we found that anxiety and the period after treatment were factors that significantly influenced supportive care needs of Korean colorectal cancer survivors. However, in this research, the QoL was not a factor affecting supportive care needs. The reason might be because the QoL of colorectal cancer survivors was not different from that of the general population [39]. As breast cancer survivors with QoL problems show higher levels of unmet needs [38], further studies on the influence of QoL on supportive care needs should be conducted for other types of cancer survivors.

Results of our research were similar to those of previous studies that indicated that patients who completed treatment recently had high supportive care needs [32] and that anxiety was associated with supportive care needs and QoL in breast cancer survivors [40]. Our results were also similar to results of a previous study on factors influencing supportive care needs of breast cancer survivors in South Korea [38]. This means that supportive care needs of cancer survivors may increase immediately after treatment because of anxiety about new changes, although it is believed that supportive care needs are decreased as patients adapt to life [41]. Therefore, a patient's emotional state should be evaluated immediately after treatment. If the patient has a high degree of anxiety, the priority of management should be considered. Support should also be given to patients so that survivors can adapt to life well.

It would be important to recognize the need for survivor management immediately after completion of colorectal cancer treatment. Interventions should be provided to manage survivors' emotional problems such as anxiety. Supportive care needs of colorectal cancer survivors identified in this study could be used as basic data for implementing education and intervention programs for colorectal cancer survivors. This study particularly provides a basis for what needs to be focused on when designing programs for managing survivors in the field of oncology nursing. This research also sets the standard for beginning the management of a survivor. We believe that if there is a growing interest in survivor nursing with an increase in nursing intervention among survivors, the field of oncology nursing will be continuously broadened.

Limitations

This study included a convenience sample of patients in a single institution. Hence, findings of this study have limited generalizability. Furthermore, patients with Stage IV colorectal cancer were excluded. Therefore, additional studies should be performed to further evaluate Stage IV colorectal cancer patients who have completed the treatment.

Conclusion

Colorectal cancer survivors showed the highest need for health care staff and social support. Their supportive care needs were correlated with anxiety, depression, and QoL. The period after treatment and anxiety had significant effects on their supportive care needs. Based on these results, we can infer that interventions that can help reduce anxiety should be provided immediately after treatment completion to meet supportive care needs of colorectal cancer survivors. Eventually, procedures are required at the start of colorectal cancer survivor management to evaluate the emotional state of survivors. This study is the first one that identifies supportive care needs of colorectal cancer survivors in South Korea. Our findings could serve as a basis for developing interventions to address supportive care needs of colorectal cancer survivors.

Conflict of interest

The authors have no conflicts of interest to disclose.

References

1. National Cancer Information Center. Cancer statistics [Internet]. Goyang: National Cancer Information Center; 2017 [cited 2020 Jul 19]. Available from: http://www.cancer.go.kr
2. Russell L, Gough K, Drosdowsky A, Schofield P, Aranda S, Butow PN, et al. Psychological distress, quality of life, symptoms and unmet needs of colorectal cancer survivors near the end of treatment. J Cancer Surviv. 2015;9(3):462–70. https://doi.org/10.1007/s11764-014-0422-y
3. Schlairet M, Heddon MA, Griffis M. Piloting a needs assessment to guide development of a survivorship program for a community cancer center. Oncol Nurs Forum. 2010;37(4):501–8. https://doi.org/10.1188/10.onf.501-508
4. Besora S, Santos C, Izquierdo C, Martinez-Villacampa MM, Bruna J, Velasco R. Rechallenge with oxaliplatin and peripheral neuropathy in colorectal cancer patients. J Canc Res Clin Oncol. 2018;144(9):1793–801. https://doi.org/10.1007/s00432-018-2691-8
5. Neibart SS, Manne SL, Jabbour SK. Quality of life after radiotherapy for rectal and anal cancer. Curr Colorectal Cancer Rep. 2020;16(1):1–10. https://doi.org/10.1007/s11888-019-00448-w
6. Drury A, Payne S, Brady AM. Cancer survivorship: advancing the concept in the context of colorectal cancer. Eur J Oncol Nurs. 2017;29:135–47. https://doi.org/10.1016/j.ejon.2017.06.006
7. Scheele J, Lemke J, Meier M, Sander S, Henne-Bruns D, Kornmann M. Quality of life after sphincter-preserving rectal cancer resection. Clin Colorectal Canc. 2015;14(4):e33–40. https://doi.org/10.1016/j.clcc.2015.05.012
8. Kotronoulas G, Papadopoulou C, Burns-Cunningham K, Simpson M, Maguire R. A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum. Eur J Oncol Nurs. 2017;29:60–70. https://doi.org/10.1016/j.ejon.2017.05.004

9. Hui D. Definition of supportive care: dose the semantic matter? Curr Opin Oncol. 2014;26(4):372–9. https://doi.org/10.1097/CCO.0000000000000086
10. Mayer DK, Nasso SF, Earp JA. Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. Lancet Oncol. 2017;18(1):e11–8. https://doi.org/10.1016/S1470-2045(16)30573-3
11. Geller BM, Vacek PM, Flynn BS, Lord K, Cranmer D. What are cancer survivors' needs and how well are they being met? J Fam Pract. 2014;63(10):E7–16.
12. Ahn S, Jung H, Kim S, Shin SJ, Park CG, Chu SH. Quality of life among Korean gastrointestinal cancer survivors. Eur J Oncol Nurs. 2017;30:15–21. https://doi.org/10.1016/j.ejon.2017.07.002
13. Vodermaier Andrea, Linden Wolfgang. Social support buffers against anxiety and depressive symptoms in patients with cancer only if support is wanted: a large sample replication. Support Care Canc. 2019;27:2345–7. https://doi.org/10.1007/s00520-019-04737-w
14. Catherine EM, Joseph GW, Barbara AG, Paul RH, Bert HO. Mental health outcomes during colorectal cancer survivorship: a review of the literature. Psycho Oncol. 2016;25(11):1261–70. https://doi.org/10.1002/pon.3954
15. Santin O, Murray L, Prue G, Gavin A, Gormley G, Donnelly M. Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors. Eur J Oncol Nurs. 2015;19(4):336–42. https://doi.org/10.1016/j.ejon.2015.01.009
16. Averyt JC, Nishimoto PW. Psychosocial issues in colorectal cancer survivorship: the top ten questions patients may not be asking. J Gastrointest Oncol. 2014;5(5):395–400. https://doi.org/10.3978/j.issn.2078-6891.2014.058
17. Gordon LG, Patrao T, Kularatna S, Hawkes AL. A telephone-delivered multiple health behaviour change intervention for colorectal cancer survivors: making the case for cost-effective healthcare. Eur J Canc Care. 2015;24(6):854–61. https://doi.org/10.1111/ecc.12345
18. Ministry of Health and Welfare. Third term comprehensive national cancer management plan. Sejong: Ministry of Health and Welfare; 2019. p. 29–33. Korean.
19. Park JH, Jung YS, Jung YM. Factor influencing posttraumatic growth in survivors of breast cancer. J Kor Acad Nurs. 2016;46(3):454–62. https://doi.org/10.4040/jkan.2016.46.3.454. Korean.
20. Han SJ, Kim HW, Yoon DS, Kim MR. Quality of life and supportive care needs of back-to-work breast cancer survivors. Kor J Adult Nurs. 2019;31(5):552–61. https://doi.org/10.7475/kjan.2019.31.5.552. Korean.
21. Yang YH. A path analysis on factors influencing second primary cancer screening practices in stomach, colon, and breast cancer survivors. J Kor Acad Nurs. 2014;44(2):139–48. https://doi.org/10.4040/jkan.2014.44.2.139. Korean.
22. Byeon JY, Lee MK, Chung JY, Yoo S, Jeon JY. Exercise participation experiences of colorectal cancer survivors. Asian Oncol Nurs. 2019;19(2):98–105. https://doi.org/10.5388/aon.2019.19.2.98. Korean.
23. Cohen J. Statistical power analysis for the behavioral sciences. 2nd ed. Hillsdale, NewJersey: Lawrence Erlbaum Associates; 1988. p. 407–65.
24. Shim EJ, Lee KS, Park JH, Park JH. Comprehensive needs assessment tool in cancer (CNAT):the development and validation. Support Care Canc. 2011;19:1957–68. https://doi.org/10.1007/s00520-010-1037-0
25. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67(6):361–70.
26. Oh SM, Min KJ, Park DB. A study on the standardization of the hospital anxiety and depression scale for Koreans. J Kor Neuropsychiatr Assoc. 1999;38(2):289–96. Korean.
27. Ward WL, Hahn EA, Mo F, Hernandez L, Tulsky DS, Cella D. Reliability and validity of the functional assessment of cancer therapy-colo-rectal(FACT-C) quality of life instrument. Qual Life Res. 1999;8(3):181–95.
28. Kim H, Yoo HJ, Kim YJ, Han OS, Lee KH, Lee JH, et al. Development and validation of Korean functional assessment cancer therapy-general (FACT-G). Kor J Clin Psychol. 2003;22(1):215–29. Korean.
29. den Bakker CM, Schaafsma FG, Huirne JAF, Consten ECJ, Stockmann HBAC, Rodenburg CJ, et al. Cancer survivors' needs during various treatment phases after multimodal treatment for colon cancer – is there a role for eHealth? BMC Canc. 2018;18:1207. https://doi.org/10.1186/s12885-018-5105-z
30. Burg MA, Adorno G, Lopez ED, Loerzel V, Stein K, Wallace C, et al. Current unmet needs of cancer survivors: analysis of open-ended responses to the american cancer society study of cancer survivors II. Cancer. 2015;121(4):623–30. https://doi.org/10.1002/cncr.28951
31. Kwoun HJ, Shin YH. Impact of bowel function, anxiety and depression on quality of life in patients with sphincter-preserving resection for rectal cancer. J Kor Acad Nurs. 2015;45(5):733–41. https://doi.org/10.4040/jkan.2015.45.5.733. Korean.
32. Wieldraaijer T, Duineveld LA, van Asselt KM, van Geloven AA, Bemelman WA, van Weert HC, et al. Follow-up of colon cancer patients; causes of distress and need for supportive care: results from the ICARE cohort study. Eur J Surg Oncol. 2017;43(1):118–25. https://doi.org/10.1016/j.ejso.2016.08.011
33. Aminisani N, Nikbakht H, Asghari Jafarabadi M, Shamshirgaran SM. Depression, anxiety, and health related quality of life among colorectal cancer survivors. J Gastrointest Oncol. 2017;8(1):81–8. https://doi.org/10.21037/jgo.2017.01.12
34. Alacacioglu A, Binicier O, Gungor O, Oztop I, Dirioz M, Yilmaz U. Quality of life, anxiety and depression in Turkish colorectal cancer patients. Support Care Canc. 2010;18(4):417–21. https://doi.org/10.1007/s00520-009-0679-2
35. Baek YA, Yi MS. Factors influencing quality of life during chemotherapy for colorectal patients in South Korea. J Kor Acad Nurs. 2015;45(4):604–12. https://doi.org/10.4040/jkan.2015.45.4.604. Korean.
36. Batty GD, Russ TC, Stamatakis E, Kivimaki M. Psychological distress in relation to site specific cancer mortality: pooling of unpublished data from 16 prospective cohort studies. BMJ. 2017;356:j108. https://doi.org/10.1136/bmj.j108
37. Sakamoto N, Takiguchi S, Komatsu H, Okuyama T, Nakaguchi T, Kubota Y, et al. Supportive care needs and psychological distress and/or quality of life in ambulatory advanced colorectal cancer patients receiving chemotherapy: a cross-sectional study. Jpn J Clin Oncol. 2017;47(12):1157–61. https://doi.org/10.1093/jjco/hyx152
38. Chae BJ, Lee J, Lee SK, Shin HJ, Jung SY, Lee JW, et al. Unmet needs and related factors of Korean breast cancer survivors: a multicenter, cross-sectional study. BMC Canc. 2019;19(1):839. https://doi.org/10.1186/s12885-019-6064-8
39. Pate Amy, Jan Lowery, Kilbourn Kristin, Blatchford Patrick J, McNulty Monica, Risendal Betsy. Quality of life and the negative impact of comorbidities in long-term colorectal cancer survivors: a population-based comparison. J Cancer Surviv. 2020;11. https://doi.org/10.1007/s11764-020-00876-w
40. Akechi T, Momino K, Miyashita M, Sakamoto N, Yamashita H, Toyama T. Anxiety in disease-free breast cancer patients might be alleviated by provision of psychological support, not of information. Jpn J Clin Oncol. 2015;45(10):929–33. https://doi.org/10.1093/jjco/hyv112
41. Cheng KK, Wong WH, Koh C. Unmet needs mediate the relationship between symptoms and quality of life in breast cancer survivors. Support Care Canc. 2016;24:2025–33. https://doi.org/10.1007/s00520-015-2994-0

