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Situations of Domestic Violence against Children and Adolescents in a Northeastern Brazilian Capital

Eliane Santos Cavalcante[1]*, Francisco Arnoldo Nunes de Miranda[2], Lannuzya Veríssimo e Oliveira[1], Glauber Weder dos Santos Silva[2], Gustavo Ávila Dias[3], Romeika Carla Ferreira de Sena[2], Suerda Lillian da Fonseca Lins[2], Cleonice Andréa Alves Cavalcante[1], Izaura Luzia Silvério Freire[1], João Evangelista da Costa[2]

[1]Health School, Federal University of Rio Grande do Norte, Natal, Brazil
[2]Nursing Department, Postgraduate Program in Nursing, Federal University of Rio Grande do Norte, Natal, Brazil
[3]Natal Health City Department, Natal, Brazil

Email: *eliane@es.ufrn.br

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Abstract

Objective: To describe the epidemiological profile of children and adolescents who are victims of domestic violence. Method: This is a cross sectional and descriptive study, following a quantitative approach, conducted from September to December 2013, at the SOS CHILD service, in the city of Natal, Rio Grande do Norte, Brazil. The research protocol was approved by CEP/UFRN under CAAE 0166.0.051.000-11. Results: In the analysis of 69 children, the results were presented from three points of view: 1) the victim—female (56.5%), aged one to 11 years old (66.7%) and lived with one of the parents (43.5%); 2) the abuser—female (60.9%) in the 14 - 23 years old and 34 - 43 years old, with the same percentage (24.6%), history of alcohol use and abuse (42.0%), the mother was the one who attacked the most (34.7%); 3) types of violence, among the physical ones, the most frequent were slaps (43.2%) and punches (18.9%); the prevalence, among the psychological violence, were curses (35.4%) and abuse (27.8%); negligence, omission of care (73.5%), deprivation of care for personal appearance (18.4%); among sexual violence: sexual caresses (57.1%) and forced sex (42.9%). Conclusion: Children and adolescents placed in an unfavorable social-economic context, under the care of mothers with a history of use and abuse of alcohol and other drugs, are more vulnerable to intra-domiciliary violence.

Keywords

Exposure to Violence, Domestic Violence, Child Health, Adolescent Health

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1. Introduction

The violence, understood as the violation of human rights, is considered as a global, current, complex, polysemic phenomenon, and occurs in a heterogeneous and asymmetrical way, practiced by individuals against other individuals. It assumes different contexts and different impacts on the social, political and cultural relations [1]. On the one hand, the media and its expressive vehicles report about poor living conditions, vulnerability and human security; on the other hand, after a few minutes of sensationalism, the suffering of the victims and their families are doomed to mediatic oblivion [2].

Epidemiological data indicate a significant increase in morbidity and mortality resulting from violence in recent decades, both in industrialized countries, such as Brazil [3]. In the spectrum of the victims of all kinds of violence committed by family and non-family members, there are children and adolescents, emerging as one of the most exposed and vulnerable to violations of their rights, directly and indirectly affecting their physical, mental and emotional health [4].

Violence against children and adolescents in Brazil is not a state, but rather a process that takes many faces and nuances, and is present in every action or omission capable of causing injury, damage and inconvenience to the full development of children and adolescents [5]. In other words, one can say that occasional cases of violence to these people could be due to an asymmetric and unequal power relationship, manifested by physical force, by economic or political power, for domination and family or generational oppression. This violence can come to configure also structurally, that is, the implementation of educational, health or economic policies which don't offer any kind of contribution or even prevent the growth and development of children [4].

The scenario or itinerary of violence often begins within domestic space and passes through schools and their surroundings, the community and other institutions, as terminating sources and conditions that produce violence. The physical, social, emotional and cognitive burden of the victims may permanently compromise children and adolescents. The perverse effects may incur construction of a violent playback circle and feedback, because it is recognized that children and adolescents tend to reproduce what they live through their play, attitudes and learning, corroborating other pairs to become the main victims of violent actions [4] [6].

In Brazil, since 2001, the notification of violence involving children, adolescents, women and elderlies has been mandatory in order to provide visibility to the problem, and characterize its magnitude, size, specificity and complexity to fight this problem. It was implemented by the Ministry of Health through the Diseases Notification Information System-SINAN (*Sistema de Informação de Agravos de Notificação* in Portuguese) in 2009 [7]. It is noteworthy that the focus of this study concerns the violence of children and adolescents.

This type of measure taken by the Unified Health System in Brazil contributes to the formulation of public policies with inter-sectorial, inter-institutional, interdisciplinary and networking actions. For this, the collecting must be universal, continuous and compulsory in situations of violence [8]. Notifying violence should be understood as an instrument that goes beyond the mere collection of epidemiological information. It should, therefore, be seen as one of the instruments to guarantee rights, to preserve the health and life and to articulate and integrate the social protection and the comprehensive health care network, following the line of health care [4].

A characteristic of the domestic violence against children and adolescents is the omission of parents, relatives or any other people who are responsible for these individual's custody, which may cause damage or suffering—physical, sexual or psychological—also negligence (the most frequently cause of notifications reported), and falls unequally on race, gender, age and other factors. It is considered as an act rooted Brazilian culture historically proven. However, this phenomenon lacks a more comprehensive statistic, a significant fact [9].

It is clear that the seriousness and scope of this issue in so far as this study seeks to better understand the phenomenon in order to support decision-making aimed at prevention and control, in addition to supporting other studies. From this premise, based on experience and coexistence in the Child and Adolescent Protection Service—SOS CHILD, which belongs to the State Foundation for Children and Adolescents of Rio Grande do Norte, Brazil (FUNDAC/RN), the question is: What are the epidemiological characteristics of children and adolescents victims of violence assisted at the emergency rooms in the city of Natal and referred to children and adolescents' protection agencies?

In this sense, the present study aimed to describe the epidemiological profile of children and adolescents victims of domestic violence reported by SOS CHILD.

2. Method

This is an epidemiological, descriptive and cross-sectional study. The descriptive epidemiology analyzes how the incidence (new cases) or prevalence (existing cases) of certain disease or condition related to health varies according to certain characteristics, such as gender, age, educational attainment and income, among others [10].

The research was developed with all the children and adolescents attended by the SOS CHILD Service, in the city of Natal, capital of Rio Grande do Norte, Brazil, who were victims of domestic violence, from September 15th to December 31st, 2013. To characterize the study population, the WHO classification criteria was adopted [11], in which the child's age goes from zero to less than 10 years and adolescence goes from 10 to 19 years old.

In this sense, the following inclusion criteria were established: children and/or adolescents from zero to 19; residents in the metropolitan area of Natal/RN; referred and treated at the SOS CHILD in the second half of 2013; victims of domestic violence. Unconfirmed cases and individuals who refused to participate were excluded. Therefore, the sample consisted of 69 subjects, included in a non-probabilistic way, by convenience.

The data were collected by two instruments, namely: 1) information contained in the guides that accompany the victims and in the register of spreadsheet reports used and treated at SOS CHILD; 2) and a form applied to the child, when possible, and to the legal guardians/companion of the victim, which, besides complementing the information on the victim, his/her family and the aggressor, gave information about the circumstances of the violence. The data were collected after the researchers provided detailed information on the investigation and signature of the Informed Consent Form by the parents or legal guardians.

It was submitted to the Research Ethics Committee of the Federal University of Rio Grande do Norte (CEP-UFRN) protocol number 139/2011, CAAE number 0166.0.051.000-11, in accordance with the provisions of Resolution number 196/1996 of the Brazil National Health Council (CNS), valid at the development of the research. However, the current resolution is number 466/2012/CNS.

For constructing the databases, the statistical treatment of the software *Microsoft Office Excel* 2013® was used to descriptively summarize the data with absolute frequencies and percentiles, presented by tables.

3. Results

In the studied period, the SOS CHILD of Natal/RN tended 69 cases of violence against children. After data analysis, it was observed that the impact of violence on children and adolescents are presented under three points of view: the victim, the offender and the types of violence. It is noteworthy that the boundaries among the causes that support the violence are so precarious that they are didactically presented in order to clarify and understand as a provisional and recent result of the child and adolescent victimization process.

The victim—Table 1 shows that most of the victims of domestic violence were female (56.5%), mostly aged from one to 11 years (66.7%), with minimum age of two days, and maximum age of 16 years. The majority attended school/kindergarten (52.2%). They lived with one of the parents (43.5%), in Natal, and the West Zone had the highest number of notifications (44.9%).

The aggressor—Table 2 shows that most of the aggressors were female (60.9%), with predominant age groups of 14 - 23 years and 34 - 43 years, with the same percentage (24.6%), with educational attainment of no literacy/basic education (65.2%), unemployed (53.6%), with a history of alcohol use and abuse (42.0%). As for the kinship with the victims, the mother was the most frequent (34.7%).

Types of violence—Table 3 shows the types of violence reported by SOS CHILD. The physical violence (62.3%), followed by psychological (60.8%), was the most frequent. Among physical violence, the most frequent were slaps (43.2%) and punches (18.9%). Concerning psychological violence, the most frequent were offenses (35.4%) and abuse (27.8%). Among the most common disregards were omission of care (73.5%) and deprivation of care for personal appearance (18.4%). The reported sexual violence was submission to sexual caresses (57.1%) and forced sex (42.9%).

4. Discussion

According to the World Report on Violence and Health [12], researches about the subject showed that cases of abuse occur more intensively in poor areas where there is little

Table 1. Characterization of the victims of domestic violence attended at SOS Child, Natal/RN, Brazil, 2016.

Variables		n	%
Gender	Female	39	56.5
	Male	30	43.5
Age group	Less than 1 year	6	8.7
	1 - 11 years	46	66.7
	12 - 16 years	17	24.6
Attended schools/kindergartens	Yes	36	52.2
	No	27	39.1
	No information	6	8.7
Lived with	One of the parents*	30	43.5
	Father	14	20.3
	Mother	12	17.4
	Parents	1	1.4
	Maternal grandparents	4	5.8
	Paternal grandparents	1	1.4
	Others	7	10.2
Residence region	West	31	44.9
	North	18	26.1
	East	17	24.6
	South	3	4.4

Source: research database.

Table 2. Characterization of the domestic violence victims' aggressor attended at SOS Child, Natal/RN, Brazil, 2016.

Variables		n	%
Gender	Female	42	60.9
	Male	27	39.1
Age group	14 - 23 years	17	24.6
	24 - 33 years	16	23.2
	34 - 43 years	17	24.6
	44 - 53 years	14	20.3
	Over 54 years	5	7.3
Educational attainment	Illiterate/Incomplete elementary school	45	65.2
	Complete elementary school/Incomplete high school	13	18.9
	Complete high school/Incomplete college	10	14.5
	Complete college	1	1.4
Occupation	Yes	32	46.4
	No	37	53.6
Risk factor	Use and abuse of alcohol	29	42.0
	Use and abuse of drugs	15	21.7
	Weakened family relationship	8	11.6
	Psychological disorders	7	10.2
	Jealous	3	4.3
	Others	7	10.2
Kinship with the victim	Mother	24	34.7
	Father	18	26.1
	Stepfather/Stepmother	12	17.4
	Uncle/Aunt	6	8.7
	Grandmother/Grandfather	4	5.8
	Others	5	7.3

Source: research database.

Table 3. Characterization of the domestic violence reported by SOS CHILD, Natal/RN, Brazil, 2016.

Variables		n	%
Types of violence*	Physical	43	40.2
	Psychological	42	39.3
	Negligence	17	15.9
	Sexual	5	4.7
Type of physical violence*	Slaps	32	43.2
	Punches	14	18.9
	Pushes	12	16.2
	Hair pulling	3	4.1
	Kicks	3	4.1
	Others	10	13.5
Type of psychological violence*	Offenses/Yells	28	35.4
	Insults	22	27.8
	Threat/Blackmail	12	15.2
	Humiliation	11	13.9
	Isolation from friends and family	6	7.6
Negligence*	Care omission	36	73.5
	Care deprivation of personal appearance	9	18.4
	Arbitrary study deprivation	4	8.2
Type of sexual violence*	To submit to sexual caress	4	57.1
	To force to have sex	3	42.9

Source: research database. *Not informed if mother or father. **n ≠ from 69. The child or adolescent was victim of more than one type of violence.

institutional support. This was evident when one observes greater number of cases in the western area of Natal, known as an area of unfavorable socioeconomic conditions and with a significant number of children and adolescents in situations of social vulnerability and risk of illness and death [13].

The rise and persistence of cases of violence and prevalence of female victims are consistent with other studies about the subject, which show a higher frequency of violence among female children and adolescents [14] [15].

Other studies show a higher number of cases of abuse against children in an age group higher than the one found in this series. Thus, the violence to which children are exposed is inversely proportional to their age, based on the defense disability, long periods at home, physical and emotional fragility, and dependence on their parents and/or caregivers, making them an easy target [5] [16].

The World Report on Violence and Health, 2002 [12], relates age and sex of children as factors that enhance vulnerability to child abuse. Regarding age, the indexes show that cases of physical abuse vary from country to country and in the case of sexual abuse, these rates tend to rise after the onset of puberty reaching the highest rates particularly during adolescence, although also found in younger children. Regarding the victim's gender, its prevalence depends on the type of abuse, being girls 1.5 to 3 times more likely to abuse than boys, who, in turn, are more likely to severe physical punishment.

Several studies have identified a higher proportion of victims in lower social strata. The attackers are mainly family members or colleagues, especially parents [4] [14] [15]. For some authors, the association between family structure and well-being of children has been the subject of studies, especially in developed countries, where there are researches to measure the importance of family, education and parental behavior in quality of life, being determinant factors in physical and mental health of children [17].

In 2009, IBGE expanded its knowledge of different risk and protection factors to the health of adolescents through the National Health Research of the School, conducted with students from the ninth grade of elementary school in the cities and capitals and the Federal District. In relation to the family, it was shown that 58.3% of respondents lived in households with presence of both parents, 31.9% of the total lived only with their mothers, 4.6% lived only with their fathers and 5.2% lived without their parents in residence [13].

The parents' low educational attainment parents has been suggested by some authors as family/social risk factors associated with the occurrence of domestic violence [4]. There is no consensus in the literature about the predominant type of domestic violence; however, some authors refer to supremacy in physical violence [18]. Nevertheless, statistics from various municipalities, conducted by the Laboratory of Child Studies of the Institute of Psychology of the University of São Paulo [19] suggest different results, demonstrating, at first, negligence (41.1%), followed by physical violence (31.0%), psychological violence (16.6%) and, finally, sexual assault (10.9%). The data on domestic violence against children and adolescents obtained in SOS CHILD in Natal/RN, in just three months in the second half of 2011, with 69 reported cases, show a significant demand for this event, highlighting the victim's fear to denounce, setting the "silence policy" of communities and family.

The greater visibility and severity of the problem and greater number of reporting by professionals from different services of reference and care to children and adolescents in Natal/RN/BR may explain the fact.

Violence against children and adolescents is a phenomenon that has accompanied the history of mankind and still seems to be rooted in contemporary societies. Patriarchy, gender violence, economic problems, ethnic and low education are some of the factors that have a close relationship with this kind of violence [15].

Regarding the affected anatomical structure or body site, many of the characteristics of the violent situations experienced by children and adolescents depends on the stage of their life cycle, time, place and social group [7]. Specialists in Legal Medicine claim that soft tissue lesions occur in 80% - 100% of cases of domestic violence against children and adolescents. These data corroborate this study, highlighting the head as the main location for distribution of these lesions [20].

According to the results of the study on the increase in notification percentage performed by health professionals, among the reports, health professionals are those who most refer suspected and confirmed cases to SOS CHILD [21]. Among other causes, the creation of the Ministry of Health Ordinance [22] [23] may explain this fact, as it made mandatory the reporting by all health professionals of suspected and/or confirmed domestic and sexual violence, significantly contributing to break the "silence pact" in the context of abuse against children and adolescents.

Despite the advances in the legal field, such as the Adolescent and Child Laws and Ordinances of the Ministry of Health, studies also highlight a high under-reporting of violence, also considering it a problem that requires solution in Brazil. These studies point to the need for political and administrative decisions as the implementation of epidemiological surveillance activities that act in a more active and targeted manner in order to present positive results regarding the systematization and visibility of reported cases.

It is also emphasized the importance of constructing "Institutional Networks" that integrate existing services and with policies to enable funds to be allocated to vocational training in identifying, reporting and referring, concerning the cases, providing the implementation of effective strategies to interrupt the victimization cycle [18].

5. Conclusions

Besides favoring a particular view of the research population group, the epidemiological profile outlined with children and adolescents who are victims of domestic violence reveals a harsh reality, concluding that, regarding the epidemiological profile of the victims, female children and adolescents, experiencing early childhood, under the responsibility of parents, cared by female adolescent and young adults who use and abuse alcohol and other drugs, have more chances of suffering physical violence, followed by psychological and sexual abuse. The social-economic context and social vulnerability are also factors that influence on the chances of suffering any type of violence.

This study aimed to subsidize the formulation of a system to intervene, socially control and sensitize about the problem of violence against children and adolescents. From this effort, it intends to ensure the empowerment of state and civil society organizations that seek to develop strategies to promote safety and prevention/support to child and adolescent victims of intra- or extra-domestic violence in the most vulnerable areas.

Among other contributions, it also allows a diagnosis of the local reality to support the formulation of state projects and public policies to confront and prevent violence that compromises growth and healthy development of children and adolescents and that finally allows breaking the cycle of such violence.

This study presents some limitations, such as: coverage area; limited time and a small number of individuals researched; however, these elements do not imply less importance or relevance to the understanding of the violence phenomenon by the Protection Department of Natal/RN, Brazil. These evidences point for future studies and the implementation of an educational work along with people and/or SOS CHILD professionals.

It is also emphasized the urgent need to create and integrate a support social network embedded in the proper context to interact, thus, may promote a culture of peace and prevention of violence grievance in a systematic way, with the support of institutions and sectors responsible for the care and protection of these victims.

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Coping, Personality and Post Traumatic Stress Disorder in Nurses Affected by Super Storm Sandy

Mary Ellen Roberts, Judith T. Caruso, Eileen H. Toughill, Bonnie A. Sturm

Seton Hall University College of Nursing, South Orange, NJ, USA
Email: maryellen.roberts@shu.edu

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Abstract

Objectives: To identify the incidence of post-traumatic stress disorder experienced by nurses as a result of a natural disaster, and its relationship to personality and coping style. Design and Sample: A descriptive correlational design was used to examine the relationships between and among the variables using an anonymous online survey. Measures: Post Traumatic Stress Disorder (PTSD) was measured using the PTSD-8 [1]. The Brief COPE [2] was used to measure coping style. Personality was measured utilizing the State Trait Personality Inventory [3]. Participants answered demographic questions such as gender and age, and how they were affected by the storm. Results: Over 19% percent of the nurse participants met the criteria for PTSD. The significant predictors of PTSD were the personality characteristics of state-anxiety, state-trait and trait depression, and the coping strategies of active coping, denial, acceptance, instrumental support, behavioral disengagement, venting and planning. The final regression model explained 90.7% of the variance in high PTSD-8 score. Conclusions: The findings of this study support the literature and the researchers' belief, that there is a relationship among coping, personality, and PTSD. More research is needed to understand the individual coping mechanisms that nurses utilize during times of stress and how they are related to personality and PTSD.

Keywords

PTSD, Coping, Personality, Nurse, Natural Disaster

1. Introduction

Usually picturing themselves as caregivers, many nurses became care-recipients during Sandy putting them at risk for PTSD. The authors of this study evidenced colleagues expressing stress, depression and an inability to function when they returned to work.

1.1. Background

On October 29, 2012 Super Storm Sandy made landfall in New Jersey (NJ) and New York (NY). Sandy struck with a storm surge never before seen in the area, the coasts taking the brunt of the assault. It resulted in the most property damage in the area ever caused by a natural disaster. According to the Federal Emergency Management Agency [4], there were 4.8 million power outages, widespread damage to the transportation infrastructure, and broad communication disruption. Over 650,000 homes received major damage or were destroyed. Over 14 million cubic yards of debris were deposited on roads and waterways impeding travel. Damage at refineries, terminals, and pipelines caused massive gasoline shortages [4]. Those affected experienced significant stressful events, including exposure to extreme weather conditions, displacement from their homes, and lack of basic resources.

The literature supports that victims of natural disasters experience Post-Traumatic Stress Disorder (PTSD) and that there is a relationship between PTSD and coping, and PTSD and personality [5]-[8]. Mason *et al.* [6] investigated the psychological impact of a flood in the United Kingdom. Criteria for PTSD were met by 27.9% of this adult sample, 24.5% for anxiety and 35.1% for depression. Females had higher mean scores for these variables than men. Having to evacuate, previous experience with flooding and poor health were associated with greater stress. Rational, detached, and avoidant coping strategies were most frequently used, emotional coping the least. In studies following Hurricane Katrina, Kamo *et al.* (2011) [5] found that women coped better than men, and Oni *et al.* (2012) [8] found a significant relationship between PTSD and coping strategies in a sample of pregnant women. In a study of New Zealanders after the Canterbury earthquakes of 2010 and 2011 [7], a positive relationship was found between PTSD and neuroticism (a personality trait characterized by anxiety, fear, worry, frustration and loneliness).

The DSM-V diagnostic criteria for PTSD stipulate that the exposure must be an inciting event that involves actual/expected death or serious injury. Symptoms include re-experiencing the traumatic event (intrusive recollection), avoiding stimuli associated with the event (avoidance/numbing), and hyper-arousal (persistent symptoms of increasing arousal) [9]. Countless symptoms, from a persistent and distorted sense of blame of self, to a diminished interest in activities, to an inability to remember key aspects of the event, may occur.

Over seven million American adults age 18 and older, 3.5% of people in this age group, have PTSD in a given year [10]. Associated factors include psychiatric co-morbidities and poor social-support. Mills *et al.* (2011) [11] found that 38% of Katrina survivors experienced PTSD one year after the storm. PTSD was related to have been present during the storm, material losses, losing a loved one and needing healthcare during/after the storm. Females were found to be at higher risk of developing PTSD symptoms.

1.2. Statement of the Study Aims, Research Questions, and/or Hypotheses

The purpose of this pilot study was to examine the incidence of post-traumatic stress disorder (PTSD) in a sample of nurses who self-reported experiencing Super Storm Sandy, and to examine the relationships between and among PTSD, personality and coping (see Figure 1).

1.3. Research Question

What are the relationships between and among PTSD, coping, and personality in nurse survivors of Super Storm Sandy?

2. Design and Sample

A pilot study was conducted using a cross-sectional, descriptive correlational design to examine the relationships between and among the variables of PTSD, coping, personality and selected demographics one year post Super Storm Sandy. The study took place over a 6 week period. Prior to the study, IRB approval was received. A convenience sample of registered nurse members of NJ or NY state nursing associations who live or work in areas affected by the storm were emailed a solicitation letter explaining the

Sidebar Definitions	
Post-traumatic stress disorder (PTSD)	A mental health condition, triggered by a terrifying event.
Personality Trait	A stable and characteristic aspect of personality with discrete manifestations such as attitudes, feelings, and actions.
Personality State	A temporary behavior or feeling depending on the situation and motives at a particular time.
Coping Strategies	Thoughts or actions that people engage in when under stress.
Problem-focused coping	Seeks to solve the stressful event and targets the cause/s of the stress
Emotion-focused coping	Seeks to reduce the negative emotional responses associated with the stress but not the stressor itself
Constructive/adaptive	Reduces stress levels
Destructive/maladaptive	Stress levels increase
COPE Acceptance	Accepting that a difficult situation is real and must be addressed
COPE Active Coping	Accepting the stressor, then attempting to decrease its negative outcome/s
COPE Behavioral Disengagement	Stopping the effort of coping and trying to avoid the stressful situation rather than dealing with it
COPE Denial	Refusing to acknowledge that an event has occurred
COPE Emotional Support	Getting moral support, sympathy, or understanding
COPE Humor	Joking about the situation
COPE Instrumental Support	Receiving material goods and services or financial aid
COPE Planning	Thinking about how to confront the problem),
COPE Positive Reframing	Trying to see things in a better light
COPE Religion	Turning to religion
COPE Self Blame	Seeing oneself as responsible for the problem
COPE Self Distraction	Doing something to take your attention off the strong emotion
COPE Substance Use	Using drugs or alcohol to take one's mind off the problem
COPE Venting	The outward expression of emotions

Figure 1. Sidebar definitions.

intent, voluntary nature and ability to withdraw from the study at any point without consequences. Participants then clicked to the anonymous, on-line survey.

3. Measures

PTSD was measured using the PTSD-8 [1], which measures the likelihood of having PTSD. Hansen *et al*. (2010) [1] developed this short screening instrument for easier clinical use detecting adverse psychological responses. The PTSD-8, an 8-item scale adapted from the first 16 questions of the Harvard Trauma Questionnaire, corresponds to the DSM-IV PTSD criteria. The PTSD-8 measures the following:

1) Recurrent thoughts or memories of the event.
2) Feelings as though the event is happening again.
3) Recurrent nightmares about the event.
4) Sudden emotional or physical reactions when reminded of the event.
5) Avoiding activities that remind you of the event.
6) Avoiding thoughts or feelings associated with the event.
7) Feeling jumpy, easily startled.
8) Feeling on guard correlation.

It had good psychometric properties in three independent studies: 1710 whiplash patients (a = 0.83), 305 rape victims (a = 0.84), and 516 disaster victims (a = 0.85) [1]. Items are answered on a four-point Likert scale: 1) “not at all”, 2) “a little”, 3) “quite a bit”, and 4) “all the time” and measures the three core symptom clusters of the PTSD diagnosis: intrusion, avoidance, hypervigilance. The summed score provides a score for symptom severity, with the threshold of at least one symptom from each PTSD symptom cluster equal to or greater than three. Cronbach’s alpha for the current study was 0.899.

Coping was measured with the 28-item Brief COPE [2]. The tool was derived from the Cope Inventory [12]. In a study of 168 victims of Hurricane Andrew, subscale coefficient alphas ranged from 0.50 to 0.90 with nine greater than 0.65 [2]. The Brief COPE consists of 14 scales with two items each on a 4-point Likert scale, with answers ranging from 1) “I haven’t been doing this at all” to 4) “I’ve been doing this a lot”. The 14 scales are measured independently. Higher scores indicate greater intensity of use of that coping strategy. In the current study, 12 of the items showed reliability above the acceptable range of 0.60. Cronbach’s alpha for denial was 0.57, for behavioral-disengagement 0.53.

Personality was measured utilizing the State Trait Personality Inventory an 80-item self-report questionnaire measuring state and trait anxiety, anger, depression and curiosity [3]. Cronbach’s alphas for the trait and state domains respectively were reported as: Anxiety 0.86 and 0.93, Anger 0.93 and 0.87, Depression 0.81 and 0.81, and Curiosity 0.76 and 0.86. The Inventory has appeared in over 3000 studies and been translated into over 30 languages [13]. Participants answer 40 *state* items on a 4-point Likert scale describing *their present feelings* with answers ranging from 1) “Not at all” to 4) “Very much so”, and 40 *trait* items on a 4-point Likert scale where participants describe how they *generally feel* with answers from 1) "Almost Never" to 4) "Almost Always". State and Trait personality domains are scored individually. Higher scores indicate greater disposition in that trait or state. For the current study, Cronbach's alphas were all above 0.70.

Subjects answered demographic questions describing how they were affected by the storm including whether they were evacuated and the amount of property damage they experienced.

Analytic Strategy

Analysis was conducted in SPSS V22. The threshold of at least one symptom from each PTSD subscale (intrusion, avoidance, hypervigilance) which was equal to or greater than three was utilized to determine the score on the PTSD-8. Participants were divided into two groups: high-likelihood of PTSD (satisfying the criteria for PTSD-8 score) and low-likelihood (not satisfying the criteria for PTSD-8 score). The Pearson Correlation and Spearman Rho were utilized to determine if there was a correlation between PTSD-8 scores with demographics. Levene's Test for Equality of Variances and Independent t-test was utilized to determine the relationship between PTSD scores and the severity of the disaster. Fischer's Exact was utilized to determine the relationship between PTSD scores and flood insurance. Pearson Correlation and a backward stepwise logistic regression were utilized to determine the likelihood of PTSD given coping style and personality.

4. Results

The sample was composed of 129 nurse respondents from the NY-NJ area affected by the storm. The majority were female (n = 123) aged 20 - 79, married (54%), and employed full time in nursing (n = 113). Almost 60% were employed in an acute care facility. Forty-five experienced evacuation, from one to 365 days.

Of the 129 respondents, 25 (19.5%) satisfied the criteria for PTSD. There was no significant correlation between PTSD score and age (rho (129) = −0.037, $p = 0.674$) nor years practicing nursing (r (129) = −0.026, $p = 0.767$). Because distribution for marital status was skewed (54% married, 22.5% single, and 23.2% other), it was divided into two groups: married and not married. There was no significant difference between the two marital groups (F (1, 127) = 0.006, $p = 0.941$) with PTSD.

The severity of the experience of Sandy was measured by two questions: "How long were you evacuated?" and "Did you have flood insurance?" Forty-five nurses were evacuated. The average length of evacuation was 52.87 days, the median 8 days. For the 45 evacuees, there was no significant correlation between length of evacuation and PTSD. The majority of respondents did not have flood insurance (58%). There was no significant difference in PTSD score between nurses having flood insurance (n = 14) and those without (n = 11).

There was a wide range of property damage, from *none* (n = 42) to *totally destroyed* (n = 9). Logistic regression indicated that as damage increased in intensity, the likelihood of symptoms on the PTSD-8 scale would be 1.8 times more likely to occur. However, the intensity of damage was not significantly correlated to the PTSD-8 score and was not a significant predictor of PTSD.

The most frequently used coping strategies by the entire sample (N = 129) were acceptance (n = 102), active-coping (n = 89), positive-reframing (n = 87), planning (n = 86), emotional-support (n = 85), self-distraction (n = 84) and venting (n = 80). For those who satisfied the criteria for PTSD (n = 25), acceptance, active-coping and planning were used by 96%, and self-distraction and emotional-support by 92%. See Table 1 for the descriptive statistics for the entire sample and those who did/did not meet the criteria for PTSD. The coping strategies of acceptance and humor were not significantly different between those who scored high on the PTSD-8 and those who did not.

For the entire sample (N = 129) there were high and moderate correlations for many of the coping strategies and personality traits and states. For those with a high PTSD-8 score (n = 25), there were strong positive correlations between both behavioral-disengagement and self-blame with state and trait anxiety and depression. The coping strategy of denial was positively and significantly correlated with state depression (see Table 2).

Table 3 shows the correlations between coping strategies and personality with the PTSD-8. There was a significant positive correlation between PTSD and two coping styles. Correlation is significant at the 0.01 and 0.05 level (2-tailed) Behavioral-disengagement was used by 60% (n = 15) of the nurses with a high PTSD-8 score and self-blame by 68% (n = 17). There were strong positive correlations between both trait and state anxiety and depression with PTSD.

A backward stepwise regression was run to explore a possible model using both coping strategies and personality to explain PTSD (n = 25) (see Table 4). The regression

Table 1. Descriptive statistics of the frequency of use of coping strategies.

	Total (n = 129)			PTSD-8 Not Present (n = 104)			PTSD-8 Present (n = 25)		
	Mean	Std. Dev.	Median	Mean	Std. Dev.	Median	Mean	Std. Dev.	Median
COPE Acceptance	5.33	2.16	6	5.18	2.27	6	5.92	1.53	6
COPE Active Coping	4.41	2.15	4	4.17	2.2	4	5.40	1.63	5
COPE Planning	4.36	2.12	4	4.07	2.13	4	5.60	1.63	6
COPE Positive Reframing	4.22	2.02	4	4.05	1.99	4	4.92	2.02	5
COPE Religion	4.18	2.29	4	3.89	2.24	3	5.36	2.16	6
COPE Emotional Support	4.02	1.91	4	3.75	1.88	3	5.16	1.57	5
COPE Self Distraction	3.90	1.83	4	3.66	1.8	3	4.88	1.62	5
COPE Instrumental Support	3.88	1.91	4	3.60	1.81	3	5.08	1.91	6
COPE Venting	3.58	1.57	3	3.35	1.47	3	4.56	1.66	4
COPE Humor	3.16	1.61	2	3.11	1.61	2	3.40	1.63	3
COPE Self Blame	2.95	1.54	2	2.71	1.3	2	3.96	2.01	3
COPE Behavioral Disengagement	2.50	0.90	2	2.34	0.75	2	3.16	1.18	3
COPE Substance Use	2.47	1.23	2	2.29	1	2	3.24	1.74	2
COPE Denial	2.36	0.81	2	2.17	0.43	2	3.16	1.37	3

Table 2. Correlations of coping strategies with personality traits and states.

COPE Strategy	State Anxiety	Trait Anxiety	State Curiosity	Trait Curiosity	State Anger	Trait Anger	State Depression	Trait Depression
All Respondents N = 129								
Self-Distraction	0.515**	0.346**	0.03	−0.036	0.411**	0.336**	0.382**	0.343**
Active Coping	0.387**	0.268**	0.002	−0.131	0.267**	0.255**	0.256**	0.268**
Denial	0.365**	0.395**	−0.236**	−0.302**	0.287**	0.182*	0.461**	0.383**
Substance-Use	0.376**	0.379**	−0.207*	−0.189*	0.244**	0.285**	0.355**	0.425**
Emotional-Support	0.355**	0.223*	0.168	−0.026	0.256**	0.137	0.205*	0.224*
Instrumental-Support	0.345**	0.183*	0.087	−0.012	0.265**	0.169	0.219*	0.185*
Behavioral-Disengagement	0.559**	0.553**	−0.309**	−0.401**	0.532**	0.408**	0.599**	0.598**
Venting	0.423**	0.326**	0.027	−0.165	0.381**	0.317**	0.335**	0.337**
Positive-Reframing	0.281**	0.115	0.144	−0.062	0.1	0.028	0.096	0.104
Planning	0.497**	0.345**	−0.022	−0.16	0.370**	0.311**	0.338**	0.372**
Acceptance	0.264**	0.210*	0.052	−0.096	0.168	0.211*	0.174*	0.238**
Religion	0.309**	0.11	0.132	−0.071	0.219*	0.112	0.152	0.142
Humor	0.329**	0.273**	0.157	−0.077	0.217*	0.336**	0.236**	0.216*
Self-Blame	0.626**	0.600**	−0.169	−0.249**	0.426**	0.402**	0.541**	0.589**
PTSD-8 Present n = 25								
Behavioral-Disengagement	0.478*	0.500*	−0.39	−0.488*	0.26	0.07	0.515**	0.463*
Denial	0.16	0.24	−0.13	−0.28	0.11	−0.19	0.412*	0.21
Positive-Reframing	−0.15	−0.11	0.23	0.02	−0.18	−0.398	−0.10	−0.27
Self-Blame	0.567**	0.499*	−0.28	−0.439*	0.25	0.13	0.473*	0.572**
Substance-Use	0.402*	0.549**	−0.39	−0.517**	0.15	0.22	0.35	0.436*

**Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed).

model was significant (F (11, 13) = 11.561, $p < 0.001$)

5. Discussion

Much has been written about nurses caring for disaster victims and has examined professional responses to exposure to traumatic events as part of their work or volunteerism. To the authors' knowledge, no research has examined the nurse-as-victim of a natural disaster and its relationship among PTSD, coping and personality.

Nurses in the current study were not exempt from the ravages of Super Storm Sandy: 45 indicated that they were evacuated from their homes, eight for 150 days or more. Nine experienced major damage, some lost their homes entirely. Nurses who view themselves as caregivers now became care-recipients. This experience led nurses, like other storm survivors, to undergo psychological stress. For 19% (n = 25) of the nurses, this experience led to PTSD. This number is higher than the reported prevalence of PTSD for American adults aged 18 and older (3.6%), or for American women (9.7%) [10]. This is lower, however, than the reported incidence of PTSD in disaster survivors.

Table 3. Correlations between PTSD-8 score, coping style, and personality (n = 25).

	Pearson Correlation	Sig. (2-tailed)
COPE Behavioral-Disengagement	**0.547**[**]	0.00
COPE Self-Blame	**0.474**[*]	0.02
COPE Substance-Use	0.21	0.30
COPE Religion	0.2	0.35
COPE Denial	0.07	0.74
COPE Humor	0.03	0.89
COPE Instrumental-Support	0.02	0.94
COPE Positive-Reframing	−0.01	0.98
COPE Self-Distraction	−0.07	0.74
COPE Active Coping	−0.1	0.64
COPE Emotional Support	−0.12	0.57
COPE Planning	−0.12	0.57
COPE Venting	−0.13	0.54
COPE Acceptance	−0.28	0.17
State Anxiety Score	**0.607**[**]	0.00
State Curiosity Score	−0.506[**]	0.01
State Depression Score	**0.500**[*]	0.01
State Anger Score	0.23	0.26
Trait Anxiety Score	**0.468**[*]	0.02
Trait Depression Score	**0.438**[*]	0.03
Trait Anger Score	0.05	0.80
Trait Curiosity Score	−0.37	0.06

[**]Correlation is significant at the 0.01 level (2-tailed). [*]Correlation is significant at the 0.05 level (2-tailed).

Table 4. Regression using coping style and personality to predict PTSD (n = 25).

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
	B	Std. Error	Beta			Tolerance	VIF
(Constant)	5.265	3.316		1.588	0.136		
State Anxiety Score	0.535	0.115	0.740	4.645	0.000	0.281	3.555
State Anger Score	0.193	0.075	0.386	2.561	0.024	0.314	3.183
Trait Anger Score	−0.431	0.108	−0.597	−3.997	0.002	0.320	3.126
Trait Depression Score	0.341	0.102	0.561	3.349	0.005	0.254	3.934
COPE Active Coping	2.429	0.443	1.002	5.480	0.000	0.213	4.686
COPE Denial	−1.451	0.322	−0.504	−4.504	0.001	0.570	1.754
COPE Instrumental Support	1.197	0.323	0.578	3.699	0.003	0.292	3.425
COPE Behavioral Disengagement	1.111	0.397	0.331	2.797	0.015	0.510	1.960
COPE Venting	−0.777	0.334	−0.326	−2.327	0.037	0.364	2.748
COPE Planning	−3.416	0.640	−1.409	−5.336	0.000	0.102	9.772
COPE Acceptance	1.015	0.339	0.391	2.989	0.010	0.417	2.398

Mason *et al.* (2010) [6] found an incidence of 27.9% for victims of a flood, and Mills *et al.* (2011) [11] found an incidence of 38% for victims of Katrina. After Hurricane, Andrew, David *et al.* (1996) [14] found that 36% of their sample met the criteria for PTSD.

Surprisingly in the current study, the number of nurses experiencing PTSD was not significantly correlated to their amount of property damage, whether a nurse was evacuated or the amount of time evacuated. These findings are different from those of David *et al.* (1996) [14] who found that material losses was related to PTSD, and Mason *et al.* (2010) [6] and Mills *et al.* (2011) [11] who found that both material losses and evacuation were related to PTSD. This pilot study used a convenience sample with a wide range of evacuation time, from one day to a year and the lack of statistical significance may be due to the small number of nurses who experienced a major loss (n = 9) or evacuation for a long period of time (n = 8).

Declercq, Meganck, Deheegher, and Van Hoorde (2011) [15] studied 136 nurses and ambulance personnel (28% nurses) working in military facilities. They found that how health care workers responded to a stressor contributed to the development of PTSD symptoms. Fear, helplessness and horror were associated with developing symptoms. The authors of the current study considered that coping strategies would be related to personality and that strategies would vary based on how participants experienced/viewed the event. While coping is one of the most widely studied topics, and there is much disagreement as to which coping strategies are helpful in relieving stress. Coping behaviors have been categorized in the literature as emotional or problem-solving, and as constructive/adaptive or destructive/maladaptive.

Carver (1997) [2] viewed planning, active-coping, and instrumental support as problem-focused coping strategies, and positive-reframing, religion, humor, and seeking emotional support as emotion-focused coping. Less useful/maladaptive strategies include behavioral-disengagement, venting, self-distraction, self-blame, and substance use.

All three types of coping strategies were found to explain the current model, however, the results were not as expected. Use of the positive-coping strategies of active-coping and instrumental-support increased the PTSD score by 2.429 and 1.197 respectively, while the positive-coping mechanism of planning decreased it by 3.416. Emotion-focused coping was unexpected in that acceptance increased the PTSD score by 1.015 while denial was somewhat protective, decreasing the score by 1.451. Review of the less useful coping strategies of behavior-disengagement and venting indicated a variance in that while venting was somewhat protective in reducing the PTSD score (−0.777), and behavioral disengagement was not (1.111).

Carver *et al.* (1989) [12] felt that after a major life event individuals might utilize both emotional and problem-focused coping in the short term and that emotion-focused coping might predominate as individuals are overwhelmed with major disruption and envision. Mason *et al.* (2010) [6] found that emotion-focused coping was the least used form of coping six months after a flood. In the current study, two problem-focused and two emotion-focused were most frequently used, and no one type of coping was found to be largely protective of PTSD severity. Planning had the largest effect on explaining the model and decreasing PTSD severity (−3.416).

Folkman & Lazarus (1980) [16] held that three processes occurred in reaction to a stressor. Primary appraisal involves perceiving a threat. Secondary appraisal means thinking of a possible response to the threat, and coping is executing that response. Carver *et al*. (1989) [12] considered that planning is a secondary appraisal, whereas active-coping occurs during the coping phase when a plan is actually implemented. While thinking about how they might respond to the events of Super Storm Sandy (planning) reduced the severity of the PTSD score for the sample, while the actual ability to implement that plan by active coping was not, and increased the severity of PTSD symptoms. Nurses are planners and doers so it might be expected that their inability to implement their plans would increase the severity of the symptoms of PTSD. These findings must be viewed with some caution, as the VIF for the coping strategy of planning was 9.772, and for active coping it was 4.686, indicating that some collinearity of variables may exist.

More research is needed on the use of instrumental support and its effect on PTSD symptoms. Oni *et al*. (2012) [8] found that this problem-focused coping mechanism was associated with worsened symptoms of PTSD ($p < 0.05$) after Katrina. Similar findings were noted in the current study where instrumental support increased the PTSD score by 1.197 ($p = 0.003$). Although the majority of respondents with a high score on the PTSD-8 had flood insurance, there was no significant difference in PTSD score between those with and without this instrumental-support. The newspapers continue to be awash with horror stories of Sandy survivors whose insurance did not cover any or the majority of needed home repairs. If support is still required years after the storm, and the expected insurance is not sufficient, it is understandable that this might lead to continued or escalating stress. Instrumental-support had small to moderate positive correlations with three personality states (domains related to the present situation): state depression (0.219, $p < 0.05$) state anger (0.265, $p < 0.01$) and state anxiety (0.345, $p < 0.01$). Thus nurses required to accept their current situation led to increased stress ($B = 1.105$). These viewpoints regarding insurance are based on conversations with nurses and are not fully explored within this study. Improved understanding of how nurses view this coping strategy is warranted.

The emotion-focused coping strategy of positive-reframing was the 3rd highest coping strategy used by the entire sample, used by 67% of all participants. And while 80% ($n = 20$) of those with high PTSD-8 scores used this strategy, it was not found to explain the final model. Different results were found by Borja and Callahan (2008) [17] in their study of victims of Hurricane Rita. Reframing was one of the predictors of good mental health which accounted for 43% of the variance, while Oni *et al*. (2012) [8] found that positive-reframing was not significantly associated with PTSD in the Hurricane Katrina victims they studied. More investigation of this coping strategy is warranted.

The researchers also theorized that personality was related to the type of coping strategies that nurses would use, and that adaptive coping strategies would be negatively correlated with personality traits and states of anxiety, anger and depression. Surprisingly, most of coping strategies were positively correlated with these personality domains. More research is clearly needed on this finding. Do nurses, because of their education and experience, utilize all types of coping strategies regardless of personality traits or the situation in which they find themselves in order to be able to function for the good of others?

The literature varies in findings of PTSD found in health care providers working during or after a disaster. Stewart, Mitchell, Wright and Loba (2004) [18] found that 46% of disaster workers met the criteria for PTSD after the Swiss Air crash. Jonsson, Segesten and Mattsso (2003) [19] and Clohessy and Ehlers (1999) [20] found PTSD rates of 12.2% and 21%, respectively, in ambulance drivers exposed to repeated traumatic events. While Declercq *et al.* (2011) [15] found no relationship between the frequency of encountered incidents and PTSD, they did find that supply and resource limitations had the most intense effect. More research is needed to understand how health care workers are impacted by disasters as part of their work life, and when they become the victim rather than the caregiver. In the current study, it is unclear how many of the participants were not only victims but returned to their work life of helping others, and what impact that had on acquiring or being protective of PTSD.

The relationship theorized by the researchers that personality and coping strategies would be related to PTSD was found. The final model (n = 25), using coping strategies and personality traits and states, explained 90.7% of the variance to predict a high PTSD-8 score. Predictors included trait and state anger, trait depression and state anxiety. Studies of PTSD have found anger as the major symptom in predicting PTSD. Novaco and Chemtob (2002) [21] studied 143 Vietnam veterans and found anger as the greatest predictor of PTSD, accounting for over 40% of the variance. Interestingly, in the current study, only trait anger ($B = -0.431$, $p = 0.002$) was protective of nurses from PTSD symptoms, while being angry in the current situation (state anger) was not ($B = 0.192$, $p = 0.02$). As nurses experienced anger in reaction to Sandy, their PTSD symptoms were likely to increase or increase in intensity.

Gros *et al.* (2010) [22] theorized that depression was inherent in the PTSD diagnostic criteria and, therefore, may or may not significantly affect the relationship between PTSD and anger. Spinhoven *et al.* (2015) [23] studied 359 individuals exposed to a traumatic event, 14.4% of whom developed post-traumatic PTSD. They found that depression and trait rumination of the event predicted PTSD but explained only 17% of the variance. For the current study, trait depression (a tendency towards chronic feelings of sadness and a general loss of interest) had a positive relationship with PTSD. Nurses who usually felt sad were more at risk for PTSD symptoms or the severity of the symptoms. Interestingly, this supported the researchers' idea that what we observed in nursing colleagues with trait depression was increased PTSD symptoms and that it was related to personality.

State anxiety had the highest correlation with PTSD of all the personality domains (B

= 0.535, $p = 0.000$). It is not unexpected that victims of Sandy would have a high level of state anxiety in the current situation, and that it would increase PTSD symptomology. The severity of PTSD symptoms increased as anxiety in the current situation increased. But unlike Weems *et al.* (2007) [24] who found pre-disaster anxiety in children after Hurricane Katrina predicted post-traumatic stress, trait anxiety did not explain the current model. Mason *et al.* (2010) [6] found that women had higher scores for PTSD and anxiety than men. The current findings may be related to the small number of male nurses ($n = 6$) who responded to the survey. So although there was a strong relationship between state anxiety and PTSD (0.607, $p < 0.01$) these findings must be viewed with caution.

Limitations

This is a pilot study and thus has limited generalizability. The lack of statistical significance in demographic questions, particularly the relationship between property damage, evacuation and PTSD may be due to the small number of subjects who experienced a major loss or evacuation. The sample was predominately female with only six men responding. Eighty-eight percent of respondents were employed in acute care settings so that generalizing these results to all nurses must be done cautiously.

Implications for Additional Research

Based on the findings of this pilot study, more research on nurses-victims of a disaster and the relationship of PTSD to coping strategies and personality in this population is indicated. The majority of coping strategies that the subjects employed were positively correlated with state and trait personality domains regardless of the strategies being considered adaptive or maladaptive.

More study is indicated regarding coping mechanisms in different populations. The findings that instrumental support, used by 80% of the 25 nurses who scored high for symptoms of PTSD and increased the severity of PTSD symptoms, deserves further inquiry. Carver *et al.* (1989) [12] found that instrumental support was problem-focused and helped reduce stress. Does this coping strategy vary in different populations and different situations?

The number of nurses who scored high on the PTSD-8 was higher than the average found in the general population but lower than that found in other victims of disasters. Was this number related to the response rate or to a characteristic of nurses? Are nurses more resilient because of their education and practice experience? How does work-life and setting impact a nurse's ability to withstand a natural disaster?

This study supports the use of short assessment tools. The PTSD-8 involves little participant burden and makes research immediately after a stressful event more feasible. It allows identification of responders quickly after a stressful situation and affords them the opportunity to for immediate support.

Similarly, the Brief COPE showed good reliability. Additional research with this short tool regarding the individual strategies, as well as the entire tool as a composite score, will allow study of this concept with less burden for users.

This study found that personality was correlated with coping and PTSD. It is common practice to look at personality styles of management staff to support them in being more effective in their positions. Development of short personality tools, as was done with the PTSD-8 to assess PTSD, would allow nurses at all levels of practice to understand more about themselves and how they function in everyday life and in stressful situations. In a study of 248 emergency room nurses exposed to traumatic work events, not related to a disaster, Adriaenssens, de Gucht and Maes (2012) [25] found that almost 9% met the clinical level of PTSD. Knowing more about how and why nurses react to stress will help provide support, intervention and educational programs for nurses at all levels.

It is important to remember that nurses, when faced with difficult personal or professional situations, are at risk for unresolved stress. When faced with massive natural disasters such as Super Storm Sandy, nurses go into high-gear helping others. They need to know to take care of themselves. Disaster preparedness programs prepare nurses for their professional role. Expansion of these, to help nurses understand their risk factors based on personality traits and the coping measures that might be most helpful to reduce stress is indicated. Additional research to better understand how nurses are affected during stressful times will help nursing managers plan for staffing during times of disasters and oversee their staff during these difficult situations. Finally, in depth qualitative inquiry, giving voice to nurses' experiences would help provide additional understanding about what the ravages of this storm meant to participants.

