



EDITORIAL

Evolving Methodologies and Technologies in Nursing Science

From the time of Florence Nightingale, the beginning of modern nursing, nurse scientists have been committed to helping patients improve their quality of life and health through positive interaction with the environment (Nightingale, 1992). Our vision of what nursing science seeks to accomplish (the promotion of health, management of disease, and assurance of a peaceful death) has been constant over time. However, the methodologies and technologies we have used as part of our science continue to evolve.

Florence Nightingale used observation and numbers to promote the health of the soldiers for whom she cared. As our science has expanded we have added additional methodologies and technologies. For example, we have come to understand the value of both qualitative and quantitative research, and we now embrace the value of a mixed-methods approach (National Institutes of Health, 2011). We no longer limit our science to paper-and-pencil tools but now use behavioral, physiologic, and psychologic measures. This is an exciting time for nursing science as nurse scientists incorporate an unprecedented number of new tools in their scientific repertoire.

Where once we strove to use clinical trials to find out whether a nursing intervention worked, we now are also conducting pragmatic trials. Pragmatic trials are designed to see if a treatment that might be effective in experimental conditions actually works in routine practice (MacPherson, 2004). Moreover, we now realize that there are times when it is more appropriate to conduct pragmatic trials than clinical trials as pragmatic trials can help with questions of generalizability (Patsopoulos, 2011).

Not surprisingly, given Nightingale's propensity for data, nurse scientists are not only embracing new methodologies but also new technologies such as big data (Brennan & Bakken, 2015). Big data enables us to do predictive analysis and to personalize health interventions by comparing outcomes over very large data sets. Big data also enables us to use information from a number of different data sources, such as electronic health records, sensors, and laboratory findings.

Big data techniques are necessary to fully utilize the power of large-volume data sources such as electronic health records. For example, big data techniques allow nurse scientists to identify trends over large numbers of patient encounters. Because of the volume of data

produced when studying molecules, big data also results from any of the "omic" technologies.

Nurses have embraced the "omics" and are actively engaged in assuring that the next generation of nurse scientists is adequately prepared to use these technologies (Conley et al., 2015). We are all familiar with genomics—the study of the function and expression of genes (Conley et al., 2013)—but exciting work is also occurring using metabolomics, microbiomics, and proteomics.

Measuring small molecules in samples (metabolites) can help us understand pathways underlying disease. Metabolomics helps nurse scientists identify biomarkers to indicate when a pathologic process is occurring (Li, Dunlop, Jones, & Corwin, 2016).

Examining the microorganisms that live in us and on our skin (microbiomics) can potentially help to predict health outcomes. Again, as is true with all of the "omics," precision health—identifying the intervention most likely to work for an individual—is enhanced if we understand the underlying make up of a person's microbiome. Our individual microbiomes, the 100 trillion cells that coexist with us, help us maintain our health and, as we are coming to understand, interact with our genome and environment to exacerbate disease (Dunlop et al., 2015). Similarly, the study of proteins, proteomics, is essential to increasing our understanding of a number of health states (Nilesh & Brassil, 2015).

This is indeed an exciting time for nurse scientists. New methodologies and technologies facilitate working in interdisciplinary teams to answer questions that were previously unsolvable. Here at JNS, we remain committed to providing you with the latest information about the technologies and methodologies that will shape our science for years to come.

Susan Gennaro
Editor

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CLINICAL SCHOLARSHIP

Effects of Multivitamin Supplements on Cognitive Function, Serum Homocysteine Level, and Depression of Korean Older Adults With Mild Cognitive Impairment in Care Facilities

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Abstract

Purpose: To examine effects of multivitamin supplements on cognitive function, serum homocysteine level, and depression of Korean older adults with mild cognitive impairment (MCI) in care facilities.

Design: A quasi-experimental pretest-posttest control group design was employed.

Methods: Forty-eight adults 65 years of age and older with MCI (experimental, $n = 24$; control, $n = 24$) who were living in care facilities in Gyeong-gi-do, Korea, were recruited. Multivitamin supplements as experimental treatment consisted of vitamin B6, B12, and folic acid. Multivitamin supplements were taken at a dosage of one pill every day for 12 weeks through the oral route. Measures were Mini Mental State Examination-Korean, serum homocysteine level, and Geriatric Depression Scale Short Form Korea Version. Collected data were analyzed using SPSS version 21.0 statistical software (SPSS Inc., Chicago, IL, USA).

Findings: There were significant effects of multivitamin supplements on cognitive function ($F = 3.624, p = .021$), serum homocysteine level ($F = 6.974, p = .001$), and depression ($F = 10.849, p = .001$).

Conclusions: Multivitamin supplements increased cognitive function, and decreased serum homocysteine level and depression of Korean older adults with MCI in care facilities.

Clinical Relevance: Multivitamin supplements can be utilized for improving cognitive ability and for decreasing depression of Korean older adults with MCI in care facilities.

Mild cognitive impairment (MCI) is the middle stage between normal status and the state of dementia and is becoming a crucial stage of early diagnosis and treatment for reducing the prevalence of dementia (Mitchell & Shiri-Feshki, 2009). About 5% to 10% of MCI patients progress to dementia. Because those with MCI are classified as belonging to the high dementia risk group, the early detection and treatment of MCI are also significant in preventing degenerative neurological damage (Mitchell & Shiri-Feshki, 2009). In particular, there is a higher prevalence of Alzheimer's disease among MCI patients (Jack et al., 2004). Progression to

dementia in MCI patients is preventable with treatment, but most cases progress to dementia without treatment (Gauthier et al., 2006). As such, accurate diagnosis and treatment at the right time are very important to prevent disease progression. MCI patients have a certain degree of discernment and learning abilities, and plasticity and preservation of the cerebrum are possible even in the elderly (Gauthier et al., 2006). As such, the interest in cognition-based intervention for cognitive function improvement before progression to dementia is increasing (Smith, Housen, Yaffe, Ruff, & Mahncke, 2009).

Background

Sociodemographic, physical and psychological, and social factors have been suggested as risk factors associated with decreased cognitive function in the elderly (Hwang & Kwon, 2009; Lee & Kahng, 2011; Trojano et al., 2003), and of these, malnutrition, including folic acid and vitamin B group (e.g., B6 and B12) deficiency, has been drawing attention. As such, the importance of appropriate nutrition management for elderly people came to the fore to improve their quality of life and health. Low income, aging, degenerative disease, medication intake, and inappropriate food intake were indicated as causing malnutrition in elderly people (Shahar, Shai, Vardi, & Fraser, 2003), which suggests that food and nutrition intake is closely related to the incidence of malnutrition in the elderly (Song, Chung, & Cho, 1995). The nutrition status of elderly who are staying in nursing homes was reported to be particularly poor compared to that of elderly staying in their respective homes (Kim, Ahn, & Song, 2000). This study investigated the nutrition status of elderly in aged care facilities and showed that the residents of such facilities could not even reach the required intake amount of most nutrients, which shows the significantly poor nutrient intake of the elderly (Kim et al., 2000). The poor intake of vitamin B and folic acid may cause hyperhomocysteinemia (Irizarry et al., 2005). Homocysteine is a by-product of protein from food during the process of catabolism. A previous study reported that genetic deficiency or the mutation of various enzymes produced during the metabolism of methionine, and the inactivation of coenzymes due to nutrition deficiency (vitamin B6, B12, or folic acid), increased the level of homocysteine in the blood (Frosst et al., 1995). Hyperhomocysteinemia has been reported in patients with Alzheimer's disease, one type of dementia, and vascular dementia (Smith et al., 1998). Homocysteine is a nonessential amino acid and has been reported as an independent risk factor for cerebral and neurological diseases, including psychological diseases and dementia, due to its stimulation of neurologic degeneration (Morris, 2003; Selhub, 2008). Many studies have been conducted on the etiology of dementia, but multiple factors rather than one definite cause are considered related to it. In particular, Alzheimer's disease, a type of dementia, and MCI, a dementia pre-stage, show higher levels of homocysteine with age (Obeid, Schorr, Eckert, & Herrmann, 2004).

Many overseas studies have investigated the correlation between a high homocysteine level and decreased cognitive function in the elderly (Garcia & Zanibbi, 2004; Nelson, Wengreen, Munger, & Corcoran, 2009; Stewart, Asonganyi, & Sherwood, 2008; Tucker, Qiao, Scott, Rosenberg, & Spiro, 2005) and reported that the

serum level and intake of B vitamins and folic acid that affect the serum level of homocysteine were associated with cognitive function (Kado et al., 2005; Koike et al., 2008; Stewart et al., 2008; Wang et al., 2001). Also, some intervention studies have reported that decreasing the homocysteine level from vitamin B supplement intake affected cognitive function (Balk et al., 2007; Dangour et al., 2010; Durga et al., 2007).

Studies on depression and homocysteine have reported that folic acid, vitamin B12, and homocysteine level were associated with depression, and that low folic acid and vitamin B12 levels and a high serum level of homocysteine were associated with depression (Sachdev et al., 2005). Other studies also have reported that the nutrition status of the elderly may cause depression (Iizaka, Tadaka, & Sanada, 2008). Depression in the elderly is complex and may occur due to various reasons and in various circumstances. Physiological changes with age, sleep cycle change, decreased neurotransmitter level, and change in the level of neuroendocrine substances may trigger depression. Stroke, physical disorders, vitamin B deficiency, loss of hearing ability, and pains have also been confirmed to be associated with depression (Somoliner et al., 2009). Depression may manifest as mild symptoms, such as a strong response to loss and temporary sadness. Minor and major depression has the same risk factors in the elderly, from severe psychotic depression to severe degeneration of pseudodementia (Kee & Kim, 2003). One of the neuropsychological symptoms that may manifest during the progression of MCI to dementia is depression (Somoliner et al., 2009). A study was conducted to compare the activities of daily living and cognitive functions depending on the depression symptoms in elderly utilizing welfare centers (Kim, Lee, Jeon, Chae, & Cho, 2008).

Gender (Anderson et al., 1992) and age (Brattstrom, Lindgren, Israelsson, Anderson, Hultberg, 1994) are two of the factors that affect the serum homocysteine level. Various lifestyle factors, including smoking, drinking alcohol, drinking coffee, and exercising, are also considered as influencing factors, apart from genetic factors and nutrition factors, including vitamin B6, B12, and folic acid deficiency (Nygard et al., 1995). Cognitive function was found to be improved using various cognitive-based intervention programs (e.g., imagery using video tapes, food list learning, image-name connection method, massed practice, paired-associate learning, relaxation technique, and reminiscence therapy) in studies of older adults or MCI patients (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007; Sok, 2015; Subramaniam & Woods, 2012; Webster & Gould, 2007; Zhou et al., 2012).

Taking vitamin supplements is known to be necessary for the elderly with degenerative cerebral diseases, but not many local studies have been conducted on vitamin

supplement intake. In particular, there has been no study on the effect of the use of vitamin supplements in Korean elderly staying in aged care facilities.

Purpose

The aim of this study was to examine the effects of the intake of multivitamin supplements containing vitamin B6, B12, and folic acid on cognitive function, serum homocysteine level, and depression of the elderly with MCI in aged care facilities.

Methods

Design

A quasi-experimental pretest-posttest control group design was employed.

Participants

The study sample included 48 elderly participants (experimental, $n = 24$; control, $n = 24$) in two care facilities in Korea. The study sites were long-term care facilities with professional nurses, and two facilities were very similar in environmental surroundings. Samples in study criteria were included with convenience sampling in this study. Participants in Facility A were assigned to the experimental group and those in Facility B to the control group. Participants were adults 65 years of age or older who agreed to take part in the study. They had MCI (score of 20–23 on the Mini Mental State Examination) and the capability to verbally mutually understand in Korean. All participants completed the study, and there was no retention.

Measures

The questionnaire was designed to measure general characteristics, cognitive function, and depression. Serum homocysteine level was examined through blood sampling. General characteristics consisted of gender, age, education, religion, spouse, economic status, current smoking, diabetes mellitus (DM), hypertension, and heart disease.

The Mini Mental State Examination-Korean (MMSE-K) for elderly people developed by Kwan and Park (1989) was used in this study to measure the degree of cognitive function of the female participants. It consists of a total of 12 questions. The possible score range was 0 to 30, and the higher the score, the higher the level of cognitive function. A score of 24 or over indicated normal cognitive function; 20 to 23 indicated MCI; and

19 or below indicated definite dementia. The reliability of the instrument in this study was Cronbach's $\alpha = 0.89$.

The Geriatric Depression Scale Short Form Korea Version (GDSSF-K) measured the level of depression. It consisted of 15 items with a "yes" or "no" response. Possible score range was 15 to 30, and the higher the score, the higher the level of depression. The reliability of this scale was Cronbach's $\alpha = 0.87$.

Serum homocysteine level was examined and analyzed by fluorescence polarization immunoassay analysis in a Korean medical institute. The normal range for a serum homocysteine level is $9.75 \pm 3.80 \mu\text{mol/L}$; $15 \mu\text{mol/L}$ or over indicates a higher risk for stroke or dementia.

Intervention

Multivitamin supplements as experimental treatment consisted of vitamin B6, B12, and folic acid. Study participants took multivitamin supplements 30 min after breakfast for 12 weeks. After no oral intake for 8 hr, a 5-mL blood sample was drawn from study participants. Blood sampling was done before the experiment and at week 12 in both groups.

Data Collection

The Institutional Review Board of a university in Seoul, Korea, approved this study. The period for data collection was February to September 2013. The researchers visited the care facilities for study permission, and explained the purpose of this study, participation details, and questionnaire to the prospective study participants. Information was provided about risk or discomforts (e.g., blood draws, a little pain) to participants. The questionnaire was completed by self-reporting, and researchers collected the completed questionnaire. Taking multivitamin supplements as an experimental intervention was applied to the experimental group by the researcher. Study variables were measured subsequently before the experiment and at week 12 in both groups. Participants were informed that their participation in the study was voluntary and they could withdraw at any time. Participants were also informed of the anonymity and confidentiality of the data. Written consent was provided. Each of the participants took approximately 20 to 25 min to finish the survey.

Data Analysis

SPSS PC+ version 21.0 statistical software (SPSS Inc., Chicago, IL, USA) was used for data analysis. General characteristics of participants and degrees of study variables were the descriptive statistics compiled. Group

Table 1. General Characteristics of the Study Participants ($N = 48$)

Characteristics		Experimental group ($n = 24$) n (%)	Control group ($n = 24$) n (%)	χ^2 /t Fisher's exact	p
Gender	Male	9 (37.50)	11 (45.83)	.343	.558
	Female	15 (62.50)	13 (54.17)		
Age, mean years (SD)		76.08 (5.15)	78.33 (4.98)	-1.539	.131
Education	Elementary school or below	11 (45.83)	12 (50.00)	.358	.999
	Middle or high school	12 (50.00)	11 (45.83)		
	College or above	1 (4.17)	1 (4.17)		
Religion	Christian	10 (41.67)	10 (41.67)	6.326	.099
	Buddhist	2 (8.33)	8 (33.33)		
	Catholic	7 (29.17)	2 (8.33)		
	None	5 (20.83)	4 (16.67)		
Spouse	Yes	0 (0.00)	3 (12.50)	1.482	.234
	No	24 (100.00)	21 (87.50)		
Economic status	High	4 (16.67)	5 (20.83)	1.482	.697
	Moderate	19 (79.16)	18 (75.00)		
	Low	1 (4.17)	1 (4.17)		
Current smoking	Yes	0 (0.00)	4 (16.67)	2.154	.109
	No	24 (100.00)	20 (83.33)		
Diabetes mellitus	Yes	15 (62.50)	14 (58.33)	.087	.768
	No	9 (37.50)	10 (41.67)		
Hypertension	Yes	13 (54.17)	14 (58.33)	2.154	.845
	No	11 (45.83)	10 (41.67)		
Heart disease	Yes	4 (16.67)	3 (12.50)	.374	.999
	No	20 (83.33)	21 (87.50)		

Note. χ^2 test: gender, diabetes mellitus, hypertension. Two-group t test: age. Fisher's exact test: education, religion, spouse, economic status, current smoking, heart disease.

differences at baseline were analyzed using two-group t test, chi-square test of association, or Fisher's exact test. The effects of multivitamin supplement intake were analyzed by repeated-measures analysis of variance. A p -value of less than .05 was considered statistically significant.

Results

General characteristics of the study participants are presented in **Tables 1** and **2**. Women (experimental group, 62.50%; control group, 54.17%) were the primary gender. Mean age in the experimental group was 76.08 years; mean age in the control group was 78.33 years. For academic background, 45.83% of the experimental group completed elementary school or below, as did 50.00% of the control group. The distribution of religion showed that Christian comprised the largest proportion, 41.67% in both groups. Most of the participants had no spouse (experimental group, 100.00%; control group, 87.50%), had moderate economic status (experimental group, 79.16%; control group, 75.00%), and did not smoke (experimental group, 100.00%; control, 83.33%). For the health state, participants had DM

(experimental group, 62.50%; control group, 58.33%) and hypertension (experimental group, 54.17%; control, 58.33%). However, most of participants had no heart disease (experimental group, 83.33%; control, 87.50%). As for the general characteristics of the experimental and control groups, as well as the study variables before the experiment, there were no group differences at baseline at a statistical significance level of $p < .05$.

Effects of multivitamin supplements are shown in **Table 2**. It was confirmed that the multivitamin supplements had statistically significant positive effects on cognitive function ($F = 3.624$, $p = .021$), serum homocysteine level ($F = 6.974$, $p = .001$), and depression ($F = 10.849$, $p = .001$) for elderly staying in care facilities.

Discussion

The result of this study conducted on elderly people with MCI in aged care facilities showed that the experimental group, to whom vitamin supplements were administered, had significantly increased cognitive function compared to the control group. The study conducted by Lee, Chun, and Kim (2000) also showed improved

Table 2. Effects of Multivitamin Supplements ($N = 48$)

Study variables	Group	<i>n</i>	Pre <i>M</i> (SD)	<i>t</i>	<i>p</i>	Post <i>M</i> (SD)	Source	<i>F</i>	<i>p</i>
Cognitive function	Exp	24	21.04 (0.98)	1.120	.268	21.79 (1.14)	Group	.384	.539
	Con	24	20.76 (0.78)				Week	2.604	.065
							G*W	3.624	.021*
Serum homocysteine level	Exp	24	19.29 (7.09)	.967	.338	10.92 (1.67)	Group	2.242	.142
	Con	24	17.57 (5.40)				Week	1.620	.200
							G*W	6.974	.001*
Depression	Exp	24	22.88 (2.46)	-.575	.568	22.17 (2.68)	Group	13.916	.284
	Con	24	23.24 (1.94)				Week	2.668	.059
							G*W	10.849	.001*

Note. Exp = experimental group; Con = control group. * $p < .05$.

cognitive function in the elderly after oral vitamin intake, consistent with the outcome of this study. In studies on elderly people with MCI, the groups with a low serum vitamin B level had decreased cognitive function and increased serum homocysteine levels (Kado et al., 2005; Koike et al., 2008; Stewart et al., 2008). The results of this study are also consistent with those of previous studies, showing a correlation between vitamin intake and cognitive function. This study also suggests that the intake of vitamin B6, B12, and folic acid alleviates cognitive function impairment (Salerno-Kennedy & Cashman, 2005) and supports the results of previous studies by showing the effect of the serum vitamin level on cognitive function (Kado et al., 2005; Kim et al., 2011; Koike et al., 2008; Stewart et al., 2008). A study on elderly Japanese people showed that the serum folic acid level was positively correlated to the MMSE score (Stewart et al., 2008). A population-based longitudinal study conducted in Sweden reported a correlation between the serum folic acid level and the MMSE score (Wang et al., 2001). A previous study also found that the intake of folic acid supplements improved cognitive function (Durga et al., 2007), and other studies (Garcia & Zanibbi, 2004; Ravaglia et al., 2003; Tucker et al., 2005) found that folic acid intake, apart from the intake of B vitamins, independently improved cognitive function, consistent with this study's results.

The result of this study that increased serum homocysteine level is related to decreased cognitive function was also consistent with the results of previous studies (Ravaglia et al., 2003). A population-based study on elderly Italians reported that the subjects with MMSE for dementia screening (MMSE-DS) scores of 24 to 25 and 26 to 28 had a higher risk for hyperhomocysteinemia of 15 $\mu\text{mol/L}$ or more (odds ratio 3.81, 95% confidence interval [CI] 1.9, 7.5; odds ratio 1.96, 95% CI 1.3, 3.0) than did those with a score of 28 or higher (Ravaglia et al., 2003). A prospective cohort study on people 65 years of

age or older reported that the serum homocysteine level was negatively correlated with the MMSE-DS score at 5 years (McCaddon et al., 2001). A Dutch study investigated the correlation of the MMSE-DS score representing impaired cognitive function at 2.7 years and the serum homocysteine level after age, sex, and education level adjustment and found that there was no correlation between them (Kalmijin et al., 1999), which contradicts the result of this study. The correlation between the serum homocysteine level and impaired cognitive function is still controversial, according to various studies (Kalmijin et al., 1999; Ravaglia et al., 2003). Some studies claimed that the influence of the serum homocysteine level on impaired cognitive function decreased after age adjustment, presenting impaired cognitive function as just one of the symptoms of aging (Ravaglia et al., 2003). The result of this study confirmed, however, that vitamin supplement intake was an effective intervention for cognitive function improvement in elderly people with MCI in aged care facilities.

This study showed a significant decrease in the serum homocysteine level in the experimental group, to whom vitamin supplements were administered, compared with the control group. A randomized clinical study (The Hope Outcome Prevention Evaluation, 2006) showed that the experimental group to whom vitamins B6 and B12 and folic acid had been administered had a significantly lower serum homocysteine level compared with the control group, presenting the excellent effect of the vitamin B group in lowering the serum homocysteine level. The serum homocysteine level had a strong negative correlation with the level of folic acid, and a higher folic acid level was associated with a lower homocysteine level. The serum vitamin B12 level also had a strong negative correlation with the serum homocysteine level. The subjects with Alzheimer's disease were reported to have lower folic acid and vitamin B12 levels as well as higher serum homocysteine levels (Clarke et al., 1998), which

confirmed the results of a previous study showing that a low serum vitamin level is associated with an elevated serum homocysteine level (Kim et al., 2011). Moreover, previous studies on subjects with MCI and Alzheimer's disease showed that lower folic acid and vitamin B12 levels with an elevated homocysteine level were observed in subjects with Alzheimer's disease and MCI, and that the subjects with MCI had significantly elevated serum homocysteine levels compared with the healthy control group (Gallucci, Zanardo, De Valentin, & Vianello, 2004; Lee, Lee, & Kim, 2010). Cho et al. (2006) reported that folic acid and vitamin B12 intake lowered the serum homocysteine level in their subjects, and Lautenschlager, Flicker, Vasikaran, Leedman, and Almeida (2005) also reported that patients with MCI had significantly higher serum homocysteine levels.

Quadri et al. (2004) divided their study subjects with MCI into three groups based on their serum homocysteine levels and found that the group with higher levels showed a 2.6-fold prevalence of MCI compared to the group with lower levels. Folic acid and the vitamin B group, which are involved in one-carbon metabolism, act as coenzymes in the metabolism of homocysteine in different biochemical stages, and affect the serum homocysteine level. The levels of these vitamins in the body are closely associated with the serum homocysteine level based on various previous studies (Danggour et al., 2010; Kim et al., 2011). Kim et al. (2011) reported the negative correlation between the serum homocysteine level and the levels of folic acid and vitamin B12 in the body, which is consistent with the results of local studies, including a cohort study in Ansan, South Korea (Kim et al., 2007) and a study in elderly people in the Caribbean (Stewart et al., 2008). A cohort study on aging in the Ansan area (Kim et al., 2007) reported a strong correlation between homocysteine and folic acid levels in elderly subjects with MCI, as opposed to healthy elderly subjects. A study that reported a significant correlation between the serum homocysteine level and the level of vitamins in the body also showed that vitamins B6 and B12 and folic acid are related to metabolism, which lowers the homocysteine level (Kim et al., 2011). Vitamin B6 deficiency may cause homocysteine to accumulate in the brain, which has been proven by many epidemiologic studies and by various studies on the vitamin B group (Balk et al., 2007; Danggour et al., 2010; Nelson et al., 2009). As such, vitamin supplement intake was confirmed to lower the serum homocysteine level in elderly subjects with MCI in aged care facilities. Most of the previous studies investigated the correlation between the serum homocysteine level and MCI rather than the change in the serum homocysteine level after vitamin supplement intake, as was done in this study. As such, this study is considered

meaningful in terms of obtaining objective information through experimental intervention.

In this study, the experimental group, to whom vitamin supplements were administered, showed significantly alleviated depression compared with the control group. Previous studies have reported that cognitive function is correlated with depression even if there has been no study that showed alleviated depression after vitamin supplement intake in elderly people with MCI in aged care facilities (Roberts, Shema, Kaplan, & Strawbridge, 2000; Won & Kim, 2008). Melvin and Werbach (1991) reported that deficiency in even a single nutrient could affect psychological function and could cause disorders, including anxiety and depression, and that the intake of folic acid and vitamin B12 and B6 supplements significantly alleviated depression. Studies on the correlation between depression and nutrition reported that severe depression is associated with poor nutrition intake (An, 1989). Antioxidant-rich vitamins or foods containing these vitamins are known to alleviate the severity of depression (Finley & Penland, 1998). Minerals and vitamins have been reported to alleviate depression in subjects with depressive symptoms (Carroll, Ring, Suter, & Willemsen, 2000). Epidemiological and clinical studies reported that the serum homocysteine level is a risk factor for neurologic diseases such as impaired cognitive abilities, dementia, Alzheimer's disease, and depression (Guo et al., 2000; Seshadri, Drachman, & Lippa, 1995). In such studies, folic acid and vitamin B12 deficiency lowered the serum homocysteine level and caused depression due to the interrupted monoamine formation (Faba et al., 1997). As such, this study showed that vitamin supplement intake decreased depression in elderly people in aged care facilities.

In the end, this study confirmed that the effects of the use of vitamin supplements for Korean elderly staying in aged care facilities would hold true. It seems that the clinical significance as well as the statistical significance of the findings of this study exist in nursing practice. The effects of these changes will be meaningful in the lives of elderly with cognitive impairment. Additionally, standards of practice related to the use of multivitamin supplements in this population are needed. In this study, multivitamin supplements routinely were given in practice. However, enough scientific evidence to recommend this as a best practice should be sought in a future study.

Limitations

The limitation of this study was the generalizability of results. The participants were recruited from only two care facilities in South Korea by convenience sampling, which limited the characteristics of the resulting data.

However, the main aim of this study was to provide information on which to build future investigations. In addition, the power of the repeated measure model was not assessed prior to data collection. These preliminary findings will be strengthened by replicating this study with a larger sample.

Implications for Nursing Practice and Future Research

Vitamin supplement intake as a nursing intervention can be applied to improve cognitive function, decrease serum homocysteine levels, and alleviate depression in elderly people in aged care facilities. Furthermore, the results of this study could be utilized to decrease the incidence of cognitive disorders or depression in elderly people in aged care facilities, and could help them better adapt to such facilities and have a better quality of life through vitamin supplement intake.

In future studies, to confirm the effects more objectively in elderly people with MCI in aged care facilities, the long-term intake of vitamin supplements and the repetitive evaluation of improvement at various time points should also be conducted as a nursing interventional study.

Conclusions

The experimental group in this study, to whom vitamin supplements were administered, showed improved cognitive function, lowered serum homocysteine levels, and alleviated depression compared with the control group. As such, the effects of vitamin supplement intake in improving cognitive function and preventing dementia were confirmed.

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Clinical Resources

- Korean Association of Geriatric Hospitals: <http://www.kagh.co.kr>
- Korea Nursing Home Association: <http://www.knursinghome.or.kr>

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CLINICAL SCHOLARSHIP

Girlhood Betrayals of Women Childhood Trauma Survivors in Treatment for Addiction

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Key words

Adverse childhood event, attachment, betrayal, child abuse, substance abuse

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Abstract

Purpose: This research explored the understanding of trauma from the perspective of women who had experienced abuse and neglect in childhood. The goal was to better conceptualize potential avenues or interventions for prevention and treatment.

Design: Qualitative description of the accounts of eight women who were childhood trauma survivors and in treatment for addiction. Open-ended interviews focused on key events or experiences during childhood and adolescence and the use of drugs and alcohol.

Findings: Four levels of betrayal fit the accounts the participants gave as the dominant theme in their narratives. “Primary betrayal” referred to the direct victimization by a perpetrator; “secondary betrayal” referred to the complicity, denial, or indifference of another adult to the child’s victimization; “tertiary betrayal” referred to failures of responsible individuals in community settings to protect the child; and “quaternary betrayal” represented self-betrayals. Substance misuse was an adolescent self-betrayal that provided initial solace yet ultimately threatened the integrity of the girls. We found an almost complete lack of support in family and community settings for the participants.

Conclusions: These findings on betrayal inform health care for trauma survivors and can be a framework for preventing violence against children.

Clinical Relevance: Interventions for child and adolescent trauma survivors are critical to prevent the life-long health sequelae of childhood trauma. Pivotal times to engage these survivors include periods when they may be accessed in school and healthcare settings.

The World Health Organization (WHO, 2006) prioritizes the importance of child maltreatment, sets the objective of implementing prevention programs in all countries, and identifies nurses as significant players in these efforts. This and other reports point out that child abuse generally is perpetrated by family or close others, making intervention a challenge. The landmark Adverse Childhood Experiences (ACE) study by the Centers for Disease Control and Prevention (CDC, 2014) examined a mainstream, insured adult U.S. population, and demonstrated that over 60% had experienced childhood trauma, with 16% reporting complex trauma (multiple

types of abuse, severe abuse, or abuse over a long period). Even higher rates of physical and emotional child abuse were found in a recent study of a more diverse U.S. sample (Cronholm et al., 2015). Childhood trauma is associated in a dose-related manner to lifelong physical and mental health problems (CDC, 2014). Because child abuse constitutes preventable violence and because of its enduring impact on health, it is important that nurses around the world understand childhood trauma. Further, nurses working in the field of child and adolescent health have the additional opportunity of contributing to the prevention and treatment of childhood trauma.

The purpose of this research was to explore trauma survivors' perspectives on what had happened to them. The experiences expressed by participants of this study could be framed within a larger ecological framework for violence prevention. The Social-Ecological (SE) Model, initially developed by Bronfenbrenner (1979), has been used as a public health lens for examining the risk and protective factors for violence such as child abuse and neglect (CDC, 2011). The individual level includes the child's gender, age, and personality factors; the relationship level involves close family, friends, and peers; the community level encompasses schools, neighborhoods, and healthcare providers; and the societal level involves public policy, behavioral norms, and socio-economic factors. The goal of the current study was to gain an understanding of what occurred at pivotal times during the childhood and adolescence of female survivors of child abuse. The researchers had extensive experience providing primary and mental health care to homeless and drug-addicted women, and had observed the common threads of childhood traumas, addiction, and mental health problems among these women. This research focused on key experiences during childhood and adolescence, relationships with family members, the role of drugs or alcohol, and moments when the participants (as girls) might have responded to help.

Methods

Qualitative description (QD; Sandelowski, 2000, 2010) guided this study; in QD, there is less interpretation or theory development than in other qualitative methodologies (Sandelowski, 2010). Following the qualitative description, we moved to a deeper interpretive level regarding the major theme of betrayal and studied this in more detail from a narrative perspective through thematic analysis (Riessman, 2008). It was assumed that the narratives were infused with the informant's own understandings of what happened to them; it was also assumed that our perspectives affected our interpretations of the women's narratives. From an analytic perspective, we went into the study only understanding that childhood trauma was related to mental distress and substance abuse, but with no other preconceived notions. The nature of betrayal in the lives of the women was a serendipitous discovery during the analysis. Salient themes discovered in the earliest interviews sensitized us to the theme of betrayal, but we remained open to other concepts as well. We worked together to discern meanings and connections when analyzing the data to maintain integrity and neutrality regarding the data. Strategies in QD include coding data from the interviews

reflectively, identifying similar patterns through a process of expanding and collapsing concepts, identifying those concepts that hold most true for the data, and comparing findings to existing knowledge (Miles & Huberman, 1994).

Recruitment and Informed Consent Procedure

The study was approved by a university institutional review board in a large metropolitan city in the south-eastern United States. A purposive sample of participants was identified based on the report of childhood trauma during a primary care visit at a clinic at their drug treatment center. Clinic staff provided clinic visitors with a flyer describing the study, and for interested women, arrangements for the interview were made by return phone call. Participant questions about the study were answered, and written informed consent was obtained prior to the interviews. Inclusion criteria for the study were a history of childhood trauma and current drug or alcohol treatment. Exclusion criteria were acute distress, intoxication, and inability to understand or speak English. All participants were provided with clinic information where free mental health care by psychiatric advanced practice nurses was available if desired.

Data Collection

Single face-to-face, semistructured interviews focusing on events of childhood and adolescence were conducted with a sample of eight women. Interviews were conducted between 2009 and 2012 in private space at the drug treatment center, each lasting approximately 1 hr. Participants were compensated for travel and inconvenience with a \$20 gift card. The atmosphere of the interview was private and respectful to increase the participants' sense of safety. Demographic and health information was obtained at the start of the interview. The interview guide focused on memories of childhood and adolescence, experiences of adversity, and the initiation of substance use. Examples of interview questions were "Can you tell me what things were like for you when you were growing up?" and "What was your experience at school?" Inquiry about abuse was limited to the relationship to the perpetrator and the nature and the length of abuse, so as to avoid triggering negative emotion. General opening questions usually led to the participants recounting relevant incidents, and the interviewer (first author) used open-ended prompts such as "what happened next?" to enhance the breadth and depth of the data. The interviews were audio recorded, transcribed professionally, proofed, and then coded and managed using the N-Vivo software program (QSR International, Burlington, MA, USA).

Data Analysis

Qualitative description using thematic analysis was accomplished through the weaving together of sequences of events into wholes to understand and convey the significance of these events in contexts attributed by the participants as they recalled them from an adult perspective. The assumption is that the truth is embedded in the subjective understanding of the interviewee. In the data analysis, which occurred over 2 years, similar content in the transcripts was grouped together in a dynamic, ongoing effort, with these elements repeatedly expanded and collapsed to derive the most meaningful interpretations of the data. Rigor of interpretation was strengthened by groupings of concepts by the analysts first independently, then together, followed by discussions of the concepts and their linkages, review of field notes, rereadings of the interviews, recontextualizing quotations, and multiple reviews of the data. When no new themes emerged after the eighth interview, the interviews were concluded.