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Research Article

Illness Experiences of Adults with Spina Bifida: Protecting the Whole Self

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SUMMARY

Purpose: To understand and describe the illness experiences of adults with spina bifida (SB) which is an incurable birth defect and chronic condition that must be managed throughout life.
Methods: A qualitative study using grounded theory was adopted. Data were collected through individual interviews with 16 adults with SB between 2016 and 2017 in South Korea. All interviews were audiotaped, and the transcribed data were analyzed using constant comparative analysis.
Results: The basic socio-psychological process that underlies the illness experiences of adults with SB was identified as protecting the whole self. This consists of three stages: strict self-concealment, attempting self-disclosure, and balancing between self-concealment and self-disclosure. These stages reveal a process of establishing a firm sense of self by freeing oneself from the shame and stigma of society. Three different patterns of living emerged as a result: living as a non-disabled person, living as a marginal person between non-disabled and disabled, and living as a disabled person.
Conclusion: Adults with SB struggle to protect their whole self while managing their chronic conditions by having to constantly balance between self-concealment and self-disclosure. Intervention for adults with SB needs to be based on the stage of sociopsychological maturation. In the early stage, intervention needs to be focused on self-concealment to help establish a firm sense of self. On the other hand, in the later stage when psychological maturity occurs, an intervention that focuses on self-disclosure would be helpful so as not to be isolated from society.

Introduction

Spina bifida (SB) is a congenital birth defect caused by an incomplete closure of the neural tube and the spine. It is a disease classified as incurable and one that should be managed throughout life as a chronic condition. The prevalence of Koreans with SB has been increasing. The cases have increased from 2.7 SB cases per 10,000 live births between 2005 and 2006 [1] to 8.1 between 2008 and 2014 [2]. The rate of surviving to adulthood has also increased and ranges from 75.0% to 85.0% [3,4], resulting in a proportional increase of adults living with SB.

There are three types of SB: occulta, meningocele, and myelomeningocele. Myelomeningocele is the most serious type. While people with SB occulta and meningocele experience few or no symptoms, those with myelomeningocele experience more symptoms, ranging from mild to severe, including complete paralysis with bladder and bowel dysfunction, an inability to walk, and cognitive impairment. Those with severe symptoms are later exposed to various secondary complications, including pain, urological problems such as renal insufficiency, pressure ulcers, obesity, hypertension, and sexual dysfunctions [5–7]. Management typically begins soon after birth and may include bladder and bowel management regimens. It is reported that about 70% of people with SB have to manage urinary and/or fecal incontinence [8].

During childhood and adolescence, people with SB not only experience difficulties in managing physical symptoms and complications from the disease but also face psychosocial difficulties mainly due to teasing and bullying by their peers, especially at school [9–12]. In addition, most of them have further difficulties

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adapting to school because SB often affects learning abilities related to appropriate developmental tasks. They are also highly dependent on their parents who are often overprotective of their children [12,13], hindering autonomy and independence [14,15].

After becoming an adult, most adults with SB have a hard time establishing and maintaining a normal social life. Although they have learned self-management during childhood and adolescence, they still have various psychological and social problems that come along with managing their physical symptoms [16,17]. They tend to be more isolated and depressed when compared with control groups [18]. Their sexual function is reported to be very low [19−21], and their quality of life is also reported to be low [22,23]. And for those with severe difficulties controlling incontinence or with more severe levels of disability, normal social participation, such as dating, marriage, and employment, is especially restricted [20,24].

In South Korea, there had only been a few studies on this, but that has changed in recent years with research being conducted on children and adolescents to investigate factors affecting self-management [25] and the effectiveness of the bowel management programs [26,27]. Of those, only one study examined the sexual function and quality of life of adults with SB [28]. Also, most studies were conducted using quantitative methods, describing cause and effect or other variables specific to those studies. Thus, a more in-depth and comprehensive understanding of the lives of adults with SB is greatly needed for health professionals to better establish effective patient-centered interventions that could help those affected by this condition lead more productive lives and have a higher quality of life.

One of the advantages of a qualitative-method study is it produces an in-depth and comprehensive understanding of the participants' lives from their own perspectives rather than the researchers'. Among the many different qualitative methods available, grounded theory is based on symbolic interactionism, which is a theoretical approach to understanding the relationship between humans and society [29]. It assumes that people act on the premise of a shared understanding of meaning within their social context. Thus, using a grounded theory method would be very helpful to understand what kinds of problems adults with SB encounter while interacting with others and also how their actions and interactions are influenced by others while solving the problems they encounter. In sum, it would be beneficial to analyze and understand patterns of communication, interpretation, and adjustment between adults with SB and those with whom they interact.

This study used grounded theory to develop an explanatory theory of how adults with SB construct their own social realities by gaining a more substantive, data-driven view of these people. The research question for this study is “What is the adjustment process of the adults with SB?”

Methods

Data collection

To recruit the participants, one of the researchers (first author) explained the purpose of the study to the president of the Korean Spina Bifida Patients Association (KSBPA) and asked her to introduce us to adults with SB who were articulate, reflective, and willing to share their illness experiences with the interviewer. The first two participants were recruited in this way. Then, theoretical sampling [30,31] was used to identify what data were needed to ensure that we had obtained exhaustive information. That is, the decision about what information to collect after the first two participants were interviewed was made by developing codes and categories that emerged from the initial analysis. The subsequent participants were recruited using snowball sampling [32], whereby those already in the study recruited other participants from among their acquaintances. In addition, physicians and nurses in an outpatient clinic for SB at one hospital were asked to introduce us to those who they presumed to be the most articulate adults with SB. The researcher contacted eligible participants by telephone. Only one refused to participate in the study due to the fear of privacy infringement.

Data were collected and analyzed between November 2016 and February 2017 in Seoul. Data collection was completed when the theoretical saturation was regarded to be accomplished at the end of the interview with the 16th participant. Among the 16 participants, 8 participants were interviewed in a hospital seminar room on the day of their hospital visit and the remaining participants at their homes. The semistructured interview began with open-ended questions, such as “Can you please tell me about your personal experiences related to your condition?” During the interview, they were encouraged to talk in detail about their experiences in their own terms. The interviewer listened carefully, using prompting questions and nonverbal cues, such as nodding, to obtain free-flow information that is considered to be highly credible. A list of previously prepared open-ended questions was also used to collect data on various issues in more depth. As the data collection and analysis were performed simultaneously, codes and categories that were identified during the initial analysis were used as interview questions in the later stages of data collection. Sociodemographic data were also collected after each interview (Table 1).

The average interview time was 2 hours, ranging from 1 to 4.5 hours. All interviews were audio-recorded and transcribed verbatim. To ensure the accuracy of the transcribed data and to supplement unclear data, follow-up interviews were conducted with all participants at least once by mobile phone or *Kakao Talk*, which is a *WhatsApp*-style messaging service in Korea.

Data analysis

The data were analyzed by two researchers. First, one researcher (first author) analyzed the data. Then, the initial analysis was reviewed by the other investigator, and any discrepancies were discussed and revised. The data were analyzed using constant comparative analysis through inductive processes by comparing consistencies, similarities, and differences. Coding procedures such as open coding, axial coding, and selective coding were used to build a theory from the data [30].

The actual processes were as follows: Open coding was performed after data were obtained from the first and second participants. For open coding, codes and categories were created by comparing relevant similarities and differences. Based on the codes and categories that emerged, more data were collected to examine and develop categories, their properties, and their dimensions. The analysis was expanded by comparing the codes and categories of each participant in this way. Axial coding was then carried out using a paradigm linking related categories to the causal conditions, phenomena, contextual conditions, intervening conditions, action/interaction strategies, and consequences. For selective coding, the core category was identified as *protecting the whole self*. All other categories were then integrated around this core category.

Data saturation in this study was reached after interviewing the 16th participant; by that point, no new information could be obtained, and further coding was no longer feasible.

Table 1 *The Demographic Characteristics of the Participants (N = 16).*

No.	Gender	Age (years)	Marital status	Religion	Occupation	Diagnosis	Urinary incontinence	Fecal incontinence	No. of daily CIC	Ambulation
1	Man	35	Single	Protestant	Self-employed	MMC	No	Yes	5	Wheelchair
2	Man	25	Single	No	College student	MMC	Yes	Yes	3	Walk
3	Man	42	Single	Protestant	Self-employed	LMMC	Yes	Yes	3~5	Walk
4	Man	25	Single	No	Part-time worker	MMC	Yes	Yes	6~8	Walk
5	Man	22	Single	No	College student	LMMC	Yes	No	5~6	Walk
6	Woman	45	Married	Protestant	Full-time worker	LMMC	Yes	Yes	6~7	Walk
7	Woman	21	Single	No	College student	MMC	No	No	8	Walk
8	Man	33	Married	Protestant	Full-time worker	MMC	Yes	Yes	3~4	Walk
9	Woman	25	Single	No	College student	LMMC	Yes	No	6	Walk
10	Woman	33	Single	Catholic	Full-time worker	LMMC	No	Yes	0	Walk
11	Woman	31	Single	No	Graduate student	LMMC	No	No	3~5	Walk
12	Man	25	Single	No	College student	MMC	Yes	Yes	0	Walk
13	Woman	35	Married	Protestant	House wife	MMC	Yes	Yes	4~6	Walk
14	Man	32	Single	No	None	MMC	No	No	4	Walk
15	Man	35	Single	No	None	LMMC	No	Yes	5	Walk
16	Woman	22	Single	Buddhist	Full-time worker	LMMC	No	Yes	4~6	Walk

Note. CIC = Clean intermittent catheterization; LMMC = Lipomyelomeningocele; MMC = Myelomeningocele.

Rigor

To ensure the rigor of this study, we used the qualitative evaluation criteria proposed by Sandelowski [33]. To ensure the credibility of the data, we made an effort to select information-rich participants using theoretical sampling and snowball sampling. Semistructured interviews with open-ended questions, audio-recordings, and verbatim transcriptions of all interviews also helped us to establish credibility. We followed the procedures of grounded theory to ensure the credibility of the analysis and interpretation.