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Patient Life Experience and Activity of Daily Living before and after Total Knee Arthroplasty

Pi-Chu Lin[1*], Kimie Fujita[2], Su-Yu Chang[3,4], Yo-Yi Liu[5]

[1]Master Program in Long-Term Care and School of Nursing, College of Nursing, Taipei Medical University, Taiwan
[2]Department of Health Sciences, Faculty of Medical Sciences, Kyushu University, Fukuoka City, Japan
[3]School of Nursing, Taipei Medical University, Taiwan
[4]Department of Nursing, Taipei Veterans General Hospital, Taiwan
[5]Department of Nursing, Taipei Medical University Hospital, Taiwan
Email: *pclin02@gmail.com, fujitak@hs.med.kyushu-u.ac.jp, sychang6@vghtpe.gov.tw, Taiwan. Rado@h.tmu.edu.tw

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Abstract

Background: As the population ageing, more patients suffer from joint disease. Joint replacement surgery performed in Taiwan is about 10,000 to 20,000 cases yearly. Aims: The purpose of this study is to realize Total Knee Arthroplasty (TKA) patients' views about life experiences and difficulty in daily life before and after the surgery. Methods: In this study, in-depth interview with interview guideline was used to analyze patients' experience by using a qualitative research method, and questionnaires were used to collect quantity data. Results: 1) A total of 20 participants were recruited. Average age was 75.15 (SD = 6.468). Eighteen of the participants were female and the other two were male. The majority of participants indicated that their home facilities were convenient or very convenient. 2) Motivations of the participants to undergo TKA were joint pain, limited joint range of motion, and weakness in legs. Participants' expectations after surgery were no more pain and ease in walking, and able to manage daily life. 3) Depending on the time after surgery, joint pain and walking ability had improved to some extent. The joint range of motion increased, but kneeling remained difficult, and the participants' mood and exercise capacity were improved. Conclusions: The finding can be as a reference for clinical practitioner to provide preoperative education for total knee arthroplasty patients.

Keywords

Total Knee Arthroplasty, Quality of Life, Activities of Daily Life, Patient Experience, Qualitative Research

1. Introduction

As the number of older people in Taiwan increases, so does the proportion of individuals with osteoarthritis. Severe osteoarthritis causes pain and disability, posing a heavy burden on patients. Knee replacement is a common orthopaedic procedure that can greatly improve quality of life and provide pain relief [1]. Past studies have tracked Total Knee Arthroplasty (TKA) surgical outcomes; and most of these have been quantitative studies following up on patient joint function, pain, and quality of life with questionnaires [2] [3]. Questionnaires that have been used include the 36-Item Short Form Health Survey (SF-36) [4]-[6], Western Ontario and McMaster Universities Arthritis Index (WOMAC) [4] [6] [7], Knee injury and Osteoarthritis Outcome Score [8], Arthritis Impact Measurement Scales 2 [9] [10], and Lysholm Knee Scoring Scale [11]. Only a few qualitative studies examining the experiences of artificial hip and knee replacement patients exist [12] [13]. Fujita *et al.* interviewed 20 artificial hip patients and found that patients exhibited significant improvement postoperatively in terms of pain and disability, but also faced significant body image stress related to their artificial joint [12]. Gustafsson *et al.* used a phenomenological hermeneutical approach to study participant experiences of hip and knee replacement intervention across the entire perioperative period. Sixteen participants aged ≥65 years old were recruited, and the study illuminated the meaning of reflections related to hip and knee replacement surgery. Four themes were identified: Choosing the challenge, past memories relating to the current situation, moving from happiness to everyday life, and moving from despair towards reluctant acceptance of unexpected poor health in everyday life. The participants exhibited inner negotiations about whether to undergo surgery and existential anxiety indicating to them that life cannot be taken for granted [13].

Although joint replacement has proven substantially more effective than implanted prosthesis, with up to 80% of artificial joints lasting over 15 years, TKA prostheses originated in the West, with artificial joint design and development primarily conducted for Westerners and in consideration of Western lifestyles and needs. Artificial joint design is largely conducted by using the Activities of Daily Living (ADLs) of Westerners for determining hip and knee range of motion, geometry, dimensions, and design. Although in the Taiwanese lifestyle, dissimilar to that of the Japanese, kneeling and sitting cross-legged is not common [14], typical families reside in apartment-style residences and therefore must climb stairs to enter into their homes or access indoor elevators. This daily stair climbing poses significant challenges for patients with severe joint disease and for patients who have received artificial joint replacements. Artificial joints are designed to satisfy the needs of Western patients, and whether they are similarly suitable for East Asians is unclear. Because many patients anticipate the ability to completely engage in regular daily activities after receiving a joint replacement, determining whether artificial joints satisfy the needs of East Asians is also critical.

Aims

Therefore, the purpose of this study was to elucidate TKA patients' views about their life experiences and difficulty in daily life before and after the surgery.

2. Methods

In this study, in-depth interview with interview guideline was used to analyze patients' experience by using a qualitative research method, and questionnaires were used to collect quantity data.

2.1. Participants

Purposive sampling and snow-ball methods were used to recruit patients at orthopaedic ward or OPD. Inclusion criteria: 1) could speak Mandarin or Taiwanese; 2) admitted for TKA or post TKA. Exclusion criteria were difficulties in speaking and understanding the Mandarin Chinese and obvious dementia. Interview patients until data saturated, after 20 interviews, no new categories or subcategories were developed, and then we stopped data collection. Total of 20 TKA patients were interviewed in this study.

2.2. Data Collection

All patients were informed about the study purpose and interviewing process verbally by the correspondent author. After giving their written consent, the hospitalized patients were guided to the meeting room of the ward, while for OPD patients who were arranged in an unoccupied room, where interviewing were conducted by the correspondent author who have had 30 years of orthopaedic clinical experience. Interview guide was developed by Prof. Fujita *et al.* (**Table 2**) [11]. Interviews were tape-recoded. Each interview took about 30 - 40 min. After each interviews completed, the researcher repeated listening to recordings and interviews were translated into text file. Demographic data and data on diseases and past operative experience were collected from the patient records.

2.3. Analysis

Data were analyzed using qualitative content analysis as described by scholars [15]. First, the recorded tapes were repeatedly listened to and all the interview records were read through in order to get an overall sense of the patients' views. Next, the verbatim data were read line-by-line in order to identify statements related to TKA. These statements were marked, and tentative codes were written in the margin for the detection of emerging patterns. Differences and similarities among codes were compared, and codes that were similar in content were subsequently grouped and classified into various categories.

2.4. Trustworthiness

In this study, Lincoln and Guba [16] qualitative research raised the trustworthiness was used as the evaluation criteria.

In truth, the majority of respondents through snowball manner, they were introduced by familiar person and they should be pleased to provide experience and establish a trust relationship with the researchers, in order to authenticity and reliability of the information provided. To validate the results, responses to questions were further probed several times during the interview, to gain deeper understanding.

In this study, data from in-depth interviews and from many different backgrounds living experience undergoing knee replacement surgery before and after surgery, it is gathered from a wide range of information can increase the future applications. Coding and development of the categories were done by the first author. The third author read all the condensed units of meaning and also questioned the preliminary analysis.

2.5. Ethical Considerations

Ethical considerations were observed according to the recommendations of Helsinki declaration, as suggested by Wilkie (1997) [17]. The Research Ethical Committee at the TMU Hospital approved the study (IRB No. 201503030). Before the study all participants were informed the right to stop interview any time. To take account of privacy and human rights, patient real name would not appear in the results and the code instead of the patient's name.

3. Results

3.1. Basic Information and Lifestyle of Participants

This study interviewed 20 patients who underwent artificial joint replacement. The average age was 75.15 (SD = 6.468), between 67 - 83 years age. Eighteen of the participants were female and the other two were male. Among them, six were preoperative patients (30%), eight patients were 2 - 3 months post surgery (40%), and six patients were 1 - 3 years post surgery (30%). More demographic data can be found in **Table 1**.

The participants were asked whether they were inconvenienced in their daily lives by their inability to squat. In response, all the participants indicated that they used sitting toilets at home, and because most of their beds and dining tables were of normal height, they were able to eat while sitting. A more common inconvenience was the need to climb stairs to return home or to climb indoor stairs inside homes. However, when the participants were asked if their living circumstances were convenient, the vast majority of them indicated that their home facilities were convenient or very convenient; only three indicated that their living circumstances were inconvenient. The respective lifestyles of the research subjects are shown in **Table 1**.

3.2. Motivations of the Participants to Undergo TKA

Three major themes can be drawn from the experiences of the participants (**Table 2**).

3.2.1. Knee Joint Pain

Many participants complained that pain while walking and the inability to walk long distances. C18 said: "*The pain is so serious I can't even walk. Walking is so painful, I can't walk at all*". C3 said: "*The director* [*the doctor*] *said that the bone is all worn down. It was really painful before I had the surgery*". Other participant said: "*I just*

Table 1. Basic information and lifestyle of the participants.

Case No.	Basic information			Home environment				
	Age	Sex	Pre/post-op (mo.)	Stairclimbing/ indoor obstacles	Toilet	Dining table	Bed height	Living convenience at home
1	83	2	12	No/Yes	Sitting	Normal height	Standard	Very convenient
2	79	2	2	No/Yes	Sitting	Normal height	Standard	Convenient
3	87	2	12	Yes(3F)/No	Sitting	Normal height	Standard	Very convenient
4	76	2	2	Yes(2F)/Yes	Sitting	Normal height	Standard	Convenient
5	75	2	Pre-op,	Yes(2F)/Yes	Sitting	Normal height	Standard	Slightly inconvenient
6	76	1	Pre-op,	No/No	Sitting	Normal height	Standard	Very convenient
7	75	2	Pre-op,	Yes(2F)/Yes	Sitting	Normal height	Standard	Convenient
8	80	2	Pre-op,	No/No	Sitting	Normal height	Standard	Convenient
9	73	2	Pre-op,	Yes(2F)/Yes	Sitting	Normal height	Standard	
10	69	2	2	No/No	Sitting	Normal height	Standard	Very convenient
11	66	2	2	Yes(4F)/No	Sitting	Normal height	Floor Level	Very convenient
12	67	2	2	Yes(2F)/No	Sitting	Normal height	Standard	Very convenient
13	84	2	3	Yes(4F)/No	Sitting	Low stool	Standard	Convenient
14	70	2	12	Yes(4F)/Yes	Sitting	Normal height	Standard	Slightly inconvenient
15	70	1	Pre-op,	Yes(3F)/No	Sitting	Normal height	Standard	Convenient
16	73	2	2	Yes(3F)/No	Sitting	Normal height	Standard	Convenient
17	76	2	24	Yes(2F)/No	Sitting	Low stool	Standard	Convenient
18	78	2	36	Yes(4F)/Yes	Sitting	Low stool	Standard	Convenient
19	76	2	2	No/Yes	Sitting	Normal height	Standard	Slightly inconvenient
20	70	2	22	Yes(2F)/No	Sitting	Normal height	Standard	Very convenient

Table 2. Interview guide and theme of participant experiences.

Interview guide	Theme of participant experiences
1) Motivation of participants to undergo TKA	Primary reasons participants pursued surgical treatment: 1) Knee joint pain: Walking is painful and inability to walk long distances 2) Limited joint range of motion: Difficulty climbing stairs and inability to bend down or squat 3) Weakness in legs: Limpness and difficulty walking
2) Expectations of participants about TKA	1) No more pain and ease in walking 2) Able to manage daily life
3) Life changes from preoperative to postoperative periods	1) Initial postoperative outdoor walking capabilities differ depending on the individual 2) Pain improved: Participants are able to walk farther and do what they want to do postoperatively. 3) Joint range of motion improves postoperatively, but squatting remains difficult 4) Improved mood: Normalisation of daily life post operation and ease in going outdoors, leading to improved participant mood 5) Increase the amount of exercise: Participants forced to reduce exercise volume prior to surgery, but could gradually increase exercise after surgery 6) ADL difficulty: Participants able to conduct ADL preoperatively, but ADL remained difficult within 3 months after surgery

can't walk for a long time. It hurts, so I can't walk far" (C2). C1 said: "*Walking is very difficult, so I don't walk far and don't want to leave the house.*" A family member of C13 said: "*Before Mom had her surgery, we would hear her screaming, 'Ah! Ah! Ah!'*" C6 said: "*When I want to get out, I meet difficulties getting on and off vehicles, so I try to avoid it as much as possible*".

3.2.2. Limited Joint Range of Motion

Participants complained that difficulties climbing stairs and standing up after sitting for long periods of time and the inability to bend down or squat. C18: "*I couldn't stand or climb stairs, so I had to get surgery*". "*Standing up after sitting down hurts, so I can't stand up*" (C13). C14 said: "*Climbing up and down stairs is more difficult and takes more energy, so I have to do it slowly while holding onto the handrails*". "*All the cartilage inside has degenerated, so it hurts, and I can't bend down*" (C19). Other participants (C16) said: "*I'm afraid of squatting now, and I can't even kneel either*". "*My joints are tight, and so I can't stand up after sitting for a long time*" (C17).

3.2.3. Weakness in Legs

Because of weakness in legs, participants complained difficulty walking and limping. C6 said: "*I don't have strength after walking for longer distances—my legs feel limp, and I feel very tired after buying groceries at the market. I decided to get surgery because walking is inconvenient*". C2 similarly said: "[*There is*] *no strength in my legs.* [*I*] *walk unsteadily. I drag my feet* [*and am*] *very tired when I walk.* [*I*] *walk slower. I can't stand for a long time, I can't stand it. All of my movements are more difficult*". C4 said: "*It doesn't hurt, I just don't have any strength in my legs*".

3.3. Expectations of the Participants about TKA

The expectations identified from the interviews are as follows.

3.3.1. No More Pain and Ease in Walking

The participants expected that they would be able to walk after the surgery. "*To be able to walk, to be able to run! Just as long as I don't hurt anymore*" (C19). "*I just hope that it won't hurt anymore after I have the surgery and I will be able to walk well*" (C3). "*I hope that it won't hurt anymore after the surgery and I will be able to walk normally*" (C15).

3.3.2. Able to Manage Daily Life

The participants anticipate self-care independently after the operation is completed. "*The main thing is so that it stops hurting, and then being able to manage my own life*" (C1). "*I hope that I will be able to conduct normal activities and go through daily routines normally*" (C20). "*My family members all encourage me to go through with the operation. They tell me that after I have the operation, we can travel throughout Taiwan on vacation every year and walk wherever we want to walk*" (C5).

3.4. Life Changes from the Preoperative to Postoperative Period

The changes in the lives of the participants from the preoperative stage to 2 - 3 months or 1 - 3 years post operation summarised from the interviews are as follows.

3.4.1. Initial Outdoor Walking Capabilities Differed Depending on the Individual

For example, C2 (2 months post operation) said: "*I haven't left home since the operation. I can't go out to buy things, and it's harder to walk—it's very tiring to walk*". However, some of the participants were able to engage in outdoor activities soon after the operation; C13 (3 months post operation) said: "*I walked down the stairs and out* [*of the house*] *three days after the operation. I go to the park every day and walk outside every day. I bring an umbrella with a small, black anti-slip tip when I go out. If it hurts a little, then I walk slowly*". C4 (2 months post operation) said: "*Today, I took the train from Hsinchu, then the MRT, and then the bus up here* [*to Taipei for a check-up*]. *My husband came with me, and I've been able to get on and off vehicles just fine*".

3.4.2. Pain Improved

Participants are able to walk farther and do what they want to do. Because walking was painful prior to the operation, the participants were unable to walk long distances and therefore did not want to go outside. When the participants had to go out, they had to be cautious; some participants only rode motorcycles when travelling outside. One year after the operation, most of the participants indicated that they were satisfied with walking, going outdoors, and their daily lives. Although a few participants continued to experience a mild degree of pain, it improved after the operation.

For example, C14 (1 year post operation) said: "*I couldn't really walk before the operation, but now I can walk much better. I started walking downstairs about* 1 *or* 2 *months after the operation*". Similarly, C1 (1 year post operation) said: "*It stopped hurting after the operation—now I can walk far without anyone accompanying me*". C20 (22 months post operation) said: "*I can walk to places far away and have no problems leaving the house. My daily life is normal*".

Some participants indicated that they still felt joint pain after the operation, such as C14 (1 year post operation), who said: "*It still hurts when I get up* [*from the toilet*] *after the operation. This tendon back here is very tight and painful*". C3 (1 year post operation) said: "*I thought that it would stop hurting after a few months. I didn't think that it would still be swollen and painful even after a year. The recovery process has been slower than I thought, but it is improving. To be honest, I regretted my decision when I first returned home because of the pain, but the pain before the operation is different from the pain after the operation. It was really hard to stand before the operation, but it really improved after the operation*".

3.4.3. Joint Range of Motion Improved but Squatting Remained Difficult

Climbing stairs was difficult because of limited joint range of motion before the operation. Furthermore, participants were unable to squat and had a difficulty getting up after sitting for a long time. These conditions improved post operation, but the participants were still unable to squat.

For instance, participants indicated that: "*It was really hard climbing stairs before the* *operation. It was really slow, and I had to hold on to the handrail*" (C14). "*I crawled up stairs while holding onto the handrail, grabbing onto it until my hands hurt*" (C5). "*Walking down stairs was painful, and sometimes my legs would feel weak. It wasn't easy*" (C7). "*I couldn't squat before the operation and it hurt when I stood up after sitting down for a long time, so I tried to sit in a low chairs as little as possible. Standing up from the sofa was difficult, so I stood up slowly instead of all at once. Otherwise, I just got up while holding onto the side, like this*" (C6).

Postoperative participants said: "*Although my knee movement has improved, it is still not ideal—I still can't squat*" (C20, 22 months post operation). "*I still can't do a squatting motion; I couldn't squat before the operation and I still can't*" (C1, 1 year post operation). "*It can't bend! I still can't squat. Maybe it has to do with rehab. My legs are still really tight, and I can't do anything about it*" (C18, 3 years post operation).

However, one participant reported no improvement after the operation: "*I could still squat before the operation, but not anymore. Before the operation, I would go to church and kneel, but now my priest tells me not to kneel. My friends can do the splits and sit cross-legged, and I can't do either*" (C3, 1 year post operation).

3.4.4. Improved Mood

Due to the normalisation of daily life post operation and fewer problems going outdoors, the participants experienced more positive moods. For example, C1 said: "*I was more or less depressed before the operation because I was different from other people. Now* [1 *year post op*] *I walk very naturally and can go out for walks every morning. Morning walks are the best—I can walk far away and go out to see the sights. My mood is better—I mean I'm in better spirits. I don't need to put on ointment all day. I have kidney disease, so I can't take painkillers, and now I don't need to, so my kidneys have gotten better*". C20 said: "*Now* [1 *year post op*] *I can go to the market to buy groceries by myself. I go every day now since it doesn't hurt. I can go farther and do what I want, like exercising, shopping, going to the market. My mood is really different now*".

3.4.5. Increased the Amount of Exercise

Participants were forced to reduce their regular exercise prior to the operation because of knee pain. Although the participants were unable to return to their regular exercise routine in the initial period after the operation, the amount of exercise they could perform began gradually increasing after 1 year.

Regarding the preoperative period, C7 said: "*I usually exercised, but I stopped* [*doing so*] *about a month before the surgery because my knee started hurting*". C13 said: "*When I went out on trips before the operation, I couldn't walk at all. I would ride the car to a set point and just sit there waiting, just to get some fresh air away from home. And then I would get in the car when it was time to get in, and then* [*later, at destinations*] *I would get out and take a look, because I couldn't walk*". Similarly, C5 said: "*I couldn't participate when going to some scenic spots. If they required walking, I would just sit down and wait for everyone to come back*".

Two months post operation, mobility had yet to recover, as in the case of C2 (2 months post operation): "*I used to grow vegetables before the operation—it was a form of exercise. Now, after the operation, I can't bend down, so I can't go plant.*" C3 (1 year post operation) said: "*There is a school next door, so I go there every day to exercise. I walk quickly for* 30 *minutes, then do some exercises*".

3.4.6. ADL Difficulty

Patients suffering from osteoarthritis of the knee did not affect the execution of ADL preoperatively, but ADL difficulties within 3 months post operation.

Most of the participants were able to care for themselves prior to surgery; they were able to perform housework and prepare meals. For instance, C1 and 6 said: "*I could shower, do housework—I did everything by myself, including preparing three meals a day. Buying ingredients was easy, and I did my laundry and cleaned my house myself. I would alternate between doing chores and resting*". C5 said: "*I really didn't have any problems taking care of myself before the operation. I would even help bathe my grandchildren, cook, and do laundry by myself. When my grandchildren would come back they would need to eat, but my husband did the mopping*". C7 said: "*I would do all the housework by myself before the surgery without any problems*".

There were difficulties in the execution of ADL within 3 months post operation. C2 (2 months post operation): "*When I use the toilet, I need to hold on to a handrail with one of my legs bent like this*". C13 (3 months post operation): "*I have to hold on to the walls when I walk around at home. I need something to hold, and so I hold on to the handrails when I climb up and down stairs*". C2 (3 months post operation) said: "*I need to use my arms when standing up from a chair, and I need to hold on to a handrail when standing up from the toilet*". Furthermore, C19 (6 months post operation) said: "*I currently have some problems in my daily life because of this leg, so I'm still afraid of going out*". C4 (2 months post operation), who lived in a three-storey building, said: "I've been afraid of going upstairs since the operation. I can't, so I just stay on the first floor".

4. Discussion

This study conducted in-depth interviews regarding the subjective life experiences of TKA patients before and after the operation. The main interview topics—experiencing joint pain and difficulty walking before the operation, changes from before and after the operation, and changes in ADL difficulty before and after the operation—are discussed as follows.

4.1. Experiencing Joint Pain and Difficulty Walking before the Operation

Most of the participants decided to undergo surgery because of knee joint pain. Walking was painful, preventing them from walking long distances or to their desired locations. Furthermore, participants indicated difficulty climbing up and down stairs; although they were not completely unable to climb stairs, doing so constituted a great challenge for them. The inability to bend down was also a problem, as was the sensation of leg weakness and limpness. These factors affected the quality of life and mood of the participants. These results are similar to those of Lin [18], who examined preoperative pain in 93 (83.9% TKA) artificial hip and knee replacement patients. The patient experiencing the most pain had a total of 3.87 points (on a 0 - 10-point scale), whereas the average pain index for the patients was 1.93 points, indicating that they endured significant joint pain prior to the operation. These results are also consistent with Desmeules *et al.* [19], who showed that patients waiting for knee replacement have poor function, knee pain, stiffness, and HRQoL.

As such, patient expectations towards receiving artificial knee joint replacement surgery are based on their hopes of reducing joint pain, having healthy legs, and regaining freedom of movement; all patients hope to normalise their lives. As emphasised by Parke [20], postoperative measures for artificial knee replacement surgery should focus on reducing pain and rehabilitation exercises to restore walking ability. These findings are consistent with those of Rudan, Harrison, and Grant [21], indicating that reducing pain and restoring walking ability are the main hopes of patients undergoing artificial hip and knee replacement.

4.2. Major Changes before and after Surgery

After surgery, the participants primarily exhibited improvement in terms of pain. This study found that walking ability was typically poorer during the initial 2 - 3 months post operation compared with before the surgery. However, the ability to walk longer distances gradually improved over time. Regarding mobility, because most of the participants lived in homes that required stair climbing, some were able to walk down stairs and go outdoors soon after surgery, whereas others rarely left their homes in the 2 - 3 months post operation. As such, when medical personnel provide health education for patients before the operation, they should clearly let patients know that joint surgery does not restore regular function rapidly, thereby preventing the patients from holding incorrect expectations and being disappointed. Interviews with the participants 1 - 3 years post operation revealed significant improvement in walking and mobility ability. When people are able to walk outdoors and do what they like, they naturally have a higher quality of life. Past studies have utilised questionnaires to track patient pain, body function, and quality of life before and after undergoing artificial knee joint replacement surgery, but few have examined the effects of knee joint range of motion on patient lifestyle after surgery. The findings of this study confirm the findings of past quantitative research.

A systematic review by Ethgen *et al.* of 74 studies on TKA or THA patient quality of life reported that overall, these procedures were found to be quite effective in terms of improvement in health-related quality-of-life dimensions, with the occasional exception of the social dimension [2]. Jones and Pohar reviewed 33 articles and found that after total hip and knee arthroplasty, disease-specific measures reported large and crucial changes, primarily for pain and function over short- and long-term recovery [3].

Regarding the improvement process of post arthroplasty surgery, scholars have found that joint pain improved between 6 weeks [10] and 3 months after surgery, whereas walking and mobility required 3 and 6 months, respectively, for recovery [10]. Furthermore, Chen found that patients exhibited significant improvement in all categories (role physical, physical functioning, bodily pain, general health, social functioning, mental health, and role emotional) of the SF-36 quality of life survey 3 months after the surgery, except for "vitality", which did not reach a level of statistical significance. Furthermore, the pain, stiffness, and physical function indices of WOMAC exhibited significant improvement 3 months after hospital discharge compared with preoperative conditions [4]. Hsu tracked patient quality of life for 3 months following surgery and found that patients exhibited significant improvement on both the SF-36 and WOMAC scales [6]. In addition, Chen tracked TKA patients for 6 months to 1 year after surgery and found that they exhibited moderate quality of life after the surgery, with social interaction function scoring the highest and symptomatic function scoring the lowest [9]. Nunze *et al.* conducted a prospective study with 7 years of follow-up. Significant differences were observed between pre- and post-operative WOMAC pain, stiffness, and function scores, especially for the pain dimension. Overall, 86% of the patients were satisfied with the outcomes of TKA [7].

Regarding knee flexion, as dictated by the payment system of the Taiwan National Health Insurance system, TKA patients must exhibit knee flexion angle ≥90˚ before they can be discharged. The participants interviewed in this study indicated that they were still unable to squat; although they had sitting toilets, normal height chairs and beds, improved postoperative joint range of motion, and did not need to sit on the floor, they still encountered multiple inconveniences in daily life. Hemmerich *et al.* indicated that a mean maximum flexion of 157˚ ± 6˚ at the knee joint was required for squatting with heels up [22]. Mulholland and Wyss emphasized that artificial joints and product functions must match culture and patient lifestyle habits. Although East Asians may need to squat in everyday life or sit cross-legged during religious worship activities, these motions requiring great ranges of motion remain difficult for the patients [14].

4.3. Changes in ADL Difficulty before and after Surgery

Prior to surgery, the participants were largely able to independently care for themselves without assistance from others; many are even able to assist through, for example, bathing grandchildren or preparing meals. Difficulties were encountered in the inability to walk long distances (because of pain), thus affecting personal shopping activities, exercise habits, travel, and using public transportation. The participants in more desirable circumstances had beds, tables, chairs, and toilets of appropriate height, enabling them to perform regular functions in daily life unimpeded regardless of knee function. Subjective experiences drawn from the interviews confirmed the results of past studies, including those of Chen *et al.*, who examined 92 TKA patients [23]. The research results indicated that patient physical function (eating, bathing, toileting, dressing, grooming, walking, going up and down stairs, moving in and out of bed, and moving in and out of chair) prior to surgery was largely favourable (17 out of 18), indicating that most of the patients were able to care for themselves before surgery. The lowest score was for climbing stairs and chair sitting, indicating that these activities are more difficult.

The participants in this study reported experiencing some difficulty in performing daily life activities during the initial postoperative period. These results are consistent with those of Lin *et al.* [24], who examined the physical postoperative recovery of 83 TKA patients. Lin *et al.* found that the patients averaged a physical function score of 14.95 (out of 18) 2 weeks after hospital discharge, with stair climbing exhibiting the lowest score of 1.02 (0 - 2 points). Four weeks after discharge, patient scores improved to an average of 16.59 points, with stair climbing exhibiting a score of 1.43 points—both lower than the preoperative scores. The participants in the current study attained normal function in daily routines and outdoor activities 1 - 3 years post operation, indicating a significant improvement compared with the preoperative scores. These personal experiences drawn from knee arthritis patients spanning from the preoperative to postoperative periods are extremely valuable and can be used as references in preoperative health education for patients, providing them with empirical data drawn from real patient experiences.

5. Conclusion

The current results revealed that different participants experienced knee joint pain, difficulty in walking, an inability to walk long distances, and limited joint range of motion preoperatively, and that though the participants had no difficulty caring for themselves, the limitations on mobility and freedom of movement significantly affected their mood. Pain eased after surgery, but participant's ability to walk and participate in outdoor activities varied widely within 2 - 3 months of hospital discharge. However, all the participants exhibited positive results in 1 - 3 years post operation, improved moods, and approached normality in daily life. Although joint range of motion improved significantly, participants were still unable to squat.

6. Study Limitation and Recommendation

This study conducted purposive sampling at one medical centre and one teaching hospital. As such, the study was unable to be expanded to include more medical institutions. Therefore, future studies should examine patients from hospitals of different levels and with varying characteristics to extend the scope and generalizability of this research. Furthermore, the patient experiences obtained in this study come from different participants and may have been affected by the personal background characteristics of each participant. As such, this study recommends that future research be conducted in a longitudinal fashion on the same group of patients.

The results of this study and real patient experiences can be used in future medical communications, especially in the design of health education for knee joint replacement patients. Preoperative measures should focus on the topics that patients are most concerned with, such as pain improvement and walking ability, to provide information and professional advice with an empirical basis. For instance, patients can be reassured that pain will be eased and joint range of motion will improve, though squatting will continue to be difficult. Furthermore, patients should be informed that ideal walking and mobility recovery cannot occur until after a period of time post operation. These measures will assist patients in developing realistic expectations and satisfaction towards TKA surgery, and the provision of preoperative information will enhance postoperative results and improve patient confidence.

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Knowledge, Health Beliefs and Screening Status of Prostate Cancer among Middle-Aged and Elderly Men

Eunjoo Lee[1], Youngsuk Park[2]*, Jeongsook Park[3]

[1]Department of Nursing, Kyungnam University, Changwon, South Korea
[2]Department of Nursing, Daegu Science University, Daegu, South Korea
[3]College of Nursing, Keimyung University, Daegu, South Korea
Email: abigail@kyungnam.ac.kr, *manic4428@naver.com, jsp544@kmu.ac.kr

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Abstract

Purpose: The aim of this study was to examine and evaluate the level of prostate cancer knowledge and health beliefs among middle-aged and elderly men. Methods: In this descriptive study carried out in December 20, 2015 through January 20, 2016, we enrolled 147 men aged 50 - 70 years old. Data were collected by using three questionnairs including knowledge, health beliefs, and screening status of prostate cancer. Results: Our findings showed that only 20.4% of interviewers had experience of digital rectal examination or prostatic specific antigen test for prostate cancer screening. The prostate cancer knowledge was found to be significantly high in prostate cancer examinees compared to non-examinees. The correct answer rate of prostate cancer knowledge was only 44.7% at average. Despite of good perceived seriousness about prostate cancer, the screening rate was only 20.4% and the examinees indicated significantly high perceived sensitivity compared to non-examinees. The level of the perceived barrier was lower in men who had experience in health examination or prostate cancer examination than without experience. Conclusion: The significant factors including age, educational level, income and cancer insurance status need to be considered in nursing education program in order to deliver accurate knowledge about prostate cancer. Also, the effective interventions are necessary to increase sensitivity and reduce barriers of prostate cancer and screening.

Keywords

Prostate Cancer, Knowledge, Health Beliefs, Men

1. Introduction

Prostate cancer is a cancer in very high incidence across the world including North

America, Oceania and Europe [1]. It is ranked as the 5th following gastric cancer, colorectal cancer, lung cancer and liver cancer among men in Korea. The incidence rate of prostate cancer tends to increase dramatically from 3.2% in 1999 to 11.6% in 2012, whereas the incidence of lung cancer and liver cancer has been shown a decreasing tendency [2]. Although the exact cause of prostate cancer has not been identified, common risk factors are age, family history, race (African American), male hormones, diabetes, obesity, westernized diet and infections [2] [3]. The most powerful factor is the age and the men over age 50 is more affected than younger men [3].

Early stage of prostate cancer has often no symptoms which tend to appear as the cancer progresses. Screening can help to find cancer at early stage when men may have a better prognosis. Moreover, prostate cancer detected by screening test can be treated most effectively. Two of the most common screening tests for prostate cancer are PSA (Prostate Specific Antigen) test and DRE (Digital Rectal Exam). PSA test is to measure the level of PSA, a protein produced by the prostate gland in blood and an elevated PSA level means higher risk of prostate cancer. Physicians have commonly used in conjunction with a DRE to screen for prostate. Because the DRE can find cancers in men with normal PSA level, several studies suggest that men have both tests. And also DRE is a relatively simple procedure to detect the growths in or enlargement of the prostate gland by using a finger [2]. Therefore, if prostate cancer is detected earlier through regular PSA test or DRE, mortality rate for prostate cancer may decline through being treated prostate cancer early.

The guideline of American Cancer Society recommends to consult with a family doctor and then decide whether to screen prostate cancer earlier, after determining potential risk and benefit of screening through getting information about uncertain parts [4]. PSA test is generally recommended to commence from the age of 50, but it is recommended to commence from the age of 45 if the person is an African American or has a first-degree relative with prostate cancer. And if there is any family member who developed prostate cancer in earlier age, screening should be started from 40. According to the guideline of Europe on Prostate Cancer, PSA test is generally recommended at the age of over 50, while at the age of over 45 if any family history [5]. In Korea, recently the efforts for earlier detection of prostate cancer by Prostate Cancer Treatment Guidelines [6] and Prostate Health Promotion Programs have been exerted.

In order to enhance the compliance rate in prostate cancer screening, the knowledge about prostate cancer and screening plays an important role [7]. Although the knowledge level is depending on cultures and cancer policies country by country, some studies have showed that the level of prostate cancer knowledge was below 60% in most countries [8] [9]. At present, prostate cancer is not included in the National Cancer Screening Program (NCSP) in Korea. Therefore, Korean men were not particularly concerned for prostate cancer. Besides, studies of prostate cancer knowledge have seldom been conducted in Korea.

Some studies showed that there was a close relationship between health behaviors and health beliefs in prostate cancer [10]. Health beliefs are a crucial factor which has an effect on health behaviors for preventing diseases [11] and can account for both change and maintenance of health-related behaviors [12]. It is reported that the higher the perceived benefit for an earlier screening method is, the higher the participation rate is, while the higher the disability is the lower the participation rate is [13]. In particular, in U.S. with the highest incidence of prostate cancer in the world, the status about low knowledge and inappropriate health beliefs for prostate cancer in men is being consistently identified and a variety of intervention studies are proceeding to improve knowledge and health beliefs [14]. However, in Korea it was challenging to find out the literature on health beliefs for prostate cancer.

Studies conducted in Korea, including "Disease Experience of The Elderly with Prostate Cancer" [15], Symptom and Quality of Life on Patients undergoing the surgery on Prostate [16] and "Symptom of Patients receiving Prostate Hormone Therapy" [17], and the like, focused primarily on the symptom, experience, and quality of life of patients with prostate cancer. However, there was little research on the status of prostate cancer screening for early detection, the knowledge and health beliefs for prostate cancer.

Thus, this study aims to investigate screening status of prostate cancer, and to determine the degree of the knowledge and health beliefs of prostate cancer and to look at the difference of the knowledge and health beliefs targeting mid-aged and elderly men, an affected age group of prostate cancer. Through this, we intend to raise awareness for prostate cancer and prepare basic data to develop educational programs for improving knowledge and health beliefs for prostate cancer.

2. Methods

2.1. Research Design

This study is a descriptive study to determine knowledge and health beliefs of prostate cancer and the screening status targeting mid-aged and elderly men.

2.2. Research Participants

The participants of this study were sampled using a convenience sampling method among non-probability sampling methods. The men who enrolled as subjects are fathers or their parents' brothers of students in nursing departments of K University in Changwon and D university in Daegu. Inclusion criteria for subjects were 1) men at the age of 50 – 70; 2) those who communication was possible and had no psychiatric problems; 3) those who understood the purpose of research and allowed for such participation whereas the exclusion criteria were males who were then diagnosed as prostate cancer or were being treated for prostate cancer. The sample size was verified using G power 3.1 program and ANOVA. We calculated with effect size as 0.30, level of significance as 0.05, and power ($1 - \beta$) as 80. The sample size was 160 with considering dropout rate of 10% but 13 insufficient responses were excluded. Finally, 147 of men were included for final analysis.

2.3. Research Tool

The questionnaires were including the Knowledge of prostate cancer, Health beliefs of prostate cancer and Screening status on prostate cancer.

1) Knowledge of prostate cancer: a draft of the 19-item questionnaire was based on literature review by researchers [18]-[21]. Thereafter, the validity of the questionnaire was verified by 3 urologists, 1 professor in adult nursing and 1 nurse with more than 5 years of experience of prostate cancer unit. As a result of calculating CVI (Content Validity Index) using 4-pointLikertscale for each item, a total of 18 items was finally organized after excluded 1 item with below 80% CVI. The excluded item "Surgical procedures are surely necessary for treatment of prostate cancer" might cause confusion as whether to operate depends on the patient's severity and also raising the probability of incorrect answer due to words of "surely necessary" so the item was deleted eventually. Each final item was answered as "Yes", "No", and "Do Not Know", One-point was scored to a correct answer while an incorrect answer scored to zero-point, and those scores were summed. The higher score means the more knowledge on prostate cancer. In our study, the KR-20 was found to be 0.79.

2) Health beliefs of prostate cancer: researchers prepared the draft of 14-item questionnaire as subcategories of the perceived sensitivity on the risk of one's developing prostate cancer, the perceived seriousness on thinking of how threatening the prostate cancer is, the perceived benefit on the prostate cancer screening, and the perceived barrier, referring to a previous study [20] [21] related to prostate cancer based on a health beliefs model. The validity of the tool was verified by three specialists in urology, one professor in adult nursing, and one professor in community nursing. A total of 13 items exclusive of 1 item below CVI 80% was organized finally. The excluded item was "if developing prostate cancer, he/she will die normally within 5 years" and was excluded because the life expectancy varies depending on the severity of prostate cancer. A total of 13 items was organized; the perceived sensitivity of 3 items, the perceived seriousness of 3 items, the perceived benefit of 2 items, and the perceived barrier of 5 items. Each item was scored ranging from 4 score for 'Strongly Agree to 1 score for "Strongly Disagree" and the higher score means the higher health beliefs related to the prostate cancer examination. The level of perceived barrier used reverse coded scores because the higher score means the lower health beliefs. In our study, Cronbach's α value was 0.89 for the perceived sensitivity, 0.90 for the perceived seriousness, 0.87 for the perceived benefit, and 0.67 for the perceived barrier, respectively.

3) Screening status of prostate cancer: the variables were experience in hearing about the examination of prostate cancer, whether or not to have taken the examination, the place and reason, and the reason of not taking the examination, etc.

2.4. Data Collection Procedure

Firstly, we conducted a questionnaire preliminary survey to five males over 50 years old and then modified difficult terms into easy ones in a questionnaire. Data was collected from December 20, 2015 through January 20, 2016. We asked the students to collect data from one male at the age of 50 - 70 among their fathers or their parents' brother, after instructing the purpose and methods of this study sufficiently to nursing students of two universities. Students were asked to distribute questionnaires to their fathers or their parents' brothers at home and make them self-reports and it took 15 - 20 minutes to complete a questionnaire. After one week of distribution, questionnaires were collected by a student representative and those students who not submitting questionnaires were urged to submit, just once more.

2.5. Data Analysis

The collected data was analyzed using SPSS statistical software (version 23.0). Descriptive analyses were used to describe the characteristics of the subjects and related to prostate cancer, knowledge and health beliefs of prostate cancer: frequency, percentage (%), mean and standard deviation. t-test and one-way ANOVA were used to explore difference of knowledge and health beliefs of prostate cancer according to characteristics of the subjects and prostate cancer. $p < 0.05$ was considered statistically significant for all test.

2.6. Ethical Considerations

Informed consent in writing was obtained from the study subjects. The instruction statement contained the contents saying that participation is voluntary based on the willingness of the study subjects, participation can be withdrawn at any time when the subject wants to do so, the collected data will be used only for the purpose of research and the confidentiality and anonymity will be guaranteed, and the survey data will be not used for any purposes other than purposes of research.

3. Results

3.1. Screening Status of Prostate Cancer

It was found that the number of the subjects who had heard about the prostate cancer screening was 77 (52.4%), whereas 70 (47.6%) had not. Where hearing about the prostate cancer screening, the media such as newspaper, radio, TV, and the like was mentioned most frequently by 42 (53.2%), followed by 18 (22.8%) from private clinics and hospitals, 11 (13.9%) from relatives and family members' friends, and 8 (10.1%) from Internet.

It was shown that the number of those who having experience in a prostate cancer screening was 30 (20.4%), whereas the opposite was 117 (79.6%). For the timing of a recent blood test as part of prostate cancer examination, the number of those who responded as within 3 years was the highest at 9 (33.3%) while for the timing of a recent rectal examination, the number of those who answered as within 1 year was the highest at 9 (37.5%). For the reason of examination, 13 (43.3%), the highest number among the subjects, answered that "I think that I need to take an early screening for preventing prostate cancer for myself", followed by 7 (23.3%) answering that "the symptoms such as urinary problems appeared", 7 (23.3%) answering that "there was a recommendation by a medical staff", 2 (6.7%) answering that "My family members had developed prostate cancer or other cancers", 1 (3.3%) answering that 'there was a recommendation by a family member, a relative, or a friend' in order of mention. As for screening places, general hospitals/university hospitals were mentioned by 17 (56.7%), followed by 12 (40.0%) of professional private clinics. For the reason of not taking such screenings, 68 (29.9%), the highest number among the subjects, answered that I "think that I am healthy", followed by 31 (26.5%) answering that "I have no interest", 11 (9.4%) answering that "I have no time to do so", 4 (3.4%) answering that "there is no appropriate screening institutes", 2 (1.7%) answering that "the screening cost is burdensome", and 1 (0.9%) answering that "I have fear on the possibility of being diagnosed as cancer" in order of mention.

3.2. Extent of Prostate Cancer Knowledge in Mid-Aged and Elderly Men

Result of measuring the extent of prostate cancer knowledge using an 18-item tool showed only 44.7% of correct answer rate at average. The highest correct answer rate is 74.1% and the items with high score were "In order to prevent prostate cancer, it is advisable to intake as many as fruits and vegetables while eating less meat". It was followed by "It is more likely to develop prostate cancer if there is any family member (father, brothers) of developing prostate cancer" of 64.6%, "Prostate cancer can be curable easily if found early" of 63.3%, and "Younger men can be prone to prostate cancer compared to older men" of 61.2% in order of mention.

The lowest correct answer rate was only 14.3% and the items with lower score were "Higher figure of serum prostate-specific antigen means that someone has already gotten a cancer in prostate". It was followed by "If the prostate cancer metastasis is identified then a hormone treatment needs to be carried out to inhibit male hormones" with 15%, "The prostate cancer is faster in progression than other cancers" with 19.7%, and "Prostatic hyperplasia escalates into prostate cancer" with 23.8% (Table 1).

3.3. Extent of Health Beliefs for Prostate Cancer in Mid-Aged and Elderly Men

The scores of health beliefs for prostate cancer ranged from 20 score as the lowest and to 42 score as the highest with an average of 2.51 (out of 4 score). At average scores of items for subcategories of health beliefs, the perceived sensitivity was 2.46 (0.86), the perceived seriousness was 2.68 (0.90), the perceived benefit was 2.61 (1.01) and the perceived disability was 2.39 (0.55) score, respectively.

3.4. Difference of the Knowledge and Health Beliefs of Prostate Cancer According to General Characteristics

Table 2 provides the difference of prostate cancer knowledge according to general characteristics, the knowledge for prostate cancer was found to be higher in the age of 50 - 60 (t = 3.36, p = 0.001) and having cancer insurance (t = 2.96, p = 0.004) than the age of

Table 1. Screening practice of prostate cancer.

Item	Correct answer	%
1) In order to prevent prostate cancer, it is advisable to intake as many as fruits and vegetables while eating less meat.	O	74.1
2) Men who have a father or brother with prostate cancer are more likely to develop it.	O	64.6
3) Prostate cancer is curable easily if it is detected early.	O	63.3
4) The younger men are prone to prostate cancer compared to the older.	X	61.2
5) Prostate cancer is rapidly on an upward tendency in our country.	O	59.9
6) The onset of prostate cancer is associated closely with intake of animal fat.	O	57.1
7) The most common symptom of prostate cancer is dysuria.	O	56.5
8) In most cases, there is no symptom at the initial stage of prostate cancer.	O	48.3
9) Prostate is where to produce sperm in the male genital organ.	X	46.3
10) PSA is an examination of early diagnosing prostate cancer early.	O	46.3
11) Generally, prostate cancer screenings are conducted commencing from the age of 50.	O	42.9
12) Any prostate cancer treatment has no effect on sexual function.	X	41.5
13) DRE is an examination method of palpating prostate cancer by inserting a finger into the anus.	O	38.8
14) If prostate cancer metastasizes into bones, then the back pain occurs.	O	30.6
15) BPH advances to prostate cancer.	X	23.8
16) Prostate cancer has fast progression compared to other cancers.	O	19.7
17) If the metastasis of prostate cancer is confirmed, then a hormone treatment shall be conducted to inhibit male hormones.	O	15.0
18) Higher figure of serum prostate-specific antigen means to have already gotten a cancer in prostate.	X	14.3
Total		44.7

61 - 70 and without cancer insurance, respectively. In addition, the difference was shown due to educational level and monthly earnings and as result of conducting Scheffe post hoc test. The specific difference of groups in the prostate cancer knowledge was found to be higher in the highest education level than other education level ($F = 4.16$, $p = 0.007$) and also higher in more than 3.01 million won of monthly earning than less than 2.00 million ($F = 7.90$, $p < 0.001$).

On the difference of health beliefs for prostate cancer according to general characteristics, the perceived sensitivity was found to be significantly higher in the age of 50s - 60s ($t = 3.02$, $p = 0.003$), not married ($t = 2.30$, $p = 0.023$), and not smoking ($t = 2.49$, $p = 0.014$) than where at the age of 61 - 70, married, and smoker, respectively. The perceived benefit was found to be significantly higher men who drinking than not drinking. The difference of groups in education level showed significantly higher perceived benefit in men who had an academic career of 2-year college as a result of Scheffe post hoc test ($F = 3.06$, $p = 0.030$). The perceived barrier also showed the difference in religion and monthly earnings and it was found to be higher in Catholic and no religion than Christianity ($F = 4.82$, $p = 0.003$), and higher in the group of more than 4.01 million won of

Table 2. Differences of knowledge and health beliefs of prostate cancer according to general chracteristics.

Characteristics	Categories	Knowledge			Perceived sensitivity			Perceived seriousness			Perceived benefit			Perceived barrier		
		M (SD)	F or t	*p*	M (SD)	F or t	*p*	M (SD)	F or t	*p*	M (SD)	F or t	*p*	M (SD)	F or t	*p*
Age (years)	50 - 60	8.84 (3.81)	3.36	**0.001**	5.67 (1.96)	3.02	**0.003**	9.07 (2.20)	1.07	0.285	6.38 (1.55)	0.78	0.432	12.21 (2.75)	1.20	0.232
	61 - 70	6.62 (3.89)			6.77 (2.37)			9.47 (2.07)			6.16 (1.60)			11.64 (2.79)		
Religion	Christian a	6.86 (4.44)	1.46	0.227	6.05 (2.85)	2.21	0.089	9.04 (2.53)	2.14	0.098	6.02 (2.03)	3.02	**0.032**	10.59 (3.22)	4.82	**0.003**
	Catholic b	8.40 (3.56)			8.68 (1.69)			8.37 (2.04)			5.78 (1.51)			12.56 (2.72)		b, d > a
	Buddhist c	8.51 (3.80)			8.21 (1.91)			9.48 (1.95)			6.58 (1.28)			12.21 (2.15)		
	None d	8.37 (3.92)			5.37 (1.93)			9.45 (1.95)			6.72 (1.21)			12.00 (2.53)		
Education	Middle school a	6.66 (4.72)	4.16	**0.007**	6.66 (2.74)	0.74	0.530	9.11 (2.21)	0.63	0.594	6.16 (1.88)	3.06	**0.030**	13.22 (3.76)	2.30	0.080
	High school b	7.55 (3.73)		d > a, b	6.07 (2.13)			9.04 (2.21)			6.35 (1.53)		d > c	11.87 (2.38)		
	College c	7.31 (3.51)			5.63 (2.12)			9.77 (2.38)			5.50 (1.62)			11.00 (3.14)		
	University d	9.76 (3.79)			6.02 (2.04)			9.23 (1.92)			6.71 (1.33)			12.00 (2.77)		
Marital status	Married	8.07 (4.02)	0.46	0.644	5.96 (2.14)	2.30	**0.023**	9.21 (2.13)	−0.00	0.995	6.35 (1.52)	1.48	0.140	12.00 (2.74)	0.08	0.994
	Others	7.44 (3.28)			7.66 (2.23)			9.22 (2.58)			5.55 (2.12)			12.00 (3.42)		
Monthly income (10,000 won)	≤200 a	6.00 (3.95)	7.90	**<0.001**	6.38 (2.95)	0.37	0.768	9.66 (2.51)	0.798	0.497	5.89 (1.84)	1.55	0.202	10.89 (3.08)	3.68	0.014
	201 - 300 b	7.63 (3.66)		d, c > a	5.90 (2.13)			9.00 (2.23)			6.27 (1.53)			12.00 (2.88)		d > a
	301 - 400 c	9.15 (3.47)			5.96 (1.63)			9.15 (1.79)			6.62 (1.45)			12.46 (2.50)		
	≥401 d	9.96 (3.74)			6.00 (1.60)			9.03 (1.90)			6.65 (1.31)			12.90 (2.16)		
Smoking	Yes	8.15 (3.62)	0.23	0.817	6.73 (2.26)	2.49	0.014	9.71 (1.93)	1.85	0.065	6.68 (1.34)	1.97	0.050	11.91 (2.54)	−0.27	0.782
	No	7.99 (3.62)			5.77 (2.09)			9.00 (2.22)			6.13 (1.64)			12.04 (2.88)		
Drinking	Yes	8.35 (4.08)	1.03	0.304	8.31 (2.11)	1.49	0.137	9.31 (1.95)	0.59	0.551	6.65 (1.42)	2.21	0.028	12.35 (2.57)	1.64	0.102
	No	7.67 (3.84)			5.77 (2.23)			9.10 (2.37)			6.00 (1.69)			11.60 (2.59)		
Private cancer insurance	Yes	8.66 (3.82)	2.96	0.004	8.01 (2.27)	0.412	0.681	9.23 (2.21)	0.13	0.869	6.44 (1.55)	1.66	0.098	12.12 (2.79)	0.79	0.427
	No	6.59 (3.97)			6.18 (1.95)			9.18 (2.04)			5.97 (1.57)			11.72 (2.73)		

monthly earning (F = 4.82, p = 0.003) than below 2.00 million won (F = 3.68, p = 0.014), respectively (Table 2).