Framework for the Levels of Betrayal

The initial traumas of the girls (now women) were perpetrated at home or in a caregiver’s home, but the impact of the abuse rippled out to interactions with other family members, and into the school and community settings. The overarching experience of betrayal seemed to be the most significant commonality among the women’s stories. Because of a complex array of betrayals, it made sense to organize them into a conceptual framework that would capture these different levels. Initially sequential and subsequently simultaneous, the girls experienced primary, secondary, tertiary, and quaternary levels of betrayal. We defined primary betrayal as the direct abuse or neglect by an older perpetrator, usually by a provider of care; secondary betrayal was the connivance or willful indifference of an adult in the face of abuse, usually by the mother or relatives; tertiary betrayal occurred outside the family circle, mainly in school, but also in health care, legal, and social service situations. The final or quaternary betrayal for all of these women was the betrayal of self, including their own ambivalence regarding their abuse as children and engagement in self-harming behaviors as adolescents.

Sample

The description of participants may be found in **Table 1**. Among substances abused, the women reported alcohol and cocaine most frequently, but other drugs included methamphetamine, marijuana, PCP, opiates,

Table 1. Demographic Findings for the Eight Participants

Age (years)	Range	26–46
	Mean	37
Race or ethnicity	Caucasian	3
	African-American	4
	Caucasian-Native American	1
Educational level	8 th or 9 th grade	5
	GED	1
	Some college	2
Type of trauma	Physical	4
	Sexual	8
	Emotional	8
Age of earliest abuse (years)	3	1
	4–5	4
	6–8	3
Have children		8
Have spouse or partner		3

heroin, and barbiturates. Five of the participants had chronic health conditions, including lupus, asthma, rheumatoid arthritis, and hypertension. Mental health diagnoses reported by the women included depression, bipolar disorder, attention deficit disorder, and schizophrenia. All but two were taking psychiatric medication such as trazadone, Seroquel, or Risperdal.

Findings

Although many themes were evident in the narratives of the women, the core element was their experience of betrayal. The women identified environments, events, and social settings of betrayal and remembered feeling betrayed even as children; other betrayals were recognized retrospectively from the vantage point of maturity. Some of these women never had the nurturing and secure attachment they needed as children, and they voiced ongoing bewilderment regarding their abuse and longing for parental love, security, boundaries, self-esteem, and mental well-being.

Primary Betrayal

The traumas the women experienced during their girlhoods were physical, sexual, and emotional in nature; all of the perpetrators were family or close others. Most of the women endured multiple forms of abuse, and for several women more than one perpetrator was involved. Perpetrators were of both genders; they were parents, relatives, and people close to the family. Contact sexual abuse by uncles and stepfathers was the most common type of abuse and involved molestation and rape. Abuse generally occurred over years, with an average duration of about 6 years, starting as early as age 3 and lasting as late as age 16.

Physical abuse was meted out by mothers or close relatives. Two of the women endured harsh beatings, mainly from their mothers, such as being placed in scalding water, punched in the head, or hit with hard objects, sticks, or shoes, “anything she [mother] could find to get her hand on.” Neglect, another form of primary betrayal, was associated with the mothers’ drug use, narcissism, or inability to deal with their own adversities: “My mother never knew where I was . . . she didn’t know I was getting beat up” [by a boyfriend at age 13]. For lack of her mother’s attention, this girl sought love from “somebody that meant me harm” and her self-esteem was so low, she believed she deserved the beatings. Although some of the girls’ mothers were absent from their children’s lives due to addiction or their own traumatic lives, other mothers could not connect with their daughters due to dissociation or other mental illness: “My mother was in one world and we was in another. It was like we was there but we wasn’t there.” This lack of attachment to a primary caregiver undermines a child’s development of a sense of self and connection to others, both of which are critical to social functioning. It also elucidates the trans-generational nature of abuse and mental health problems.

Ordinary childhoods, even playing like other children, were not a feature of the girls’ lives. One was told monthly to call someone new “father,” noting that her mother “. . . put men before she did me.” In some cases, the girls were not allowed to leave their apartments, in order to keep the abuse secret. Some girls parented their siblings: one, by age 7, was engaged in housework, cooking, and tending to children rather than age-appropriate play or out-of-school activities. Extreme lack of nurturance and affection was evidenced by direct rejection from some of the mothers, including some girls being forced from their homes in early adolescence, generally because the child was seen as competition for the attention of a mother’s boyfriend. In other cases (as young as age 13), some of the girls chose to run away from home to escape chaos and abuse. Invariably, they escaped to other abusive environments.

Emotional abuse was a substrate in the lives of all eight participants. This type of abuse involved invalidation and demeaning statements from parents and relatives. Feelings of worthlessness were echoed by all of the participants: “I wasn’t no good, I didn’t have no sense, I would never amount to nothing.” One participant was told something was wrong with her and she would be put up for adoption: “I’ve spent most of my life feeling dirty . . . I know I am a good person, but it’s like in my heart, I have a hard time liking who I am.” Two participants were repeatedly called “black sheep.” This indicates a scapegoating of the girls by families and a betrayal of

them as “true kin.” The women recalled feeling anger and confusion as children, but all remained in their situations of continuing trauma.

Secondary Betrayal

Secondary betrayals occurred when a family member was told of the primary abuse and failed to act, or was complicit with the abuse. When the girls disclosed their abuse and asked for help, their immediate caregivers responded to disclosures inadequately and inappropriately, often with rage (towards the child), punishment, denial, or passive acceptance. Paradoxically, some of the girls were accused of “betraying” the perpetrator or the family itself when they disclosed the abuse. Four types of experiences of caregiver response to the disclosure of abuse were found in the secondary level of betrayal: not being believed, being punished for disclosure, being denied help, and being treated like an object. We found that primary betrayers (direct abusers) and secondary betrayers (those who failed to protect the child) sometimes moved between these positions. Despite some sympathetic ancillary figures such as grandparents or adult friends and relatives, the girls perceived that they were unable to turn to adults for help, because of futility or fears of not being believed.

Not being believed. When one of the girls disclosed to her grandmother that her uncle “was touching me in places I don’t want him to touch,” she was told to go away and not to lie; she took this to mean that the abuse was acceptable. “So after that . . . I felt like it was okay” and she continued to “suck it up and deal with it because in about two minutes it would be over.” Another girl who was sexually abused by two males in the household was not believed for some years until her mother finally witnessed coitus. The boyfriend was only temporarily “kicked out” of the household, which demonstrated to the child her lesser value. Another mother refused to speak with her daughter upon learning of the child’s molestation by a neighbor boy some years before. Some of the participants speculated that their female caregivers had been abused and betrayed themselves as children. If disclosure of abuse evoked thoughts that the caregivers themselves were blocking, this might partially explain their adamant denials and failures to protect the girls.

Being punished for disclosure. Punishment for disclosure took form in physical beatings, rejection, or exclusion. An aunt whose husband was molesting one of the girls responded to her niece’s disclosure by beating her with a hairbrush. For another girl, the

secondary betrayal of not being believed was compounded by exclusion and isolation by other female family members. She was emotionally banished, recognizing, even in childhood, the hypocrisy of her female relatives who had claimed they would protect her: “They contradicted themselves because they’d say, ‘if something ever happens, you let me know,’ and then I let you know and it’s like a big brushoff.” This “contradiction” was the closest that any of the women came to a clear identification of betrayal felt as a child, although as adults, they clearly felt they had been betrayed. One of the girls went outside the family seeking help for her sexual abuse, including rape, by a stepfather which occurred during 4 years of her childhood. The act of seeking external help resulted in the girl being forced out of the house by her mother, and her exile lasted 4 years.

Being denied help. Participants repeatedly mentioned the futility of disclosure to unresponsive caregivers. One said “nothing was done” when she was raped on two occasions in early adolescence. This lack of response conveyed the acceptability of violence and sexual aggression. In another case, disclosure of molestation by an uncle was “shoved under the carpet.” When one girl disclosed abuse to teachers, her grandmother told the girl she should have kept her “mouth shut—it was a hush-hush thing” and halted her therapy after a single visit due to the “shame.” This girl was the only one who ever received counseling. All the participants experienced chronic stress and depression, and typical of the participants, one woman recalled being “distant, isolated, a very sad child, a very angry child.” Retrospectively, they wished they had received psychological support.

Being treated as an object. Abuse meant that the child served as an object for someone else’s purpose or pleasure, and the girls felt this as invalidation and humiliation. After a harsh beating, one bruised girl was put on show to relatives by her mother to demonstrate her father’s brutality, although the mother more often beat the girl herself. “I can remember feeling so bad It was almost like I was nonexistent. I was just this object. I wasn’t a child, I was just an object.” Instead of attending to her daughter, who had injuries on her legs, arms, and face from being hit with a belt, the mother focused on her own need for validation from her mother-in-law. Another girl’s father was highly abusive, emotionally, physically, and sexually, and she bitterly recounted that outside the home, he maintained a charade of being the perfect father, showing off his children with seeming pride and even demonstrating affection in public settings.

Tertiary Betrayal: School, Healthcare, Law Enforcement, and Social Services

School performance ranged widely among the participants. A few excelled academically while others had learning problems and were placed in special education or behavior disorders classrooms. The girls’ school experiences ranged from a source of comfort (understanding, validation, and achievement) to severe stress (profound exclusion, bullying, and violence, including one rape in a school bathroom). Beaten at home, one girl was also passive with her peers and would “freeze” when confronted by threat; two girls were hospitalized for injuries inflicted by peers outside of school. Another remembered having razors put in her food, a hunting knife pulled on her, and being hit in the head with a typewriter at school. Although there were school personnel who tried to help three of the girls, in general, the girls felt a blind eye was turned on the bullying.

Some of the girls reached out in school for help regarding their home abuse, but help was not forthcoming. In three cases, school authorities initiated contact with child protective services, but each investigation was terminated almost as soon as it began, and the disclosures of family secrets at school accentuated the abuse at home. Although teachers and counselors at one girl’s school “knew the whole story” of her rape by her stepfather, no protective action occurred; she began to do poorly in high school and dropped out. Two of the girls came close to being helped by school staff; however, both remained in families where brutality was the rule. In one case, a teacher found a shoe print on the girl at age 11 (after years of beatings) and reported her case to child protective services, but no protective action nor any therapy came of this. In an unexpected twist, one girl, caught drinking at school, was protected by teachers who chose not to inform her parents, knowing that at home she would only receive a beating in response. “My high school knew that I was being abused. I would make up all kinds of excuses for the bruises I had. I mean how could you not know? They knew. Everyone knew.” Although the girls reported no efforts by providers in healthcare settings to connect with them, one was repeatedly taken by her mother to a physician to be checked for her virginity; her mother believed that her husband was having sex with her daughter; however, there was no follow-up by healthcare team members.

Quaternary Betrayal: Self-Betrayal

Components of the quaternary dimension of self-betrayal involved ambivalent or self-defeating behaviors

and emotions such as self-blame and dissociation; these responses were all the girls could do under the circumstances, but these survival responses also undermined their chances of rescue or help. Nondisclosure of abuse or dissociative responses to abuse reduce the likelihood of challenging a perpetrator, which could invite further violence. None of the women spoke directly about dissociation, but this emotional state is common in complex trauma situations. Dissociation is self-protective, distancing the child from the experience of abuse, but this coping mechanism reinforces passivity and vulnerability. In addition to ambivalence, a second type of self-betrayal included risky and self-harming behaviors, including substance use.

Ambivalence. Although children usually keep abuse to themselves, in light of our results regarding the lack of action in responses to disclosure, nondisclosure is hardly surprising. The girls clung to the only stability they knew, even if it was violent and frightening. In some cases, the girls undermined opportunities for help when it arrived. One expressed relief that her molester (uncle) was sober on the day of her only child protective services visit: “they didn’t find anything to put me from the house, so they left and just closed the case. . . .” Her fear of being taken from the only home she knew exceeded her rage at her uncle’s abuse. One girl bleeding from lacerations caused by her mother was comforted by a school nurse who wanted to “get my mom for child abuse,” but she refused to cooperate, thereby foiling the only attempt ever made to help her. She protected the only security she knew, and believed that her beatings would intensify if she complied with the nurse. In retrospect, she wishes to have been removed from her home.

Other forms of understandable self-betrayal among the girls were their guilt and shame. The confusing and negative messages from attachment figures led to a sense of worthlessness and being undeserving of good. This mindset was integrated into their senses of self. One believed she deserved the beatings of her boyfriend, even when hospitalized with a concussion. Due to her low self-esteem and self-blame, “I lived a double life. I kept a smile on my face. My teachers thought I was the best student they’d ever had. I never caused a problem, to keep what I was doing a nice big secret . . . hiding. Nobody knew me.”

Self-betrayal through drugs and alcohol. For all of the girls in this sample, substance use in early adolescence translated to their being accepted socially, experiencing relief from depression, and feeling a decreased sense of being different and isolated. Until she drank,

one girl said, “I never fit in. I was always an outcast.” All of the women connected relief of dysphoric emotions with their use of substances—a sense of “escape [and] freedom.”

It was like the depression went away. I was like all the other kids. . . . I had never felt that before. . . . It helped take away that emotional pain . . . numbed me from head to toe. I didn’t think, I didn’t feel.

Drug use became a feature of most of the girls’ lives in early adolescence, at a developmental level when belonging is important. By age 13, one described:

A joint while I walked to the bus stop . . . on lunch break at school . . . and walking home . . . I’d have a bottle of vodka in my book-bag and I’d be taking sips throughout classes. Soon my drinking got real heavy and I got real promiscuous with it.

By their late teens, some of the girls were already addicted to substances. “Every day was just get up, go find a way to . . . get some more money to get high again.” For some, crack became the drug of choice because it numbed “feelings and emotions,” but involved “sleeping with men, women, you know almost anything I had to do for the drugs . . . just to get me some money.” Crack, with its short half-life and high, meant this girl constantly needed to get it. She fell into homelessness, crime, and abuse by drug dealers. For the participants, the final stroke in this cascade of betrayals occurred because the promise of relief with substance use was eventually trumped by the severe consequences of addiction, as their lives spiraled out of control.

The stories of the women painfully underscore how drug-using behaviors served as a release and relief from intense and long-standing unhappiness and as a means to attain social inclusion. But the positive effects of substance abuse were overshadowed by its proclivity to lead to poor choices. Some of the women connected their use of drugs to sexual promiscuity, and others related their promiscuous behavior to their abuse. One had sex with at least 30 boys at age 15, but she was unable to enjoy it and was “starved for attention . . . very, very, very promiscuous. . . . Nobody could please me. There was nothing I enjoyed.” Another blamed the uncle who molested her for her subsequent promiscuity. “[If it] was ok for my uncle to do this, it’s ok for other guys to do it.” Feeling unloved at home, she “went out on the streets and got it,” reflecting both her vulnerability and her profound need for connection.

Discussion

General Considerations

The intent of this study was to explore the understanding of trauma from childhood trauma survivors' perspectives. As the study evolved, we saw that betrayal content was resoundingly the most important part of their histories. Freyd's Betrayal Trauma Theory (BTT) has differentiated between high- and low-betrayal traumas and has identified betrayal as significantly linked to post-traumatic and dissociative responses (Freyd, 1996; Platt & Freyd, 2015). A natural catastrophe is a kind of low-betrayal trauma, but child abuse is a type of high-betrayal trauma, because the child is dependent on the abuser for survival and the abuse significantly violates the child's trust and well-being (Freyd & Birrel, 2013; Goldsmith, Freyd, & DePrince, 2012). In general, a healthy adult response to betrayal is to withdraw from a relationship, but a child cannot do so. BTT posits that children ignore or block their sense of betrayal in an effort to maintain an essential, dependent social relationship; her concept of "betrayal blindness" suggests that dissociation—the adaptive breakdown of the connection between consciousness and memory—accounts for children's memory loss of trauma events. Dissociation eventually leads to significant interpersonal problems for the individual later on. "Double betrayal" has been used to refer to high-betrayal trauma occurring with a negative response to disclosure, such as disbelief, inaction, or even punishment; double betrayal has been linked to higher rates of amnesia for childhood sexual abuse and sexual revictimization later in life (Wager, 2013). High-betrayal trauma survivors who experienced post-traumatic stress disorder (PTSD) have shown higher rates of substance abuse via pathways of self-destructiveness and risk-taking behaviors (Delker & Freyd, 2014).

We initially interpreted the levels of betrayal (Figure 1) as time-ordered events, but in the analysis it became clear that they overlapped and occurred simultaneously. Most of the primary betrayers (direct abusers) of the girls were associated with basic securities of food and shelter, but the despair of the girls particularly crystallized around the four types of secondary betrayal that compounded the harm from the direct abuse. The secondary betrayer (usually mother, grandmother, or aunt) failed to protect the child, signaling either that she was frightened or ashamed or that she valued the primary betrayer (perpetrator) more than the girl herself. The girls further learned that in disclosing to an adult, they would be blamed, scapegoated, or further devalued. The derogatory self-views described by the participants in the current research correspond to the core beliefs of

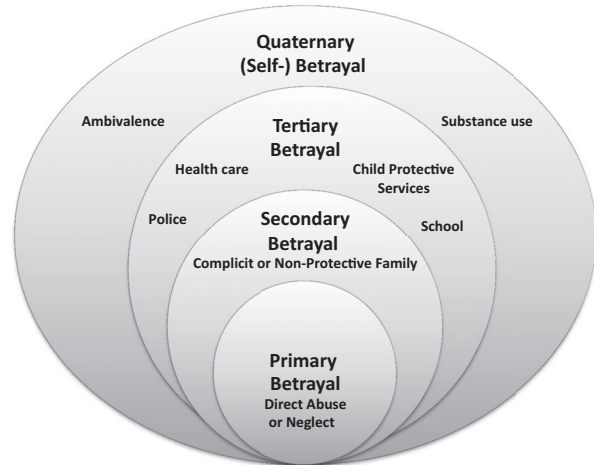


Figure 1. The levels of betrayal. The components of each layer of betrayal described by the women.

worthlessness and negative view of self that Hall (2000) has described; these have also been identified as shame-based identifications (Heller & LaPierre, 2012). The girls were degraded and their selfhoods violated, making normal childhood developmental milestones difficult to negotiate. According to van der Kolk (2014), severe childhood trauma causes a disconnection between the sense of self and the ability to feel fully alive, and brain scans of PTSD patients with early life trauma show almost no activation of any of the self-sensing portions of the brain.

Primary and secondary betrayals were reinforced by tertiary betrayal, the failure of community members who suspected abuse and might have helped the girls. Although some community members tried to reach out to the girls, none of the girls were removed from their abusive environments and none received professional help for their emotional distress or substance abuse. The experiences reported here underscore inadequate communication and missed opportunities among police, healthcare providers, teachers, and child protective service workers. These missed opportunities were not isolated instances, but the norm for these girls. Although none of the women blamed "society" for what had happened to them, we were repeatedly struck by the collective blindness of society to interpersonal violence on children. It is as if society does not want child maltreatment to be real and therefore it is neither "seen" nor addressed.

The quaternary level of betrayal included the girls' behaviors and emotions that may have endangered them and undermined efforts to help them. At least two of the girls seemed to have acted against their own best interests when help was offered. Their fear of being removed from the home (or fear of being punished for disclosure)

terminated their chance of rescue. It was not until several of the girls were capable of some measure of self-sufficiency as young teenagers that they began to run away from their abusive households. Substances served as solace but eventually were destructive. Promiscuity may have been an attempt to fill an interpersonal void they all felt. A sense of shame also contributed to self-destructive behaviors.

Freer, Whitt-Woosley, and Sprang (2010) found that survivors of trauma did not recognize abuse as abnormal, and while some of the current participants responded to secondary betrayal as a signal that abuse was to be expected, others knew that there was something fundamentally wrong with what they were experiencing. The term moral injury or wound has been used to describe the feelings of returning veterans whose sense of right and wrong has been deeply violated. Whereas PTSD is associated with fear, a "moral wound" is associated with a sense of ambiguity and betrayal, eliciting guilt, shame, rage, and grief (Wood, 2014). Such wounds do not respond to standard PTSD treatments, nor do the moral injuries to wounded children, who are even less able than veterans to understand the dilemmas in their lives. Van der Kolk (2014) contends that "developmental trauma" in children is significantly different from PTSD and warrants a separate psychiatric classification.

Many childhood trauma survivors are resilient and do well in adulthood, but emotion dysregulation, mental health consequences, and shame-based identifications were rife among the participants of the current study; their mental conditions were such that normal functioning in adulthood was seriously compromised. In general, individuals who emerge from families of insecure attachment patterns or outright abuse deal with considerable psychological difficulties as adults (Berry, Danquah, & Wallin, 2014; McWilliams & Baily, 2010); many heal with the help of therapists. For those with complex trauma who can afford therapy, Dialectical Behavior Therapy (Linehan, 2014) is ideal, but it may take years to develop a sense of self, interpersonal skills, and the ability to lead an ordinary life (Spermon, Darlington, & Gibney, 2013). The women in this study were not so fortunate. They were part of a large social substrate that lives with interrupted education, low income, unemployment, addiction, mental illness, homelessness, and a lack of health insurance and any mental health care. It seems that those who have unfairly borne family maltreatment at an early age often go on to bear collective social marginalization as adults. While the plight of children commonly elicits compassion, public attitudes toward the survivors of childhood trauma are far less sympathetic: hostile youth and marginalized

adults (particularly addicts) are seen as social deviants, morally weak, and undeserving of assistance.

The ACE studies have demonstrated the widespread nature of childhood trauma and its astounding health ramifications. ACEs are the most preventable causes of serious mental illness, HIV risk behaviors, and drug and alcohol use (Putnam, Harris, Lieberman, Putnam, & Amaya-Jackson, 2015), but the ACE study has been called "the most important public health study you never heard of" (Stevens, 2012). The American Academy of Pediatrics has issued a policy statement recommending that its members look for toxic stress in their patients, but response is slow. Primary and other healthcare providers have been reluctant to screen for ACEs because of personal discomfort or feeling unprepared (Starecheski, 2015). Nevertheless, there is widespread momentum currently to address ACEs, and nurses, known to be the most trusted of professionals, can take a leadership role. It has been calculated that in 2014 in the United States, the lifetime cost of childhood trauma was \$1.8 million per individual (Perryman Group, 2014); a CDC estimate was that just 1 year of confirmed cases of child maltreatment costs \$124 billion over the lifetime of the traumatized children, and this is likely an underestimation, because most cases of abuse are never investigated or confirmed (Fang, Brown, Florence, & Mercy, 2012).

Prevention of ACEs is critical, and nurses are in a position to engage in (a) primary prevention, before any harm has been done; (b) secondary prevention (i.e., case finding and interventions to interrupt the development of sequelae of abuse); and (c) tertiary prevention that is instituted when the sequelae of trauma have occurred (e.g., aggression, conduct disorder, delinquency, antisocial behavior, substance abuse, intimate partner violence, teenage pregnancy, anxiety, depression, and suicidality), in order to reduce their impact. The Social-Ecological (SE) Framework for Violence Prevention, with its four levels—individual, relationship, community, and society—is a prompter for strategies to effect change, which can occur at each level or simultaneously across multiple levels (CDC, 2011). The levels of betrayal identified in our research have been superimposed on the SE Framework in **Figure 2**. This fosters a clearer visualization of points at which nurses can play a role. The magnitude of childhood trauma and its aftermath calls for us to "transcend the traditional boundaries of our siloed health and human service systems. Children affected by ACEs appear in all human service systems throughout the lifespan—childhood, adolescence, and adulthood—as clients with behavioral, learning, social, criminal, and chronic health problems" (Stevens, 2012).

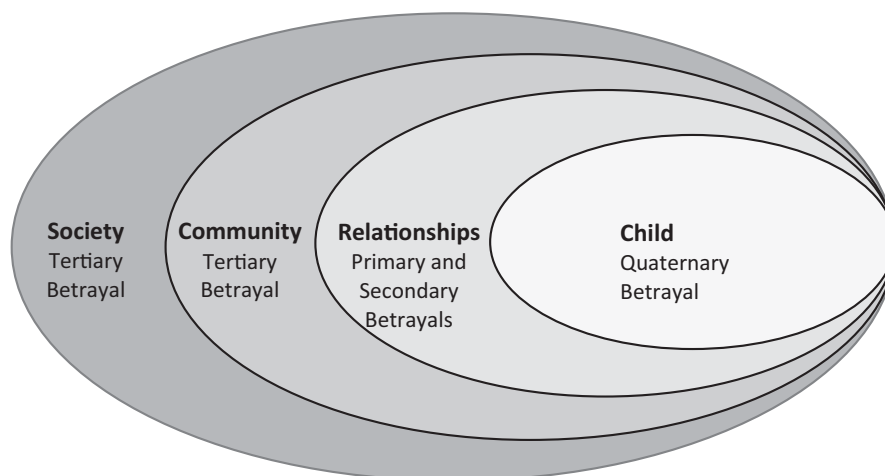


Figure 2. Levels of betrayal superimposed on the Social-Ecological Model: A Framework for Prevention. To sustain the prevention of violence against children over time, action across multiple levels is important.

SE Model: Clinical Implications for Nurses

The individual. Nurses commonly see children, adolescents, and adults who are at risk for abuse or have been abused. While clear evidence of abuse and neglect requires mandated reporting, nurses can directly help all survivors by providing trauma-informed care, keeping in mind that the individual may have experienced several layers of betrayal. This means being cognizant of the likelihood of trauma for the majority of patients and removing the blinders that serve to protect the healthcare provider from an unpleasant reality while doing nothing to support the patient.

Trauma-informed care involves a willingness to ask about trauma history in a sensitive, accepting, and matter-of-fact manner, and offer support, education, and mental health referrals, without expecting to “fix” the problem. Simply listening and empathizing without pity is highly validating; contrary to a widespread belief among health professionals that asking about trauma will trigger negative behaviors, clients are almost universally grateful that a provider would ask. The 10-item ACE questionnaire can be completed (or not, should they so choose) by patients on their first interaction in a clinical setting, and can provide a platform for education about the impact of trauma and availability of trauma therapy resources, if desired. A list of therapists who are skilled in trauma treatment should be offered. A validating, strengths-focused interaction between the patient and healthcare provider is in itself highly therapeutic. A resiliency-focused nurse might ask, “What is it about you that helped you survive your trauma?” or “What or who helped you get through?” It is not helpful or appropriate to probe about the abuse itself, which may indeed

cause the patient to become dysregulated. There are no current guidelines for ACE interventions, but Waite, Gerrity, and Arango (2010) provide a comprehensive approach on the assessment and response to ACEs and Kalmakis and Chandler (2015) have urged advanced practice nurses to incorporate ACE assessments into their practices. Nurses can compassionately ask children, adolescents, and adults about self-destructive behaviors (e.g., cutting and drug use); although these behaviors are maladaptive, they actually are an attempt to cope with their problems.

The 2015 Institute of Medicine Report on Psychosocial Interventions for Mental and Substance Use Disorders (Adams, 2015) calls for “low-intensity” programs to target “biological, behavioral, cognitive, interpersonal, social, or environmental factors with the goal of improving health functioning and wellbeing.” The Community Resiliency Model (CRM; Miller-Karas, 2015) offers a “low-intensity,” non-pathology-focused intervention of self-mental wellness care which can be taught by trained individuals, even non-healthcare providers (Trauma Resource Institute, 2016). CRM is useful for anyone, but particularly for individuals with emotion dysregulation and trauma. The link for CRM mental wellness skills is www.ichillapp.com or the “ichill” app can be downloaded to a smartphone for free.

It may be that any successful program to prevent or treat childhood trauma among children will need to address the quaternary level of betrayal: the inadvertent, self-protective, within-self-betrayal by the child. Children often cannot be identified as abused, so it may be that universal efforts to help children cope with stress, low self-worth, and interpersonal relationships are needed. School-based programs, such as the Collaborative for

Academic, Social, and Emotional Learning (2015), aim to promote children's awareness of beliefs and attitudes about self and others and are being introduced in some school systems. Somatically focused therapies, such as the Trauma Resiliency Model, show promise for overcoming or preventing the aftermath of trauma for all ages (Miller-Karas, 2015).

Relationships. The family is the key to interventions at this level: positive and nurturing relationships between parent and child are critical. Due to the trans-generational nature of abuse, parents who were not parented in a nurturing manner do not know how to parent their own children. In many cases, the parents are the perpetrators of the abuse. Successful family interventions can ensure that all children's needs are predictably met, offering parents support for healthy discipline and good parenting when they lack skills and resources. Evidence-based interventions and promising practices may be found at the National Child Traumatic Stress Network (2016) website. The goals of these programs are to reduce traumatic stress, behavioral problems, and PTSD symptoms. The Community Guide (CDC, 2016) recommends home visitation as a means of reducing child maltreatment; this entails visiting parents and children at home during the child's first 2 years of life to provide information, support, or training about child health, development, and care. The Community Guide also makes recommendations for children and adolescents to reduce psychological harm from traumatic events. Interventions need to afford maltreated children relationships with adults who can be genuinely trusted, as well as experiences where they are believed and protected. All children deserve the experience of a nonbetraying, loyal person or mentor to help in preventing or mitigating the effects of abuse and neglect. Likewise, parents who are traumatized can benefit from support and education.

Community. Neighborhoods, schools, healthcare organizations, and other community agencies provide milieus for preventing abuse or supporting individuals with trauma histories. Healthcare settings and other service systems have unwittingly, but frequently, been a source of further traumatization for already traumatized people, as in the case of using seclusion and restraint. A heightened awareness of ACEs among service providers and collaboration among law enforcement, social services, criminal justice, teachers, and healthcare providers is essential. Such collaboration is beginning to happen in some urban centers, as evidenced by recent cross-specialty ACE summits in Iowa, California, and North Carolina.

Society. Child maltreatment can be prevented but will require the engagement of the public and policy makers. The state of Washington has been a leader in efforts to respond to the ubiquity of childhood trauma and has served as a model for other states and nations. Its Family Policy Council shaped an across-the-state community response to complex ACE-related social problems and has delivered an empirically supported model of ACE response, with strong positive results to decrease ACEs in children (Hall, Porter, Longhi, Becker-Green, & Dreyfus, 2012). The WHO report, "Preventing Child Maltreatment," offers guidelines to develop child protection policies as well as algorithms for healthcare providers (WHO, 2006). The International Society for the Prevention of Child Abuse and Neglect (2015) is a means to connect with agencies across the globe to prevent within-family violence.

ACEs have been referred to as a "chronic public health disaster" because of our collective blindness to childhood abuse and neglect; we have been comfortable seeing childhood trauma as cases in isolation, and further, we have relied on child protective services, criminal justice, foster care, and alternative schools to deal with ACEs. However, these agencies alone can only offer "a dressing on a greater wound" (Stevens, 2012). Trauma-informed practices are beginning to appear around the world now in educational, mental health, corrections, public health, hospital, shelter, substance-abuse treatment, child/youth service, domestic violence shelter, and courtroom settings. Some parents are now determined not to pass their high ACE scores on to their children and because of this, there will be significant reductions in healthcare, social services, and criminal justice costs (Stevens, 2012). Children do not advocate for themselves, nor do most trauma survivors, but nurses are in unique and powerful positions around the world to help individuals by being trauma-informed healthcare providers and to help populations as agents of prevention and change.

Limitations

This study had several limitations. Only women with complex trauma and subsequent substance use disorders were included. No attempt was made to separate different types of primary trauma. Finally, only single interviews were conducted; multiple interviews would have assured more consistency, information, and clarification. It is common knowledge that just as 1 in 4 girls faces sexual abuse, so does 1 in 6 boys (CDC, 2014). It is therefore likely that men in drug treatment may have experienced sexual or other abuse as children. However, because of differences in social opportunity and gender expectations, the experiences and responses to abuse

and betrayal of men and women will be different. More research needs to be done regarding betrayal and abuse suffered by men who develop addiction. Our findings should not be the basis of developing interventions for men until more is known about men's experiences of betrayal and abuse as children.

Conclusions

The linked problems of child abuse, substance abuse, and mental health disorders are preventable public health problems. The costs of childhood trauma are beyond estimation, and the repercussions of trauma on the individual extend through the lifetime, affecting quality of life, health, and longevity itself. The findings on betrayals in this research should inform the discussion on how best to protect children and intervene with children and adolescents who are emerging from traumatic backgrounds. Understanding the perspective of trauma survivors may promote a better understanding of trauma-related processes across the lifespan.

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Clinical Resources

- ACEs 360: <http://www.iowaaces360.org>
- ACEs Too High: <http://acestoohigh.com>
- Adverse Childhood Experiences Study: www.acestudy.org; <http://www.cdc.gov/violenceprevention/acestudy/index.html>
- Betrayal Trauma Theory: <http://dynamic.uoregon.edu/jjf/defineBT.html>
- Childhood Adversity Narratives: www.canarratives.org
- International Society for the Prevention of Child Abuse and Neglect: www.ispcan.org
- Leadership Council on Child Abuse & Interpersonal Violence: www.leadershipcouncil.org
- National Center for Trauma-Informed Care: www.samhsa.gov/nctic
- National Child Abuse Hotline: www.childhelp.org and 1-800-4-A-CHILD
- National Child Traumatic Stress Network: www.nctsn.org

- Nurse Family Partnership: <http://www.nursefamilypartnership.org>
- Prevent Child Abuse America: www.preventchildabuse.org
- Published International Literature On Traumatic Stress (PILOTS): <http://www.ptsd.va.gov/professional/pilots-database/>
- Stop it Now: www.stopitnow.org
- Trauma Resource Institute: www.traumaresourceinstitute.com

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CLINICAL SCHOLARSHIP

Visualization of Data Regarding Infections Using Eye Tracking Techniques

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Abstract

Objective: To evaluate ease of use and usefulness for nurses of visualizations of infectious disease transmission in a hospital.

Design: An observational study was used to evaluate perceptions of several visualizations of data extracted from electronic health records designed using a participatory approach. Twelve nurses in the master's program in an urban research-intensive nursing school participated in May 2015.