We used memos during the whole process of analysis not only to develop codes and categories but also to identify relationships abstracted on a higher level of analysis in the later coding process. One of the researchers (first author) worked as a nurse teaching self-catheterization to patients with SB and their families for about 10 years and also worked as an outside advisor for the KSBPA. Writing memos on those professional experiences helped raise awareness about the subtleties of meaning within the data. We also used bracketing, which is a method to avoid harmful effects that may taint the research process due to the researchers' prior experiences and preconceptions [34]. In this way, the research process could be rooted solely on the research topic and questions. Credibility in our study was also assured by receiving feedback about the results of the analysis from three participants. Using data saturation to describe the illness experiences as thoroughly as possible also helped ensure credibility.

For fittingness or transferability, we included sociodemographic and medical characteristics of the participants in the report. Thorough descriptions using well-developed categories in multiple contexts helped increase the possibility that the findings would have meaning to other groups or in other contexts. To ensure auditability, we described the data collection and analysis procedures in detail and included quotations from the participants in the findings. Confirmability, which is related to whether the researchers minimized prejudice and maintained neutrality, was secured by establishing credibility, fittingness, and auditability.

Ethical considerations

Before the research was conducted, it was approved by the Research Ethics Review Committee (IRB No H-1611-012-804) at the Seoul National University Hospital where the researchers were employed. One of the researchers approached eligible participants and explained the purpose of the study. The specific goals and procedures of the study were explained to the potential participants in detail, along with assurances of anonymity and privacy. The duration of the interviews and the fact that they would be voice recorded were also explained. The participants were also informed that they were able to discuss their discomfort and withdraw from the study at any time during the interview without any penalty. After providing answers to all questions from the eligible participants, the researchers encouraged them to make a careful, voluntary decision to participate in the study. Before each interview began, written, informed consent was obtained from all participants, and a nominal monetary reward was given to them.

Results

The participants' sociodemographic information is described in Table 1. Nine participants were male. The average age was 30 years, ranging from 22 to 45 years. All but three were single, and nine of them declared no religion. Seven of them reported having an occupation, and six were currently attending college or graduate schools. Regarding medical diagnoses, eight had myelomeningocele, and the remaining eight had a lipomyelomeningocele. Nine participants reported having urinary incontinence and eleven had fecal incontinence. Fourteen participants needed intermittent urethral catheterization, ranging from three to eight times per day. All were able to walk on their own except one, who needed a wheelchair.

As a result of constant comparative analysis, *protecting the whole self* was identified as the core category. It represents a basic sociopsychological process in which adults with SB adjust as they interact with themselves and others (Figure 1). It includes three stages: strict self-concealment, self-disclosure attempts, and balancing between self-concealment and self-disclosure. The double-headed arrows in Figure 1 represent a long-term and complex process of moving back and forth from the previous stage rather than moving forward unilaterally or linearly. The causal conditions were identified as *shame* and *stigma*, and the intervening conditions were *understanding and* support *of others* and *degree of illness and physical deformity*. As a consequence, three patterns of living emerged: *living as a non-disabled person*, *living as a marginal person between non-disabled and disabled*, and *living as a disabled person*.

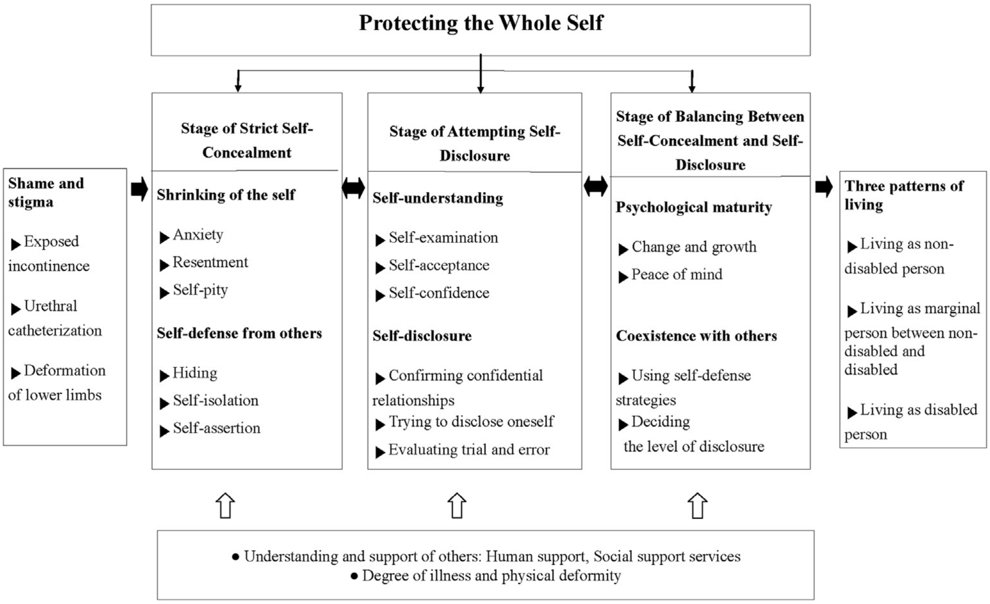

Figure 1. Socio-psychological process of illness experience of adults living with spina bifida.

Causal conditions: Shame and stigma

The causal conditions were caused by exposed incontinence, urethral catheterization, and deformation of the lower limbs. The participants felt shame and stigma for the first time during childhood and adolescence, and these feelings persisted when they became adults. Shame was generated while interacting with themselves; stigma, which causes shame, came from their physical appearance and behaviors. The participants often failed to conceal urinary and fecal soiling, which made them feel ashamed of themselves. They felt more ashamed of fecal soiling than urinary leakage because the odor was not at all controllable. Fecal soiling often occurs at unexpected times, so they are more disheartened by it. One male participant recollected his fecal soiling experiences as follows:

> *I pooped in my pants a lot of times, although I rarely peed in my pants. Whenever I pooped in my pants, I was so embarrassed and cried hard because the kids already knew the weird smell of poop came from me … (Participant 5)*

The participants were also ashamed of urinary catheterization itself. Female participants felt shameful because they had to search for their urethra using a mirror. It was extremely awful for them to accept. Moreover, males felt shame when holding their penis to insert a catheter by themselves. Those who had started catheterization from birth accepted it relatively easily since they had begun to catheterize themselves during puberty. Nevertheless, whenever someone other than family members noticed them using a catheter, it caused them to feel ashamed, even in adulthood. In the case of urinary catheterization during puberty, however, shame or humiliation was even worse. One of the male participants stated his feelings as follows:

> *[Urethral catheterization] was so shameful. I was in puberty at that time, in the second grade of middle school. I was too shy and embarrassed to do it by myself, so my mom helped me. It was so embarrassing for me to have my mother help me with that, and I hated doing it. (Participant 5)*

Deformation of the lower limbs also creates a great deal of shame and stigma. Even after undergoing orthopedic corrective surgery during childhood, most of them were not free from the stares of others because they still limped or wobbled while walking. The most fearful thing for them was to be stigmatized as disabled. Sympathy and help from others are usually regarded as supportive. However, these often provoked more shame because they did not want to be treated as disabled. They often fell into this kind of shameful, paradoxical situation with feelings of nervousness and insecurity.

> *I hated people treating me like a disabled person. I went out to play with my friends, but I honestly didn't use welfare cards or disability cards to get on the subway. The staff at the station told me, noticing my limping, “You can ride with a disability card.” I hated the way they looked at me. (Participant 11)*

Intervening conditions: Understanding and support of others, degree of illness and physical deformity

The intervening conditions that facilitate or hinder the process of *protecting the whole self* were identified as *understanding and supporting others* and the *degree of illness and physical deformity*. A lack of understanding or support from others led to a more intense shrinking of the self and a prolonged stage of self-concealment. The sources of support differed slightly depending on the participants' developmental stage. Until elementary school, family support was important because family members, especially mothers, had taken the lead in managing the participants' conditions, including urethral catheterization. During the school years, teachers and friends were major supporters in managing incontinence and other disabilities. However, in adulthood, colleagues and acquaintances' understanding and recognition became a more important part of their support systems. In addition, public support services, including welfare and health care benefits for the disabled, greatly helped some participants, especially those with economic instability.

The *degree of illness and physical deformity* of the participants also influenced the *process of protecting the whole self*. The worse the symptoms and physical deformity are, the harder those with SB fight to protect their whole self, which is a basic sociopsychological process.

Core category: Protecting the whole self

The core category, *protecting the whole self*, refers to a basic sociopsychological process in which the participants seek to lead a life of personal fulfillment, treating themselves as valuable persons who are not swayed by others, even if they have chronic conditions to manage. *Protecting the whole self* consists of three stages: strict self-concealment, self-disclosure attempts, and balancing between self-concealment and self-disclosure.

Stage of strict self-concealment

This stage is characterized by a period of excessive restraint due to others' cold looks. *Shrinking of the self* and *avoidance of others* were identified as subcategories. This stage can be shortened by understanding and support from colleagues and acquaintances. If the individual has less severe symptoms, he or she is able to endure this stage more easily.

Shrinking of the self. Whenever the participants felt shame due to their exposed incontinence, urethral catheterization, and/or deformation of their bodies, their pride was hurt, and their self-esteem collapsed. They felt negative emotions, such as anxiety, resentment, and self-pity, and had to be vigilant at all times for potentially dangerous situations. For example, male participants, who cannot use urinals like other male friends, could not protect themselves from ridicule even if they could manage their incontinence in a private toilet, and this made them anxious and nervous. Indeed, previous experiences during childhood and adolescence reinforced their negative emotions. One male participant, who had no urinary or fecal incontinence, underwent urethral catheterization four times a day; he explained his experiences as follows:

> *You know, when you go to the restroom, you are subject to teasing by kids. So, I hate revealing my catheterization, thinking what would happen if it were seen by others. I was frightened of it a lot and got stress about being teased. When I was in the second and third year of middle school, I was bullied most severely. At that time, I was teased because I was short, too. (Participant 14)*

All participants were also disappointed when they had learned that the disease could not be cured. They felt a deep sense of grief and often blamed their parents and doctors for the disgrace of being born. In addition to this resentment, they became mired in feelings of self-pity that they were a worthless person who could not marry or get a job in the future.

Self-defense from others. The participants tried to defend themselves, as they were constantly being intimidated by others. Self-defense included hiding, self-isolation, and self-assertion. Hiding can be thought of as either hiding one's body or hiding incontinence products, such as diapers and urinary catheters, so as not to provide any reason for others to tease them and to avoid unwanted attention from others. Self-isolation, unlike hiding, indicates a strategy of distancing themselves from others and shutting themselves off from relationships. It was used whenever they noticed or felt a strange gaze or attitude from someone around them. Self-assertion, which is the act of asserting their own rights and opinions, is identified as an important strategy to defend themselves. For example, the participants actively tried not to lose in quarrels with their peers who were teasing them. It helped them not only to protect their shrunken self, but also to refuse to be intimidated by the stigma from others anymore.

Stage of attempting self-disclosure

This is a stage in which the participants attempted to expose themselves to others to reduce their psychological burden and to escape isolation brought about by self-concealment. It was accomplished by focusing on themselves rather than being conscious of others. This stage typically began in their early twenties, as they transitioned from a strict school life, and better circumstances to deal with their physical conditions unfolded. For example, using toilets had become easier, and college peers did not make fun of the participants even if they had been seen using diapers or performing catheterizations.