3.5. Difference of the Knowledge and Health Beliefs of Prostate Cancer According to Characteristics Related to Prostate Cancer

The level of knowledge of prostate cancer was found to be significantly higher in the group that is having experience in taking the prostate cancer examination than the men who did not have it (t = 2.01, p = 0.46). For the difference of health beliefs for prostate cancer according to the characteristics related to prostate cancer, firstly, the perceived sensitivity was shown to be significantly higher in the men who have family history in prostate cancer than men who have no family history (t = 3.46, p = 0.001). The men who having experience in being hospitalized in urology was shown to be significantly higher than no experience of hospitalization (t = 2.81, p = 0.006). The men who having experience in taking the prostate cancer examination were shown to be significantly higher than no examination (t = 4.37, p < 0.001). The perceived barrier was also significantly higher in men who have an experience in being hospitalized in urology than the men who have no hospitalization (t = 2.15, p = 0.033). On the other hand, there were no significant differences in perceived benefit and seriousness according to characteristics related to prostate cancer (Table 3).

4. Discussion

Recently incidence of prostate cancer has rapidly increased among Korean men. Although there are little studies targeting the public among studies related to prostate cancer, our study is meaningful in having suggested basic materials for preventing prostate cancer by determining the knowledge, health beliefs, and screening status for prostate cancer in mid-aged and elderly men who do not contract prostate cancer.

Out of a total of 147 study subjects, 30 (20.4%) had taken prostate cancer screening whereas 117 (79.6%) had not. It is similar to the previous studies that showed the re-

Table 3. Differences of Knowledge and Health Beliefs of Prostate cancer according chracteristics of prostate cancer.

Characteristics	Categories	Knowledge			Perceived sensitivity			Perceived seriousness			Perceived benefit			Perceived barrier		
		M (SD)	F or t	*p*	M (SD)	F or t	*p*	M (SD)	F or t	*p*	M (SD)	F or t	*p*	M (SD)	F or t	*p*
History of Prostate ca.	Yes	9.76 (3.53)	1.65	0.101	8.00 (2.23)	3.46	0.001	9.46 (1.98)	0.42	0.671	6.46 (1.05)	0.37	0.710	11.30 (2.49)	−0.95	0.343
	No	7.87 (3.98)			5.88 (2.09)			9.19 (2.17)			6.29 (1.61)			12.07 (2.80)		
Experience of visit to urology	Yes	8.60 (5.29)	0.45	0.647	7.90 (2.02)	2.81	0.006	9.00 (1.88)	−0.33	0.742	6.90 (0.87)	0.07	0.217	10.20 (2.85)	2.15	0.033
	No	8.00 (3.88)			5.93 (2.13)			9.23 (2.18)			6.26 (1.60)			12.13 (2.73)		
Experience of health exam. Within the last	Yes	8.20 (2.00)	0.533	0.595	6.06 (2.37)	−0.01	0.986	9.33 (2.35)	0.70	0.481	6.07 (1.77)	1.86	0.065	12.33 (2.90)	1.52	0.130
	No	7.85 (3.44)			6.07 (1.96)			9.08 (1.92)			6.55 (1.28)			11.64 (2.59)		
Experience of prostate ca. screening	Yes	9.33 (4.08)	2.01	0.046	7.53 (2.51)	4.37	<0.001	9.06 (2.46)	−0.42	0.669	6.33 (1.66)	0.10	0.916	11.70 (2.66)	−0.67	0.499
	No	7.70 (3.89)			5.69 (1.92)			9.25 (2.08)			6.29 (1.55)			12.08 (2.80)		

sults. The study targeting men at the age of 50 - 70 in Iran reported about 87.2% with no DRE and 95.6% with no PSA test [8]. However, the study of USA men reported that 45.8% of African-American men and 74.8% of US white men have taken PSA test [22] [23]. There was a difference in examination rate among countries. It was considered to be due to the fact that in western countries the examination or treatment methods have already been generalized and developed since westerners were more prone to prostate cancer than easterners. For an international comparison in relative survival rates for main cancers, it was reported that Korea has higher survival rates in stomach cancer, colon cancer, liver cancer, and the like, which were included in the National Cancer Program, whereas the survival rate for prostate cancer was lower [2]. Therefore, the interest and promotion about prostate cancer on population will be necessary at the nation-wide level.

For the reason of not taking prostate cancer screenings in this study, "I think that I am healthy" was the highest as 58.1% of the respondents, followed by responses such as "no interest" (26.5%), "no time" (9.4%), and "no reliable screening institutes" (3.4%). Similarly, Park [24] reported that "because there is no special symptom and I am healthy" showed the highest rate, followed by "cannot afford it economically", "have no time available", and "difficult to receive the examination process" in order of mention. For the last 10 years, the reasons of not taking a national cancer screening were also reported like "because I am healthy", "no time available", and "difficulty in taking the examination process" [25]. These results mean that Korean men are not willing to take screenings until a special symptom occurs. And it causes risky outcomes because most cases of symptoms of prostate cancer appears when it metastasizes. In contrast, the reasons of non-screening in foreign countries were shown to be unfamiliarity with time, cost, pain and discomfort at the time of screening and a fear of diagnosis for disease [26].

At the timing of screening in prostate cancer examinees, it passed one year since last screening in 33% - 48% of 30 examinees. In Korea, men over the age of 50 are recommended to take an annual prostate cancer examination [6] but it is known that many of them actually fail to abide by such recommendation criteria on the examination timing. The reasons of conducting screenings were found to be "because of thinking of having to take earlier screenings to prevent prostate cancer for oneself" responded by 43.3% among the subjects, "because of occurrence of urination problem symptoms" by 23.3%, and "because of a medical staff's recommendation" by 23.3%, while Kroger-Javis [27] reported 37% by a doctor's recommendation, 29% by knowing its importance for oneself, and 19% by a wife's recommendation. An [28] also emphasized that it was necessary to make an effort to induce the subjects to participate voluntarily in taking cancer screenings through the effort to improve perception of men by health professionals.

In this study, it was indicated that 52.4% of the total subjects responded that they had heard about the prostate cancer screening and the subjects obtained the most information through the mass media (newspaper, radio, TV). The study of Kroger-Javis [27] targeting US men indicated that 83% among them responded that they had enough information about the prostate cancer examination while they contacted such information most frequently through health professionals, showing the difference from this study. The half of subjects in this study heard about the screening information but the actual screening ratio was less than 20%, it can be presumed that information through the mass media cannot be of much help to perform screening test. In particular, the knowledge should be delivered in an effective and exact manner through skilled specialists because it is the most basic element to improve correct recognition about cancer [20] [29]. Therefore, qualified and effective method including health information should be applied by health care professionals [27].

Knowledge level of prostate cancer is not high with 44.7% of the correct answer rates in this study. In Iran revealed that their knowledge about the prostate cancer was below 7 score (poor) 21.6%, 7 - 9 score (fair) 65.5%, and 10 - 12 score (good) 12.7% [8] while Kroger-Javis [27] reported that only 25% of mid-aged and elderly men in US responded that they did not know well about the knowledge of prostate cancer. These results indicate the significant difference of level of knowledge by country. The mortality of prostate cancer is increasing in low-income countries, whereas its incidence is increasing in high-income countries [1]. This is thought that the prostate cancer knowledge will be also affected by a national management system for cancer. In this study, items showing a correct answer ratio above 60% were associated with the knowledge about "the risky factors of prostate cancer" such as old-age, family history, meat diet. While below 50% of correct answer ratio were associated with the items are distinctive contents of prostate cancer including function of prostate, screening examination method, initial symptoms, progression symptoms, treatment. Therefore, when planning an intervention approach to improve the prostate cancer knowledge, it is necessary to make persistent effort to improve the knowledge of the people with consideration for level of basis for knowledge for each country.

In this study, the prostate cancer knowledge was found to be significantly high in prostate cancer examinees compared to non-examinees. Namely, it means that if they have the knowledge for prostate cancer, they may perform the prostate cancer examination. As can be seen in the results, the subjects of this study took early screenings mentioned "in order to prevent prostate cancer for oneself" as a reason of screening. Plowden [29] also reported that the knowledge for prostate cancer and early screening was an important factor in decision-making for taking an early screening. Furthermore, it was indicated that the knowledge was higher in 50s than 60s and also the knowledge score was shown the highest at the high education group. Winterich *et al.* [20] also reported that the lower educational level shows the lower level of knowledge for prostate cancer screenings, which has been discussed as attributed to lack of understanding. Therefore, we should make efforts to develop a communicative method or a simple and systematic training program to enhance the understanding in consideration of old-aged or low-educated men.

Additionally, knowledge about prostate cancer was significantly higher in men with monthly earnings was higher and a cancer insurance in this study. On the other hand, a study reported the opposite result that cancer screening intention was higher among poor person with low-income and without health insurance [29]. The reason of different results between studies may be caused different age groups. Therefore, planning a method to enhance the screening of prostate cancer must be prepared in consideration of age group.

Health beliefs are known as factors that has an effect on cancer screening behaviors especially as well as enhances health-promoting behaviors in a variety of diseases [13] [26]. Despite of good perceived seriousness about prostate cancer, the screening rate was only 20.4% in the result of this study. As a similar result, it was found that for non-examinees of liver cancer screenings in Korea the examination ratio of early screenings was shown to be low compared with high level of perceived seriousness [24]. In this study, 58.1% of non-examinees responded "because I think that I am healthy" as a reason of not taking screenings. It is considered to be because they are recognizing the seriousness but thinking that they never have prostate cancer. In other words, this is because their perceived sensitivity about the disease is low. Meanwhile, Ghodsbin *et al*. [8] reported that the perceived benefit among prostate cancer health beliefs was the highest whereas the perceived seriousness was the lowest, while Capik and Gozurn [26] reported that the perceived benefit was the highest followed by perceived seriousness, barrier, and sensitivity. These different results by studies are considered because different race, culture, social conditions of each country.

This study showed that the examinees indicated significantly high perceived sensitivity compared to non-examinees. It was consistent in the result of Kim [30]'s study that low perceived sensitivity on diseases was presented as a main reason for not taking the screenings. Moreover, the perceived sensitivity was significantly higher in 50s age group, smokers, being married and having a family history, and having experience of hospitalization in urology. In other words, the men who are non-smokers, not married, without family history and 60s are more likely to overlook the importance of early screenings. Because they may that they will have low probability of developing prostate cancer. Therefore, it is necessary to promote persistently prostate cancer prevention training and promotion programs for men. Also it should be centered on the contents with risky factors of prostate cancer, screening methods and symptoms of disease in order to enhance the sensitivity about the disease.

The perceived barrier scores used by reverse coding. In items asking the perceived barrier, 57% agreed that "a prostate cancer screening is painful and uncomfortable" and also, 57.3% agreed that "a screening makes me feel shame and shyness". Moreover, it is shown that the perceived barrier was higher in men having experience of hospitalization in urology than men who has no experience. Although there was no statistical difference, the level of the perceived barrier was also higher in men who having experience in health examination or prostate cancer examination then without experiences. That is, higher level of the perceived barrier maybe induced by the factors such as shame, pain and discomfort related to the exam. As noted in a previous literature, reducing these barrier factors can influence examination behaviors for prostate cancer screenings [13]. Thus, a strategy shall be established to form a positive attitude toward screenings and enhance screening intention by educating the exact procedure and purpose of a prostate cancer examination [24]. Furthermore, multilateral efforts shall be exerted together to address environmental obstacles such as lack of time, cost, and information [31].

Through the results of this study, it could be determined the screening status of prostate cancer with the strengths and weaknesses of the knowledge and health beliefs for prostate cancer in Korean men. Our finding suggests that effective interventions are necessary to enhance the prostate cancer knowledge and the importance of early screenings by increasing sensitivity of the disease in mid-aged and elderly males. Additionally, systematic information through health care professionals' not indiscriminate information on the mass media shall be provided to men. As previously shown in this study, a training program should be organized with the distinctive contents of prostate cancer including screening examination methods, initial symptoms, and progression symptoms with lower score of knowledge.

5. Conclusions and Implications

Result of measuring the extent of prostate cancer knowledge of mid-aged and elderly men using an 18-item tool showed 44.7% of correct answer rate at average. In this study, items showing a correct answer ratio above 60% were associated with the knowledge about "the risk factors of prostate cancer", such as old age, family history, meat diet and "the advantages of earlier detection". Whereas items showing a correct answer ratio below 50% were associated with function of prostate, screening examination method, initial symptoms, progression symptoms and treatment. Mostly, the items with distinctive contents about prostate cancer showed low knowledge scores. Therefore, persistent support is required to improve the prostate cancer knowledge by educational intervention. It should be compendious to provide knowledge including types of screening examination, initial symptoms and progression symptoms of prostate cancer.

In the average scores of the subcategories in health beliefs, the perceived severity was the highest and followed by the perceived benefit, sensitivity, and barrier. The prostate cancer screening rate was higher among the participants with high prostate cancer knowledge and the perceived sensitivity. While "I think that it is necessary to prevent prostate cancer for myself" was the most frequent response as a reason of taking a prostate cancer screening and "I think I am healthy" was the most frequent response as a reason of not taking it. Therefore, it will be necessary to deliver the exact knowledge about prostate cancer to men for improving the prostate cancer screening rate, and also make them have recognition for preventing prostate cancer for themselves and establish training plans which can enhance the sensitivity for prostate cancer.

We found that the prostate cancer knowledge was significantly high in prostate cancer examinees compared to non-examinees. Also, prostate cancer knowledge was higher in age of 50s, the highest education, the highest monthly income, and having a cancer insurance group. Therefore, our finding suggests that the significant factors including age, educational level, income and cancer insurance status need to be considered in nursing education program in order to deliver accurate knowledge about prostate cancer.

Limitations of this study include the following. First, convenience sampling method was used for easy availability of study participants and therefore this study may have sampling bias. Second, our study population included Korean men who were living in an urban area, so the results may not be applicable to other populations. Thus large-scale surveys using representative samples are required for further studies.

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Simulation and Millennials—The Perfect Storm

Gwen D. Erlam, Liz Smythe, Valerie Wright

Department of Health and Environmental Sciences, Auckland University of Technology, Auckland, New Zealand
Email: gerlam@aut.ac.nz, lsmythe@aut.ac.nz, vwright@aut.ac.nz

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Abstract

Simulation in its various forms has developed extensively over the past 15 - 20 years for use in undergraduate nursing programs. The widespread integration of technology-based educational tools into nursing curricula is raising concerns that technology rather than sound philosophically-based pedagogy is informing nursing education. Some believe that educational soundness has been overtaken by a focus on technological prowess. The manikins used in this immersive classroom often breathe, blink, and even speak in response to lecturer-controlled commands. This research explores how Millennials as a generational cohort (18 - 30 years of age) interface with the teaching/learning platform of simulation. This action research study is unfolded in three distinct action cycles involving 161 undergraduate nursing students. Millennial characteristics of confidence, high achievement, team orientation, technology focus, feedback-saturated, and trophy-seeking traits make them especially adept in immersive simulation environment. If supported by appropriate philosophical underpinnings, simulation as a teaching/learning platform has the potential to become the preferred classroom for Millennial nursing students.

Keywords

Simulation, Undergraduate Nursing, Millennials, Scaffold, Action Research

1. Introduction

A new generation is rising—the Millennials. These are individuals born between 1982 and 2002. They are unlike any other youth generation in living memory [1]. They are more numerous, more affluent, better educated, and more ethnically diverse than previous generations [1]. For today's students to acquire complex problem-solving, critically reflexive analytical thinking, and succinct communication skills in appropriately technology-assisted contexts, educators will have to approach teaching differently [2].

Human patient simulation involves a computer-controlled manikin that mimics human interaction with students in a controlled simulated clinical setting. The human patient simulator is a computerized full-body manikin that is able to provide real-time physiological and pharmacological parameters of persons of both genders, varying ages, and with different health conditions [3]. This study looks at the interface occurring when simulation and Millennials engage. Of interest are the Millennial responses to simulation when employed as an immersive classroom. Through these observations, various instructional strategies are outlined to maximize simulation for undergraduate Millennial nurses.

2. Background

It has been noted that organizations who take their companies from good to great must first pay attention to who is on their bus [4]. Who is working in their organization? Who is attending their university? It has also been correctly noted that the people on the bus are changing. This change is about the retirement of Baby Boomers (born approximately 1940-1960) from the workplace, combined with the emergence of Millennials (born approximately 1982-2002) in unprecedented numbers in universities and places of employment. Millennials are the largest generation (76 million) to enter the workforce since the Baby Boomers [5]. While the Baby Boomers are the "me" generation desiring money, title, and recognition; Millennials are the "we" generation enjoying instead the interaction of discussing content, collaborating, teamwork, and work-life balance [6].

While some have resisted the uniqueness of generational persona, it has long been known that history as a living force shapes generations. As Martin Heidegger observed, "The fateful act of living in and with one's generation completes the drama of human existence" [7]. Three attributes contribute to the persona of a generation: 1) perceived membership; 2) common beliefs and behaviors; and 3) a common location in history [1]. Millennials as a generational cohort have seven distinguishing traits:

1) *Special*: Millennials feel they are collectively vital to whatever nation they belong, and to their parents.

2) *Sheltered*: Millennials have been on the receiving end of numerous safety rules and devices (e.g. car seats, bike helmets).

3) *Confident*: Millennials exhibit high levels of trust and optimism coupled with endless hours in tutoring and lessons. This has produced high levels of confidence in this generation.

4) *Team-oriented*: Millennials have grown up in a culture of school uniforms and classroom group learning. They possess strong team instincts and tight peer bonds. This characteristic also involves a high association with technology [8].

5) *Achieving*: With accountability and continuing higher school standards, Millennials are on the way to becoming the best-educated adults in history.

6) *Pressured*: Pushed to study hard, avoid personal risks, and take advantage of collective opportunities, Millennials feel a "trophy kid" pressure to excel.

7) *Conventional*: Millennials take pride in improving their behavior and are more comfortable with their parents' values than any other generation in living history. They

support convention—the idea that social rules can help [1] [9]-[12].

It is evident that further research is needed to promote awareness and understanding of the expectations of today's students and to reform nursing pedagogy to accommodate the current generation of learners. In this article, the context of intergenerational diversity is explored, the importance of evidenced-based practice is reinforced, and current nursing pedagogy is examined, with the intention of stimulating a philosophical discourse among nurse educators regarding fundamental values and beliefs around pedagogical practice in simulation design.

3. Methods

Following ethics approval (AUTEC #12/208), this study employed action research in three investigative cycles to answer the question, "How do Millennials respond to simulation as a teaching/learning tool?" Action research was chosen as it is a proven methodology in the instigation of change [13] [14]. Change is required in order to better integrate the use of simulation in undergraduate healthcare environments.

This study occurred at a large nursing school in Auckland, New Zealand between December 2012 and April, 2014. The reconnaissance phase began (Cycle one) with focus groups to critique current practice in simulation from which a one-hour simulation scenario was created embedding suggestions for improvement. Insights led to Cycle two where second year students participated in a newly designed scenario which employed pre- and post-questionnaires to determine which elements employed in the simulation were most helpful. Student feedback led to Cycle three where final semester nursing students engaged in a simulation suite of three scenarios.

The simulation questionnaire (Cycle two) encompassed the following items:

- Likert scale inquiring as to effectiveness of previous simulation in the undergraduate nursing program (*i.e.* before the day of the revised simulation);
- Most valued aspect of revised simulation (*i.e.* simulation on day of data collection);
- Least valued aspect of revised simulation;
- What (if anything) hindered learning during the simulation/debriefing?
- Likert scale inquiring as to effectiveness of revision simulation on learning and professional performance (1 - 5).

The responses to these questions were transcribed and coded using NVivo™ in the manner described in **Table 1**.

4. Participants

Recruitment methods for this research varied within each cycle. Cycle one recruited participants aged 18 - 32 (Millennials) via global email and involved students from all three years of an undergraduate nursing programme in Auckland, New Zealand (n = 15). Cycle two included Millennials in the second year of the nursing programme who were willing to answer a pre- and post-questionnaire while participating in a high-fidelity simulation scenario (n = 125). Cycle three employed recruitment via email to final semester Millennials which quickly expanded to snowballing as involved students

Table 1. Example of descriptive thematic analysis.

Original sentence examples	Free Node (Code)	Tree Node (Category)	Theme
What I really hate about the simulation is the glass. I'd love the educator to be down on the floor with us.	Anxiety-producing	Supportive learning environment	Facilitator training in situated teaching
Being in the simulation knocked my confidence. When you're running around like headless chickens you think, "When this does happen in the hospital, am I going to know what to do?"	Anxiety producing (decreased confidence)	Supportive learning environment	Facilitator training in debriefing
I do not think we have enough opportunities. We should be doing one a week.	Practice	Simulation opportunities	Scaffolded simulation program
Knowing at the beginning what is expected of us would have been helpful, rather than being chucked as a group into the room. They just start the simulation and we wonder what it is we should be doing.	Lack of orientation	Simulation design	Sound pedagogical underpinnings in design
If we go from the parenting thing, we know the educators can ride a bike. We need to have the training wheels on at first until we can gain the confidence to take the training wheels off.	Practice	Simulation opportunities	Scaffolded simulation program

recruited participants through a student-operated Facebook™ page (n = 21). Sample size was determined by the number of students available to participate alongside full-time study. There was no power calculation or other justification for this.

Demographic information sought for these participants involved primarily their generation cohort (*i.e.* Millennial students were recruited). Students in Cycle One were 100% female; of which 80% were Caucasian, 13% Asian, and 7% Maori (native New Zealanders). In Cycle Two, demographics were narrowed to include any Millennials wanting to participate (*i.e.* 18 - 32 years of age). Cycle 3 included 21 Millennials. Of these, 86% were Caucasian, while 14% were Asian. One student of the 21 was male.

5. Results

Millennials as a generational cohort were recruited into this study with the intention of understanding how specific generational preferences influenced the effectiveness of simulation with undergraduate nurses. Specific detail as to what helped and hindered learning became the focus of investigation. In the second action cycle, students (n = 125) were asked to fill out a pre- and post-simulation questionnaire evaluating what contributed most powerfully to their learning during the simulation.

The data were coded employing descriptive thematic analysis. Raw data were coded in NVivo™ based on content representation from each line, breaking down data into smaller units or free nodes [15] [16]. These were then grouped based on shared concepts into what NVivo™ describes as tree nodes using the research question as a guide [15]. An example of this content analysis can be seen in **Table 1**.

The four most valued aspects of the simulation were: 1) Educator modeling of expected simulation performance; 2) opportunity to repeat simulation after feedback; 3) supportive debriefing; and 4) using the ISBAR tool to recruit support from other professionals. These responses can be seen in Figure 1.

When considering key Millennial traits in conjunction with the most valued aspects of the simulation (Figure 1), it is interesting to note that the most valued aspect was *educator modeling of expected performance*. The students found the modeling both instructive and inspiring as evidenced by the questionnaire feedback below:

> *The role play that the educator did was really helpful to show us all of the roles needed and assessments that needed to be done.*
> *What I value from today's simulation is how the educator demonstrated it to us before the simulation started. That helps with our self-confidence.*
> [*The educator*] *gave us a role play and how to react appropriately. If I did not have a chance to watch the role play by* [*the educator*], *I think I would still be confused.*

Students' second most valued aspect was the opportunity to *repeat their performance* in the simulation after being given feedback. Repetition emerges as a philosophical underpinning from the behaviorist theorists, and results in skill improvement and mastery. Once this occurs, students can focus on critical thinking and problem solving. When asked about the opportunity to repeat the simulation, one student stated:

> *Yes, this helped immensely. It gave me an opportunity to "right what was wrong". Doing this provided me the confidence to know that I was capable of implementing the proper nursing interventions in a scenario as such. Being told what went wrong, and then leaving it at that is not enough for me to know that I have learnt it properly. I am a strong believer in hands on practical learning, so being given the opportunity to actually practice and redo the simulation following feedback meant that I was able to implement and consolidate what I had been told from my tutor.*

Debriefing was the third most valued aspect of the simulation. Within the context of simulation, debriefing weaves together the students' prior understandings with new knowledge in a manner which helps them, in Dewey's words, form new impulses which will clarify confusion [17]. Student comments from questionnaire feedback supported debriefing as an educational construct:

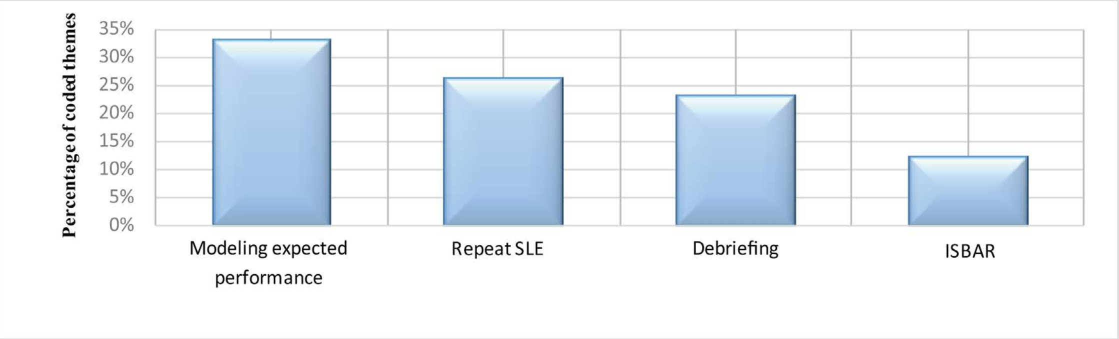

Figure 1. Top four instructional strategies employed in simulation design.

> *Getting feedback that was constructive really helped improve straight away.*
> *Individualized advice and support helped me. One-on-one feedback. Learnt structured steps and roles to be completed in respiratory event.*
> *I felt that letting us do it ourselves with our knowledge and then giving us guidance gave us confidence.*

The fourth most valued educational construct was teaching the *ISBAR tool* (Identify, Situation, Background, Assessment, Request) to students as a format for eliciting help in a deteriorating patient situation. Student feedback from questionnaires were as follows:

> *I feel more confident as I now know effective communication skills. I mostly appreciated learning that in a live situation we must be fully prepared before calling doctors as being hung up on in reality would be extremely humiliating.*
> *Teach us about ISBAR was most valuable. This is life-saving information yet we are not taught until year three*?
> *Each* [*student should*] *have a turn at ISBAR*!

The use of a structured method of communication employing a standardized tool can improve the quality of information exchange. The ISBAR tool contributes to improved communication as well as to increased practitioner confidence in getting other professionals to engage in a deteriorating situation [18]. The acronym is able to be recalled correctly in most cases, and the use of visual prompts is helpful in keeping the communication on track. The students felt that the tool kept them focused when stress and other compounding factors were producing anxiety and distraction. In essence, it enabled them to better manage the complexity of the situation, and in educational terms it reduced the load on working memory [19].

6. Discussion

This research has focused on considering the appropriateness of simulation as an educational platform for Millennial students. The top four educational strategies students reported as helpful to their learning were: 1) Educator modeling of expected simulation performance; 2) opportunity to repeat simulation after feedback; 3) supportive debriefing; and 4) using the ISBAR tool to recruit support from other professionals. These form an interesting tapestry when woven together with the seven distinctive Millennial traits: 1) special; 2) sheltered; 3) confident; 4) team oriented; 5) high-achieving; 6) pressured (trophy kids); and 7) conventional [1] [9]-[12].

6.1. Modeling: Demonstrate Best Practice in the Midst of the Storm

When student-prioritized instructional strategies are taken in order, distinctive Millennial preferences emerge. For example, Millennial students' top preference in simulation design is to have the expected performance modeled to them. Modeling allows for impulse formation, which paves the way for the integration of new habits [17] [20]. This is a constructivist philosophical underpinning. To the constructivist, learning is a result of the learner building their own set of content to solve a particular problem [21] regardless of previous knowledge. The content is not delivered, but constructed in a learner-centric, team-based, collaborative learning environment. Through modeling, new information was provided which could be integrated into cognitive schema allowing students to construct their own revised performance [22].

Millennials are described as *pressured*, which means that they are pushed to study hard, but *avoid personal risks* while taking advantage of collective opportunities offered [1]. Modeling of expected performance reduces Millennial risk by allowing them to see an example of what they are to do. They prefer this as it reduces their risk of 'losing face' in front of their peers. It is therefore not surprising that Millennials would prefer to reduce risk by watching another perform first. Employing modeling as an instructional strategy reduces student risk of poor performance thus increasing student engagement in simulation.

6.2. Repeat Performance: Give Opportunities for Improvement in Managing the Storm

The second student-prioritized instructional strategy was allowing the students to repeat their performance after feedback. Recall that Millennials are achieving; they want to be at the top of their game [1]. They see themselves as indispensable beings who desire to be highly sought after. They are generally high-achievers due to the large amount of support and privilege they have received from parents and teachers [1] [9]-[12].

Allowing students to repeat the simulation gives opportunity to put feedback into action. These achieving Millennials desired this as they did not want to simply be told what they had done wrong, but to have a chance to correct themselves. This repetition is a behaviorist theoretical underpinning which assists students to refine skills [23]. This path to learning is through the stimulus-response cycle. The stimulus (or cue) is often a physiological sign which students miss the appropriate response to on the first run. Learning appropriate responses to stimuli leads to satisfying results, and the repetition of these satisfying results produces learning [24]. Skill development of this type requires regular feedback in order for students to modify their performance and gain competence [25]. Repetition as an instructional strategy encourages skill mastery which then allows the student to focus on critical thinking and problem solving [25].

6.3. Debriefing: Clarifying Confusion in the Midst of the Storm

Debriefing is the third most valued instructional strategy noted by Millennial students. Debriefing is a reflective scaffold [26] which encourages students to self-monitor and self-assess. It is a means of reflecting with the educator and peers as to ways to improve performance. Debriefing can occur in the midst of the simulation in the form of situated teaching [27], or at the end as a reflection on overall performance. It weaves together students' prior understandings with new knowledge in a manner which helps form new impulses which clarify confusion [17] [20]. Effective debriefing is the most important step to promoting student learning because it encourages self-regulation and self-direction to apply forethought [28].

As Millennials tend to be team oriented, achieving, and confident (often through extensive tutoring) [1] [9]-[12], debriefing affords a powerful collaborative instructional strategy. They are also the most catered for, tutored generation to emerge, and debriefing offers the availability of personal feedback which resonates with their desire to achieve and improve in confidence. Skilled debriefing is central to the development of critical thinking skills, achievement of expected learning outcomes, reflective learning, and the intent to apply the knowledge that has been acquired [28]. In effect, debriefing helps to clear the storm of confusion which often arises in managing deteriorating patient situations.

6.4. ISBAR Tool: Effective Communication While Navigating the Storm

The fourth most valued instructional strategy identified by Millennials was being instructed in how to effectively recruit assistance through the use of the ISBAR tool. Instructional strategies for simulation need to focus on safety breaches, communication, ability to make decisions and interpersonal interactions [29]. Millennials have grown up working in teams, along with being the most protected generation (sheltered). Their schooling gets the credit for instilling good teamwork skills, as most school assignments were done collaboratively [30]. Parents get credit for safety measures being put into place (sheltered).

Teamwork consists of a collection of behaviors and attitudes that promote efficient processing of information and ultimately lead to timely and proper actions carried out by various team members [31]. Excellent teamwork demands refined and effective communication skills in order to ensure that all members are both valued and effective in their roles. As Millennials tend to be team-oriented and sheltered, being on the receiving end of numerous safety rules [30], effective communication strategies are particularly relevant.

The ISBAR communication tool assists Millennials in prioritizing and categorizing significant information in order to clarify the crisis at hand and recruit assistance [18]. Using the tool helps decrease assumptions by making the reason for the communication obvious at the outset and encouraging those involved to state the obvious. It also increases practitioner confidence in getting other professionals to engage in a deteriorating situation [18]. Effective communication helps to maximize teamwork and student confidence at the same time. While Millennials are considered the "always connected generation" [9] [12], there is evidence to suggest that there is room for improvement in verbal communication skills [8]. It is therefore essential to build communication into instructional strategies of simulation design.

7. Limitations

There were several limitations which impacted this study. The head of simulation research, who also played a key role as a supervisor in this research, resigned the semester before cycle three commenced. Her extraordinary ability to secure funding, as well as support equipment acquisition and generate business plans, was lost at a most critical time. While her involvement continued as a third supervisor, she was no longer able to be the bridge to higher level decision making and resource allocation. Instigating this research at a time of leadership change has limited opportunity to involve "leaders" in the change process. Such change initially impacted this study, particularly in having the opportunity to stay closely aligned to key leaders within the school as the findings emerged.

8. Recommendations

Educators working in the design and implementation of simulation with undergraduate nurses should be mindful of aspects of this teaching platform which "resonate" with Millennial learners. Educators working in simulation would benefit from becoming familiar with characteristics of preferred Millennial classrooms, as well as overall tendencies of Millennial learners. Appropriate pedagogical underpinnings should be used to underpin simulation design in order to maximize the impact of this powerful learning platform.

9. Conclusions

This study has highlighted the relevance of modeling to demonstrate best practice in the management of deteriorating patient situations, repetition to give opportunity for improvement, debriefing to help clarify confusion, and use of the ISBAR tool to improve patient safety through effective and efficient communication.

These four instructional scaffolds have particular relevance to Millennial students who are pressured and expected high levels of performance (achieving). Firstly, Millennials prefer to have expected performance modeled to ensure their own performance is perfected before being viewed by peers. Secondly, Millennial students desire a second opportunity to demonstrate improved skills and communication. This is again tied to their tendency to feel pressured and achieve to a high level.

Thirdly, Millennials want to be given feedback in the form of debriefing in order to perfect their performance, and improve teamwork. This instructional strategy resonates with Millennial tendencies to work in teams while receiving personal feedback to assist in perfecting their performance (achieving).

Fourthly, Millennials have been sheltered in their upbringing, causing a focus on safety to be predominant. Use of the ISBAR tool helps to ensure patient safety by decreasing assumptions, improving overall communication structure, and improving student confidence thus resonating with Millennials' need to achieve well while working in teams.

In conclusion, today's educators (most likely from Gen X and Baby Boomer generations) must be willing to adopt different modes of delivery when working with millennials students. Collaborative and immersive learning environments embedded with teamwork and technology are often preferred by this generation. Pedagogical practices, which may be considered mundane by Millennials (*i.e.* teacher driven passive learning models) will need to be revised in order to accommodate the expectations of this generational cohort. Student-driven, active learning models which embrace Millennial strengths in visual processing and cooperation have the potential to breathe life into the tired bones of many classrooms.

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Factor Analytical Examination of the Evidence-Based Practice Beliefs Scale: Indications of a Two-Factor Structure

Cecilie Katrine Utheim Grønvik[1]*, Atle Ødegård[1], Stål Bjørkly[2]

[1]Faculty of Health Sciences and Social Care at Molde University College, Specialized University in Logistics, Molde, Norway
[2]Faculty of Health Sciences and Social Care at Molde University College, Specialized University in Logistics and Oslo University Hospital, Oslo, Norway
Email: *cecilie.gronvik@himolde.no, atle.odegard@himolde.no, stal.bjorkly@himolde.no

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Abstract

Background: Promotion of Evidence-Based Practice (EBP) in nursing appears to be developing slowly. Research indicates that nurses' beliefs in EBP may play an even more significant role than knowledge and resources in making implementation feasible. To address this issue, measurement of nurses' beliefs regarding EBP is paramount. Aims and objectives: This study explores the internal consistency reliability and the construct factor structure of the Norwegian version of the original Evidence-Based Practice Beliefs Scale (EBP-BS). Methods: The study has a Non-experimental exploratory survey design. A Norwegian translation of the EBP-BS was tested in a convenience sample of 118 healthcare professionals (95% nurses) attending a continuing education program at a University College in Norway. The response rate was 95% (n = 112). The internal consistency of the scale was measured by Cronbach's alpha, and an explorative Principal Component Analysis (PCA) was used to explore the construct structure. Results: The overall internal consistency of the EBP-BS was acceptable. The PCA indicated a four-factor structure. The psychometric properties of two of the factors were too weak for expanding to a four-factor model. Based on our investigation of the EBP-BS, we suggest a two-factor structure model. The factors were named 1) *General knowledge and confidence concerning EBP* and 2) *Task specific beliefs in EBP.* This finding differs from previous results that indicated a unidimensional structure. Conclusion: As a starting point, reliable and valid measurement of nurses' beliefs about EBP is required in order to identify possible obstacles and to optimize implementation in the individual clinical setting. Our results indicate that the EBP-BS has a two-factor structure. Further exploration of the factor structure is needed. Further empirical research may contribute to the resolving of controversies concerning basic understandings of the concept of EBP.

Keywords

Evidence-Based Practice, Beliefs Scale, Nurses, Psychometric Evaluation, Principal Component Analysis

1. Introduction

Over the past two decades, we have seen a growing emphasis on the implementation of evidence-based practice to advance the quality of nursing. Evidence-Based Practice (EBP) is a problem-solving approach to the delivery of care that integrates the best evidence from well-designed studies with a clinician's expertise and patient preferences and values [1].

Several studies have reported that evidence-based nursing practices have a positive impact on patient outcome [2]-[4]. EBP also reduces healthcare costs [5] [6] and improves the quality of care [4] [7]. Even though the positive effects of EBP on patient outcomes and healthcare costs have been described in the literature for years, promotion of EBP in nursing appears to be developing slowly. Nurses' beliefs, skills, and knowledge related to EBP have an impact on the use of evidence in practice [8]. Strong beliefs in the value of EBP and positive attitudes toward it are associated with nurses' use of evidence in practice and are seen as important mediators in changing behavior related to EBP [9]. Given the influence of practitioners' beliefs on the successful implementation of EBP, a first step in its implementation may be to assess the nursing staff's beliefs regarding this approach. If their perceptions of this approach are positive, the chances of success are good; if not, there is a high risk of failure.

Despite the globalization of EBP, studies reporting the translation and adaption of instruments that measure EBP beliefs are scarce. Reliable and valid measurement of beliefs towards EBP is crucial to further progress.

In 2003, Melnyk and Fineout-Overholt developed the EBP Beliefs Scale (EBP-BS) to examine nurses' beliefs about EBP and their opportunities to use research results in practice [10]. The self-report scale is based on Prochaska and Velicer's Transtheoretical Model of Organizational Change [11], a recognized model for changing health behavior, and the ARCC model (Advancing Research and Clinical Practice through Close Collaboration) for implementation of research into clinical practice [12]. These models demonstrate that organizational culture and climate for EBP may have an impact on clinicians' beliefs about its value and the extent to which they deliver evidence-based care [13]. EBP is a complex process that may involve changes both in clinicians' behaviors and in healthcare systems' operations. Key factors facilitating EBP adoption include strong beliefs that EBP improves patient care and outcomes [7]. Therefore, it is crucial to have instruments that assess nurses' beliefs, culture, and readiness for EBP.

In a recent publication, Gu, Ha, and Kim [14] reported on the development of an objective instrument for assessment of entry-level EBP knowledge and skills in nurses.

They claimed objective measurement to be superior to self-reported perceptions of knowledge and skills concerning EBP.

Still, the psychometric properties of the EBP-BS have been tested in the U.S. [9] [15], China [16] and Iceland [17], and these studies generally report that the EBP-BS has a well-established construct validity and acceptable internal consistency reliability. Previous research by both Melnyk *et al.* [9] and Thorsteinsson [17] concluded that the EBP-BS had a unidimensional factor structure. However, Estrada [15] suggested that the scale described four dimensions of EBP: 1) knowledge beliefs, 2) value beliefs, 3) resource beliefs, and 4) time and difficulty beliefs. A clear construct structure and firm psychometric properties are of paramount importance to the use and relevance of an instrument. The main aim of this research is to explore the internal consistency and the factor structure of the EBP-BS.

2. Methods

2.1. Design

This study has a non-experimental, exploratory, and descriptive study design.

2.2. Sample

We used a convenience sample of 118 (N) students in a continuing education program at a university in Norway. We included all available students, but apart of six dropouts (n = 112). The part-time students all worked in community or specialist health services. The majority of the participants, 106 students (95%) had bachelor degrees in nursing, and the remaining six participants had health or social work education at the bachelor level. Hundred and nine of the participants were women, and three were men.

2.3. Materials and Data Collection

Data were collected in 2011 ($n = 56$) and in 2015 ($n = 56$). The EBP-BS consists of 16 items and is a self-report instrument for investigating clinicians' beliefs about the impact of EBP on clinical care, their ability to implement EBP, the knowledge and skills needed for EBP and the behaviors related to use of EBP, and their confidence in how EBP can improve clinical practice [10]. Examples of items are "I am sure that evidence-based guidelines can improve clinical practice" and "I believe I can overcome barriers to implementing EBP". The respondents rated each of the 16 items on a five-level Likert scale, ranging from 1 = *strongly disagree* to 5 = *strongly agree*. The items are presented in Table 1.

2.4. Translation of the EBP-Belief Scale

The WHO principles [18] for bidirectional translation and adaption of instruments were followed when translating the EBP-BS scale to Norwegian. A group of bilingual researchers from the Centre for Evidence-Based Practice, Faculty of Health and Social Sciences, at the University College of Bergen translated the scale. To insure the original

Table 1. Descriptive statistics of EBP-BS items ($n = 16$).

Item	Mean	Standard deviation
1. I believe that EBP results in the best clinical care for patients	3.92	0.74
2. I am clear about the steps of EBP	2.28	1.15
3. I am sure that I can implement EBP	3.26	1.00
4. I believe that critically appraising evidence is an important step in the EBP process	4.13	0.59
5. I am sure that evidence-based guidelines can improve clinical care	4.16	0.67
6. I believe I can search for the best evidence to answer clinical questions in a time efficient way	3.45	0.67
7. I believe that I can overcome barriers in implementing EBP	3.90	0.70
8. I am sure that I can implement EBP in a time efficient way	3.16	0.75
9. I am sure that implementing EBP will improve the care I deliver to my patients	3.95	0.61
10. I am sure about how to measure the outcomes of clinical care	2.77	0.70
11. I believe EBP takes too much time [reversed scored]	3.00	0.84
12. I am sure that I can access the best resources in order to implement EBP	3.11	0.79
13. I believe EBP is difficult [reversed scored]	2.87	0.89
14. I know how to implement EBP sufficiently enough to make practice changes	2.52	0.87
15. I am confident about my ability to implement EBP where I work	2.60	0.89
16. I believe the care that I deliver is evidence-based	3.07	0.93

meanings were preserved, a bilingual researcher discussed the Norwegian items with the developers of the scale [10]. The goal of the translation was to establish a semantic equivalent to the original instrument rather than a word-for-word translation. The Centre for Evidence-Based Practice, Faculty of Health and Social Sciences, at the University College of Bergen gave permission to use the translated EBP-BS.

2.5. Statistical Analyses

The Statistical Package for Social Sciences [SPSS] software version 22 for Windows analyzed the data. Individual items that had missing data were eliminated by the list-wise deletion option in SPSS. Only nine observations [0.50%] out of a total of 1792 scores were missing. Missing values were replaced by mean score values. Based on Melnyk *et al.*'s [9] recommendations, reverse scoring of two negatively phrased items (Items 11 and 13) was done to fit the score scale of the other items, before performing the calculations.

The internal consistency values of the scale and the factors were calculated with Cronbach's α [alpha]. A Cronbach's α value of 0.70 or more was considered to reflect good internal consistency [19]. To test the appropriateness of using factor analysis on this data set, we used the Kaiser-Meyer-Olkin (KMO). The KMO index was >0.72 (p <

0.01), well above the recommended value of 0.50. Gorsuch (1983) claimed that five respondents per variable would be sufficient for a reliable factor analysis. Our investigation tested 16 variables, and, according to Gorsuch's criterion, 80 respondents would have been sufficient for a full factor analysis study (Gorsuch, 1983).

A principal component analysis (PCA) was used to explore the meaning structure of the scale. The reason for not using a Confirmatory Factor Analysis was that investigations of the factor structure of the BPS-BS are scarce and inconclusive. We conducted an orthogonal rotation with a Varimax rotation process [20]-[22].

Thus, based on several statistical procedures and considerations, our data met the basic criteria to fit a factor analytic design. Since the significance of a factor loading depends on the sample size, we set the cut-off for factor loadings at 0.51 [23]. The One-Sample Kolmogorov-Smirnov Test [24] was used to test the mean scores and distributions of the items in the scale. The scores were significantly different from a normal distribution, but according to Jolliffe [25], a PCA does not require normality.

2.6. Ethical Considerations

We received permission from the University College to conduct the study. The sample received oral and written information about the study, and their participation was voluntary. Only students who gave informed consent were included in the study. The sample completed the questionnaire anonymously. The study was reported neither to the Regional Committee for Medical Research Ethics nor to the Norwegian Social Science Data Services because no demographic variables were registered and the respondents could withdraw their consent to participate at any time.

3. Results

The response rate was 95% (n = 112). The overall Cronbach's alpha value for the scale, with 16 items, was 0.73. The Descriptive scores on the items are presented in **Table 1**.

We found some very large differences in mean score values between items. Items 2 (lowest) and 5 (highest) were at the extremes. Item 2 (I am clear about the steps of EBP) covers perceived knowledge or competency concerning EBP, whereas Item 5 (I am sure that evidence-based guidelines can improve clinical care) measures perceived belief in EBP. It is not very easy to apprehend that assessing one's knowledge of and one's belief in the effect of EBP belong to the same underlying dimension. There are reasons to question the unidimensional quality of a scale with items that cover such different features as these two items do. As will be seen in the PCA analysis, Item 2 and Item 5 measure different aspects of beliefs concerning EBP, and, in our model, they do not belong to the same factor.

3.1. Principal Component Analysis [PCA]

The eigenvalues were inspected to determine the numbers of factors to be extracted. The eigenvalue criterion [greater than 1.0] suggested extraction of a maximum of four factors (see **Table 2**). An inspection of the scree plot indicated a five-factor structure,

Table 2. Explained variance in principal component analysis*.

Component[1]	Eigenvalues	Total % of variance	Cumulative % of variance
1	3.86	24.14	24.14
2	2.17	13.55	37.70
3	1.53	9.57	47.27
4	1.23	7.71	54.98

Note: * = Orthogonal Varimax rotation. 1: Component is used synonymously with *factor* in the text.

but the fifth factor did not meet the eigenvalue criterion. Four factors explained 55% of the variance in the original items (**Table 2**).

The first factor had an eigenvalue of 3.86 and accounted for 24% of the variance in the scale. Three other factors had eigenvalues greater than 1.0 [2.2, 1.5, and 1.2, respectively]. They accounted for 13.5%, 9.5%, and 8% of the variance in the scale.

The PCA analysis clustered the 16 items into four different factors with loadings ranging from 0.52 - 0.79 (**Table 3**).

Investigating the Internal Consistency in the Factors

Cronbach's alpha was used to examine the internal consistency reliability in each factor derived from the PCA analysis. The results showed that the internal consistency of the factors ranged from 0.53 - 0.72 (**Table 4**).

Estimates of internal consistency were not entirely satisfactory for all four factors, indicating that the data did not support a four-factor structure. The two first factors appeared to be psychometrically solid with regard to internal consistency (reliability and interpretability). Low internal consistency values in Factor 3 and 4 raised doubts about the validity of these factors as distinguishing parts of the EBP-BS factor structure. Based on the item content, the factors were preliminarily named as follows: 1) General knowledge and confidence concerning EBP (four items) and 2) Task specific beliefs in EBP (four items). The first factor, General knowledge and confidence, comprised nurses' own confidence concerning implementation of EBP in their work. The second factor, Task specific belief in EBP, covered more practical issues like the use of EBP-related resources and finding the time to apply EBP, such as use of resources and finding time to apply EBP. We refrained from further interpretation of Factor 3 and 4 due to low reliability scores.

4. Discussion

4.1. Exploration of the EBP-BS

The main aim of this investigation was to explore the factor structure of the underlying construct of the EBP-BS. Results from previous studies have shown that the items of the EBP-BS generally have high construct validity [9] [16] [17] and that the factor structure of the scale is unidimensional. Melnyk and colleagues [9] found a major factor accounting for 40% of the variance. They did detect three other factors, but decided to

Table 3. Principal component matrix with factor loadings for the 16 items*.