Methods: A convergent parallel mixed method was used to evaluate nurses' perceptions on ease of use and usefulness of five visualization conveying trends in hospital infection transmission applying think-aloud, interview, and eye-tracking techniques.

Findings: Subjective data from the interview and think-aloud techniques indicated that participants preferred the traditional line graphs in simple data representation due to their familiarity, clarity, and easiness to read. An objective quantitative measure of eye movement analysis (444,421 gaze events) identified a high degree of participants' attention span in infographics in all three scenarios. All participants responded with the correct answer within 1 min in comprehensive tests.

Conclusions: A user-centric approach was effective in developing and evaluating visualizations for hospital infection transmission. For the visualizations designed by the users, the participants were easily able to comprehend the infection visualizations on both line graphs and infographics for simple visualization. The findings from the objective comprehension test and eye movement and subjective attitudes support the feasibility of integrating user-centric visualization designs into electronic health records, which may inspire clinicians to be mindful of hospital infection transmission. Future studies are needed to investigate visualizations and motivation, and the effectiveness of visualization on infection rate.

Clinical Relevance: This study designed visualization images using clinical data from electronic health records applying a user-centric approach. The design insights can be applied for visualizing patient data in electronic health records.

Approximately 1 in 25 U.S. hospital patients suffers from a healthcare-associated infection (HAI; Magill et al., 2014). Healthcare professionals, particularly nurses,

comprise the crucial workforce that can help to minimize the transmission of infections (Cimiotti, Aiken, Sloane, & Wu, 2012). The estimated numbers of common HAI were

approximately 93,300 cases of urinary tract infection and 157,500 cases of surgical site infection in 2011 (Magill et al., 2014). In the recent largest outbreak of Middle East Respiratory Syndrome (MERS) in South Korea, Nature reported news on transmission between healthcare workers and patients (Butler, 2015a, 2015b), similar to the case of the global spread of severe acute respiratory syndrome (SARS) during 2002–2003 (Chau et al., 2008; Cheng, Chan, To, & Yuen, 2013; World Health Organization, 2003). Visualization techniques using information technology such as infographics may increase awareness and mindfulness among nursing staff of patterns of infectious disease transmission in their workplaces.

Visualization involves visual stimulation with a chart, plot, or diagram, which can vary in size, color, and display platform to represent information or data. One integrated review identified approximately 160 different types of visualization methods, and the preferred type of visualization heavily depends on a specific discipline or work setting (Lengler & Eppler, 2007). For example, flow charts are frequently used in computer science and engineering, and the three-dimensional (3D) format is commonly used in architecture. In epidemiology, visualization has been used since the 19th century for conveying population-level statistics, communicating new insights and hypotheses, and assisting decision makers. John Snow's visualization of the cholera outbreak demonstrated that the vehicle for spread of the disease was water rather than air (Parkes, 2013), and Florence Nightingale used visualizations to show that more deaths resulted from contamination in hospitals than from the war (Small, 1998).

Despite a century of history, the field of visualization is currently fragmented, and wider application of visualization techniques has been constrained by barriers such as lack of organizational support, data access, and usability research (Lengler & Eppler, 2007). While it is quite feasible for visualization techniques to be incorporated into an electronic health record for improving patient care, it is challenging given the fact that clinicians work under time-pressured environments in hospitals. Visualizations integrated in an electronic health record may not be used effectively among clinicians if visualizations are not evaluated. Further, each clinician has varying visual literacy to interpret the visualizations (Lengler & Eppler, 2007; Matsumoto, Uto, Muranaga, & Kumamoto, 2013). One solution to these barriers is to apply a participatory approach to design user-centric visualizations (Carroll et al., 2014), which can help the audience reconstruct and integrate the knowledge and ultimately motivate them to meaningful action (Lengler & Eppler, 2007). In order to overcome the clinicians' barrier of lack of time when they are provided with infection rate reports, user-centric

usability evaluation of the infection rate reports such as measuring time of the cognitive process and cognitive burdens is crucial.

Conceptual Framework

Perceived ease of use and perceived usefulness from Davis' Technology Acceptance Model guided this visualization evaluation study (Davis, 1989). Davis' model has been extensively validated in the field of health information technology (HIT) and visualization (Bresciani & Eppler, 2009). Perceived ease of use describes the ease with which users understand and learn as well as the aesthetic value of the visualization (e.g., how the space and color help to convey the incidence). Perceived usefulness describes the usefulness by which users grasp complex information containing multiple indicators faster (e.g., how usefully the graph synthesizes several information pieces such as time, incidence, and prevalence with few elements). Perceived usefulness describes the utility by which users may improve their performance by providing immediate insights (e.g., how the graph allows for quick comparisons for decision making to choose *Clostridium difficile* or ventilator-associated pneumonia prevention education this month).

Aims

Using Davis' Technology Acceptance Model, this study aimed to evaluate among professional nurses the perceived ease of use and usefulness of various types of visualizations that convey information regarding HAI. The research questions were: (a) What are nurses' preferences among various types of visualization to convey information regarding HAI? (b) Which types of visualizations are easy for nurses to understand? (c) Do the participants appropriately identify the meaning of a visualization while they are viewing it? And (d) How long are nurses attentive to visualizations to convey information regarding HAI?

Methods

Design

This evaluation study employed a convergent parallel mixed method and three techniques—interview, think-aloud, and eye tracking—to evaluate nurses' perceptions of several visualizations to convey information regarding HAI.

Settings, Sample, and Recruitment

This study was conducted at a school of nursing in an urban research-intensive university in the northeast

region of the United States. The visualizations tested were based on actual infection data extracted from electronic health records stored in a research database as part of a larger study (R01 NR010822). Sample size was estimated using the sample size calculator for visualization usability (<http://blinkux.com/usability-sample-size/>). Twelve participants were required for the study based on the following: number of groups = 1, number of designs = 5, number of designs visible to each user = 5, eye tracking use = qualitative assessment. Eligible participants were master's students with clinical experience at the school of nursing within the institution. The study was approved by the institutional review board of the academic health center.

Measurements

This study measured user's cognitive burden while processing visualization information regarding hospital infection rates with the following three measures: (a) user's verbalized preference by an interview, (b) user's comprehension by questionnaires, and (c) objective visual attention. Measuring users' attention via interview, think-aloud, and eye tracking as described later is a common way to assess consumer responses of design in industry and has been found to be feasible and acceptable among healthcare providers (Stephenson, Gold, Mohan, & Gorsuch, 2014). Operationalization of the concepts of perceived ease of use and perceived usefulness for this evaluation study are summarized in **Table 1** (available with the online version of this article).

Interview. After each visualization was displayed, participants were asked the following questions: (a) This visualization is about [topic]. What does the visualization tell you? (How does the urinary tract infection [UTI] in room 21 compare to that of other rooms in September?) (b) Which of the visualizations do you prefer and why? (c) What is the most intuitive visualization? And (d) Would this visualization motivate you to address HAI issues? (Which is the most useful visualization? Will the visualization will help me to be aware more quickly of the incidence of UTIs?) See **Figure S1** for additional information (available with the online version of this article).

Think-aloud. In order to measure perceived ease of use regarding the visualizations, this study applied concurrent and retrospective think-aloud techniques, which are commonly used in cognitive science, linguistics, and psychology research (Ericsson & Simon, 1993; Nielsen, 1994). During the concurrent think-aloud (CTA), the data collector encouraged participants to express what

they felt and thought while they were viewing visualization (e.g., "this [visualization] is much better than putting numbers [in the infection report]"). Once they finished viewing the set of visualizations, the data collector encouraged the participants to articulate their reflections, thoughts, and feelings aloud (retrospective think-aloud [RTA]; Boren & Ramey, 2000; Dumas & Redish, 1999). While CTA assesses the spontaneous thought process of human working memory, RTA investigates the thought process relying on a participant's recall memory. CTA slows down the normal viewing process and interferes with the speed of normal thought process, affecting reliability (Hertzum, Hansen, & Andersen, 2009; Jong & Schellens, 2000). Considering the cognitive burden for nurses in their work environment, CTA and RTA were both applied to comprehensively detect design usability issues of the visualizations.

Eye tracking. A Tobii X2 eye tracker (<http://www.tobii.com/>), a noninvasive tool, was used to measure the speed of eye movement in an unobstructed manner similar to a web camera. The eye tracker measures view sequence, view frequency, and user attention, calculating the velocity of eye movements. The eye tracking software, Tobii Pro Studio™ (<http://www.tobii.com/en/eye-tracking-research/global/products/software/tobii-studio-analysis-software/>), produces a quantified dataset to export and further analyze using other statistical software (millisecond time units in rows and different measures quantifying eye movement characteristics in columns). Similar to other popular usability evaluation software such as Morae (<https://www.techsmith.com/morae.html>), Tobii Studio allows voice and screen video recording and provides frames and tools for an investigator to transcribe, comment, code, mark, and organize users' verbal and nonverbal responses. Unlike subjective self-reported data, an eye-tracking technique measures users' attention and response in an objective way by tracking where they look (<https://www.youtube.com/watch?v=WCmfVuyImC0>). Researchers can benefit from using an eye-tracking technique to collect richer data with complementary objective measures and more data from quiet participants or participants with short memory spans, and issues unnoticed by participants.

An eye tracker produces milliseconds of characteristics of eye movement with over 100 measures. User eye movements can be used to assess the ease of use and comprehension of the visual stimuli by providing characteristics and patterns of millisecond-eye movement (e.g., fixed eye movement indicating comprehension occurring and rapid eye movement indicating lack of comprehension as well as larger pupil size, which indicates higher

attention reflecting ease of use and usefulness of the visualization; Bonhage, Mueller, Friederici, & Fiebach, 2015; Kim, Lombardino, Cowles, & Altmann, 2014; Schumacher et al., 2015). The eye tracker device collects the spatial position of each eyeball to detect where a participant looks, and the software stores the collected data as numbers, heat maps, and sequence diagrams. In order to calculate the amount of users' attention, the eye tracking measures the frequency and duration of moments when the eye is stable to acquire visual information (fixation and dwell time). Higher frequency and duration of fixation and larger pupil size indicate good attention to a visual stimuli (Wedel & Pieters, 2000). Fixation (I-VT filter, velocity thresholds 30 degrees/seconds) and dwell time, which is known to be reliable indicators of a person's attention, was used in this study (Fox, Krugman, Fletcher, & Fischer, 1998; Pieters & Wedel, 2007).

Data Collection

Visual stimuli. Three nurses who had worked at the clinical unit from which the data were extracted and two epidemiologists participated in the design process. Each scenario included one traditional line graph and one or two infographics. The designs were based on three scenarios: Scenario 1 described infections including bloodstream infection, urinary tract infection, pneumonia, and surgical site infection in a single room via line graph (**Figure S2**) and infographic (**Figure S3**); Scenario 2 described infections in a unit via line graph (**Figure S4**), two-dimensional (2D) infographic (**Figure S5**), and 3D infographic (**Figure S6**); and Scenario 3 described infections in a unit for 6 years via line graph (**Figure S7**) and infographic (**Figure S8 & Figure S1**, all Figures available with the online version of this article). The visualizations were designed with incremental complexity in each scenario: infection in a room (Scenario 1), infection in a unit (Scenario 2), and infection in a unit for 6 years (Scenario 3). A total of five designs (Scenario 1: one infographic with body site infection pictograms; Scenario 2: two infographics with different dimensions; Scenario 3: one infographic with microorganism pictograms) representing HAI in a single hospital unit were created using the data extracted from electronic health records within the institution.

Five designs included (a) Infographic 1 using body site pictographs (e.g., urine cups) in Scenario 1 (see **Figure S3**); (b) Infographic 2 using round icons in Scenario 2 (see **Figure S5**); (c) Infographic 3 using 3D pictographs with radar charts in Scenario 2 (see **Figure S6**); (d) Infographic 4 using microorganism pictograms in Scenario 3 (see **Figure S8**); and (e) line graphs for all scenarios (see **Figures S2, S4, S7**). Each design in **Figures S2** through

S8 includes different content suggested by the nurses who worked on the unit (user-centric approach). The designs nurses on the unit requested included visualizations of infection in a room where they were in charge, infection in their own unit, and infection of specific microorganisms. The infographics convey content of increasing complexity based on three scenarios, including body site infection rates in a single room (infection in a room), body site infection rates in a unit with multiple rooms (infection in a unit), and infection rates with specific microorganisms over a period of 6 years (infection in a unit for multiple years). Further, the designs contain different graphical components, including dimension (2D and 3D) and variations in pictograms (recognizable and unrecognizable objects to the naked eye).

This study used design software including GIMP (<http://www.gimp.org/>), VISIO, and Google SketchUp (<http://www.sketchup.com/>). The size of the frame and font of the visualizations were uniform (12 × 6 inches, 20 point bold for title, 18 point for questions, months, and legends, 12 point for number of patients and cases) in this study. The resolution of the screen was 1,366 × 768 pixels (horizontal × vertical) in this study.

Procedure. Twelve participants were recruited among graduate nursing students with clinical experience by using flyers and direct email to students in order to measure user's cognitive burden (comprehension including time spent for understanding the visualizations, attention measured by objective eye tracker, and preference verbalized by users) when processing information regarding hospital infection rate visualizations. The data collector showed the set of visualizations to the participants repeating three rounds with the following three steps: (a) comprehension, (b) comparison, and (c) reflection section (**Figures S9**). First, the participants were asked to complete the comprehension test questions with three scenarios. In the comparison step, the data collector repeatedly showed the same set of visualizations provided during the first step, and instructed participants to freely and naturally view the designs. While the participants were viewing freely, they were encouraged to verbalize their preference between traditional line graphs and infographics and to compare them. Unlike displaying a single visualization at a time in the Step 1 comprehension test, two or three visualization designs aligned side by side were simultaneously displayed per screen during the Step 2 comparison section to assist participants in comparing the designs. A blank page was provided before and after visualization stimulus to wipe out memory and to reduce eye fatigue during the comparison step. In order to complement qualitative self-report responses, pupil movement during the

comprehension and comparison section was concurrently collected using eye-tracking techniques.

During the third step, the data collector showed a video of a screenshot marked with eye-tracking results and they were asked to verbalize reflection and additional thoughts regarding whether the visualization could ultimately motivate nurses (see **Table 1**). Time to complete each session ranged from 20 to 30 min. A progressive focusing process (Parlett & Hamilton, 1972), in which a qualitative analyst interacts with the information and iteratively refines the focus, was applied while data were collected. After obtaining informed consent, verbal feedback was digitally recorded. Participants received no monetary compensation.

Data Analysis

Numerical data were descriptively analyzed using R (<http://www.r-project.org/>) and IBM SPSS Statistics for Windows, Version 22 (IBM Corp., Armonk, NY, USA). Nonparametric tests including the Wilcoxon signed rank sum test (Hothorn, Hornik, Mavd, & Zeileis, 2015) and Friedman test were applied for comparing the median of the numerical results (Hollander, Wolfe, & Chicken, 2013) of visualizations within each scenario. Data collected from interview and think-aloud protocols were coded and thematically analyzed using Tobii Studio 3.2.3 (www.tobii.com).

Results

Sample

The sample of 12 masters' nursing students with clinical experience was mostly female ($n = 11$, 92%) and White ($n = 8$, 67%). Mean interview duration was 20 min per participant (SD 9.2 min). A total of 577,077 events of eye movements of 12 participants (average 48,089 events/participant) were exported from the eye tracker. On average, each participant had 114 instances of eye fixation (SD 61.8, eyes stable to acquire visual information) and 251 instances of rapid eye movement (SD 145.3, eyes unstable) per design. According to the validity score reporting how certain it is that an eye tracker found a specific eye (the lower the value, the more certain the eye tracker is), the measurement validity score of capturing participants' eye movement was high on participants' left eyes (.54) and right eyes (.47) on a 0 to 4 scale (0 = *highly confident*, 4 = *not confident*).

Comprehension

Scenario 1 (Infection in a Room). For the comprehension questions (for the line graph, which

month had the highest urinary tract infection? for the infographic, which month had the highest bloodstream infection?), all participants promptly recognized the correct answer, with a mean response time of 10.1 s (SD 7.16). In Scenario 1, there was a significant difference (d) in correct response time between the line graph and the infographic for the simple visualization (mean 12.4 \pm 8.87 s vs. 7.8 \pm 4.13 s, $d = 4.61$ s, respectively, $p = .046$).

Scenario 2 (Infection in a Unit). For the comprehension questions (for the line graph, what are the two rooms with a high rate of pneumonia patients throughout the year? for the infographic, what are the two rooms having UTI patients frequently throughout the year?), the complex visualizations took three times longer (mean 31.9 s, SD 15.64) to answer correctly as compared to the questions in the simple visualizations (Scenario 1). There was a significant difference in correct response time between the line graph and the infographic (mean 37.6 \pm 17.68 s vs. 26.2 \pm 11.28 s, $d = 11.47$ s, respectively, $p = .01$) in Scenario 2.

Scenario 3 (Infection in a Unit for 6 Years). For the comprehension questions (for the line graph, what is the most common microorganism in past 6 years? for the infographic, how many patients in 1,000 had *Klebsiella* infection in 2006 and 2007?—higher difficulty to require calculation of summing up two infection rates), it took an average 11.2 s (SD 9.25) to respond correctly. There was no significant difference in response time (7.7 \pm 2.87 s vs. 14.6 \pm 12.00 s; $p = .99$).

Attention

In the gaze analysis recorded by the eye tracker, the participants paid more attention to the infographics than the line graphs in all scenarios. **Figure S10** shows a greater degree of participants' attention in red in each infographic compared with the line graphs in all three scenarios. Attention and dwell time measured by the eye tracker are summarized in **Table 2** (available with online version of this article). There was a significant difference in total visit duration (line graph 12.3 s vs. infographic 17.9 s, $d = 5.58$, $p = .046$) and visit count (line graph 21.8 times vs. infographic 60.5 times, $d = 38.63$ times, $p = .005$) between the line graph and the infographic in Scenario 3. There was a significant difference between line graphs and infographics in visit counts among Scenario 2 visualizations (line graph 7.6 times, infographic 2D 9.3 times, infographic 3D 5.1 times, $p = .025$). There was also a significant difference in participants' pupil size between looking at line graphs and infographics (left eye 3.15 mm vs. 3.22 mm, $d = 0.07$ mm, $p < .001$; right eye 3.14 mm vs. 3.22 mm, $d = 0.08$ mm, $p < .001$).

Preference

Traditional line graphs. During the interview and think-aloud, most participants reported that they preferred the traditional line graph in Scenario 1 due to the line graphs' familiarity, clarity, and ease of reading: "I am familiar with line graphs"; "It naturally draws my attention because I learned those from school; they are easy to read"; "It is clear"; "I like this; it's easier to follow the trend."

When multiple rooms were added in the line graph in Scenario 2, the participants verbalized fatigue and difficulty reading the line graphs: "You can get glassy eyes when you see line graphs over and over again"; "I found the linear graphs easy to read but . . . they are kind of mashed together; it's difficult to read"; "I think looking at one graph is easier to digest than reading 30 graphs . . . you need to aggregate them."

In Scenario 3 where the designs depicted the rate of specific infections over time using two methods—line graph and infographics with microorganisms pictures—the participants reported that the line graph was aesthetically less attractive than the infographics, but easy to read, easy to understand, and useful to process information efficiently: "This one [line graph] is so easy to understand, the Staphylococcus is really high, but I like seeing the images of bacteria, microorganisms"; "I like this one [line graph] better even though this one [infographic] is more attractive"; "This [line graph] shows me quickly that Staphylococcus is more prevalent . . . eyes go straight to the high number."

Infographics. In certain situations in Scenario 1, the participants preferred the infographics because they used a pictogram: "The pictures make clearer where you are looking at so you don't have to keep tracking back to the graph key like . . . oh, wait! Which line is this, which line is that?"; "This [infographic] is really easy to see. I don't even necessarily need to know what the key is"; "I know what I am looking for—urinary tract infection versus bloodstream infection (without seeing the keys)."

When multiple rooms were added in Scenario 2, the participants expressed their preference for the 2D infographics with round circles since their aesthetic value (simplicity and clarity) helps the participants learn and understand information easily: "It's all separated and you can clearly see the incidence of infection so this [2D infographic] is the best. It's more understandable"; "Round is creative and innovative, not difficult to read"; "The circular bubble, it just stands out clearly and nicely when there are large number of diseases . . . because I am looking at so many rooms."

In some cases in Scenario 2, the participants preferred 3D infographics containing a room layout due to their detailed information, aesthetic values, innovativeness, and relevance to their daily work lives: "When we consider cross-contamination and cross-infection among the rooms, this [3D infographic] is much better because it provides spatial information"; "I prefer the 3D graph. This is for the nurses who want to know the detailed information (i.e., learnability), who want to read more and to do research"; "That [3D infographic] will be great for somebody on the floor who is very familiar with that floor. I think that's more powerful than other graphs."

In Scenario 3, which represented infection in a unit over 6 years, most participants liked both visualizations equally. In some cases, the participants found the infographic to be visually superior, insightful, and easier to understand than the line graph: "Both are clear; this one [infographic] is more visually interesting, and it's easy to read"; "Both are really great; actually I like them both . . . [line graph] it's so obvious, you just look at the highest in the line graph, but this [infographic] is better because the numbers are directly next to it with the size of the human"; "I like the one with the pictures; I like how the incidence is clearly numbered and sized . . . I like seeing the images of bacteria and microorganisms"; "I really like this one [infographic]. A person is larger with a higher number of people infected. For the line graph, if you look at quickly, it's a little harder, less intuitive to read—you have to read all the numbers below [in x-axis], even though you did a great job in the line graph."

Discussion

This study evaluated the ease of use and usefulness of visualizations conveying infection transmission in a large urban hospital. In order to achieve user-centric design (Carroll et al., 2014), this study applied a participatory approach in the design process of visualizing data extracted from electronic health records and conducted a usability test using mixed methods. The study findings provide insights for designing visualizations of hospital infection transmission and ultimately contribute to motivating nurses and creating a culture for a user-centric approach in hospital infection prevention. This study has substantive and methodological implications for user-centric visualizations in a hospital.

Implications for User-Centric Design

Many nurses in the past decade have been resistant to and frustrated with poorly designed electronic health records because they had to adopt them without providing any input (Ajami & Bagheri-Tadi, 2013).

The study findings of the users' positive attitudes and immediate understanding of the visualizations support the feasibility of integrating infection visualization into electronic health records when this study applied a user-centric design approach. Innovative visualizations conveying infection transmission designed by their peers may be positively adopted by nurses who work under time-pressured environments in a hospital to integrate hospital infection knowledge and ultimately motivate them to be mindful of the need for prevention efforts.

In terms of visualization detail, most participants preferred the traditional line graphs to infographics for simple data representation in Scenario 1 conveying monthly infection rates in a room. During the interview and think-aloud (CTA), participants spontaneously verbalized the reasons, such as line graphs are familiar, clear, and easy to read. The preference of line graphs may be explained by their routine use in patient records (Lengler & Eppler, 2007). Regardless of the platform of display, whether paper or electronic records, line graphs have been heavily used for decades to represent patient vital signs, including blood pressure and heart rate (Tague, Maeder, & Nguyen, 2010). The study finding implies that the line graphs are a suitable choice for simple data representation in infection transmission due to their familiarity, clarity, and ease of reading.

While traditional line graphs were well received for simple data representation during CTA, the line graphs were perceived as less useful and difficult to read for complex data representation, mostly during RTA. When multiple rooms were added in Scenario 2, the participants preferred the clarity, learnability, usefulness, and simplicity of infographics. Further, the participants paid more attention to infographics due to aesthetic values, innovativeness, and creativeness. The participants were attracted to the highly contextualized pictograms, implying that those pictures may help cognitive processing to ultimately motivate their behaviors.

Implication for Evaluation of Visualization

In terms of methodological implications, this study contributes to the field of usability evaluation. A single subjective method such as interview, survey, or focus group without objective eye tracking has been used in a conventional usability test in health information technology. However, the evaluation process in this study included three steps (Step 1, comprehension test; Step 2, step-comparison; and Step 3, step-reflection) using multiple techniques to thoroughly understand complex human visualization interaction behavior. This study found contradictory results between objective and

subjective data in Scenarios 1 and 3. While most participants preferred the line graphs during the interview, they paid more attention to the infographics (seen in red in the heat maps from eye tracking). There are multiple reasons for being highly attentive on the infographics. The attention was not because of the difficulty of processing the information of the infographics in Scenario 1 as it took significantly less time to comprehend information of the infographics than the line graphs. This implies that objective eye-tracking methods may provide a deeper understanding of human visualization interaction behavior than a conventional interview or think-aloud method. A single method to evaluate usability of visualization should be avoided. Nurses, who are the main user, have rarely been included in usability evaluation of electronic health records. This study introduced a method to collect nurses' voices objectively and subjectively in usability evaluation of electronic health records.

Limitations

According to Davis' theory (Davis, 1989), if a nurse perceives a visualization to be useful and easy to understand, the nurse will change her or his attitude toward using the visualization and actual use behaviors. In this study, the users are likely to use the infection visualization designed according to user-centric design principle. However, the extent to which actual infection prevention behaviors might be affected is not known.

The generalizability of this study is limited due to using a sample population of nurses in a master's program in a single urban university. The levels of visual literacy, cognitive abilities, and learning types may differ between master's students and the general nursing workforce in a hospital. Further, visualizations are intended to target workplaces, but this study was conducted in a laboratory-based environment. Because there might be gender differences in processing information in the form of visualizations, future studies with larger numbers of men as well as women are warranted (Feingold, 1988; Kaufman, 2007; Maeda & Yoon, 2013). Studies of real-world based settings and ethnographic studies in the field are needed to reveal barriers in workplace environments. Though the participants expressed overall satisfaction, a few minor issues with color choices and the size of the infographics used were encountered, which may warrant revisiting.

Conclusions

A user-centric approach was effective in developing and evaluating visualizations for hospital infection

transmission. According to the subjective findings in this study, most participants preferred traditional line graphs for the simple visualization, and expressed fatigue in reading the line graphs for the complex visualization. Infographics representing large amounts of information received positive feedback on their clarity, learnability, and aesthetic values of using relevant context pictograms from the users and warrants future cognitive usability research. The objective measures using eye tracking and a comprehension test identified that the infographics in all three scenarios received more attention than the traditional line graphs. The objective and subjective data in this study support the feasibility of integrating user-centric design of infection transmission visualization into electronic health records. Visualizations may inspire clinicians to be mindful of hospital infection transmission. The authors recommend that user-centric design with visualizations and user-centric usability evaluations be considered to improve data representation and facilitate rapid clinician comprehension in electronic health records in general.

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Clinical Resources

- Agency for Healthcare Research and Quality. Patient Safety Network: <https://psnet.ahrq.gov/primers/primer/7/health-care-associated-infections>
- Centers for Disease Control and Prevention. Healthcare-associated Infection (HAI) Guidelines and Statistics: <http://www.cdc.gov/hai/>
- Centers for Medicare & Medicaid Services: https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/HospitalAcqCond/Hospital-Acquired_Conditions.html
- The Joint Commission. HAI portal: <http://www.jointcommission.org/hai.aspx>
- National Action Plan to Prevent Health Care-Associated Infections: <http://health.gov/hcq/prevent-hai.asp>

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web site:

Table S1. Concepts, Measurements, and Examples of the Questions.

Table S2. Attention and Dwell Time Measured by Eye Tracking. Scenarios 1 and 3: the Wilcoxon signed rank sum test; Scenario 2: Friedman test. The boldfaced values indicate statistical significance. info = infographics. * $p < .05$, ** $p < .01$.

Figure S1. Evaluation scenarios.

Figure S2. Infection in a room (line graph, Scenario 1). Question: Which month had the highest rate of urinary tract infection (UTI) in 2010?

Figure S3. Infection in a room (infographic, Scenario 1). Question: Which month had the highest rate of blood stream infection (BSI) in 2010?

Figure S4. Infection in a unit (line graph, Scenario 2). Question: What are the two rooms with high rates of pneumonia patients throughout the year?

Figure S5. Infection in a unit (two-dimensional infographic, Scenario 2). Question: What are the two rooms

having patients with urinary tract infections (UTIs) frequently throughout the year?

Figure S6. Infection in a unit (three-dimensional infographic, Scenario 2).

Figure S7. Infection in a unit for 6 years (line graph, Scenario 3). Question: What is the most common microorganism in the past 6 years?

Figure S8. Infection in a unit for 6 years (infographic, Scenario 3). Question: How many patients in 1,000 patients had *Klebsiella* infection in 2006 and 2007?

Figure S9. Three steps of visualization evaluation and methods.

Figure S10. User's attention between a line graph and infographics measured by an eye tracker. The red marks in the heat map show that infographics received more attention than the traditional line graphs in all three scenarios (top). The opaque map shows where the participants were looking. The participants rarely paid attention to the line graph compared to the pictures in the infographic (bottom).

CLINICAL SCHOLARSHIP

Illness Representations of Injury: A Comparison of Patients and Their Caregivers

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Caregivers, comparative survey, illness representations, injury

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Abstract

Purpose: This study examined the differences between illness representations of injured patients and those of their caregivers.

Design: A comparative descriptive survey was used.

Methods: The study setting was the surgical wards of a teaching hospital in Taiwan. Data were collected at 3 to 6 months after hospital discharge. Participants were 127 pairs of injured patients and their caregivers. The participants completed sociodemographic data and completed the Chinese Illness Perception Questionnaire Revised-Trauma, which is composed of eight subscales. Clinical data of the injured patients was obtained from medical records.

Results: Injured patients and their caregivers were pessimistic about the injury. Patients perceived significantly more physical symptoms than caregivers did. Caregivers for patients who were severely injured or admitted to an intensive care unit (ICU) had more negative perceptions than did those who were providing care for moderately injured patients or those not admitted to an ICU. Caregivers who did not share their caring responsibilities had more negative perceptions than did those who shared their caring responsibilities with others.

Conclusions: This study found that patients and caregivers had negative illness representations several months after injury. Caregivers who provided care for severely injured patients or who did not share caring responsibilities perceived different extents of illness perceptions about the injury. The interventions should highlight the need to assist patients and caregivers after injury.

Clinical Relevance: Exploring the discrepancies in illness perceptions between injured patients and their caregivers can help clinicians to provide individualized care, and to design interventions that meet patients' and caregivers' needs.

Injury is a significant cause of mortality and morbidity. The complicated consequences of injury have received increasing attention, as injuries are predicted to be the world's fourth leading cause of disability by 2030 (Mathers, Boerma, & Ma Fat, 2009). The medical costs

for people with injuries are increasing; these costs may not include the substantial costs associated with family or community care. Patients who suffer from an injury experience short-term and long-term disabilities, and those disabilities have been identified systematically (Holtslag,

Post, Lindeman, & Van der Werken, 2007; Lee, Chaboyer, & Wallis, 2010). However, the totality of problems experienced by an injured individual may result in expanded responsibilities for the patient's whole family.

Background

Clinicians have become increasingly aware that injury has a long-term adverse impact on family members because they have a critical supporting role in the recovery process (Kreutzer, Marwitz, Godwin, & Arango-Lasprilla, 2010). To enable better outcomes for injured patients and their caregivers, it is necessary to understand the problems faced by patients in healing from an injury, and also to understand the related needs of their caregivers (Griffin, Friedemann-Sanchez, Hall, Phelan, & van Ryn, 2009; Kreutzer et al., 2010). The Common Sense Model of Illness Representation (CSMIR) provides a structure for understanding how an individual perceives the threats of illness and how those perceptions influence the individual's health behaviors (Leventhal, Leventhal, & Cameron, 2001). Illness representation is the central stage of the CSMIR. Five organized components of cognitive beliefs are included in illness representations (Leventhal et al., 2001). The first component, identity of the illness, is used to identify the physical symptoms of an illness. The second component, timeline belief, reflects the perceived progress and duration of an illness (acute, chronic, or cyclic). The third component, consequences, is the experienced consequences of the illness affecting the individual's work, family, lifestyle, and finances. The fourth dimension is control or cure, which is associated with perceptions of how the illness is susceptible to personal control, and whether the illness can be cured or treated. Causal beliefs, the last component, relates to the perceived causes of the illness (Leventhal et al., 2001).

Illness representation is described as the internal processes by which individuals create the definitions or the representations of a health threat. An individual's illness representations may influence his or her responses to illness-related problems via parallel cognitive and emotional representations (Leventhal, Brissette, & Leventhal, 2002). The emotional pathway interacts with the cognitive pathway when an individual is forming reactions to the health-threatening experience (Leventhal et al., 2002). Moreover, illness representations consist of perceptions of the given threat to the individual's health based on bodily sensations or symptoms. These symptoms are produced using information from the environment, such as information provided by significant others or the individual's own past experiences with illness (Leventhal et al., 2001). Hence, both internal and external stimuli

invoke illness representations from specific health-related situations. Once these representations are formed, coping and appraisal occur. In summary, illness representations assist an individual with the process of self-regulation, which is defined as the regulation of cognitive and emotional perceptions, including the development of coping behaviors used when adapting to an illness (Leventhal et al., 2002).

Researchers have sought to understand the factors that influence the development of illness representations. For example, positive illness representations have been found to be associated with better self-regulation in patients with injury (Lee et al., 2010), and with better self-care in patients with heart failure (MacInnes, 2013). Studies have also linked illness representations to different health-related outcomes such as self-efficacy (Lau-Walker, 2004) and quality of life (Lee, Chaboyer, & Marianne, 2008). Illness representations have been shown to be related to certain characteristics such as age (Gump et al., 2001), gender (Lau-Walker, 2004), and length of hospital stay (Lee et al., 2008).

Previous studies have indicated that injured patients do hold illness representations related to their injury (Chaboyer, Lee, Wallis, & Chien, 2012; Lee et al., 2010). A cohort study conducted follow-ups with 114 injured patients after their injuries, and the responses of these patients indicated that some components of their illness perceptions had changed at either 3 months or 6 months after hospital discharge. First, the patients experienced many injury-related physical symptoms before hospital discharge, but then the patients reported only two to three symptoms at 3 to 6 months after injury. Second, the patients did not have strong perceptions about the reasons for the injury. The majority of the patients were injured by a car accident or a fall, but they could not identify a cause, such as "bad luck" or "personal behavior" that may have led to the injury. Third, the patients had moderate to higher degrees of emotional reactions toward an injury. Fourth, the patients did not have strong ideas about the timeline to recover from an injury. Last, the patients perceived several consequences brought on by the injury at 3 to 6 months after injury, but they believed their injury could be controlled or cured and they had the ability to comprehend the conditions for their injury (Lee et al., 2010). Another study has shown that the predictors of quality of life in injured patients are their physical symptoms, their timelines to recovery, and their emotional representations at 6 months after injury (Chaboyer, Lee, Wallis, Gillespie, & Jones, 2010).