Self-understanding. In this stage, the participants moved toward self-understanding through self-examination, self-acceptance, and self-confidence. As they entered their twenties or college life, they were able to escape from the gaze of others. They began to grasp and reflect on the meaning of others' actions toward them. They also realized that adults' reactions to and interest in their urination or wearing of diapers were much different from those of their former adolescent friends. These mature reactions and the indifference of adults served to change their ways of thinking about their condition as well. That is, they realized that it was wise for them to live with their SB like a friend, a lifelong companion, by keeping complications to a minimum even though it was uncomfortable. They accepted themselves as they began to know how to cherish themselves and respect their value as a person. One 25-year-old male participant stated the following:

> *When you look at your face in the mirror, is there anyone out there who cannot accept him or herself? Maybe you wish to look more handsome or beautiful. However, you can never reject yourself! Although it was hard for me to accept that the disease is incurable, I accept my disease as mine. (Participant 4)*

Through self-examination and self-acceptance, their sense of self was protected and their self-esteem improved. As they were empowered further with self-confidence, they began to challenge prejudices and stigma by attempting to reveal themselves to others.

Self-disclosure. Most participants tried to open up to others to reduce their psychological burden, which came from self-concealment. This attempt was made possible by their inner reflections, a restoration of self-esteem, and the mature responses and understanding from others. The participants felt the necessity to disclose themselves primarily to people close to them, such as their roommates in a dormitory. Indeed, they had to open up because they knew that their condition could not be hidden. They were also able to disclose themselves because they felt they had nothing to lose by opening up, and it was bothersome to hide their condition all the time.

In disclosing their conditions and sense of self to others, the participants tried to explain their situations actively, but not openly. That is, the participants narrowed down those to whom they could explain their situations, namely, trusted friends who would keep their confidence. They also tried to give the least amount of information possible when asked by others. Then, they evaluated whether their secrets were maintained; this involved continuously undergoing an internal trial and error process where they evaluated the benefits of disclosing their secrets until they finally mastered the strategies of protective self-disclosure.

Through cautiously opening up, they began to make a few friends with whom they could get along.

> *I told my friend that I was urinating with a catheter. He was just surprised but kept the secret. He did not talk about it to his other close friends. After talking with him, I became more comfortable using the toilet when I was with him. (Participant 9)*

Stage of balancing between self-concealment and self-disclosure

This is a period in which there is harmonization between looks from others and the state of mind of the participants. In this period, there is peaceful coexistence with others as well as self-maturation by appropriately controlling self-concealment and self-disclosure. This stage is facilitated mainly by a favorable environment that enables the use of self-management and social welfare systems.

Psychological maturity. As the participants overcame various difficulties, they felt more secure in themselves. The participants were able to ignore negative responses from others regarding their catheterization, incontinence, or bodily deformation. They simply accepted that it was natural for others to respond in such a way. This was not because the others were right, but because it was difficult or meaningless for the participants to explain their disease to others. They were able to protect themselves by focusing on their strengths with positive thinking. They were also empowered and no longer pitied themselves but pitied others who mocked them. Some of them relied on their religion as a way to minimize any damage from being stigmatized. Through this process, they finally found peace of mind with humbleness and gratitude.

> *I don't feel sorry for the pain or the discomfort my body went through, and I try to grow inside and feel gratitude without looking at my body and comparing it to others', so I'm going to live with real freedom. (Participant 6)*

Coexistence with others. In this stage, the participants establish good relationships with others to maintain a normal life as much as possible. Coexistence refers to existing peacefully together. The participants realized that they had to prioritize their management of urination and incontinence rather than being conscious of others. To this end, most were prepared to have a preconceived self-management plan for the future. Some of them changed their jobs to be self-employed or work in telecommunications, which allowed them to freely use the bathroom and adjust their workload to prevent strain on their bodies. Others became beneficiaries through the National Basic Livelihood Security Program, particularly those whose health had deteriorated.

All participants developed their own definitive criteria for self-concealment or self-disclosure. They were able to decide whether they would conceal or open up about their condition and how much information they would provide. If they were confident that they could completely cover up their conditions, they did so. However, if self-disclosure was more beneficial than self-concealment, participants voluntarily explained their conditions. Finally, they could live more freely by releasing themselves from stigma and other restrictions that had oppressed them for decades.

Consequences: Three patterns of living

Based on psychological maturity, coexistence with others, and levels of adjusted self-disclosure, three patterns of living emerged: *living as a non-disabled person*, *living as a marginal person between non-disabled and disabled*, and *living as a disabled person*. These patterns were also affected by the degree of illness and physical deformity, which was identified as the intervening condition.

Living as a non-disabled person refers to a lifestyle pattern that can make voluntary self-disclosure relatively easy alongside high levels of psychological maturity and coexistence with others. The participants in this pattern were able to easily open up about or cover up their illness to others depending on their own strategies, as their symptoms were mild and could be easily hidden. They tended to open up about themselves to close friends to reduce any psychological burden, but in cases of official relationships, such as at work, they tried to conceal themselves by limiting the scope of interpersonal relationships. Moreover, as most of them have few complications from the condition aside from urinary catheterization, they tended not to see the problem of incontinence and urethral catheterization as a major flaw.

Thus, the participants in this pattern treated themselves as almost normal or not perfectly normal, but not a disabled person. They were rarely restricted to social activities due to their physical conditions. They pursued a stable and typical life path, such as pursuing continued education in graduate school, and employment became a priority for them. They had a higher tendency to take on the challenges of fulfilling their dreams to overcome isolation and emotional withdrawal. Here is one participant's reaction:

> *I am not a perfectly normal person, but I do not feel like a disabled person, and my urination is something others do not know about unless I tell them. (Participant 9)*

Living as a marginal person between non-disabled and disabled refers to a lifestyle pattern in which the participants have a hard time making voluntary decisions to self-disclose because they are anxious and cannot interact comfortably with others. However, most of them did not treat themselves as disabled and tried to maintain a relatively positive self-image like non-disabled persons. They thought that they could maintain their social life if urethral catheterization and incontinence were not exposed to others. Since the participants in this pattern did not easily open up to others, they could not receive any support from others when needed. For example, in the workplace, they could not open up easily even when they needed a break or needed to care for their incontinence since they had the same workload as others. As a result, when a sudden instance of incontinence occurred, they could not concentrate on their work, resulting in a greater physical and psychological burden. As this vicious cycle repeated, they became more discouraged from pursuing life as a non-disabled person. They often felt that they were stuck in-between. A 42-year-old male participant expressed his agony as follows:

> *If I could expose my conditions with ease to the others, I think I would not suffer so much from inner conflict… It is an irony for me to live as a normal person in a society. When you are at a borderline between normal and abnormal, your life is like walking on a tightrope. (Participant 3)*

Finally, living as a disabled person refers to a lifestyle pattern in which the participants see themselves as disabled, as do others. The participants in this pattern tended to have visible deformities, such as a limping gait or wheelchair ambulation, in addition to bladder and/or bowel incontinence and catheterization. Thus, they felt more at ease when interacting with others because the attention of others was focused on their gait or wheelchair. Unlike participants with other patterns of living, they did not have to open up about their incontinence or catheterization, which could have caused psychological insecurity. Indeed, they had to focus on managing their physical disabilities and secondary complications, such as pressure ulcers or urinary tract infections, while also seeking economic stability.

The participants living as disabled persons mainly depended on the National Basic Livelihood Security Program for living and housing subsidies and welfare to help reduce the burden of medical expenses. The participants in this pattern hoped to be recognized as disabled by the government and were in a situation where they had to prove to the government that they had physical disabilities. Here is one participant's thoughts on the matter:

> *The biggest benefit of being a basic livelihood security recipient is the medical coverage. The burden of hospital bills has been reduced a lot. I'm trying to maintain my basic qualifications. (Participant 1)*

Discussion

This study was conducted to provide a comprehensive and in-depth understanding of the lives of adults with SB using grounded theory. As a result of the constant comparative analysis from the data collected in the interviews with 16 Korean adults with SB, *protecting the whole self* was identified as a core category or basic sociopsychological process. The participants needed to protect themselves from being hurt as a result of the shame and stigma caused by their physical conditions and behaviors. These findings are associated with studies in which children with SB have lower self-concepts [35,36]. This suggests that self-reinforcement needs to be a central aspect for programs that help people with SB throughout their lives.

This study identified shame and stigma as major causal conditions. This finding is consistent with previous studies on various Korean patients with chronic disease who are stigmatized by society, such as epilepsy patients [37], patients with an ostomy [38], women with eating disorders [39], and adults with hemophilia [40]. Thus, it is necessary to promote public awareness to minimize stigma and to support people with disabilities on a social level.

In this study, fecal incontinence, especially fecal smells, had a more severe impact on shame, stigma, and interpersonal relations than urinary incontinence or lower limb deformation. This finding is consistent with studies showing that fecal incontinence due to various diseases causes negative effects on the quality of life [23,41,42]. This suggests that health professionals should emphasize the importance of regular bowel self-management for Korean SB patients, which has been overlooked.

In the first stage of *protecting the whole self*, the participants tried to conceal themselves from others. This finding is consistent with a study that explored how opening up to others is difficult in reality when it involves incontinence in the workplace [43]. Our study findings suggest that self-concealment needs to be considered as a positive strategy and, thus, be integrated into the development of a psychosocial intervention to recover from a shrunken sense of self. In this stage, adults with SB were anxious and resentful and tried to avoid others by hiding and isolating themselves. These findings support other studies that describe the emotional distress of adults with SB [20,44] and social isolation among adults with SB [45]. This indicates that psychosocial intervention focusing on self-identity achieved by raising self-esteem and self-confidence is greatly needed in the early stages of adjustment among adults with SB.

In the second stage, the participants tried to open up to others to overcome psychological problems and isolation. This finding is similar to findings from other studies on opening up to others, including studies focused on protective opening up [46] and preventive opening up [47]. It is important to note that being open is needed to maintain a job [48]. Our study's findings further show that self-disclosure and opening up to others were facilitated by continuously evaluating through trial and error and by improving self-understanding. We suggest that self-help group activities would not only support the participants when they face psychological burdens but would also allow them to share useful strategies established from trial and error with each other.

The final stage was identified as balancing self-concealment and self-disclosure. In this stage, the participants showed psychological maturity and could coexist with others, armed with self-defense strategies based on appropriate levels of self-disclosure. However, they preferred cautious self-disclosure rather than active openness. This was mainly due to SB's status as a rare congenital disease, making it difficult for them to explain the condition to others and ensure their understanding in Korea. Considering this very real dilemma, health professionals need to understand and acknowledge that although self-disclosure is an important strategy, interventions need to be carefully developed by considering effective ways to help patients open up about their condition and balancing between self-concealment and self-disclosure.

This study identified three patterns of living as a consequence of these processes. These patterns were mainly categorized according to the level of adjusted self-disclosure. This finding is somewhat similar to a study of adolescents with SB on self-understanding with respect to their physical disability, which found three primary types of identity: identity as overcoming disability, identity as objectifying disability, and identity as integrating disability [49]. The current study adds to this existing literature about physical disability in adolescents by providing a more comprehensive understanding and insight into the lives of adults with SB, which can be helpful in creating patient-specific interventions for these adults.

This study has some limitations that should be considered while interpreting the results. Since culture is an important factor that can influence how people think and behave, an application of the findings is limited to those countries where cultural contexts are similar to Korea. Korea has a collectivist culture [50] that stresses harmony in interpersonal relationships, while individualistic cultures stress the needs of the individual over the needs of the group. Thus, the findings reflect interdependent characteristics of the participants' interactions within their own social realities.