Items/Components	1	2	3	4
General knowledge and confidence concerning EBP 14. I know how to implement EBP sufficiently enough to make practice changes	0.79			
3. I am sure that I can implement EBP	0.73			
15. I am confident about my ability to implement EBP where I work	0.71			
2. I am clear about the steps of EBP	0.63			
Task specific beliefs in EBP 6. I believe I can search for the best evidence to answer clinical questions in a time efficient way		0.72		
8. I am sure that I can implement EBP in a time efficient way		0.64		
12. I am sure that I can access the best resources in order to implement EBP		0.63		
10. I am sure about how to measure the outcomes of clinical care		0.62		
Component 3 1. I believe that EBP results in the best clinical care for patients			0.65	
5. I am sure that evidence-based guidelines can improve clinical care			0.62	
11. I believe EBP takes too much time [reversed scored]			−0.61	
4. I believe that critically appraising evidence is an important step in the EBP process			0.56	
Component 4 7. I believe that I can overcome barriers in implementing EBP				0.68
13.. I believe EBP is difficult (reversed scored)				0.67
9. I am sure that implementing EBP will improve the care I deliver to my patients				0.59
16. I believe the care that I deliver is evidence-based				−0.52

Note: * = Principal component analysis with Varimax rotation.

leave these out as the scree plot indicated discontinuity between the first and the second factors, concluding that "a single-factor solution was the most parsimonious interpretation of the results (9:212)". They reported, however, that the three other factors accounted for 26% of the variance (11%, 8%, and 7%). We question whether not including these three factors in the model actually may have hidden a multifactorial structure of the EBP-BS, such as the two-factor structure found in our study.

In our view, the findings of two factors in the scale concurs with the complexity that the Beliefs Scale intends to measure. This result may also invite for a differentiation into at least two belief foci, general knowledge and confidence and task specific EBP practice, in order to enhance the implementation process of evidence-based practice in nursing.

Evidence as a construct is characterized by a high degree of complexity, and differences in understanding and definition of the concept have led to debate in clinics and academia [26]. As suggested by Estrada [15], nurses may understand EBP as a multifactorial phenomenon. The two main factors found in our study overlap relatively with Estrada's [15] theoretical categories: beliefs related to knowledge and beliefs related to the value of EBP. The finding of a two-factor structure with factor loadings above 0.62

Table 4. Internal consistency values for four components found by principal component analysis of the EBP-BS.

Components	No. of items	Cronbach's alpha	Cronbach's alpha if item deleted
1) General knowledge and confidence concerning EBP	4	0.72	
Item 14			0.56
Item 3			0.66
Item 15			0.66
Item 2			0.74
2) Task specific beliefs in EBP	4	0.70	
Item 6			0.68
Item 8			0.58
Item 12			0.62
Item 10			0.67
3) Component 3	4	0.53	
Item 1			0.39
Item 5			0.36
Item 11 (rev.)			0.61
Item 4			0.45
4) Component 4	4	0.54	
Item 7			0. 41
Item 13 (rev.)			0.45
Item 9			0.41
Item 16			0.59

and meaningful and interpretable clusters of items indicate that our two-factor structure has relatively high content validity.

4.2. Reliability and the Construct Factor Structure

According to Nunnally and Bernstein [27], the internal consistency of the scores in the EBP-BS would be acceptable for early stages of the testing of research tools. They recommend 0.70 as an acceptable value. The results on internal consistency concur with similar findings in previous tests of the scale's internal consistency, which have yielded Cronbach's alpha values over 0.80 in different contexts [9] [16] [17]. This preliminary finding suggests that the questionnaire is a reliable tool for measurement of the strength of beliefs about EBP. A high internal consistency value for an instrument is essential because it indicates that raters appear to assess the items in a consistent way. However, some statistical issues must be considered in interpreting internal consistency values. The most important one is that if one expands a tool with more and similar items, the consistency estimates will automatically become higher. This does not mean that the tool has improved by adding items. A high internal consistency has no value unless the validity of the tool is good. Redundancy of items is a significant threat because it makes a tool less user-friendly and more time-consuming.

The first factor was labeled *General knowledge and confidence concerning EBP.* Knowledge and confidence skills affect beliefs [7], and Bandura [28] emphasized that belief in self-efficacy increases motivation, academic performance, and interest in the topic. It is therefore vital that EBP instruments measure participants' self-efficacy in relation to evidence-based practice. Measures of EBF beliefs that reveal low levels of perceived self-efficacy may indicate the need for more education about what EBP actually is and to moderate groundless fear and undervaluation of professional competency.

Nurses generally report favourable views of EBP and believe in its value for quality of care [29]. However, these positive beliefs toward research do not necessarily translate to an increased use of research findings in practice [30].

The second factor in our model was *Task specific beliefs in EBP.* According to Bandura [28], positive attitudes and beliefs in one's own knowledge and skills can increase motivation for engagement in making changes in one's practice. If we in a nursing staff identify a discrepancy between very low scores on confidence in specific EBP skills and high scores on positive beliefs regarding EBP application in practice, we may hypothesize that the motivation for EBP is very good, whereas the confidence in one's own competency is low. This would be an action-triggering type of information that indicates a need for further education focused on development of the necessary skills [task specific] required for engaging in EBP. Building knowledge and self-confidence emerges as a vital platform for implementing EBP in clinical units. Thus, the idea of identifying factors turns out to have more practical change value than just interpreting a total score value on a unidimensional EBP-BS.

At this stage, Factors 3 and 4 appear as two groups of preliminary redundant items. Further large-scaled studies are required for a more permanent decision on the interpretation of these possible factors. The following discussion of these items must be interpreted within the limitations set by the weak reliability estimates for them. The loadings of Factors 3 and 4 had one item each with a negative correlation. Item 11 (I believe that EBP takes too much time) correlates negatively with the other items in Factor 3. This signifies that if nurses reported that EBP takes too much time, this would suggest low scores on beliefs in core values concerning EBP, such as critical appraisal of evidence, EBP results in the best clinical care, and being sure that evidence-based guidelines can improve clinical practice. It makes sense that a nurse would underrate possible positive aspects of EBP if she perceived that it took too much time. In contrast, it does not make much sense that if you believe strongly that your work is evidence-based (Item 16), then you believe that you cannot overcome barriers to implementing EBP (Item 7), you are sure that EBP cannot improve care [Item 9], and you believe that EBP is difficult (Item 13).

4.3. Further Development of the EBP-BS

Based on our investigation of the EBP-BS, we suggest a two-factor structure model. It will be of special interest to investigate whether large-scale studies can confirm the preliminary findings of the beliefs concerning EBP as a two-factor phenomenon. As Nunnally and Bernstein (1967) point out, "Most measures should be kept under constant surveillance to see if they are behaving as they should (p. 87)."

In our opinion, this research provides a conceptual framework and point of departure for further developments of the Evidence-Based Practice Beliefs Scale. Nunnally and Bernstein [27] claim that as a first step in a measurement procedure, a researcher should specify the domain of indicators of a construct. Thus, any attempt to operationalize a theoretical construct such as EBP-BS on the empirical level may be encumbered with errors. Therefore, it is essential to specify the domains to prevent the instrument from including irrelevant information or under representing the constructs [31]. In the case of EBP, a firm focus on domain specifications will increase the likelihood of clarifying EBP in a given study and reducing the chances of confusion about which aspects of EBP are referred to.

In practice, there are good reasons to assume that various mediators and moderators may have an impact on the two factors of our model, such as work experiences and educational background. There may be a discrepancy regarding EBP beliefs between nurses who were recently educated and those who were not educated in EBP. Therefore, nurse leaders and educators play a key role in creating a context to support clinical environments that optimize best practices for patient outcomes [32]. Furthermore, it would also be useful and interesting to investigate how the two factors are influenced by other phenomena such as organizational culture, leadership, and climate for EBP [13] [33]. Our understanding of EBP as a phenomenon, as well as its relationship to other influences and potential outcomes, remains limited.

4.4. Study Limitations

The possibility of making inaccurate predictions or assumptions is normal in small-scale studies [34]. Therefore, we must interpret the results within the limitations set by the small-scale design of our research.

First, the participants involved in the testing were not randomly selected. Second, the principal component analysis involved a relatively small sample, limiting generalizability and making it more difficult to replicate and interpret the results. However, it should be borne in mind that MacCallum [35], among others, claims that common rules of designing sample size in factor analysis may not always be useful. Wetzel [36] posits that factor analysis methods can be done to explore validity in studies with fewer respondents than 100. With reference to Gorsuch [37], we assume that a sample of 112 respondents is sufficient.

Third, even if we did not plan any comparison of respondents, it may be a limitation that we did not collect and analyze data of respondents' background variables such as gender, age, seniority, and discipline. However, this limitation is moderated by Squires *et al.* [38] finding of no significant relationships between gender, age, seniority, and discipline and beliefs and behaviors related to EBP.

The high response rate in our investigation may also indicate that the qualitative understanding of the content in the Norwegian translation was adequate. The finding of no significant deficiencies in completing the EBP-BS indicates that the questionnaire was easy to use. The fact that the respondents came from different parts of both municipal and specialist health services increases the likelihood that the participants were representative of other nurses.

5. Conclusion

Due to a limited number of empirical investigations, our main scope was to explore the factor structure of the scale. To our knowledge, this was the first study that systematically examined the reliability and validity of the EBP-BS in a Norwegian context. The results indicate that the EBP-BS has a two-factor structure. However, further exploration of the factor structure is requisite, especially because there are still controversies regarding the concept and the application of EBP.

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Cognitive Ability in Elderly in a City in Northeastern Brazil: An Analytical Study

Francisca Patrícia Barreto de Carvalho[1]*, Glauber Weder dos Santos Silva[2], Clélia Albino Simpson[2], Ana Géssica Costa Martins[1], Narjara Beatriz Queiroz da Silva[1], Mônica Gisele Costa Pinheiro[2], João Evangelista da Costa[2], Lucídio Clebeson de Oliveira[1], Amélia Carolina Lopes Fernandes[1], Francisco Arnoldo Nunes de Miranda[2]

[1]State University of Rio Grande do Norte, Mossoró, Brazil
[2]Federal University of Rio Grande do Norte, Natal, Brazil
Email: *patriciabarreto36@gmail.com

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Abstract

To analyze the cognitive ability of elderly people assisted by the Family Health Strategy (FHS) in a northeastern Brazilian city, a cross-sectional, analytical study was conducted with 406 elderly assisted by the FHS in Mossoro-RN, Brazil, from March to May 2014. The data were collected through two validated questionnaires. For the data analysis, the Alpha Cronbach's, Kruskal-Wallis test, chi-square and Pearson correlation statistical tests were applied. There was a predominance of women (67.98%) in the survey. Among the respondents, 50% had an index of up to 27 points in Pfeffer Instrument, identifying greater degree of dependence in performing instrumental daily activities related to mobility in the community (39.7%) and financial management (57.1%). On Mini-Mental State Examination (MMSE), 75% of seniors had an index above 27 points, with the scores classification as standard (50.99%), mild (25.12%), moderate (22.66%) and severe (1.23%). Although changes have been identified in cognitive performance and independence of elderly people in some areas, these difficulties do not completely affect the lives and daily activities of the elderly.

Keywords

Primary Health Care, Geriatric Assessment, Cognitive Aging, Geriatric Nursing

1. Introduction

Aging is part of the human life, being a global reality [1]. Different societies exhibit characteristics with short and long-term effects, such as the falling birth rate, increased life expectancy, population aging and the increase in chronic and degenerative diseases [2].

Population aging, evidenced from the second half of the twentieth century, is the sharpest demographic transformation seen in developing countries [3]. Brazil is already considered as a country with a high number of elderly people, since the number of people aged over 60 years old is greater than 21 million, which means about 11% of the total population [4].

The increase in life expectancy, in addition to the reduction in fertility rates, technological and scientific advances, characterizes the human aging, presenting ethical challenges that impose the need to reconsider the later stages of life, since the concept of aging and being elderly is linked to emotional state, the level of dependence, autonomy, memory impairment, social participation and changes in the appearance and health [5] [6].

Since it is a universal biological phenomenon with varied social and psychological consequences, aging must be understood in all its amplitudes. It is a stage of life with values and characteristics responsible for changes in cognitive and functional development of the subject, affecting his/her organic base, metabolism, biochemical balance, memory, language, immunity and nutrition [7].

The cognitive impairment may occur due to the decline of aging physiological process or a transitional stage for diseases and dementias [8]. Cognitive changes present in normal aging have, as results, the gradual decline of functions such as language, perception, motor skills and executive functions; the memory loss is the most significant among the general population, since it hampers various daily activities [9].

Given this, the cognitive deficits need to be early identified in the elderly, in order to ensure that, during the aging process, the individual can maintain his/her autonomy, self-care and independence without prejudice [10].

This multidimensional knowledge of the elderly living in the community is essential for the proper planning of their health care, seeking greater quality of life in the aging process. One of the practice sites of this monitoring and care of the elderly is the Family Health Strategy (FHS), the main access to the health system in Brazil. In the FHS context, taking into account the elderly, the attendance to this public should focus on early identification of pathological, physical and mental changes common to the aging process [11].

2. Method

An analytical, quantitative study was conducted in all areas covered by the FHS in the urban area of the city of Natal, Rio Grande do Norte (RN), Brazil. The data were daily collected from March to May 2014 through home visits to 406 elderly, accompanied by their Community Health Agents.

Inclusion criteria were: age from 60 years old and living in an area covered by the FHS, urban area, in the city of Mossoro/RN. The exclusion criteria were: the elderly who had physical and mental disabilities, such as limitation in fine motor coordination, hearing loss, visual impairment and/or any type of dementias already diagnosed, as these could interfere with the results of the MMSE test.

Data were collected at the elderly home by applying two validated questionnaires with objective and subjective questions: 1) Mini-Mental State Examination (MMSE) and 2) Pfeffer Questionnaire.

The MMSE is one of the most used tests in clinical practice to evaluate the change of cognitive state of geriatric patients [12]. It consists of questions grouped into seven different categories, each one with the aim of evaluating the global cognitive ability and specific cognitive functions, which are: orientation (time and place), three-word record (short term memory), attention and calculation, recall of three words (recall), language and visual-constructional ability [13].

The score ranges from zero to 30, so that the lowest performance score is zero. The educational attainment is the primary demographic factor to determine the cut score used in the final score, with the following notes: 20 (illiterates), 25 points (one to four years of education), 26.5 points (five to eight years of education), 28 points (nine to 11 years of education) and 29 points (education ≥ 11 years) [14].

As for the Pfeffer Index, it consists of objective questions involving items related to the individual's ability to perform Instrumental Activities of Daily Living (IADL) and cognitive/social functions [15]. In this questionnaire, ten items are evaluated with respect to functionality considering the individual independence degree, so that the score ranges between zero, the minimum score, and 30, the maximum score. The presence of functional impairment is considered from the score three, in which, in this index, the higher the score, the greater the degree of dependence of the patient [16].

The database was built in Microsoft Office Excel® 2010 program, for the construction of descriptive tables. Next, the data were exported to SPSS 20.0 and Free R 3.0.0, to apply the following statistical tests:

- **Cronbach's Alpha**, which verifies the reliability of data from both instruments, obtaining the results of 0.849 for Pfeffer and 0.701 for MMSE, classifying the data as satisfactory;
- **Kruskal-Wallis**, to compare statistical difference between the performances of the respondents in the two instruments, concluding that the subjects classified as normal and mild according to the MMSE showed better performance in the Pfeffer index. The test to correlate the participants' gender and level of performance was also used in the instruments, among others;
- **Chi-square test**, to verify the dependence or Independence between the variables and;
- **Pearson's correlation**, to verify the association between the variables.

The variables inserted in the database were: number of elderly participants, gender and the issues raised by the two instruments. After the construction of the database, the data were submitted to inferential analysis, being also expressed as mean, standard deviation, as well as they allowed the construction of tables with simple frequencies and percentages.

The privacy of the participants was maintained and the entire data collection process was conducted ensuring the ethical principles recommended by Resolution 466/12 of the National Health Council and under approval of an opinion by the Research Ethics Committee of the State University of Rio Grande do Norte, under number 389,587/2014 and CAEE number 14624513.8.0000.5294.

4. Results

There was a predominance of women: 67.98% (n = 276) of the study population consisted of women and 32.02% (n = 130), of men. However, there was no evidence of statistical difference of the MMSE and Pfeffer questionnaire regarding the elderly's gender.

As described in Table 1, the average rate of Pfeffer in patients was 25.3 with a standard deviation of 5.28; 50% of respondents had an index of up to 27, whereas the first quartile (25%) and the third quartile (75%) showed the following results: 23 and 30, showing a diminished performance by the interviewed elderly.

Table 2 presents data regarding the degree of dependence to perform daily activities, in line with the Pfeffer Questionnaire.

It was observed that 57.1% of the elderly respondents reported they lack the capacity to perform, need help or performs the activity of managing their own money with difficulty, demonstrating a degree of significant dependence.

Another item of the Pfeffer questionnaire in which there was dependence is the elderly's ability to go to distant places and return home: 39.7% of the elderly respondents had difficulty performing the activity, needed help or were unable to do it.

Regarding the MMSE data, as Table 3 shows, the mean MMSE score of the total sample was 23.6 with a standard deviation of ±4.94. In this test, 50% of respondents had an index above 25, whereas the first quartile (25%) and the third quartile (75%) presented the results of 21 and 27, respectively.

For the application of MMSE, the patients' educational attainment was considered, so that, in the sample of the survey, 32.27% of the elderly were illiterate, representing 131 elderly. Even with this percentage, only 25% of the sample obtained results below the limit score considered for literate elderly.

According to the classification of MMSE, the majority (50.99%) had normal outcome, as observed in the following table (Table 4).

It was demonstrated that patients classified as normal and mild, considering the MMSE, had better performance in the Pfeffer Questionnaire. Table 5 shows the data according to the respondent profile.

Taking into account the variable related to the elderly residence location, there is a statistical difference between the classification of the MMSE and the sector, so that the

Table 1. Statistics of the Pfeffer index, Mossoró, RN, Brazil, 2015 (n = 406).

	Statistical data							
Instrument	**Minimum**	**Maximum**	**25%**	**Median**	**75%**	**Mean**	**SD***	**CV****
Pfeffer	4.00	30.00	23.00	27.00	30.00	25.30	5.28	20.87

Source: research data; Legend: *Standard Deviation; **Coefficient of variation.

Table 2. Dependence degree according to the results of the Pfeffer questionnaire, Mossoró, RN, Brazil, 2015 (n = 406).

Activities	Frequency	Not capable	Needs help	Has difficulty	Normal	Total
Can you manage your own money?	***n***	**19**	**152**	**58**	**172**	**401**
	%	**4.74**	**37.91**	**14.46**	**42.89**	**100.00**
Can you go shopping by yourself?	n	19	86	45	252	402
	%	4.73	21.39	11.19	62.69	100.00
Can you execute daily activities?	n	21	44	42	295	402
	%	5.22	10.95	10.45	73.38	100.00
Can you manage do accomplish your own meals?	n	9	32	26	328	395
	%	2.28	8.10	6.58	83.04	100.00
Do you know what happens to your neighbors?	n	6	19	14	359	398
	%	1.51	4.77	3.52	90.20	100.00
Can you listen to Radio/TV News, and discuss them?	n	3	4	13	385	405
	%	0.74	0.99	3.21	95.06	100.00
Can you remember your appointments dates/hours?	n	11	27	41	326	405
	%	2.72	6.67	10.12	80.49	100.00
Can you take your medicines in the right dose and times?	n	8	17	54	323	402
	%	1.99	4.23	13.43	80.35	100.00
Can you go to distant locations, using any means of transportation, and return home?	***n***	**23**	**90**	**48**	**244**	**405**
	%	**5.68**	**22.22**	**11.85**	**60.25**	**100.00**
Can you stay at home safely?	n	15	31	39	319	404
	%	3.71	7.67	9.66	78.96	100.00

Source: research data. Legend: *Featured.

Table 3. Statistics of the Mini Mental State Examination, Mossoró, RN, Brazil, 2015 (n = 406).

	Statistical data							
Instrument	**Minimum**	**Maximum**	**25%**	**Median**	**75%**	**Mean**	**SD***	**CV****
MEEM	3.00	30.00	21.00	25.00	27.00	23.60	4.94	20.93

Source: Research data. *Standard Deviation; **Coefficient of variation.

Table 4. Classification of the Mini Mental State Examination, Mossoró, RN, Brazil, 2015 (n = 406).

Classification	Absolute Frequency	%
Normal	207	50.99
Mild	102	25.12
Moderate	92	22.66
Severe	5	1.23
Total	406	100

Source: research data.

Table 5. Scores of the Mini Mental State Examination according to gender and location of the elderly residence, Mossoró, RN, Brazil, 2015 (n = 406).

			Classification		
Variable	**Normal**	**Mild**	**Moderate**	**Severe**	**Total**
			Gender		
Female	50.72%	23.19%	25.00%	1.09%	100.00%
Male	51.54%	29.23%	17.69%	1.54%	100.00%
			*X_2: 3.525; **D.F.: 3; *P-value*: 0.318		
			Sector		
Central	20.00%	20.00%	60.00%	0.00%	100.00%
East	51.79%	24.40%	23.81%	0.00%	100.00%
North	51.28%	21.79%	21.79%	5.13%	100.00%
West	55.79%	24.21%	20.00%	0.00%	100.00%
South	51.11%	15.56%	31.11%	2.22%	100.00%
			*X_2: 30.874; **D.F.:12; *P-value*: 0.002		

Source: research data; Legend: *Chi-square; **Degrees of Freedom.

elderly residents of the central region showed lower performance than other regions.

5. Discussion

In Brazil, the population aged 60 or more is approximately 10.8% of residents in the country, accounting for more than twenty and a half million people, of which 55.5% are composed of women [17]. The highest amount of elderly women in this study corroborates the so-called feminization of old age, growing phenomenon in the country. This is accompanied by changes in the epidemiological and care profile and the existence of the mortality gap between the genders, in which the number of men who die for various reasons is higher than the number of women who died [18].

In this study, there was no significant change with respect to the cognitive development of the elderly men in relation to the elderly women, as seen in other studies [19]. However, it differs from other surveys, in which the number of women with a high degree of dependence is higher than male rates [20].

Considering the results of the Pfeffer index, the elderly respondents presented dependence degree, since the maximum score in this instrument is 30 points for verifying the dependence in instrumental daily activities. Within this same index, 50% of respondents showed values above 27 points, considering the elderly dependent for certain daily activities [9].

Among the tasks that the elderly presented the highest degree of dependence, in Pfeffer, is the management of their own money, which was also reported by other authors, by the need to deal with numerical quantities [9]. According to developed researches, shopping and handling their own money stood out as the instrumental daily activities that seniors reported partially or completely needing help [21].

The difficulties in commuting to distant locations and returning home, other item with significant degree of dependence in the Pfeffer Questionnaire, can be explained by the potential exposure of the elderly to traffic accidents during the journey, violence, risk of falls or injuries to health [22] [23].

Based on the contents of the MMSE, an aspect that deserves discussion concerns the elderly who reside in the central city having higher degree of dependence than the elderly from other regions. Aging leads to increased risk for the development of vulnerability in biological, socioeconomic and psychosocial character, influenced by poor conditions of education, income and health. According to the degree of occurrence, these aspects of illness generate possibilities and difficulties of access to care resources available in the community [24], which can illustrate the difference in levels of dependency according to the elderly's residence location.

When applying MMSE, despite considerable rate of illiterate, the elderly had good cognitive performance. The reality seen in this study differs from other studies showing that the low educational attainment interfere with the autonomy, independence and, hence, the functional and cognitive capacity of the elderly [20].

In the aging process, when identifying functional and cognitive decline, the inclusion of the elderly in practical programs of physical exercise emerges as one of the ways to promote their autonomy and continuous physical development. Elderly people who perform regular physical activity or perform daily household activities have better functional capacity, resulting in lower risk of falls than individuals who do not perform such activities [25].

For promoting the elderly's health, primary care and the FHS need to develop experience groups, organize discussion about lifestyles or adverse and favorable situations that occur in the elderly's routine, as well as discuss the influence of the environment on their lives. This favors the identification of possible changes in their life and health and intervention strategies for the maintenance of the elderly in community life, reducing loneliness and possible depressive symptoms, as well as rescues the self-worth and self-confidence of these subjects [11] [26]-[28].

From the diagnostic evaluation of the occurrence of cognitive and functional changes, health professionals, including nurses, should operationalize assistance for continuous health, with actions aimed at maintaining independence, functional and cognitive autonomy, as well as increased quality of life, with appropriate explanations to the elderly and their family regarding identified changes, treatment and prognosis in order to understand that the problems affecting the elderly reach, beyond this subject, the family, the community, as well as the administrative, political and health environment of these subjects [11]-[29].

6. Conclusions

From the results of the Pfeffer Questionnaire and the MMSE, it becomes clear that, although the cognitive performance, autonomy and independence of this population have been shown to be preserved in most of the questions, there is still dependence and difficulties in aspects of their everyday life, which, in turn, directly influences the functional capacity of these elderly.

In the study, there is higher degree of dependence in performing instrumental daily activities related to mobility in the community and financial management. However, tasks such as the maintenance of the home environment, food preparation and information management maintain their degree of normality, showing that the difficulties do not completely affect the lives and daily activities of this population.

Although, in this study, there are dependencies related to activities regarding the elderly's educational attainment, it is found that the impact of education cannot be regarded as the single definer of the scores average, since the subjects with no education have achieved significant test scores, especially in the MMSE. It is noteworthy to mention that the sample is consisted of a large number of individuals with some educational attainment, which tends to influence positive results.

As for the relation of the scores of MMSE and Pfeffer questionnaire regarding the gender of the studied population, there is no influence of this variable in the definition of functional/cognitive dependency of the elderly. The study findings also reveal that the scores of the two instruments are correlated because when the results are satisfactory in one of the tests, this data is replicated in the second questionnaire.

As the study gap, there is a need for more studies on the fact of higher dependence of the elderly who reside in the central region when compared to the elderly from other parts of the city. The study also has limitations such as the recruitment sample, made by community health workers and the inclusion criteria, which may have favored the participation of elderly people with a lower level of cognitive deficits and with a greater degree of autonomy, in addition to restricting the search field only to the city of Mossoro-RN/BR, not allowing the generalization of data to a wider population.

Given the study reality, it emphasizes the importance of continuous and periodic evaluation of functional and cognitive aspects of the elderly, working these instruments as early forms of detecting probable diseases, in order to preserve their autonomy and quality of life.

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Therapeutic Camps and Their Impact on the Family of Children with Special Health Care Needs: A Mixed Method Study

Brandi Lindsey

Middle Tennessee State University, Murfreesboro, TN, USA
Email: Brandi.Lindsey@mtsu.edu

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Abstract

Respite care through therapeutic summer day camps is a service used to relieve the physical and mental strains placed on caregivers of children with special health care needs while also creating unique opportunities to benefit the child. The purpose of this study is to determine how respite care in the form of a therapeutic summer day camp for children with special needs impacts a family's ability to manage their child's special health care needs within their family. This research study used mixed methodology combining quantitative data collection through pre- and post-survey and qualitative data collection through interviews that worked to answer questions relating to the effects of a therapeutic summer day camp on parents' perspective and management of their child's condition. The theoretical framework used to guide the study is the Family Management Style Framework. Twenty-two parents completed The Family Management Measure that was administered prior to and at the conclusion of an 8-week therapeutic summer day camp program. Qualitative interviews with 11 parents helped to better understand specific interventions and experiences of the therapeutic camp that benefitted their child and family. Although the quantitative analysis did not yield statistically significant changes in the family's ability to manage their child's condition as a result of attendance at the camp, the qualitative interviews demonstrated robust evidence that the camp provided meaningful experiences for the campers and parents while alleviating stress within the family. Themes include: 1) Family-Child themes of *loss of normalcy*, *relationships affected*, *increased stress*, *family adaptations*, *and love for the child*; 2) Camp-Child themes of *meeting individual needs*, *creating happiness*, *and behavior changes*; and (3) Camp-Parent themes of *improved perception of the child*, *decreased stress*, *parent involvement with staff*, *and need for specific environment at camp*. Implications of the results are discussed, along with recommendations for future research.

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Keywords

Respite Care, Special Needs, Children, Therapeutic Camps

1. Introduction

Children with a chronic illness or disability can encounter many difficulties throughout their lifetimes. Hardships may include physical, mental, developmental, and social issues that not only impact the child but also may increase demands and burdens experienced within the family unit. Caring for a child with a chronic illness or disability can cause many challenges within the family and may contribute to poor family functioning, inadequate management of the child's condition, negative perceptions of the child's disability, and a lack of integration of the child's condition into family life resulting in caregiver burden [1]. Families of children who have a chronic illness or disability may encounter certain issues that make family management more difficult than other families in a typical situation.

These difficulties faced by families of children with chronic disabilities need to be understood, so health care professionals can assist these families in achieving optimal functioning and incorporate strategies into their daily life that increase their ability to manage their child's condition. Because these obstacles can affect the everyday life of the child and family, it is important that support services are identified and understood to meet the needs of these children and their families. Respite care is used to relieve the physical and mental strains placed on caregivers while also creating unique opportunities to benefit the child.

The problem to be addressed in this study is the lack of evidence surrounding the benefits of therapeutic camps as respite care on the family and their ability to manage their child's special health care need. Therapeutic camps have been shown to provide valuable experiences for the child while also meeting the needs of the caregivers [2]-[7]. There is research that supports these outcomes, but there is little evidence that shows how therapeutic camps assist the family in managing their child's special health care needs. There is scant research that identifies the specific components of therapeutic camps as respite care that are meaningful to the families' view of the child and their ability to manage the condition.

The purpose of this study was to explore how respite care in the form of a therapeutic summer day camp for children with special needs influenced a family's ability to manage their child's special health care need within their family. The researcher sought to understand the implications of attendance at a summer therapeutic camp on the parent's perspective of the child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parental mutuality. These components are all in accordance with the theoretical framework used to guide the study, the Family Management Style Framework [8] and the instrument used in the study, the Family Management Measure (FaMM) [9]. Specific interventions and/or experiences at the camp that benefitted the family and improved their management styles were explored through interviewing the parents. The information gathered from the interviews supplemented data obtained through the administration of the FaMM. The researcher also made visits to the camp to gather field notes regarding specific interventions and experiences discussed by the parents in the interviews. The qualitative portion of the data included analysis of the field notes. This added to the understanding of specific interventions and experiences at camp that may assist the parents' ability to manage their child's condition and increase family functioning.

A sequential, exploratory mixed method approach was used to obtain data that explored the effect of a therapeutic summer camp on the family's ability to manage their child's condition. Statistical data were combined with data collected by qualitative interviews to give a more complete understanding of the research purpose.

2. Research Questions

The research questions for this study are:

1. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to the child's condition?
2. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to condition management ability?
3. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to the child's condition management effort?
4. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to family life difficulty?
5. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to the view of the condition's impact?
6. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to parental mutuality?
7. Are there differences in the family's ability to manage their child's condition (according to the FaMM) prior to and at the conclusion of the child's attendance at an 8-week therapeutic summer day camp?
8. What are the perceptions of parents of children with special health care needs of the interventions and experiences at a therapeutic summer day camp program?
9. What interventions or experiences (if any) impacted the parents' perceptions regarding the management of their child's condition?

The specific aims of the researcher are:

1. To understand and evaluate the outcomes that respite care through a therapeutic

summer day camp program has on family management styles of families of a child with a special health care need.

2. To understand and examine any specific interventions or experiences at camp that assisted parents in improving their perspective of the child's condition on their family life and ability to function as a family.

3. To use the findings to develop specific interventions or create experiences at therapeutic camps that camp organizers can use to promote positive family outcomes and improve family management styles.

3. Literature Review

A child's chronic disability or special need may negatively impact the child's emotional, physical, and developmental health. The consequences of a chronic condition in children may include physical disabilities, cognitive and academic deficits, school performance issues, behavioral adjustment, adaptive functioning, and socialization [10]. These changes and disabilities can adversely influence the child's family functioning by increasing family caregiver burden [1]. The family burden encountered after a child's diagnosis of a chronic disability can be related to the stress associated with the management of the child's conditions, perceptions of those close to the child, and the disruption to the normal family processes [11]. Demands placed on the caregiver of a child with special needs contribute directly to both the psychological and the physical health of the caregivers [12]. The family's ability to function affected health directly and influenced the concepts of self-perception, social support, and stress management.

Caring for a child with special health care needs can have an overwhelming impact on all aspects of family life [13]. The family burden that is encountered after a child's diagnosis of a chronic disability can be related to the stress associated with the management of the child's condition, perceptions of those close to the child, and the disruption to the normal family processes [11]. Evidence has demonstrated that families with a child with a chronic illness or disability are at a greater risk for problems with family cohesion, parent-child interactions, problem solving skills, family conflict [14], and lower family functioning [15] [16]. For families of children with special health care needs to function normally, they must be able to integrate their child's condition into daily family life, see their child's life and their family life as normal, and manage their stress through social support [15] [16]. There are many services that seek to provide interventions for these families and children. Respite care is an intervention that can provide valuable support for families and children with special health care needs.

Respite care is identified as a way to alleviate the family's burden of caring for a child with a disability or chronic illness [5] [17]-[20]. Respite care has also been identified as a very positive experience for both the child and the family [13]. Respite care can provide relief from the emotional and physical strains that are prevalent while providing care, and respite care can provide opportunities for the child to gain new experiences and interact socially.

Therapeutic camps are created to give children with special health care needs opportunities to participate in activities that other typical children may experience in the camp setting. Activities focus on children's abilities instead of their disabilities. Camps provide children with social interaction and time to experience fun activities that they might not have been able to experience otherwise. Camps can range from overnight weekly camps to day camps in the summer. Counselors are specially trained to meet each child's individual needs. Therapeutic camp programs for children with special needs are unique because they are designed to create goals and experiences for the children with disabilities in order to help them achieve their maximum potential. Therapeutic camps often focus on increasing self-management skills, enhancing emotional adjustment, enhancing self-esteem, and engaging in one-on-one and group social activities [4].

4. Methods

An exploratory mixed methods design with a sequential approach was used to collect data. A quantitative instrument titled The Family Management Measure, by [9], was used by the researcher to measure family management styles. This tool does not specifically address the effects of a therapeutic camp on family management styles, so interviews addressing this specific concept were added to the research to explain and augment the findings from the quantitative instrument. Both of these types of data collection complement each other and minimize weaknesses to create robust information regarding the phenomenon being studied. This study occurred over a period of 8 weeks during the summer of 2014.

The quantitative portion of this study used a quasi-experimental, within-subjects design. The FaMM [9] was administered to the same group of participants within 1 week at the start of camp and within 1 week prior to the conclusion of camp. Randomization was not used because the sample consisted of all consenting participants who have children enrolled at the chosen therapeutic camp for the summer of 2014.

The paired samples *t*-test was used to compare the mean differences of the data. The complete analysis of the results of this test is discussed in the analysis section. The instrument scoring of the FaMM was based on a Likert-type Scale with values ranging from 1 to 5 with 1 being *Strongly Disagree* and 5 being *Strongly Agree*. Tests for normality were conducted on the pretest and posttest data that also showed normality. The paired sample *t*-test compared the results from the same groups at the appointed time intervals. This analysis yielded no significant changes ($p > 0.05$) in any of the scales from the beginning of camp to the end of the 8-week camp.

5. Ethical Considerations

The researcher followed ethical guidelines by obtaining IRB permission from the researcher's educational institution. The camp director provided a letter of support that indicated his enthusiastic approval for the research to be conducted in the summer camp. The parents were invited to participate and were made aware that there would be no penalty for their child at camp if they chose not to participate. The researcher stressed that participation was voluntary, and each parent was given the opportunity to sign the informed consent document. In the observation phase the researcher only observed parents who had signed the informed consent document. Children over the age of 17 were not included in the observations. Children who may have been present in the observation had consent documents signed by their parents. Any observations that occurred with children who were capable of understanding an assent document would have been given the opportunity to sign the form. However, no children met this criterion in the observation, so no assent forms were signed.

6. Quantitative Instrument

The measure used for this study derived from the FMS framework was the Family Management Measure [9]. The FaMM is an experiential condition specific measure that includes six family management factors that were identified in a quantitative validation study. These are 1) the child's daily life, 2) the impact of the condition on family life, 3) the difficulty of family life, 4) the effort managing the condition, 5) the ability to manage the condition, and 6) parental mutuality [9]. The instrument has 53 items for partnered parents and 45 items for nonpartnered parents. Research was conducted to assess the psychometric properties of the FaMM including factor structure, internal consistency, test-retest reliability, and construct validity [9]. The FaMM was initially tested with 579 parents from 417 families with a wide array of chronic conditions [9]. There were 162 families in the sample that had two parents participating. The parents responded to the 65-item FaMM along with measures of family functioning (Family Assessment Device, child adaptation (Eyeberg Child Behavior Inventory), and child functional status (Functional Status Measure II). In order to evaluate construct validity, hypotheses testing was used and reliability assessment was also completed. The calculations of reliability and validity were modified to account for variations in which both parents were in the home. Based on this analysis, internal consistency reliability for the scales ranged from 0.72 - 0.90. Sixty-five parents were also retested within 2 - 4 weeks, and this retest reliability was calculated at 0.75 - 0.94 [9].

The FaMM was developed to understand family management over time and compare family management styles at different points in the child's life while assessing interventions that change the problematic aspects of family management and promote other interventions that strengthen child and family outcomes [9]. The instrument was used for this study to measure how a therapeutic summer day camp for children with special needs affects a family's ability to manage their child's condition. It was also one component used to determine if the camp can be identified as an intervention that promotes optimal child and family outcomes. This measurement was chosen because it was specifically developed to assist the practitioner in understanding how families are able to manage their child's chronic condition. The components of the measurement are directly related to a family's ability to normalize their child and family situation, and it correlates with the items outlined in the Family Management Style Framework. This tool provided a description of each family's management abilities prior to and at the completion of camp. This offered the researcher insight into the outcomes that the camp had on the family's ability to manage their child's illness and family life.

7. Sampling Plan

The therapeutic camp in which the study was conducted is located in the southeastern region of the United States. This camp is a Christian, summer day camp for children with special health care needs 6 - 25 years of age. The initial contact with families that participated in the research study occurred within the first week of camp. The researcher set up a table near the nurse and camp director at the beginning of the camp day and at the end of the camp day to meet with the parents and discuss the possibility of participation in the research. All of the information in regards to the research was given to the parents of campers at this time. There was a designated room on this hallway that was used for privacy to fill out the questionnaire. As the parents interacted with the nurse and director, the researcher approached them in a friendly manner that invited conversation about the well-being of their child and family. This provided an opportunity for the researcher to explain to the parents about the research study and discuss the consent form. The researcher was present at the table at the close of camp when parents were passing by to pick up their children from the camp. Many of the families know the researcher, so trust was already established. The researcher explained that although she has worked in the camp before, her role would be exclusively to obtain research data throughout the summer camp experience.

At the initial contact with the participants, the researcher presented them with a flyer that explained the importance of the research study and gave a brief description of the procedure for obtaining data. The flyer also contained the researcher's information and goals of the research study along with a discussion of both the qualitative and quantitative portions of the study. If they decided to participate, the researcher then initiated the consent procedure. At this time consent was explained and the consent form was presented. Once parents signed the consent form, the researcher asked if they would like to fill out the questionnaire in a private room at the camp or if they would like to take the questionnaire home with them and return it to camp that week. All parents chose to take the questionnaire home.

In this study convenience sampling was used. Because the number of eligible participants was small, all eligible participants were recruited. Participants came from the same camp to limit confounding variables that may have occurred from including other camps in the area such as differing schedules, types of interventions, and overall environment. Specific inclusion and exclusion criteria were implemented for this study. Purposive sampling was used to recruit participants for the qualitative strand of the study. Prospective participants for the interviews were contacted via phone to describe the interview, discuss the importance of the interview to the study, and establish trustworthiness with the participants. Interviews were conducted on site at the camp after approximately 7 weeks of participation in the camp activities. Interviews were scheduled prior to parents picking up their children or after they were dropped off in the morning.

All participants had children enrolled in the chosen respite summer day camp program at least 5 days a week. Inclusion and exclusion criteria included the following characteristics: 1) parents of campers between the ages of 6 and 25 at the time of camp participation; 2) parents were excluded if they have children with a comorbid, possibly terminal illness such as cancer, because this may alter the parent's perspective on the child's condition; 3) families of children with a special health care need must include at least one parent who resides in the same household as the child and speaks English; 4) chronic conditions or disabilities may include autism, down syndrome, cerebral palsy, or any child who has or is at risk for a chronic physical, developmental, behavioral, or emotional condition and requires additional health services; 5) only parents of children between the ages of 6 and 17 may participate in the interviews; 6) only children ages 6 through 17 whose parents had consented may be observed in the camp setting during the field note collection. Only one parent from each household was recruited for participation in the study to complete the FaMM.

8. Interview Process

Interviews were conducted on site at the camp after approximately 7 weeks of participation in the camp activities. Interviews were scheduled prior to parents picking up their children or after they were dropped off in the morning. Interviews occurred at the camp site at a convenient time mutually agreed upon with the parents. Permission to use a private room at the camp setting was obtained from the camp director. This room provided a neutral location that was consistently available to each family. In this study only mothers consented to participate in the interviews. Because the researcher had already met all of the parents at the initial meeting and she had worked at the camp before, trust between the researcher and the participants was established. Once consent was obtained for participation, the researcher spent time at the camp interacting with the parents to demonstrate her care and concern for the child and family to continue to build trust.

Interviews were conducted solely by the researcher and were transcribed verbatim by the researcher. Interviews consisted of the researcher and participant being coparticipants. Each interview lasted approximately 30 minutes. The researcher asked the participants to describe their overall experiences of caring for their child within the context of family life. Benefits of camp and specific interventions that occurred at camp were also explored. Guiding questions were used to understand how the child's condition and the attendance at the camp impacted family life.

Prior to the interviews open-ended questions were formulated by the researcher. Open ended questions were developed using the Family Management Style Framework as a guiding principle for question development. The FMSF has three components that are the definition of the situation, management behaviors, and perceived consequences [21]. Through the interviews the researcher sought to assess how these principles are perceived within the family to better understand the family's ability to manage their child's condition. A sample of the guiding questions follows:

- How has your child's condition affected your daily life? Your family life? Your social life?
- What are some things that help you manage your child's condition within your family?
- How does the camp help you better manage your child's condition?
- Are there certain experiences at the camp that impact your ability to care for your child's special health care needs?
- How does the camp help you better manage your family?
- What are some specific things that occur at the camp that help you view your child's special need in a different way?
- How does the camp affect your family when camp is over?
- Is there anything else you would like to tell me about how the camp has affected your child and family's ability to manage your child's special needs?

After the interviews began a common thread of parental stress related to the child's condition began to emerge. Applying hermeneutical reasoning along with the expert advice from the dissertation committee, the researcher added the following guiding questions to the interview:

- How does managing your child's condition create stress in your family?
- What aspects of camp (if any) help alleviate the stress surrounding caring for your child?

Once the interviews were completed, some specific interventions that were discussed in the interview process were observed by the researcher in the natural field setting. The field notes were used to complement the interview data.

9. Results

9.1. Sample

Based on the sampling criteria, 30 primary caregivers from 30 different families were eligible to participate. The final quantitative sample could have included mothers or fathers, but in this study it was mostly mothers (20 mothers, 1 grandmother, and 1 father) who were present at the camp and able to provide consent. The number of diagnosis for each child ranged from 1 to 6 ($M = 2.09$), and the length of time since diagnosis ranged from 3 years to 23 years or since birth ($M = 11.25$). Demographic data showed 20 participants were Caucasian and 2 participants were African American. The age of parents ranged from 25 years to 73 years ($M = 46.6$, $SD = 10.1$). Twelve of the parents reported other children living in the same home as the child with special health care needs. At the beginning of the study 16 parents indicated they were partnered. In this study partnered was defined as living with a partner in the same household as the child. At the conclusion of the study 17 parents indicated they were partnered. Participant educational levels are as follows: 2 with high school diploma, 1 with technical or trade school, 10 with some college or 2-year degree, 5 with a bachelor's degree, and 3 with a graduate degree with one not reporting. Hours of employment per week are as follows: less than 10 hours = 3; 11 - 20 hours = 2; 21 - 30 hours = 2; 31 - 40 hours = 6; 41 - 50 hours = 5; Over 50 hours = 3 with one not reporting. Income ranges are as follows: \$10,000 to \$14,999 = 1, \$15,000 to \$19, 999 = 2, \$25,000 to \$34,999 = 1, \$35,000 to \$49,999 = 3, \$50,000 to \$74,999 = 5, Greater than \$75,000 = 9 with one not reporting. Parents indicated they spent a range of 4.5 hours a day to 24 hours a day provided care for their child (M = 12.7). The participants' children enrolled in the camp were 11 boys and 11 girls ranging in age from 6 years to 23 years of age (M = 13.8). For 6 children, it was their first time at camp. The number of diagnosis for each child ranged from 1 to 6 (M = 2.09), and the length of time since diagnosis ranged from 3 years to 23 years or since birth (M = 11.25). Diagnosis included autism, hydrocephalus, Down Syndrome, developmental delay, PTSD, reactive attachment disorder, seizures, Angelman syndrome, ADHD, craniosynostosis, blindness, Partial Trisomy 18, and Fetal Alcohol Syndrome with a larger number (10) diagnosed with autism. Twelve of the children had siblings ranging in ages from newborn to 23 years. None of the families participated in any other respite care services.

For the qualitative portion, 11 parents consented to participate in the interviews. The interview participants were all Caucasian females and mothers of the campers. The mothers ranged in age from 35 to 57 (M = 44.5). The children (6 boys and 5 girls) ranged in age from 7 - 17 years (M = 10.4). The children had a variety of diagnosis including autism, developmental delay, seizures, fetal alcohol syndrome, cerebral palsy, and Angelman syndrome. The years passed since the child's initial diagnosis ranged from 4 years to 17 years (M = 9.8). Eight parents indicated they were partnered and 8 indicated they had other children living at home. Only one parent indicated it was their child's first time to attend camp. Parents indicated they spent a range of 7 hours a day to 24 hours a day providing care for their child (M = 12.8). Participant educational levels are as follows: 1 with high school diploma, 1 with technical or trade school, 4 with some college or 2 year degree, 3 with a bachelor's degree, and 2 with a graduate degree. Hours of employment per week are as follows: less than 10 hours = 2; 11 - 20 hours = 2; 21 - 30 hours = 1; 31 - 40 hours = 2; 41 - 50 hours = 3; Over 50 hours = 1. Income ranges are as follows: \$10,000 to \$14,999 = 1, \$15,000 to \$19, 999 = 1, \$25,000 to \$34,999 = 1, \$35,000 to \$49,999 = 1, \$50,000 to \$74,999 = 2, Greater than \$75,000 = 5.

9.2. Quantitative Results

For data analysis of the FaMM, each response for the questionnaires was entered into SPSS version 21. Each of the scales was scored according to the instructions provided [9]. These scales included the child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parent mutuality. In this research study internal consistency was affirmed through the calculation of Cronbach's alpha. Internal consistency values ranged between 0.66 and 0.93 for the scales of the FaMM in this sample as shown in Table 1.

All participants completed the first five scales and 15 of the parents completed the scale on parent mutuality. Analysis included resulting scores for each scale prior to and

Table 1. Description of Cronbach's Alpha.

Scale	Number of Items	Pretest Cronbach's alpha	Posttest Cronbach's alpha
Child's Daily Life	5	0.73	0.66
Condition Management Ability	12	0.87	0.74
Condition Management Effort	4	0.68	0.89
Family Life Difficulty	14	0.93	0.92
Condition Impact	10	0.67	0.75
Parent Mutuality	8	0.93	0.90

at the conclusion of camp. The alpha level selected for this study was 0.05. Because the researcher expected the sample size to be small due to convenience sampling, a medium effect size of 0.5 was determined to be adequate. In order for this to occur a sample of 50 was needed for the study. Because the final sample was 22, the effect size was not met. An effect size of 0.3 could be used for the study with the number of participants, but this would not yield clinically significant results.

The data yielded no significant changes ($p > 0.05$) in any of the scales (child's condition, condition management ability, condition management effort, family life difficulty, view of condition impact, and parent mutuality). The small sample size was a threat to statistical conclusion validity. Although this sample was less than the original desired number, it was 73% of the eligible participants based on inclusion and exclusion criteria and 47% of the total participants at camp. The researcher chose one camp site in order to control for varying degrees of schedule changes, other activities, and time variations that may be present in other camps. Although the sample was small, it is typical of the variety of special health care needs and disabilities at other camps similar to this one in southeast area of the United States.

One of the most important reasons that the FaMM may not have yielded significant results is that it did not measure any interventions or occurrences that are specific to camp that benefitted the family. The researcher sought to understand what aspects of camp would be meaningful to the participants and determine if camp would affect the family and/or the child in a positive way. After conducting the interviews and analyzing the data, the emerged themes clearly showed that many of the benefits of participating in the camp discussed by the mothers were not specifically addressed by the FaMM.