Researchers have shown interest in discrepancies in illness representations between patients and their caregivers. For example, caregivers for recurrent psychosis patients believed that psychosis was chronic in nature.

Their perceptions of psychosis differed from those of the patients themselves in that they saw psychosis as having more consequences and being less controllable. Having more negative perceptions in the control or cure dimension caused these caregivers to experience substantial distress and anxiety, as well as lower self-esteem (Kuipers et al., 2007). Those caring for patients with adolescent diabetes, meanwhile, saw diabetes as being more chronic and less controllable than did the patients themselves. Also, they had more negative emotional reactions than the patients (Olsen, Berg, & Wiebe, 2008). Moreover, caregivers were more pessimistic than stroke patients about the post-stroke symptoms, the timeline for recovery, and the consequences related to stroke (Twiddy, House, & Jones, 2012). Research has demonstrated that caregivers' illness representations of negative consequences, emotional reactions, and controllability of an illness are correlated with their perceived care burden (Rexhaj, Python, Morin, Bonsack, & Favrod, 2013). In another study, three types of negative illness perceptions, namely, emotional representations, cyclical timelines, and consequences, were found to be significant determinants of quality of life among caregivers for injured patients. The findings indicated that when caregivers perceive many physical symptoms, many consequences, negative emotions, and that recovery would take a long time, it may reduce their quality of life. In contrast, enhancing the positive perceptions of caregivers, including the belief that the injury is well controlled or can be cured, may improve their quality of life (Wu, Lee, Hsu, Huang, & Bai, 2014).

Illness representations have been found to influence health-related outcomes in injured patients (Lee et al., 2010) and in caregivers for injured patients (Wu et al., 2014). Previous studies have concluded that discrepancies between the illness perceptions of patients and their caregivers may have negative impacts on caregivers in noninjury patient groups (Kuipers et al., 2007, Olsen et al., 2008). Draper and Ponsford (2009) have reported that caregivers for patients with a head injury could effectively reflect the patient's daily functioning and the consequences of the injury. Thus, caregiver's health outcomes may be associated with patient's postinjury conditions, and potentially could be used to improve the patient's outcomes. Exploring the discrepancies between the illness perceptions of injured patients and their caregivers may provide a way of resolving the impacts caused by an injury. This study tested the following hypotheses: (a) Injured patients and their caregivers would have different illness representations related to an injury; (b) injured patients' demographic and clinical characteristics would be related to caregivers' illness

representations; and (c) caregivers' own demographic characteristics would be related to their own illness representations.

Methods

This comparative descriptive survey compared illness perceptions between injured patients and caregivers at 3 to 6 months after hospital discharge.

Participants

The participants in this study consisted of patients with injury and their caregivers. The participants were enrolled using convenience sampling, and were recruited from a teaching hospital in Taiwan. Injury type and severity will likely influence patient outcomes (Halcomb, Daly, Davidson, Elliott, Griffiths, 2005); thus, recovery among some patient subgroups, such as patients with burns or brain injuries, may be unique to that subgroup. Thus, this study focused on general injury patients. The inclusion criteria were: 20 years of age or over, injury caused by unintentional reasons, and an Injury Severity Score (ISS) of 9 or greater. An ISS of 9 to 15 indicates that a patient has a moderate injury, while an ISS of 16 to 24 or greater indicates a severe injury (Baker & O'Neill, 1976). Participants were excluded if they were discharged from hospital within 24 hr, were unable to provide informal consents due to cognitive impairment, had severe brain injuries or stroke, had burn injuries, or were victims of hangings, poisonings, or any other injuries not caused by force, and had hired a foreign worker after discharge. In this study, the caregivers consisted of immediate family members or other relatives of the injured patients. It is fairly common practice among Taiwanese families to hire a foreign worker from Southeast Asia to take care of a sick family member, so a point was made of excluding such foreign workers from this study. Selection criteria consisted of caregivers 20 years of age or older, nonemployed caregivers such as foreign workers, and those who cared for a patient who had been injured. As patients appear to have more psychological or cognitive problems at 3 months after an injury (Lee et al., 2008), it was determined that this time point was appropriate to capture illness representations for patients and their caregivers in order to obtain more evidence for application in trauma care.

Data Collection

Data were collected from February 2012 to January 2013. Participants were screened through the injury

database of the hospital's computer system. A senior nurse screened outpatient department (OPD) appointments for potential participants. Caregivers were identified from the patients' nursing records to select those who were patients' immediate family members or other relatives. Participants who met the inclusion criterion were invited to join the study during their OPD visits. Clinical data of the injured patients were obtained from medical records. Sociodemographic data and the items of illness representations of patients and caregivers were collected at OPD visits by the same nurse. Patient and caregivers provided written informed consent before completing the questionnaires. Data were collected either before or after OPD consultations in a separate room to avoid cross-contamination of responses. Ethical approval was granted from the institutional research board of the study hospital. No previous literature has reported on the correlation between illness perceptions in injured patients and their caregivers. Thus, there is no ideal method for calculating the necessary sample size. The data collection period was estimated as 6 months. The recruitment period was ultimately extended for an additional 6 months, however, after the sample size gathered during the initial 6 months of data collection was considered insufficient.

Measures

Demographic data of patients and caregivers (Lee et al., 2008, 2010), and clinical data of patients were selected based on previous studies (Lee et al., 2010). The Chinese Illness Perception Questionnaire Revised-Trauma (the Chinese IPQ-R-Trauma), which is based on the CSMIR, was used to assess the illness perceptions of injured patients and their caregivers. This instrument was derived from the original Illness Perception Questionnaire Revised (IPQ-R), and it can be used to explain health-related behaviors in various patient groups (Moss-Morris et al., 2002). The original scale was developed to provide a quantitative assessment of the five components of illness representations in the CSMIR. The developers of the IPQ-R recommend modification of certain items can be adapted for a specific condition such as the injury group (Moss-Morris et al., 2002). A multiple-step instrument translation and validation method was undertaken for the Chinese IPQ-R-Trauma. Forward translation and back-translation, content validity, exploratory factor analysis (EFA), Cronbach's alphas, and split-half reliability were used for the scale. Items related to identity and causes can be adapted for the injury group (Chaboyer et al., 2012).

The Chinese IPQ-R-Trauma consists of 50 items that are divided into eight subscales: (a) Ten items regarding

physical symptoms (score range 1–10, with higher scores indicating more symptoms related to an injury). The experienced symptoms were indicated by ticking yes or no to understand the identity of the injury; (b) Ten items to measure the perceived causes of an injury (score range 5–50, with each item scored from 1 to 5 with one reason such as “my emotional state” or “stress or worry”). Higher scores on the subscale indicate higher levels of agreement with the idea that the reasons listed had caused the injury. And finally, (c) six other subscales scored from 1 to 5 to measure the patient's perceptions about the injury (Chaboyer et al., 2012).

The other six subscales are as follows: the “emotional representations” subscale (range 7–35), which refers to the participant's emotional reactions to an injury; the “timeline-acute/chronic” subscale (range 6–30), which represents how long the injury-related effects lasted and whether the effects are acute or chronic; the “timeline cyclical” subscale (range 4–20), which identifies whether the effects of an injury are episodic or not; the “consequences” subscale (range 4–20), which refers to the expected outcomes (i.e., in terms of work, lifestyle, and finances) of the injury; the “control/cure” subscale (range 5–25), which refers to the participant's beliefs about the personal control or cure of an injury; and the “illness coherence” subscale (range 4–20), which refers to how the participant comprehends an injury. The assessment of both positive and negative representations can be conducted through these six subscales. High scores on the “timeline-acute/chronic,” “timeline cyclical,” “consequences,” and “emotional representations” subscales demonstrate that the participant has more negative perceptions toward to an injury. The four subscales are scored from 1 best to 5 worst. In contrast, high scores on the “control/cure” and “illness coherence” subscales indicate that the participant perceives more positive feelings about an injury. The two subscales are scored from 1 worst to 5 best (Chaboyer et al., 2012).

The EFA demonstrated a factor structure that explained 60.3% of the total item variance in the scale (Chaboyer et al., 2012), which was similar to the original western IPQ-R (Moss-Morris et al., 2002). The Cronbach's alphas ranged from 0.69 to 0.80 for each subscale, and the split-half reliability coefficients ranged from 0.7 to 0.82 (Chaboyer et al., 2012). For the current study, an item-level content validity index (I-CVI) for the instrument was determined by five trauma experts (Polit & Beck, 2006). Just a few words were fixed after expert checking. An average of 88% for all subscale items was scored by the experts, indicating that the validity of the scale was guaranteed. Moreover, the Cronbach's α of the scale ranged from 0.69 to 0.79 for patients and from 0.71 to 0.75 for caregivers in this study.

Table 1. Demographic and Clinical Characteristics of Patients

Demographic data			Clinical data		
Variables	<i>n</i>	%	Variables	<i>n</i>	%
Age (years, <i>M</i> ± <i>SD</i>)	55.4 ± 12.5		Cause of injury		
Gender			Vehicle accident	89	70.1
Male	69	54.3	Fall	36	28.3
Female	58	45.7	Other	2	1.6
Education level			ISS (score, <i>M</i> ± <i>SD</i>)	12.5 ± 7.0	
0–12 years	105	82.7	Moderate (9–15)	94	74.0
>12 years	22	17.3	Severe (≥16)	33	26.0
Marriage status			ICU stay (days, <i>M</i> ± <i>SD</i>)	3.1 ± 8.2	
Unmarried	56	44.1	Yes	43	34.0
Married	71	55.9	No	84	66.0
Employment			Length of hospital stay (days, <i>M</i> ± <i>SD</i>)	11.4 ± 10.5	
No	55	43.3			
Yes	72	56.7			

Note. ICU = intensive care unit; ISS = Injury Severity Score.

Data Analysis

Data were analyzed using the Statistical Package for the Social Sciences, version 18.0 (SPSS, Inc., Chicago, IL, USA). The demographic and clinical characteristics of the study subjects were presented as number and proportion for categorical variables or as mean (*M*) and standard deviation (*SD*) for continuous variables. Due to the paired nature of the data, patients' and caregivers' scores for the Chinese IPQ-R-Trauma were compared using paired sample *t* tests. The Chinese IPQ-R-Trauma scores among different categories of patients and caregivers (i.e., those with different characteristics) were compared by independent sample *t* tests (when there were only two levels for the given characteristic) or by one-way analysis of variances (when there were three or more levels for the given characteristic). The pairwise multiple comparisons (Scheffe's post hoc test) among any two groups for a given characteristic were performed when an *F* test indicated a significant difference between the two groups overall. In order not to inflate the type I error (mass significance), this study set the level of significance at $0.05/8 = 0.00625$ because there were eight interrelated subscales in the Chinese IPQ-R-Trauma.

Results

Characteristics of the Participants

A total of 148 caregiver–patient dyads were screened, and 127 pairs of injured patients and their caregivers completed the survey. Twenty-one pairs of patients and caregivers were excluded because they hired foreign workers to care for the patients after hospital discharge. The patients' mean age was 55.4 (*SD* 12.5) years, more

were male (54.3%), most had been educated for 12 years or less (82.7%), more were married (55.9%), more were employed before their injury (56.7%), most were injured by a vehicle accident (70.1%), most had a moderate injury (74.0%), and about one third (34%) had been to an intensive care unit (ICU). The caregivers' mean age was 46.6 (*SD* 11.1) years, more were female (63.8%), most had been educated for 12 years or less (87.4%), most were married (83.7%), most were employed (83.5%), and most did not share care responsibilities with others (69.3%). The familial relationships of the caregivers to the patients were mother (37.8%), spouse (29.1%), son or daughter (17.3%), daughter-in-law (7.9%), father (3.9%), and other relatives (4%; see **Tables 1** and **2**).

Illness Representations of Patients and Caregivers

The mean subscale score for identity that reflects the number of physical symptoms among the patients was significantly greater than that for their caregivers ($p < .001$). There were no significant differences in the scores for the remaining seven subscales between the patients and caregivers (**Table 3**). Both patients and the caregivers perceived an average of six to seven physical symptoms caused by the injury, but the mean subscale scores for causes among both patients and caregivers were low, indicating that both groups had weak perceptions about the reasons for the injury. Both the patients and caregivers presented very high subscale scores for three types of negative perceptions, including those covered by the "emotional representations" subscale, the "timeline acute/chronic" subscale, and the "consequences" subscale. The patients and caregivers also had

Table 2. Demographic Characteristics of Caregivers

Variables	<i>n</i>	%
Age (years, <i>M</i> ± <i>SD</i>)	46.6 ± 11.1	
Gender		
Male	46	36.2
Female	81	63.8
Education level		
0–12 years	111	87.4
>12 years	16	12.6
Marriage status		
Unmarried	13	10.0
Married	106	83.7
Other	8	6.3
Employment		
No	21	16.5
Yes	106	83.5
Share care responsibilities		
Yes	39	30.7
No	88	69.3
Familial relationship of caregivers		
Mother	48	37.8
Spouse	37	29.1
Son/daughter	22	17.3
Daughter-in-law	10	7.9
Father	5	3.9
Other relatives (e.g., siblings)	5	4.0

moderate to high subscale scores with regard to the negative perceptions covered by the “timeline cyclical” subscale, suggesting that they believed the effects of the injury were episodic. For the two positive illness perceptions, the findings indicated that patients and caregivers had moderate to high perceptions on “controlling/curing” and understanding of the injury.

Caregiver Illness Representations Based on the Patient’s Data and Caregiver’s Data

Differences in caregiver illness perceptions based on patient demographics and clinical data were analyzed. First, caregivers for severely injured patients perceived more physical symptoms than did the caregivers for moderately injured patients. Second, caregivers whose family had been admitted to an ICU perceived more physical symptoms and believed, on average, that the post-trauma condition of the given patient would require a longer recovery period than did those whose family had not been admitted to an ICU. Lastly, caregivers for patients who had been admitted to the hospital for 1 to 2 weeks tended to have more positive views on the control or cure of the injury than did those who cared for patients who were admitted to the hospital for under 1 week or over 2 weeks (**Table 4**).

The results indicated that a caregiver’s age and gender were not correlated in any significant way with any of the subscales of the Chinese IPQ-R-trauma. Caregivers who did not share caring responsibilities perceived more physical symptoms, longer time to recover, more consequences, and better control or cure than did those who had someone to share their care work (**Table 5**).

Discussion

This study examined the differences between illness perceptions of injured patients and their caregivers. Patients and their caregivers held similar illness representations in the dimensions of “causes,” “emotional representation,” “timeline acute/chronic,” “consequences,” “timeline cyclical,” “control/cure,” and “illness coherence.” However, the patients and their caregivers indicated significant differences in terms of their perceptions of physical symptoms.

The average ISS of 12.5 ± 7.0 found in the study by Lee et al. (2010) was similar to that found in the present study (13.2 ± 4.2); however, patients perceived far more physical symptoms and more consequences, much stronger negative emotions, that the recovery time would be much longer, and that there were more episodic changes than did the injured patients in the previous study. In this study, 70% of the patients were injured by vehicle accidents, while 30% were injured by falls. However, over 95% of the injured patients in the study conducted by Lee et al. (2010) were injured by vehicle accidents. These differences among studies may reflect the possibility that the illness perceptions people produce depend to a large degree on the nature of their different situations (Leventhal et al., 2001, 2002), including being affected to a high degree by the nature and severity of their injuries. The caregivers in this study had many negative perceptions about the injury, including perceptions that there were many physical symptoms, highly negative reactions, many consequences, and chronic and episodic timelines for recovery. These findings are consistent with a previous study that found that caregivers for injured patients were pessimistic about recovery (Wu et al., 2014). Thus, caregivers for injured patients may need additional support after hospital discharge to minimize the negative impact of caregiving.

Patients and caregivers held similar illness perceptions toward the injury in this study. In Taiwan, family members are quite close and give support to the member who is sick. This may be the reason for patients and caregivers holding similar perception tendencies, and the findings may be culture-bound in nature. These results are unlike those of previous studies, which found that patients

Table 3. Scores of Illness Representations of Patients and Caregivers

Subscale	Number of items	Observed range	Patient mean (SD)	Caregiver mean (SD)	t	p
Identity ^a	10	0–10	6.99 (1.55)	6.43 (1.90)	–3.82*	<.001
Causes ^b	10	1–5	1.60 (0.40)	1.53 (0.41)	–2.15	.033
Emotional representation ^c	7	1–5	4.24 (0.53)	4.15 (0.48)	–2.60	.010
Timeline acute/chronic ^c	6	1–5	4.59 (0.56)	4.57 (0.52)	–0.91	.367
Consequences ^c	4	1–5	4.63 (0.55)	4.54 (0.48)	–2.20	.029
Timeline cyclical ^c	4	1–5	3.46 (0.56)	3.47 (0.54)	–0.63	.529
Control/cure ^d	5	1–5	3.71 (0.72)	3.70 (0.58)	0.19	.846
Illness coherence ^d	4	1–5	3.45 (0.70)	3.46 (0.69)	0.91	.366

Note. Data not specified in the table were expressed as means (SD). ^aHigher scores indicate more symptoms. ^bHigh scores indicate more agree on the reasons caused injury. ^c1 best to 5 worst. ^d1 worst to 5 best. **p* < .00625.

Table 4. Caregiver's Illness Representations According to Patient's Characteristics

Subscale	Identity	Causes	Emotional representation	Timeline acute/chronic	Consequences	Timeline cyclical	Control/cure	Illness coherence
Age (years)								
≤40	6.12 (2.17)	1.53 (0.42)	4.05 (0.64)	4.45 (0.73)	4.45 (0.65)	3.26 (0.63)	3.69 (0.74)	3.73 (0.64)
41–64	6.65 (1.90)	1.53 (0.33)	4.24 (0.46)	4.59 (0.49)	4.61 (0.54)	3.49 (0.48)	3.79 (0.55)	3.34 (0.74)
≥65	6.44 (2.18)	1.56 (0.43)	4.19 (0.48)	4.62 (0.53)	4.61 (0.57)	3.55 (0.43)	3.68 (0.66)	3.41 (0.69)
F (p)	0.78 (0.458)	0.10 (0.903)	1.67 (0.191)	1.11 (0.333)	1.18 (0.310)	4.32 (0.015)	0.50 (0.610)	4.04 (0.020)
Marriage								
Unmarried	6.55 (1.91)	1.50 (0.32)	4.25 (0.54)	4.65 (0.51)	4.64 (0.55)	3.44 (0.54)	3.84 (0.59)	3.63 (0.66)
Married	6.32 (2.22)	1.58 (0.44)	4.10 (0.51)	4.49 (0.62)	4.50 (0.61)	3.45 (0.51)	3.62 (0.68)	3.35 (0.72)
t (p)	–0.65 (.515)	1.12 (.266)	–1.77 (.078)	–1.67 (.097)	–1.43 (.155)	0.12 (.908)	–2.07 (.040)	–2.43 (.016)
ISS								
Moderate	6.08 (1.93)	1.55 (0.39)	4.13 (0.56)	4.49 (0.63)	4.53 (0.62)	3.40 (0.56)	3.71 (0.65)	3.56 (0.65)
Severe	7.38 (2.23)	1.52 (0.39)	4.29 (0.40)	4.75 (0.33)	4.67 (0.48)	3.56 (0.38)	3.74 (0.65)	3.25 (0.81)
t (p)	3.49* (.001)	–0.50 (.621)	1.63 (.105)	2.38 (.019)	1.28 (.201)	1.67 (.098)	0.21 (.837)	–2.36 (.020)
ICU stay								
No	5.81 (2.00)	1.55 (0.39)	4.10 (0.57)	4.44 (0.65)	4.48 (0.64)	3.39 (0.58)	3.69 (0.63)	3.56 (0.66)
Yes	7.61 (1.71)	1.53 (0.40)	4.30 (0.41)	4.79 (0.30)	4.72 (0.44)	3.55 (0.38)	3.78 (0.69)	3.32 (0.78)
t (p)	5.48* (<.001)	–0.34 (.732)	2.28 (.024)	3.57* (<.001)	2.32 (.022)	1.85 (.066)	0.82 (.414)	–1.92 (.057)
Length of hospital stay (weeks)								
≤1	5.80 (2.22)	1.55 (0.44)	4.11 (0.71)	4.42 (0.69)	4.51 (0.630)	3.41 (0.69)	3.63 (0.64)	3.62 (0.64)
1–2	6.63 (1.82)	1.51 (0.33)	4.20 (0.41)	4.62 (0.52)	4.62 (0.510)	3.49 (0.430)	3.83 (0.54) ^a	3.42 (0.74)
≥2	6.75 (2.89)	1.73 (0.56)	4.13 (0.60)	4.58 (0.58)	4.39 (0.83)	3.28 (0.52)	3.29 (1.00)	3.44 (0.67)
F (p)	2.53 (.083)	2.12 (.123)	0.45 (.637)	1.61 (.204)	1.31 (.274)	1.22 (.297)	5.65* (.004)	1.09 (.338)

Note. Data not specified in the table were expressed as means (SD). ISS = Injury Severity Score.

^aValues of 1–2 weeks were significantly greater than that of ≥2 weeks using the Scheffe post hoc test.

**p* < .00625.

had fewer consequences (Kuipers et al., 2007; Twiddy et al., 2012), less negative emotion (Olsen et al., 2008), and fewer symptoms and shorter timeline to recover (Twiddy et al., 2012) than did their caregivers. These findings also may be injury-bound because the injury was caused by an unexpected accident, and thus the illness perceptions of the patients and caregivers would not be similar to those relating to patients who had chronic illnesses.

The results from this study indicated that the injured patients' and caregivers' expectations with regard to

recovery were not met. The findings showed that the patients and caregivers perceived many negative perceptions even several months after the injuries. Clinicians could encourage patients and caregivers to express their positive and negative illness perceptions, and help them to listen for and be aware of any differences or discrepancies between their perceptions. In turn, clinicians could then more easily focus on the patients' and caregivers' problems and assist them by enhancing their problem-solving abilities. However, even though these findings could help clinicians to influence the abilities of patients

Table 5. Caregiver's Illness Representations According to Caregiver Characteristics

Variable	Subscale							
	Identity	Causes	Emotional representation	Timeline acute/chronic	Consequences	Timeline cyclical	Control/cure	Illness coherence
Age (years)								
≤40	6.38 (2.09)	1.60 (0.48)	4.09 (0.52)	4.53 (0.52)	4.51 (0.52)	3.44 (0.51)	3.56 (0.73)	3.49 (0.69)
41–64	6.35 (2.15)	1.54 (0.37)	4.16 (0.54)	4.54 (0.62)	4.55 (0.62)	3.42 (0.53)	3.77 (0.63)	3.45 (0.73)
≥65	7.30 (1.06)	1.40 (0.00)	4.59 (0.28)	4.88 (0.22)	4.95 (0.16)	3.70 (0.50)	3.88 (0.38)	3.70 (0.51)
<i>F</i> (<i>p</i>)	0.96 (.385)	1.10 (.337)	3.73 (.026)	1.67 (.192)	2.45 (.090)	1.29 (.278)	1.79 (.171)	0.57 (.569)
Gender								
Male	6.56 (2.05)	1.51 (0.36)	4.21 (0.47)	4.62 (0.49)	4.60 (0.54)	3.54 (0.520)	3.77 (0.61)	3.45 (0.75)
Female	6.30 (2.12)	1.57 (0.41)	4.14 (0.57)	4.51 (0.65)	4.53 (0.62)	3.36 (0.51)	3.68 (0.68)	3.50 (0.68)
<i>t</i> (<i>p</i>)	0.74 (.459)	−1.02 (.307)	0.81 (.421)	1.06 (.291)	0.75 (.453)	2.14 (.034)	0.87 (.386)	−0.38 (.702)
Share care responsibilities								
Yes	5.60 (2.68)	1.59 (0.49)	4.07 (0.64)	4.29 (0.71)	4.31 (0.730)	3.35 (0.58)	3.46 (0.66)	3.51 (0.65)
No	6.80 (1.63)	1.52 (0.33)	4.21 (0.47)	4.68 (0.46)	4.68 (0.460)	3.49 (0.49)	3.84 (0.61)	3.46 (0.74)
<i>t</i> (<i>p</i>)	−3.39* (.001)	0.95 (.345)	−1.49 (.139)	−4.02* (<.001)	−3.75* (<.001)	−1.49 (.137)	−3.38* (.001)	0.33 (.739)

Note. Data not specified in the table were expressed as mean (SD).

**p* < .00625.

and caregivers to perform self-care activities, it is also recommended that clinicians consider the potential necessity of evaluating the coping and appraisal skills of patients and caregivers.

Evidence from a previous study has shown that negative illness perceptions, including emotional representations and consequences, are significant predictors of quality of life in injured patients (Chaboyer et al., 2010). Another study has reported that physical symptoms, consequences, negative emotions, and longer timelines to recovery are negatively related to quality of life in caregivers (Wu et al., 2014). In this study, high degrees of negative perceptions, including perceptions of a high number of physical symptoms, serious consequences, very negative emotions, and longer and episodic timelines to recovery, were found among both patients and caregivers. These results would presumably indicate that quality of life for the patients and caregivers was not satisfactory. Because enhancing positive perceptions regarding the control and healing of an injury among caregivers may improve their quality of life (Wu et al., 2014), there may be a turning point to help patients and caregivers better self-regulate because both groups in this study had relatively positive perceptions about controlling or healing the injury, in addition to better comprehension of the postinjury conditions.

Caregiver illness representations based on the injured patients' characteristics and those of the caregivers themselves were also tested. The results showed that caregivers of patients who were severely injured and admitted to an ICU perceived more episodic changes resulting from the injury, more physical symptoms, longer time to recover, more emotional reactions, and more consequences. These

results may indicate that being admitted to an ICU typically means that the patient has a more serious injury, which may cause many problems for the caregiver. In contrast, caregivers of patients who were moderately injured and admitted for 1 to 2 weeks had positive illness perceptions in controlling and understanding the injury, as those patients had uncomplicated conditions. Previous studies have shown that age, ISS, and length of hospital stay may influence a patient's illness representations (Lee et al., 2008; Gump et al., 2001). The results from this study, however, found that those factors are not associated with a caregiver's illness representations. However, the severity of the injury did influence the caregiver's internal beliefs in terms of the identified physical symptoms, the time period for recovery, and the degree of control over the injury. Injury severity might be a significant factor for illness representations, but further testing is required to make a clear determination in that regard.

Caregivers perceived more physical symptoms, believed that the time required to recover would be longer, and saw more consequences when they cared for an injured patient alone. These findings are easy to understand as most caregivers were employed. Thus, if no other person shares the care work, caregivers may feel overloaded and produce negative illness representations. Interestingly, caregivers had positive perceptions on controlling or curing the injury when they cared for patients alone. This may be because they needed to continually care for the patient and thus understood the changes in condition well. These findings may reflect culture-bound phenomena. However, determining whether or not these findings are translatable to other cultures may require further investigation.

From the results, we found that not only did patients interpret their injury-related symptoms and the recovery process, but their caregivers did as well. However, we also found that patients rarely talk about their illness perceptions regarding their injury, which is also true of their caregivers. Since the results have allowed for a better understanding of the implicit belief systems of injured patients and their caregivers, it is essential that clinicians help those patients and caregivers to express and organize any discrepancies between their illness representations and the medical treatments the patients are given. As illness representation is a relatively new concept for most clinicians, not all are familiar with the mechanisms behind illness representations. Thus, clinicians may need support and education to aid in clinical practice. Some topics regarding the theories and skills required to assess illness perceptions can be addressed during in-service training.

In order to facilitate patients' and caregivers' self-regulating processes, clinicians can assess the illness representations of patients and caregivers by using a quick assessment tool (Broadbent, Petrie, Main, & Weinman, 2006) in the admission and discharge nursing instructions. If more negative perceptions are found, an extra consultation or follow-up may be needed for the patient and caregiver in question. In contrast, positive and appropriate illness representations may be beneficial for better health outcomes. By discussing positive perceptions, it may be possible to determine strategies by which patients and their caregivers can better cope with an injury. Moreover, a supportive intervention based on the CSMIR could consist of the provision of negative illness representations to help patients and caregivers reduce inconsistencies between their expectations and the real situation.

This study has provided additional evidence that the CSMIR can be applied with regard to both injured patients and their caregivers. Some interventions should be administered to patients and their caregivers at rehabilitation units or during OPD visits. First, hospitals may provide a series of instructions focusing on reducing injury-related symptoms, as both patients and caregivers still perceived several symptoms after injury. Second, psychological assessments may be given to patients as well as caregivers as part of a routine effort to better understand how to improve their psychological outcomes. Third, a brief illness perception scale (Broadbent et al., 2006) may be applied to quickly assess patients' and caregivers' expectations regarding an injury, and to help them enhance their self-regulation abilities. Lastly, a trauma case management system may be the best way to provide comprehensive care, including nursing interventions, both before and after hospital discharge, with the ultimate aim

of improving the health outcomes of those patients and their families. Thus, nursing interventions based on the CSMIR can be applied in nurse-led case management that incorporates nurses and other clinicians to provide continuous care to help patients and their caregivers achieve better adjustment after an injury.

Limitations of This Study

This study has some limitations. First, it was conducted using a cross-sectional design, and we were thus not able to see any changes in illness representations of patients and caregivers over time. Second, the study collected data in only one hospital using a convenience sample, which may limit the external validity of the study, as well as the applicability of its results to some clinical situations. Lastly, as the mechanisms of injury are complicated, the findings of this study may be limited in terms of their applicability to various types of injured patients.

Conclusions and Clinical Implications

This study found that illness representations of injured patients and caregivers are not divergent, but only differ in terms of the intensity of injury-related symptoms. Both the patients and caregivers had several negative illness perceptions that were associated with poor quality of life. The findings suggested that patients do not fully recover from an injury even several months after hospital discharge. We suggest that transprofessional interventions be established to help patients and their caregivers have increased ability to self-regulate the recovery process of the injury. The interventions should highlight the need to assist patients and caregivers in constructing and reshaping their illness representations during the recovery trajectory and assist them in assessing how much support and coping strategies they can use to help themselves. Also, the interventions could consist of the provision of negative illness perceptions to help patients and caregivers reduce inconsistencies between their expectations and the real situation. When factors related to negative illness representations are present, such as a caregiver caring for a patient with a serious injury or a caregiver not being able to share caring responsibilities with others, it may be necessary to provide more attention to the patient and caregiver in question.

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Clinical Resources

- American Trauma Society: <http://www.amtrauma.org/>
- Australasian Trauma Society: <http://www.traumasociety.com.au/>
- British Trauma Society: <http://www.bts-org.co.uk/>
- Society of Orthopaedic and Trauma Nursing: http://www.rcn.org.uk/development/communities/rcn_forum_communities/orthopaedic_and_trauma
- Society of Trauma Nurses: <http://www.traumanurses.org/>
- Trauma Association of Canada: <http://www.traumacanada.org/>

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CLINICAL SCHOLARSHIP

Parents' Perspectives on Supporting Their Decision Making in Genome-Wide Sequencing

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Key words

Decision making, decision support, exome sequencing, genetic counseling, genome sequencing, genome-wide sequencing, nursing, parent perspective

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Abstract

Purpose: The purpose of this study was to explore parents' perceptions of their decisional needs when considering genome-wide sequencing (GWS) for their child. This is a partial report and focuses on how parents prefer to receive education and information to support their decision making about GWS.

Design: This study adopted an interpretive description qualitative methodological approach and used the concept of shared decision making and the Ottawa Decision Support Framework.

Methods: Participants were parents who had already consented to GWS, and had children with undiagnosed conditions that were suspected to be genetic in origin. Fifteen parents participated in a focus group or individual interview. Transcriptions were analyzed concurrently with data collection, iteratively, and constantly compared to one another. Repeat interviews were conducted with five of the parents to confirm, challenge, or expand on the developing concepts.

Findings: Participants felt that their decision to proceed with GWS for their child was an easy one. However, they expressed some unresolved decisional needs, including a lack of knowledge about certain topics that became relevant and important to them later and a need for more support and resources. Participants also had ongoing informational and psychosocial needs after the single clinical encounter where their decision making occurred.

Conclusions: Participants expressed unmet decisional needs, which may have influenced the quality of their decisions. The strategies that participants suggested may help create parent-tailored education, counseling, decision support, and informed consent processes.

Clinical Relevance: Health care professionals who offer GWS for children should assess parents' values, priorities, and informational needs and tailor information accordingly. There are opportunities for nurses to become involved in supporting families who are considering GWS for their child.

Many genetic conditions present in childhood (Biesecker & Green, 2014) as undiagnosed conditions that require a "diagnostic odyssey" to define the cause (Friedman et al., 2006). However, the technological advances of

genome-wide (whole genome or exome) sequencing (GWS) enable geneticists to test the entire genome at once. This may greatly reduce both time and expense (Ayuso, Millan, Mancheno, & Dal-Re, 2013), and

provide a specific genetic diagnosis in at least 25% of cases (Yang et al., 2013), resulting in immediate benefits, such as more accurate genetic counseling, access to resources, and possible treatment.

Background

While GWS can provide diagnoses, this testing often reveals incidental findings (IFs): unanticipated results unrelated to the primary concern (Ormond et al., 2010). IFs may predispose a patient to conditions ranging from trivial to potentially severe in the present or sometime in the future. Healthcare professionals (HCPs) therefore have the challenging task of communicating accurate and sufficient information about the benefits and potential adverse implications of GWS to facilitate families' testing decisions. Genetic counselors (GCs) have expressed challenges with the length, complexity, and content of the GWS consent process (Machini, Douglas, Braxton, Tsipis, & Kramer, 2014). Specifically, GCs had difficulty ensuring their patients accurately understood the benefits, limitations, potential results, and implications of GWS for themselves and their family members (Machini et al., 2014). GCs expressed interest in having access to resources related to guidelines on consent, result communication, ethical, and counseling issues (Machini et al., 2014). These challenges align with the recommendation of the American Society of Human Genetics (ASHG), which states that HCPs who provide pediatric genetic testing need to have appropriate expertise and training in interpreting and communicating genetic information (Botkin et al., 2015). Furthermore, genetic HCPs should establish a long-term communication plan for all results, including, which individuals are involved in the communication and the staging of information (Botkin et al., 2015). HCPs should provide basic genetic counseling and must have appropriate knowledge and skills related to testing, interpreting and communicating GWS and its' results to patients and families (Botkin et al., 2015).