The application of the findings is further limited because it did not involve those with cognitive impairment or severe psychological withdrawal. Additionally, most of the participants were single and young adults; therefore, issues regarding marriage and sexual life did not emerge as major categories. Based on these issues, more exploratory research focusing on marriage and sexual life is needed to obtain a more comprehensive picture of the lives of adults with SB.

Conclusion

The results of this study could help health professionals develop effective patient-centered programs by providing rich information and insights into the lives of adults with SB. *Protecting the whole self* is the basic sociopsychological process that explains how adults with SB adjust to their environment while managing their chronic conditions. Self-concealment was found to be a basic strategy in the early stage of this process, while self-disclosure was a major strategy in the later stage. Therefore, there is a need to develop patient-specific interventions based on the patient's sociopsychological stage. In the early stage, intervention needs to be focused on self-concealment rather than self-disclosure to establish a firm sense of self, which can be hindered by shame and stigma.

However, in the later stage, when psychological maturity occurs, intervention focusing on self-disclosure is helpful to keep people with SB from becoming isolated. The findings also suggest that it is necessary to assess the pattern of living before developing patient-specific interventions.

Conflict of interest

No conflict of interest has been declared by the authors.

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References

1. Choi JS, Suh G, Han YJ, Lee SU, Bu YG, Lee SU, et al. Congenital anomaly survey and statistics (Report No. 2009-62). Ministry of Health & Welfare, Korea Institute for Health and Social Affairs, Korean Medical Record Association; 2009. p. 56–8.
2. Ko JK, Lamichhane DK, Kim HC, Leem JH. Trends in the prevalences of selected birth defects in Korea (2008–2014). Int J Environ Res Publ Health. 2018;15(5):923. https://doi.org/10.3390/ijerph15050923
3. Bowman RM, McLone DG, Grant JA, Tomita T, Ito JA. Spina bifida outcome: a 25-year prospective. Pediatr Neurosurg. 2001;34(3):114–20. https://doi.org/10.1159/000056005
4. Davis BE, Daley CM, Shurtleff DB, Duguay S, Seidel K, Loeser JD, et al. Long-term survival of individuals with myelomeningocele. Pediatr Neurosurg. 2005;41(4):186–91. https://doi.org/10.1159/000086559
5. Liptak GS, Garver K, Dosa NP. Spina bifida grown up. J Dev Behav Pediatr. 2013;34(3):206–15. https://doi.org/10.1097/DBP.0b013e31828c5f88
6. Roach JW, Short BF, Saltzman HM. Adult consequences of spina bifida: a cohort study. Clin Orthop Relat Res. 2011;469(5):1246–52. https://doi.org/10.1007/s11999-010-1594-z
7. Wagner R, Linroth R, Gangl C, Mitchell N, Hall M, Cady R, et al. Perception of secondary conditions in adults with spina bifida and impact on daily life. Disabil Health J. 2015;8(4):492–8. https://doi.org/10.1016/j.dhjo.2015.03.012
8. Sawin KJ, Liu T, Ward E, Thibadeau J, Schechter MS, Soe MM, et al. The National Spina Bifida Patient Registry: profile of a large cohort of participants from the first 10 clinics. J Pediatr. 2015;166(2):444–50. https://doi.org/10.1016/j.jpeds.2014.09.039
9. Bellin MH, Sawin KJ, Roux G, Buran CF, Brei TJ. The experience of adolescent women living with spina bifida part I: self-concept and family relationships. Rehabil Nurs. 2007;32(2):57–67. https://doi.org/10.1002/j.2048-7940.2007.tb00153.x
10. Fischer N, Church P, Lyons J, McPherson A. A qualitative exploration of the experiences of children with spina bifida and their parents around incontinence and social participation. Child Care Health Dev. 2015;41(6):954–62. https://doi.org/10.1111/cch.12257
11. Lim SW, Lee HE, Davis M, Park K. Perceived barriers and difficulties of intermittent catheterization: in Korean patients with spinal dysraphism and their parents. Neurourol Urodyn. 2016;35(3):395–9. https://doi.org/10.1002/nau.22716
12. Lim SW, Yi M. Mothers' perceived difficulties in the management of chronic conditions of children with spina bifida: a qualitative descriptive approach. Child Health Nurs Res. 2016;22(4):247–56. https://doi.org/10.4094/chnr.2016.22.4.247. Korean.
13. Holmbeck GN, Johnson SZ, Wills KE, McKernon W, Rose B, Erklin S, et al. Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: the mediational role of behavioral autonomy. J Consult Clin Psychol. 2002;70(1):96–110. https://doi.org/10.1037/0022-006X.70.1.96
14. Davis BE, Shurtleff DB, Walker WO, Seidel KD, Duguay S. Acquisition of autonomy skills in adolescents with myelomeningocele. Dev Med Child Neurol. 2006;48(4):253–8. https://doi.org/10.1017/S0012162206000569
15. Sawin KJ, Bellin MH, Roux G, Buran CF, Brei TJ. The experience of self-management in adolescent women with spina bifida. Rehabil Nurs. 2009;34(1):26–38. https://doi.org/10.1002/j.2048-7940.2009.tb00245.x
16. Ridosh M, Braun P, Roux G, Bellin M, Sawin K. Transition in young adults with spina bifida: a qualitative study. Child Care Health Dev. 2011;37(6):866–74. https://doi.org/10.1111/j.1365-2214.2011.01329.x
17. Rofail D, Maguire L, Kissner M, Colligs A, Abetz-Webb L. A review of the social, psychological, and economic burdens experienced by people with spina bifida and their caregivers. J Neurol Ther. 2013;2(1-2):1–12. https://doi.org/10.1007/s40120-013-0007-0
18. Dicianno BE, Kinback N, Bellin MH, Chaikind L, Buhari AM, Holmbeck GN, et al. Depressive symptoms in adults with spina bifida. Rehabil Psychol. 2015;60(3):246. https://doi.org/10.1037/rep0000044
19. Choi EK, Ji Y, Han SW. Sexual function and quality of life in young men with spina bifida: could it be neglected aspects in clinical practice? Urology. 2017;108:225–32. https://doi.org/10.1016/j.urology.2016.11.052
20. Heller MK, Gambino S, Church P, Lindsay S, Kaufman M, McPherson AC. Sexuality and relationships in young people with spina bifida and their partners. J Adolesc Health. 2016;59(2):182–8. https://doi.org/10.1016/j.jadohealth.2016.03.037
21. Verhoef M, Barf HA, Vroege JA, Post MW, van Asbeck FW, Gooskens RH, et al. Sex education, relationships, and sexuality in young adults with spina bifida. Arch Phys Med Rehabil. 2005;86(5):979–87. https://doi.org/10.1016/j.apmr.2004.10.042
22. Rofail D, Maguire L, Kissner M, Colligs A, Abetz-Webb L. Health-related quality of life is compromised in individuals with spina bifida: results from qualitative and quantitative studies. Eur J Obstet Gynecol Reprod Biol. 2014;181:214–22. https://doi.org/10.1016/j.ejogrb.2014.07.048
23. Szymanski KM, Cain MP, Whittam B, Kaefer M, Rink RC, Misseri R. All incontinence is not created equal: impact of urinary and fecal incontinence on quality of life in adults with spina bifida. J Urol. 2017;197(3):885–91. https://doi.org/10.1016/j.juro.2016.08.117
24. Törnbom K, Törnbom M, Sunnerhagen S. Swedish citizens with cerebral palsy or spina bifida—perceived experiences of social life and employment. Review of disability study. Int J. 2017;13(1):1–17.
25. Yun HJ. Factors related to self-management behaviors of children with spina bifida: a mixed method approach [Doctoral dissertation]. Republic of Korea: Yonsei University; 2013.
26. Choi EK, Im YJ, Han SW. Bowel management and quality of life in children with spina bifida in South Korea. Gastroenterol Nurs. 2017;40(3):208–15. https://doi.org/10.1097/SGA.0000000000000135
27. Choi EK, Shin SH, Im YJ, Kim MJ, Han SW. The effects of transanal irrigation as a stepwise bowel management program on the quality of life of children with spina bifida and their caregivers. Spinal Cord. 2013;51(5):384–8. https://doi.org/10.1038/sc.2013.8
28. Choi EK, Ji Y, Han SW. Sexual function and quality of life in young men with spina bifida: could it be neglected aspects in clinical practice? Urology. 2017;108:225–32. https://doi.org/10.1016/j.urology.2016.11.052
29. Mead GH. Mind, self and society. Chicago: University of Chicago Press; 1934.
30. Corbin J, Strauss A. Basics of qualitative research: techniques and procedures for developing grounded theory. 4th ed. CA: Sage Publications; 2015.
31. Glaser BG, Strsuss A. Discovery of grounded theory: strategies for qualitative research. Chicago: Aldin; 1967.
32. Patton MQ. Qualitative research & evaluation methods. 3rd ed. CA: Sage; 2002. p. 145–98 Chapter 5, Desinging qualitative studies.
33. Sandelowski M. The problem of rigor in qualitative research. Adv Nurs Sci. 1986;8(3):27–37. https://doi.org/10.1097/00012272-198604000-00005
34. Tufford L, Newman P. Bracketing in qualitative research. J Qual Soc Work. 2012;11(1):80–96. https://doi.org/10.1177/1473325010368316
35. Moore C, Kogan BA, Parekh A. Impact of urinary incontinence on self-concept in children with spina bifida. J Urol. 2004;171(4):1659–62. https://doi.org/10.1097/01.ju.0000117865.98229.e5
36. Nahal MS, Axelsson ÅB, Imam A, Wigert H. Palestinian children's narratives about living with spina bifida: stigma, vulnerability, and social exclusion. Child Care Health Dev. 2019;45(1):54–62. https://doi.org/10.1111/cch.12625
37. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. Sociol Health Illness. 1986;8(1):26–43. https://doi.org/10.1111/1467-9566.ep11346455
38. Yoo M. Being reborn as me with a gold pouch: the psychological adjustment of cancer patients with ostomy [dissertation]. Seoul: Seoul national university; 2016.
39. Han D. Disease experience of Korean women with eating disorders. J Kor J Adult Nurs. 2015;27(6):695–706. https://doi.org/10.7475/kjan.2015.27.6.695. Korean.
40. Yi MS, Kim WO, Kang HS. Psychosocial adjustment of young adult to hemophilia: living like a normal person. J Kor Acad Nurs. 2003;33(7):875–84. https://doi.org/10.4040/jkan.2003.33.7.875. Korean.
41. Dibley L, Coggrave M, McClurg D, Woodward S, Norton C. “It's just horrible”: a qualitative study of patients' and carers' experiences of bowel dysfunction in multiple sclerosis. J Neurol. 2017;264(7):1354–61. https://doi.org/10.1007/s00415-017-8527-7
42. Dibley L, Norton C. Experiences of fecal incontinence in people with inflammatory bowel disease: self-reported experiences among a community sample. Inflamm Bowel Dis. 2013;19(7):1450–62. https://doi.org/10.1097/MIB.0b013e318281327f
43. Evans D. Coping with continence problems at work. Nurs Times. 2007;103(19):46–9.
44. Verhoef M, Barf H, Post M, Asbeck F, Gooskens R, Prevo A. Secondary impairments in young adults with spina bifida. Dev Med Child Neurol. 2004;46(6):420–7. https://doi.org/10.1017/s0012162204000684
45. Johnsen V, Skattebu E, Aamot-Andersen A, Thyberg M. Problematic aspects of faecal incontinence according to the experience of adults with spina bifida. J Rehabil Med. 2009;41(7):506–11. https://doi.org/10.2340/16501977-0373

46. Berlin KS, Sass DA, Davies WH, Jandrisevits MD, Hains AA. Cystic fibrosis disclosure may minimize risk of negative peer evaluations. J Cyst Fibros. 2005;4(3):169–74. https://doi.org/10.1016/j.jcf.2005.05.012
47. Marcks BA, Berlin KS, Woods DW, Davies WH. Impact of Tourette Syndrome: a preliminary investigation of the effects of disclosure on peer perceptions and social functioning. Psychiatr Interpers Biol Process. 2007;70(1):59–67. https://doi.org/10.1521/psyc.2007.70.1.59
48. Butler JA, Modaff DP. Motivations to disclose chronic illness in the workplace. Qual Res Rep Commun. 2016;17(1):77–84. https://doi.org/10.1080/17459435.2016.1143387
49. Kinavey C. Explanatory models of self-understanding in adolescents born with spina bifida. Qual Health Res. 2006;16(8):1091–107. https://doi.org/10.1177/1049732306292092
50. Trandis HC. Individualism and collectivism. NY: Routledge; 2018.