9.3. Qualitative Results

At the conclusion of the coding and categorizing process there were several themes that emerged. The themes for Family-Child categories are: 1) *loss of normalcy*, 2) *relationships affected*, 3) *increased stress*, 4) *family adaptations*, *and* 5) *love for the child*. The themes for Camp-Child categories are: 1) *meeting individual needs*, 2) *creating happiness*, *and* 3) *behavior changes*. The themes for Camp-Parent categories are*:* 1) *improved perception of the child*, 2) *decreased stress*, 3) *parent involvement with staff*, *and* 4) *need for specific environment at camp*. Throughout the interviews each parent discussed a *loss of normalcy* ($n = 11$) since the child had been diagnosed with a special health care need. This loss was apparent in family life and outside relationships. Participant 20 concluded,

> "*It affects everything that you do, you know, from your other kids, I mean we have older kids, you know, it affects them, it affects them, we were big campers and stuff and she can't sweat, so we don't do anything outdoors now you know, from every aspect it affects your life.*"

The loss was evident in the lost dream for a normal family. Participant 18 stated,

> "*Well you never expect to have a child with special needs, um, that was a tough blow, and then since my boys are older they have been able to help some but they get super frustrated with her autism behaviors, they don't get it, it's just different than what we expected but I guess that is true with any special needs family. Um, I am a lot busier than I expected to be at my age, I am a lot more tired, it's just harder than I expected it be at this stage in my life.*"

The *loss of normalcy* theme ($n = 11$) was also discussed within the context of relationships. The mothers expressed a change in their relationships with their friends, spouses, extended families, and other children because of caring for their child. Four of the mothers reported that they had lost the ability to have normal relationships with their friends and families because of their child's condition. This isolation from others was deemed as a loss. Although mothers ($n = 7$) reported a loss of a certain dream for their family, a sense of adaptation, realization, and acceptance of the way their life had turned out with their child was apparent. This life they were living was their reality and they had come to better understand their life with their child and family. Mothers who expressed these ideas had gone through an initial adjustment period with their child's diagnosis and accepted their new "normal" reality with their child. Participant 16 stated, "And then you reach that point of acceptance, and there is still the isolation. So then the gears changed to the acceptance and living with it". Several of the mothers ($n = 4$) reported a sense of optimism and hope as they had "gotten better" at caring for their child.

Another recurring problem for these mothers involved making time for their other family members. In the summer months mothers felt there was an added stress because of the constant demands of caring for their child that left them very little time to spend with their other family members. Some mothers ($n = 4$) discussed a sense of guilt over the loss of time with their other children and reported that the other children felt neglected. This added to the mother's stress level because she was unable to divide her time equally.

One of the predominant themes within the Family-Child category was the idea of the family adapting ($n = 10$) to the child's special health care needs. All of the mothers reported they had to learn to adapt in order to have a successful family unit. The predominant categories within this theme include family limitations and modifying the family routine, shared responsibilities, and coping mechanisms. The mothers identified changes they had made in their family that limited what they could do because of the needs of their child. Many mothers reported that certain activities such as camping, hiking, or swimming were no longer part of their family routine because their child could not participate in these activities. There was also a significant modification in the family routine in order to care for their child. Therapy schedules, house design, sleep routines, and other normal activities were modified to meet the needs of the child. Several of the mothers reported that the child's needs came first, so the family had to learn to adapt to the child's needs. Participant 21 stated, "She is paramount, for her well-being, her emotional, mental, security well-being." Summer was seen as an especially difficult time because the children were not in school, which created less time for the mothers to have breaks. Every mother did not have the same coping mechanisms, but all mothers reported that they needed breaks in order to decrease stress. For this reason, the therapeutic camp provided much needed respite for the families.

Another category of themes included the benefits from the camp to the child and family. These included: 1) *meets individual needs*, 2) *creates happiness*, *and* 3) *behavior changes*. The mothers were very consistent in discussing the idea that camp met their child's individual needs (n = 10). Every mother stated that their child needed a consistent routine, socialization, and high energy activities to be happy and have their needs met. The camp schedule addressed all of these needs for the child. Most of the mothers indicated that they believed their child enjoyed camp (n = 8). Even though some of the children were nonverbal, the mothers felt that they could tell their child looked forward to camp and/or enjoyed being there. Four of the mothers stated that their child became excited and looked forward to attending camp. The mothers concluded that camp made their child happy because it met their needs of socialization, routine, and participation in activities. Participant 20 expressed,

> "*She is a social butterfly*, *so she would like let's say the week before camp starts and they are out of school she has to go to work with us*, *you know*, *or we split it up*, *you know*, *and we will go home with her half a day*, *she is not happy with that*, *she likes to be around people*, *she likes to be involved*, *and we own our own business*, *so it's not like we can just take vacation whenever we want and just take her somewhere*, *so with that*, *um*, *honestly I think that that is probably the main thing that camp does*. *It gives her something to look forward to and gives us something to look forward to in the summer because we don't want her to be bored*."

Camp also changed some of the parent's perceptions of their child as they saw them participate in activities and mature in certain areas. Parents appreciated the group activities for their child, Bible stories, and one-on-one interaction of the counselors with the children. They felt that camp met certain needs of their child that they, as mothers, were unable to fulfill. This included the child's high energy needs and participation in other outside activities such as recreation and other group activities. One mother stated, "I was so happy when she got old enough to come to camp". Participant 15 expressed her sadness about camp coming to an end for the summer when she said,

> "*And I can't believe next week is the last week, yeah, I hate to see it end. It gives us good memories, and I told my husband that we are going to send (their child) to camp until he ages out of it." We love it. We will be back. We love it. It's just good respite for her and for you and your family—it gives her what she needs." It has been a wonderful thing for her—we wouldn't trust them at a regular day care but we do at camp so that is good—it has been great for her.*"

Although parents mentioned certain activities their child enjoyed such as swimming, bowling, and Bounce U, it was the overall specific camp environment that impacted the parent's perspective of managing their child's needs. The camp staff's love and concern for the child impacted the parents in a positive way. The unique environment of camp geared towards meeting their child's individual needs and focusing on their abilities instead of their disabilities was refreshing to the parents. Participant 21 concluded, "This camp is wonderful, yes, everything, because this camp, they attend to our kid's needs." Participant 22 stated, "This is the only place that knows my kid's needs." This interaction with the camp staff was crucial to the parent's level of decreased stress. Participant 28 commented on how camp affects her view of her child,

> "*It is for me the activities, the karate, when I can see the pictures where he interacts with ballplayers, on the field trips, hearing how well he does on those things, because these are things that we can't do at home….. being able to see him do things like that that we can't do—those are things—seeing him act like a typical child, he is having a good time and playing—he seems to be able to adapt to this better at camp and I don't get to see him do these things at home.*"

The parent theme of *decreased stress* (n = 10) is important to this study because it shows that camp provided a remedy to the theme of *increased stress* (n = 10) in the discussion of Family-Child themes. The mothers discussed that caring for a child with special health care needs increased stress within their family, but the attendance at camp decreased stress within their family. One of the most prevalent reasons that camp decreased stress was that it filled a void of something for their child to do for the summer and created a specific environment for their child that met their needs while at camp. One mother expressed, "Let me tell you what happened after we started going to camp—I became not desperate, that is what I became because you have to understand from the end of May until August, there is no help." Seven of the mothers directly reported that camp decreased stress for their family. The decrease in stress was a result of extra time for the mothers to participate in other activities and rest, communicating with other parents at camp, relief of parental guilt, extra time to spend with others in the family, and decreased financial burden due to the affordability of camp. Camp also decreased stress because it gave the mothers peace of mind knowing their child was safe and happy at camp.

Throughout the data collection and analysis process, the value of using a mixed methods study became apparent. Based on the findings from the quantitative strand of data collection, the results were not significant, demonstrating no significant improvements in the parent's perceptions of the child's condition, condition management ability, condition management effort, family life difficulty, view of condition impact, and parent mutuality after attending the summer therapeutic camp for 8 weeks. If this was the only phase of the study, the results would demonstrate no significant benefit from the child's attendance at camp. The researcher was not certain if the FaMM would yield results to measure the true benefits of the camp, so the qualitative strand of data collection was added to the study from the outset, as part of the study design to understand the specific benefits from camp as perceived by the parents. The results from these interviews demonstrated that parents and children indeed benefitted from attending the camp as evidenced by the themes that emerged in the data-collection phase. The results were compared and synthesized to make meaning of the data to formulate recommendations for future research, implications for nursing, camp organizers, and camp staff, and to suggest specific activities and interventions for this camp and other similar camps. This study was unique in comparison to other studies that research the benefits of therapeutic camps because it identified certain interventions that benefitted the child and family. The benefits from the longer duration of the camp also demonstrate the uniqueness of these study results.

10. Implications for Research

Both phases of this study provided data that can be used for future nursing research. In regard to the quantitative phase, the FaMM needs to be used in other studies to understand the family's perspective and ability to manage their child's condition. For this study the 8-week time frame for the summer camp was not long enough to demonstrate any statistical significance as measured by the FaMM. The time frame suggested by the researcher for future studies using the FaMM is 6 months to a year with the child completing the entire summer session at the therapeutic camp along with attendance at the respite care days offered throughout the year. Another recommendation for future research includes using a larger sample to increase the power and effect size of the quantitative portion of data collection. The use of a larger camp or several similar camps in the same area may be useful for future research endeavors. Future research should also include questionnaires from both parents with comparisons from each viewpoint in order to see any statistical difference based on the various parent perspectives.

In the future demographic characteristics that are related to parental stress should be examined. Because the idea of stress within the family was a predominant theme in the study, a scale that measures stress along with demographic questions that assess possible stress factors should be included in future research studies with this population. The Parenting Stress Index [22] is a scale that has been used within this population to measure the stress associated with caring for a child with special health care needs [18] [22]. This type of scale along with the use of the FaMM may contribute to a greater understanding of the impact that camp has on the parental stress associated with caring for a child with special health care needs. It may also be beneficial to add components of the themes that emerged from the qualitative strand of data collection to the FaMM.

This would give quantitative data that are based on the emergent themes from the study.

For the qualitative phase of the study, the data showed that families of children with special needs indeed benefit from a respite therapeutic summer camp. Future research should be aimed at understanding the exact interventions that are meaningful to the parents, the specific training of the counselors, and behavior changes that are apparent within the child as a result of camp. All of these areas were mentioned in the interviews, but they were not fully explored. It would also be beneficial to conduct interviews with both parents to determine the perspective of the father in comparison to the mother. Future interview questions should be developed to determine the specific components of camp that are meaningful for the parents and the child. A sample of these questions includes:

1. What is the difference in the environment at camp vs the environment at school?
2. What does your child learn while at camp?
3. Does camp impact the way you and your partner are able to care for your child's condition?
4. What activities are the most meaningful to your child at camp?
5. What can be done better at camp to help meet your needs and your child's needs?
6. How do the counselors help your child at camp?

Each of these questions targets a specific area that needs to be further explored to make more specific recommendations for the structure of the camp.

11. Limitations

This study was limited by the small number of participants recruited for the quantitative strand based on the inclusion and exclusion criteria. A larger sample that encompasses one or two more camps may be beneficial for future research. Convenience sampling was employed in the quantitative strand of the study; therefore, the results are not generalizable. The fact that mostly mothers filled out the questionnaires and only mothers participated in the interviews is also a limitation of the study. Future research should be aimed at recruiting more fathers and parent pairs to participate in the research. The time frame for the study was also only 8 weeks, which could have contributed to a lack of statistical significance. The camp setting was a nonprofit Christian camp that may diminish the transferability to other camps that are not similar in setting or philosophy. The specific training of the counselors and special needs of the children at camp could also lead to varying results.

12. Conclusions

This mixed method study used a sequential design imploring both quantitative and qualitative strands to better understand the perceptions of parents of children with special health care needs after the attendance of a therapeutic summer camp. The researcher also sought to determine the effects of the camp on the parent's perspective in regards to the child's condition, condition management ability, condition management effort, parental mutuality, and family life difficulty.

These themes supported the theoretical framework used for this study, the Family Management Style Framework, and they were supported by the current literature surrounding the benefits of respite care. Although the quantitative phase did not yield significant results, the study overall yielded very significant results and provided insight into the lived experiences of parents caring for a child with a special health care need and the effects on their child and family from attending a therapeutic camp. The qualitative phase of the data collection demonstrated important results concerning the positive outcomes of camp for the child, the family, and the parents. The benefits of the camp on the parent's stress level and family management were paramount in the interviews. Camp also benefitted the children through meeting their individual needs, changing some of their behaviors, and creating happiness for them while at camp. Camp was seen as beneficial to the families and children because it met their emotional and social needs while giving the parents time to rest and spend time doing other activities and being with their families.

The results of the study helped provide recommendations for future research and identify camp activities and interventions that were meaningful to parents. These activities can be implemented in other camps to enhance the overall experience for the child and family. Better communication between the parents and staff along with increased time for parents to socialize with other parents at camp was identified as important modifications to future camps. Future research should be aimed at using larger sample sizes and using both qualitative and quantitative data collection techniques to assess the impact of therapeutic summer camps on parental stress.

This population of parents is a very special group that has specific needs that nurses and other health care providers should seek to meet. This research demonstrated their extreme care and compassion for their children as they sought to provide the best care and gave up so much within their families to care for their child. I hope that this research will serve them well and be meaningful to them as I continually strive to offer them better experiences through nursing and respite care. I hope to always look on the positive side of life and never take for granted the things that I hold dear. One mother stated in the interviews,

It has affected our family life, but in a positive way, it brings us together. Oh yeah, there is always a positive side to it too, and it has helped us recognize the needs around us too. It's a humbling experience to have a child with special needs, sometimes you see things differently. So, it definitely has a positive side too.

May we as nurses always look on the positive side and strive each day to "see things differently".

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Chronic Pain and Pharmacotherapy in Chronic Renal Patients on Hemodialysis

Olvani Martins da Silva[1,2], Bruna Bautitz[2], Fanierli Benedeti[2], Ligyani Pauly[2], Eneida Rejane Rabelo-Silva[1]

[1]Graduate Programa at Federal University of Rio Grande do Sul, Porto Alegre, Brazil
[2]Santa Catarina State University, Chapecó, Brazil
Email: olvanims@hotmail.com, brunabautitz@gmail.com, fani_benedetti@outlook.com, ligi_pauly@hotmail.com, eneidarabelo@gmail.com

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Abstract

Objective: To analyze the intensity of chronic pain and pharmacotherapy in chronic renal patients on hemodialysis. Method: This is a cross-sectional, prospective study conducted in a Service of Substitute Renal Therapy in the South region of Brazil. Seventy adult patients with chronic renal disease, who were undergoing hemodialysis treatment in the first half of 2015, participated in the study. We used the Graduated Scale for Chronic Pain. The data were analyzed with the Statistical Package for Social Sciences software version 18.0. The study was approved under N°. CAAE: 20138913.4.0000.0118. Results: Fifty-one (72%) patients reported some forms of pain in the last six months, 17 (24%) reported severely limiting pain, high interference and persistence. Painkillers were most widely used therapy for pain management, in 19 patients (27%). Conclusion: Chronic pain was reported in different degrees of intensity, with severely limiting character, high interference, and persistence. Painkillers were the most widely used pharmacological class to control it.

Keywords

Hemodialysis, Chronic Pain, Pain Management

1. Introduction

Chronic pain is one of the most common symptoms reported by chronic renal patients. This pain is complex and its management is a challenge for health professionals, primarily by its individual character and manifestations that vary among individuals [1]. In a sample involving 591 participants, pain was perceived by 72.4% of patients, being described as of moderate or severe intensity by 46.5% [2]. Similar results were demonstrated in a study conducted by Masajtis-Zagajewska *et al.* [3]

Studies [1] [4] indicate that chronic pain is referred by chronic renal patients with varying intensity, which induces the use of analgesics and consequent polypharmacy. The presence of pain brings as a consequence the reduction of physical function [5], changes in the sleep pattern [6] [7], depressive symptoms, and hindering of the quality of life [8] [9]. Despite these limitations, it is a little valued symptom, in detriment to other priorities related to treatment [10], or under notified due to recognition and appropriate management barriers such as time limitations for assessing the patient, unavailability of evaluation instruments, lack of experience on the part of the professional, or belief that chronic pain is more difficult to be evaluated and handled [11].

Some studies [10] [12] [13] demonstrated concern regarding the pain of chronic renal patients in hemodialysis to provide better management of care as well as by the need to implement more effective treatments to achieve relief [14].

The use of pharmacotherapy continues to be a positive element in the treatment of pain, even with limited evidence regarding the pharmacology of some medications for this population. On the other hand, non-pharmacological management strategies based on evidence for the management of pain have been described especially for pain of musculoskeletal origin [11].

The identification and evaluation of pain intensity by means of validated scales allow the implementation of routines in pain management and contribute to the relationship between professionals and patients [1]. However, studies that investigate the presence of pain and its management in chronic renal patients in hemodialysis by using validated scales are incipient in Latin American centers.

In this perspective, this study was conducted to analyze chronic pain in chronic renal patients in hemodialysis and pharmacotherapy used by patients. This study becomes relevant for aiding health professionals on planning for the evaluation and control of the pain of patients in this condition.

2. Methods

2.1. Type of Study

This is a transversal and prospective study performed in a service specialized in caring for patients with chronic renal diseases in all types of renal substitution therapy in the southern region of Brazil.

2.2. Sample and Participants

The participants were adult patients with chronic renal disease undergoing hemodialysis treatment. We included patients regardless of period of early treatment and excluding those with co-morbidities that might confuse pain not caused by renal disease and its complications.

For the estimation of the sample, a prevalence of 27 (77%) was considered, as described in a study [4] carried out with chronic renal patients in hemodialysis treatment that referred pain daily. The sample size of the study was calculated to be 70 individuals of the 150 patients being cared for in the unit. We assumed the same percentage of pain, considering a sampling error of 6%, and a confidence level of 90%.

2.3. Data Collection and Instrument

Data collection occurred in the first half of 2015, during the hemodialysis session by previously trained researchers. We used an instrument with sociodemographic and clinical variables to characterize the sample. To evaluate the pain, the graduated scale for chronic pain * was adopted, adapted, and validated for Brazil [15]. This scale is made up of eight items that assess the frequency, intensity, and disability linked to pain. The questions are reminders, concerning the presence of pain in the last six months. From question two (02) to eight (08), the questions aid the individual to remember the pain of the past three months, marking on a Likert scale of 10 points [15].

The classification of chronic pain in degrees is determined by calculating the scores from the Likert scale, in which zero is without pain, I low pain intensity, II high pain intensity, III moderately limiting pain, and IV severely limiting pain. Once the degree is established, it is possible to check the interference of pain, which can be described as low interference (grade I and II) and high interference (grade III and IV). Persistence of pain is established for the days in which the patient presented pain, being low persistence between 1 and 87 days and persistent between 90 and 180 days [15].

2.4. Data Analysis

The data was tabulated and processed in the Statistical Package for Social Science (SPSS) program, version 18.0, and analyzed through descriptive statistics so that continuous variables were expressed as mean values and standard deviation, and categorical with absolute and relative frequencies.

The study was carried out according to the ethical and legal premises provided for in Resolution 466/2012, which regulates research on humans in Brazil. It was approved by the Ethics Committee of the State University of Santa Catarina, under opinion no. 453,508 on 11/8/2013, CAAE 20138913.4.0000.0118. The patients agreed to participate by signing an informed consent form in two copies.

3. Results

3.1. Characteristics of the Sample

The sample was composed of 70 patients, 37 (53%) male with mean age of 58 ± 16 years old. The median time of treatment was of 3 (1 - 6.5) years old. Among the patients, 51 (72%) reported having felt some kind of pain in the last six months. The most affected site was the lower limbs in 20 (28%) patients, followed by column in 17 (24%), and in smaller percentages pain in other regions of the body. These characteristics are shown in Table 1.

3.2. Classification of Chronic Pain Regarding Intensity, Interference, and Persistence

Of the patients who reported pain, the intensity was referred to as severely limiting by

Table 1. Distribution of patients in hemodialysis according to treatment time and site of pain.

Variables	n = 70
Age (years old)	58 ± 16
Sex (male)	37 (53%)
Treatment time (years)*	3 (1 - 6.5)
Presence of pain in the last 6 months	51 (72%)
Site of pain	
Lower limbs	20 (28%)
Back (lumbar, spine)	17 (24%)
Headache	4 (6%)
Other sites	10 (14%)

*Continuous variables are expressed as mean ± standard deviation, median and interquartile interval; n = 70.

17 (24%), moderately limiting by 13 (19%), and of high intensity pain by 11 patients (16%). Regarding interference, high interference was reported by 31 patients (44%) and low interference by 13 (19%). As for persistence of the pain, 29 patients (41%) complain of long persistence. The data are presented in Table 2.

3.3. Pharmacotherapy Used by Chronic Renal Patients in Hemodialysis Treatment

Of the patients who reported pain, 35 (50%) use pharmacotherapy for treatment and relief. Analgesics were presented as elective medicines for pain management in 19 (27%) patients. Other medicines appeared in smaller proportion, and 12 (17%) patients used other non-nominated medicines (Table 3).

4. Discussion

This is one of the few studies that examined the presence of chronic pain and therapy used in chronic renal patients undergoing hemodialysis. The results indicated that over 70% of the studied patients presented pain in the six months prior to the study. Of those patients, more than half showed moderate to severe pain intensity, and used analgesics to relief.

A study that evaluated 164 patients in hemodialysis and compared the prevalence of pain, their locations, features and use of analgesics, evidenced that 54% of patients presented pain in more than one location [3]. In addition, approximately 35% of the complaints during the hemodialysis session are related to recurrent or constant pain, many of physiopathological origin, which can be diagnosed and treated, as muscle pain from cramps and musculoskeletal pain, caused by bone dystrophy [15].

Musculoskeletal pain is one of the most common symptoms of chronic pain in patients with terminal renal failure [16] [17]. In this study, pain was reported by 20 (28%) patients in the lower limbs, and by 17 (24%) associated with the back (lumbar and spine). Similar results were found in studies [3] [18] in which the location of greatest

Table 2. Classification of chronic pain regarding intensity, interference, and persistence.

Degree of intensity	n (%)
Degree IV: severely limiting pain	17 (24%)
Degree III: moderately limiting pain	13 (19%)
Degree II: high intensity pain	11 (16%)
Degree I: low intensity pain	03 (4%)
Without pain	19 (27%)
Interference of the pain	
High interference pain	31 (44%)
Low interference pain	13 (19%)
Without pain	19 (27%)
Persistence of the pain	
Persistent pain	29 (41%)
Non-persistent pain	17 (24%)
Without pain	19 (27%)

Table 3. Pharmacotherapy used by chronic renal patients in hemodialysis.

Variables	n (%)
Pharmacotherapy used	
Presents pain and uses medication	35 (50%)
Presents pain and does not use medication	09 (13%)
Pharmacological class	
Analgesic	19 (27%)
Nonsteroidal analgesic and anti-inflammatory	02 (3%)
Benzodiazepines	02 (3%)
Was not able to inform	12 (17%)

frequency was in the lower limbs, followed by the lumbar region. Authors speculate that pain in these areas can be associated with the positioning of the patient, who remains in the same position for hours, causing discomfort, in addition to corroborate to vascular complications in the lower limbs [3] [19].

Changes in the structure and function of the muscles may be manifested by atrophy, weakness of the lower limbs, impaired ambulation, and cramps [20]. Even though it is known that bone alterations may induce diffuse and constant pain, affect lower limbs and the spine, and even compromise an individual's mobility [14].

Recently, a cross-sectional study investigated 456 patients with chronic renal disease for the presence of chronic musculoskeletal pain and its associated factors. The results showed that slightly more than half of the sample presented chronic musculoskeletal pain, and this was significantly and independently associated with hyperuricemia and high levels of calcium and phosphorus [16]. This study did not seek to identify the association of pain with laboratory results, unlike the study by Hsu *et al.* [16], which point out that patients in end-stage renal disease suffered from more severe chronic pain compared to other stages of the disease, possibly due to co-morbidities generated by hyperuricemia, in addition to calcium-phosphorus imbalance [16].

Another cause of bone pain can be attributed to the long time of hemodialysis treatment depending on the deposition of amyloid and beta2-microglobulin [14] [21] and the high levels of parathyroid hormone (PTH) agents of bone resorption [22].

Severe pain was also observed by Masajtis-Zagajewska *et al.* [3], who observed that, among patients in HD, 55% described the pain as intense, and 40% as moderate. In this study, most patients reported severely limiting pain, of high interference and persistence. In the United States, Barakzoy and Moss found pain classified as serious by 34 (76%) patients [23]. In Europe, 61 (75%) patients, of a sample of 123 chronic renal patients, reported that the pain completely or partially limited their daily activities, such as cleaning, shopping, and cooking [10].

Pain interferes potentially at work, domestic activities, ability to walk and perform physical activities, sleep and rest, in the mood and satisfaction with life, in addition to harming interpersonal relationships [13].

A Brazilian study noted that pain interferes fully in professional and domestic activities (57.14%), ability to walk (53.57%), sleep and rest (46.43%), mood (39.29%), satisfaction with life (32.14%), and interpersonal relationship (25%) [4], activities considered common in the daily life of people who are suffering interference, an limitation by the presence of pain, often inducing the use of some kind of analgesia.

Although the prescription of analgesics is recommended, it should be employed only after clinical examination and proper evaluation of pain intensity measured by scale of pain intensity, as advocated by the World Health Organization [24].

Corroborating with this statement, a prospective cohort evaluated the effectiveness of the use of the analgesic scale of WHO to treat pain in patients with terminal renal disease. A sample of 45 patients in hemodialysis was assessed for the type and severity of pain using Short-Form McGill Pain Questionnaire, and later received drug treatment for pain, in accordance with the scale of WHO, for four weeks. At the end of this period, pain relief was observed in 96% of patients, proving the effectiveness of the scale [23].

In this study, pharmacotherapy used for pain relief was pointed out by 35 (50%) patients who reported chronic pain, and the most used drug classes were analgesics (19 (27%)), followed by the association of analgesics with non-steroidal anti-inflammatory and benzodiazepines.

A higher percentage for the use of medication was found by Dallaroza *et al.* [25], in which 86 (80.4%) individuals with chronic pain reported using them, being that 54% used simple analgesics, especially dipyrone or acetaminophen, and 38.2% used anti-inflammatory drugs. Benzodiazepines appeared in a lower proportion [25].

Dipyrone is the most employed analgesic for patients with chronic renal disease, for its clinical efficacy, low cost, wide availability, and safety margin for renal patients. Non-steroidal anti-inflammatory drugs (NSAIDS), in their turn, have potential risks of bleeding in uremic patients, fluid retention, increased blood pressure, and reduction in glomerular filtration rate (GFR) [17].

In the study by Gamondi *et al.* (2013) [10], the use of NSAIDS or similar agents predominated in 65(80%) patients. Hsu *et al.* [16] did not observe any difference regarding the use of NSAIDS or Chinese herbal medication among patients with hyperuricemia and without hyperuricemia. The explanation found for this condition was the fact that patients were usually recommended to avoid the use of NSAID drugs to protect their renal function [16].

In this perspective, some authors have investigated non-pharmacological techniques for the treatment of pain of chronic renal patients, to avoid side effects of pharmacotherapy [19] [26]. Techniques such as meditation, biofeedback, breathing exercises, hypnosis, yoga, spiritual counseling, cognitive behavioral therapy and psychological therapy can help as alternative treatments for the management of pain [27].

Recently, a study pointed out an alternative method to treat and control chronic pain in patients on hemodialysis, to evaluate the effectiveness of the *Tuiná* massage therapy in the treatment of pain in the lower limbs of chronic renal patients in hemodialysis, in which 125 patients were divided randomly into: control group (n = 63), which received treatment with analgesics for pain relief; and intervention group (n = 62), which received the massage. The pain was measured by the analog visual scale. The authors concluded that the use of *Tuiná* massage was effective in the treatment of pain, since from the 62 patients undergoing the intervention, 56 reported no pain at the end of the study [19].

The *Tuiná* massage is part of alternative therapies, based on the vitalist paradigm that emphasizes the general state of the patient, not the disease, to interpret it as internal imbalance and not only as a consequence of the invasion of pathogens. Alternative therapies are called complementary health practices, are legitimized, and inserted in the public health system [28], although little widespread and rarely used in healthcare practice for the treatment of chronic pain in patients on hemodialysis.

The relaxation technique was also pointed out as an ally for pain control, through a controlled trial that examined the effects of Benson's relaxation technique on the intensity of pain and quality of life in chronic renal patients. In total, 81 completed the segment (41 patients in the intervention group and 40 in the control group). Patients in the intervention group were instructed to listen to an audio tape of the relaxation technique twice a day for 20 minutes, for eight weeks [29].

Pain and quality of life were assessed through scales at the beginning and at the end of the intervention. The results showed efficacy for the relief of pain intensity in patients undergoing hemodialysis over time, and it also improved quality of life [29].

Other non-pharmacological technique was conducted through a quasi-experimental study in a sample of 79 patients with chronic pain of different etiologies, to assess the impact of a psychoeducational program of eight weeks in pain intensity, disability and depressive symptoms of patients with chronic pain. The assessment was performed through cognitive behavioral approach, which in the end proved effective for the control of chronic pain by reducing significantly the scores of pain intensity, disability related to depressive symptoms and pain in the studied sample [26].

4.1. Clinical Implications of the Study

The implications of this study for the practice is to serve as an alert to the stress that the recognition of chronic pain in chronic renal patient on hemodialysis by the health team can help in improving the treatment and quality of life of the patient.

The use of pharmacotherapy, although it produces an instant effect in reducing or controlling the pain, brings undesirable side effects, therefore the use of non-pharmacological techniques may be a safe low risk alternative and that makes possible to reduce the intensity of the pain. Clinical studies using non-pharmacological therapies must be explored.

4.2. Study Limitations

The inclusion of laboratory tests such as calcium and phosphorus was not part of the objective of this study and, therefore, was not collected. This prevented the association of these variables with the presence of pain.

5. Conclusion

Chronic pain was present in many of the chronic renal patients undergoing hemodialysis. When present, its nature was severely limiting, of high interference, and persistent. Analgesics were the most widely used pharmacological class to control pain.

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Factors Affecting Maternal Coping in Korean Mothers of Children with Cancer

Shanzida Khatun[1], Hee Soon Kim[1,2*], Hyun-Bong Park[1]

[1]College of Nursing, Yonsei University, Seoul, South Korea
[2]Mo-Im Kim Nursing Research Institute, Seoul, South Korea
Email: *khssoon@yuhs.ac

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Abstract

Background: The childhood cancer is increasing throughout the world. The incidence of children and adolescent (1 - 19 years old) mortality by cancer was 4.49 by 2006 (Korea Statistics, 2014). Mothers of children experienced a difficult situation in coping when their children were diagnosed with cancer. Based on Mishel's Uncertainty in Illness Theory, maternal uncertainty and perceived social support are important factors that may have an impact on maternal coping in mothers of children with cancer. Therefore, it was worth to investigate this phenomenon in the context of Korea where no such study was conducted. Objective: To identify the factors affecting maternal coping in mothers of children with cancer. Methods: The study was conducted by using a descriptive design. This study was approved by the Institutional Review Board, Yonsei Health System, Severance Hospital, Seoul, Korea and informed consent forms were obtained from the participants. Fifty-nine mothers completed three questionnaires: 1) Parent's Perception of Uncertainty Scale, 2) Multidimensional Scale of Perceived Social Support, and 3) Coping Health Inventory for Parents. The internal consistency of these instruments was satisfactory, all with alpha coefficients over 0.86. Results: Hierarchical multiple regression analysis revealed that perceived social support and maternal uncertainty together explained 35% of the variance in the maternal coping in mothers of children with cancer ($R^2 = 0.353$, $F = 15.255$, $p = 0.000$). Perceived social support and maternal uncertainty had an impact on maternal coping. Conclusions: The findings provided information that could be used in a further intervention study to increase maternal coping in mothers of children with cancer.

Keywords

Coping, Factors, Mothers, Children, Cancer

1. Introduction

The childhood cancer is a devastating disease. Globally, approximately 163,300 children develop cancer each year [1] and 84% of these children live in developing countries [2]. In Korea, the annual incidence of cancer in children and adolescents was 1700 in 2001-2005 [3]. The rate of child (under 5) mortality is 3.4/1000 live births [4]. From 2011 to 2014, there were 7.8 million children and adolescents who were diagnosed as cancer in Bangladesh [5].

Studies indicated that children with cancer experienced a loss of hair [6], pain, social rejection of peers [7], anxiety and depression [8], and behavioral disturbances [9]. In addition, parenting a child with cancer is very distressing, with parents reporting a sense of loss of control, stress, anxiety, depression, sleep disturbance, and uncertainty [10], despair followed by fear and guilt [11] [12], feelings of hopelessness [13], poor psychological well-being [14], and feeling deprived of a context of normality [15]. More specifically, childhood cancer can cause a great deal of physical and emotional stress on mothers [16]. Some Korean and Bangladeshi mothers believed that chronic illnesses like cancer were a type of fate and punishment or a curse from God [15] [17]. A study of Martinson *et al*. [11] found that Korean mothers of children with cancer felt guilty when they did not receive adequate support from their relatives.

A number of factors contributed to maternal coping in response to stressful events. Studies confirmed that education levels were positively correlated with an active coping style [17]-[19]. The age of both fathers and children and the length of time since diagnosis showed direct correlations to paternal uncertainty and coping [20]. Besides these factors, two significant factors contributing to maternal coping are uncertainty and perceived social support, based on Mishel's Uncertainty in Illness Theory (MUI) [21].

Bowers [22] found that uncertainty had a direct effect on emotion-focused coping, regardless of the appraisal of the uncertainty as danger or opportunity. "Chronicity and uncertainty" are responsible for both perceived stress and coping strategies [23]. Another study revealed that parents of young children with chronic conditions with intermittently unpredictable symptoms reported significantly more distress than parents of children with more predictable symptoms [24]. However, a study by Lee, Yoo, and Yoo [25] found that parenting stress was related to ambiguity, lack of clarity, and lack of information, but not related to unpredictability. A study by Bowers [22] found that social support was significantly associated with danger and opportunity. Perceived social support contributed to parental distress [26], stress [25] [27] [28], and maternal psychological adjustment [29] [30]. Martinson *et al*. [11] identified that most Korean mothers received support from their spouse, physicians, nurses, family, neighbors, friends, and religious practitioners. However, social support did not demonstrate any potential effect on mothers' distress 5 years after their child's diagnosis with cancer (T4) [31].

Although there have been many studies as assessing psychological adjustment and coping for parents of children with cancer, relatively few have highlighted the cognitive state of uncertainty and illness-related distress, and social support were associated with maternal coping. Moreover, previously published studies were conducted using diverse families from different cultures, and presented inconsistent findings. In addition, in the existing literature, there are no studies on maternal uncertainty, social support, and maternal coping based on Mishel's Uncertainty theory. Therefore, it is necessary to investigate factors affecting maternal coping among mothers of children with cancer. Information obtained from this study can guide interventions for pediatric oncology nurses to help mothers manage uncertainty and enhance effective coping when their child is diagnosed with cancer.

Conceptual Framework

The conceptual framework of this study was guided by the Uncertainty in Illness Theory (UIT) [21]. The theory proposes that uncertainty exists in illness situations that are ambiguous, complex, and unpredictable. The theory explains how individuals cognitively process illness-related stimuli and how they structure meaning around those events [21]. The theory focuses on the ill individual and the parent or family of that individual. According to the UIT, "uncertainty is the inability to determine the meaning of illness-related events, occurring when the decision maker is unable to assign definite value to objects or events, or is unable to predict outcomes accurately" [21]. It is a cognitive state created when an individual cannot adequately structure or categorize an illness event because of insufficient signals [21]. In this study, maternal uncertainty can be defined as the inability of the decision maker (the mother) to adequately structure, categorize, and determine the meaning of illness-related events. Structure providers, such as social support, influence uncertainty, directly or indirectly. Social support directly influences uncertainty by providing information and guidance to temper ambiguity, complexity, lack of information, and unpredictability [21]. In this study, perceived social support is the mother's perception of whether she receives adequate support from family, friends, and significant others. Maternal coping is an outcome variable in this study. Maternal coping is the specific effort, both behavioral and psychological, that mothers employ to master, tolerate, and reduce stressful events. According to this theory, the researchers assume that maternal coping can be predicted by maternal uncertainty and perceived social support. **Figure 1** is the conceptual framework of this study (**Figure 1**).

2. Methods

2.1. Setting and Participants

Participants were recruited from a single health center in Korea. The mothers in this study were the primary caregiver of their children. The study was conducted from December 2013 to April 2014 at inpatient and outpatient departments for children's care delivery. The sample size in this study was estimated by using statistical power analysis. Using G-power 3.13 for multiple linear regression analysis 80% power was produced with 58 participants with a medium effect size ($f^2 = 0.25$) and $\alpha = 0.05$ (Cohen, 1988). However, the final sample for this study consisted of 59 mothers of children with can-

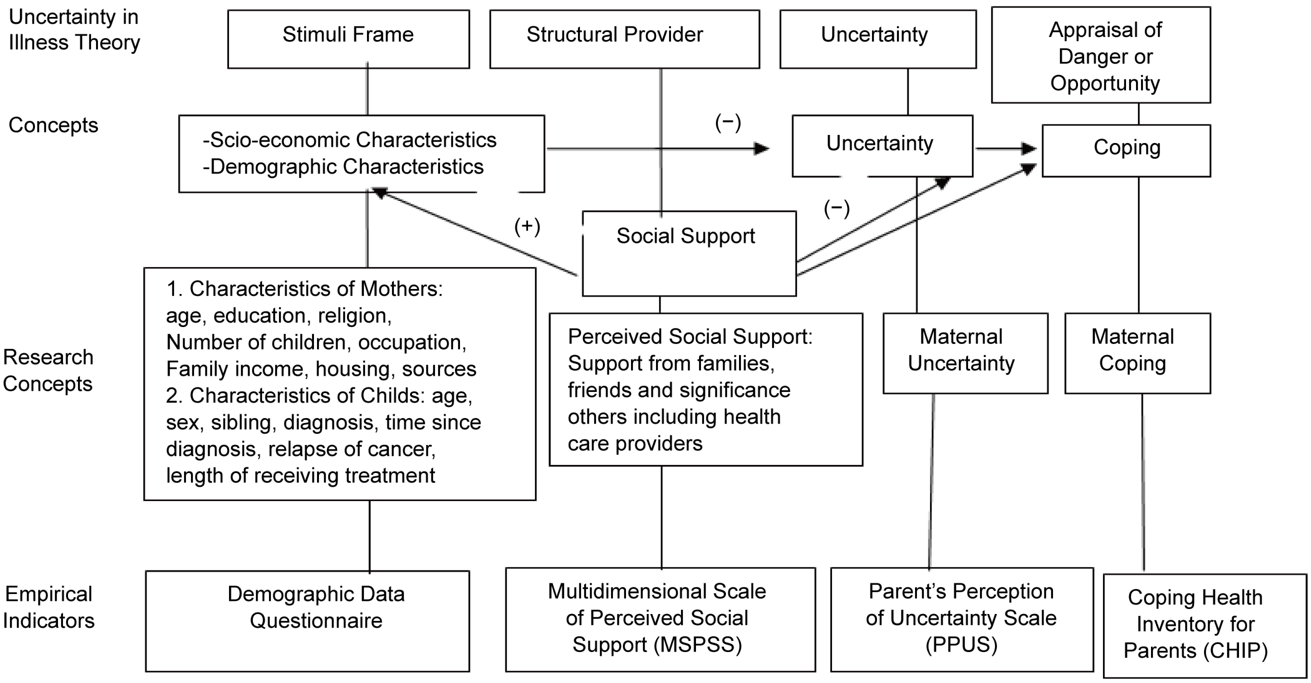

Figure 1. Conceptual framework of the study.

cer. A purposive sample of mothers was invited to complete the self-report questionnaire after the research study was announced by doctors. All mothers met the following inclusion criteria: 1) have adequate perception to person and place; 2) able to understand and speak Korean; 3) have a child aged 2 - 6 years old who was admitted to the hospital with a cancer diagnosis (and no additional diagnoses at least 1 month prior to the study); and 4) the child with a cancer diagnosis was undergoing treatment. Multicultural mothers were excluded from this study.

2.2. Ethical Considerations

This research was approved by Institutional Review Board, Yonsei Health System, Severance Hospital, 50-1, Yonseiro, Seodaemungu, Seoul, Korea and Yonsei Cancer Center, Yonsei Health System, Severance Hospital, 50-1, Yonseiro, Seodaemungu, Seoul, Korea. Written consent form obtained from the mothers. All mothers were informed about the study purposes and methods. A small gift was given to the participants as compensation.

2.3. Measures

Data were collected by using four questionnaires: 1) Demographic Data Questionnaire, 2) Parent's Perception of Uncertainty Scale (PPUS), 3) Multidimensional Scale of Perceived Social Support (MSPSS), and 4) Coping Health Inventory for Parents (CHIP).

2.4. The Demographic Data Questionnaire

The Demographic Data Questionnaire was designed by the researcher based on the literature reviewed. The characteristics of mothers consisted of age, education, religion, number of children, occupation, monthly family income, and housing status. The characteristics of children consisted of age, sex, siblings, diagnosis, time since diagnosis, relapse of cancer, and the duration of treatment.

2.5. PPUS

Maternal uncertainty was measured using the PPUS. The original items of the PPUS [32] were derived from Mishel's Uncertainty in Illness Scale for Adults (MUIS-A). The PPUS consists of 31items with four subscales: ambiguity (13 items), lack of clarity (9 items), lack of information (5 items), and unpredictability (4 items). All items were on 4-point Likert-type scale, ranging from strongly disagree (1) to strongly agree (4). The range of possible scores on the 31-items PPUS is 31 to 124, with a higher score indicating greater uncertainty. The Cronbach's alpha of the total PPUS was 0.86 [32] for the Korean version, the Cronbach's alpha was 0.86 [25].

2.6. MSPSS

Perceived social support was measured using the MSPSS [33]. The MSPSS consists of 12items with three domains: support from family (4items), friends (4items), and from a significant other (4items). All items were on a 5-point Likert-type scale, ranging from strongly disagree (1) to strongly agree (5). Total and subscale scores range from 1 - 5, with higher scores suggesting greater levels of perceived social support. The alpha coefficient for the total scale was 0.93 [34]; for the Korean version, the Cronbach's alpha was 0.85 [35].

2.7. CHIP

Maternal coping was measured by using the CHIP [36], which assesses parents' appraisal of behaviors they use to manage their family life when they have a child who is seriously and/or chronically ill. The CHIP consists of 45 items. In this study, 36 items were used with three subscales: efforts for an optimistic definition of the situation (16 items), efforts for emotional stability (15 items), and efforts to resolve the problem (5 items). All items were scored on a 4-point Likert-type scale, ranging from strongly disagree (1) to strongly agree (4). The range of possible scores on the 36-item CHIP was 36 to 120, with a higher score indicating greater maternal coping. The overall reliability coefficient was 0.88 [36]. This instrument was back translated and revised into a Korean version by Sung (2003). The Cronbach's alpha for the 36-item scale was 0.92 [37].

2.8. Data Collection

A descriptive approach was used. Data were collected through self-report questionnaires. After getting permission from the Director of the Yonsei Cancer Center, the research assistant met with the nurse manager of the selected ward and the participants who met the inclusion criteria. The research assistant introduced herself and briefly explained the purpose of the study. The research assistant explained informed consent and that mother had a right to refuse to participate in the study at any time. The research assistant asked participants to provide answers in accordance with the questions being asked. The interview time ranged from 30 - 40 minutes. The research assistant checked the completeness of the questionnaires. The data were collected from November2014 to January 2015.

2.9. Data Analysis

Both descriptive and inferential statistics were used to analyze the data. Descriptive statistics were used to analyze the characteristics of mothers and their children. The differences between characteristics and maternal coping were analyzed using T-tests and one-way analyses of variance. The relationships between maternal uncertainty, perceived social support, and maternal coping were analyzed using Pearson's Product Moment correlation coefficients. A hierarchical multiple regression model was used to analyze if maternal uncertainty and perceived social support can predict maternal coping in mothers of children with cancer.

3. Results

3.1. Participants

Fifty-nine mothers of children with cancer with a mean age of 35.34 ± 4.68 years (range, 21 - 46) participated in this study. More than half of the mothers had a college education (59.3%) and a majority were religious (69.5%). A majority of mothers had more than two children (69.8%). A large number of mothers had no paid employment (83.1%), however, the average monthly family income was 527.55 ± 463.31 million Korean Won. Half of the mothers did not own their homes (instead, rented or leased a home). A majority of mothers got information from their health care providers (64.4%) (Table 1).

3.2. Characteristics of Children

The average age of children was 4.27 ± 1.59 years old. Thirty-five (59.3%) children were male and a majority had a sibling (69.5%). Approximately 55.9% children had solid cancer (brain tumor, neuroblastoma) and others types of cancer. The mean time since diagnosis was 2.29 ± 0.87 years and a large number of children had not relapse condition (76.3%). The average treatment period was 18.68 ± 1.11 months (Table 2).

3.3. Maternal Uncertainty, Perceived Social Support, and Maternal Coping

Table 3 shows that the descriptive statistics of each independent variable and the dependent variable. The mean of the maternal uncertainty was 67.03 (SD = 9.92); scores ranged from 46 to 87. The mean of the ambiguity subscale was 28.03(SD = 5.41) and scores of this subscale ranged from 15 to 36. The mean of the lack of clarity subscale was 19.02 (SD = 2.91) and scores ranged from 11 to 24. The average of the lack of information subscale was 10.31 (SD = 1.90) and scores ranged from 5 to 14. The mean of

Table 1. General characteristics of mothers ($N = 59$).

Characteristics	Categories	n	%	M ± SD
Age (yrs)	<35	24	40.7	35.34 ± 4.68
	≥35	35	59.3	
Education level	Less than college	8	13.6	
	Vocational	16	27.1	
	College or more	35	59.3	
Religion	Religion	41	69.5	
	No religion	18	30.5	
Number of children	1	18	30.5	1.85 ± 0.69
	≥2	41	69.8	
Employment status	Employed	10	16.9	
	Unemployed	49	83.1	
Monthly income (Won)	<4 million	32	54.2	527.55 ± 463.31
	≥4 million	21	35.6	
	Missing	6	10.2	
Housing	Own house	29	49.2	
	Other	30	50.8	
Information from health provider	Yes	38	64.4	
	No	21	35.6	

Table 2. General characteristics of children ($N = 59$).

Characteristics	Categories	N	%	M ± SD
Age (yrs)	2 - 3	21	35.6	4.27 ± 1.59
	4 - 6	38	64.4	
Sex	Male	35	59.3	
	Female	24	40.7	
Sibling	Yes	41	69.5	
	No	18	30.5	
Diagnosis	Leukemia	26	44.1	
	Solid cancer	33	55.9	
Time since diagnosis	<1 year	26	44.1	2.29 ± 0.87
	≥1 yrs	33	55.9	
Relapse of cancer	Yes	14	23.7	
	No	45	76.3	
Treatment duration	<1 year	28	47.5	18.68 ± 1.11
	≥1 yrs	31	52.5	

Table 3. Descriptive statistics of maternal uncertainty, perceived social support, and maternal coping in mothers of children with cancer (*N* = 59).

Variable	Categories	M ± SD		Range
		Total	Item	
Maternal Uncertainty	Total maternal uncertainty	67.03 ± 9.92	2.16 ± 0.32	46 - 87
	Ambiguity	28.03 ± 5.41	2.16 ± 0.42	15 - 36
	Lack of clarity	19.02 ± 2.91	2.11 ± 0.32	11 - 24
	Lack of information	10.31 ± 1.90	2.06 ± 0.38	5 - 14
	Unpredictability	9.68 ± 1.66	2.42 ± 0.41	7 - 14
Perceived Social Support	Total perceived social support	46.22 ± 6.31	3.85 ± 0.52	29 - 60
	Support from family	16.81 ± 2.50	4.20 ± 0.62	8 - 20
	Support from friends	15.25 ± 2.63	3.81 ± 0.66	4 - 20
	Support from significant others	14.15 ± 3.16	3.53 ± 0.79	7 - 20
Maternal Coping	Total maternal coping	104.73 ± 11.72	2.91 ± 0.32	77 - 137
	Effort for optimistic definition of the situation	49.08 ± 5.69	3.06 ± 0.35	38 - 62
	Effort for emotional stability	40.12 ± 7.50	2.67 ± 0.5	25 - 70
	Effort to resolve the problem	15.53 ± 2.17	3.10 ± 0.43	10 - 20

the unpredictability subscale was 9.68 (SD = 1.66) and scores ranged from 7 to 14. The mean of the perceived social support scale was 46.22 (SD = 6.31) and scores ranged from 29 to 60. The mean of the support from family subscale was 16.81 (SD = 2.50) and scores ranged from 8 to 20. The mean of the support from friends subscale was 15.25 (SD = 2.63) and scores ranged from 4 to 20. The mean of the support from significant others subscale was 14.15 (SD = 3.16) and scores ranged from 7 to 20. The average of the maternal coping score was 104.73 (SD = 11.72) and scores ranged from 77 to 137. The mean of the effort for optimistic definition of the situation subscale was 49.08 (SD = 5.69) and scores ranged from 38 to 62. The mean of the effort for emotional stability subscale was 40.12 (SD = 7.50) and scores ranged from 25 to 70. The mean of the effort to resolve the problem was 15.53 (SD = 2.17) and scores ranged from 10 to 20.

3.4. Differences in Maternal Uncertainty, Perceived Social Support, Maternal Coping and Demographic Characteristics of Mothers and Their Children

Table 4 and Table 5 show the differences in maternal uncertainty, perceived social support, maternal coping and characteristics of mothers and their children. Maternal uncertainty was statistically significantly different by maternal education ($t = 4.004$, p = 0.024) and by the child's relapse status ($t = 2.826$, p = 0.006). There was a statistically significant difference in perceived social support based on a mother's employment status ($t = 2.390$, p = 0.020). Maternal coping also significantly varied based on maternal employment status ($t = 2.258$, p = 0.028).