In Canada, GWS has been carried out in the research setting for several years, and clinical GWS is becoming available. There are Canadian (Boycott et al., 2015), American (Green et al., 2013) and European (van El et al., 2013) professional recommendations for the use of clinical GWS. Canadian recommendations state that prior to testing, patients and families should undergo genetic counseling with a qualified person with a comprehensive understanding of clinical GWS (Boycott et al., 2015). The recommendations also state the inclusion of specific content to discuss during consent (Boycott et al., 2015). Given that GWS will ultimately impact patients, parents, and individuals, input is needed from them. In Europe and North America, parents have voiced con-

cerns about GWS decision making, including the lengthy and often elaborate consent process (Rigter et al., 2013; Tabor et al., 2012), and the challenges of discussing complex concepts such as IFs (Levenseller et al., 2013). Research on parental perspectives has focused mainly on return of IFs or results (Daack-Hirsch et al., 2013; Kleiderman et al., 2013; Sapp et al., 2013; Townsend et al., 2012); however, exploration of what elements and supports parents perceive as important to their educational preparation, pretest discussion, counseling, and informed consent is sparse: we have little understanding of parents' perceptions of their decisional needs when making a choice about GWS for their child. Decisional needs are factors influencing decision making, including knowledge, expectations, values, support, resources, and individual characteristics (O'Connor, 2006). Decisional needs should be met or resolved to optimize the quality of the person's decisions (O'Connor, Stacey & Jacobsen, 2011).

The purpose of this study was to explore parents' perspectives of their decisional needs when contemplating GWS for their child. More specifically, this article examines and describes how parents prefer to receive education and information about GWS. Understanding their viewpoints will enable HCPs to improve the education, counseling, and informed consent for parents considering such testing for their child.

Genomics and Nursing

It is imperative for nurses to be involved and knowledgeable about new clinical methods such as genomic testing (Calzone et al., 2013). Nurses have a legal and professional duty of care to their patients (Young, 2009), which includes the professional responsibility to serve as patient advocates (Hamilton, 2009), to promote informed decision making, and to ensure fairness by raising ethical, legal, and social concerns (Badzek, Henaghan, Turner, & Monsen, 2013) relating to GWS. A primary goal of nursing research is to enhance health care for families. This study aims to explore the potential for nurses to assist in this by exploring parental perspectives prior to the widespread implementation of clinical GWS.

Methods

The qualitative methodological approach known as Interpretive Description (Thorne, Kirkham, & Macdonald-Emes, 1997) was selected to explore this phenomenon. Shared decision making (Charles, Gafni, & Whelan, 1999) and the Ottawa Decision Support Framework (O'Connor, 2006; see Appendix S1, available with the online version of this article) were used as the

contextual basis for exploring the decision-making process in this study. The research proposal was approved by the University of British Columbia Behavioral Research Ethics Board. This study took place in British Columbia, a province in western Canada, where GWS is not yet a standard of care in clinical practice and is only available in limited circumstances through special appeal to British Columbia's Medical Services Plan. The Canadian health care system is publicly funded and provides universal coverage for medically necessary services based on need.

Recruitment and Sampling

At the inception of the study, there were only a few children who had undergone GWS in British Columbia; therefore, participants were recruited at a local children's hospital through convenience sampling. English-speaking parents who had experienced the decision-making process and had consented to GWS for at least one child were targeted. Parents had children with a range of conditions suspected to be genetic in origin. Twenty-four families were invited via email or telephone and 15 parents from 15 families consented to participate. They were instructed to read a short information sheet (see Appendix S2, available with the online version of this article) about GWS and watch two video links (Aulakh, 2010; Sanderson, 2012) intended to help participants gain a basic understanding of GWS.

Purposeful theoretical sampling was used to obtain maximum variation on the themes that initially emerged from the analysis (Thorne et al., 1997). After collecting data from all 15 participants (first round), the primary investigator purposefully selected those participants who would provide the most useful information for repeat interviews (Thorne et al., 1997). Useful information was based on participants' unique contexts, perspectives, or themes that needed clarification (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Selected participants had less common circumstances compared to the majority of other participants, such as a parent who had adopted their child. This sampling method was used in the latter part of the data collection stage.

Data Collection and Analysis

As a qualitative study using an Interpretive Description methodology (Thorne et al., 1997), this approach supports the use and integration of a variety of data collection techniques to better support a substantial in-depth analysis of the rich data acquired by these different methods.

Data were collected through a 90-min focus group (June 2013), eleven individual semistructured interviews of 30 to 60 min (May–July 2013), and five repeat interviews, held at a convenient time and location chosen by the participants (October 2013–January 2014). The focus group was used to capitalize on group engagement and dynamics, leading to a deeper level of discussion or expression of opinion (Polit & Beck, 2012). A trained facilitator guided the focus group discussion and the primary investigator was present to address participants' questions. Of the 15 consenting participants, 4 individuals chose to participate in one focus group session. Due to participants' scheduling conflicts or participants' comfort level in a group setting, the remaining 11 participants chose to partake in individual interviews. Interview dates were chosen based on participants' availability. Three participants chose interview dates before the focus group session, and eight participants chose dates after the focus group session. Semistructured individual interviews also enhance the credibility and authenticity of emerging themes (Thorne et al., 1997). Five separate parents from the first round of data collection participated in repeat individual interviews, which served to enhance the rigor of the study by ensuring that the emerging conceptualizations were firmly grounded in the data and represented participants' shared perceptions (Thorne et al., 1997).

The focus group and interviews were audio-recorded, transcribed verbatim, and de-identified with pseudonyms. Transcriptions were audited for accuracy, and only the primary investigator could connect the pseudonyms to the participants. Focus group and interviews were facilitated by a topic guide (see Appendix S3, available with the online version of this article) that included questions about types of information, resources, support, and contextual, personal or social factors that influence decision making. The topic guide was constructed based on the Ottawa Decision Support Framework (see Appendix S1), which is a well-validated instrument, and the final guide was edited and reviewed by the research team. Participants also raised topics that were important to them.

Data were collected and emerging themes were identified concurrently in order to help shape the direction of the study (Thorne et al., 2004). Data were collected iteratively, until participants were no longer raising new issues or themes. Tentative themes were discussed with the research team, who assisted in generating or clarifying follow-up questions for five repeated interviews. These repeated interviews explored further similarities, differences, or elaboration of specific attributes of participants' perceptions (Thorne et al., 2004).

A content analysis was performed using NVivo 10 (QSR International, 2013). All transcribed data were entered, initially read, and reread several times by the primary investigator. They were coded during this process to establish consistent thematic elements emerging from the data, and possible relationships between them.

Rigor

The elements from the data, coding, and interrelationships were independently reviewed by the other members of the research team, and edited and further refined. A group consensus of the final elements, their interrelationships, and mapping was then agreed by all the team members. In addition, the primary investigator maintained a reflective journal and NVivo 10 facilitated a decision audit trail. The primary investigator used NVivo 10 to log when and why elements emerging from the data were coded.

Results

All names used in this article are pseudonyms. **Table 1** describes the demographic characteristics of the 15 participants. The timeline between the GWS decision and the interview or focus group ranged from 6 months to 2 years. The age of the child varied between 6 months and 13 years. Six participants reported they received results, and nine reported they did not receive results. Of the three participants that had a diagnosis for their child, two reported they received it from GWS. Ten participants reported they did not receive a diagnosis, and two participants preferred not to respond.

Qualitative results are presented below in the broad themes of parents' decisional context, informational needs, psychosocial needs, and supporting strategies identified by parents. Subthemes are described in each section.

Parents' Decisional Context

The overall data highlighted the context-dependent nature of decision making for GWS. Participants' diverse circumstances and other elements such as personality, values, beliefs, and amount of prior knowledge influenced and personalized their decision making and was believed by many participants to be a factor in the amount and type of information they needed.

Despite parents' diverse circumstances, commonalities emerged from the data. Most participants (*n* = 12) described having children who were sometimes acutely ill, requiring medical attention or hospitalization, or undergoing a diagnostic odyssey for several months or years.

Table 1. Participant Demographics

Demographic	No. of participants (<i>N</i> = 15)
Gender	
Female	12
Male	3
Age (years)	
20–29	2
30–39	4
40–49	9
Highest level of education completed	
High school	3
Postsecondary trade/vocational school	1
University/college	11
Graduate/doctorate	0
Marital status	
Single	1
Common law	1
Married	12
Separated	1
Employment	
Student	1
Employed outside the home	6
Homemaker	7
Unemployed	1
Total household income	
<\$10,000	1
\$10,000–\$29,999	1
\$30,000–\$49,999	0
\$50,000–\$69,999	1
\$70,000–\$89,999	5
\$90,000–\$99,999	0
\$100,000 or more	3
No response	4
Ethnicity	
Asian	3
Caucasian	8
Other	3
No response	1
Current residence	
Within Vancouver	2
Outside Vancouver but <15 km from Vancouver	1
>15 km but <30 km from Vancouver	2
>30 km from Vancouver but within British Columbia	8
Outside of British Columbia	2
Clinical or research genome-wide sequencing	
Clinical	4
Research	11
Affected child has a diagnosis	
Yes	3
No	10
No response	2

Participants' experiences included multiple visits to different HCPs and diagnostic and genetic tests. Participants unanimously felt that their decision to proceed with GWS was easy to make.

Informational Needs

This is a partial report. Participants brought up more concerns related to the process of receiving information than the content of information. Participants' prioritized different content for decision making, and these are mentioned elsewhere (Li, 2014).

Volume of information. Participants received information from HCPs in the form of education, genetic counseling, and consent. Most participants ($n = 13$) felt that they received "enough" information, but two felt they received "too much." Kirsten said, "It was too much information. One thing leads to the other. It's too much to remember. Especially with a lot of things going on with my son. You're trying to absorb things, little by little." Many participants ($n = 10$) thought that a large volume of information given at one point in time was not helpful. Candace said, "If I had asked the questions in the beginning, it wouldn't have been a flood of information and knowledge all at one time. I would have known a little bit along the way."

Lack of knowledge. Several participants ($n = 8$) realized that they had personal knowledge gaps about specific topics that became relevant to them later:

I think (incidental findings) would have been good to have been brought up. I think at the time we were all just really excited to get it done. So there wasn't much discussion. But now looking back there was an incidental finding with my genes as a part of the whole sequencing for my son that just popped up, it was kind of a surprise. It would have been good to know beforehand that that sort of stuff could have popped up. (Candace)

Psychosocial Needs

Another identified theme was participants' psychosocial needs. Participants commonly spoke about the relational and psychosocial aspects of their decision-making process.

Relationship with healthcare professionals (HCPs). Most participants ($n = 13$) described the importance of the HCP–parent relationship during decision making about GWS. Participants prioritized different attributes of the relationship, including trust ($n = 7$), continuity ($n = 7$), a clear and effective communication style ($n = 6$), and being knowledgeable or informative ($n = 10$) and collaborative ($n = 4$). Many participants mentioned more than one attribute. An HCP–parent

relationship with these attributes helped participants feel at ease with their decision making. Tracy said, "[My child's doctor and I] have a close connection and made it very easy for me. I have a very strong relationship with [my child's doctor]."

Parents' well-being. Many participants ($n = 10$) felt that their own well-being was affected or compromised due to their current circumstances. Participants described feelings of fear, anxiety, uncertainty, frustration, or feeling out of control:

The frustration of not knowing. My daughter has challenges and it all adds up to the ongoing conditional challenge plus having no control over when the information comes [from the HCP]. So basically you're out of control, and when you don't have control over the situation, it's just frustrating. (Felix)

Participants valued the instances when HCPs recognized and considered their well-being as parents in a vulnerable or stressful situation:

Something (that) I liked from (my child's doctors) was that they were thinking everything about the baby and also caring for (me). "Are you ready? (Do) you have too much stress here?" I like[d] that they were worried about me. (Gloria)

Supporting Strategies

Participants made suggestions or agreed with other participants about best supportive strategies during the decision-making process for GWS. These strategies are summarized below.

Brief and understandable summaries. Participants preferred brief and understandable summaries, a "Coles Notes" version:

One paragraph of "this is really what you're about to read" then into detail as required. Basically the bottom line up front, these are the worst things that can happen, these are the advantages that could come out of it. Sort of an abbreviated version of the best-case scenario, worse-case scenario. (Felix)

Participants valued explanations in lay language that avoided medical jargon:

I'm just an ordinary mom. (The doctor) leveled with me. He explained to me things step by step, the simplest way, so I would be able to understand things. So that's very important. This is not our daily language (laughs). (Kirsten)

Approaches to information delivery. Participants acknowledged that every person has different communication needs and preferences for obtaining information. They suggested tailored approaches to information delivery using different media: Sydney said, "I think definitely the information to get was good on the paper, but I'm a visual person too. I think with the videos and having the sheets in front of you ... that's a pretty good explanation."

Most participants ($n = 12$) had a preference for a face-to-face discussion for the initial informed consent process, the return of results, receiving "bad news," or any situation that required multiple questions or explanations. Sandy said, "Of course face-to-face is best but is not always possible. If I was going to get some bad news, I would definitely want it face-to-face."

Layers of information. Each participant had different perceptions of what was "adequate" or "relevant" information. They favored receiving layers of information rather than receiving a large volume of information at one point in time. For example, receiving information ahead of the HCP discussion or meeting could allow parents to better absorb the information given to them: Sharon said, "Educational material should be provided in advance of the consent because rarely can someone sit and absorb a lot of the information and then reasonably be able to provide consent." In addition, participants suggested that take-home material be made available for review:

It's good to have a walk-away, something to give parents like a pamphlet or a video. Generally when you're being taught something you're listening but maybe once you've left you're like "oh, jeez I forgot to ask that." Well, if you have a pamphlet or a Q and A type DVD, you can always put that on and be like "Oh, okay, I get it, oh right, that's what they were talking about." (Aida)

Related to the layers of information, one participant proposed the idea of "layers of consent" to differentiate consenting for the primary diagnosis from consenting to receipt of IF results. The participant further suggested that IFs be treated differently—just being mentioned as a possibility during the first discussion and considered in more detail in a second layer of consent.

Sources of information. Participants valued credible sources of information: Sydney said, "A lot more people would be at ease if they would get information strictly from an actual doctor or a professional, and links to the

pages to read, rather than you trying to Google it." Participants emphasized the importance of HCP availability to answer their questions: Aida said, "Making sure that the parents know that if they do have any more questions they can contact whoever is presenting the information".

Discussion

Most participants were in GWS research studies (see **Table 1**) that involved an affected child who was acutely or chronically ill, and participants had prior experiences with genetic testing. Similar to Bernhardt et al.'s study (2015), these contextual factors likely influenced how the HCP conducted the consent session and participants' subsequent decision making. Given most participants' circumstances, it was not surprising that proceeding with GWS was perceived as an easy decision. Participants' past experiences of having an acutely ill child, or undergoing a diagnostic odyssey and other genetics tests, and their focus on finding solutions, has likely influenced the ease of their decision. Parents value a diagnosis (Makela, Birch, Friedman, & Marra, 2009) and are unlikely to pass up the possibility of finding answers for their child.

At the inception of the study, the researchers predicted that participants would articulate priority informational needs prior to making a decision about GWS for their child. However, participants raised other relevant topics, including the lack of relevant knowledge they received, the strategy of providing layers of information and consent over time, and the possibility that psychosocial needs may be more significant than their informational needs. Even though participants felt that they received adequate or too much information, some parents realized that they lacked information they would like to have had at the decision time. The participants' lack of knowledge may be attributable to numerous factors, such as the urgency of participants' circumstances, lack of time during the counseling or consent process, complexity and volume of the information presented, or participants' poor recall of information.

Participants consented to GWS in the interest of their child, a decision they considered easy. However, this should not take away the importance of properly informing them about the nature and possible outcomes of proceeding with GWS. From an ethical standpoint, providing this information to parents respects their role as representatives of the best interest of their child (Dondorp, Sikkema-Raddatz, de Die-Smulders, & de Wert, 2012).

Most participants thought that large volumes of information given at one time can result in "information overload." Dondorp and colleagues (2012) discussed the

challenge of obtaining meaningful informed consent in genome-wide array testing and commented that HCPs do not have time to discuss all of the possible outcomes from GWS prior to testing. The extent and complexity of GWS counseling has also been described by researchers in the United States (Levenseller et al., 2013; Ormond et al., 2010). Genetic counselors acknowledge that participants cannot devote up to 6 hr to consent, or comprehend all of the information in the documents and counseling session (Bernhardt et al., 2015). Thus, there is a need to use approaches that avoid making parents feel overwhelmed with too much information all at once, while at the same time ensuring they are well informed.

Participants preferred to have information made available as it became more relevant to them, suggesting that not all participants' informational needs were met, and supporting the concept of providing layers of information and layers of consent over time to help prevent information overload. Appelbaum et al. (2013) support "staged consent" as one way to improve current consent practices. The participant would be alerted to the possibility of IFs, with additional information provided when and if IFs are found to facilitate informed decision making about return of the IF results. Layers of information and consent may be a suitable approach for parents considering GWS.

The participants' suggestions of supportive strategies should be empirically tested to assess their effectiveness for parents' knowledge acquisition, comprehension, positive psychosocial outcomes, and ability to make a quality decision about GWS for their child. For example, the feasibility, effectiveness, and sustainability of providing layers of information alongside layers of consent should be clinically studied. There is a need to test this and other strategies to provide people with education that is sufficient to ensure meaningful and well-informed decisions. Some example strategies suggested by researchers include different informed consent or return of results models, such as generic consent (Ormond et al., 2007), a self-guided management approach for GWS results (Yu, Jamal, Tabor, & Bamshad, 2013), and a tiered-layered-staged informed consent model (Bunnik, Janssens, & Schermer, 2013).

Psychosocial health can be viewed as the degree to which a person has more positive beliefs and feelings (e.g., psychological well-being, self-efficacy), and fewer negative beliefs and feelings (e.g., worry, anxiety, fear; Street, Makoul, Arora, & Epstein, 2009). Participants described factors that contributed to their psychosocial needs, such as having a good HCP-parent relationship and HCPs' consideration of parents' well-being. The importance of the HCP-patient relationship and its

associated positive effects on health outcomes is not new (Kaplan & Greenfield, 1989). Aspects such as trust and the provision of emotional support have been found to lead to more positive working relationships and less decisional conflict (Stewart, Pyke-Grimm, & Kelly, 2005). Thus, it is important for HCPs to be mindful of the aspects of the relationship that have the potential to impact parents' psychosocial needs and their decision making (Matthias, Salyers, & Frankel, 2013; Stewart et al., 2005). Participants' psychosocial needs may be as important as their informational needs.

Limitations

The sample size was small ($N = 15$) and it was composed primarily of female Caucasian Canadians of higher socio-economic status. The study did not include the views of parents who opted not to participate or parents who declined GWS. It will be important to include these parents' views as they may have different perspectives on parental decisional needs. Whereas the study has a narrow context that precludes global generalizability of the results, the findings suggest the value of a larger, more diverse study.

The age of the participant's child and the timeline between the GWS decision and the interview or focus group were not specifically collected; however, some participants indirectly reported this data as they told their stories. Participants were unable to recall the length of their child's diagnostic trajectory, and data on this were not collected.

There were no direct observations of the genetic counseling session, decision making, or informed consent process, so the information that the HCPs actually conveyed to each participant (and their interactions) was not accessible. Furthermore, participants may have inaccurate recall of their experiences and decision-making processes. Nonetheless, the participants' perspectives provided common concepts that emerged from the data.

Conclusions

Participants felt that their decision to proceed with GWS was easy to make; however, they had unmet decisional needs. Unresolved decisional needs may adversely affect decision quality, which could affect the parents' actions and emotions, and the child's long-term health and appropriate use of health services (Jacobsen, O'Connor, & Stacey, 2013). It is essential for HCPs around the world that offer GWS to consider the current settings and processes that may contribute to creating unmet decisional needs and to execute strategies to address these needs.

Practice Implications

The supportive strategies that the participants suggested should be considered to help improve education, counseling, decision making, and the informed consent process for parents considering GWS for their child. Participants' views were congruent with genetic counselors' perspectives about summarizing main topics, tailoring the delivery of content based on the family's level of knowledge, interests, and concerns, and guiding families to ask questions (Bernhardt et al., 2015). Genetic counselors can evaluate families' understanding by assessing non-verbal cues (e.g., eye contact, nodding), the number and type of questions that families ask, and checking their understanding during the session (Bernhardt et al., 2015). It is important for HCPs to assess parents' individual values, priorities, and informational needs and tailor information accordingly (Bernhardt et al., 2015; Durand, Stiel, Boivin, & Elwyn, 2010; Jackson, Cheater & Reid, 2008; Ormond et al., 2007).

Interventions to support unmet decisional needs may be needed. Decision support can include a variety of methods, including a service (e.g., decision coaching), a system (e.g., an interactive decision aid), or products such as pamphlets, videos, or websites (Elwyn, Frosch, Volandes, Edwards, & Montori, 2010). Implementing a variety of such decision support may be a way to help mitigate information overload, prevent gaps in knowledge about GWS, tailor information that is most relevant and important, and help support parents to make decisions that are right for themselves and their families. However, further research is needed to explore whether such decision support interventions are feasible, effective, and sustainable.

Implications for Nursing

It was clear that participants required support and resources related to understanding and deciding on GWS for their child. On the other end, genetic counselors have expressed challenges with GWS counseling and consent, and ensuring the patients understood the content and its implications (Machini et al., 2014). To ensure quality clinical practice, the ASHG recommends that HCPs involved with pediatric genetic testing need to have appropriate training (Botkin et al., 2015). With the expected growth of genomic testing, there may be inadequate trained medical geneticists and counselors to support patients and families. Therefore, clinical nongenetic HCPs may need continuing education and support to address the challenges related to integrating genetics and genomics into practice. The anticipated increasing number and use of genetic and genomic tests will need more

genetic counselors, physicians, and genetically competent nurses (Botkin et al., 2015).

Nursing's emphasis on patient advocacy (Hamilton, 2009), health promotion, caring, and understanding individuals and their relationships (Calzone et al., 2013) brings a valuable perspective to the application of GWS. The profession has a commitment to being patient focused by striving to understand patients' and families' perceived needs, priorities, and expectations for health care, and reorganizing services around those needs (Lutz & Bowers, 2000). Nurses have an intimate knowledge of patients' and families' perspectives, and are also skilled in communications, building partnerships, and understanding clinical processes and procedures as well as the biologic underpinnings of health and disease.

Nurses working in various areas can help incorporate genetic and genomic information into different aspects of the healthcare system. For example, nurses could help parents clarify their values and expectations, guide them to relevant resources, and work with genetic HCPs to support the family through a shared decision-making process. Furthermore, the nurse may be the HCP that the patient or family is most comfortable with during the decision-making process. There are, therefore, opportunities for nurses to become more involved in supporting patients and families who are considering GWS. Information for nurses who are interested in learning about genetics, genomics, and nursing already exist (see Clinical Resources).

The need for nursing to continue educating its practicing workforce in genomics and to be prepared to respond to patients' GWS inquiries only grows (Calzone et al., 2013). Many nurses are unprepared to respond to patients' genetic testing inquiries, and general nursing competency in genomics remains limited (Calzone et al., 2012). In Canada, there is inadequate attention to genetics and genomics in nursing curricula at all levels (Bottorff et al., 2005). Current efforts to integrate genetics into Canadian nursing education are unknown. Efforts to establish and refine nursing competency in genomics are most well defined in the United States (Calzone, Jenkins, Prows, & Masny, 2011), the United Kingdom, and Japan (Kirk, Calzone, Arimori, & Tonkin, 2011).

Genomic technologies have far-reaching applications in health promotion, disease prevention, diagnostics, and treatment, and will become increasingly important across all areas of nursing practice.

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Clinical Resources

- Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics. Frequently Asked Questions: <http://www.genome.gov/17517146>
- Genetics and Genomics in Nursing: <http://www.genome.gov/17515679>
- American Nurses Association and Personalized Medicine: <http://www.nursingworld.org/genetics>
- Journal of Nursing Scholarship Genomic Nursing Series: <http://www.genome.gov/27552093>
- Health Professional Education: Genomics and Genetics: <http://www.genome.gov/17517037>
- International Society of Nurses in Genetics: <http://www.isong.org/index.php>
- Journal of Nursing Scholarship Genomic Nursing Webinar Series: <http://www.genome.gov/27552312>
- Learn Genetics: <http://learn.genetics.utah.edu/>
- Learning Genetics: Learn about Exome Sequencing and Secondary Findings: <http://www.learninggenetics.org/>

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web site:

- Appendix S1.** Ottawa Decision Support Framework
- Appendix S2.** Information Sheet
- Appendix S3.** Topic Guide



CLINICAL SCHOLARSHIP

Concept Analysis of Maternal Autonomy in the Context of Breastfeeding

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Abstract

Purpose: The purpose of this article is to analyze the concept of maternal autonomy in the context of breastfeeding and propose a clearer definition of the concept.

Methods: A concept analysis was undertaken using Walker and Avant's eight-stage approach.

Findings: The concept analysis suggests that maternal autonomy in the context of breastfeeding refers to a mother's ability to make autonomous decisions using her control, agency, independence, and ethical reasoning. The antecedents are maternal competence, availability of support, nature of the setting, and available alternatives with respect to breastfeeding. The consequences are improvement in child health, maternal-child bonding, breastfeeding decisions, and maternal healthcare-seeking behavior.

Conclusions: A clearer understanding of maternal autonomy in the context of breastfeeding will guide the development of a conceptual framework and expand nursing knowledge development.

Clinical Relevance: A clearer definition of the concept of maternal autonomy in the context of breastfeeding will guide clinicians, researchers, and policy makers in protecting, promoting, and supporting breastfeeding globally towards achieving the United Nations Sustainable Development Goals, 2015-2030.

Breastfeeding provides ideal nutrition for young children. To reduce childhood mortality and morbidity rates, the World Health Organization (WHO) recommends exclusive breastfeeding during the initial 6 months of a child's life and emphasizes continued breastfeeding along with complementary feeding until the child is 2 years old (World Health Organization, 2015). Although nurses act as key mediators in the promotion, protection, and support of breastfeeding practices of lactating mothers, the success of breastfeeding greatly relies on autonomous decisions made by the mothers (Brunson, Shell-Duncan, & Steele, 2009; Shroff et al., 2011; Vaz, Pratley, & Alkire, 2015). Nurses often encounter situations where maternal autonomy regarding breastfeeding is in conflict with healthcare advice and welfare of young

children (Murphy, 1999; Sundean & McGrath, 2013). Nurses are obliged to respect patient autonomy and assure the utmost welfare of their patients at all times (International Council for Nurses, 2012). Infants cannot make autonomous feeding decisions, and therefore nurses need to consider the autonomy of lactating mothers when safeguarding the welfare of young children.

While substantial literature in nursing concerns the concept of autonomy (Ballou, 1998; Keenan, 1999; Wilkinson, 1997), the concept of maternal autonomy has yet to be fully explored. Although several social science researchers have studied maternal autonomy (Brunson et al., 2009; Cox & Turnbull, 1998, 2000; Schmied & Lupton, 2001; Ziaei et al., 2014), these studies lack a clear understanding of the concept and reveal little consensus

in its definition. Moreover, the concept of maternal autonomy has yet to be analyzed in the context of breastfeeding. Therefore, this article uses Walker and Avant's (2011) eight-stage approach to concept analysis to analyze the concept of maternal autonomy in the context of breastfeeding and offer a clearer definition. Such insight is vital for nurses to improve delivery of care to lactating mothers and safeguard the welfare of young children.

Significance

It can be argued that the current understanding of autonomy is sufficient to guide knowledge development regarding maternal autonomy and offer direction for maternal-child nursing practice. So why is it essential to analyze the concept of maternal autonomy in the context of breastfeeding? Autonomy, as currently understood, works well in the context of adults whose autonomy is concerned only with their own welfare. However, it does not completely apply in the context of maternal-child health, where maternal autonomy holds direct implications for the welfare of young children.

Concept analysis is a rigorous process by which an abstract concept can be defined, explored, clarified, compared, refined, validated, or differentiated from similar concepts (Morse, Hupcey, Mitcham, & Lenz, 1996; Walker & Avant, 2011). This concept analysis will be useful in guiding research regarding maternal autonomy in the context of breastfeeding and in delivering quality care to lactating mothers. Moreover, it will assist stakeholders and policymakers in protecting, promoting, and supporting breastfeeding globally toward achieving the United Nations Sustainable Development Goals, 2015–2030 (United Nations, 2015).

Methods

Walker and Avant's eight-stage approach (Walker & Avant, 2011) was utilized to undertake the conceptual analysis. Although this method is heavily criticized for its simplistic approach and positivist nature, it is a well-tried and tested approach for concept development (Cutcliffe & McKenna, 2005). Moreover, the approach is useful for concepts that are unclear and underdeveloped (Hupcey & Penrod, 2005), as is the case here. The eight stages include selecting a concept, determining the purpose of analysis, reviewing relevant literature, clarifying the attributes, presenting a model case, clarifying the antecedents, identifying consequences, and defining empirical referents (Hupcey & Penrod, 2005; Walker & Avant, 2011).

Having already identified the concept of maternal autonomy in the context of breastfeeding and determining

the purpose of the analysis (i.e., identifying its implications for the practice setting), a literature search was undertaken using various databases, including PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, and Google Scholar. Manual searches were also carried out using the Internet and reference lists of the shortlisted articles. The search used the key words "maternal autonomy" OR "women's autonomy" AND "breastfeeding" OR "lactation" AND "autonomy" OR "decision." The search was limited to English-language articles published between 1995 and 2015.

Findings

The concept of autonomy has been widely discussed in the nursing literature as one of the ethical principles in nursing that is meant to ensure respect, integrity, and worth of an individual (Hanssen, 2004), uplift the professional status of nursing (Ballou, 1998), advance clinical nursing practice (Keenan, 1999), and deliver nursing care in partnership with an autonomous patient (Wilkinson, 1997). With the progress of the feminist movement and disparities surrounding maternal health, the notion of maternal autonomy emerged as one of the associated concepts related to the broad concept of autonomy (Dangal & Bhandari, 2014; Friedman, 2003).

During the past decade, the concept of maternal autonomy has been widely referred to in the social science and health literature. Although the concept is gaining popularity in nursing and other disciplines due to its implications in practice, research, and theory development, a review of the literature suggests several controversies with respect to concept definition. Sullivan and Douglas (2006) consider maternal autonomy an ethical and moral right of a woman that must be fulfilled and respected. In the context of maternal health, Ross et al.'s (2011) population-based cohort study describes women's autonomy as the degree to which a woman demonstrates dependence on her partner and seeks her husband's approval to undertake any decisions in her daily life circumstances, including attending a healthcare facility, spending money, and buying or selling anything. Another study undertaken with the aim to explore factors affecting breastfeeding describes maternal autonomy as self-assessment and appraisal of the dependence on, as well as bond and association with, significant others (Boettcher, Chezem, Roepke, & Whitaker, 1999). While acknowledging the different schools of thought and existing definitions of maternal autonomy, a child health nutritional study defines maternal autonomy as women's ability to decide, control their bodies, and

utilize resources without consulting anyone (Brunson et al., 2009). In a cross-sectional study, maternal autonomy is referred to as independence, freedom of movement, and decision-making power for self, child, and family (Ziaei et al., 2014). In the context of breastfeeding, maternal autonomy has been discussed as a mother's ability to achieve breastfeeding goals and manage breastfeeding without much assistance from midwives (Cox & Turnbull, 1998, 2000). Schmied and Lupton (2001) discuss maternal autonomy in breastfeeding as women's sense of self, control, and independence.

Besides noting controversies in the conceptual understanding of maternal autonomy, the terms maternal autonomy and women's autonomy appear to be defined similarly and even used interchangeably; as not all women are mothers, this adds confusion as well as complexity to gaining insight into the concept of maternal autonomy. Moreover, the oftentimes lack of a clearly presented context further compounds the problem. In view of Walker and Avant's (2011) concept analysis method, the following sections present attributes, a model case, antecedents, consequences, empirical referents, and an analyzed definition of maternal autonomy in the context of breastfeeding.

Attributes of Maternal Autonomy

Walker and Avant define attributes as characteristics of concepts (Walker & Avant, 2011). Based on the literature, the derived attributes for the concept of maternal autonomy in the context of breastfeeding are control, mother's agency, independence, and ethical reasoning, as described below.

Control. This attribute refers to mothers' control over their lives, their own bodies, available information, resources, and decisions no matter whether the demonstrated action is in disagreement with others (Bloom, Wypij, & Gupta, 2001; Brunson et al., 2009; Muers, 2010; Schmied & Lupton, 2001). In the context of breastfeeding, control as an attribute of maternal autonomy is also reflective of a mother's control over gender role expectations, cultural practices, and social circumstances that may or may not be in favor of breastfeeding (Liamputtong, 2010; Shaw, 2004). From the perspective of sexual roles assigned to women (i.e., reproduction and preservation), women's bodies and their bodily functions, such as menstruation, pregnancy, childbirth, and breastfeeding, are considered to have little connectedness with their autonomy and control over their choices (Boyd, 2010; Hausman, 2004; Shaw, 2004). In view of this perspec-

tive, mothers, as women, may encounter challenges to exercising control over their bodies, gender roles, reproductive rights, and social circumstances, and this may concurrently affect their autonomy with respect to breastfeeding.

Mother's agency. Mother's agency refers to a mother's ability to make choices from the available options (Cassidy & Tom, 2015; Fineman, 2004; Reece, 2008). Women's agency denotes the capability of a mother to make appropriate decisions and responsible choices in view of her circumstances (Cassidy & Tom, 2015; Kukla, 2006). In the context of breastfeeding, a mother as an autonomous being may use her agency to either breastfeed in public in response to her child's hunger (Stearns, 1999) or choose not to sustain breastfeeding. Mother's agency is one of the essential attributes of maternal autonomy in the context of breastfeeding as it well acknowledges the notion of contextual differences and capability of lactating mothers to make informed, timely, and situation-specific choices with respect to breastfeeding.