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Research Article

Psychometric Evaluation of the Korean Version of the Student Evidence-Based Practice Questionnaire (S-EBPQ)

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ABSTRACT

Purpose: Evidence-based practice (EBP) is a key competency that undergraduate nursing students need to learn, as EBP competence is essential for the effective implementation of EBP. However, few studies have comprehensively assessed the aspects of EBP competence using a reliable and valid measure specific to Korean nursing students. This study aimed to translate the Student Evidence-Based Practice Questionnaire (S-EBPQ) into Korean and evaluate its psychometric properties.

Methods: The original S-EBPQ was translated into Korean. After a pilot test, a convenience sample of 249 college students with more than four weeks of clinical training experience was selected from three universities in September 2017. Reliability and construct validity were evaluated using exploratory and confirmatory factor analyses. Concurrent validity was evaluated by correlating the measure with informatics competency.

Results: The exploratory factor analysis revealed four factors that explained 66.3 of the variance. The confirmatory factor analysis yielded a 4-factor structure ($\chi^2/df = 1.52$, $p < .001$, standardized root-mean-square residual = .07, root-mean-square error of approximation = .07, goodness of fit index = .84, comparative fit index = .91). The Cronbach's α was .81 for the total scale. The scale's correlation with informatics competency was r = .55.

Conclusions: The Korean S-EBPQ is a reliable and valid tool that has utility for assessing EBP competence in Korean nursing students and for making comparisons of the EBP competence of nursing students from other countries.

Introduction

Evidence-based practice (EBP) involves a scientific evidence-based problem-solving method that is essential for improving healthcare quality and patient outcomes [1]. Nurse's EBP competency refers to the knowledge, attitudes, and implementation of EBP utilized in nurses' daily working life [2]. While instruments to measure clinical nurses' EBP competency have focused on applying EBP to patient care to provide reliable healthcare [2], tools assessing students' EBP competency need to focus on the acquisition of knowledge and attitudes toward EBP, as well as the related learning skills [3,4]. Furthermore, undergraduate nursing students' EBP competency is critical as it influences their future behavior and application of EBP [5,6]. EBP has been emphasized as a key competency that undergraduate nursing students need to master before graduation [3].

Evaluating nursing students' EBP competency is needed to understand their acquisition of EBP-related education [2]. Unlike nurses in practice, nursing students are not in an environment where EBP competency is directly applicable [2]. Thus, their EBP competency should be evaluated in different ways.

Some instruments have been developed to measure EBP in nursing students; however, they have limitations. For instance, the Nurses' Readiness for EBP was designed for use among nurses. Previous studies assessing EBP competence in undergraduate nursing students in Korea have used measures originally designed for clinical nurses or medical students, focusing on knowledge or attitudes related to EBP competence [7,8]. The Evidence-Based Practice Evaluation Competence Questionnaire (EBP-COQ), developed for nursing students [6], was only partly evaluated in Korea;

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the skill subscale was not included in the evaluation [7]. Therefore, there is a need for a reliable and valid instrument that can measure EBP competence more comprehensively and is comparable to measures used in other populations.

The Student Evidence-Based Practice Questionnaire (S-EBPQ) was developed to assess EBP competence in nursing students, based on the steps of EBP [9] and the recommendations of the Bologna Process [6] that have stated that nursing curricula should promote the development of EBP-related knowledge, attitudes, and skills [10]. An evaluation of the S-EBPQ identified an internally consistent scale with 21 items on four subscales: Frequency of Practice, Attitude, Retrieving and Reviewing Evidence, and Sharing and Applying EBP. The S-EBPQ is an appropriate instrument for evaluating EBP-related knowledge and attitudes and its implementation in an educational environment [10]. It has been validated with nursing students in the United Kingdom, Australia, and China [10–12]; Recently, S-EBPQ was applied to Korean nursing students [13]. However, some items were loaded on different factors compared to the original tool, and the need for further research was suggested as construct validity assessment for the subscales of the original tool was not conducted [13].

Informatics competency is a factor affecting EBP competency [14]. As its significance for improving the efficiency of nursing practice has been demonstrated, informatics competency has emerged as an important competency [7,15]. Additionally, with the recent increase in the utilization of various information technologies for performing EBP, the importance of informatics competencies as a measure of the ability to perform and use EBP has also been highlighted [15,16]. Prior research has shown that information literacy education can be utilized to improve EBP knowledge [17,18]. Therefore, informatics competency is suitable for comparison with EBP competency.

This study aimed to translate the S-EBPQ into Korean and then evaluate the psychometric properties of the Korean version of the S-EBPQ. The findings would provide evidence concerning the validity of a tool that can be used to assess EBP competence in Korean nursing students. Furthermore, a Korean version of the S-EBPQ would enable cross-country comparisons with undergraduate nursing students of other countries.

Methods

Study design

Researchers employed a methodological study design to translate the S-EBPQ [10] into Korean and evaluate its validity and reliability.

Participants

Participants included junior and senior undergraduate students from three nursing colleges located in three cities in South Korea. Only undergraduate students with more than four weeks of clinical training experience were included. The total number of participants was 260, considering the recommendation of having a sample that was at least 10 times the number of items for factor analysis, as well as the possible dropout rate [19]. Due to incomplete questionnaires, the final sample included 249 participants.

Data collection

Data were collected from the three nursing colleges in September 2017. After obtaining permission to conduct research at the three universities, self-reported questionnaires were distributed to students. An explanatory statement and a consent form were attached to each questionnaire. Students were asked if they understood the purpose of the study and instructed to sign the consent form confirming that they understood and voluntarily agreed to participate in the study. They were also reassured that their anonymity would be guaranteed and that the study results obtained would only be used for research purposes. The first author collected the completed questionnaires in a sealed envelope, and small gifts were provided to participants who completed the questionnaire.

Instruments

The S-EBPQ is a scale to assess the EBP competency of undergraduate nursing students [10]. The S-EBPQ has 21 items and four subscales: Frequency of Practice (six items), Attitude (three items), Retrieving and Reviewing Evidence (seven items), and Sharing and Applying EBP (five items). Each item is measured on a 7-point Likert scale. Higher scores indicate higher EBP competence. The reliability of the tool was examined based on the item response theory, and its construct validity was evaluated using an exploratory factor analysis [10]. The Cronbach's α coefficients for the factors ranged from .76 to .91 [10]. In this study, the S-EBPQ was translated in accordance with the World Health Organization guidelines [20]. After the initial translation, four experts, including two nursing professors with experience in the development and translation of tools, one translator, and one field expert, reviewed the translation's appropriateness. Next, the S-EBPQ was back-translated by a bilingual expert, and any differences in meaning from the original version of the S-EBPQ were adjusted in the final version. After a pilot test of 20 undergraduate junior and senior nursing students using cognitive interviewing, the final version was used for the survey.

The Informatics Competency Tool was used with the permission of the original developers [21] and the author who translated the scale into Korean [22]. The tool has 30 items and five subscales: Basic Computer Usage (ten items), Medical Informatics-Related Software Usage (seven items), Computer-Related Information Management (six items), Perception of Informatics (five items), and Information Search Using the Internet (two items). Each item is measured on a 5-point Likert scale, with higher scores indicating better informatics competence. Given that informatics competency is an important factor in performing EBP [21], this index was viewed as being appropriate for evaluating the concurrent validity of the S-EBPQ. The items containing phrases, such as “my hospital” were revised to be written as “I,” and the verbs were revised to be preceded by “may” to be applicable for students. The revised questionnaire was used after conducting a pilot test.

Data analysis

The data were analyzed using IBM SPSS Statistics 20 and Amos 20.0 software (IBM Corp., Armonk, NY, USA), with two-sided tests at a significance level of .05. The general characteristics of the participants were summarized using frequencies, percentages, means, and standard deviations. Each item's normality was evaluated with regard to skewness and kurtosis. The criteria of the absolute value of skewness less than 3 and the absolute value of kurtosis less than 10 were used [23]. Corrected item-total correlations were calculated.

The construct validity was evaluated using exploratory factor analysis (EFA) and confirmatory factor analysis (CFA). The total sample of 249 was randomly divided into two separate subsamples. The first half of the sample ($n = 124$) was used for EFA, and the second half ($n = 125$) was used for CFA. The EFA was performed using a varimax rotation of the principal component analysis (PCA).

Table 1 *General Characteristics of the Participants (N = 249).*

Characteristics	Category	*n* (%)
Gender	Men	28 (11.2)
	Women	221 (88.8)
Year in college	Junior	117 (47.0)
	Senior	132 (53.0)
Satisfaction with their major	Dissatisfied	13 (5.2)
	Moderate	83 (33.4)
	Satisfied	153 (61.4)
Nursing research subject	Completed	169 (67.9)
	None	80 (32.1)
Statistical subject	Completed	105 (42.2)
	None	144 (57.8)
Research experience	Yes	107 (43.0)
	No	142 (57.0)

Prior to factor analysis, the Kaiser-Meyer-Olkin (KMO) test ($\geq$.60) and Bartlett's test of sphericity ($p < .05$) were performed to evaluate the suitability of the data for conducting a factor analysis [24]. Items with a factor loading of $\geq$ .50 were selected [25]. Next, in the CFA, the goodness of fit index (GFI), comparative fit index (CFI), standardized root-mean-square residual (SRMR), and root-mean-square error of approximation (RMSEA) were assessed. For GFI and CFI, with a cut-off value of .80, optimal goodness of fit was determined when the values were .90 or higher [26]. For RMSEA, a value of less than .08 indicated high goodness of fit, while a value of less than .10 indicated moderate goodness of fit [27]. For SRMR, the cut-off value of $\leq$.80 was used [23]. We also considered modification index values above 10 in order to improve the model fit, if necessary [28,29].

Convergent validity was assessed using construct reliability (CR), with the cut-off value of >.70, and average variance extracted (AVE) [30]. AVE > .50 indicates good convergence [30], while AVE > .40 is considered acceptable [31]. Discriminant validity was determined by comparing the factor's AVE square root value and the correlation between the factors of the instrument [30].

For concurrent validity, Pearson's correlation coefficient was used to assess the relationship between EBP competence and informatics competence in nursing, which has been shown to be correlated [7,15]. Cronbach's α was calculated to determine the reliability of the S-EBPQ.