Table 4. Differences in maternal uncertainty, perceived social support, and maternal coping in mothers of children with cancer according to demographic characteristics (*N* = 59).

Other Related Factors	Categories	Maternal uncertainty		Perceived social support		Maternal coping	
		M ± SD	t/F (p)	M ± SD	t/F (p)	M ± SD	t/F (p)
Age of mothers	<35	68.29 ± 11.476	0.804 (0.425)	45.58 ± 5.926	−0.639 (0.526)	104.46 ± 12.690	−0.146 (0.885)
	≥35	66.17 ± 8.763		46.66 ± 6.611		104.91 ± 11.194	
Education	Bellow college	58.38 ± 3.316	4.004 (0.024)	47.38 ± 2.162	0.453 (0.638)	108.75 ± 9.867	0.573 (0.567)
	Vocational	69.31 ± 2.325		47.06 ± 1.293		103.44 ± 12.522	
	Above college	67.97 ± 1.608		45.57 ± 1.163		104.40 ± 11.850	
Religion	Religion	66.88 ± 8.989	−0.161 (0.873)	47.07 ± 6.544	1.587 (0.118)	105.17 ± 9.947	0.369 (0.716)
	No religion	67.39 ± 12.050		44.28 ± 5.421		103.72 ± 15.308	
Number of Children	1	69.17 ± 9.294	1.096 (0.277)	47.50 ± 7.540	1.033 (0.306)	106.00 ± 9.604	0.549 (0.585)
	≥2	66.10 ± 10.146		45.66 ± 5.704		104.17 ± 12.607	
Employment status	Employed	64.30 ± 7.040	−0.956 (0.343)	50.40 ± 6.851	2.390 (0.020)	112.10 ± 9.689	2.258 (0.028)
	Non-employed	67.59 ± 10.376		45.37 ± 5.911		103.22 ± 11.609	
Monthly income	<4 million	67.72 ± 8.049	0.472 (0.640)	45.44 ± 4.866	−0.636 (0.530)	103.75 ± 10.042	−0.757 (0.452)
	≥4 million	66.33 ± 11.757		46.71 ± 8.320		106.14 ± 12.897	
Housing	Own house	67.14 ± 10.575	0.079 (0.938)	46.28 ± 6.546	0.066 (0.948)	105.66 ± 13.573	0.590 (0.558)
	Other	66.93 ± 9.417		46.17 ± 6.187		103.83 ± 9.756	
Age of child	2 - 3 yrs	67.52 ± 12.703	0.248 (806)	46.05 ± 6.111	−0.155 (0.877)	104.71 ± 14.125	−0.007 (0.994)
	4 - 6 yrs	66.76 ± 6.111		46.32 ± 6.498		104.74 ± 10.368	
Sex	Male	67.26 ± 8.998	0.207 (0.837)	46.46 ± 6.797	0.345 (0.731)	104.71 ± 11.473	−0.011 (0.991)
	Female	66.71 ± 11.319		45.88 ± 5.652		104.75 ± 12.323	
Sibling	Yes	66.10 ± 10.146	−1.096 (0.277)	45.66 ± 5.704	−1.033 (0.306)	104.17 ± 12.607	−0.549 (0.585)
	No	69.17 ± 9.294		47.50 ± 7.540		106.00 ± 9.604	
Diagnosis	Leukemia	66.54 ± 10.432	−0.338 (0.737)	46.19 ± 4.850	−0.030 (0.976)	105.92 ± 8.980	0.692 (0.492)
	Solid cancer	67.42 ± 9.637		46.24 ± 7.336		103.79 ± 13.562	
Time since diagnosis	<1 yr	67.31 ± 10.468	0.187 (0.853)	46.46 ± 6.205	0.258 (0.797)	103.62 ± 12.841	−0.644 (0.522)
	≥1 year	66.82 ± 9.619		46.03 ± 6.483		105.61 ± 10.880	
Relapse	Yes	73.21 ± 8.903	2.826 (0.006)	45.57 ± 7.511	−0.437 (0.663)	104.64 ± 13.258	−0.031 (0.975)
	No	65.11 ± 9.502		46.42 ± 5.971		104.76 ± 11.364	
Duration of treatment	<1 yr	67.57 ± 10.412	0.393 (0.696)	46.89 ± 6.505	0.775 (0.441)	103.50 ± 13.02	−0.763 (0.449)
	≥1 year	66.55 ± 9.595		45.61 ± 6.173		105.84 ± 10.504	

Table 5. Descriptive statistics independent t-tests, and ANOVAs among characteristics of mothers and their children and maternal coping in mothers of children with cancer (*N* = 59).

Other Related Factors	Categories	Total Maternal Coping		Maternal Coping (Effort for optimistic definition of the situation)		Maternal Coping (Effort for emotional stability)		Maternal Coping (Effort to resolve the problem)	
		M ± SD	t/F (p)	M ± SD	t/F (p)	M ± SD	t/F (p)	M ± SD	t/F (p)
Age of mother	<35	104.46 ± 12.690	−0.146 (0.885)	48.08 ± 5.725	−1.122 (0.267)	40.42 ± 10.017	0.251 (0.803)	15.96 ± 2.053	1.277 (0.207)
	≥35	104.91 ± 11.194		49.77 ± 5.647		39.91 ± 5.294		15.23 ± 2.224	
Education	Bellow college	108.75 ± 9.867	0.573 (0.567)	53.00 ± 5.099	2.536 (0.088)	39.88 ± 5.249	0.523 (0.596)	15.88 ± 2.696	0.17 (0.841)
	Vocational	103.44 ± 12.522		49.25 ± 6.309		38.56 ± 6.491		15.63 ± 1.708	
	Above college	104.40 ± 11.850		48.11 ± 5.268		40.89 ± 8.366		15.40 ± 2.278	
Religion	Religion	105.17 ± 9.947	0.369 (0.716)	49.63 ± 5.276	1.122 (0.267)	40.12 ± 6.435	0.005 (0.996)	15.41 ± 2.377	−0.589 (0.558)
	No religion	103.72 ± 15.308		47.83 ± 6.528		40.11 ± 9.725		15.78 ± 1.629	
Number of Children	1	106.00 ± 9.604	0.549 (0.585)	49.67 ± 5.053	0.517 (0.607)	40.06 ± 4.193	−0.042 (0.966)	16.28 ± 2.761	1.528 (0.140)
	≥2	104.17 ± 12.607		48.83 ± 5.991		40.15 ± 8.610		15.20 ± 1.792	
Employment status	Employed	112.10 ± 9.689	2.258 (0.028)	52.20 ± 4.756	1.944 (0.057)	42.60 ± 4.575	1.151 (0.255)	17.30 ± 1.947	3.034 (0.004)
	Non-employed	103.22 ± 11.609		48.45 ± 5.697		39.61 ± 7.908		15.16 ± 2.045	
Monthly income	<4 million	103.75 ± 10.042	−0.757 (0.452)	48.63 ± 4.187	−0.560 (0.580)	39.72 ± 7.314	−0.566 (0.574)	15.41 ± 2.061	−0.484 (0.631)
	≥4 million	106.14 ± 12.897		49.48 ± 6.088		40.95 ± 8.411		15.71 ± 2.552	
Housing	Own house	105.66 ± 13.573	0.590 (0.558)	49.17 ± 6.709	0.115 (0.909)	40.72 ± 7.995	0.606 (0.547)	15.76 ± 2.325	0.810 (0.421)
	Other	103.83 ± 9.756		49.00 ± 4.616		39.53 ± 7.080		15.30 ± 2.020	
Information from health care provider	Health care provider	101.95 ± 10.519	−2.568 (0.013)	47.92 ± 5.237	−2.180 (0.033)	38.45 ± 7.195	-2.394 (0.020)	15.58 ± 1.954	0.253 (0.801)
	Others	109.76 ± 12.345		51.19 ± 5.997		43.14 ± 7.248		15.43 ± 2.561	
Age of child	2 - 3 yrs	104.71 ± 14.125	−0.007 (0.994)	48.81 ± 6.282	−0.274 (0.785)	40.62 ± 10.893	0.310 (0.759)	15.29 ± 2.327	−0.628 (0.533)
	4 - 6 yrs	104.74 ± 10.368		49.24 ± 5.420		39.84 ± 4.885		15.66 ± 2.096	
Gender	Male	104.71 ± 11.473	−0.011 (0.991)	49.51 ± 5.948	0.697 (0.489)	39.74 ± 7.326	−0.461 (0.646)	15.46 ± 2.119	−0.290 (0.773)
	Female	104.75 ± 12.323		48.46 ± 5.357		40.67 ± 7.878		15.63 ± 2.281	
Sibling	Yes	104.17 ± 12.607	−0.549 (0.585)	48.83 ± 5.991	−0.517 (0.607)	40.15 ± 8.610	0.042 (0.966)	15.20 ± 1.792	1.528 (0.140)
	No	106.00 ± 9.604		49.67 ± 5.053		40.06 ± 4.193		16.28 ± 2.761	
Diagnosis	Leukemia	105.92 ± 8.980	0.692 (0.492)	49.12 ± 4.744	0.036 (0.971)	41.62 ± 6.579	1.371 (0.176)	15.19 ± 2.020	−1.048 (0.299)
	Solid cancer	103.79 ± 13.562		49.06 ± 6.413		38.94 ± 8.058		15.79 ± 2.274	
Time since diagnosis	<1 yr	103.62 ± 12.841	−0.644 (0.522)	49.00 ± 5.650	−0.101 (0.920)	39.27 ± 10.094	−0.769 (0.445)	15.35 ± 2.097	−0.560 (0.577)
	≥1 year	105.61 ± 10.880		49.15 ± 5.810		40.79 ± 4.622		15.67 ± 2.245	
Relapse	Yes	104.64 ± 13.258	−0.031 (0.975)	47.71 ± 6.832	−1.032 (0.306)	40.86 ± 9.272	0.419 (0.677)	16.07 ± 2.235	1.080 (0.285)
	No	104.76 ± 11.364		49.51 ± 5.303		39.89 ± 6.968		15.36 ± 2.144	
Duration of treatment	<1 yr	103.50 ± 13.02	−0.763 (0.449)	48.82 ± 5.945	−0.335 (0.739)	39.21 ± 9.792	−0.878 (0.383)	15.46 ± 2.134	−0.204 (0.839)
	≥1 year	105.84 ± 10.504		49.32 ± 5.540		40.94 ± 4.589		15.58 ± 2.233	

3.5. Relationships among Maternal Uncertainty, Perceived Social Support, and Maternal Coping

Table 6 shows a statistically significant negative relationship between maternal uncertainty and maternal coping in mothers of children with cancer (r = −0.398, p = 0.002). There was a statistically significant moderate and positive relationship between perceived social support and maternal coping in mothers of children with cancer (r = 0.527, p = 0.000).

3.6. Factors Affecting Maternal Coping

After testing the assumption of regression analysis, it was found that all of the assumptions were acceptable. Hierarchical multiple regression analysis was performed to identify the main factors affecting maternal coping in mothers of children with cancer. The model included maternal uncertainty, perceived social support, and general variables, such as maternal employment status, and sources of information, that were significantly related to maternal coping in the prior analyses (**Table 7**). The results indicated that maternal uncertainty and perceived social support were significant predictors of maternal coping in mothers of children with cancer. Maternal uncertainty and perceived social support together explained 35% of the variance in the maternal coping in mothers of children with cancer ($R^2 = 0.353$, $F = 15.255$, p = 0.000). The regression coefficients of maternal uncertainty and perceived social support were −0.283 ($t = -2.544$, p = 0.014) and 0.455 ($t = 4.097$, p = 0.000), respectively (**Figure 2**).

4. Discussion

The present study examined factors that affect maternal coping in Korean mothers of children with cancer. The present findings contribute to the ability to predict and understand maternal coping in mothers of children with cancer. According to the UIT, uncertainty and social support are the major factors that determine a parent's coping. In the present study, maternal uncertainty and perceived social support predicted maternal coping in mothers of children with cancer. Maternal uncertainty and perceived

Table 6. Pearson's product moment correlation between maternal uncertainty, perceived social support and maternal coping in mothers of children with cancer (*N* = 59).

Variables	Maternal Uncertainty	Perceived Social Support	Maternal Coping
Maternal Uncertainty			
Perceived Social Support	−0.254		
Maternal Coping	−0.398**	0.527**	
Maternal Coping (Effort for optimistic definition of the situation)	−0.565**	0.594**	0.762**
Maternal Coping (Effort for emotional stability)	−0.156	0.255**	0.832**
Maternal Coping (Effort to resolve the problem)	−0.132	0.407**	0.526**

*p < 0.05, **p < 0.01.

Table 7. A hierarchical multiple regression of maternal uncertainty and perceived social support with maternal coping in mothers of children with cancer ($N = 59$).

Variables	B	β	$t\,(p)$	R^2	$F\,(p)$
Maternal uncertainty	−0.334	−0.283	−2.544 (0.014)	0.353	15.255 (0.000)
Perceived social support	0.846	0.455	4.097 (0.000)		

Adjusted $R^2 = 0.387$.

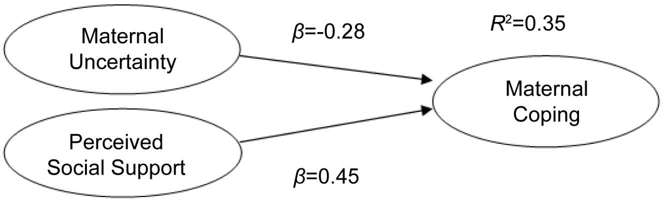

Figure 2. Regression coefficients and multiple correlations of maternal uncertainty and perceived social support maternal coping in mothers of children with cancer.

social support together explained 35% of the variance in the maternal coping. The results are also consistent with other studies among different populations [20] [38]-[40].

It was found that maternal uncertainty had a significant effect on maternal coping in mothers of children with cancer. The regression coefficient of maternal uncertainty was −0.283 (t = −2.544, p = 0.014), indicating that uncertainty is a stressor for Korean mothers of children with cancer, which puts these mothers at a greater risk for negative maternal coping. This result is consistent with the theory stating that uncertainty in illness is the inability to determine the meaning of illness-related events; this occurs in situations where the decision-maker is unable to assign a definite value to objects or events or is unable to predict an outcome due to a lack of sufficient cues [21]. The results are also consistent with other studies that were conducted with diverse populations. Lin Lin [41] found that lower parental uncertainty was associated with improved parental coping in Taiwanese parents of children with cancer. Moreover, a study by Madeo *et al.* [42] indicated that when parents perceive greater uncertainty, they perceive less control over their child's condition. Furthermore, Sterken [20] found that parents' perceptions of uncertainty were significantly related to fathers' coping styles. A study of Lipinski *et al.* [43] found that uncertainty was an independent predictor of parental coping and the regression coefficient of uncertainty was 0.20 (SE = 0.070, p = 0.004). The results of the present study are not consistent with a study by Lee *et al.* which found that uncertainty did not significantly predict distress [44]. Tak and McCubbin also found a non-significant direct effect between family stress and coping among mothers of children with congenital heart disease [39].

Perceived social support, as defined in this study, was the mother's perception as to whether she received adequate support from family, friends and significant others. Thus, if a mother perceived greater social support, she might also be likely to report a higher level of coping. In the present study, perceived social support significantly contributed to maternal coping in Korean mothers of children with cancer. The magnitude of perceived social support coefficient was 0.455 ($t = 4.097$, $p = 0.000$). The soundness of the conceptual model of maternal coping in mothers of children with cancer derived from Mishel's uncertainty in illness theory was supported by the present study. The result is consistent with those from previous studies. A study found that maternal perceived social support significantly contributed to the prediction of maternal coping in mothers of children with congenital heart disease ($\beta = 0.39$, $p = 0.000$), accounting for 15% of the variance [39]. Han found a significant relationship between perceived social support and coping in mothers of children with cancer ($r = 0.48$, $p < 0.000$) [29]. Beltrao *et al.* indicated that mothers perceived that support from their family members, health care team, and friends helped them cope with their children's disease and its effects [45]. Another study found that parents of children with life-threatening and non-life-threatening illnesses reported significant differences in social support and coping behavior [46]. Lee *et al.* found that social support explained 33.3% of parenting stress [25]. Study of Tak and McCubbin indicated that interventions should be directed at enhancing social support, as there is empirical evidence that perceived social support is a predictor of family coping [39].

4.1. Implications for Nursing Practice

Nurses can provide informational and emotional support to mothers, as mothers need support in coping with the constant uncertainty of the illness-related situation.

4.2. Implication for Future Studies

Further studies are necessary to explain the causal relationships among the UIT variables. An intervention design also may help mothers feel more support and less uncertainty.

4.3. Limitations

A measurement error was likely to have influenced the results. Regarding answering the item of monthly income, the participants were rigid to answer this question. In addition, the questionnaire was missing an item regarding marital status, which may contribute to maternal coping. In terms of generalizability, the subjects were limited to mothers of children with cancer admitted in to a specialized Korean hospital.

5. Conclusion

This study demonstrated the implication of the Mishel's UIT in examining factors affecting maternal coping in mothers of children with cancer. The findings indicated that maternal uncertainty and perceived social support were significant determinants of maternal coping. Therefore, it is suggested that nurses actively participate in facilitating information and provide support to mothers. Providing support may alleviate uncertainty and assist mothers in coping with the diagnosis and treatment of their children. Mothers need information about what is happening and what to expect before and after treatment, and advice and encouragement that change the level of uncertainty and improve maternal coping when their children are diagnosed with and receiving treatment for cancer.

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Therapeutic Lifestyle Changes (TLCs) Improve the Quality of Life in the Elderly with Hypertension

Kuslan Sunandar, Tati Suheti, Achmad Husni

Health Polytechnic, Bandung, Indonesia
Email: Kuslan_sunandar@yahoo.com

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Abstract

Hypertension was one of the most serious diseases that affect many people in Indonesia in the age group of 18 years old and above. Hypertension can affect the quality of life, especially for the elderly, so the quality of life for the elderly will be disrupted and the life expectancy of elderly people will also decrease. Elderly people who have a good quality of life will have inner satisfaction, which can be judged from the physical, psychological and social aspects. This study only measured the quality of life of physical dimensions, especially blood pressure (systolic and diastolic). Improved quality of life of people with hypertension can be pursued with behavioral changes that increase blood pressure. One way can be given is the Therapeutic Lifestyle Changes (TLCs). The aim of this study was to determine the effect of the Therapeutic Lifestyle Changes (TLCs) on improving the quality of life of the elderly with hypertension in Puskesmas Pasirkaliki Bandung. This research is a quasi-experimental design with two group pre-post tests with control group. The statistical test used Wilcoxon test and Mann Whitney with a standard error of 5% or $\alpha = 0.05$, because the data distribution was not normal. In the total sample, there were 52 respondents who had hypertension. Therapeutic Lifestyle Changes (TLCs) was done once a week for 4 weeks. The results prove that there is a statistically significant difference in systolic and diastolic blood pressure (quality of life) ($Z = -4.415$; $Z = -4.208$ $p < 0.05$). It is advisable for people with hypertension to expect to remain consistent in the Therapeutic Lifestyle Changes (TLCs) in their activity of daily life.

Keywords

Therapeutic Lifestyle Changes in Hypertension

1. Background

Hypertension is a problem in the elderly because it is often found to be a major factor in heart failure and coronary disease. More than half the deaths over the age of 60 years old are due to heart and cerebrovascular diseases. Hypertension in the elderly is divided into two types: the first one is with increased systolic and diastolic pressure commonly in middle age, whereas the second is the systolic hypertension found in over 65 years old [1].

The prevalence of hypertension in Indonesia obtained through measurement at age ≥18 years old was 25.8 percent, the highest in Bangka Belitung (30.9%), followed by South Kalimantan (30.8%), East Kalimantan (29.6%) and Java west (29.4%). The prevalence of hypertension in the city based on the number of patients who went to the clinic was 12.10%, ranks second out of 20 diseases. In the sub-district Puskesmas Pasirkaliki Cicendo Bandung in November 2013, hypertensive disease was ranked first by the number of hypertensive patients seeking treatment at health centers, which was as many as 550 people [2] [3].

High blood pressure in the long term will damage the arterial endothelium and accelerate atherosclerosis. Complications of hypertension include damage of organs such as the heart, eyes, kidneys, brain and major blood vessels. If the patient has hypertension and cardiovascular disease, the morbidity and mortality of the cardiovascular disorders will be increased. According to the Framingham study, patients with hypertension have an increased risk for coronary disease significantly, stroke, peripheral artery disease, and heart failure [4].

In the elderly the risk of hypertension increases, and it is caused by natural changes in the heart, blood vessels and hormones. The change is accompanied by other factors that can trigger the occurrence of hypertension [5]. Hypertension which occurs in the elderly is a prolonged illness and brings the complex effects for the sufferer. While not all kinds of hypertension constitute a life-threatening disease, it would be also an economic burden for individuals, families, and communities as a whole. Hypertension will lead to medical, social and psychological problems that would restrict the activities of the elderly, which will cause a decrease in quality of life [6].

The problems that arise as a result of hypertensive disease are affecting the ability of the elderly to live independently. Due to functional impairment of the body, the problems can hinder everyday activities such as bathing regularly, preparing meals independently, or performing activities outside the home, thus affecting the quality of life. The presence of hypertension among the elderly poses a risk of functional decline in the elderly population and can affect the quality of life of the elderly [7].

In order to assess the quality of life that is appropriate for the elderly receiving nursing care, this model can be used as a guideline. Issues surrounding the quality of life of the elderly are very broad, but researchers will discuss four specific issues that have a major impact on QOL domain. The problem has a capacity which affects all domains, including psychological health domain for the elderly, the pain, the spirituality of parents and social domain.

The WHO assessment of the quality of life for adults (WHOQOL-OLD) was originally developed by the WHOQOL group to examine the quality of life of the elderly.

This assessment consists of six aspects: sensory abilities, autonomy, activities past, present and future, social participation, thinking about death and the state of the terminal as well as friendship and love [8].

Based on the results of preliminary studies by observation and interviews of five elderly people in Posbindu RW 07 Baladewa Bandung in January 2015, all the elderly with hypertension have the limitations of daily activities, so special attention is needed in addressing the quality of life of the elderly. Behavior modification or lifestyle in elderly is expected to be able to adapt to the state of the disease and control the impact that may arise. One model modification that can be done is the Therapeutic Lifestyle Changes (TLCs). To the researchers, interventions will be provided to the elderly on a visit so that the effects of interventions for the elderly could be seen during a visit to Posbindu.

2. Material and Methods

This research method uses Quasi Experiment with the design of two groups of pre and post test with control.

This research was conducted in Posbindu Pasirkaliki Baladewa Padjadjaran District of Cicendo Bandung. This research was conducted in October 2015 after obtaining ethical approval from the local ethics committee.

Research Samples:

Samples in this study were elderly people who regularly followed the Posbindu activities.

The number of samples in this study is 26 in intervention group and 26 in control group, which includes a total of 52 respondents. The sampling techniques on research conducted by the non-random purposive sampling, with the inclusion criteria were as follows:

a). Elderly with mild to moderate hypertension.

b). Elderly uninterrupted physical activity.

c). Elderly able to hear and speak clearly.

d). Elderly cooperative and willing to become respondents.

While the exclusion criteria in the study are:

1). Elderly people who already have experience to diet and exercise regularly.

2). The elderly who do not regularly come to Posbindu.

3). Elderly who has a hearing impairment.

The data collection procedure is as follows:

1. Identify elderly who meet the inclusion criteria both in the intervention and control group.

2. Elderly who meet these criteria are given an explanation (informed consent) and seek approval for the respondent.

3. After obtaining the agreement of the respondent then measuring the blood pressure (quality of life) either the intervention group or the control group.

4. Once identified the quality of life of elderly given intervention model of Therapeu-

tic Lifestyle Changes (TLCs), this intervention is done once a week for four weeks, while the control group did not do the application of the model Therapeutic Lifestyle Changes (TLCs) but only given standard care in Posbindu.

5. To maintain the principle of justice for the sample, then the control group after the blood pressure measurement prior to the intervention (pre-test) was given a leaflet on diet and physical activity of patients with hypertension, then given them the opportunity to read for 1 hour. Blood pressure measurements after the intervention (post-test) in the intervention group and the control is done serially according to the stages of intervention.

After the data is collected, it will be done editing, coding and tabulation, and then analyzed.

With the following phases:

Prior to further analysis, first test data normality and homogenity of variance.

The normality test results obtained data were not normally distributed, the non-parametric test, the Wilcoxon signed rank test to see the difference of the respective proportions and Mann Whitney U test to compare the proportion of each difference between the intervention group and control group.

3. Results and Discussion

The results of this study are as follows.

a. Normality test.

Normality and homogeneity test is a prerequisite test before hypothesis test. Normality test that uses Kolmogorof-Smirnov indicate $p < 0.05$. This means that the distribution of the data on initial tests and final tests revealed abnormal. Base on the data, normality test recommended using bivariate test with the Wicoxon Paired test and the independent Mann Whitney test.

b. Hypothesis testing

Based on the results of the Wilcoxon test, in Table 1 showed that the interventon group there are differences in systolic and diastolic blood pressure (quality of life) is very significant in the value pretest and posttest ($Z = -4.415$; $Z = -4.208$ $p < 0.05$). The difference is shown by a significant difference in systolic blood pressure between pretest and posttest ($p < 0.05$). The differences are indicated with a mean decrease of 20.25 mmHg (pre test = 144.81; post test = 123.85). Results of statistical analysis on diastolic blood pressure values of the same data also show that there is a very significant difference in diastolic blood pressure values between the pretest and posttest ($p < 0.05$). The differences are indicated by a decrease in the average value of diastolic blood pressure by 10 mm Hg (pretest = 93.08; posttest = 83.08). Based on the analysis, it can be concluded that statistically the Therapeutic Lifestyle Changes (TLCs) effect on a decrease in systolic and diastolic blood pressure (improved quality of life).

Table 2 shows that the Wilcoxon test results there was no significant difference in quality of life between pretest and posttest ($z = -1.890$, $p > 0.05$). The results indicated by the absence of significant mean difference in systolic blood pressure between pretest

Table 1. Effect of Therapeutic Lifestyle Changes (TLCs) in the intervention group.

No.	Variable	z Value	p Value
1	Systolic blood pressure before and after	−4.415	0.000
2	Diastolic blood pressure before and after	−4.208	0.000

Table 2. Effect of Therapeutic Lifestyle Changes (TLCs) in the control group.

No.	Variable	z Value	p Value
1	Systolic blood pressure before and after	−3.207	0.001
2	Diastolic blood pressure before and after	−1.890	0.059

and posttest ($p > 0.05$). with a mean decrease of 4.6 mmHg (pretest = 140.77; posttest = 136.15). Based on the analysis, it can be concluded that statistically the Therapeutic Lifestyle Changes (TLCs) has no effect on blood pressure reduction (improved quality of life).

Effect of Therapeutic Lifestyle Changes (TLCs) in the intervention and the control group based on Mann Whitney test results in Table 3 show statistically the influence of the Therapeutic Lifestyle Changes (TLCs) towards improving the quality of life of patients with hypertension ($z = -4.163$; -4.372, $p < 0.05$).

Based on the analysis, it can be concluded that statistically the Therapeutic Lifestyle Changes (TLCs) effective in improving quality of life, blood pressure systolic and diastolic hypertension.

4. Discussion

Based on the analysis of data in the intervention group, it appears there is a significant difference in the reduction in systolic and diastolic blood pressure. The research results proved that Therapeutic Lifestyle Changes (TLCs) can lower blood pressure in hypertensive patients. Although these results are statistically proven to lower blood pressure, it does not mean people with hypertension do not need medical treatment again to lower the pressure, because in substance Therapeutic Lifestyle Changes (TLCs) has not been able to reduce blood pressure to the normal range of systolic blood pressure and diastolic in patients hypertension. The average systolic and diastolic blood pressure after TLCs still above the normal value (130; 87.12), so as clearly TLCs intervention merely in the statistical analysis, while according substance they need be evidenced with more research further.

Therapeutic Lifestyle Changes (TLCs) is not the only way that can lower blood pressure, so that in certain circumstances, when the blood pressure is being increased significantly the hypertensive patients still need medical treatment in the form of drug therapy to lower blood pressure.

Other factors need is controlled by people with hypertension is a diet that with calorie intake and certain substances in the form of salt and physical activities like sports.

The decrease in blood pressure after getting Therapeutic Lifestyle Changes (TLCs)

Table 3. Differences in systolic and diastolic blood pressures in the intervention and control groups before and after TLCs.

No.	Variable	Nilai z	Nilai p
1	Systolic blood pressure before TLCs	−1.146	0.252
2	Systolic blood pressure after TLCs	−4.163	0.000
3	Diastolic blood pressure before TLCs	−0.178	0.859
4	Diastolic blood pressure after TLCs	−4.372	0.000

can be described as follows; that in the human nervous system are the central nervous system and the autonomic nervous system. The function of the central nervous system is controlling the movements that you want, such as the movement of the hands, feet, neck, and fingers. The autonomic nervous system serves to control the movements are automatic, such as the digestive system function, the function of the cardio-vascular system, endocrine system function including sexual arousal. The autonomic nervous system consists of a stand-alone subsystems that work in opposite, consisting of the sympathetic nervous system and the parasympathetic nervous system. The sympathetic nervous system is working to improve stimulation or stimulate the body's organs, stimulate increased heart rate and breathing, cause constriction of peripheral blood vessels and enlarged blood vessels center, lowers skin temperature and skin resistance, and will inhibit the function of the digestive system and sexual. Instead parasympathetic nervous system works to stimulate the decrease of all functions is increased by the sympathetic nervous system and stimulate the rise of all the functions derived by sympathetic nerves. During such systems are functioning normally and balanced, then the activity levels of the system that will inhibit or suppress the effects of other systems [9] [10].

The situation is influenced by the chemistry of body fluids (blood) levels of salt, cholesterol and others. In addition to the chemical levels in the blood, are affected by stress conditions. Therefore, in addition to lifestyle changes are closely related to diet, activity, rest and sleep. Patterns of activity and good sleep will restore the condition of the body so that it becomes more relaxed. In this relaxed state, the body will experience a resting phase. At that time, the body will activate the parasympathetic nervous system [10]-[12].

The working of the parasympathetic nervous system causes a decrease in heart rate, respiratory rhythm and blood pressure. Conversely, when the body is under stress or in uncomfortable conditions, the sympathetic nerves and muscles of the blood vessels to contract so that the cross-sectional diameter of small blood vessels decreases that resulted in an increase in blood pressure [9] [10].

The results of this study also showed that the drop in blood pressure in patients with hypertension have an impact on improving their quality of life both physically, psychologically, socially and comfort and the feeling in general [13]-[15]. Research has proven that blood pressure reduction causes an increase in the quality of life of patients with hypertension. Decreased blood pressure in the blood vessels in the head and caused a decline in brain stimulation to stimulation of pain and headaches suffered over the years. This condition indicates improved quality of life in the physical dimension and will certainly affect also the emotional and psychological conditions [16]-[18]. Research conducted by Baune *et al.* (2005) [9] states that all dimensions of quality of life that consists of psychological, physical, social and environmental statistically significant relationship with hypertension. In a relaxed state, the body through the brain will produce endorphrin which serves as the body's natural painkillers and can relieve pain (physical complaints).

Likewise psychological dimension, there will be the release of negative emotions such as anger, anxiety, and others that are the implications of increasing the quality of life of the psychological side. Patients with hypertension feel more able to control his emotions when facing things that are unpleasant and can provoke emotional reactions. Mood changes very volatile and unhappiness that usually accompanies the disease course of hypertension decreases. Change negative emotions into positive emotions turned out to cause a significant impact on the social life of people with hypertension. Relationships with others become better and more social activity started to run because of reduced pain during the time felt. Pain in the head can cause disruption of life for their patients with significant disabilities lose time to work and interact socially [19] [20]. Pain in the head can also degrade the quality of life of patients that can lead to large losses due to the economic terms loss number of working days and the amount of medical expenses to be incurred. All the changes that occur both from the physical, psychological and social is all dimension of quality of life. Research conducted by Soni concluded that there is a relationship between hypertension and decreased quality of life, which in the study stated that the elderly with hypertension was 4.6 times life is less qualified than the elderly who do not have hypertension. In hypertensive patients got worse quality of life in physical health dimension, i.e. 64.6% impaired physical functioning, 60.0% disruption in the physical role, and 60.4% suffered from health problems as a whole [21] [22].

5. Conclusions

Based on the results of statistical analysis that have been done, it can be concluded:

1. Statistically there are differences in systolic and diastolic blood pressure (quality of life); and the differences are very significant in the pretest and posttest values ($Z = -4.415$; $Z = -4.208$ $p < 0.05$).
2. Therapeutic Lifestyle Changes (TLCs) have an effect on improving the quality of life of patients with hypertension.
3. Interventions of Therapeutic Lifestyle Changes (TLCs) in patients with hypertension have effects on the reduction of blood pressure.

6. Suggestions

1. With evidence of the effectiveness of the Therapeutic Lifestyle Changes (TLCs), it is advisable in patients with hypertension to remain consistently in doing Therapeutic

Lifestyle Changes (TLCs) in an effort to control blood pressure.

2. The cadres of Posyandu should continue to give health education with Therapeutic Lifestyle Changes (TLCs) to patients with hypertension in their respective areas.

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The Hole in Holistic Patient Care

Connie Drury, Jennifer Hunter

School of Nursing and Health Sciences, University of Missouri-Kansas City, Kansas City, MO, USA
Email: cdrury@sehcollege.edu

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Abstract

Throughout its history, the nursing profession has claimed to provide holistic patient care, which is defined as bio-psycho-socio-*spiritual* care. Today, however, many nurses do not feel comfortable with the "spiritual" element of care and are uncertain about their professional role in the assessment and delivery of spiritual care. Discomfort and avoidance of attending to the spiritual needs of human beings creates "a hole" in holistic patient care. Contributing factors to the "hole in holistic patient care" include: 1) blurring of boundaries in the language and definitions of "spirituality" and "religion", 2) insufficient attention to definitions of spirituality and spiritual distress; 3) confusion and role conflict with professional identity among disciplines related to responsibility for spiritual care; 4) insufficient education and skill development for nurses and other healthcare professionals in the assessment, intervention and appropriate referral of patients experiencing spiritual distress. The purpose of this article is to explore the history of holistic nursing as it pertains to the human dimension of spirituality and conclude with practice models for spiritual assessment and spiritual care that can "fill" the hole in holistic nursing care.

Keywords

Spirituality, Holistic, Nursing, Spiritual Distress

1. Introduction

Life threatening illness and related suffering are arguably situations in which holistic care is the most important. Holism, a century old concept, refers to healing the whole person—body, mind and spirit—rather than solely focusing on the physical suffering and treatment of a disease or condition. Holistic healing is the creation of a harmonious healing balance among the body, mind and spirit of each patient to achieve health for the entire being [1] [2]. *Holistic care* thus includes care for the whole person, including physical, psychosocial, emotional and *spiritual care*. Avoidance of spiritual care,

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that is, attending to the spiritual needs of human beings by any health care professional, creates “a hole” in holistic patient care.

Provision of spiritual care is significant, as research has shown not only that spiritual health is related to better overall health outcomes but also that healthcare consumers believe that spiritual needs should be addressed by healthcare providers [3]. Better health outcomes that can be promoted with spiritual care include disease prevention and recovery, sense of overall wellbeing, and enhanced ability to cope with illness and adjust to stress-related life events [4]-[7]. Spiritual and religious interventions have been shown to decrease suicide rates, substance abuse, divorce and depression in some populations [8] [9]. Research findings indicate that patients expect nurses to help them explore the meaning of suffering, and arrange for privacy for participation in spiritual and religious customs [7] [10]. It will be argued that nurses have the unique opportunity to enrich the hospital experience, to improve the quality of life for patients suffering from serious to terminal disease, and to improve patient’s satisfaction by attending to the spiritual needs of their patients.

Nursing, as a profession, has historically claimed to provide holistic care, yet, research indicates that many nurses do not feel comfortable or are not adequately trained to address the “spiritual care” dimension of their patients [11]-[14]. Holistic nursing is defined by the American Holistic Nurses Association as “all nursing that has healing the whole person as its goal” [15]. The following sections will explore the history of holistic nursing as it pertains to the dimension of spirituality, barriers and misconceptions related to spiritual care, and end with a review of existing practice models for spiritual care and spiritual assessment tools that could promote the filling of the “hole” in holistic care.

2. Holistic Nursing: Historical Perspectives on Spirituality in Healthcare

Humans have inherently cared for the sick thus, the history of nursing worldwide is quite substantial [16]. A brief history of nursing is fundamental for understanding the progression of spiritual care in addressing the holistic health needs associated with human suffering. Holistic origins, the attrition of spirituality from nursing with the advancement of the scientific era, to the re-emergency of spirituality in healthcare will be reviewed.

2.1. Holistic Origins

Dating back 20,000 years, Shamanism is the oldest approach to healing and still exists today [17]. Practically every native community used some type of Shamanism [16]. Shamanism assumes that the combination of body, mind and spirit is a single inseparable entity rather than a consolidation of parts [16]. Shamans are individuals who the tribe believes possess special gifts for understanding and controlling the spiritual realm of others. Incantations, spells, drums, chanting, medicinal plants and rituals are used in the treatment of pain, sickness and suffering. The source of illness within Shamanism is attributed to the loss of “personal power” that makes an individual vulnerable to sickness [17].

In 500 B. C. an ancient Greek physician, Hippocrates, advised those who nursed the sick be attentive to the spiritual wellbeing of their patients and "to do no harm" [18]. From 700 B.C. to 300 A.D. ancient Greeks erected healing temples called Asclepions (named after the Asclepius, the Greek god of healing) which were sites of healing for the body, mind, and spirit [17]. Ancient Greek health practices offered in the temples included art, drama, music, prayers to the gods, rest, massage, herbs and basic surgeries, with some interventions performed by priest healers [17] [19].

In the early years of Christianity, widows were the caretakers of the poor and afflicted. The term "widow" was a title that referred to pious older women who devoted their time caring for the less fortunate, elderly, and those stricken with illness [17]. Later the widows formed religious orders that performed acts of charity and works of mercy. Corporal works of mercy meant nurturing the spirit through tending to the physical ailments of the body. Treatment often involved exorcism, as illness was attributed to possession by evil spirits.

Christianity reigned throughout the Middle Age era with religious orders establishing hospitals to facilitate the care of sick [16]. Medieval hospitals had high mortality rates due to the lack of hygiene and curative treatments. Nursing care was limited to comfort measures such as providing shelter, nourishment, personal care, and prayer. Thus, the primary focus in caring for the sick was nursing the soul.

2.2. Holistic Care Wanes with Scientific Revolution

The era of holistic healing began to fade with the onset of the Scientific Revolution [17] [19]. Rene Descartes, a 17th century philosopher expressed the perception that the body and mind are each a separate entity that can best be understood through separation, rationalization, and reasoning [17]. This Cartesian dualism ushered in the scientific approach to viewing and treating illness from a purely physiological perspective. As specializations evolved in medical science, Western medicine distanced itself even further from the healing of the human spirit.

Florence Nightingale was the first nurse trained within a scientific curriculum who is recognized for practicing holistic care to patients by combining spirituality and science [17]-[19]. Nightingale believed that healing is a dynamic process of recovering from an affliction or disease, mending that which is damaged and, restoring and transforming the individual's body, mind, and spirit [20]. Nightingale personified her principle that spirituality is both "intrinsic to humans and compatible with science" [21].

Most early to mid-20th century nursing schools in the United States maintained some aspect of spirituality through their affiliation with major religious denominations [18]. Yet, as nursing curricula focused more on the scientific approach to nursing care, the characteristics of care, compassion, and empathy became less obvious [17]. In the later 20th century, university and college-affiliated programs established baccalaureate, masters, and doctoral programs in nursing. Great advances were being made in medical technology and knowledge in the biological and behavioral sciences was flourishing.

Along with these advancements, the focus of nursing curricula shifted from preparation for a spiritual vocation to preparation for a skilled, scientific profession. It can be said that the paradigm of nursing shifted from an art to a science [18].

2.3. Re-Emergence of Spirituality within Healthcare

In the past few decades, the role of spirituality in health care has regained the attention of health care providers, nursing organizations, regulating agencies, researchers and consumers During the 1970's and 1980's the importance of holistic health care was re-ignited, as was spiritual health and spiritual care of the sick. In 1981, the American Holistic Nurses Association was established in by Charlotte McGuire in response to a substantial nursing shortage, as nurses were leaving acute care settings to pursue opportunities that would allow them to refocus on healing the "whole" rather than merely curing disease [15] [22]. Holistic healthcare was defined by Cathie Guzzetta in 1988 as, "a sensitive balance between art and science, analytic and intuitive skills, and the ability and knowledge to choose from a variety of treatment modalities to promote balance and interconnectedness of body, mind, and spirit" [23]. Within this definition and others, spiritual needs are viewed as equally important to the physiologic and psychosocial needs in the provision of nursing care [18].

In 2001, the American Nurses Association developed a Code of Ethics for Nurses, declaring that nurses are to implement measures that promote the physical, psychological and spiritual wellbeing of their patients. Joint Commission on the Accreditation of Health Care Organizations has since mandated that accredited health care institutions "accommodate" both religious and spiritual care needs of their patients [23]-[25]. Research has strengthened the push for spiritual care by revealing not only that spiritual health is related to better overall health outcomes but also that the majority of healthcare consumers believe that spiritual needs should be addressed by healthcare providers [3]. Findings have reliably established a direct relationship between spiritual health and medical outcomes including disease prevention and recovery, sense of overall wellbeing, and enhanced ability to cope with illness [4] [6] [7]. A meta-analysis of 49 studies encompassing over 13,000 subjects linked positive religious coping to an individual's ability to adjust to stress-related life events, while negative religious coping was associated with anxiety, depression, and distress [4]. In another study, supportive spiritual care in terminally ill patients was associated with improved quality of life, patient satisfaction, increased hospice referrals, decline in the use of extensive medical treatments, and decreased medical expenses [5]. A study on the coping abilities of patients with human immunodeficiency virus (HIV), revealed that intense spiritual events allowed them to better cope with pain, anxiety, despair, and impending death [4]. Multiple studies have associated spiritual and religious interventions in the mentally ill with decreased readmission rates, suicides, substance abuse, divorce, depression, criminal behavior, and improved overall mental health [8] [9].

In studies of patient perceptions, patients have consistently professed their desire for physicians and nurses to "consider" religious and spiritual needs and preferences in the delivery of patient care [5] [26]-[28]. Research findings indicate that patients expect nurses to help them explore the meaning of suffering, and arrange for privacy to allow for participation in prayer, spiritual customs and rituals [7] [10]. It is argued that nurses have the unique opportunity to enrich the hospital experience, improve the quality of life for patients suffering from serious or terminal disease and improve patient satisfaction by tending to spiritual needs of their patients. Resolution of spiritual uncertainty ushers in the spiritual peace necessary to achieve a heightened quality of life [7] [26] [28]-[31]. All of these effects are well documented in a large body of research on spirituality in patients diagnosed with a serious, advanced or terminal illness [5] [7] [27] [32]-[35]. Thus, evidence supports regulatory and organizational actions, discussed above, which have formally re-established the need for the role of the nurse to be a healer of the integral tapestry of the human, body, mind and spirit. If one thread of this integral tapestry begins to unravel, the whole tapestry is at risk for disintegrating into a meaningless pile of thread.

3. Barriers to Spiritual Care

Regardless of research evidence and organizational and accreditation mandates, attention to spirituality often falls short in the current health care system [36]. Reasons for this include: a) a blurring of religion and spirituality boundaries; b) insufficient attention to definitions of spirituality and spiritual distress; c) role conflict with professional identity and role confusion among disciplines related to responsibility for spiritual care; and d) insufficient education and skill development for nurses and other healthcare professionals related to assessment, intervention, and appropriate referral for patients experiencing spiritual distress [11] [23] [36] [37]. Although these barriers affect various healthcare providers however, in the following section, we will predominantly address how they apply to the nursing profession. As seen, nursing as a profession has historically claimed to provide holistic care, the definition of which includes spiritual care, yet research indicates that many nurses do not feel comfortable or adequately trained to address the "spiritual" dimension of their patients [11]-[14].

3.1. Blurring of Religion and Spirituality

One challenge of defining spirituality is that the boundaries between spirituality and religion are often poorly defined or nonexistent. This erroneous blurring of the two is often seen in the language of both research and practice related to spiritual care wherein it is implied that religion and spirituality are synonymous terms [12] [38]. Spirituality naturally exists within each human being while one's religion or religious affiliation is a personal choice [12]. Religion can be defined as an organizational system created by an individual or group that accept the same beliefs, values, sacred text, rituals and divine being [12] [38] [39].

Spirituality is a broader concept that may be expressed through an individual's religious beliefs, practices and rituals but, religion is not necessary for spirituality to exist [12] [36] [40]-[43]. The word "spirituality" originates from the "Latin *spiritus*, meaning breath, and relates to the Greek pneuma or breath, which refers to the vital spirit or soul" [12]. Dossey and Keegan [12] describe spirituality as:

> The essence of our being. It permeates our living in relationships and infuses our unfolding awareness of who we are, our purpose in being, and our inner resources. Spirituality is active and expressive. It shapes– and is shaped by–our life journey. Spirituality informs the ways we live and experience life, the ways we encounter mystery, and the ways we relate to all aspects of life. Inherent in the human condition, spirituality is expressed and experienced through living our connectedness with the Sacred Source, the self, others, and nature.

According to Vachon [43], "…spirituality could be defined as 'a search for meaning and purpose in life' or as, 'a feeling to have found a meaning and purpose in life and death'". Pesut [44] and others have described spirituality as the core of our being and existence: "To be human is to be spiritual".

3.2. Insufficient Attention to Definitions of Spirituality and Distress

Most researchers agree that developing a simple standardized definition of spirituality to fit all individuals in all situations is an ambiguous, if not, impossible task. However, many human experiences are subjective and difficult to standardize, yet our study of these subjective human experiences proceeds. Similarly, it is possible to identify a working definition of spirituality for research and practice by drawing on the essential aspects of various definitions. These include:

- a search for and/or sense of meaning and purpose in life,
- connectedness to something beyond the self, which can include a higher power, loved ones, nature, art or music, and
- a source of inner strength to transcend the stressors of existence and suffering and optimally, to maintain physical, psychosocial and spiritual wellness.

These essential aspects within definitions of spirituality form the logical basis for the nursing diagnosis of "Spiritual Distress" as described by the North American Nursing Diagnosis Association (NANDA) [45] [46]. NANDA's current definition of spiritual distress is, "A state of suffering related to the impaired ability to experience meaning in life through connections with self, others, the world or a superior being" [47]. Symptoms that may indicate spiritual distress per NANDA include: anxiety, crying, fear, fatigue, insomnia, anger, guilt, isolation, hopelessness and isolation. A stronger awareness and focus on these essentials–the search for life meaning, a need for connectedness, and inner strength to transcend suffering–as well as the related NANDA definition of spiritual distress would: a) decrease the blur between religion and spirituality; b) enable relevant spiritual assessment, patient education, interventions and referrals related to spiritual health; and c) help clarify role confusion among disciplines.

3.3. Conflict with Nursing "Professionalism"

Issues around spirituality for nursing are largely related to the strong, though erroneous, equating of spirituality with religion, and religion being something they most often do not see as a part of their professional scope of practice, given its now strong scientific basis. As society and health care have become increasingly secularized, nurses have grown more anxious and unsure about balancing their own beliefs and professional nursing roles when providing spiritual care [48]. Secularization and intolerance to religious beliefs has made nurses apprehensive in addressing patients' spirituality for fear of being accused of proselytizing personal beliefs and values on their patients [12] [48]. Those nurses who aspire to include spiritual care in their nursing practice, however, are aware that providing such care to their patients can be accomplished without imposing personal and religious beliefs or needing expertise in any particular religion [12] [48]. As a profession, nurses must become knowledgeable, proficient and secure in providing spiritual care, per accurate definition of spirituality, in order to truly be holistic caregivers.

3.4. Role Confusion among Disciplines

Much of the literature identifies that one of the key challenges in addressing the spiritual tasks of patients is the inability to clearly identify the provider of spiritual care [2] [7] [40]. According to Brunjes [49], physical pain is treated by the patient's physician, mental anguish by the psychiatrist, and social pain attended to by a social worker or other social support system, but the referral agent for spiritual pain remains a mystery. The answer to this riddle is not such a mystery for those who attest that the chaplain is the spiritual expert in treating the soul, much like the physician is the expert for the physical body [23] [25] [50]. Healthcare providers tend to agree that referral to the hospital or palliative care chaplain is logical for addressing the spiritual and religious needs of patients [2] [7] [51].

Pastoral care professionals are trained to provide spiritual care and guidance to diverse religious denominations, those who do not have a particular religious affiliation, and those who claim to have no faith whatsoever [23] [50]. In reality, however, the ratio of chaplains to patients is quite small and chaplaincy programs have not gained the momentum to train more chaplains, as jobs in healthcare are scarce and salaries are low [45] [50]. Thus, the more realistic question may not be "Who is the responsible health care professional to provide spiritual care to patients" but rather "What is the role of each healthcare provider on the multi-disciplinary team in meeting the spiritual needs of patients?" Many feel that all healthcare professionals should claim at least a share of the responsibility for addressing the spiritual needs of patients since the establishment of trust between any healthcare provider and patient, at any given moment, can open the door for honest communication concerning spiritual feelings that could lead to the resolution of spiritual distress [23] [52]. Who provides spiritual care is not nearly as important as assuring that each healthcare professional has the resources, guidance and interdisciplinary support to meet the spiritual needs of any patient or family who trusts them enough to share spiritual concerns [49].