Independence. As per the gender roles expected from women in a particular social context, their level of independence and capacity to make autonomous decisions may vary. While respecting a women's motherhood, independence as an attribute of maternal autonomy in the context of breastfeeding enables lactating mothers to practice freedom in their choices regarding breastfeeding, develop positive self-identities, and demonstrate decision making with a low level of dependence on others (Fineman, 2004; Hausman, 2013; Waltz, 2014). As breastfeeding involves an intimate mother-child relationship, it is imperative that mothers have a high level of independence in their decisions and actions around breastfeeding.

Ethical reasoning. In the context of breastfeeding, the literature includes discussions about mothers maintaining an ethical relation with their children and using their ethical reasoning to make autonomous decisions in the best interests of themselves and their children (Shaw, 2003). This attribute reflects a mother's ability to distinguish an ethically sound persuasion from any manipulation and coercion from society or healthcare workers (Kukla, 2006). The demonstration of ethical reasoning in the context of breastfeeding is evident in various situations. For example, to ensure child survival, an HIV-positive homeless mother may decide to continue her feeding practices when no other feeding option is available to her. Similarly, a mother after termination of pregnancy may decide to donate breastmilk at milk banks to

benefit other children whose mothers cannot breastfeed. A low-income full-time employed mother with a preterm child may decide not to sustain breastfeeding in order to cover the cost of health care for her child.

Model Case

The model case presented following is reflective of the identified attributes of maternal autonomy in breastfeeding: control, mother's agency, independence, and ethical reasoning.

Alina is a first-time mother who lives in a nuclear family and has twin babies. She is struggling to maintain an adequate supply of breastmilk for both children. She lacks adequate support from her husband in sharing household responsibilities. At times, she finds it overwhelming to breastfeed her twin babies together, get adequate rest, look after herself, and manage household responsibilities. Although healthcare providers and societal norms expect her to provide on-demand exclusive breastfeeding to her twins, she considers her household responsibilities and makes an informed choice to supplement breastfeeding with formula feeding at least three times a day. After 2 weeks, she realizes that her twin babies are losing weight and refusing to accept the breast because formula feeding through a bottle has led to nipple confusion. Alina prepares a list of questions regarding her current challenges with breastfeeding. She schedules an appointment with a lactation consultant and seeks healthcare advice on her breastfeeding management issues to ensure that her actions are in the best interests of her children.

Antecedents

Based on the literature, the identified antecedents for the concept of maternal autonomy in the context of breastfeeding are support, competence, setting, and alternatives, as discussed in following text.

Support. Support refers to the availability of emotional, tangible, and educational assistance that allows mothers to make informed choices with respect to breastfeeding (Raj & Plichta, 1998). Availability of support enables lactating mothers to achieve their breastfeeding-related goals (Cox & Turnbull, 2000; Labbok, 2006). Support may be offered by healthcare professionals, peer counsellors, family members, neighbors, friends, employers, and colleagues and can facilitate maternal autonomy regarding breastfeeding (Boyd, 2010; Cox & Turnbull, 2000; Fineman, 2004; Friedman, 2003; Raj & Plichta, 1998; Reece, 2008; Sullivan & Douglas, 2006; Wolf, 2006).

Competence. Ethically and medically, a mother can demonstrate autonomy only if she is competent to make decisions (Sullivan & Douglas, 2006). Competence as an antecedent of maternal autonomy in the context of breastfeeding refers to physical, intellectual, social, emotional, and moral competence of the mother. Without these, a mother cannot demonstrate the key attributes of maternal autonomy (i.e., control, agency, independence, and ethical reasoning). As per medical ethics, mothers who are comatose, in a vegetative state, or have serious psychiatric conditions are considered to lack moral judgment skills. They therefore do not possess the competence required to make autonomous decisions, including breastfeeding decisions, for themselves and their children (Kulju, Stolt, Suhonen, & Leino-Kilpi, 2015; Leo, 1999; Wheeler, 2012). According to the literature, lactating mothers who are young, single, first-time mothers, or have low self-esteem are also considered to lack competence to demonstrate autonomy regarding breastfeeding. This is due to inadequate knowledge and no prior breastfeeding experience (Bloom et al., 2001; Copeland & Harbaugh, 2004).

Setting. Setting determines the extent to which a mother can demonstrate her autonomy (Bloom et al., 2001; Hausman, 2004). For instance, a mother may demonstrate greater autonomy at home where she has control over factors such as privacy and time as compared to hospital, workplace, or public settings where her control, agency, independence, and ethical reasoning may vary according to the demands of the situation. As an antecedent, setting is also reflective of boundaries that may be within or beyond the personal comfort zone of a lactating mother. Setting may foster or restrict breastfeeding practices depending on the availability of privacy, societal acceptability of breastfeeding, people's respect for motherhood, people's attitudes towards breastfeeding, and the presence of breastfeeding-supportive policies (Hausman, 2004; Schmied & Lupton, 2001; Stearns, 1999).

Alternatives. In the context of breastfeeding, alternatives include options that a lactating mother may consider before making an autonomous decision about breastfeeding. Alternatives include using a wet nurse to feed the child, choosing commercial milk products, feeding expressed breastmilk, accessing donor's milk at a milk bank, or introducing solid food before 6 months of age (Bassett, 2000; Kukla, 2005; Smith, 2015). The consideration of risks, benefits, cost, feasibility, accessibility, and contextual acceptability associated with each of the alternatives to breastfeeding enable mothers to demonstrate ethical reasoning, which is one of the key attributes of maternal autonomy in the context of breastfeeding.

Consequences

The seventh stage of concept analysis is clarification of the consequences or outcomes of the concept (Walker & Avant, 2011). Based on the literature, the consequences of maternal autonomy in the context of breastfeeding are improvement in child health, bonding, breastfeeding decisions, and healthcare-seeking behavior, as described following.

Improvement in child health. One of the key consequences of maternal autonomy in the context of breastfeeding is improvement in the child's health and nutritional outcomes. The literature identifies maternal autonomy with respect to breastfeeding as serving as a protective factor for a child's health (Ross-Suits, 2010; Shroff et al., 2011), preventing children from malnutrition and growth failure (Shroff et al., 2011), and improving a child's nutritional status (Brunson et al., 2009; Carlson, Kordas, & Murray-Kolb, 2015).

Bonding. Maternal autonomy pertinent to breastfeeding facilitates development of a satisfying, harmonious, and close relationship between a lactating mother and her child, that is, maternal and child bonding (Schmied & Barclay, 1999; Schmied & Lupton, 2001). This outcome is reflective of the notion that, no matter whether a mother makes a decision to sustain her breastfeeding or not, her autonomous decision concerning breastfeeding increases her capacity to maintain a healthy relationship with her child.

Breastfeeding decisions. Maternal autonomy enables women as mothers and as autonomous beings to thoroughly analyze their rights as a woman, societal norms, cultural context, personal capabilities, and social circumstances before making breastfeeding decisions. Empirical evidence reveals positive associations between maternal autonomy and breastfeeding (Cox & Turnbull, 2000; Shroff et al., 2011). Maternal decisions to discontinue or continue breastfeeding (with or without feeding substitutes) are noted to be mostly dependent on the attributes and antecedents of maternal autonomy in the context of breastfeeding, as discussed earlier (Dangal & Bhandari, 2014; Wolf, 2006).

Healthcare-seeking behavior. Another key consequence of maternal autonomy noted repeatedly in the literature is increased maternal healthcare-seeking behavior (Bloom et al., 2001; Iyengar, Iyengar & Gupta, 2009; Matthews, Brookes, Stones, & Hossain, 2005; Woldemicael & Tenkorang, 2010). In the context of breastfeeding, autonomous mothers who demonstrate

key attributes of maternal autonomy (i.e., control, mother's agency to decide as per her context, independence in her decisions, and ethical reasoning) ultimately have a high potential to seek health care without any constraints or dependency needs.

Empirical Referents

The last step of concept analysis is determining the empirical referents of the concept, which refers to determining the existence of the concept by exploring how the concept or its attributes have been measured (Walker & Avant, 2011). Cox and Turnbull (1998, 2000) focus on the effects of support offered by midwives to enhance maternal autonomy. Their instrument measured maternal autonomy by assessing a mother's ability to independently attach an infant to her breast and manage breastfeeding without much assistance. Although these studies do not report the validity and reliability of the instrument, they do measure maternal independence, which we identify as a key attribute of maternal autonomy.

In the context of the nutritional status of children 3 to 10 years of age, Brunson et al. (2009) utilize the Rendille Culture-Specific Instrument, an 11-item tool with an acceptable Cronbach's alpha of 0.83, to measure maternal autonomy. All items in this instrument address the main theme of maternal decision making, specifically regarding accessing health care, purchasing food, buying medicines, utilizing birth control, selecting a child's school, spending money, and selling or slaughtering animals. This instrument thus seems to encompass the key attributes of maternal agency and independence in making decisions for herself, her children, and household resources.

A study by Bloom et al. (2001) notes the association between maternal autonomy and healthcare utilization during pregnancy and childbirth. The degree of autonomy was assessed using a nine-item instrument composed of items surrounding three major areas: control over finance within household (two items), power of decision making in the household (three items), and extent of freedom of movement (four items). Although this instrument lacks adequate validity and reliability scores, it attempts to measure maternal autonomy by assessing the attributes of control, decision-making power (mother's agency), and freedom of movement (independence).

Ziaei et al. (2014) utilize a 17-item instrument with a high Cronbach's alpha ($\alpha = 0.91$) to measure the association between maternal autonomy and feeding practices of children 0 to 36 months of age. The instrument is composed of items surrounding the themes of financial independence, freedom of movement, and power

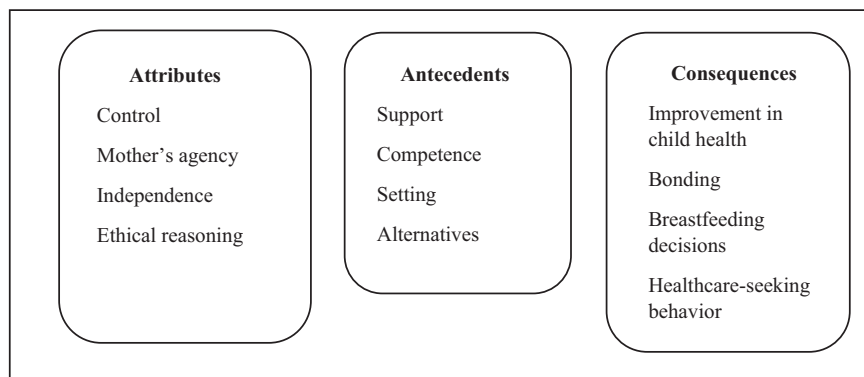


Figure 1. Attributes, antecedents, and consequences of maternal autonomy in the context of breastfeeding.

of decision making for self, child, and household. This instrument measures two of the identified attributes of maternal autonomy (independence and mother's agency) in the context of breastfeeding.

Thus, the literature suggests that no validated and reliable instruments have been developed to specifically measure maternal autonomy in the context of breastfeeding.

Definition

Based on the concept analysis undertaken herein, the concept of maternal autonomy in the context of breastfeeding can be defined as the maternal ability to make autonomous decisions using her control, agency, independence, and ethical reasoning that is preceded by maternal competence, availability of support, nature of the setting, and available alternatives in breastfeeding. Maternal autonomy in the context of breastfeeding results in improvement of child health, bonding, breastfeeding decisions, and maternal healthcare-seeking behavior.

Discussion

Because breastfeeding is a natural phenomenon whereby the maternal body serves as a source of food, medicine, and comfort for the child (Hausman, 2004), gaining conceptual understanding of maternal autonomy in the context of breastfeeding is essential but complex. The concept of maternal autonomy lacked a clear definition in the context of breastfeeding and had therefore been applied inconsistently in past research. This lack of conceptual clarity could lead to gaps in the provision of consistent and effective nursing care for lactating women. With the attributes, antecedents, and consequences of maternal autonomy in the context of

breastfeeding now more clearly articulated (summarized in **Figure 1**), nurses in practice and research can critically reflect on situations with more information. They can, in turn, better understand the possible answers to questions such as "Why do some mothers sustain their breastfeeding and some not?" "How can nurses promote autonomy of lactating mothers?" and "Why is it essential to promote maternal autonomy in the context of breastfeeding?"

In view of the key attributes presented herein, maternal autonomy is seen not only as making decisions but as reflective of a mother's control of situations and her agency to make informed choices as per her context, level of independence, and ethical reasoning while making decisions. Although some research studies consider maternal independence in decision making and control over resources as major components of maternal autonomy (Bloom et al., 2001; Brunson et al., 2009; Ziaei et al., 2014), the concept has not been viewed holistically because the components of maternal agency and ethical reasoning were not included. Consideration of all four identified attributes is anticipated to facilitate development of a comprehensive and validated research tool to measure maternal autonomy in the context of breastfeeding.

Although the literature highlights the importance of lactation counselling to facilitate mothers' decisions about breastfeeding (de Oliveira, Giugliani, do Espírito Santo & Nunes, 2014), breastfeeding counselling is not the only way to promote maternal autonomy. Maternal autonomy in the context of breastfeeding is preceded by the availability of support, maternal competence to make autonomous decisions, the nature of the setting, and feeding alternatives available to the mother. These antecedents can be utilized to design nursing interventions to enhance breastfeeding in diverse care settings and target intervention studies that analyze effects of these antecedents on exclusivity and continuation of breastfeeding.

The identified consequences of the concept validate the notion that maternal autonomy with regard to breastfeeding equally affects maternal and child health (Dangal & Bhandari, 2014). The consequences of this concept indicate that it is imperative for nurses to facilitate maternal autonomy in the context of breastfeeding to achieve improvements in child health, enhance maternal-child bonding, facilitate breastfeeding decisions in the best interest of the infant, and improve maternal healthcare-seeking behaviors.

Without doubt, the literature debates the pros and cons of concept analysis (Draper, 2014; Paley, 1996; Risjord, 2009). However, it is important that nurses continue to analyze undefined concepts as a contribution to the proposed theory-practice gap in nursing. Clearly defined concepts can then become part of theories to be tested, thus generating empirical evidence that builds knowledge for use in nursing practice. This concept analysis is expected to promote the development of nursing knowledge through research and application of developed knowledge in practice to promote autonomy of lactating mothers, safeguard the welfare of young children, and contribute toward maternal and child health in society.

Conclusions

Considering the lack of clarity and consensus with respect to the definition of maternal autonomy, insight into the concept of maternal autonomy in the context of breastfeeding was needed. Using Walker and Avant's (2011) method, we proposed a definition for this concept by critically analyzing the empirical and theoretical-conceptual-philosophical literature. We anticipate that the definition proposed for the concept of maternal autonomy in the context of breastfeeding will provide direction to nurse clinicians, researchers, educators, policymakers, and community leaders for understanding maternal autonomy from a holistic perspective. Nurses may use this concept to develop a conceptual framework pertinent to maternal autonomy in the context of breastfeeding, design breastfeeding projects to enhance maternal autonomy, develop research tools, and undertake nursing research in this area.

Clinical Resources

- I'm not a 'Nipple Nazi', I'm a breastfeeding counselor: <http://www.theguardian.com/commentisfree/2015/mar/27/im-not-a-nipple-nazi-im-a-breastfeeding-counsellor>

- WABA gender assessment practice tool for international board certified lactation consultants (IBCLCs) physicians and health care professionals: http://www.waba.org.my/pdf/gender_brochure_03.pdf

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PROFESSION AND SOCIETY

Factors Associated With Full Implementation of Scope of Practice

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Nurse, professional autonomy, scope of practice, self-efficacy

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Abstract

Purpose: To describe whether nurses fully implement their scope of practice; nurses' perceptions of future practice implementation; and the association between scope of practice implementation with professional autonomy and self-efficacy.

Design: A descriptive correlational study was conducted using a convenience sample of 145 registered nurses with post-basic certification from two Israeli university hospitals, from May 2012 to September 2013.

Methods: Five questionnaires were distributed: (a) Demographic and Work Characteristics, (b) Implementation of Scope of Practice, (c) Attitudes Towards Future Practice, (d) Practice Behavior Scale, and (e) Practice Self-Efficacy. Descriptive statistics for all demographic and questionnaire data were analyzed. Two regression models were developed, where current and future implementations were the criterion variables and demographic and work characteristics, professional autonomy, and self-efficacy were the predictors.

Findings: High levels of professional autonomy, self-efficacy, and attitudes towards future practice were found in contrast to low or moderate levels of current implementation of the full extent of scope of practice. Primary reasons associated with low implementation were lack of relevance to practice and permission to perform the practice. Significant associations were found between professional autonomy, self-efficacy, and attitudes towards future practice, but not with current implementation.

Conclusions: Nurses wanted to practice to the full extent of their scope of practice and felt able to do so but were hindered by administrative and not personal barriers.

Clinical Relevance: Even though staff nurses with post-basic certification had high levels of professional autonomy and self-efficacy, many were not implementing the full extent of their scope of practice. Similar to findings from around the world, external factors, such as administrative and policy barriers, were found to thwart the full implementation of nurses' full scope of practice. Therefore, practicing nurses should be aware of these barriers and work towards reducing them.

Nursing scope of practice refers to those actions, functions, or procedures that nurses are legally permitted to perform. The exact range of authorized practices is based on the nurse's education, training, competencies, and

experience, as well as the laws and regulations of the state, and the policies of the local institution where the practices are performed (Bryce & Foley, 2014; Queensland Nursing Council, 2005). Nursing scope of practice

has been changing and expanding due to changes in the healthcare environment (Bohmer & Imison, 2013; Brodsky & Van Dijk, 2008).

The need to provide increasingly complex healthcare services at decreased costs induced countries from around the world to develop their own human resource solutions. For example, the English National Health Service instituted a national initiative changing the roles and scope of practice of physicians and nurses (Bohmer & Imison, 2013). Australia implemented initiatives further redefining and expanding the roles of enrolled and registered nurses. The Congress of the United States passed the Patient Protection and Affordable Care Act, thereby presenting a unique opportunity to improve healthcare by reforming scope of practice policies (Villegas & Allen, 2012) and encouraging nurses to practice to the full extent of their authority, especially in advanced nursing and primary care (Institute of Medicine [IOM], 2011; Kunic & Jackson, 2013).

Israel, a country in the Middle-East with socialized medicine, has also developed a solution. Over 30 years ago, the Israel Ministry of Health authorized advanced practices and procedures within the framework of post-basic certification. Certification is obtained by registered nurses who complete a course that is approximately 1 year in length and includes both theoretical and clinical content. Nurses must also pass a theoretical and clinical examination in order to have post-basic certification. These courses are not given within an academic framework and initially did not require an academic degree. Areas of post-basic certification include midwifery, intensive care (neonatal, pediatric, and adult), emergency, oncology, geriatrics, and others. The scope of practice of nurses with post-basic certification is expanded from that of the registered nurse and includes a specific set of practices based on the type of certification (Ben Natan & Oren, 2011; Israel Ministry of Health, 2015; **Table 1**).

Only in 2009 did the Israel Ministry of Health authorize an advanced-practice role, that of nurse specialist in palliative care. Since that time, several other specialist roles have been introduced (Israel Ministry of Health, 2013, 2015). Scope of practice for the specialist role includes management of patient medications and treatments (not including hospital admission), follow up and discharge care, ordering tests (including blood tests, x-rays, and scans), and ordering referrals to consultants and the emergency department. However, the nurse and all of his or her decisions are under the authority of the physician in charge of the department (Israel Ministry of Health, 2015). Nurses must have post-basic certification in a related area of nursing in order to apply to become a specialist.

There are reports of nurses not working to the full extent of their education and training or scope of practice (IOM, 2011; D'Amour, Dubois, Dery, Clarke, Tchouaket, Blais, & Rivard, 2012). Previous studies have shown that lack of full implementation of the scope of practice might be due to internal as well as external factors. Internal factors include feelings of incompetence (McConnell, Slevin, & McIlpatrick, 2013) or personal characteristics, while external factors include organizational support (Shiu, Lee, & Chau, 2012), work environment (Oelke, White, Besner, Doran, Hall, & Giovannetti, 2008), institutional policies (McConnell et al., 2013), and local and national health policy (IOM, 2011).

Two internal factors that might be related to the full implementation of scope of practice are professional autonomy and self-efficacy. Professional autonomy can be defined as control over one's professional practice (Bahadori & Fitzpatrick, 2009). Dempster (1990) described four aspects of professional autonomy: readiness (ability, skill, and mastery), empowerment (perception of the legitimacy to practice), actualization (decision making, authority, and responsibility), and valuation (an evaluation of professional worth and quality). Kilpatrick et al. (2012) found that increased levels of professional autonomy were associated with increased implementation of scope of practice among a sample of Canadian nurse practitioners. Goldberg, Kertzman, Van Dijk, & Eisenberg (2012) also found a positive relationship between professional autonomy and attitudes towards expanding the scope of practice among a sample of Israeli nurses.

Self-efficacy in this context can be defined as the assessment that a nurse is able to perform the roles and practices within the scope of practice. Efficacy expectations are defined as the belief that one is able to successfully perform a specific task for a specific purpose. These expectations influence whether one will attempt to perform the specific tasks as well as the amount of effort that will be expended to complete them (Bandura, 1977). No study was found that investigated the relationship between self-efficacy and implementation of scope of practice. However, it would seem logical that nurses who felt that they were not able to perform a practice successfully would neither attempt to perform it nor expend a lot of effort to do so. This information might be important to policymakers when they are deciding whether to endorse the expansion of certain practices into nursing.

Significance

Nurses are expected to deliver safe, high-quality, and cost-effective care (Kunic & Jackson, 2013). However, nurses working below the full extent of their scope of

Table 1. Extended Practices for Nurses With Post-Basic Certification

Practice	Type of certification				
	Adult ICU	Neonatal/pediatric ICU	Emergency	Oncology	Midwifery
Handheld defibrillation	✓		✓		
Attach pacemaker electrodes and set heart rate	✓		✓		
Set ventilator settings for weaning	✓	✓	✓		
Connect and disconnect patient to ventilator	✓	✓	✓		✓
Insertion of arterial line		✓			
Removal of arterial line	✓	✓	✓	✓	✓
Draw blood from an arterial line	✓	✓	✓	✓	✓
Administer drugs IV push	✓	✓	✓	✓	✓
Administer drugs IV push to central line	✓	✓	✓	✓	✓
Draw blood for type and cross-matching	✓	✓	✓	✓	✓
Care of a Swan-Ganz catheter	✓		✓		
Blood drawing for laboratory tests, including arterial blood gases	✓				
Drawing of mixed-venous blood from a Swan-Ganz catheter	✓				
Draw peripheral arterial blood from a newborn		✓	✓ (up to 1 year old)		
Insert peripheral IV to newborn		✓	✓ (up to 1 year old)		
Draw venous blood from newborn peripheral vein		✓	✓		
Insert peripheral venous line on the scalp and legs of newborn		✓			

Note. ICU = intensive care unit; IV = intravenous.

practice may have lower job satisfaction and increased turnover, leading to increased costs and decreased quality of care (D'Amour et al., 2012). While one of the major conclusions of the American IOM report on the future of nursing (2011) was to promote nurses to work to the full extent of their education and training, few studies have investigated whether nurses, especially staff nurses, from other countries are having similar problems. Even fewer have determined what factors are associated with nurses implementing the full scope of their practice.

Aims

The aims of this study were to describe whether nurses worked to the full extent of their scope of practice; whether these nurses wanted to expand their scope of practice in the future; and whether demographic and work characteristics, professional autonomy, or self-efficacy were predictors of working to the full extent of the scope of practice or attitudes towards expanding scope of practice in the future.

Design

This study was a descriptive, correlational study.

Methods

Sample

The target population was Israeli nurses who had completed post-basic certification courses. The accessible

population was nurses from two university hospitals. Nurses were chosen using convenience sampling of units that are expected by the Israel Ministry of Health to hire nurses with post-basic certification. The units that were included were intensive care (adult, pediatric, and neonatal units), emergency, oncology, and maternity departments. A power analysis found that a minimum of 134 subjects were needed to achieve a power of .80, with an alpha level of .05 with a moderate effect size (Cohen, 1992).

Instruments

Five instruments were used in this study: (a) Demographic and Work Characteristics Questionnaire, (b) Implementation of Scope of Practice Scale, (c) Attitudes Towards Future Practice Scale, (d) Practice Behavior Scale (Dempster, 1990), and (e) Practice Self-Efficacy Scale.

Demographic and work characteristics scale.

This scale included the variables of age, sex, family status, religion and religiosity (measures of ethnicity in Israel), unit, role, experience as a nurse and on the current unit, professional education, type of post-basic course, and date of course completion.

Implementation of scope of practice scale.

This scale was designed by the investigators in order to measure the level of current implementation of

nursing practices that are included in the Israel Ministry of Health list of expanded practices (practices allowed only by registered nurses with post-basic certification; see **Table 1**). The scale consists of a list of the practices relevant to the type of post-basic certification (range: 5–13 practices). Participants are asked to describe on a Likert scale to what extent they perform each practice independently (i.e., not require a physician or other health-care provider to perform the practice), from 1 (*never*) to 5 (*always*). Higher scores indicate a higher level of current implementation of the full extent of the nurse's scope of practice.

In the event that the participant responded with an answer in the range of 1 to 3, the participant was asked (using a checklist) why they did not perform this practice. Possible responses were no time, not have relevant knowledge or training, not enough confidence, and lack of permission or prohibited by a superior.

The questionnaire was sent to five content experts (five nurses with expertise in policy and administrative issues related to scope of practice and advanced practice) to evaluate its content validity. Only minor changes were requested in the questionnaire. Cronbach's α reliability scores ranged from .31 (for midwives) to .67 (for the emergency and pediatric intensive care groups). Test-retest reliability (data collection with a difference of three weeks) was $r = .92$.

Attitudes towards future practice scale. This questionnaire was also designed by the investigators and describes attitudes towards the expansion of the scope of practice in the future. The questionnaire is based on that of Brodsky and Van Dijk (2008). The original questionnaire was distributed to nurses and physicians and described attitudes towards the introduction of the advanced practice role. The current questionnaire is addressed only to nurses with post-basic certification, and several additional items were added that were relevant to the current population. The questionnaire asks respondents to describe on a Likert scale from 1 (*strongly disagree*) to 6 (*strongly agree*) their level of agreement with 15 items. The questionnaire includes items such as what is the nurse's agreement with expanding their scope of practice to include prescriptive authority or whether they agree that further expansion of their scope of practice will improve their quality of patient care. Scores can range from 15 to 90, with higher scores indicating more positive attitudes towards increasing the extent of scope of practice in the future. The questionnaire was sent to five content experts (five nurses with expertise in policy and administrative issues related to scope of practice and advanced practice) to evaluate its content validity. Only minor changes were requested in the questionnaire.

Cronbach's α reliability was .92 and test-retest reliability (data collection with a difference of three weeks) was $r = .99$.

Practice behavior scale. This tool is a 30-item, Likert type questionnaire designed to measure professional autonomy (Dempster, 1990). The questionnaire is divided into four sections: readiness (11 items), empowerment (7 items), actualization (9 items), and valuation (3 items). Items are rated on a scale from 1 (*not at all*) to 5 (*strongly agree*). Final scores range from 30 to 150, with higher scores demonstrating higher levels of autonomy.

Written permission was granted by the author of the questionnaire for its use and translation into Hebrew. The Brislin method (1970) was used for forward and back translation. Cronbach's α for the entire scale was found to be .90, with subscale scores ranging from .69 to .85.

Practice self-efficacy scale. Self-efficacy is a concept that must be measured within a specific context; therefore, this scale was designed by the authors for this study. The scale consists of nine items that measure efficacy expectations, a type of self-efficacy. Each item measures the level to which the respondent feels he or she is able to perform a specific nursing practice. For example, "I think that I am able to interpret x-ray reports (after instruction) in an acceptable, safe and efficient manner." Items are measured on a Likert scale from 1 (*strongly disagree*) to 4 (*strongly agree*). Higher scores indicate higher levels of efficacy expectations for the specific practice.

The questionnaire was sent to five content experts (five nurses with expertise in policy and administrative issues related to scope of practice and advanced practice) to evaluate its content validity. Cronbach's α reliability was found to be .89, while test-retest reliability (3 weeks apart) was $r = .99$.

Data Collection

After institutional ethical approval, the investigators received approval from the nurse managers to collect data. Some nurse managers preferred that data be collected during a staff meeting. A brief explanation was given about the study, and then nurses were asked to complete the questionnaire while one of the investigators was present to answer any questions. On other units, questionnaires were individually distributed. Questionnaires were returned to a closed envelope.

Ethical Issues

The study was approved by the ethics boards of both institutions. Questionnaires were anonymous and were

Table 2. Demographic and Work Characteristics

Demographic characteristics			Work characteristics		
Variable	<i>n</i>	Result	Variable	<i>n</i>	Result
Age (years)	141	<i>M</i> = 42.7 <i>SD</i> = 9.7 <i>Range</i> = 26–66 Missing: 4	Experience as RN	144	<i>M</i> = 15.8 <i>SD</i> = 9.2 <i>Range</i> = 2–43 Missing: 1
Sex	145	Female: 131 (90.3%) Male: 14 (9.7%)	Experience on current unit	143	<i>M</i> = 9.9 <i>SD</i> = 7.6 <i>Range</i> = 1–36 Missing: 2
Family status	143	Married: 109 (76.2%) Single: 24 (16.8%) Divorced: 9 (6.3%) Other: 1 (0.7%) Missing: 2	Years since post-basic certification	140	<i>M</i> = 10.6 <i>SD</i> = 8.6 <i>Range</i> = 1–36
Religion	144	Jewish: 131 (90.3%) Muslim: 9 (6.3%) Christian: 3 (2.7%) Other: 1 (0.7%) Missing: 1	Type of certification	145	Neonatal/Pediatric ICU: 47 (32.4%) Midwifery: 37 (25.5%) Adult ICU: 30 (20.7%) Emergency: 18 (12.4%) Oncology: 13 (9.0%)
Place of birth	140	Israel: 87 (62.1%) Eastern Europe: 39 (27.9%) Americas: 8 (5.7%) Western Europe: 4 (2.9%) Africa: 2 (1.4%) Missing: 5	Nursing education	144	BA in nursing: 68 (46.9%) MA in nursing: 20 (13.8%) MA in other field: 19 (13.1%) RN: 19 (13.1%) BA in other field: 18 (12.4%)
			Role	145	Staff nurse: 38 (26.2%) Senior nurse: 88 (60.7%) Nurse administrator manager: 19 (13.1%)

Note. ICU = intensive care unit.

distributed and stored according to the local ethics board regulations.

Statistical Analysis

Descriptive statistics were used to describe the sample and results of the questionnaires. This included mean, standard deviation, and frequency data. Associations between variables were assessed using Pearson product moment correlations. Two regression models were designed. The predictor variables for both models were professional autonomy, self-efficacy, age, sex, years of experience as a nurse, years worked on the current unit, nursing education, role, and type of post-basic certification. The criterion variable for the first model was current implementation of scope of practice while future implementation of scope of practice was used for the second model.

Results

Questionnaires were distributed to 207 nurses from 13 units in two institutions, and 145 were returned (70% response rate). The mean age of nurse participants was 43 years, with a mean of 16 years as a nurse and 10 years working on the current unit. Most nurses were women ($n = 131$, 90%) with an academic education (BA or MA; $n = 88$, 61%). For further demographic data, see **Table 2**.

The mean level of implementation of current scope of practice was 2.77 (standard deviation [*SD*] = 0.91; possible range: 1–5). The highest percentage of nurse implementation (defined as often or always) for the six practices that were common to all units was for giving an intravenous drug (IV push) ($n = 96$, 67%; mean [*M*] = 3.7, *SD* = 1.6). The lowest level of implementation was for removal of an arterial line ($n = 63$, 44%; $M = 2.8$, *SD* = 1.9). Levels of implementation

Table 3. Mean Levels of Current Implementation of Scope of Practice by Type of Certification

Practice	Type of certification, <i>M</i> (<i>SD</i>)				
	Adult ICU (<i>n</i> = 30)	Neonatal/pediatric ICU (<i>n</i> = 47)	Emergency (<i>n</i> = 18)	Oncology (<i>n</i> = 13)	Labor and delivery (<i>n</i> = 37)
Handheld defibrillation	2.5 (1.3)		2.3(1.4)		
Attach pacemaker electrodes and set heart rate	2.5 (1.3)		2.6(1.4)		
Set ventilator settings for weaning	4.0 (1.2)	1.8(1.2)	1.6(0.9)		
Connect and disconnect patient to ventilator	4.6 (0.6)	4.0(1.5)	3.6(1.1)		1.0(0.0)
Insertion of arterial line		1.2(0.8)			
Removal of arterial line	4.7 (0.6)	3.9(1.5)	1.5(1.2)	1.0(0.0)	1.1(0.7)
Draw blood from an arterial line	4.6 (1.0)	4.7(0.5)	1.4(1.0)	1.3(1.1)	1.0(1.3)
Administer drugs IV push	4.6 (1.0)	4.6(0.8)	3.0(1.6)	3.8(1.3)	2.0(1.3)
Administer drugs IV push to central line	4.4 (1.2)	4.3(1.0)	1.8(1.4)	3.7(1.4)	1.1(0.7)
Draw blood for type and cross-matching	3.5 (1.7)	3.0(1.7)	1.6(1.3)	4.4(1.2)	4.8(0.9)
Care of a Swan-Ganz catheter	2.7 (1.6)		1.1(0.5)		
Blood drawing for laboratory tests, including arterial blood gases	4.7 (0.8)				
Drawing of mixed-venous blood from a Swan-Ganz catheter	1.8 (1.2)				
Draw peripheral arterial blood from a newborn			√ (up to 1 year old)		
Insert peripheral IV to newborn		3.4(1.6)	√ (up to 1 year old)		
Draw venous blood from newborn peripheral vein		2.6(1.6)	√		
Insert peripheral venous line on the scalp and legs of newborn		3.0(1.6)			

Note. ICU = intensive care unit; IV = intravenous.

for other practices are detailed in **Table 3**. Nurses who had certification in intensive care had the highest level of current implementation ($M = 3.7$, $SD = 0.5$), while nurses with labor and delivery post-basic certification had the lowest levels of implementation ($M = 1.8$, $SD = 0.4$). This difference was statistically significant, $F(4,140) = 66.0$, $p \leq .01$. The majority of nurses with labor and delivery post-basic certification did not implement any of the six extended practices (57–100% of nurses), with the exception of taking blood for type and cross-matching ($n = 2$, 5%). This is in contrast to the finding that 8 of 12 extended practices were implemented often or always by the majority (60–97%) of intensive care unit (ICU) nurses.