Ethical considerations

The study was performed with the approval of the Kyung Hee University's Institutional Review Board (KHSIRB-17-063(NA), KHSIRB-18-019(EA).

Results

Participants' characteristics

The mean age of the participants was 23 years (SD = 1.16), a large majority were women (88.8%), and slightly more than half (53.0%) were in their senior year. Table 1 shows the participants' general characteristics.

Item analysis

Table 2 shows the results of item analysis. The corrected item total correlations were found to be .44 to .74, which exceeded .30 [24]; therefore, no items were deleted. The skewness of each item ranged from −1.14 to 0.17, and the kurtosis ranged from −0.39 to 0.92; thus, both values satisfied the guidelines for normality (Table 2).

Table 2 *Item Analysis and Reliability of the Korean Student Evidence-Based Practice Questionnaire (N = 249).*

Subscale/Item	Mean ± SD	Skewness	Kurtosis	Corrected item-total correlation	Cronbach's α
Frequency of Practice	4.61 ± 0.86				.74
1. Formulated a clearly answerable question	4.31 ± 1.10	−0.51	0.72	.58	
2. Tracked down the relevant evidence	4.70 ± 1.11	−0.36	0.46	.60	
3. Critically appraised, against set criteria	4.23 ± 1.15	−0.25	−0.15	.63	
4. Integrated the evidence	4.55 ± 1.12	−0.33	0.39	.62	
5. Evaluated the outcomes of your practice	4.63 ± 1.09	−0.39	0.24	.73	
6. Shared this information with colleagues	5.23 ± 1.26	−0.91	0.92	.54	
Attitude	5.09 ± 1.00				.77
7. I resent having my clinical practice questioned	4.95 ± 1.16	−0.54	0.49	.48	
8. Evidence-based practice is a waste of time	5.46 ± 1.41	−1.14	0.91	.52	
9. I stick to tried and trusted methods	4.84 ± 1.28	−0.60	0.07	.44	
Retrieving and Reviewing Evidence	4.26 ± 0.82				.73
10. Research skills	3.63 ± 1.00	−0.09	−0.25	.62	
11. Converting your information needs	3.79 ± 1.05	−0.19	−0.39	.68	
12. Awareness of major information types	4.64 ± 1.17	−0.19	−0.03	.68	
13. Knowledge of how to retrieve evidence	4.61 ± 1.09	−0.33	0.41	.63	
14. Ability to analyze critically	4.15 ± 1.07	0.17	−0.08	.74	
15. Ability to determine how valid	4.43 ± 1.09	−0.41	−0.39	.66	
16. Ability to determine how useful	4.55 ± 1.05	−0.61	0.44	.57	
Sharing and Applying EBP	4.64 ± 0.80				.83
17. Ability to identify gaps	4.17 ± 1.03	−0.38	0.69	.62	
18. Ability to apply information	4.38 ± 0.97	−0.16	−0.01	.67	
19. Sharing of ideas and information with colleagues	5.21 ± 1.06	−0.56	0.29	.66	
20. Dissemination of new ideas	4.83 ± 1.09	−0.30	−0.16	.58	
21. Ability to review your own practice	4.62 ± 1.07	−0.19	0.05	.72	
Total Scale	4.57 ± 0.69				.81

Note. EBP = evidence-based practice; SD = standard deviation.

Construct validity

EFA

Both the KMO test result of .82 and Bartlett's test of sphericity ($\chi^2 = 1562.85$, $p < .001$) demonstrated the suitability of the factor analysis. The PCA with varimax rotation revealed four factors with an eigenvalue >1.0. The factor loadings ranged from .62 to .85, with four factors explaining 66.3% of the total variance (Table 3). There was no cross-loaded item based on the factor loading of $\geq$ .50.

CFA

The CFA was performed with the original S-EBPQ 4-factor structure (Figure 1). The model fit indices were $\chi^2 = 334.23$ ($p < .001$), $\chi^2/df = 1.83$, SRMR = .07, RMSEA = .08, GFI = .80, and CFI = .85. Since some values did not meet the recommended levels, the model was revised using model modification indices. After setting the covariance between errors associated among four item-pairs (3–9, 6–19, 10–11, and 15–16), the model fit indices were as follows: $\chi^2 = 271.44$ ($p < .001$), $\chi^2/df = 1.52$, SRMR = .069, RMSEA = .07, GFI = .84, and CFI = .91. The Korean translated version of the S-EBPQ exhibited a 4-factor structure, which was the same as the original measure and the current EFA.

Regarding the convergent validity, the result showed that the AVE values ranged from .46 to .52, and CR values were above .70 (Table 3). The standardized factor loadings in the CFA ranged from .57 to .93. Regarding discriminant validity, the square roots of AVE, ranging from .68 to .72, were greater than the correlation coefficient for each factor.

Concurrent validity

There was a significant positive correlation between the S-EBPQ total score and the total score on the Informatics Competency Tool. Significant correlations were also found between the S-EBPQ subscale scores and the Informatics Competency Tool score (Table 4).

Internal consistency reliability

The Cronbach's α for the S-EBPQ was .81. The internal consistency of the four factors ranged from .73 to .83 (Table 2).

Discussion

The S-EBPQ is a measurement tool that assesses EBP competency in undergraduate nursing students. In the present study, we assessed the psychometric properties of the Korean translated version of the S-EBPQ. The findings showed that the Korean S-EBPQ had acceptable reliability and validity, suggesting that it could be a useful scale to measure EBP competence in Korean nursing students.

The construct validity was verified using EFA, CFA, and concurrent validity analysis. The EFA identified four factors. It was consistent with those of the original S-EBPQ and previous studies [10–13]. The explanatory power of the 4-factor model was 66.26%, which was similar to the findings in previous studies [12,13]. In addition, there was no cross-loaded item. This result was similar to the finding of one previous study [12] but differed from the finding of another study showing that Item 6 was cross-loaded between two factors of "Frequency of Practice" and "Sharing and Applying EBP." [11] Although the Australian study removed the cross-loaded item [11], we retained all items based on the EFA results.

The CFA demonstrated an acceptable fit for the original 4-factor structure. Although the revised model exhibited a better fit, the CFA indices indicated that the 4-factor structure did not fit well with the data. This result differed from the findings of previous studies in Australia and China in that the fit indices indicated that the four

Table 3 *Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA) Results of the Korean Student Evidence-Based Practice Questionnaire.*

Subscale	Item	EFA (n = 124)				CFA (n = 125)				
		Factor				λ	C.R.	p	CR	AVE
		1	2	3	4					
Retrieving and Reviewing Evidence	15	.82	.08	.16	.01	0.67	6.08		.87	.50
	11	.80	.00	.16	.18	0.66		<.001		
	10	.78	.08	.23	.19	0.59	6.82	<.001		
	14	.78	.05	.23	.19	0.78	7.01	<.001		
	16	.76	.09	.21	.05	0.67	6.02	<.001		
	13	.75	.02	.23	.05	0.82	7.00	<.001		
	12	.74	.06	.27	.09	0.72	6.47	<.001		
Frequency of Practice	5	.12	.85	.20	.24	0.77	6.33		.84	.46
	3	.15	.81	.07	.03	0.63		<.001		
	2	.05	.80	.08	.04	0.73	6.42	<.001		
	1	.06	.80	.04	.04	0.58	5.17	<.001		
	4	.05	.80	.08	.06	0.70	6.14	<.001		
	6	.10	.62	.34	.10	0.64	5.68	<.001		
Sharing and Applying EBP	20	.21	.01	.81	.15	0.70	7.20		.84	.52
	19	.34	.13	.79	.03	0.75		<.001		
	17	.27	.11	.70	.05	0.63	6.34	<.001		
	18	.44	.11	66	.06	0.67	7.03	<.001		
	21	.45	.21	.62	.07	0.85	8.34	<.001		
Attitude	7	.16	.03	.07	.83	0.93			.74	.50
	9	.11	.13	.02	.76	0.57	4.87	<.001		
	8	.15	.11	.14	.76	0.57	4.24	<.001		
Eigenvalue		7.11	3.57	1.93	1.31					
Percent of the total variance explained		33.9	17.0	9.2	6.2					
Percent of cumulative variance		33.9	50.9	60.1	66.3					
Kaiser-Meyer-Olkin measure of sampling adequacy					.82					
Bartlett's test of sphericity		Approx. Chi-square			1562.85					
				df	210					
				Sig	<.001					

Note. AVE = average variance extracted; CR = construct reliability; C.R. = critical ratio; df = degree of freedom; EBP = evidence-based practice; Sig = significance level.

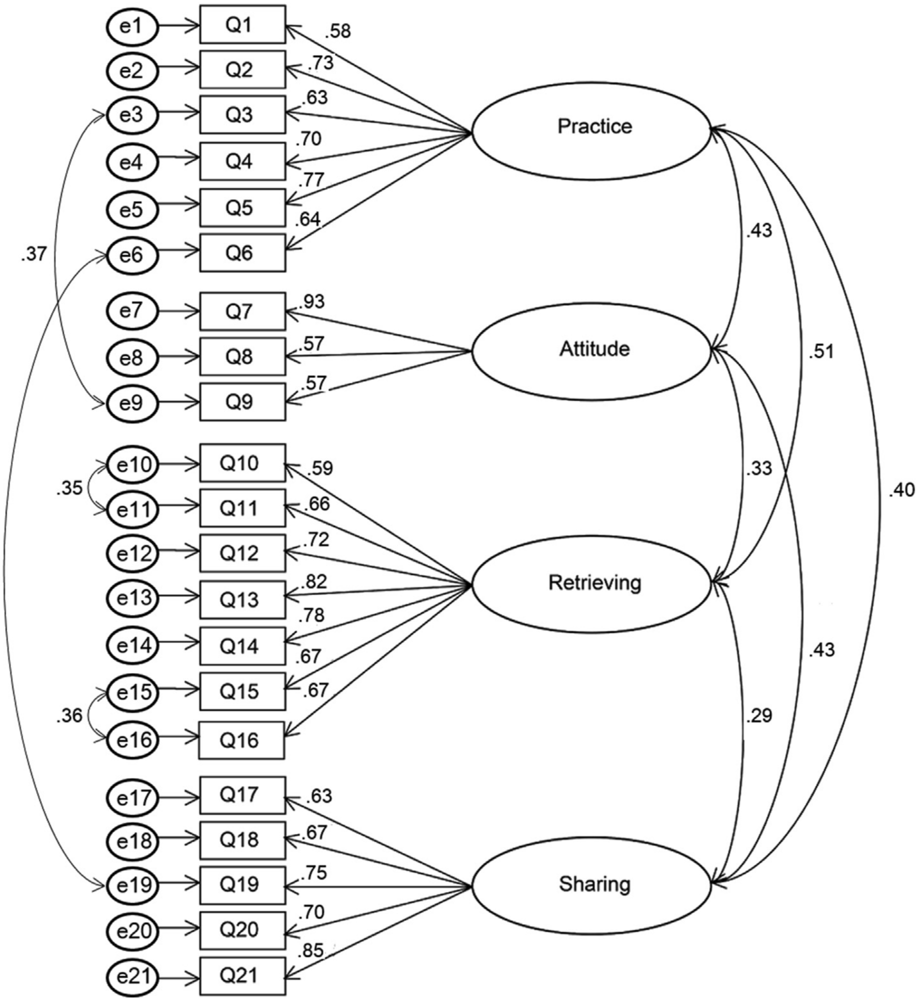

Figure 1. Final model of the Korean Student Evidence-Based Practice Questionnaire (S-EBPQ).

factors fit the data well [11,12]. Such differences may be due to the sample characteristics with different educational backgrounds. For instance, to become a registered nurse, Australia's nursing education features three-year programs [32,33]. The Australian study's participants were students enrolled in an EBP course, generally in the third year of study [11]. China's nursing education comprises various levels, such as a three-year nursing program for the Diploma, a three-year associate nursing degree program for the Advanced Diploma, and a five-year bachelor of the nursing program, based on a biomedical model [33,34]. Participants in the Chinese study were undergraduate nursing students in a bachelor's program [12]. Korea's undergraduate nursing curriculum has a four-year duration; although EBP education is not mandatory in the undergraduate program, recent attempts have been made to implement it as an independent subject [35,36]. Additionally, our sample size was slightly smaller than the generally recommended sample size of at least 300 [25]. It might result in a less strong model fit than in previous studies [11,12].