3.5. Lack of Education and Skill Development for Spiritual Care

The lack of education and direction within nursing curricula hinders the ability to incorporate spiritual care into practice for patients experiencing spiritual distress [2] [5] [7] [29] [53]. Improving the competence of nurses in defining spirituality beyond religion, and in identifying and addressing symptoms of spiritual distress would enhance patient outcomes of finding life meaning and purpose, connectedness, inner strength and a state of spiritual peace—all of which can be severely disrupted by life threatening illness and impending death [12]. Through guidance and mentoring, nurses and other health care professionals can be empowered to provide spiritual care, to advance holistic practice and to better meet the needs of patients and their families [7]. Nursing faculty, who may also feel inadequacies related to spiritual care, can be assured that creating such guidance for students does not rest solely on their shoulders, but, that numerous models of spiritual care and tools for spiritual assessment already exist.

4. Spiritual Care Models, Assessment Tools and Basics of Intervention

Awareness of existing resources for spiritual care and a level of proficiency in assessing spirituality is necessary. However, it is not meant to intrude or intervene in religious areas, but rather to explore the patient's individual sources of meaning, purpose and strength in life, sense of hope, connectedness, beliefs and values, and, most importantly, how illness has impacted these essential life structures [42] [54]. The erroneous use of vocabulary associating spirituality solely with religion can be avoided by continually drawing on holistic definitions of spirituality and the nursing diagnosis of spiritual distress.

In Cadge and Bandini's [36] review of the evolution of spiritual assessment tools, authors identify that over 40 such tools have been developed since the 1970s, predominantly by chaplains, nurses, physicians and social workers. Tool creation has occurred far more often in disciplinary silos than through interdisciplinary collaboration. Cadge and Bandini [36] assert that the evolution of spiritual assessment tools, and the involvement of the disciplines creating them, reflects larger societal shifts in the U.S. across the years. The various societal shifts and health care responses are also reflected in newer models for spiritual care, some which are interdisciplinary. Such societal influences have included the development of clinical pastoral education (CPE) that integrated psychology and theology, Medicare reimbursement based on diagnosis related groups (DRGs), the history of holistic care reflected in nursing, the hospice and palliative care movement, Joint Commission standards for health care organizations, and ongoing chaplaincy debates between approaches of unstructured spiritual presence versus a more structured approach to spiritual diagnosis and care planning. The latter is similar in many ways to nursing's path to professionalism, inclusive of the "nursing process" structure, theory and research to support an evidence based practice. Territoriality, often spawned by the disciplinary survival need to document their contribution to patient care, has also influenced claims of who is best qualified to diagnose spiritual problems and implement spiritual care. In response to both increased interdisciplinary collaboration, as well as territoriality, spiritual assessment has also undergone a "triage" process of sorts, being divided into screening processes for immediate crises, followed by more in depth spiritual histories. The result is a diversity of tools ranging from the two-question variety to full narrative, life history assessments.

As nurses review various spiritual care models to find an approach most relevant to their practice—they can compare the language, structure and functioning of disciplines within the models to see what might fit best within their given health care structure and philosophy of care. Likewise, when reviewing assessment tools to find resources most relevant to individual practice settings, perhaps the most important aspects to compare in the structure, language and questions posed in these tools are: 1) their focus, whether religion-limited or broader life meaning, purpose and connectedness; and 2) the length and time required to complete the tool; 3) where the tool should be integrated into practice, *i.e.* admission screening or a more in-depth spiritual assessment or spiritual history; and 4) how the tool can be used in practice *i.e.* using it as a formal tool or adaptation to an informal, conversational approach to spiritual assessment. Although not all inclusive, several spiritual care models are briefly described here, followed by several existing spiritual assessment tools.

4.1. Practice Models for Spiritual Assessment and Spiritual Care

4.1.1. The Spiritual Care Implementation Model

According to Christine Puchalski, the creator of the Spiritual Care Implementation Model [25], spiritual care is necessary in any patient-centered health care system. The model is described as a relational model, and illustrates a process of how the patient and interdisciplinary healthcare providers should work together in discovering, communicating, collaborating, managing, evaluating and follow-up to verify the effectiveness of the plan and modify the treatment plan as needed. The Spiritual Care Implementation Model has two "sub-models," one being a specific model for inpatient and a second, different model, for outpatient clinical settings. The Spiritual Care Implementation Model is also described as a "generalist-specialist model of care" in that board-certified chaplains are considered the spiritual care specialist of the team, but all members of the team should be generalists in their ability to be "first responders" to spiritual needs—that is, to identify, assess and respond initially and potentially to make a referral to the chaplain specialist [25].

In the Inpatient Model, the implementation of spiritual care begins with a brief spiritual screening to promptly determine if the patient is experiencing spiritual distress [25]. A more in-depth spiritual assessment is included within the psychosocial history portion of the clinical record to aid in identifying significant information regarding the patient's essential needs, hopes, and available resources that can help health care providers determine whether the patient's spiritual status will enhance or complicate the overall medical care. If concerns arise regarding the patient's spiritual health, a referral brings a board-certified chaplain who will complete a comprehensive spiritual assessment which allows the patient to tell their story. The board-certified chaplain will develop a spiritual treatment plan which will be communicated to the entire treatment team, and will extend to discharge planning, bereavement care, and procedures that enable the interdisciplinary team follow-up contact with family and loved ones after the patient's death.

4.1.2. The Principle Components Model

The Principle Components Model is the result of grounded theory study by Wilfred McSherry [52], based on interviews with members of multiple health care disciplines. The model emphasizes six components, which include: individuality, inclusivity, inter-intra-disciplinary, integrated, innate and institution. Individuality refers to the numerous characteristics that shape the uniqueness of an individual's spirituality, such as culture, religious affiliation life events, social positioning, experiences and traditions. Inclusivity refers to consideration of patient, health care providers and family caregivers in assessing understanding, uncertainties and specific languages of spirituality that are meaningful, versus those that could alienate patients from seeking spiritual guidance. Inter-intra-disciplinary indicates that no single discipline is exclusively responsible for the provision of spiritual care, but that collaboration is imperative. Lastly integrated is the component that motivates the healthcare team to avoid fragmenting holistic care by separating the spiritual from the physical or psychosocial aspects of each patient in the delivery of healthcare. Implementation of the Principle Components Model could aid in finding a language of spirituality that is meaningful and applicable for the assessment and treatment of patients experiencing spiritual distress, developing practice guidelines for the delivery of spiritual care to diverse populations, structuring services involved in the provision of spiritual care and advancing the knowledge and skills necessary for understanding, assessing and providing for the spiritual needs of patients and their loved ones.

4.1.3. The Four Domains Model of Spiritual Health and Wellbeing

The Four Domains Model of Spiritual Health and Wellbeing, developed by John Fisher, ascribes that the spiritual state of each individual determines the general wellbeing of all other human dimensions [55]. In this model the domains of spirituality are identified as "personal, communal, environmental and transcendental" [55]. Every domain consists of two aspects, knowledge and inspiration. Spiritual health is attained by cultivating positive connections within each domain and is enhanced by integrating additional domains, a process termed "progressive synergism." Personal growth within a domain not only strengthens the domain, but also overall spiritual health. The four domains model can be utilized as a foundation for development and refinement of theory and spiritual assessment tools.

4.1.4. The 7 × 7 Model

The 7 × 7 Model was designed and published in the late 1980s and early 1990s by an interdisciplinary team headed by chaplain researcher George Fitchett, to provide a framework that views spirituality as an inseparable entity from the body and mind yet does not presume what spirituality entails [56]. The model identifies seven holistic dimensions including: medical, psychological, family systems, ethnic and culture, societal and spiritual, as they intersect with seven attributes of spirituality including "beliefs and meaning, vocation and consequences, experience and emotion, courage and growth, ritual and practice, community, authority and guidance." The aspects of the 7 × 7 model are described in detail without the inclusion of a formal set of questions allowing the healthcare professional flexibility in the amount of time allotted for the assessment and consideration of the patient's clinical circumstances.

4.2. Spiritual Assessment Tools

According to Cadge and Bandini [36], currently there are over 40 spiritual assessment tools identified in United States literature that have been created by various healthcare professionals including physicians, chaplains, nurses and social workers. Few of these tools were created through multidisciplinary collaboration or intended for interdisciplinary use; most were created within disciplinary silos. Lack of cooperation between disciplines in assessing spirituality has presented challenges in the communication among healthcare professionals about patients' spirituality and planning spiritual care as well as, wide-spread variation in the care provided. Language used in various tools ranges from traditional focus on faith and religion to a broader more existential approach. It is important to examine the content of assessment questions, therefore, to ensure a match with nursing philosophy and diagnoses. Just a few of these tools are briefly described here.

4.2.1. The Spiritual Profile Assessment (SPA)

An exception to the lack of cross disciplinary work occurring in the 1980s, physician Elisabeth McSherry collaborated with chaplains to develop the first physician's spiritual assessment tool, the Spiritual Profile Assessment (SPA). The SPA included three questionnaires-the Professional Health Inventory, Religiosity Index, and Ultimate Values Test [36] [57]. The purpose of the comprehensive Spiritual Profile Assessment was to assist chaplains in planning and documenting spiritual care for individual patients.

4.2.2. The JAREL Spiritual Wellbeing Tool

The JAREL tool [58] is an example of spiritual assessment tools designed for a specific population. This tool was designed by nurses to evaluate faith, life and satisfaction of patients over the age of 65 years, meant to build on clients' strengths and help foster personal growth.

4.2.3. The FICA Tool

The FICA tool was published 1996 by physician Christine Puchalski to help physicians and other health care professionals address spiritual issues [31] [36]. The FICA acronym prompts questions related to F: Faith and belief, I: Importance, C: Community, and A: Address. "Address" refers to questions about how their spirituality can be addressed within their health care.

4.2.4. The HOPE Tool

In 2001, Gowri Anandarajah and Ellen Hight introduced the HOPE tool at least in part in response to Joint Commission requirements [36] [59]. The initial intent of the HOPE tool was to aid medical students and physicians in posing questions regarding patients' sources of "H: hope, meaning, comfort, strength, peace, love and connection; O: organized religion; P: personal spirituality and practices; E: effects on medical care and end-of-life issues [59].

4.2.5. Screening for Spiritual Distress

Many nursing assessments done in hospitals upon admission of a patient have a "spiritual assessment tool" which is boiled down to one or two questions. Questions, such as "what is your religion (if any)?" and "would you like to see a chaplain?" seem intended to pass the buck versus actually learn anything about the patient. Keeping with the need to be efficient by limiting the assessment to a few questions, yet seeking to increase the effectiveness of those questions, Blanchard, Dunlap and Fitchard [45], developed and initiated a quality improvement project aimed at improving the collaboration between nurses and chaplains in assessing and referral of oncology patients who may experience spiritual distress during hospitalization. The primary goal was to train nurses to be more proficient at identifying patients who are at risk for experiencing spiritual distress. A simple algorithm commences with the nurse's statement, "Our team is committed to the whole person. Do you have a belief, spiritual or otherwise, that is important to you?" Based upon the patient's response, the nurse inquires, "Is that helping you now?" or "Was there a time that you did?" [45]. Through this algorithm, two types of spiritual distress are distinguished. In the first type, the patient reports having specific established beliefs, but these beliefs are not a source of support at this time. The second type, the patient had specific established beliefs in the past but does not adhere to those beliefs currently. In both types of responses, the nurse initiates a chaplain referral. By placing these two questions on the nursing assessment, not only was the risk for spiritual distress identified early in hospitalization, but it allowed for the initiation of spiritual dialogue between the patient and nurse.

4.3. Unstructured Assessment and Intervention

Even if a formal assessment tool is not available, spiritual assessment and the simple intervention of listening can be accomplished by asking open-ended questions that ease the patient into a candid discussion about how illness has impacted their ability to enjoy the things that are meaningful to them and how it has impacted their sense of purpose in life. Though very often religion will often be involved in that meaning and purpose, the nurse need not worry about asking direct questions about religion.

Communication skills are vital for building a patient relationships founded on trust, identifying spiritual distress, and implementing interventions that can ease the patient's suffering soul [52]. Especially important is the art of cultivating trust through active listening and presence so as to help the patient feel secure enough to be open about spiritual concerns and needs [13] [52] [60]. As an attentive listener, the healthcare provider must be able to involve the whole self in listening to the patient without intolerance or pondering on how to respond. While being attentive to the patient's posture, expressions and other “nonverbal cues” that might indicate spiritual struggle or suffering. In the business of the healthcare environment, it is easy to miss signals that a patient simply does not want to be alone, and presence may be the single, most vital spiritual intervention a healthcare provider can implement.

Much like active listening, presence requires the body, mind, and spirit of the nurse to be exclusively present for the patient. Resonating the Zen Buddhist philosophy, an American physician suffering from terminal illness, wrote a leaflet entitled, “Don’t just do something, stand there” [60]. There comes a time when patients simply want to feel the security and companionship of human presence [33] [43]. Through the gentle caring presence of the healthcare, empathy for the patient’s pain and suffering is personified allowing the patient to feel valued and respected [13] [60] [61]. Each of these skills has a twofold purpose, spiritual assessment and spiritual intervention.

Other interventions may be more specific to religious aspects, such as supporting religious rituals, practices, and prayer. When asked about spiritual interventions, nurses and patients often allude to prayer [7] [32] [33] [62]. The varieties of prayer differ from person to person and may be founded upon religious affiliation and culture [12]. According to Dossey & Keegan [12], “prayer flows from the yearnings of the soul that rise from a place too deep for words and moves to a space beyond words.” A patient’s need for prayer may be satisfied through song, sacred text, meditation, speaking in tongues, silence, reciting traditional prayers, dance, or experiencing nature through simply being in the moment. Healthcare providers can facilitate prayer or contemplation by simply providing privacy and a quiet, peaceful atmosphere for patients and family.

Sawatzky and Pesut [19], defined spiritual care as “an intuitive, interpersonal, altruistic and integrative expression that is contingent on the nurse’s awareness of the transcendent dimension of life, but that reflects the patient’s reality”. This definition of spiritual care is practical because it highlights that spiritual care should commence with the patient’s current reality rather than meet some standardized guidelines or nurse expectations [60]. In the clinical setting, spiritual care is rarely based upon some preexisting, written, plan of care rather, it is often the nurse acting in response to a sudden unexpected patient dilemma [60].

5. Summary

Although U.S. health care claims to provide holistic care, research shows that many nurses, as well as other professionals, do not feel comfortable or are not adequately trained to address the “spiritual” dimension of their patients. This dimension has been both separated and integrated into health care through history from ancient times to scientific eras. Spiritual care has most recently received increasing attention, and is currently mandated by various health care organizations. Despite this, and despite the existence of numerous spiritual assessment tools and spiritual care models, barriers continue to exist, such as blurred boundaries between spirituality and religion, related role conflict over providing care deemed “religious”, role confusion over bearing responsibility for spiritual care, and inadequate training for health care professions related to spiritual assessment and care. In recent research, there are conflicts revealed between existing definitions of spirituality and understanding of the meaning of spirituality by health care providers, as well as differences in understanding between health care providers and patients. A return to basic spirituality definitions—focusing on life meaning and purpose, connectedness (to others, a higher power, nature), and inner strength to transcend stress and suffering—as well as interdisciplinary communication to promote common language and goals related to spiritual care can do much to provide increased clarity of purpose, role, and processes of spiritual care giving.

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The Evidence of Interdisciplinary Teamwork in the Rehabilitation of Stroke Patients with Aphasia

Signe Vallumrød[1]*, Tone Knudsen Oddvang[2], Elisabeth Severinsson[1]

[1]Department of Nursing Science, Centre for Women's, Family and Child Health, Faculty of Health Sciences, University College of Southeast Norway, Kongsberg, Norway
[2]Department of Nursing Science, Nord University, Mo i Rana, Norway
Email: *signe.vallumrod@hbv.no

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Abstract

The aim of this review was to investigate the evidence of interdisciplinary teamwork in the rehabilitation of stroke patients with aphasia. A total of 248 studies were read and nine included. The papers were analysed and data were extracted by categorizing the four components of rehabilitation: assessment, goal setting, intervention and reassessment. The results revealed that interdisciplinary teamwork was a prerequisite for rehabilitation and that nurses' position in post-stroke care was unclear and limited. In addition, rehabilitation strategies, interdisciplinary cooperation, education and training are important aspects of the rehabilitation process. This study highlights the need for one valid and reliable assessment tool that incorporates communication problems. In conclusion, persons with aphasia should be more involved in their own rehabilitation, which means that the interdisciplinary team members must be educated to communicate appropriately with them.

Keywords

Stroke, Aphasia, Communication, Interdisciplinary Team, Rehabilitation, Assessment Tool

1. Introduction

Approximately 15 million people suffer a stroke annually, of whom around 6.7 million die as a result [1] [2]. Despite the fact that the mortality rate has decreased in recent decades, stroke remains the second greatest cause of death all over the world [3] and is one of the main causes of limitations in daily activity defined as disability [4]. Stroke survivors suffer from a wide variety of disabilities that limit their ability to perform the activities of daily living (ADL), as well as different degrees of physical, cognitive, emotional and social limitation [5]. As a disabling disorder, stroke can be classified within the framework of the WHO International Classification of Function, Disability and Health (ICF), which encompasses health and health-related domains, disability and disease, impairments, activity limitations and participation restrictions. As the functioning and disability of an individual occur in a context, the ICF includes a list of environmental factors. The ICF is the WHO framework for measuring health and disability [6].

Aphasia, which influences most social activities, affects one third of stroke patients [7]. Aphasia differs in character and content in the various phases after stroke. The severity varies from mild or moderate problems to complete inability to identify or find words, or to speak and understand language, making it impossible to express oneself. The linguistic disorders differ across aphasia types and include difficulty in understanding the meaning of words (semantic disorder), trouble in producing word sounds (phonologic disorder) and problems in constructing sentences (syntactic disorder) [8]. Difficulties of speaking, writing and reading change the status of persons with aphasia from independence to dependence, sometimes leading to a life dominated by therapy, concentration problems and a drop in material and economic standards, in addition to limited access to information and communication technologies [4] [5] [9]. The subjective experiences of persons with aphasia seem to be isolation, boredom, bewilderment, fear, anger, shame, apathy, hopelessness, resignation and depression [10]. Because communication constitutes the key to social participation [8], the healthcare services should pay more attention to the delivery of stroke chronic care, where effective rehabilitation strategies are important [3]. A prerequisite for improving stroke rehabilitation focuses on stroke survivors' impairments, as many people survive stroke and are forced to continue life with aphasia and communication difficulties. Aphasia strikes like greased lightning, threatening the person's autonomy, independence and ability to express basic needs. Due to the fact that communication affects most human activities, aphasia rehabilitation should be prioritized from the start and followed up in the chronic stage by a competent community based rehabilitation team to reduce or eliminate activity limitation and restrictions on participation [6] [11]. Long-term consequences of stroke constitute a top-10 research priority, which includes helping stroke survivors and their families to cope with speech problems [12].

Speech problems require rehabilitation, which after stroke is described as long-term and process dependent. Stroke rehabilitation typically entails a cyclical process involving: 1. Assessment, to identify and quantify the patients' needs; 2. Goal setting, to define realistic and attainable goals for improvement; 3. Intervention, to enable progress towards agreed goals for improvement; and 4. Reassessment, to assess progress towards agreed goals [4]. An important strategy is to conduct an assessment prior to rehabilitation in the area of communication, in order to reduce the suffering caused by social isolation, activity limitation and participation restrictions, as well as to diminish the consequences of the health burden [13]. Stroke units with an interdisciplinary rehabilitation team competent in speech and language therapy, medical therapy, nursing, occupational therapy and physiotherapy should be established to provide optimal rehabilitation for stroke patients [4]. An interdisciplinary approach is essential for the rehabilitation of the patient.

Aim

The aim of this review was to investigate the evidence of interdisciplinary teamwork in the rehabilitation of stroke patients with aphasia.

2. Methods

2.1. Review Question

The review question addressed was: How is the process of assessment, goal setting, intervention and reassessment applied by interdisciplinary teams in the rehabilitation of stroke patients with aphasia?

2.2. Search Strategy, Data Sources and Screening

Searches were conducted in online databases (Embase, Ovid Medline, Cinahl, Cochrane Library, Proquest and Web of Science). The following key-words were systematically searched for, both separately and in combination with AND and OR: *stroke*, *aphasia*, *communication impairment*, *language tests*/*hearing test*, *communication*, *speech*, *language*, *hearing*, *verbal*, *evaluation*, *mapping*, *assessment*, *check-up*, *examination* and *screening*. The first search, which was broad, took place in January 2015 in three databases, Embase, Ovid Medline and Cochrane Library, and resulted in 1206 hits. The second search in March, 2015 was refined and key search terms included: *stroke*, *aphasia*, *communication*, *interdisciplinary* and *rehabilitation*. The MeSH headings and free text terms were combined to form the more specific terms mentioned above. An example of the search in one of the main databases, Ovid MEDLINE is presented in Table 1.

Table 1. An example of the search in Ovid Medline

#	Searches	Results
1	exp *Stroke/	67,680
2	exp *Aphasia/	7631
3	stroke or brain adj -infarct* or ischemia* or attack or insult or hemorrhage or cerebral hemorrhage or cerebrovascular accident tw.	164,509
4	aphasia* or communication impairment* adj10, stroke or poststroke .tw.	992
5	or/1 - 4	186,866
6	exp communication/	374,275
7	communication.tw.	143,022
8	6 or 7	482,509
9	interdisciplinary communication/ or exp.patient care team/	64,723
10	interdisciplin* or multidisciplin*.tw.	69,984
11	9 or 10	121,925
12	rehabilitation/or "rehabilitation of speech and language disorders"/	16,678
13	rehabilitati* or habilitat*.tw.	111,432
14	12 or 13	118,092
15	8 and 11 and 14	841
16	5 and 15	91

Studies of aphasia due to causes other than stroke were excluded, as were studies conducted before 2005. Two of the authors (S.V., T.O.) assessed the data extracted. A total of 248 titles met the inclusion criteria, of which nine were included for quality assessment. One study [14] was acquired at the Norwegian Stroke Conference 2015, which we attended. The retrieval process is presented in **Figure 1**.

2.3. Inclusion and Exclusion Criteria

The inclusion criteria were: 1) peer-reviewed research; 2) published in the English language; 3) studies focusing on the stroke rehabilitation process; 4) studies from the perspective of interdisciplinary teamwork in the rehabilitation process; and 5) studies that focused on experiences of communication with patients with aphasia. Supplements, theoretical frameworks, review articles and grey literature were excluded.

2.4. Quality Assessment

Each identified article was appraised using the PRISMA checklist of items to describe and analyse the quality [16]. All included articles were reviewed twice by the first two authors, after which they were checked by the third author in order to achieve consensus on the selection.

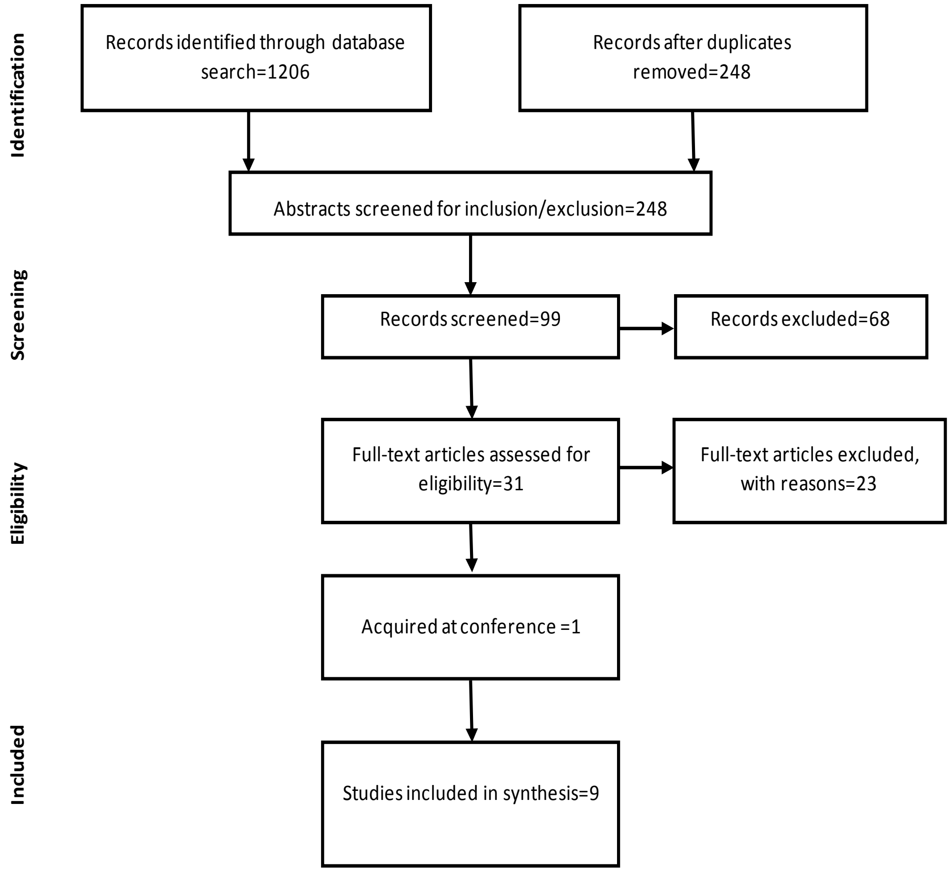

Figure 1. Flow-chart of the included studies [15].

2.5. Data Extraction

The papers were read thoroughly several times by the first two authors (S.V. & T.O.) both separately and together. The content was discussed and reread before data extraction. Data were extracted from the nine papers by systematizing: author, country, year of publication, design, sample, analysis, aim and main findings. Details of the studies included in the review are presented in **Table 2**, and main findings are highlighted by cursive italic fonts.

2.6. Assessment of Methodological Quality

The methodological quality of the included studies was thoroughly assessed by two of the authors (SV, TKO) using a modified version of the Norwegian Knowledge Centre for Health Services (NOKC) check-list for cross sectional studies [17]. This check-list is a tool for assessing the degree to which the methodology of the studies encompasses the risk of systematic bias. The check-list contains eight questions assessing: 1. Population, 2. Sampling methods, 3. Comparison of respondents and non-respondents, 4. Response rate, 5. Data collection procedures, 6. Reliability and validity, 7. Statistical methods and 8. Ethical considerations. Studies that fulfilled more than 50% of the criteria were rated as "Acceptable". Although one study was rated "Low" in terms of methodological quality as the methodology used did not appear to match the check-list criteria, it was deemed important to include its content. When in doubt, we consulted the third author (ES). No studies were excluded due to low quality. Methodological shortcomings mainly concerned criteria 3 and 8, and demonstrated in **Table 3**.

3. Results

The nine included studies were analysed and data extracted from them by categorizing the four components of rehabilitation; assessment, goal setting, intervention and reassessment [4]. The particular shared characteristics of assessment, intervention and reassessments are exemplified in **Table 4**. Goal setting is presented under sub-heading 3.1.2.

3.1. The Components of Rehabilitation

Opportunities for and barriers to an optimal rehabilitation are interpreted and presented under the following headings; assessment and assessment tools, goal setting, interventions and reassessment. A brief outline of the main positive and negative outcomes of rehabilitation of stroke patients with aphasia is presented in **Table 5**.

3.1.1. Assessment and Assessment Tools

Assessment tools that explore the whole person are useful for the rehabilitation of language [11] [19] [21] [22]. In one study, the team members had a collective responsibility for person-centred assessment [11]. The inclusion of family members and next of kin is valuable for understanding the patient as a person [2] [11] [14] [19] [20] [23]. The ICF domains are fundamental for the development of new tools [19]. Assessment of activity, participation and environment is important [11] [14] [19]. A user-friendly

Table 2. Details of the included studies.

Author Country Year	Design Sample Analysis	Aim	Findings
1) Fens *et al*. The Netherlands 2015	Longitudinal mixed methods design. Intervention. Both quantitative and qualitative outcomes. Structured assessments, interviews and self- administered Questionnaires. 77 stroke patients, 59 caregivers and 4 SCC	To examine process-related factors that could have influenced the effectiveness of the intervention in follow-up care after stroke	Healthcare professionals who perform the assessment *need special training* in effective intervention and referral options for problems such as cognition and fatigue. *GPs should be more involved in follow-up care*
2) Matos *et al*. Portugal 2014	In-depth, semi-structured and focus group interviews. N = 38 individuals who live or work with aphasia PWA = 14, FM = 14. The inclusion criteria included no cognitive disturbances and no sign of clinical depression. SLT = 10, average 12.4 years of experience. Content analysis	To explore and understand the consequences of stroke with aphasia for daily life from the perspectives of people with aphasia and those who live or work with them	Consequences of stroke and aphasia were reported, such as; body function and body structure, mental functions, neuro musculoskeletal and movement related functions. The consequences of stroke and aphasia have a considerable impact on daily life. *SLTs should use ICF-domains as a common framework* in patient-centred interdisciplinary rehabilitation. Patients with aphasia rate rehabilitation of communication and autonomy higher than FMs and SLTs. Professional practice in Portugal needs to be changed in order to integrate these findings
3) Aldous *et al*. Australia 2014	Online survey 51 respondents Statistical analysis	To investigate common practices of speech-language pathologists involved in assessments of decision-making capacity for persons with aphasia.	Various formal and informal methods were used for assessing capacity. *Discussion among interdisciplinary team members was reported to have the greatest influence on their recommendations. SLTs expressed dissatisfaction with current protocols for capacity assessment and required further education and training.*
4) Philip *et al*. UK	An instrument development team supported by medical experts, international stroke experts and post-stroke care stake-holders to create a tool for identifying post-stroke problems. Delphi technique	To develop an easy-to-use PSC to identify treatable post-stroke problems and facilitate referral for care.	*Eleven long-term post-stroke problem areas were rated highly and consistently.* The long-term problem areas were: secondary prevention, activities of daily living, mobility, spasticity, pain, incontinence, communication, mood, cognition, life after stroke and relationship with caregiver.
5) Scholberg & Sunnerhagen Norway 2011	Case study Data from four patient charts	To communicate the need for and benefits of comprehensive rehabilitation and a standardized approach to patients with LIS.	*The nurse and nurse's assistants are especially close to patients with LIS and considered valuable members of the LIS team.* Patients with LIS *require a skilled team to provide help and find alternative means of communication.* The need for more assistance to adapt to alternative communication should be considered. *Centralization of a competent interdisciplinary team with special skills is essential.* There is a need for an international network to improve skills and the quality of rehabilitation for patients with LIS.
6) Clarke UK 2010	Grounded theory approach. 220 hours of participant observation, semi-structured interviews with 34 team members and 8 patients	To understand and explain how teamwork was achieved and maintained in two stroke rehabilitation units.	The core category 'opportunistic dialogue' was based on four interrelated and interdependent categories; positive about stroke, learning and working together, concern for persons and inclusive team culture. *This included both systematic and seize-the-moment interdisciplinary practice.*

Continued

7) **Ross *et al.*** **UK** **2009**	Case-study: Mixed methods-questionnaires, qualitative evaluation, N = 107 staff working with stroke during their training, 2005-2008	To describe the development, content and evaluation of an in-service interdisciplinary training programme on psychological and communication problems after stroke	*The trained staff had confidence in their knowledge and recognition of the basic management of communication, cognitive and emotional problems after stroke.*
8) **Smith *et al.*** **UK** **2008**	Multi-methods approach: questionnaires, focus-groups and workshops. A stratified random selection of 16 private, 3 voluntary and 6 NHS healthcare homes, from which a sample comprising 115 trained nurses and 19 senior care assistants was recruited	To identify and describe the educational needs of care home staff when caring for residents with stroke related aphasia.	Both groups preferred accredited stroke education. *Care home nurses required more training in stroke assessment, rehabilitation and acute interventions, senior care assistants required more education in managing depression, general stroke information and communicating with dysphasic residents. Senior care assistants needed more information on interdisciplinary team work, while care home nurses were more concerned with ethical decision-making, accountability and goal setting.*
9) **Knight *et al.*** **Australia** **2006**	Qualitative mixed methods; Participant observation and semi-structured interviews. 7 stroke patients aged 41 - 99 years; 2 with and 5 without aphasia in acute hospital settings	To describe how health information is provided to stroke patients and their perceptions of information provision.	Only 17.5% of communication time was spent providing information. *Patients with aphasia received less information time and content than patients without aphasia. Patients left the stroke unit with little information on aphasia. Health information to patients with aphasia was only given when their significant others were present.* Transmission barriers such as poor vision, impaired hearing or language difficulties (aphasia) were described as hindrances that led to a lack of detailed information. Only verbal information was provided to patients with aphasia, even though they would prefer written information. *The pattern of information provision was infrequent, unplanned and erratic.*

SCC = Stroke Care Coordinators; ACAS = Assessment Consequences after Stroke, GP = General Practitioner, PWA = People with Aphasia, SLT = Speech and Language Therapists, FM = Family Members, LIS = Locked-In Syndrome, PSC = Post Stroke Checklist.

Table 3. Methodological quality assessment of the included studies.

First author, Year	Quality assessment question*								Total assessment quality
	1	2	3	4	5	6	7	8	
Fens 2015	Y	Y	N	Y	Y	Y	Y	Y	Acceptable
Matos 2014	N	Y	Y	Y	Y	Y	Y	N	Acceptable
Aldous 2014	Y	Y	NI	N	Y	NI	Y	NI	Acceptable
Philp 2013	NI	Y	NI	Y	Y	N	NI	NI	Acceptable
Sunnerhagen 2012	Y	N	NI	Y	NI	NI	NI	NI	Low
Clarke 2010	Y	Y	NI	Y	Y	NI	NI	Y	Acceptable
Ross 2009	NI	Y	NI	Y	Y	Y	Y	NI	Acceptable
Smith 2008	Y	Y	NI	Y	Y	Y	Y	Y	Acceptable
Knight 2006	Y	Y	NI	N	Y	NI	NI	Y	Acceptable

Note: Y = Yes, N = No, NI = No information. *Quality assessment questions: 1. Was the population from which the sample was drawn clearly defined? 2. Were sampling methods adequate? 3. Was it explained whether (and how) the participants who agreed to participate differed from those who refused? 4. Was the response rate adequate? 5. Were procedures for data collection standardized? 6. Were measures shown to be reliable and valid? 7. Were the statistical methods appropriate? 8. Were ethical issues considered?

Table 4. Categories extracted from the studies.

Assessment	Intervention	Reassessment
The ACAS is a new assessment tool developed for the home care service and inpatient rehabilitation that highlights the activities of daily life and includes communication. The ACAS was not appropriate for patients with severe aphasia or cognitive impairment. Stroke nurses assessed stroke patients [18].	The follow-up care should be tailored to a structured assessment procedure and individual needs. Few patients with aphasia were referred to the interdisciplinary team [18].	The ACAS was used as a structured referral system to guarantee continuity. [18].
In contrast to SLTs, PWA and FMs value the mental functions of language, rating energy and drive functions as the most important. Clinicians need tools that identify contextual and personal factors [19].	The interdisciplinary team should cooperate and include FMs to contribute to improvements, even for chronically aphasic persons [19].	Collaboration between SLTs, PWA and FMs is important for the provision of appropriate rehabilitation [18] [19].
SLTs commonly contribute to the assessment of the decision making capacity of persons with aphasia in both inpatient and rehabilitation settings. The scope of the assessment by SLTs and their contribution to the interdisciplinary team are not clear. The SLTs use a wide variety of formal assessment tools and informal assessment. [2].		
A PSC assessment tool was developed. The PSC is a brief and easy to use tool for identifying long-term problems [20].		Referrals for treatment should be followed up using the PSC [20].
Immediate assessment is important for the rehabilitation process and utilization of the inpatient period [21].	Successful interventions are dependent on a skilled multidisciplinary team [21].	A skilled team is required to reassess the skills and needs of patients with LIS [21].
Interdisciplinary team member negotiation is necessary to improve the quality of assessments [11].	Interventions were supervised continuously [11].	Core team members shared knowledge, experiences and values in negotiations about decisions pertaining to agreed goals [11].
Assessment of mood, cognitive problems and communication disabilities was improved, leading to less avoidance of patients with aphasia [22].	The interdisciplinary team was more alert and confident in the interventions [22].	
Care home nurses required accredited education and training in stroke assessment. The senior care assistants required more knowledge about team work in the assessment procedure [23].	In order to perform relevant interventions senior care assistants required education and training in how to communicate with dysphasic residents with cognitive, communication and speech problems [23].	Measurable standards and guidelines are warranted in the stroke rehabilitation process to identify patient needs [23].
Aphasia seems to lead to discrimination against patients in the assessment. The international Classification of functioning, disability and health is relevant for assessment. Patients with aphasia are negatively labelled [14].	Interventions are poor if assessment and goal setting are inadequate, which discriminates against patients with aphasia [14].	

ACAS = Assessment tool for long-term Consequences After Stroke; ICF = International Classification of Function, Disability and Health; SCC = Stroke Care Coordinators; GP = General Practitioner; PWA = People With Aphasia; SLT = Speech and language therapists; SLP = Speech and Language Practitioner; FM = Family Members, LIS = Locked-In Syndrome; PSC = Post Stroke Checklist.

assessment tool was developed by an international expert panel to standardize follow-up care for stroke patients [20]. Some assessment tools such as the ACAS were not appropriate for persons with severe aphasia [18]. Patients with aphasia are likely to be interpreted as having a passive role, therefore withdrawn patients require a more concerted effort [14].

In the assessment the main areas of language comprised; auditory, comprehension,

Table 5. Positive and negative outcomes of rehabilitation for persons with aphasia.

Positive aspects	Negative aspects
• Person centred assessment tool that covers ICF domains • Inclusion of persons with aphasia and their next of kin • Collective interdisciplinary responsibility and collaboration • Co-located interdisciplinary team • Defined interdisciplinary team member roles • Formal and informal education • Sharing knowledge and skills	• Use of non-appropriate assessment tools • Poor communication skills when dealing with persons with aphasia • Not considering co-morbidity and the energy level of persons with aphasia. • Lack of knowledge and skills pertaining to the steps of the rehabilitation process • Little knowledge of interdisciplinary team work • Unclear team member roles • Less continuity by not including nurses as active members of the team

verbal expression, reading and writing [2]. A variety of assessment tools were described in the included studies. Matos claims there is a need to develop a new assessment tool based on the ICF. It is important to consider all ICF domains in the rehabilitation of stroke patients and their language ability. Healthcare professionals require tools that explore the whole person and the entire situation [19]. Stroke causes impairment in language, physical ability and emotions. However, Matos claims that the social dimension is often disregarded in the assessment procedure. Tools such as Assessment for living with Aphasia and the Burden of stroke scale are suggested for exploring the situation of the whole person based on ICF domains [19]. However, such tools are not always appropriate for persons with aphasia. The ACAS, which was developed for inpatients as well as for the home care service in The Netherlands, was found to be unsuitable for patients with severe aphasia because they could be left without rehabilitation goals and relevant interventions [18]. Even from the start, assessment of patients with communication impairments due to aphasia is likely to be poor. Interdisciplinary team members interpret patients with aphasia to have a passive role [14].

A Post-stroke Checklist (PSC) was developed by international medical experts as a user-friendly tool for the identification of long term problems in stroke patients [20]. Assessment of persons with LIS prioritizes respiratory and nutritional status, communication skills and cognition. Family and next to kin are important for obtaining knowledge about the person [21].

Clinicians utilized both formal and informal assessments, as well as discussions with the multidisciplinary team and the patient's family members [2]. The main language areas (auditory, comprehension, verbal expression, reading and writing) were assessed. The patient's decision-making ability was included, especially in acute inpatient and inpatient rehabilitation settings. Assessing mood, communication and cognition was deemed essential [22].

3.1.2. Goal Setting

The patients' views and wishes are vital for defining meaningful goals and the input of family members can be helpful [21]. WHO goals pertaining to patient rights were not fulfilled, as a lack of information to patients with aphasia was revealed [14]. Important information on topics such as the causes and effects of stroke, recovery and prognosis, test results and the support available in the future was not provided to patients. Those with aphasia received less information and communication time compared to stroke patients without aphasia [14].

Social and emotional well-being was incorporated in the goalsetting by including information and involving families [11]. The goal for patients with LIS is threefold; to establish and maintain optimal respiration, nutrition and communication [21]. Quality of life goals became more visible to the members of the interdisciplinary team through the PSC tool [20].

3.1.3. Interventions

It is important to take cognition and fatigue into account to ensure effective interventions [18]. The PSC tool provides a common platform for performing quality of life interventions [20]. In order to constantly tailor the interventions they were negotiated both in structural meetings and on the spot [11].

In addition to life-supporting interventions, resources for communication and communicative skills such as eye winking should be included. To be able to interpret the patient's wishes and establish optimal communication, the staff should become familiar with adapting to and utilizing advanced communication equipment, as well as being open minded in the close relationship with the patient [21].

3.1.4. Reassessment

A structural referral system to guarantee continuity in long term chronic care is recommended [18]. The PSC provided the interdisciplinary team with a common referral system to use in the reassessment [20].

Both formal and spontaneous reassessment continuously occurred in the form of close negotiations between the members of the interdisciplinary team in order to achieve appropriate goals and interventions. Furthermore, unplanned dialogue took place when it became necessary to reconsider agreed goals [11]. Reassessment should reveal the communication skills of patients with LIS, their adaptation to advanced technology and whether more support is needed to communicate. Moreover, relevant competence should be harmonized with the needs of patients with LIS [21].

3.2. Interdisciplinary Teamwork

Interdisciplinary teamwork is a prerequisite for rehabilitation. The included studies highlight the variety of healthcare professionals involved in the rehabilitation of stroke patients with aphasia. The studies refer to SLTs, rehabilitation assistants, physiotherapists, occupational therapists, SCCs, nurses, nurse assistants, senior care assistants, healthcare assistants, dieticians, medical experts/physicians, social workers, a psychologist, an engineer and technical support. Some studies described next to kin as useful collaborative partners.

3.2.1. Rehabilitation Strategies

SLTs suggest that a broader interdisciplinary team is necessary to apply the ICF framework for patients with aphasia. FMs should be included to optimize the assessment of activity and participation. In Portugal, SLTs traditionally focus on linguistic impairments and activity limitations, and have no tradition of involving FMs [19]. Matos points out that the British National Stroke guidelines suggest that allied health professionals, health or social care workers and volunteers should have an increased role in an interdisciplinary intervention at the chronicstage of aphasia after stroke. The SLTs perceived such an intervention to be more valuable than previously appreciated. Matos stated that the assessment was performed by SLTs [19].

The team members' roles in the rehabilitation process were unclear [20]. The four main areas of language were assessed by 51 SLTs in acute and rehabilitation in-patient settings [2]. GPs might make an important contribution by identifying prognostic characteristics [18]. Psychologists could have a significant role in the interdisciplinary team due to the need to address the impact of the emotional changes that follow stroke and aphasia [19].

Clarke's study conducted at two stroke units in hospitals in Northern England focused on the close collaboration among team members when caring for stroke patients [11]. The close interdisciplinary collaboration in terms of sharing knowledge and skills facilitated negotiations (opportunistic dialogue) and led to the best problem-solving care in the rehabilitation of stroke patients. The sharing was both planned (*i.e.*, formal meetings) and unplanned (*i.e.*, seizing the moment). This collaboration went beyond the traditional features of teamwork and greatly benefitted the rehabilitation. In the opportunistic dialoguethe team members experienced person-centred assessment and a collective concern about the person with aphasia, which is an absolute prerequisite for successful rehabilitation. All team members were considered valuable for achieving the rehabilitation goals. By including nurses the study demonstrates that rehabilitation is not only the responsibility of therapy experts [11].

Nurses are mentioned as an essential part of the team caring for patients with LIS, as their assessment of the daily care is important. The skilled interdisciplinary team set shared goals, organised follow-up and reassessed skills [21]. Stroke patients need health information in the acute stroke unit, where three out of seven informants described nurses as the main information providers [14].

Stroke nurses specialized in long term care after stroke were responsible for monitoring patients in the rehabilitation process. They set goals alone without involving the other healthcare professionals in the interdisciplinary team [18].

Nurses and senior care assistants are the main staff categories in the care of persons with stroke [23]. These nurses experienced working in isolation with few opportunities for teamwork and expressed a strong need for interdisciplinary cooperation to increase the quality of the rehabilitation [23].

3.2.2. Interdisciplinary Cooperation

Patients living at home and their caregivers were referred to different healthcare professionals by the SCCs, but a cooperation strategy in the rehabilitation process was absent [18]. The rehabilitation team at Sunnaas Hospital in Norway is interdisciplinary and encompasses the different skills needed in the rehabilitation process. The team members considered interdisciplinary teamwork essential for successful rehabilitation. Patients with LIS constitute such a small group that even international teamwork is warranted to facilitate best practice in their rehabilitation [21]. Joint dialogue-based cooperation strategies are dependent on co-location of core team members, as well as regular meetings with collective thinking and engagement [11]. Moreover, joint dialogue is problem-oriented and emerges spontaneously due to team members observing problems and seizing the moment to solve them, irrespective of interdisciplinary status. The dialogue is also patient-oriented and closely linked to defined rehabilitation goals. Team members articulate knowledge, values, experiences, perceptions and beliefs [11]. In this opportunistic dialogue the rehabilitation process is based on negotiations between team members' perspectives [14]. One of the benefits of opportunistic dialogue is that teamwork makes it possible to go beyond the traditional focus on structural features. The result is shared competence and effectiveness in the rehabilitation process [11]. Allied health staff, nurses, health care assistants and therapy assistants worked together in groups of approximately 20 persons. SLTs, a primary care physician and a community continence adviser cooperated and linked the patient to specific referrals by using the PSC [20]. Interdisciplinary team members interpret patients with aphasia to have a passive role, thus patients with communication impairments are likely to be disadvantaged from the start [14].

3.3. Education and Training

There is an unmet need for learning more about interdisciplinary teamwork among senior care assistants and nursing home nurses [23]. The benefits of interdisciplinary teamwork became more integrated after a staff training programme, which led to teamwork competence and job satisfaction [22]. Allied health staff, nurses, health care assistants and therapy assistants also had formal sessions guided by psychologists, an occupational therapist and SLTs. This training resulted in increased knowledge and confidence, integrated team-working and the holistic management of patients [11]. An interdisciplinary training programme entitled "Training the trainers" was developed to support fragile communication following stroke and former stroke patients were involved in designing it. The result was less avoidance of communication with patients with aphasia and more support being offered [22].

Nursing home staff required more knowledge about interdisciplinary activities [23], as well as training and education in stroke assessment, utilizing assessment tools and goal-setting. Senior care assistants needed better skills in communicating with dysphasic patients [23], while nursing home nurses requested accredited education [23]. The interdisciplinary team needs training, while continuity can be ensured by using the same assessment tool and referral system every time. Healthcare professionals require knowledge about how cognition and fatigue influence interventions for persons with aphasia [18]. Ross' study developed an interdisciplinary training programme to increase staff knowledge in terms of recognition and basic management of emotional, cognitive and communication problems following stroke [22]. After completing the programme the interdisciplinary team members reported improved assessment skills and better management of mood, cognition and communication [22].

4. Discussion

The aim of this review was to investigate the evidence of interdisciplinary teamwork in the rehabilitation of stroke patients with aphasia. The review question addressed was: How is the process of assessment, goal setting, intervention and reassessment applied by interdisciplinary teams in the rehabilitation of stroke patients with aphasia?

As persons with aphasia and their next to kin rate the rehabilitation of communication skills as the most important aspect, it is necessary to identify components and factors that contribute to successful rehabilitation in this area. The goal is to design sustainable and beneficial assessment, goal setting, intervention and reassessment for the rehabilitation of persons suffering from aphasia.

4.1. Making a Difference for Persons with Aphasia

A problem is that healthcare professionals can misinterpret patients who suffer from aphasia after stroke. The aphasia might be understood as a vague response or lack of interest and cooperation [14]. This misinterpretation on the part of staff members can cause them to devote less attention and interaction time to patients [14], and difficulty reaching the point at which to start rehabilitation. Moreover, the emotional stress and social limitation experienced by patients with aphasia can be ignored from the start [5]. The fact that patients with aphasia are not informed about their status and prognosis might be demotivating for them [14]. When healthcare professionals' pattern of care is weak in the area of rehabilitation, it must be strengthened. As communication is a reliable key to social participation, patients with aphasia are dependent on tailored rehabilitation [4] [5] [9].

4.2. The Starting Point and the Process of Rehabilitation

Without an appropriate assessment there is no basis for rehabilitation, thus all approaches will be random. As time is a crucial factor, the assessment must start as soon as possible for in-patients [21]. Competence and confidence are required to make optimal use of the wide variety of available assessment tools. Evidence reveals that knowledge and training are essential for enabling staff members to utilize assessment tools [23]. Existing assessment tools and the ACAS were not always considered appropriate for stroke patients with aphasia or severe aphasia [2] [18]. The ICF seems to incorporate relevant factors for the assessment procedure, thus it is necessary to develop a new sustainable assessment tool based on the ICF [19] [24]. It is challenging to construct a user-friendly tool based on the ICF [20] [24]. The PSC was intended to focus on long-term assessment with an interdisciplinary approach based on the 11 relevant ICF areas for persons with impairment after stroke [20]. A prerequisite for successful rehabilitation of persons suffering from aphasia appears to be employing the ICF framework as a base for assessment by operationalizing the main components of functioning, disability and health. There is no doubt that for patients with aphasia, SLTs are the most competent professional category to carry out the assessment, set goals and decide how to intervene. The core improvements for persons with aphasia concern how language is transferred and applied to their real life [24]. Threats state that the question is how the ICF can contribute to improving the quality of life for persons with aphasia. Environmental factors influence patients' situation and have an impact on the assessment. The patient's condition can hinder or promote a successful assessment. Fatigue, depression, hunger, lack of sleep, pain, etc. can make a valid assessment impossible [23]. As patients with aphasia spend most of their time with nurses and senior care assistants, members of these two professional categories are essential for detecting such factors, thus facilitating a valid assessment.