Nurses who did not implement a practice were asked why not, using a structured checklist. The reason most commonly cited (40% of the responses) was “other.” The most cited answers for this category were that the practice was not relevant or was uncommon. The next most cited responses were lack of permission (23%) and prohibited to practice (18%). Fewer nurses reported a lack of knowledge (14%) or lack of confidence (6%) to perform the practice.

The mean score for future implementation of extended scope of practice was 4.4 ($SD = 1.0$) (possible range 1–6). Highest scores were for referral to laboratory tests and their interpretation ($M = 4.9$, $SD = 1.0$) and prescriptive authority based on standardized protocols ($M = 4.7$, $SD = 1.3$). Nurses thought that extending the scope of practice was important ($M = 4.8$, $SD = 1.4$), would im-

prove nursing care ($M = 4.7$, $SD = 1.4$), and would improve the overall quality of care ($M = 4.6$, $SD = 1.2$).

The mean level of professional autonomy was 118.8 ($SD = 12.5$; range: 81–145). Highest scores were in the subscale of actualization ($M = 4.4$, $SD = 0.5$), followed by valuation ($M = 4.2$, $SD = 0.6$), readiness ($M = 4.0$, $SD = 0.5$), and empowerment ($M = 3.4$, $SD = 0.6$). No statistically significant differences were found between the different types of post-basic certification on professional autonomy or its subscales.

The mean level of self-efficacy was 3.1 ($SD = 0.7$; possible range: 1–4). Most nurses felt able to extend their current scope of practice ($n = 86$, 59%), prescribe medications ($n = 103$, 71%), or refer patients for laboratory tests and interpret them ($n = 85$, 59%). No statistically significant differences were found between the different types of post-basic certification on levels of self-efficacy.

No statistically significant associations were found between the current level of implementation of scope of practice and future levels of implementation of extended scope of practice, self-efficacy, or professional autonomy for the entire sample. However, statistically significant associations were found between current implementation of scope of practice and professional autonomy among nurses with ICU post-basic certification ($r = .37$, $p \leq .05$) and pediatric ICU certification ($r = .36$, $p \leq .05$). Statistically significant associations were found between future implementation of extended scope of practice and professional autonomy ($r = .36$, $p \leq .01$) and self-efficacy ($r = .75$, $p \leq .01$).

The majority of the shared variance in the scores for current implementation of the scope of practice (68%) was found to be significantly predicted by a model including future levels of implementation, professional autonomy, self-efficacy, and demographic variables, $F(17,120) = 18.3, p \leq .01$. Only current role and type of post-basic certification were found to be significant predictors, where those in administrative roles and nurses with pediatric and ICU post-basic certifications were found to have higher levels of implementation. Other demographic and work characteristics were not found to be statistically significant predictors in the model. A similar model was built with future implementation of scope of practice as the criterion variable. This model was also found to be statistically significant, $F(17,120) = 11.0, p \leq .01$, explaining 56% of the shared variance, with the variables of self-efficacy and actualization of professional autonomy statistically significant predictors. Increased levels of self-efficacy and actualization predicted higher levels of future implementation. Demographic and work characteristics were not found to be statistically significant predictors in the model.

Discussion

The nurses in this study demonstrated a wide range of implementation of the extent of their scope of practice. However, the overall mean was low to moderate, where those in the adult ICUs had a moderate-high level, pediatric ICU and oncology a moderate level, and emergency and labor and delivery a low level of implementation of the full extent of the scope of practice. It was also found that nurses had positive attitudes towards increased scope of practice expansion. Participants demonstrated a high level of self-efficacy, indicating a high ability and readiness to take on expanded practices. In addition, the participants had high levels of professional autonomy that were positively associated with attitudes towards scope of practice expansion. These results point to the readiness of nurses to expand their scope of practice.

Two primary reasons were given as to why nurses do not implement the full extent of their scope of practice. The first was lack of relevance of many of the practices to the work environment. For example, nurses working in labor and delivery or oncology have little or no reason to remove an arterial line, while almost all nurses take blood for type and cross-match. Similar results were reported by Kilpatrick et al. (2012), who found a low level of implementation among nurse practitioners for those practices that were uncommon (e.g., using defibrillators).

The second reason was the lack of permission to perform the practice by supervisors or institutional policy, where approximately one quarter of the sample described

this as the reason they did not practice to the full extent of their authority. Few nurses cited lack of knowledge or time.

Nurses in this study had very positive attitudes towards expanded scope of practice, as was found in other studies (Brodsky & Van Dijk, 2008; Goldberg et al., 2012). Participants also had high levels of professional autonomy, irrespective of the type of certification. These results are also similar to findings in other studies (Cajulis & Fitzpatrick, 2007). Nurses showed high levels of self-efficacy, again without differences between types of certification. This demonstrated an across-the-board readiness and support of nurses in the field for the expansion of their scope of practice. According to Bandura (1982), this is related to a successful completion of these practices. For example, nurses in this study expressed a willingness and readiness to have prescriptive authority or referral of patients to laboratory tests, roles associated with advanced practice.

No statistically significant associations were found with current levels of implementation. These consistent results imply that predominantly external forces as opposed to internal forces seem to be related to a lack of implementation of the full extent of the scope of practice. Others have found a significant relationship between professional autonomy and implementation of scope of practice (Kilpatrick et al., 2012). One possible explanation is the differences in the healthcare systems, culture, and policies of the two countries where the research was conducted. Others have also found that as levels of professional autonomy increase, there are more positive attitudes towards expansion of scope of practice (Goldberg et al., 2012).

Two variables were found to predict the extent of implementation of the scope of practice: role and type of certification. Like Brodsky and Van Dijk (2008), those in administrative positions were more likely to have implemented their scope of practice. Such nurses are also more likely to have a higher level of commitment, levels of self-confidence, knowledge, and training. ICU nurses were also found to have higher levels of implementation. This result is consistent with the findings listed earlier that described an increased relevance of expanded practices to those who work in critical care as opposed to maternity or oncology.

Two other variables were found to positively predict future implementation: self-efficacy and actualization (a subscale of professional autonomy). While no study was found that can be related to these findings, they are consistent with Bandura's self-efficacy theory, where the higher the level of personal feelings of authority and responsibility, the higher the feeling that one is able to perform the practice and wants to perform it in the future.

It is recommended that further studies be conducted in other countries on registered nurses with different forms of education. Other factors and barriers to current and future implementation of full scope of practice such as peer and interprofessional relationships should also be investigated.

The results of this study demonstrate that nurses with post-basic certification feel willing and able to expand their scope of practice to areas associated with advanced practice. Therefore, policymakers should take advantage of this fact and promote the introduction of advanced practice in these clinical areas. Administrators and policymakers should also investigate what are the specific factors associated with administrative barriers to expanding nursing scope of practice as well as matching the expanded practices with the specific work environment.

Limitations

This study contains several limitations. First, it was conducted in only one country and in two institutions. Second, most of the questionnaires used in the study were designed by the authors. Almost all of the reliability and validity scores were within acceptable levels, except for the current level of implementation of scope of practice among labor and delivery nurses. It is possible that this score has a lower internal consistency because of the great variation in current practices across units or because most nurses did not implement most of the practices. In addition, one of the questionnaires was translated into Hebrew. While the translation was validated, there might be cultural and language differences between the two versions of the questionnaire. The response rate was 70%, which also might have led to a bias in the results. Results of this study were based on self-report, and there were no "objective" means of data collection to determine whether nurses practiced to the full extent of their scope of practice. It is also possible that other factors and barriers could be associated with implementation, such as interprofessional relationships, the work environment, or other personal characteristics, that were not investigated. Several comparisons between clinical areas were found to be statistically significant. However, it should be noted that some of the areas contained a small number of nurses, and so conclusions based on the data should be taken with caution.

Conclusions

Nurses wanted to practice to the full extent of their scope of practice and felt able to do so but were hindered by administrative barriers. Therefore, it is recommended that efforts continue to expand the scope of practice for

registered nurses, that factors associated with administrative barriers be investigated and eliminated, and that further research be conducted with other nurses and in other countries to determine what factors are associated with the implementation of the full scope of practice.

Clinical Resources

- American Nurses Association. Scope of practice: <http://www.nursingworld.org/EspeciallyForYou/AdvancedPracticeNurses/Scope-of-Practice-2>
- Nursing Council of New Zealand. Scopes of practice: <http://www.nursingcouncil.org.nz/Nurses/Scopes-of-practice>
- Nursing and Midwifery Board of Australia. Fact sheet: Contest of practice for registered nurses and midwives: <http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/FAQ/Context-of-practice-for-registered-nurses-and-midwives.aspx>

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PROFESSION AND SOCIETY

Methods to Succeed in Effective Knowledge Translation in Clinical Practice

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Abstract

Purpose: To explore the evidence around facilitation as an intervention for the successful implementation of new knowledge into clinical practice.

Organizing Construct: The revised version of the Promoting Action on Research Implementation in Health Services (PARIHS) framework, called the integrated or i-PARIHS framework, is used as the explanatory framework. This framework posits that evidence is a multidimensional construct embedded within innovation and operationalized by clinicians (individuals and within teams), working across multiple layers of context. Facilitation is the active ingredient that promotes successful implementation.

Findings: An emerging body of evidence supports facilitation as a mechanism to getting new knowledge into clinical practice. Facilitation roles are divided into beginner, experienced, and expert facilitators. Facilitators can be internal or external to the organization they work in, and their skills and attributes complement other knowledge translation (KT) roles. Complex KT projects require facilitators who are experienced in implementation methods.

Conclusions: Facilitation is positioned as the active ingredient to effectively introduce new knowledge into a clinical setting. Levels of facilitation experience are assessed in relation to the complexity of the KT task. Three core facilitation roles are identified, and structured interventions are established taking into account the nature and novelty of the evidence, the receptiveness of the clinicians, and the context or setting where the new evidence is to be introduced.

Clinical Relevance: Roles such as novice, experienced, and expert facilitators have important and complementary parts to play in enabling the successful translation of evidence into everyday practice in order to provide effective care for patients.

Knowledge translation (KT) is the generic term used to describe the process by which knowledge moves from where it was first created and refined to where it has to get to in order to make an impact on clinical practice and patient care. Many different terms have been used to describe this process, ranging from knowledge utilisation to translational research, dissemination of research findings, implementation science, and evidence-based practice or healthcare (McKibbin et al., 2010).

Historically, models representing the KT process have tended to depict it as a “pipeline” that moves from knowledge generation through a process of synthesis to uptake and implementation in practice (Haines & Jones 1994). This is based on an assumption that producers and users of research are two separate groups or communities and that translation occurs in a rational, linear way to move knowledge from producers to users (Landry, Amara, & Lamari, 2001). When KT appears to

Table 1. Elements of the PARIHS Framework and the i-PARIHS Framework

Successful implementation in the original PARIHS framework	Successful implementation in the revised i-PARIHS framework
SI = $f(E,C,F)$	SI = $Fac^n(I + R + C)$
SI = successful implementation	SI = successful implementation
f = function (of)	Achievement of agreed implementation/project goals
E = evidence	The uptake and embedding of the innovation in practice
C = context	Individuals, teams, and stakeholders are engaged, motivated, and “own” the innovation
F = facilitation	Variation related to context is minimized across implementation settings
	Fac ⁿ = Facilitation
	I = innovation
	R = recipients (individual and collective)
	C = context (inner and outer)

Note. i-PARIHS framework = Promoting Action on Research Implementation in Health Services integrated framework; PARIHS framework = Promoting Action on Research Implementation in Health Services framework.

be slow or incomplete, the metaphor of “translational gaps” is used, and various bridging strategies are proposed to try to close the gap. However, evidence from KT research repeatedly highlights the complexity of the process and the multifaceted factors that determine whether and how research-based knowledge finds its way into health-care policy and practice (Kitson, Harvey, & McCormack, 1998). These factors include the negotiated and contested nature of evidence in healthcare decision making, meaning that good research is not sufficient in itself to ensure its uptake in practice (Rycroft Malone et al., 2004), and the significant impact of context on the way knowledge is taken up (Damschroder et al., 2009; McCormack et al., 2002). Systematic reviews also indicate that so-called “multifaceted” or complex interventions are more effective than “single” or simple interventions (Harvey & Kitson 2015a), but there is no consensus on what constitutes a complex intervention, how it’s done, who should do it, or indeed how it would be evaluated.

In framing this article, we have drawn on several years’ experience in working with groups of clinicians and researchers in trying to understand the nature of such complex interventions and how new knowledge moves into practice. Our work has been around developing, testing, and refining the Promoting Action on Research Implementation in Health Services (PARIHS) framework (Kitson et al., 1998; Kitson et al., 2008; Rycroft-Malone et al., 2002). The PARIHS framework is a widely used approach to creating a structured method to introduce KT principles into practice. It has been used as an organizing framework (Helfrich et al., 2010) and as an evaluation tool within research studies (Gibb, 2013).

From its inception, PARIHS argued that successful implementation (SI) of evidence into practice was a function of the quality and type of evidence (E), the characteristics of the setting or context (C), and the way in which

the evidence was introduced or facilitated (F) into practice. Each of these elements was subdivided into discrete dimensions that helped to explain the complexities and interdependencies in action when new knowledge was being put into practice (Rycroft-Malone et al., 2002). It has recently been refined and the new framework, called the i-PARIHS framework, contains a practical set of instructions for people wishing to use it (Harvey & Kitson, 2015b).

Facilitation as the Active Ingredient in KT

The i-PARIHS framework has refined the dimensions around evidence (E); refined the context elements (C); and added a new dimension around the individuals and teams who have to decide how they want to use the new knowledge or evidence (termed recipients or [R] in the framework). **Table 1** provides a summary of the original PARIHS formula and the new i-PARIHS approach. The core constructs of the i-PARIHS framework are facilitation (F), innovation (I), recipients (R) and context (C), with facilitation represented as the active element assessing, aligning, and integrating the other three constructs.

In i-PARIHS, the term innovation describes the focus or content of the implementation effort. It has been extended to encompass what we know about innovation theory and how individuals react to characteristics of new knowledge in addition to its evidence base. It is the role of the facilitator, working with the clinical team and other stakeholders, to work out what the nature of the new knowledge is that is being translated into practice. Is it the implementation of existing evidence such as a clinical guideline or results or a systematic review, or is it a service change or improvement that has less evidence to support it? Who or what is driving the proposed change

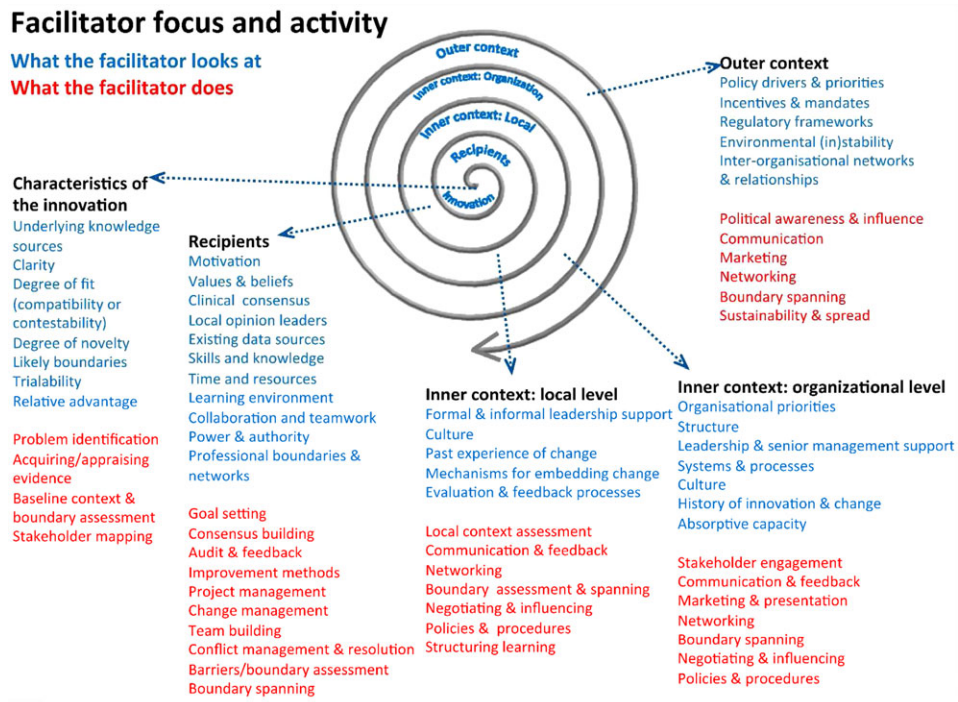


Figure 1. The Promoting Action on Research Implementation in Health Services integrated framework (i-PARIHS framework): facilitation as the active ingredient (reprinted with permission from Harvey & Kitson, 2015).

will also influence how other clinicians respond to the implementation process, and the degree of novelty between the new knowledge and what teams currently do will influence individual and team reactions.

After considering the characteristics of the proposed “innovation,” the facilitator next considers the “recipients” of the new knowledge and how they will respond to the changes required to implement the innovation. The term recipient within the i-PARIHS framework refers to staff, support services, and patients that will be directly involved in and affected by the implementation process. The facilitator will explore issues related to individual and team motivation and their ability to change behavior in relation to the new knowledge and work with them to make those necessary changes.

A further dimension of the facilitation process within the i-PARIHS framework is developing an understanding of contextual factors and how best to handle these, both within and outside of the organization, in terms of their potential impact on the success of the KT process. Contextual factors include local characteristics such as leadership style, culture, past experience of change and mechanisms used to embed change, and routine methods of providing feedback on performance. By contrast, the characteristics at the organizational level of context include consideration of organizational priorities and the amount of alignment to the new KT initiative, leadership

and senior manager understanding and support of the initiative, history of successful innovation and improvement, and the amount of capacity the organization has to cope with innovation.

The final part of context within i-PARIHS is the outer context. This is where the facilitator assesses the wider policy drivers and proprieties that might influence the KT initiative locally, incentives and mandatory requirements, regulatory frameworks, and interorganizational networks and relationships. **Figure 1** summarizes the new i-PARIHS dimensions in terms of what the facilitator focuses upon and consequently what they have to do.

Why Facilitation?

Facilitation is defined as a process of enabling individuals, groups, or teams to work effectively together to achieve a common goal (Schwarz, 2002). Facilitation as a method is derived from three philosophical traditions: therapeutic, client-centered approaches (Rogers, 1969); group learning experiences (Heron, 1989; Reason, 1988), and action science (Argyris & Schon, 1996). These traditions emphasize the importance of shared, experiential learning in order to achieve individual and organizational change. Argyris and Schon’s work in particular recognized the importance of acknowledging the individual in the system and how, by unlocking their ability to

Table 2. Core Activities of Facilitators Within the i-PARIHS Framework (adapted from Harvey & Kitson, 2015)

Facilitator	Skills and experience
Novice	<ul style="list-style-type: none"> Beginning to build up repertoire of comparing organizational contexts and cultures Learning how to speed up/refine certain processes Networking people across sites and building capacity Embedding innovations into organizational infrastructure Understanding how to sustain the innovation and promote its spread across the system Knowing how to measure impact
Experienced	<ul style="list-style-type: none"> In-depth understanding and knowledge of the organization or organizations they are working with Awareness of competing tensions and how to manage these around innovations In-depth understanding of individual motivations and productivity Knowledge of team motivation and productivity Experienced and knowledgeable in local context evaluation Able to assess system-wide activities and influence actions Aware of wider contextual issues and confident in terms of managing boundaries and political tensions
Expert	<ul style="list-style-type: none"> Coordinating facilitation networks Working with systems to improve implementation success Working across academic, service, and other organizational boundaries to integrate facilitation and research activity Developing and testing theories of implementation, innovation, and facilitation Evaluating interventions Generating new knowledge Refining and improving learning materials and mentoring processes Running workshops and advanced master classes on facilitation approaches

Note. i-PARIHS framework = Promoting Action on Research Implementation in Health Services integrated framework.

reflect on their everyday practices, they could improve what they did. Within the i-PARIHS framework, the reflective process enabled by the facilitator is to help individuals and teams think creatively about how their performance could be improved by utilizing the new knowledge being introduced. The connection between reflection and action leading to improvements naturally links facilitation to quality improvement activity and to theories of innovation and organizational change.

There is growing empirical evidence that facilitation, as a KT approach, is effective in primary care settings (Baskerville, Liddy, & Hogg, 2012; Harvey et al., 2015; Knox et al., 2011), in community development programs (Eriksson & Wallin, 2015), and in a number of acute and sub-acute care settings (Wiechula, Shanks, Schultz, Whitaker, & Kitson, 2015). In further developing and refining the evidence base around facilitation as a successful intervention, it is important to provide guidance on the role of facilitators; their selection, preparation, and support; and how their interventions can be evaluated.

Facilitation Roles

The i-PARIHS framework has identified three distinct facilitator roles: the beginner or novice facilitator, the experienced facilitator, and the expert facilitator. **Table 2** summarizes the key elements of each facilitator role, the mentoring and support mechanisms around them, and

what they are expected to be able to achieve. The beginning or novice facilitator may be someone from within the organization (clinician, manager, or administrator) who has been involved in a small improvement or research project and who has demonstrated a set of interpersonal and interactive skills that equip them to become more effective KT facilitators. Effective novice facilitators are able to clarify the task in hand; identify key stakeholders; clarify who needs to be part of the KT team; demonstrate the specific skills required to get the team working effectively; know how to engage emotionally as well as intellectually with the proposed change; and be able to engage team members as individuals, recognizing their particular learning and development needs.

The i-PARIHS framework operates by building on the facilitation skills found in individual healthcare professionals across systems. The challenge is to identify local novice facilitators who can then be mentored and supported to lead KT projects, first in their units and then across departments and ultimately across the whole organization. The facilitator's role is to enable and encourage individual clinicians to think in a systematic way and to help them create a way of working that embraces continuous improvement of their practice based on the best available evidence.

Experienced facilitators support the novice facilitator. Experienced facilitators will have worked as novice facilitators for a period of months or years, learning the skills and techniques of facilitation. This experience will

equip them to begin to take on larger, more organizational wide projects. Working under the supervision of an expert facilitator, they begin to develop their understanding of how wider contextual factors influence successful implementation. They will know how to manage competing tensions around innovations, be confident in dealing with individual motivation and productivity in more complex circumstances, and be able to develop and extend the range of techniques employed to keep teams working productively together and on task in terms of implementing the new evidence or innovation.

The experienced facilitation role also monitors and assesses wider system activities and ensures local initiatives are protected so they can be embedded into routine practices. Building upon the basic facilitation skill set (see **Table 2**), the experienced facilitator also develops skills related to developing capacity and sustaining change. These include knowing how to embed the new evidence or ideas into routine practices. Studies have shown that by standardizing the new evidence into an existing policy or procedure or task within the clinical setting, the innovation is more likely to be accepted and the changes maintained (Wiechula et al., 2015).

A second set of approaches relates to the experienced facilitator's ability to promote a positive attitude about the innovation to all stakeholders. This requires the experienced facilitator to know how to "sell" the benefits and illustrate how the proposed or new initiative benefits stakeholders. The third dimension the experienced facilitator works on is the embedding of audit and feedback processes for teams so they get continuous feedback on their performance. This shapes the evaluative and reflective culture of the clinical setting, moving it from what can be a hierarchical system of command and control to an approach that is interactive, dynamic, and based on evaluation of routinely collected data.

These techniques developed by the experienced facilitator have a sound theoretical basis. May and Finch's (2009) work on Normalisation Process Theory illustrates the importance of new ideas becoming part of everyday routines through processes such as sense making, collective action, and monitoring. Masso, McCarthy, and Kitson's (2014) study of how a number of innovations were introduced into aged care facilities across Australia found that it was the ability of teams to understand and share experiences that led them to "make sense" of the innovations that determined their eventual adoption and uptake. A key finding from this study was the variability of the amount and quality of the facilitation of the KT projects, which helped explain the variability in adoption and uptake.

The "expert facilitator" role acts as the overall strategic lead for the KT initiative. Providing coordination,

leadership, and high-level guidance on the four dimensions of the i-PARIHS framework, the expert facilitator tends to work across organizations and in particular work across the academic–healthcare boundary. Such "facilitation networks" have been promoted by organizations such as the Agency for Healthcare Research and Quality to promote practice facilitation networks for improving the uptake and adoption of new knowledge in the form of evidence into primary care practice (Knox et al., 2011). It is within the role and remit of expert facilitators to establish such networks both to promote the uptake of evidence into practice (Baskerville et al., 2012; Liddy et al., 2013) and using facilitation methods to promote longer-term sustainably (Hogg, Lemelin, Moroz, Sots, & Russell, 2008).

The expert facilitation role needs to be positioned at a strategic level with the authority to influence behaviors and actions across multiple systems. Expert facilitators would therefore be experienced in dealing with the outer system level contextual challenges as identified in the i-PARIHS framework, such as engaging stakeholders; understanding the politics and power relations; effective communication; and moving across and between multiple boundaries and organizational levels. In addition to these political negotiating skills, the expert facilitator is also a coach and mentor to other facilitators across the network—a technical expert in terms of "doing" facilitation and experienced in evaluation and research approaches.

The expert facilitator role can be located in academia with strong links to practice or it can be based in a healthcare organization with links to an academic institution. Applying learning from contemporary research into such partnerships (Harvey et al., 2015; Kitson et al., 2015) will help to develop more advanced understanding around the sorts of mechanisms that need to be established to enable the spread of new knowledge across systems.

One final aspect of the facilitator's role that has been discussed in the literature is whether the role is "internal" or "external" to the organization (Stetler et al., 2006). In studying the implementation of research findings within the Veterans Health Administration system, Stetler and colleagues outlined the pros and cons in having facilitators who belonged to (internal) or were outside of (external) the system. Knox et al. (2011) have also developed this idea and have identified a number of advantages and disadvantages to both the internal and external role. Such considerations would be part of the assessment and diagnostic phase of any KT project where expert facilitators (themselves perhaps external facilitators) would consider the internal capacity of the organization to recruit and use local novice and experienced facilitators.

Facilitating a KT Project

Expert facilitators would meet with the senior executive team and elicit from them information around the structure, culture, and processes of the organization. They would also explore the range of support roles available across the organization for activities such as quality improvement, safety, and professional development. Building on this resource, the expert facilitator would work with the executive team to identify a number of experienced facilitators who would then start to work with and mentor the local beginner or novice facilitators.

Someone with a clinical background may decide or be invited to work on a KT or improvement project, which uses best available evidence. Working under the supervision of an experienced facilitator and mentored by an expert facilitator, beginner or novice facilitators would become familiar with the use of evidence in healthcare and how that links to innovations in practice. They would also develop skills around assessing the quality of evidence and involve colleagues in talking about current practice and what can be improved. Building on the principles of effective teamwork (and outlined in Harvey & Kitson, 2015b), the novice facilitator would learn how to engage, motivate, and manage individual and team activity.

Another important dimension is developing the novice facilitator's understanding of and ability to influence the context or setting where the evidence is to be introduced. Context in the i-PARIHS framework refers to features such as resources, culture, leadership styles, and how individuals and teams give and receive feedback on what they do. From this "unit" level perspective, there are also a number of broader influences that affect what happens on the ground. These are referred to as organizational and broader system levels of context.

Common methods employed by facilitators typically involve improvement approaches such as Plan-Do-Study-Act cycles and audit and feedback, underpinned by project management (Harvey & Kitson, 2015b). This helps to address key issues such as establishing clear goals, demonstrating the potential for improvement, providing regular feedback, and trialing changes on a small scale—all important factors in terms of securing and maintaining staff motivation and commitment.

The designated facilitator role complements the formal role of the unit lead. The unit lead can draw on the facilitation and project management skills of the local novice facilitator to ensure that the whole clinical team is mindful of the core elements of evidence-based practice. Working with clinical teams to solve real problems where members can test out new ideas using best available evidence will create a culture of inquiry and innovation. Such activity is captured by the formal reporting

structure created by the KT project structure and time-frames. It is always crucial for the senior executive to set the KT project up within a tight project management timelines and clear deliverables.

In supporting this level of development and training, the senior executive team is building the capability of the workforce. Using locally identified staff to develop their facilitation skills means that the system is being enriched by encouraging individuals and teams to take a more reflective approach to their clinical practice. The senior team also operates as executive sponsors of the local work so that when problems emerge they will be able to influence decisions in other parts of the wider system. Wiechula et al. (2015) described how a facilitation approach supported by the executive nursing leadership of one organization improved the nutritional care of vulnerable patients at risk for malnutrition in the acute care setting.

Facilitation Compared to Other Enabling and KT Roles

The facilitator's role in a KT project is to enable the adoption of new knowledge into practice using action-learning techniques. They work closely with existing clinical teams and unit leads to make this happen. The Cochrane Effective Practice and Organisation of Care review group has also explored different roles, including opinion leaders, academic detailers, knowledge brokers, boundary spanners, knowledge managers, project managers, and change champions (<http://www.epoc.cochrane.org/>). These roles differ in terms of theoretical underpinning and in how the knowledge is moved between individuals and systems. For example, opinion leaders are individuals who possess authority and have the credibility to shape how their colleagues think and act. Through their leadership, they can influence the uptake of new knowledge. However, the opinion leader is not responsible for changing colleagues' behaviour, so the impact on KT is more passive if this approach is used rather than facilitation approaches.

Academic detailing has emerged from studies in medical sociology looking at how physicians could change their prescribing practices. Trained to impart precise knowledge to key stakeholder groups, the academic detailer targets individual decision makers and tries to influence their behavior by providing precise information. The academic detailer's role is not to consider the wider context or individual behavior within teams. Knowledge broker and boundary spanner roles have often been set up within large organizations (e.g., within public health structures) that have diffuse and wide-ranging

stakeholder groups that need to be kept up to date with new developments. They connect different parts of the system working across departments and organizations. As such, they reflect the stakeholder management role of the facilitator along with paying attention to the local cultures and contexts.

The role of knowledge managers is more formally linked to ways of ensuring that knowledge moves effectively throughout large organizations. The role often embraces both the technological and social networking requirements of knowledge management. The role would not generally be expected to ensure that the recipients use the knowledge resource effectively. Project managers are responsible for accomplishing the stated objectives of a project; while facilitators will have project management skills, they will also be expected to enable others to develop such skills as well as achieving the task. Change champions are individuals who voluntarily take on a role in helping the adoption, implementation, and use of something new into the system. They help to get a new idea accepted at the local level. Similar to the opinion leader role, change champions are a valuable asset in terms of shaping and influencing others' thoughts and behaviors.

Discussion

While there is growing evidence around the impact of facilitation on successful implementation of evidence into practice, there are still a number of unresolved issues. For example, Berta et al. (2015) have argued that the theoretical underpinnings of facilitation have not been sufficiently elucidated, thereby rendering the subsequent development and use of facilitation interventions difficult to measure and evaluate. Other research teams argue that leadership roles are more important in achieving uptake of new evidence (Gifford et al., 2012) and in particular leadership roles that are facilitative in nature (Wong, Cummings, & Ducharme, 2013).

Other teams have focused on the importance of context and how it influences the movement of knowledge across organization (Damschroder et al., 2009). There continues to be significant investment in the generation of new evidence in the shape of guidelines and other relevant products, although the evidence of their effective uptake and use has been disappointing. Schuster, McGlynn, and Brook's (1998) landmark study, which found that less than two thirds of patients received care based on evidence-based guidelines, was replicated in Australia. This team found that only 58% of the Australian public received evidence-based care when they visited their family physician or primary care area (Runciman et al., 2012).

This suggests that we do have to change the way we think about engaging the generators and users of new knowledge in more interactive and inclusive ways. Traditional methods do not work, and it would be fair to argue that approaches that are based on enabling local teams to change the way they interpret and use new knowledge would have merit. This is why the i-PARIHS framework has refined its way of conceptualizing the core elements thought to be influential in successful implementation. We have extended the concept of evidence to embrace the wider understanding of how innovations move across systems. We argue that evidence-based innovations are what we should be promoting in health systems. The i-PARIHS framework also acknowledges the central importance of the individual and team in all of this potential change. Perhaps not the most active word to describe the role, but the recipients are those who need to engage with and react to the new ideas. This is best done in conversations where interpretation and sense making are encouraged. That deep appreciation of the need to make sense of one's immediate environment helps shape the local and wider context: individuals and teams begin to feel more in control and able to experiment and to trial doing things differently (Masso et al., 2014). Our argument is that skilled facilitation enables this sort of approach to flourish. However, as we have indicated, there is still a lot more exploration to be undertaken before we can be confident we have all the elements clearly articulated.

Conclusions

The i-PARIHS framework has been used to explain how KT is implemented in practice and how individuals and leaders think about evidence and shaping the culture and context within which they work. This framework draws on the skills and capacity of facilitators who can work with individuals and teams to help them use the best available evidence in their practice.

Clinical Resource

- Implementing evidence-based practice in health-care: A facilitation guide: <https://www.routledge.com/products/9780415821926>

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WORLD HEALTH

The Impact of International Service-Learning on Nursing Students' Cultural Competency

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Key words

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Abstract

Purpose: This article reports research findings on the effect of an international immersion service-learning project on the level and components of cultural competence of baccalaureate (BSN) nursing students.

Design: A triangulated methodology was used to determine changes in components and level of cultural competence pre- and postexperience. The theoretical model *The Process of Cultural Competence in the Delivery of Healthcare Services* was used. It identifies five central constructs in the process of becoming culturally competent: cultural awareness, cultural knowledge, cultural skill, cultural encounter, and cultural desire. The sample of 121 BSN nursing students was gathered from three southern California universities. Data were collected from 2009 to 2013.

Methods: Using the *Inventory for Assessing the Process of Cultural Competence Among Healthcare Professionals-Student Version*© and *Cultural Self-Efficacy Scale*, constructs of cultural competency were measured in pre- and posttest participants who participated in international service-learning immersion experiences. A demographic survey and open-ended qualitative questions were completed at the posttrip meeting. Mean, frequencies, and correlations with demographic data and survey data were calculated. Pre- and posttrip means were analyzed. Qualitative analysis from six open-ended questions completed at the posttest were coded and themes emerged.