Table 4 *Pearson's Correlations between the Korean Student Evidence-Based Practice Questionnaire (S-EBPQ) and Informatics Competency (N = 249).*

S-EBPQ	Informatics Competency
Full Scale	.55*
Frequency of Practice	.44*
Attitude	.38*
Retrieving and Reviewing Evidence	.47*
Sharing and Applying EBP	.46*

Note. EBP = evidence-based practice.
**p* < .001.

Supporting the validity of the CFA, both convergent validity and discriminant validity were also confirmed. Additionally, in the present study, the total and subscale scores positively correlated with the Informatics Competency Tool score, providing support for the instrument's concurrent validity.

The internal consistency reliability coefficients of the total Korean S-EBPQ and its subscales were higher than .70. This is consistent with Cronbach's α for the subscales in the original S-EBPQ (.77–.91) and the Chinese version of S-EBPQ (.70–.92) [12]. Furthermore, the item-total correlations ranged from .44 to .74, which was acceptable, suggesting that the Korean S-EBPQ had adequate reliability [19].

Overall, the findings of this study demonstrated that the translated S-EBPQ is a reliable and valid tool. Therefore, it can be used to measure EBP competence in undergraduate nursing students in Korea. Competence in EBP has been one of the competencies needing further assessment in the training of undergraduate nursing students [3]. Future research might consider using this validated Korean version of the S-EBPQ in a comparison of Korean undergraduate nursing students' competence with students from other countries.

There are several limitations to this study that deserve mentioning. First, the findings have limited generalizability, as the sample only included junior and senior students from 4-year nursing programs at three nursing colleges. Therefore, studies need to be conducted with samples of nursing students from other colleges. Second, although the suitability of the present tool was confirmed, the CFA showed that the four-factor structure did not fit well with the data; thus, further research is needed to confirm the present findings with a larger sample.

Conclusions

The S-EBPQ was originally developed for nursing students. Therefore, it was expected to provide further differentiated information compared with other preexisting tools. The Korean translated S-EBPQ exhibited acceptable reliability and validity in this study. As such, this tool can be used in the assessment and training of Korean nursing students and used as a method to compare undergraduate nursing students' EBP competency.

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Unblinded ethics statement

The study was performed with the approval of the Kyung Hee University’s Institutional Review Board (KHSIRB-17-063(NA), KHSIRB-18-019(EA)).

Conflict of interest

The authors declare no conflict of interest.

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References

1. Melnyk BM, Fineout-Overholt E, Stillwell SB, Williamson KM. Evidence-based practice: step by step: the seven steps of evidence-based practice. Am J Nurs. 2010;110(1):51–3. https://doi.org/10.1097/01.NAJ.0000366056.06605.d2
2. Upton D, Upton P. Development of an Evidence-based practice questionnaire for nurses. J Adv Nurs. 2006;53(4):454–8. https://doi.org/10.1111/j.1365-2648.2006.03739.x
3. Kim JS, Gu MO, Chang H. Effects of an evidence-based practice education program using multifaceted interventions: a quasi-experimental study with undergraduate nursing students. BMC Med Educ. 2019;19(1):71. https://doi.org/10.1186/s12909-019-1501-6
4. Dawley K, Bloch JR, Sluppy PD, McKeever A, Schezer G. Using a pedagogical approach to integrate evidence-based teaching in an undergraduate women's health course. Worldviews Evidence-Based Nurs. 2011;8(2):116–23. https://doi.org/10.1111/j.1741-6787.2010.00210.x
5. Andre B, Aune AG, Braend JA. Embedding evidence-based practice among nursing undergraduates: results from a pilot study. Nurse Educ Pract. 2016;18:30–5. https://doi.org/10.1016/j.nepr.2016.03.004
6. Ruzafa-Martinez M, Lopez-Iborra L, Moreno-Casbas T, Madrigal-Torres M. Development and validation of the competency in evidence based practice questionnaire (EBP-COQ) among nursing students. BMC Med Educ. 2013;13(1):19. https://doi.org/10.1186/1472-6920-13-19
7. Choi MH, Kim YH, Son HM. Factors influencing evidence-based practice attitudes among undergraduate nursing students. J Korean Acad Soc Nurs Educ. 2016;22(3):274–82. https://doi.org/10.5977/jkasne.2016.22.3.274. Korean.
8. Jang KS, Kim EA, Park HY. The effects of an evidence-based nursing course using action learning on undergraduate nursing students. J Korean Acad Soc Nurs Educ. 2015;21(1):119–28. https://doi.org/10.5977/jkasne.2015.21.1.119. Korean.
9. Sackett DL, Straus SE, Richardson WE, Rosenberg W, Haynes RB. Evidence-based medicine: how to practice and teach EBM. 2nd ed. Edinburgh: Churchill Livingston; 2000. p. 261.
10. Upton P, Scurlock-Evans L, Upton D. Development of the student evidence-based practice questionnaire (S-EBPQ). Nurse Educ Today. 2016;37:38–44. https://doi.org/10.1016/j.nedt.2015.11.010
11. Beccaria R, Beccaria G, McCosker C. A confirmatory factor analysis of the Student Evidence-Based Practice Questionnaire (S-EBPQ) in an Australian sample. Nurse Educ Today. 2018;62:69–73. https://doi.org/10.1016/j.nedt.2017.12.010
12. Zhang YP, Liu WH, Yan YT, Zhang Y, Wei HH, Porr C. Developing Student Evidence-Based Practice Questionnaire (S-EBPQ) for undergraduate nursing students: reliability and validity of a Chinese adaptation. J Eval Clin Pract. 2019;25(4):536–42. https://doi.org/10.1111/jep.12897
13. Kim SK. Validity and reliability of the Korean version of student evidence-based practice questionnaires (S-EBPQ). J Ind Converg. 2020;18(1):35–43. https://doi.org/10.22678/JIC.2020.18.1.035. Korean.
14. Bakken S. An informatics infrastructure is essential for evidence-based practice. J Am Med Inf Assoc. 2001;8(3):199–201. https://doi.org/10.1136/jamia.2001.0080199
15. Cronenwett L, Sherwood G, Barnsteiner J, Disch J, Johnson J, Mitchell P, et al. Quality and safety education for nurses. Nurs Outlook. 2007;55(3):122–31. https://doi.org/10.1016/j.outlook.2007.02.006
16. Kalsy M, Lin JH, Bray BE, Sward KA. Role of nursing informatics in the automation of pneumonia quality measure data elements. Comput Inf Nurs. 2018;36(10):475–83. https://doi.org/10.1097/CIN.0000000000000451
17. Florin J, Ehrenberg A, Wallin L, Gustavsson P. Educational support for research utilization and capability beliefs regarding evidence-based practice skills: a national survey of senior nursing students. J Adv Nurs. 2012;68(4):888–97. https://doi.org/10.1111/j.1365-2648.2011.05792.x
18. Keib CN, Cailor SM, Kiersma ME, Chen AMH. Changes in nursing students' perceptions of research and evidence-based practice after completing a research course. Nurse Educ Today. 2017;54:37–43. https://doi.org/10.1016/j.nedt.2017.04.007
19. Nunnally JC, Bernstein IH. Psychometric theory. 3rd ed. New York: McGraw-Hill; 1994. p. 752.
20. World Health Organization. Process of translation and adaptation of instruments [Internet]. Geneva, Switzerland: World Health Organization; 2016 [cited 2016 October 30]. Available from: http://www.who.int/substance_abuse/research_tools/translation/en/
21. Staggers N, Gassert CA, Curran C. A Delphi study to determine informatics competencies for nurses at four levels of practice. Nurs Res. 2002;51(6):383–90. https://doi.org/10.1097/00006199-200211000-00006
22. Kim MS. Validity and reliability of informatics competencies for nurses among Korean nurses. Kor J Adult Nurs. 2008;20(3):470–80. Korean.
23. Kline RB. Principles and practice of structural equation modeling. 3rd ed. New York: Guilford Press; 2011. p. 63.
24. Field AP. Discovering statistics using IBM SPSS statistics: and sex and drugs and rock ‘n’ roll. 4th ed. London: Sage; 2013. p. 685–6.
25. Tabachnick BG, Fidell LS. Using multivariate statistics. 7th ed. Boston: Pearson Education; 2013. p. 612–785.
26. Abedi G, Rostami F, Nadi A. Analyzing the dimensions of the quality of life in hepatitis B patients using confirmatory factor analysis. Global J Health Sci. 2015;7:22–31. https://doi.org/10.5539/gjhs.v7n7p22
27. MacCallum RC, Browne MW, Sugawara HM. Power analysis and determination of sample size for covariance structure modeling. Psychol Methods. 1996;1(2):130–49. https://doi.org/10.1037/1082-989X.1.2.130
28. Yu JP. The Concept and understanding of structural equation modeling. Seoul: Hannarae Publishing Co; 2012. p. 161–372. Korean.
29. Ahn JW. Structural equation modeling of cultural competence of nurses caring for foreign patients. Asian Nurs Res. 2017;11(1):65–73. https://doi.org/10.1016/j.anr.2017.03.001
30. Hair Jr JF, Black WC, Babin BJ, Anderson RE. Multivariate data analysis. 7th ed. Upper Saddle River, NJ: Pearson Prentice Hall; 2010. p. 541–98.
31. Huang CC, Wang YM, Wu TW, Wang PA. An empirical analysis of the antecedents and performance consequences of using the moodle platform. Int J Inf Educ Technol. 2013;3(2):217–21. https://doi.org/10.7763/IJIET.2013.V3.267
32. Andre K, Barnes L. Creating a 21st century nursing work force: designing a bachelor of nursing program in response to the health reform agenda. Nurse Educ Today. 2010;30(3):258–63. https://doi.org/10.1016/j.nedt.2009.09.011
33. Wang CC. Closing the gap in nursing education: comparing nursing registration. Chin Nurs Res. 2016;3(1):1–6. https://doi.org/10.1016/j.cnre.2016.03.001
34. Eddins EE, Hu J, Liu H. Baccalaureate nursing education in China: issues and challenges. Nurs Educ Perspect. 2011;32(1):30–3. https://doi.org/10.5480/1536-5026-32.1.30
35. Song CE, Kim WG, Lim YJ. An analysis of evidence-based practice courses in Korean nursing education systems. Heliyon. 2019;5(10):e02650. https://doi.org/10.1016/j.heliyon.2019.e02650
36. Oh EG, Yang YL. Evidence-based nursing education for undergraduate students: a preliminary experimental study. Nurse Educ Pract. 2019;38:45–51. https://doi.org/10.1016/j.nepr.2019.05.010