4.3. Interdisciplinary Team Work

Impairments following a stroke are complex and require a highly complicated and specific rehabilitation, which must be provided by an interdisciplinary care team [4]. Of the healthcare professionals mentioned as part of the interdisciplinary teams that provide care to stroke patients, SLTs have the highest competence in the area of speech and language impairments. As nurses and nurse assistants spend a great deal of time close to patients with aphasia [22], they can facilitate continuity in the assessments, intervention and reassessment. Patients with aphasia receive less attention and are often negatively labelled [14]. This demands improved awareness and attention on the part of the nurses and nurse assistants to ensure that the patients are seen and communicated with.

This close relationship means that nurses are in a special position to assess the patients and conduct interventions in daily care situations [21], thus they have a central role inthe interdisciplinary team. However, stroke unit nurses did not appear to be well integrated in the interdisciplinary team [25]. There is an urgent need to re-examine the role of nurses in stroke rehabilitation to enable them to make a substantial contribution to the interdisciplinary work [11]. Nurses are not always aware of this responsibility. In-patients with stroke expected nurses to be the main information provider [14]. The fact that this is not the case means that there is unused potential in the rehabilitation process.

Different professional categories have a role in supporting the rehabilitation of patients with stroke [18]. However, the care team does not always function as an operational interdisciplinary team [11] [21]. While the interdisciplinary approach appears to function for patients with severe sequelae, our findings reveal that it tends not to function as well for patients with milder complications [2] [11] [18] [19] [23]. The question is which priority is given to active interdisciplinary rehabilitation for the group with milder complications and whether the team is designed to be goal oriented. Inefficient rehabilitation strategies could result in unused potential and reduce the patients' chances of regaining their ability to communicate. The time at which the intervention takes place and the amount of training are important for successful rehabilitation of aphasia after stroke. To achieve the best possible result, the whole team, including nurses and nursing assistants, must collaborate closely with each other and actively motivate, guide and stimulate the patient. Utilizing periods when the patient is awake, alert and motivated is crucial for success as it enables the amount of training to be increased and exercises to be transferred to different situations.

In our opinion, a successful rehabilitation team for persons with complications after stroke, especially those who suffer from aphasia, is one that collaborates closely and is co-located. Being unable to express oneself must be so full of hopelessness and fear that interpreting and facilitating rehabilitation best practice in stroke units and the community health services should be a high priority for closely collaborating interdisciplinary teams. To achieve this all health professionals, including nurses, must be integrated in the team, seize the right moments, take responsibility and interpret their role as important for the rehabilitation. A prerequisite for successful further rehabilitation in the community health service is the design of functional interdisciplinary teams that include nurses and nursing assistants.

4.4. Education and Training

A need for more education and training was one of the major findings in this review [2] [11] [18] [22] [23]. Studies show that the level of staff competence influences how patients with aphasia are communicated with [21]-[23]. A skilled team increases confidence and safeguards the quality of the rehabilitation process for stroke patients [11] [21] [22]. Results reveal greater confidence in communication with patients, use of assessment tools and in interdisciplinary collaboration after completion of a training programme [22] [23]. Staff members exhibited greater recognition and acceptance of the patients' speech problems, frustration and distress. Care for families and next of kin strengthened mutual collaboration and improved rehabilitation [14] [23]. Competence in using devices and confidence in the shared goals and strategies facilitated collaborative practice and improved the overall outcome for the person with aphasia [21].

Another way of increasing competence involves sharing professional knowledge by working in opportunistic dialogue [11]. In the team, the effect of learning and working together by sharing core skills led to a common understanding instead of professional defence. The whole team was aware of and shared the patients' goals, thus the members made a concerted effort to work towards them together, leading to successful rehabilitation. Sharing knowledge in the team increased motivation and engagement, while alternative ways of conceptualizing the rehabilitation interventions proved beneficial for patients [11]. Work satisfaction and enthusiasm make staff desirous for training [23].

Some studies mentioned experiences of designing and running training programmes [22]. To achieve a really practical and useful content, one study described how former stroke patients were recruited to assist in designing the training programme, as well as presenting some parts of it [22]. This was evaluated as a success.

5. Limitations of the Study

This systematic review has some limitations. The number of included studies is few. After reviewing the literature search it turned out that our research question limited the amount of research that could be included due to the need for research on persons with aphasia. Although this review has been thoroughly evaluated by two of the authors (SV and TKO) who read the studies several times from different perspectives, there is still a possibility that we might have missed out on or misunderstood some of the information presented. To counter the possibility of undetected bias, differences in understanding and judgment were resolved by discussions between the authors, leading to a common understanding of, as well as consensus on, the interpretation of the analysed studies. Although some of the included qualitative studies have a small sample, we consider that it would be difficult to perform large studies on this topic as persons with aphasia constitute such a limited research field. The stroke research field is strong in terms of research from a neuroscience perspective, but poor from the perspective of aphasia rehabilitation. In our opinion, smaller in-depth studies can produce valuable and easily transferable information in this area.

6. Conclusions

Ignoring the rehabilitation of communication for patients with aphasia could influence the quality of the rest of their lives and become the difference between boredom or interest, inactivity or activity, social isolation or participation, dependence or independence and apathy or hope. This study highlights the need for one valid and reliable assessment tool that incorporates communication problems. Successful rehabilitation starts with the application of a relevant assessment tool. Assessment tools require tailored competence in order to fully exploit the starting point and subsequent steps of the rehabilitation process. Interdisciplinary collaboration towards shared goals in the rehabilitation of language is decisive for success. Each professional category in a successful rehabilitation team has a defined role. To perform as a successful team, co-location and close collaboration are crucial.

The studies in this review reveal that nurses' position in post-stroke care is unclear and limited. To achieve a valid assessment and successful rehabilitation, the roles of interdisciplinary team members and their collaboration strategies must be reorganized. The contribution of nurses and senior care assistants must be acknowledged as important for continuity, successful assessment and rehabilitation as a whole.

A need for formal and informal education, both on site and accredited, was detected. The design of relevant educational programmes should be the responsibility of universities and other educational institutions. Community health services, hospital stroke units and educational organisations should collaborate to design relevant training programmes. In addition, this review revealed a need for increased knowledge and skills among interdisciplinary team members in terms of interdisciplinary team work. Persons with aphasia should be more involved in their own rehabilitation process, which implies the necessity of educating interdisciplinary team members to communicate with them.

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Contributors

The study was design by S.V and T. O. S.V. coordinated the research. All authors participated in the data analysis. All authors contributed intellectually, proof read and approved the final manuscript. E.S. supervised the study.

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Exploring the Relationship between Obstetrical Nurses' Work and Pregnancy Outcomes

Jo Watson[1,2], Monica Nicholson[1], Kelly Dobbin[3], Karen Fleming[1,4], Julia M. K. Alleyne[5,6]

[1]Women and Babies Program, Sunnybrook Health Sciences Centre, Toronto, Canada
[2]Lawrence S. Bloomberg, Faculty of Nursing, University of Toronto, Toronto, Canada
[3]College of Midwives of Ontario, Toronto, Canada
[4]Department of Family and Community Medicine, Toronto, Canada
[5]University Health Network, Toronto Rehabilitation Institute, Toronto, Canada
[6]Department of Family and Community Medicine, University of Toronto, Toronto, Canada
Email: jo.watson@sunnybrook.ca

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Abstract

The Registered Nurses Association of Ontario Healthy Work Environments Best Practice Guideline recommends that employers promote safe, healthy workplaces. Healthy workplaces include addressing the unique needs of nurses who work while pregnant. The purpose of this descriptive study, summarizing information from 120 pregnancies reported by 95 nurses, was to determine if the workload of obstetrical nurses was associated with negative pregnancy outcomes, including preterm delivery and birth weight. Full-time obstetrical nursing work is a predictor of reduced birth weight, but not of preterm birth when compared to outcomes of obstetrical nurses working part time. One third of nurses reported pregnancy complications and most nurses experienced work-related and personal stress. Further research evaluating work modifications during pregnancy is indicated to improve birth outcomes.

Keywords

Obstetrical Nurse, Pregnancy Outcomes, Preterm Birth, Birth Weight

The Registered Nurses' Association of Ontario Healthy Work Environment Best Practice Guideline recommends that employers create environments that promote safe and healthy workplaces [1]. This should be done by developing a climate of staff safety through education, research and mutual accountability between staff and work place institutions [1]. This study explored the relationship between obstetrical nurses' work and pregnancy outcomes. We were interested in understanding the impact of physically demanding work of obstetrical nurses since evidence existed suggested a relationship between heavy work during pregnancy and outcomes such as preterm deliveries and babies who were small for gestational age [2] [3].

1. Background

Women who work throughout pregnancy are generally considered to be healthier than non-workers due, in part, to the self-selection of healthy individuals who are able to work. However, some studies demonstrate that certain types of work can have a negative impact on pregnancy outcomes when compared to the general population of pregnant workers. Aside from environmental hazard exposure, where harm to workers is self-evident, the relationship between pregnancy outcomes and other work hazards such as shift work, heavy exercise and lifting, stress and job control is less clear.

Work that is considered physically demanding and includes shift work has been associated with spontaneous abortion, preterm birth and low birth weight [2]-[5]. The work of an obstetrical nurse typically involves shift work, including night work and requires physically demanding postures such as lifting, twisting, and standing for extended periods. The purpose of this study was to determine if the heavy workload and shift work patterns of obstetrical nurses had an association with adverse pregnancy outcomes such as low birth weight and preterm birth and if such a relationship existed, and to provide hospital administrators with healthy work place recommendations for obstetrical nurses.

2. Review of Literature

A PubMed search of the following terms was conducted, "pregnancy", "nurses", "shift work", "occupational exposures", "antenatal morbidity", "fatigue", "stress", "exercise during pregnancy", "preterm birth" and "birth weight" to explore factors related to work and pregnancy outcomes for the years between 1995 and 2015.

A Scandinavian systematic review conducted by Nurminen (1998) identified several studies indicating an association between shift work (that included night work) with pre-term delivery or intra-uterine growth restriction (IUGR). However, the type of occupations and shift schedules varied among the individual studies.

Three other studies demonstrated a strong association between physically demanding work, prolonged standing, shift and night work with adverse outcomes of pregnancy, specifically preterm birth and lower birth weight [3] [6] [7]. In contrast, studies conducted by Lawson *et al.* (2009) and Pompeii, Savitz, Evenson, Rogers, & McMahon (2005) [8] disputed these findings concluding that shift work and physical factors were not strong predictors of preterm birth and found no association between heavy lifting or prolonged standing with the risk of preterm birth and babies born small for gestational age. Pompeii *et al.* (2005) and Lawson *et al.* (2009) did suggest, however, that night work increased the risk of preterm birth. Lawson's study demonstrated a 3-fold higher risk of delivering before 32 weeks, but no increased risk of preterm birth between 32 - 36 weeks related to night shift work. In addition, Lawson showed a lower risk of preterm birth when pregnant nurses worked part-time versus full time and no dose-response relationship due to overtime hours worked. No studies were found that examined outcomes for nurses who work in obstetrics. These findings indicate that further investigation is required to better understand whether the heavy physical work or shift work demands of obstetrical nurse results in negative outcomes in pregnancy.

3. Methods

A survey was developed from a review of current literature as well as the experiences of several obstetrical nurses who worked during their pregnancy and left work earlier than planned in the authors' workplace. Material from these reviews formed the content of the proposed survey questions. An online survey was created that consisted of thirty-two questions including multiple choice, yes/no and open ended format. The survey gathered information about obstetrical nurses' pregnancies, physical demands and related outcomes. The study was approved by the authors' hospital research ethics board. Participants were recruited by making the survey available to nurses who were members of a provincial childbirth nurses' group with a membership of approximately 700. We invited nurses who had worked as obstetrical nurses to participate. The survey was piloted between March and September 2011 with six obstetrical nurses who worked during one or more of their pregnancies. No changes were made to the piloted survey based on the nurses' responses or feedback related to the survey design. The survey was made available online in January 2012 and two email reminders were sent to the members and responses were collected until January 2013. Participants did not receive any remuneration for completing the survey. Responses from the pilot participants were included in the survey responses.

4. Analysis

The association between predictor variables, birth weight and gestational age were described by work status using chi-square tests for associations for categorized variables and means (standard deviations) for continuous measures. Birth weight and gestational age did not differ between full-time, 12-hour shift workers and full-time, non-12 hour shift workers; thus, in the multivariable models, all full-time workers were compared to part-time workers. Logistic regression assessed the predictors of preterm delivery; the predictors of birth weight were assessed by linear regression. To account for multiple observations per person, all associations were examined by modeling outcome factors onto putative explanatory variables using a generalized estimating equation approach. All analyses were conducted in SAS 9.3.

5. Results

Ninety-five surveys were collected from approximately providing information on first, second, third and fourth pregnancies representing 120 singleton pregnancies. Only respondents identifying as working in a nursing position at the time of pregnancy were included in the analysis. Data represented 67 first pregnancies, 38 second, 12 third and

3 fourth pregnancies respectively. The nurses' age at the time of giving birth ranged from 24 to 34 years. For analysis, subsequent pregnancies were categorized as either primiparous (first pregnancy) or multiparous (2nd, 3rd, or 4th pregnancy).

Eighty per cent of the nurses (n = 84) responding to the survey identified themselves as working in labour and delivery, the remainder worked on postpartum units. Ninety of the respondents were Caucasian (94%), married (94%), non-smokers (94%). Eighty-one nurses (85%) reported they consumed no alcohol in pregnancy. Twenty-six percent (n = 25) identified that they were overweight at the time of their pregnancy.

There were no differences between groups related to parity, alcohol use or exercise activities when nurses working full time and part time were compared. While half of the respondents left work before they had intended, there was no difference between groups. Fifty-three percent of obstetrical nurses reported work stress and sixty-one percent reported other stress; these reports did not differ between part-time or full time workers. Across all groups, over one third of nurses experienced pregnancy complications ranging from antepartum hemorrhage, preterm labour, gestational diabetes and preeclampsia. The overall rate for preterm birth for all nurses participating in this study was 12.9%.

Table 1 shows the association of birth weight and pre-term delivery, reported by work status. The mean birth weight of all babies born to survey respondents was 3433 grams (SD 599.2). Part-time nurses had significantly heavier babies than those who worked full-time 12 hour shifts and non-12 hour shift (p = 0.004). Since there were no differences in birth weight among nurses who worked full-time 12 hour shifts and those who worked full-time non-12 hour shifts, multivariable regressions compared full-time vs. part-time status to assess the factors associated with birth weight and pre-term delivery.

Infants born to mothers with pregnancy complications (excluding gestational diabetes) weighed 441 grams less than those without complications. Mothers with pregnancy complications were more likely to deliver preterm than those without complications (OR = 8.74, p = 0.009). There was a difference of 3.6 (SD 4.25) weeks between the gestational age when the nurses stopped working and the gestational age at delivery (Table 2).

6. Discussion

The results of this study demonstrate there is a significant difference between the weights of infants born to full-time and part-time obstetrical nurses. On average, babies born to full-time nurses weighed 300 grams less than infants born to nurses working part-time. Full-time nursing work is a predictor of reduced birth weight. Simcox & Jaakkola (2008) [9] reported lower births weights among Finnish nurses compared to office workers and Quansah, Gissler, Jaakkola (2009) [10] reported lower birth weights for babies born to nurses versus teachers in Finland. A third study described lower birth weights for infants born to nurses compared to those born to women in general in

Table 1. Outcomes by work status.

Outcome	All respondents		Full-time, 12 hour shifts		Full-time, non-12 hour shifts		Part-time, all shifts		Test for differences (p-value)		
									Overall (comparing all 3 groups)	Comparing FT-12 hr vs. FT non-12 hr shift	Comparing FT vs. PT
Continuous Measures	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)			
Birth weight	120	3432.6 (599.2)	56	3328.3 (577.7)	27	3284.6 (602.4)	33	3687.2 (516.6)	0.015	0.763	0.004
Gestational age	120	38.7 (1.94)	56	38.7 (1.83)	27	38.3 (2.33)	33	39.3 (1.53)	0.178	0.474	0.063
Categorized Measures	n	%	n	% of work category	n	% of work category	n	% of work category			
Birth weight									0.254	0.360	0.137
<2500	9	7.8	6	10.7	3	11.1	0	0.0			
2500 to 3000	12	10.3	7	12.5	2	7.4	3	9.1			
>3000	95	81.9	43	76.8	22	81.5	30	90.9			
Preterm delivery									0.300	0.703	0.138
Yes	15	12.9	7	12.5	6	22.2	2	6.1			
No	101	87.1	49	87.5	21	77.8	31	93.9			

Table 2. Differential between gestational age at birth and gestational age stopped working.

Outcome	All respondents		Full-time, 12 hour shifts		Full-time, non-12 hour shifts		Part-time, all shifts	
Continuous Measures	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)
Gestational age stopped working	118	35.2 (4.37)	56	35.1 (4.33)	27	34.0 (5.01)	33	(36.38)
Gestational age at delivery	120	38.7 (1.94)	56	38.7 (1.83)	27	38.3 (2.33)	33	39.3 (1.53)
Differential	118	3.6 (4.25)	56	3.7 (4.29)	27	4.3 (5.04)	33	2.9 (3.57)

the province of British Columbia [11]. However, weights of babies born to nurses working full time and participating in this study did not meet the accepted low birth weight definition of less than 2500 grams [12]. We conclude that the heavy workload of full-time obstetrical nurses can be considered as a proxy for exercise in pregnancy, a factor previously associated with the outcome of lower birth weight [13].

This study showed no difference in infant birth weight when comparing full-time obstetrical nurses working 12-hour shifts versus 8-hour shifts. It is possible that reduced birth weight may have less to do with hours worked in one shift and more to do with work that includes night work and total hours worked. This finding supports earlier research conducted by Mozurkewich *et al.* (2000). This study also demonstrated a correlation between reduced birth weight and pregnancy complications (excluding gestational diabetes).

The results of this study did not suggest that full-time nursing work was a predictor of pre-term birth which had been suggested in other research [2]. The Canadian preterm birth rate is 7.8% [14] and the overall rate for obstetrical nurses in this study is 12.9%. The cost of preterm birth can be great including respiratory diseases, temperature instability, hospital re-admission and neuro-cognitive problems and is the leading case of infant mortality [15]. Although the numbers in this study are small, this finding is worthy of further investigation.

Nurses participating in this study left work three and a half weeks earlier than their delivery date. This may be because obstetrical nursing work becomes too physically demanding in late stages of pregnancy. Early departure from work may result in sick time, unpaid weeks of work, or an early start to paid maternity leave, which shortens the time a new mother has to spend at home with her baby before returning to work. Further investigation is required to determine if work modifications, for example, day shifts only or reduced hours, would enable nurses to continue working further into their pregnancy, if they so desire. There are models of workload support for medical residents such as exemption from on-call duty after 31 weeks gestation [16]. Preventive measures such as these should be considered for pregnant obstetrical nurses to decrease complications and stress.

The study's main strength is that it was the first to begin to explore pregnancy outcomes for obstetrical nurses comparing full-time with part-time work. The limitations of this study include potential recall bias as the survey asked questions about past pregnancies some of which occurred years earlier. It is recognized that nurses who responded may have been motivated to participate in based on a belief that their pregnancy was negatively affected by nursing work. Additional limitations of the study are a lack of a priori definitions of shift work or full-time versus part-time work. Nurses self-identified as full- or part-time workers. It may be possible that nurses who reported being part-time employees actually worked the equivalent of full-time hours. The study could have been strengthened if the proportion of part time nurses working night shift was known. As well, we did not ask if nurses took any preventative measures (for example, withdrawal from work, reduced hours or modification of clinical duties) to address any challenges related to working while pregnant. It was assumed that for all nurses who reported work status their status remained consistent throughout the pregnancy, but this was not confirmed. A final limitation is the small size of the study. Findings may not be generalizable to a greater population of obstetrical nurses.

The results of this study demonstrate that full-time nursing work was a predictor of reduced birth weight compared to part-time work. Birth weights of babies born to full-time obstetrical nurses were, on average, 300 grams less than infants born to those working part-time. The results of this study did not confirm that full-time nursing work was a predictor of pre-term birth as had been suggested by other research investigating similar shift-work impacts [2].

The Canadian pre-term birth rate is 7.8% [14] and the overall rate for all obstetrical nurses in this study is 12.9%. The reasons for this increased rate are not known. Although the number of participants in this study was small, nursing leaders and administrators should consider implementing preventive strategies aimed to maximize fetal growth and optimize the gestational age at which nurses begin their maternity leave and to minimize pregnancy complications. A future study evaluating work modification interventions with a large population of nurses whose work involves heavy physical demands may be warranted before recommending widespread change.

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Reliability and Validity of the Chinese Version of the Survey of Family Environment (SFE)

Junko Honda[1], Naohiro Hohashi[1]*, Sharron Kam Leung[2]

[1]Division of Family Health Care Nursing, Graduate School of Health Sciences, Kobe University, Kobe, Japan
[2]School of Nursing, Hong Kong Baptist Hospital, Kowloon, Hong Kong, China
Email: *naohiro@hohashi.org

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Abstract

This study, in which 519 child-rearing families in Hong Kong participated, examined the reliability and validity of Chinese-language version of the Survey of Family Environment (SFE-C). The SFE-C is a self-administered questionnaire containing 30 items that examines family functioning and family support needs. It is designed to yield an instrument satisfaction score (SS score: family functioning score). Internal consistency was estimated at 0.92 (Cronbach's alpha for SS scores). In a test-retest study of 33 families, the correlation coefficient for families' mean SS score over a two-week period was 0.93, indicating high test-retest reliability. Confirmatory and exploratory factor analysis using the Concentric Sphere Family Environment Theory indicated that the SFE-C's structure included seven factors, thereby supporting the SFE-C's construct validity. The SFE-C demonstrates good reliability and validity and may be used to evaluate Chinese families' functioning.

Keywords

Survey of Family Environment (SFE), Chinese, Instrument Development, Family Functioning, Concentric Sphere Family Environment Theory (CSFET)

1. Introduction

Increasing demand for family health care nursing has led nursing practitioners and researchers to focus on the family as a unit. Preparing undergraduate nurses to think in terms of the "family" crucially establishes family health care nursing as a core component of clinical practice [1]. In the past 20 years, researchers and practitioners have developed the family nursing theory/model and conducted family nursing research worldwide.

Several studies have examined family functioning in the Chinese population. The authors of the present research searched the PubMed database using variation of the terms "family functioning" and "Chinese" (searched on April 25, 2015). The search found that 86 papers were published between 1990 and 2014, of which over half were published after 2011, suggesting that academic interest in Chinese family functioning has increased over recent years. Some nursing research examined functioning in families that included patients with chronic conditions, such as diabetes or psychiatric illnesses. This research tended to address family functioning issues in terms of the whole family, rather than individual family members. Research that developed family functioning scales mainly took place in the 1970s and 1980s. Some family functioning scales were translated into Chinese, e.g., [2]-[6]. Although using the same scales between cultures offers certain advantages, e.g., it permits research to use standard methodology to examine universal constructs; transcultural literature has noted the limitations presented by imported scales. One major limitation is that some constructs tend to be culture-specific, e.g., *guanxi* (translated loosely as "connections" or "social relationships") and *renching* (literally: "relationship orientation") are important motivating forces in many East Asian cultures, but do not have a precise parallel in the West [7].

Existing family functioning scales are based on limited frameworks and may generate inconsistent evaluations of family functioning for different members of a single family [8]. The Survey of Family Environment (SFE), a newly developed family functioning scale [9], has resolved these issues and has become well established. This study therefore aimed to examine the reliability and validity of a Chinese version of the SFE.

2. Method

2.1. Measures

2.1.1. SFE

The SFE, based on the Family Environment Assessment Model (FEAM) and Hohashi's Concentric Sphere Family Environment Theory (CSFET) [10], examines families' functioning, *i.e.*, satisfaction score (SS), and needs for family support, *i.e.*, needs score (NS). The CSFET is a middle-range family nursing theory that holistically addresses the family's current environment and aims to improve family well-being. It was originally written in Japanese (SFE-J) and developed with Japanese families (n of families = 1990) [9]. The SFE-J has demonstrated good reliability and validity in research using paired partners in child-rearing families. Internal consistency was measured using Cronbach's alpha, the obtained values for which indicated high consistency (SS: 0.94, NS: 0.93). Temporal stability over a two-week interval was supported by high and significant intraclass correlation coefficients (SS: 0.92, NS: 0.90) (n of families = 1990) [9]. The SFE-J's total score was significantly correlated with scores on the Japanese version of the Feetham Family Functioning Survey (FFFS) [11], indicating acceptable concurrent validity ($r_s = -0.41$, $p < 0.0001$). Construct validity was supported by confirmatory factor analysis (CFA) that used a five-factor structure to examine the SFE-J's correlation with CSFET (GFI [goodness of fit index], AGFI [adjusted goodness of fit index], NFI [normed fit index], and RMR [root mean square residual] = 0.982, 0.989, 0.976, and

0.030, respectively). The SFE-J's family functioning scores showed no significant difference between paired partners [9].

The instructions were given to evaluate the satisfaction level for each item based not upon "perception by individual family members" but by "perception as a family unit," as shown in **Figure 1**, and is therefore able to evaluate family functioning without discrepancies between family members, including cases when responses are given by only a single family member [9].

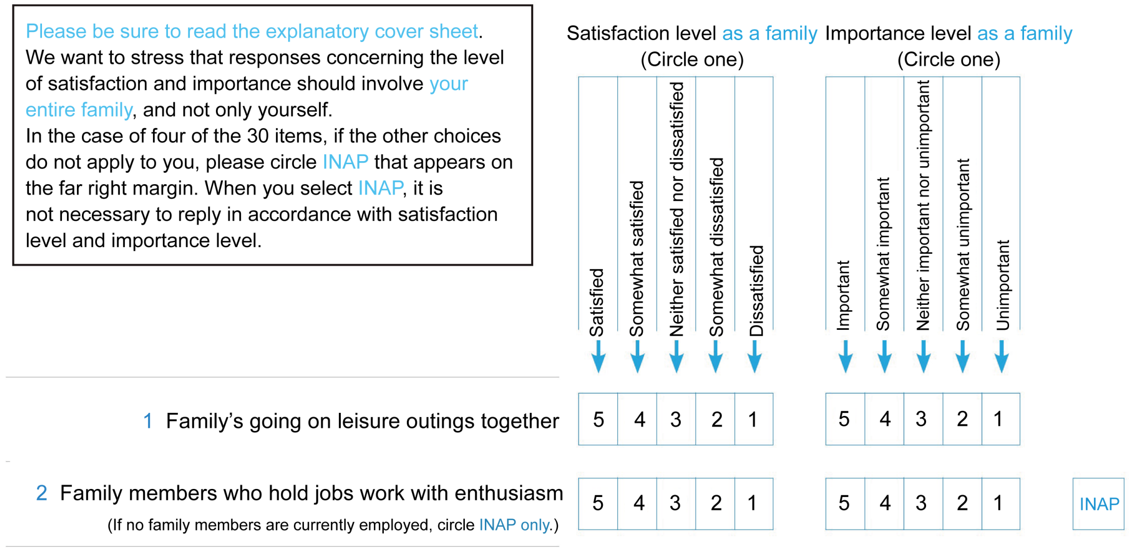
2.1.2. Scoring

The SFE is essentially a norm-referenced instrument [12] and a self-administered questionnaire consisting of 30 items structured into the following domains: suprasystem, macrosystem, microsystem, family internal environment system, and chronosystem (**Table 1**). Participants assign a satisfaction score (SS) and an importance score (IS) to each item using a 5-point Likert scale (1 = *dissatisfied/unimportant*, 5 = *satisfied/important*; see **Figure 1**). The needs score (NS) indicates the family's need for support. It is obtained for each item by cross calculating the IS against a 6 – SS (with scores ranging from 1 to 25 points). The average value of the response from the couple was treated as the family's score, and if a response could only be obtained from a single family member, then this response was treated as the family's score.

In the items related to work, children, and home care, boxes for checking inapplicable (INAP) were provided. When respondents checked INAP, those items were excluded from the scoring. As the number of items to which the respondents replied varied, the overall scores or scores broken down by domains were calculated using the item average [9].

2.2. The Chinese Translation Process

We obtained permission to develop a Chinese version of SFE from the SFE-J's develop-



Please be sure to read the explanatory cover sheet.
We want to stress that responses concerning the level of satisfaction and importance should involve your entire family, and not only yourself.
In the case of four of the 30 items, if the other choices do not apply to you, please circle INAP that appears on the far right margin. When you select INAP, it is not necessary to reply in accordance with satisfaction level and importance level.

	Satisfaction level as a family (Circle one)					Importance level as a family (Circle one)					
	Satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Dissatisfied	Important	Somewhat important	Neither important nor unimportant	Somewhat unimportant	Unimportant	
1 Family's going on leisure outings together	5	4	3	2	1	5	4	3	2	1	
2 Family members who hold jobs work with enthusiasm (If no family members are currently employed, circle INAP only.)	5	4	3	2	1	5	4	3	2	1	INAP

Figure 1. A sample of the questionnaire items.

Table 1. The Survey of Family Environment (SFE).

Item No.	Contents of Likert-type scale questions (domain name indicated in brackets)
1.	Family's going on leisure outings together [Mac]
2.	Family members who hold jobs work with enthusiasm [Mac]
3.	Children's being provided with appropriate education/child care [Mac]
4.	Family's being provided with adequate health, medical, and welfare services [Mac]
5.	Family observes societal rules [Mac]
6.	Family's using media (TV, newspapers, magazines, etc.) [Mac]
7.	Family members' involvement with religion(s) [Sup]
8.	Family's being friendly to the global environment [Sup]
9.	Family's appreciation of their country's culture [Sup]
10.	Family's interactions with non-cohabitating relatives [Mic]
11.	Family's receiving emotional support from non-cohabitating relatives [Mic]
12.	Family members' interactions with their friends [Mic]
13.	Family members' receiving emotional support from friends [Mic]
14.	Family's interactions with neighbors [Mic]
15.	Family's participating in community activities (block association, etc.) [Mic]
16.	Family's being comfortable living in the neighborhood [Mic]
17.	Bonds of affection between family members [Int]
18.	Family members' being comfortable at home [Int]
19.	Meeting with family members to discuss, and resolve, concerns and problems [Int]
20.	Managing the family budget [Int]
21.	Family's cherishing family time spent together at home [Int]
22.	Family members' observing family rules [Int]
23.	Family members' cooperation in child rearing [Int]
24.	Family members' cooperation in doing household chores [Int]
25.	Family members' cooperation in providing care during illness and convalescence [Int]
26.	Managing family members' diet [Int]
27.	Managing family members' physical and mental health [Int]
28.	Family's being able to adapt to future events [Chr]
29.	Family's being able to achieve family growth for the future [Chr]
30.	Family's being able to realize family's future hopes [Chr]

Note: Sup = suprasystem; Mac = macrosystem; Mic = microsystem; Int = family internal environment system; Chr = chronosystem. Items number 2, 3, 23, and 25 contain a box where INAP (Inapplicable) may be selected.

ers. The SFE-J was translated into Chinese by two expert translators. Then a Chinese expert translator and a Chinese researcher compiled a complete translation based on the former translation with attention to accuracy and conciseness. An expert Japanese translator who is familiar with the Chinese language then confirmed this translation's accuracy and a draft of the SFE-C was composed. A nursing researcher in Hong Kong, a Chinese graduate nursing student living in Japan, and two Japanese nursing researchers discussed this draft and revised its expressions to enable the widest possible applicability in countries and regions where Chinese is spoken.

2.3. Participants

Following the SFE-J, this study examined child-rearing families. A list of kindergartens in Hong Kong (available on the Education Bureau of Hong Kong SAR's website: http://www.chsc.hk/kindergarten/?lang=e) was used to select the examined settings. Six kindergartens in Hong Kong's three main districts (*i.e.*, Hong Kong Island, Kowloon, and the New Territories) agreed to distribute our questionnaires to parents; 1340 families received our questionnaires. According to Hatcher [13], when conducing factor analysis, the number of participants is recommended to be over five times the number of items. As the SFE-C consists of 30 items, over 150 participants were recruited.

2.4. Ethical Considerations

Ethical approval for this research was obtained from the institutional review board (IRB) of the researchers' university. Participants received an explanation of the research's purpose and that participation was voluntary; all participants were assured of confidentiality by a cover letter. Participants were advised that the questionnaire was anonymous and that although the numbering of questionnaires used by husbands and wives would enable identification of paired partners, this would not enable identification of individual participants. Completion and return of the questionnaire was considered to indicate informed consent.

2.5. Data Collection Procedures and Instruments

Our questionnaires included a family sociodemographic sheet [14], the SFE-C, and the Chinese version of the FFFS (FFFS-C) [15]. The FFFS is based on Roberts & Feetham's family ecological model (1982); it examines three areas of family functioning: "relationship between family and family members," "relationship between family and the subsystem," and "relationship between family and society." In this context, "subsystem" refers to the family's status as a component of society (*i.e.*, the macroscopic system [16]). The FFFS is a 25-item self-administered questionnaire; responses use a 7-point Likert scale. Item scores are summed; higher scores indicate less sufficient family functioning [3].

Similar to the SFE, the FFFS assesses the external and internal family environments. No other well-established and widely accepted instrument comparable to the SFE is available; the FFFS-C was therefore used to examine the SFE-C's convergent validity, *i.e.*, criterion-related validity. The FFFS-C's validity and reliability have been examined among child-rearing Japanese families [15]. Values of Cronbach's alpha for FFFS-C scores were 0.91 in an instrument development study, indicating high internal consistency. In a test-retest study examining 39 mothers, total scores' correlation coefficient over a two-week period was 0.82, indicating high test-retest reliability. CFA and exploratory factor analysis (EFA) indicated that the FFFS-C has a five-factor structure based on the family ecological model, thereby supporting its construct validity. The FFFS was used in the study that examined the SFE-J's convergent validity; the present study therefore also used the FFFS-C.

A self-administered questionnaire examining families' demographics was produced following earlier research [8]; this questionnaire examined family composition, household income, family members' age, employment status, and educational level, and whether individual family members had any disease or illness [14].

2.6. Operational Definitions of Basic Terms

"Family" was defined as unit or organization composed of individuals recognized as belonging to the family by other constituent member(s) of the family. Families were therefore composed of parents, spouses (including cohabitants and common-law and de facto marriage partners), children, and others, independent of cohabitation. "Children" referred to all family members aged less than 18 years. These terms are explained in the "Completion Instructions" included on the first page of the SFE-C. "Family functioning" referred to family's cognitive activities performed by a family and its abilities to act on the family environment through individual family members' role behavior. Family functioning was measured as the family unit's perceived satisfaction with the current state of family functioning as assessed by the individual family member.

2.7. Data Analysis

All statistical analysis used SPSS v. 21.0 and Amos v. 21.0 for Microsoft Windows (IBM Inc.). Values of $p < 0.05$ were considered statistically significant.

Reliability was estimated by measuring internal consistency using Cronbach's alpha and a test-retest procedure. Internal consistency was measured regarding the SFE-C's total score and each domain's score. The test-retest procedure involved administering the SFE-C to a single group twice over a two-week interval; this permitted estimation of score stability using inter-correlation confidence (ICC). The standard interpretation of effect size was used, *i.e.*, small = 0.10, medium = 0.30, large = 0.50 [17].

A Chinese nursing researcher, a Chinese graduate nursing student studying in Japan, and two Japanese nursing researchers examined content validity during the SFE-J's translation into Chinese. The SFE-C's convergent validity was estimated using score correlations with the FFFS-C.

CFA was used to estimate the SFE-C's construct validity by testing the SFE-J's factor structure's data fit. Data fit was measured using the chi-squared test, adjusted goodness of fit index (AGFI), comparative fit index (CFI), root mean square error of approximation (RMSEA), and Akaike's information criterion (AIC). A non-significant chi-square value, AGFI and CFI > 0.90, and RMSEA < 0.05 indicate good fit. Smaller AIC values indicate a better model. Additionally, regarding cultural considerations, EFA was performed to examine conceptual differences between the SFE-C and SFE-J.

3. Results

The researchers obtained 479 paired data sets (*n* of families = 479). The response rate in terms of number of families was 30.5% (479/1340). Among these, husbands' mean SS score was 3.89 (*SD* = 0.52) and wives' mean SS score was 3.85 (*SD* = 0.50). The Wilcoxon signed-rank test regarded each paired husband and wife's SS as a test pair. SS scores did not differ significantly within couples; couples' mean SS score was therefore used as a family functioning score in this study, in accordance with the SFE-J [9] [18].

3.1. Family Sociodemographics

Valid responses were obtained from 519 families (the response rate was 38.7% [519/1340]); Table 2 shows families' sociodemographic data. Among these families, 33 responded to the temporal stability assessment (33 husbands and 33 wives) and 155 responded to the convergent validity assessment (74 husbands and 81 wives).

3.2. Reliability

3.2.1. Internal Consistency

Table 3 shows values of Cronbach's alpha, which was used to estimate reliability via internal consistency; values were SS = 0.92, IS = 0.89, and NS = 0.89 for the overall

Table 2. Descriptive statistics for the sample of child-rearing families.

Sample variable	**Sample subcategory**	**Families ($n = 519$)**		**Husbands ($n = 484$)**		**Wives ($n = 514$)**	
		n	%	*n*	%	*n*	%
Family type	Nuclear family	414	87.2				
	Extended family	61	12.8				
Family member with disease/illness	Yes	55	11.6				
	No	420	88.4				
Highest educational level	High school or less			272	57.5	293	57.7
	Higher than vocational school			201	42.5	215	42.3
Employed	Yes			464	98.3	351	68.8
	No			8	1.7	159	31.2

Sample variable	**Families ($n = 519$)**		
	M	*SD*	Range
Family size	3.4	1.2	2 to 8
Number of children	1.3	0.8	1 to 3
Husband's age, in years	38.2	4.9	24 to 55
Wife's age, in years	35.1	4.6	22 to 55
Annual household income, in 1000 s of HK$[a]	415.0	373.4	0 to 5000

Note: Several cases were excluded from analysis due to incomplete data. a. US $1 = 7.8 HK$ (exchange rate at time of study).

Table 3. Cronbach's alpha of family's scores for the overall scale and each subscale.

Scale	Score	Cronbach's alpha
SS (Satisfaction Score)	Sup (3 items)	0.60 [0.77][a]
	Mac (6 items)	0.65
	Mic (7 items)	0.82
	Int (11 items)	0.83
	Chr (3 items)	0.87
	Overall (30 items)	0.92
IS (Importance Score)	Sup (3 items)	0.41 [0.72][a]
	Mac (6 items)	0.57
	Mic (7 items)	0.80
	Int (11 items)	0.81
	Chr (3 items)	0.84
	Overall (30 items)	0.89
NS (Needs Score)	Sup (3 items)	0.51 [0.69][a]
	Mac (6 items)	0.60
	Mic (7 items)	0.72
	Int (11 items)	0.80
	Chr (3 items)	0.86
	Overall (30 items)	0.89

Note: *n* of families = 519. Sup = suprasystem; Mac = macrosystem; Mic = microsystem; Int = family internal environment system; Chr = chronosystem. a. If item number 7 (the item related to religion[s] in the suprasystem) was deleted, Chronbach's alpha is indicated in brackets.

score and 0.41 - 0.87 in each subscale. Cronbach's alpha was low regarding suprasystem; however, omission of item 7 (which examined religion[s]) following previous research raised this subscale's Cronbach's alpha to >0.69.

3.2.2. Temporal Stability

Table 4 shows results from the two-week test-retest. ICC values between the first and second test were as follows: overall SS score = 0.93, overall IS score = 0.78, and overall NS score = 0.94.

3.3. Validity

3.3.1. Convergent Validity

The correlation coefficient between FFFS-C and SFE-C scores was −0.31.

3.3.2. Construct Validity

CFA was performed to examine the SFE-C's factor structure and to test if the SFE-C has five factors to accord with the CSFET' five systems (Table 1). The values of GFI, AGFI, NFI, and RMR were 0.87, 0.85, 0.82, and 0.03, respectively; these statistics indi-

Table 4. Test-retest correlation coefficients for family's scores over a two-week period.

Scale	Score	First compilation		Second compilation		ICC
		M	SD	M	SD	
SS (satisfaction score)	Sup (3 items)	3.56	0.49	3.70	0.55	0.79***
	Mac (6 items)	4.10	0.46	4.02	0.39	0.85***
	Mic (7 items)	3.61	0.75	3.75	0.64	0.93***
	Int (11 items)	4.05	0.55	4.05	0.57	0.88***
	Chr (3 items)	3.73	0.57	3.85	0.58	0.71***
	Overall (30 items)	3.89	0.38	3.91	0.37	0.93***
IS (importance score)	Sup (3 items)	3.62	0.54	3.72	0.52	0.62**
	Mac (6 items)	4.37	0.38	4.47	0.37	0.83***
	Mic (7 items)	3.97	0.64	4.03	0.54	0.83***
	Int (11 items)	4.64	0.34	4.61	0.33	0.67**
	Chr (3 items)	4.30	0.61	4.39	0.53	0.74***
	Overall (30 items)	4.25	0.36	4.31	0.33	0.78***
NS (needs score)	Sup (3 items)	8.95	1.80	8.84	1.93	0.85***
	Mac (6 items)	8.10	1.74	8.54	1.43	0.75***
	Mic (7 items)	8.94	2.79	8.77	2.36	0.95***
	Int (11 items)	8.79	2.55	8.82	2.56	0.90***
	Chr (3 items)	9.50	2.29	9.34	2.34	0.71**
	Overall (30 items)	8.75	1.87	8.78	1.73	0.94***

Note: Sup = suprasystem; Mac = macrosystem; Mic = microsystem; Int = family internal environment system; Chr = chronosystem; ICC = intraclass correlation coefficients. The interval between first compilation and second compilation is two weeks. $n = 33$, $^{**}p < 0.01$, $^{***}p < 0.001$.

cated that the data marginally fit the model. EFA subsequently indicated that the SFE-C has seven factors (Table 5). These were as follows: "family internal environment system", "microsystem", "macrosystem", "chronosystem", "suprasystem", "nursing care and household chores", and "management of daily living". Two items examining child-rearing and media did not belong to any factors.

4. Discussion

The present results indicate that the SFE-C, which is based on CSFET, is a valid and reliable means of measuring family functioning and needs in Chinese-speaking populations. Earlier research has developed family functioning scales; however, these do not adequately address the whole family [7]. Importantly, in the present research, the SFE-C obtained consistent scores between paired respondents, *i.e.*, husbands and wives, thereby indicating that the SFE-C is able to measure Chinese-speaking families' functioning and needs including in cases where only a single family member responds.

Table 5. Seven-factor solution of exploratory factor analysis with promax rotation.

Item No.	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7
19	0.885	0.040	0.050	−0.005	0.015	0.049	−0.168
22	0.613	0.070	−0.076	0.037	0.037	0.186	−0.028
17	0.600	−0.045	−0.070	−0.018	−0.121	−0.109	0.088
21	0.589	0.009	0.158	−0.001	0.082	−0.085	0.113
20	0.522	−0.032	0.097	0.242	−0.129	0.202	−0.132
18	0.358	−0.006	0.172	0.094	−0.210	−0.115	0.101
23	0.215	−0.117	0.032	−0.009	0.059	0.204	0.003
12	0.148	0.796	0.023	−0.001	−0.052	−0.128	−0.013
11	−0.037	0.771	0.043	−0.049	−0.057	−0.005	−0.028
13	−0.062	0.730	0.072	0.060	0.061	−0.076	−0.036
10	0.018	0.627	0.095	−0.125	−0.085	0.245	−0.058
14	−0.009	0.601	−0.079	0.033	0.096	−0.086	0.158
15	−0.155	0.554	−0.115	0.082	0.150	0.200	0.071
3	0.048	−0.003	0.588	−0.100	0.104	0.053	0.076
4	−0.076	0.075	0.547	0.038	−0.061	0.053	0.065
1	0.108	0.063	0.378	−0.004	−0.008	0.164	0.051
5	0.015	−0.129	0.334	−0.157	0.221	0.310	0.153
2	0.189	−0.014	0.328	0.147	0.175	−0.071	−0.161
16	−0.085	−0.008	0.316	0.229	−0.159	0.239	0.182
29	0.138	0.010	−0.083	0.784	0.103	−0.070	0.069
30	0.099	−0.023	0.049	0.778	0.152	−0.096	0.019
28	−0.061	0.008	0.002	0.582	−0.132	0.577	−0.073
9	0.011	0.034	0.011	0.033	0.796	0.042	−0.120
8	−0.235	0.024	0.050	0.137	0.769	0.096	0.037
7	0.085	0.092	0.175	−0.048	0.187	0.062	0.062
24	0.332	0.005	−0.177	−0.031	0.110	0.469	0.128
6	−0.125	0.014	0.171	−0.010	0.070	0.414	−0.119
25	0.297	0.048	−0.052	−0.119	0.054	0.359	0.133
26	0.030	0.038	0.149	0.015	−0.074	−0.037	0.773
27	0.405	−0.006	−0.061	0.118	0.003	−0.101	0.533

Note: n of families = 519, Extraction method: maximum likelihood, Rotation method: promax with Kaiser normalization. Factor 1 = family internal environment system; Factor 2 = microsystem; Factor 3 = macrosystem; Factor 4 = chronosystem; Factor 5 = suprasystem; Factor 6 = nursing care and household chores; Factor 7 = management of daily living. The items belonging to the respective factors are highlighted in blue.

4.1. The SFE-C's Reliability

The Cronbach's alpha values for SFE-C's overall scores were SS = 0.92, IS and NS = 0.89; these values indicate that the SFE-C is highly reliable. Nonetheless, regarding individual subsystems' results, values of Cronbach's alpha tended to be smaller in the suprasystem and macrosystem than in other systems. This trend was also observed during the SFE-J's development. Several individual items in each of these systems appeared to substantially contribute to these low Cronbach's alpha values. Adhering to the practice of the SFE-J's developers, excluding an item examining religion[s] in the suprasystem elevated this system's Cronbach's alpha value to >0.69. The SFE-J was developed in Japan, and its developers mentioned that the item examining religion tended to reduce the scale's internal consistency as religion, in general, does not play a dominant role in Japanese family life. Although religion in Hong Kong and Japan have different contexts in terms of its effect on family functioning, these differences may not be of major significance, as compared, for example to ethnic groups in Malaysia, where preceding research found that religion less strongly affects living satisfaction among ethnic Chinese (who might practice one or several religions, including Buddhism, Taoism and Christianity) as opposed to ethnic Malay people, who tend to be mostly Muslim [19]. The CSFET proposes that religion is important related to family function [8]; therefore, the item examining religion was retained in the SFE-C.

4.2. The SFE-C's Validity

We used CFA to test the hypothesis that the SFE-C would have the same factor structure as the CSFET. The results indicated marginal data fit. Construct validity was therefore supported using the CSFET; however, as the fit was marginal, we conducted EFA to further examine the SFE-C's factor structure. EFA indicated that the SFE-C incorporates seven factors, of which the first through fifth correspond to the CSFET's factor structure. We named the sixth factor "nursing care and household chores" and the seventh factor "management of daily living." These factors may have been excluded from the internal family environment in the present research because families in Hong Kong often entrust domestic tasks such as household chores and caring for family members to others, for example by engaging domestic helpers or by dining out [20]. An item examining child-rearing did not belong to any factor due to low factor load; however, as the highest factor load on this item came from "family internal environment system" and the second-highest came from "nursing care and household chores," this item was considered acceptable. Overall and among Chinese families, these results suggest that "nursing care and household chores", "management of daily living", and child-rearing are situated at the borderline between the internal and external family environment systems. The CSFET proposes that an interface exists between family systems and that each system interact with the others [10]. Considering the background of the families that participated in this study, the present EFA results may reflect interaction between families' internal environment and microsystems. This further suggests that the SFE's factor structure may be able to capture interaction between family systems when the SFE is used to examine families with different sociocultural backgrounds. Additionally, factor analysis may indicate the location of SFE items' examined parameters in target families' subsystems. That is, researchers may be able to determine items' relative functional and structural distance from family system units [10]. An item examining media (item No. 7), did not belong to any factor as its factor loading was less than 0.2. The reason for the low figure is not fully understood and further research will be needed.

The SFE-C's development makes possible transcultural study using the SFE-C and SFE-J in combination. The English version of the SFE is under development, and future research developing the SFE in other language versions is also planned.

5. Limitations

Although precautions were taken with the vocabulary of the SFE-C to enable usage throughout Chinese-speaking regions, the areas where Chinese is utilized are extensive, and because this study applies only to Hong Kong, the issue remains concerning the study's reliability and validity in all Chinese-speaking regions. Furthermore, this study applies to child-rearing families, and it is supposed that future investigation will be needed to ascertain as to whether it will also apply to other families, including families in which members have a particular illness.

6. Conclusion

This study supported the reliability and validity of the SFE-C as a measure of family functioning and needs in Chinese-speaking families.

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Declaration of Conflicting Interests

The authors declare that they have no competing interests.

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