Findings: The research findings demonstrated the impact of the international service-learning project on building cultural competency in nursing students. Quantitative findings revealed statistically significant differences between pre- and posttest surveys for two of the five constructs of cultural competence. Qualitative analysis supported the quantitative findings in cultural competency constructs found in the model.

Conclusions: The research findings support nursing education program use of international service-learning immersion experiences to foster cultural competence in nursing students. Findings from student participants demonstrated and articulated that these program experiences strengthen the process of becoming culturally competent. The research findings support the inclusion of international service-learning experiences with debriefing and reflective learning as effective teaching strategies. Researchers have demonstrated that poor healthcare outcomes are a result of health disparities, which are then compounded by healthcare workers not being prepared to care for clients from differing cultures. The American Association of Colleges of Nursing identified innovative ways for nursing students to develop skills in cultural competency, which included international experiences.

Clinical Relevance: In nursing education, this study demonstrated that international service-learning immersion experiences are of value as they impact

and improve cultural competency. Nurses graduating with enhanced cultural understanding will contribute to decreased health disparities and improved patient care quality and safety. Further research that examines nurses' cultural competency in the patient care setting who have had previous education in international nursing could further inform nursing education and contribute to the understanding of patient satisfaction.

Researchers have demonstrated that a lack of cultural competence contributes to health disparities and poor health outcomes (Betancourt, Corbett, & Bondaryk, 2014; Institute of Medicine, 2002). Healthcare disparities create healthcare issues that are costly for patients and families as well as healthcare systems. This deficiency in cultural competency creates a gap between the nurse and safe patient-centered care. An essential dynamic of quality care is the nurse's level of cultural competency (Campinha-Bacote, 2013). Analysis of the impact of growth in ethnic populations and global immigration demonstrates the need for healthcare workers to be educated in cultural competency in order to decrease health disparities and achieve quality patient-centered care (Delgado et al., 2013; Vaughn, 2009; Waite & Calamaro, 2010). Healthy People 2020 (2015) highlights the need to address the social determinants of health, including cultural competency. Challenges to cultural competency, such as a deficiency in cultural understanding and skill and an absence of cultural sensitivity, have been identified (Clifford, McCalman, Bainbridge, & Tsey, 2015; Kwong, 2009; Maltby & Abrams, 2009). As nursing education prepares future nurses who are culturally sensitive and aware, consideration of effective teaching strategies that foster cultural competency is essential.

The American Nurses Association and American Association of Colleges of Nursing (AACN) Baccalaureate Essentials mandate nursing education to focus on diversity due to increased globalization with the expectation that for nurses to provide safe high-quality care requires cultural understanding and sensitivity (AACN, 2008a; Dolansky & Moore, 2013). Numerous investigators have described opportunities in nursing education to overcome cultural competency barriers by using national and/or international service-learning projects (Amerson, 2010; Bentley & Ellison, 2007; Kaddoura, Puri, & Dominick, 2014; Kardong-Edgren et al., 2010). Nursing education findings recommend various pedagogies to prepare future nurses to care for diverse individuals, families, and populations from cultures different from their own (Hughes & Hood, 2007; Jenkins, Balneaves, & Lust, 2011; Kardong-Edgren & Campinha-Bacote, 2008). Teaching strategies include a traditional format with classroom education and workshop training, reflective journaling, role play

in simulation, and community service-learning projects (Gallagher & Polanin, 2015; Kohlbray & Daugherty, 2013; Kohlbray & Daugherty, 2015; Worrell-Carlisle, 2005).

The AACN (2008a) has identified three qualities of culturally competent baccalaureate nurses: (a) assessment of cultural variations; (b) cultural skill in communication and assessment; and (c) awareness of personal attitudes, culture, behaviors, and beliefs (Calvillo et al., 2009). Based on these qualities, the AACN established competencies and developed the AACN Tool Kit of Resources for Cultural Competent Education for Baccalaureate Nurses (AACN, 2008b). The tool kit, with various teaching strategies to improve cultural competency, identified experiential learning through immersion experiences within diverse communities as a recommendation.

The Quality and Safety Education in Nursing (QSEN) initiative by Robert Wood Johnson Foundation and the AACN further emphasized the need for education in cultural competency to elevate quality care. QSEN competencies were developed with cultural competence as a central aspect of patient-centered care (Disch, 2010). The QSEN knowledge, skills, and attitudes for nursing student graduates include: knowledge to "describe how diverse cultural, ethnic and social backgrounds function as sources of patient, family, and community values"; skills to "provide patient-centered care with sensitivity and respect for the diversity of human experience"; and attitudes that "recognize personally held attitudes about working with patients from different ethnic, cultural and social backgrounds" as well as "willingly support patient-centered care for individuals and groups whose values differ from own" (Cronenwett et al., 2007, p. 123).

Nursing education, founded on evidence-based teaching practices, has a responsibility to "build the capacity of students" through experiences that foster cultural understanding (Hall & Guidry, 2013, p. e6). The nursing literature describes international cultural immersion programs of varying lengths of time and their value to help students appreciate global factors, expand their worldview, and understand different cultures (Hunt, 2007; Larson, Ott, & Miles, 2010).

Service-learning contributes to a student's development of cultural sensitivity, social justice, collaboration, and problem solving (Bosworth et al., 2006; Reising et al.,

2008). The differences among service-learning, community clinical experiences, and volunteerism are discussed elsewhere (Kohlbray & Daugherty, 2013; Kohlbray & Daugherty, 2015). The reciprocal value of service-learning experiences are embedding student learning in facilitating goals of the community host country (McAuliffe & Cohen, 2005). The opportunities for collaboration with social service programs and community partners maximize learning and develop cultural competence (Pretorius & Small, 2007). For example, service-learning opportunities can be found in communities near international border areas where health conditions are often more severe than generally found beyond the distance of the border area (Kohlbray, 2011). Allen, Smart, Odom-Maryon, and Swain (2013) found a significant increase in perceived cultural competency and self-efficacy in cultural knowledge, skills, and attitudes among participants in a service-learning immersion activity in Peru.

Student learning often occurs in the reflective opportunities in the experience, such as debriefing (Laplante, 2007). It is often in the reflection process that assimilation of ideas and development of understanding around the experience take place. Debriefing is a valuable teaching tool in “cementing” the students’ learning and drawing out students’ understanding of their own worldview to help develop cultural awareness.

Research, anecdotal articles, and author experience identified that students found immersion experiences worthwhile and included comments, such as “this is why I wanted to go into nursing to make a difference” (Kohlbray & Daugherty, 2015, p. 245). However, there have been few studies of rigor to provide evidence of the effect and value of immersion service-learning on cultural competency. This article reports research findings on the effect of an international immersion service-learning project on the level and components of cultural competence of baccalaureate nursing students.

Theoretical Framework

Both the AACN’s and QSEN’s recommendations for cultural competency used Campinha-Bacote’s (2013) model, The Process of Cultural Competence in the Delivery of Healthcare Services, as a framework for the development of cultural competence recommendations for nursing education. The model emphasized that cultural competence is a process of becoming based on cultural encounters or face-to-face experiences, motivated by cultural desire for those experiences. The five central constructs in the process of becoming culturally competent are cultural awareness, cultural knowledge, cultural skill, cultural encounter, and cultural desire. This model emphasizes the need for students to develop skills in

communication and understanding of those from other cultures. It provides a framework for innovative teaching strategies for students to engage in the process. Nursing education is an important time to begin that process in a comprehensive way.

Methodology

A triangulated method using quantitative pre- and posttrip surveys and a qualitative questionnaire post-immersion experience were utilized to measure cultural competency and cultural self-efficacy. The study was conducted with nursing student participants from three universities with schools of nursing in California. Undergraduate students participated in service-learning type healthcare-focused trips, utilizing their nursing skills and collaborative abilities.

Data Collection Process

Institutional review board (IRB) approval was obtained from each participating university. Once the research was IRB approved by the participating university, the faculty leading an international trip invited the researcher to a trip-planning meeting. The researcher explained the purpose of the research and surveys, the rights of the participants, the pre- and postimmersion nature of the study, and invited students to participate. Participants were informed that their participation was not related to eligibility for the trip, class requirements, or grades. Informed consent was obtained and their confidentiality was maintained. Demographic and pretrip surveys were completed. All research documents were of the paper and pencil format. Within 2 weeks of the participants’ return from the experience, they completed the posttrip surveys and the written qualitative questionnaires at a posttrip meeting. However, not all students attended the posttrip meetings; therefore, fewer posttrip responses than pretrip responses were gathered.

Instruments

Two survey instruments were used to collect quantitative data on levels of cultural competence and cultural self-efficacy. The first tool, the Inventory for Assessing the Process of Cultural Competence Among Healthcare Professionals-Student Version (IAPCC-SV®), measured cultural competence in students and is based on Campinha-Bacote’s (2013) model. The tool, found in numerous studies, was used with permission. The IAPCC-SV is a 20-item Likert 4-point scale with responses ranging from “strongly agree” to “strongly disagree.” The five constructs of the model measured are cultural awareness,

cultural knowledge, cultural skill, cultural encounter, and cultural desire. The IAPCC-SV scores four levels of cultural competence. They are culturally proficient, culturally competent, culturally aware, or culturally incompetent. Cronbach's alpha reported in various studies averaged .87 (Capell, Veenstra, & Dean, 2007).

The second tool used in the study was the Cultural Self-Efficacy Scale (CSES), developed by Bernal and Froman (1993). It measures the participant's confidence level in caring individuals from different cultures, knowledge of cultural concepts, comfort in performing cultural nursing skills, and knowledge of cultural patterns among four subscale ethnic groups: African American, Hispanic, Native American, and Asian. This tool was used with permission and is in the public domain (Coffman, Shellman, & Bernal, 2004). The tool is a 30-item Likert-type 5-point scale, with 1 equaling "very little confidence" and 5 equaling "quite a lot of confidence." An integrative review of cultural competency tools by Loftin, Hartin, Branson, and Reyes (2013) included the CSES' Cronbach's alpha coefficient range of .86 to .98. Content validity of both tools was determined by an expert panel.

The qualitative data were gathered using an interview schedule with six open-ended questions:

- What were your expectations of the service-learning project?
- What did you learn about your perceptions of individuals from another culture?
- What were the positive experiences you remember?
- What were the challenges you remember?
- Do you feel the length of your trip was sufficient to change your worldview related to culture? If so, why; if not, why not?
- Describe new knowledge that you learned about transcultural nursing.

These questions were chosen to provide a focused review. The subsequent themes would add to the quantitative findings by "exploring different dimensions of the respondents' experiences" (Jackson & Trochim, 2002, p. 307). The responses to the interview schedule were uploaded into Atlas.ti version 7 (Thomas Muhr Developer, Berlin, Germany). Open coding was conducted by reading over the data. Each response was reviewed, color highlighted, and carefully coded. Words and quotations were analyzed for frequency and meaning. Similar codes were grouped together. The code groups were analyzed, and reviewed for patterns and commonality, and themes emerged. Themes were examined for relationships and linkages. Demographic data were gathered from a survey on age, sex, marital status, work status, ethnicity, university, length of trip, and country visited.

Table 1. Demographic Results

Age ranges (years)	
21–30	79%
31–40	16%
41–60	5%
Ethnicity	
Hispanic American	11%
African American	2%
Other: Filipino, Pacific Islander, Asian	32%
Non-Hispanic White	54%

Table 2. Inventory for Assessing the Process of Cultural Competence Among Healthcare Professionals-Student Version Correlated With Age

Construct	Spearman's rho	p
Awareness	−0.005	.93
Knowledge	0.06	.30
Skill	0.03	.66
Encounters	0.18	.00*
Desire	0.11	.06
Total	0.14	.025*

* $p < .05$.

Mean, frequencies, and correlations with demographic data and survey data were calculated. The pre- and posttrip surveys were grouped, as individual students were not tracked before and after trips. SPSS version 19.0 (IBM Corp., Armonk, NY, USA) was used for pre- and posttrip survey analysis for the IAPCC-SV and CSES. Qualitative data analysis of the quotations identified codes and themes using Atlas-ti version 7.

Findings and Discussion

The demographic results of the participants are summarized in **Table 1**. A total of 161 pretrip students and 121 posttrip students were analyzed. The majority of the participants were female (91%) and in the age range of 21 to 30 years (79%). Student ethnicity was primarily non-Hispanic White (54%). Depending on the university, the duration of the trip varied from 1 day to 3 weeks, and locations included Mexico, Belize, Lesotho, Vietnam, Jamaica, Dominican Republic, Swaziland, and Ghana.

Age was correlated with the IAPCC-SV. Using a Spearman rho, a significant correlation ($\rho = 0.18$) was found with the age of respondent in the cultural encounters construct (**Table 2**). The older the respondent, the stronger the correlation. This could be explained by the fact that with age comes more encounters, which builds the process of cultural competency. A significant correlation was found with the CSES scale and age. The CSES areas of "African American" and "Other" questions

Table 3. Cultural Self-Efficacy Scale Correlated With Age

CSES Areas	Spearman's rho	<i>p</i>
African American	0.15	.02*
Hispanic	0.07	.24
Asian	0.05	.46
Native American	0.09	.13
Other	0.17	.007*

**p* < .05.

Table 4. Pre- and Postimmersion IAPCC-SV Means of Cultural Competency Constructs

Construct	Preimmersion mean	Postimmersion mean	<i>F</i>	<i>p</i>
Awareness	3.55	3.6	1.74	.19
Knowledge	2.9	3.08	12.3	.001*
Skill	2.94	3.11	8.1	.005*
Encounters	3.26	3.32	2.7	.10
Desire	3.56	3.61	1.08	.298

Note. IAPCC-SV = Inventory for Assessing the Process of Cultural Competence Among Healthcare Professionals-Student Version. **p* < .01.

were significant at the Spearman rho < .01 (see *p* value) level with age of respondent (**Table 3**). With age potentially comes more flexibility and face-to-face encounters. Campinha-Bacote (2007) determined that more face-to-face cultural encounters influence the process in the healthcare professional in which the interactions with clients from culturally diverse backgrounds help to modify existing beliefs about a cultural group and to prevent possible stereotyping. Nursing students are novices and are more adaptable, which is reflected in the correlation of age and IAPCC-SV total score.

In measuring pre- and posttrip means, both surveys demonstrated an increase in overall means in all constructs of cultural competence and cultural self-efficacy (**Table 4**). Significant pre- and posttest means on the IAPCC-SV survey were demonstrated on the constructs of cultural knowledge ($F = 12.3$, $p = .001$) and skill ($F = 8.1$, $p = .005$) and were significant at $p = <.01$. Pre- and posttest CSES means were significantly different in two of the ethnic subscales ($p < .01$)—African American ($F = 10.2$, $p = .002$) and Hispanic ($F = 3.8$, $p = .05$)—and on questions related to comfort in performing cultural care ($F = 7.6$, $p = .00$).

There was no significance found between pre- and posttrip levels of cultural competency. The majority of students were at the culturally competent level pre- and postexperience, with a smaller number at the culturally aware level and a few at the culturally proficient level. None were at the culturally incompetent level. While there was movement between levels on students' post-

trip surveys, several unexpected findings were noted. On several questions students rated themselves higher on the pretrip survey than on the posttrip survey. One explanation of these findings is that students have a particular mindset or worldview before their experience. After their experience, perhaps they realized that their worldview, assumptions, and understanding were more limited. This type of experience helps students expand their worldview and requires them to ask themselves if they clearly understand the needs of an individual from another culture. The finding that most students identified themselves as culturally competent before the trip may indicate that the awareness of these students was heightened by the experience.

Every posttrip participant filled out an interview survey. All survey data were reviewed. The qualitative data gathered from the interview surveys were reread, codes were established, subsequent findings were attributed to commonality and patterns, and emerging themes were identified. Each question, answer, related phrase, and quotation was color coded using the Atlas ti version 7 software and given a code label. After rereading the data and codes, similar codes were clustered or grouped together. Because of the volume of qualitative data, repeated or similar quotations and codes were reviewed for frequency, meaning, similarity, or pattern. There were numerous quotations and phrases supporting each code. The code groups were further analyzed, and six themes emerged. The six themes were examined to determine relationships and linkages. The themes and relationship among the themes were found to be reflective of Campinha-Bacote's (2013) model.

Interestingly, three of the themes—cultural knowledge, cultural skills, and cultural awareness—directly reflect the constructs described in Campinha-Bacote's (2013) model. These themes were identified in Category 1 and directly reflected model constructs. The first theme of cultural knowledge reflected student's inclusion of learning language, cultural perceptions, customs, and beliefs. In the second theme, cultural skills, students identified the need to be creative and take into account others' cultural beliefs. The third theme of cultural awareness had some of the most frequent codes from quotations that students articulated. They described that experiences challenged their preconceptions and stereotypes of culture, and opening up their worldview. **Table 5** identifies Category 1 themes and quotations with corresponding student participant and university number.

The next three themes that emerged from the data were cultural sensitivity, cultural self-efficacy, and identifying cultural barriers. While these themes were not identical to the model, they support its constructs

Table 5. Category 1 Themes, Supporting Student Quotations and Corresponding to Campinha-Bacote's Model Constructs: University and Student Participant Numbers Noted

Theme	Student quotations
Cultural knowledge	"Learn, connect, care, learning language, learning customs and beliefs, giving hugs, encouraging others, praying for receptive individuals, [and] giving." (U1S401) "Individuals from other cultures perceive many of the same basic values as I do—family, community etc." (U2S414) "Different cultures have different healthcare norms that they use and make work. It was interesting [and] educative to see how the Vietnamese healthcare system functions similarly and differently from ours." (U1S466)
Cultural skills	"You have to keep being creative to come up with solutions that [will] take their beliefs into account and still try to help." (U1S416) "Patience is key. Education is most effective." (U1S474) "I have to work with local health beliefs and adapt accordingly." (U1S418) "How to ask questions more carefully and ensure I properly interpret responses." (U1S472)
Cultural awareness	"Keep an open and non-judgmental mind." (U2S412) "I learned to not assume anything about others in another culture, because often times I was wrong." (U3S446) "I learned that I grew tremendously after doing [a lot of] works at being culturally aware." (U3S445)

Table 6. Category 2 Themes, Supporting Student Quotations and Corresponding Campinha-Bacote's Model Constructs: University and Student Participant Numbers Noted

Theme	Student quotations
Cultural sensitivity	"I think this trip made me appreciate and value the beliefs and opinions of other cultures about health and medicine even more than before." (U1S427) "Giving education based on their cultural beliefs." (U1S442) "More patience is needed for some culture[s]." (U2S410)
Cultural self-efficacy	"I learned that things in other countries are often done very differently but it does not mean it is wrong or that care is jeopardized. I learned that other countries often provide minimal care regularly instead of full care when symptoms are horrible. I also learned that people do not go to the doctor for things unless it is interfering with how they [feel]." (U1S458) "Learning from the clients as much as they learned from me." (U1S403) "I had expectations similar to media representations that were very often inaccurate." (U3S448)
Cultural barriers	"Language barrier and getting services that they need." (U2S410) "The gender role conflict with women being treated are lesser equal men." (U1S404)

and were identified in Category 2. In the second category, the fourth theme of cultural sensitivity was identified as a greater appreciation of the value of the beliefs and opinions of other cultures about health and medication. The fifth theme described reflected self-efficacy. An example of a student response within the theme of self-efficacy described the realization that the student could make a difference, "There was a great need and feeling like I was making a difference to meet this need by working at community clinics." The sixth theme that emerged was cultural barriers, which centered on language and gender roles. These three themes support the cultural competence model constructs of cultural encounter and cultural desire. Developing cultural sensitivity and self-efficacy contribute to building cultural desire. Through the involvement in cultural encounters, one learns about cultural barriers and how to work with those from a different culture. **Table 6** identifies Category 2 themes and quotations with corresponding student participant and university number.

Limitations

One limitation of the study was the inability to determine optimal length of time for an immersion experience. A second limitation was not being able to study gender differences because of the limited number of men who participated in the study. Another limitation would be any pretrip education, orientation, or special cultural content for the international experiences that would vary according to trip, country, faculty, and university. This could prevent generalization.

Implications for Nursing Education, Practice, and Research

The findings from this research support important implications for nursing education, practice, and research. The research indicates that the teaching strategies using international service-learning immersion projects contribute to students' cultural encounters, knowledge,

skills, awareness, sensitivity, self-efficacy, and understanding of cultural barriers. These types of experiences differ from study abroad by including faculty oversight and student contributions to the healthcare in communities where the students are situated. Students are not observers of cultures; they are participants coming alongside individuals and families who live in a different culture. The students gain insight into their own responses to others' worldviews. To enhance this learning, focused debriefings that highlight and review cultural experiences in light of cultural encounters, skills, knowledge, self-efficacy, and awareness should be fostered. These opportunities contribute to student growth and in seeking to have students understand cultural differences and barriers to providing care and support to patients from a different culture. The findings from this study support the recommendation of using international service-learning in nursing education.

Future research on patient perceptions of nurses who have participated in international service-learning projects as students is needed to further understand how this type of learning experience potentially impacts nurses' cultural sensitivity. Research on faculty experience in international service-learning projects, methods of effective debriefing, and how these projects are integrated into the curriculum would further expand teaching strategies.

Conclusions

The research findings in this study describe the impact and value of an international immersion experience on the level of cultural competency of nursing students. Nursing education is charged with the responsibility to educate students in a way that fosters the development of cultural competency. Graduating future nurses who are experienced in the process of cultural competence have the potential to improve nursing practice and improve care.

In summary, cultural competency is a process that nursing education must initiate with effective teaching strategies such as international service-learning immersion experiences. When students have an opportunity to experience and learn in this type of setting, they are engaged in the learning process and the multifaceted experience imprints an understanding that potentially influences their future practice.

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Clinical Resources

- American Association of Colleges of Nursing. Tool kit of resources for cultural competent education for baccalaureate nurses: <http://www.aacn.nche.edu/Education/pdf/toolkit.pdf>
- CLAS Standards: <https://www.thinkculturalhealth.hhs.gov/content/clas.asp>
- Transcultural C.A.R.E Associates: <http://www.transculturalcare.net/>

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WORLD HEALTH

Simulation in Nursing Education—International Perspectives and Contemporary Scope of Practice

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Abstract

Purpose: This article provides insights and perspectives from four experienced educators about their approaches to developing, delivering, and evaluating impactful simulation learning experiences for undergraduate nurses. A case study format has been used to illustrate the commonalities and differences of where simulation has been positioned within curricula, with examples of specialized clinical domains and others with a more generic focus. The importance of pedagogy in developing and delivering simulations is highlighted in each case study. A range of learning theories appropriate for healthcare simulations are a reminder of the commonalities across theories and that no one theory can account for the engaging and impactful learning that simulation elicits.

Clinical Relevance: Creating meaningful and robust learning experiences through simulation can benefit students' performance in subsequent clinical practice. The ability to rehearse particular clinical scenarios, which may be difficult to otherwise achieve, assists students in anticipating likely patient trajectories and understanding how to respond to patients, relatives, and others in the healthcare team.

There is a plethora of reports about the use of simulation for healthcare education, particularly within undergraduate nursing curricula. The attraction of using simulation as an educational strategy arises from the ability to: incorporate multiple elements of practice within a learner-centered activity; address national health priorities; and trigger participants' reflection on and about practice. At an individual level, simulation can enhance students' understanding of the roles and responsibilities of the registered nurse through, to use Bourdieu's (1990) expression, forming a habitus of perceptual acuity leading to skilled, embodied practice.

The intent of assembling the chosen case studies within one article is to highlight similarities internationally in the intent and approaches in developing meaningful simulation experiences. The fundamental importance

of incorporating sound pedagogical design and relevant theories is demonstrated in each of the case studies. Details of the simulation delivery may not be explicit in all case studies, but all four experienced simulation educators followed best practices (Arthur, Levett-Jones, & Kable, 2013; Jeffries, 2007, 2014). The range of scenario topics highlights the flexibility of simulation as a learning approach; from understanding others' roles within the healthcare team, appreciating the salient aspects of post-operative patient care, increasing insight and empathy about mental health issues; and understanding how to manage critically ill patients within a team context prior to entering clinical practice.

What emerges from these case study examples is how simulation enables coproduction of knowledge, and how insights from studies of other disciplines within

and beyond health can inform and guide simulation practices.

Case Study 1: Low-Fidelity Interprofessional Ward Simulation

At the University of the West of England (UWE), Bristol, in the United Kingdom (UK), we have offered an interprofessional health and social care curriculum since 2000 involving 10 prequalifying professional programs. Evidence from internal (Pollard, Miers, & Gilchrist, 2005) and external (Salfi, Solomon, Allen, Mohaupt, & Patterson, 2012) studies reinforces the argument for including interprofessional education (IPE) in prequalifying curricula, which is mandatory in the United Kingdom (Department of Health & Quality Assurance Agency, 2006). Given some of the challenges highlighted and conclusions drawn by Pollard, Miers, and Gilchrist (2004) about students' perceptions of IPE, we were interested in discovering how simulation might enhance the delivery of IPE. Interprofessional simulation learning experiences are increasingly more common, with a focus on enhancing nontechnical skills, such as communication and collaboration (Reeves, Lewin, Espin, & Zwarenstein, 2010).

For health and social care students, it is essential that the impact of human factors and the importance of patient safety are addressed within the curriculum. This project embraces the recommendations of the "Shape of Caring" (Willis, 2015) and "The Better Training Better Care programme" (Health Education England, 2014) and recognizes the need for healthcare and social care students to learn to work together through educational initiatives in order to deliver safe and effective care (Francis, 2013; Willis Commission, 2012).

The Project—An Outline

The purpose of the project was to offer an interdisciplinary simulation experience to final year nursing and medical students that focused on patient situations they would encounter in clinical practice. The simulation offered participants the opportunity to identify and prioritize patient care, manage and delegate clinical tasks, and work together to ensure efficiency and patient safety.

The project took place in a simulated environment (a ward at night) at UWE with eight simulated patients (four acting roles and four manikins). Each patient had a full history with a developing clinical picture as each of the three phases of the simulation unfolded. At each phase, two medical and two nursing students ran the simulated ward together. Other students acted as observers or patients in the scenario. Facilitators took on roles as a patient's family member, ward manager,

and medical registrar. Verbal patient handovers were given to students at the start of each phase and between role changes. A maximum of 12 students took part in each half-day session. Nursing students worked as newly qualified nurses managing the ward, assessing patients, delegating tasks, calling the doctor to raise concerns, and initiating acute care. Medical students worked as the junior doctor on call: triaging bleeps, undertaking a variety of ward jobs, and managing sick patients. At the end of each phase, all students and facilitators left the ward and debriefing of the activity took place nearby. At each debriefing point, experiences and issues that had emerged were discussed and suggestions, solutions, and learning points were shared. All facilitators and students took part in the feedback and debriefing points, which each lasted approximately 30 min.

Results

Students were asked to self-rate their confidence on receiving handovers, prioritizing tasks, communicating with medical and nursing colleagues, and calling for help, all on pretested 10 point Likert scales, before and after the simulation. Students were also asked to rate the session (free text responses) compared to previous experiences within their curricula involving multidisciplinary team learning.

Qualitative and quantitative data collected from participants convincingly suggested that the interdisciplinary ward simulation offered a very effective way of improving confidence in prioritization and on-call skills. It was also a preferred method of understanding the different and complementary roles of nurses and doctors, and how to support each other to promote patient safety.

One quote summarized the general consensus of students' opinions about the value of this activity for future practice experiences:

The simulation itself really helped me to see how nursing and medical roles are so different but both vital in giving patients good care. The practical parts were long enough to really get into them and think about how best to prioritize patients. The debriefing sessions allowed us to share concerns and ask questions in a safe environment; it was really helpful to see how implementing the suggested changes made such a difference to the outcome of the shift each time. It was also quite comforting to know that newly qualified medical students are also just as scared as we are when we first start, which shows how much more we need to help each other! (Third year nursing student).

This project also showed the effectiveness of students acting as patients in the scenarios allowing them a fresh

perspective of interdisciplinary work, helped decrease running costs with greater student engagement, and was testament to our belief, often cited by students, that “simulation learning is fun.” This in turn reduced some initial student anxiety and contributed to a friendly and positive learning environment in which participants reacted and responded authentically to the unfolding scenario.

Discussion

The Carnegie Foundation for the advancement of teaching in the United States has funded studies into the education of professionals (Benner & Sutphen, 2007; Foster, Dahill, Golemon, & Tolentino, 2005). The Foundation, drawing upon internal and external professional perspectives and cross-professional comparisons, sought to elucidate teaching and learning for professions practice.

According to Foster et al. (2005), professional education emphasizes the importance of “professional identity, practice, commitment and integrity” (p. 100). For clergy education, seminary students are encouraged to view themselves as part of the narrative of the profession. The ability to recognize, explore, and interpret their own dispositions, beliefs, knowledge, and skills is seen as essential to discernment and action in particular situations (Foster et al., 2005). This resonates with our vision of healthcare education and the need for students to learn to be self-aware professional practitioners able to contextualize a particular situation and act with integrity and advocacy for their patients. All of the Carnegie Foundation studies draw upon three high-level “apprenticeships”—knowledge, skill, and ethical conduct—which they suggest are required for all professional practice. Through these apprenticeships, Shulman (in Benner, Tanner, & Chesla, 2009) suggests that novices should be introduced to the meaning of integrated practice, which incorporates all dimensions of the profession.

It is important to highlight that apprenticeship in this context is not used as reference to where learners are employed and work alongside skilled practitioners. In the Carnegie studies, apprenticeship is used as a metaphor for the complex embodied, cognitive, skillful, ethical, and experiential learning required in practice disciplines (Benner & Sutphen, 2007). The notion of apprenticeship is useful in professional education. Learning a complex practice, in which knowledge is situated and socially embedded, demands practical reasoning, skilled know-how, perceptual acuity, relational and communication skills, and ethical conduct (Benner et al., 2009). Such integrated practice is learned in formal programs and also through experiential learning (Lave & Wenger, 1991). In nursing and medicine, knowledge, skill, and ethical conduct must

be integrated into all teaching and learning situations and can be more fully understood through the pedagogies of interpretation, formation, contextualization, and performance.

The different pedagogies provide a framework for developing an understanding about the impact of simulation upon learning for student nurses (Berragan, 2014). As an educator, I (EB) often recognize that often I offer a linear or step-by-step approach to introduce students to clinical skills. This exemplifies what Benner and Sutphen (2007) call a narrow, technical rationality. In order to move away from this and engage with a broader version of “rationality,” where interpretation, understanding, and relationship are key to engaging students and helping them to learn to be nurses and doctors, these pedagogies offer potential. They offer an expansive approach to learning and a means of interpreting and exploring the impact of simulation for learning key aspects of inter-professional care.

Learning together and understanding co-workers’ roles, challenges, and limitations, we hope to foster more effective interdisciplinary communication and in turn improve patient safety. This project demonstrates that on-call ward simulation is an effective and achievable way of delivering this.

Case Study 2: Postoperative Simulation for Norwegian Nursing Students

Like many other countries, nurses in Norway are prepared to bachelor level over 3 years at universities or regional colleges. Nursing curricula are based on national regulations, with some variations at the institutional level in program delivery. All programs include theoretical and clinical learning components. Ten weeks (15 European Credit Transfer and Accumulation System) of the 3 years is for training and reflection upon practical skills, mostly worked on in the simulation laboratory (Ministry of Education and Research, 2008).

At the University of Stavanger, simulation-based learning (SBL) is the most applied pedagogical method for learning multiple nursing skills (e.g., to administer drugs intravenously, parenteral nutrition, and postoperative skills). The method is recognized as student centered, interactive, and beneficial in preparing students for real-world patient care experiences (Cant & Cooper, 2010). The didactic model of relation (Hiim & Hippe, 1998) makes explicit the most important factors for planning simulation activities, in this case the postoperative care course. Of particular importance is the interconnect-edness between the six factors identified within the model. All factors are mutually dependent, meaning that

changes in one have consequences for the other factors (**Figure S1**, available with the online version of this article).

Discussion follows about the planning for the postoperative simulation learning experience for students in relation to the factors within this model. Hiim and Hippe (1998) do not explicitly recommend which one of the factors to start with, but in their descriptions commence with “initial situation of the learner” and continue with “frameworks” and so on. Similarly, commentary about the application of the framework for this case example will follow the same steps.

Initial Situation of the Learner

A review of the initial situation of learners includes acknowledgement of their background and skills, experience, motivation, and if students see the benefit and have ownership of a particular course. Hiim and Hippe (1998) emphasize the importance of responding to learners at their own level of experience. These considerations resulted in production of an electronic course booklet that students could access prior to the postoperative simulation activity.

Frameworks

Frameworks include all the conditions connected to the course design, such as faculty background, competence, and experience (Hiim & Hippe, 1998). In this respect, the faculty involved in the course have a background in nursing, education, and facilitation of learning in academic and clinical settings. To ensure that the course has relevance to clinical practice, practicing nurses have reviewed and ratified the simulation scenarios. Attention to these types of frameworks provides a solid foundation for meaningful learning experiences.

Goals

The goals for the postoperative nursing course were to (a) be able to attend patients’ reactions and the need for nursing care following surgical treatment; (b) understand the most widely used therapies, with emphasis on surgical intervention; and (c) attend, observe, and document and report signs and symptoms postoperatively that are important for patient safety and that can prevent inquiry. In addition, the learning objectives of the simulation scenario included communication and working in teams.

Content and Material

Content refers to the theoretical components and intent of the course, both in subject matter and materials.

In developing the “what” aspect of the course, the following main topics were made explicit: postoperative observations and interventions, complications, pain, nausea, nursing skills, and outpatient surgery. The course is structured in three steps, comprising theory, skills proficiency, and team-based simulation. In the first step, lectures on pre-, peri-, and postoperative nursing are conducted. In the second step, skills proficiency focuses on individual learning (with one facilitator overseeing 10 students), specifically on, for example, wound care and removal of sutures. The last step is the team-based simulation (six students), where the scenario is based on a de-identified but real patient case to ensure clinical relevance.

The scenario addressed postoperative care of a 39-year-old woman who has undergone a total hysterectomy and experienced a fall in blood pressure relating to hypovolemia. When the scenario starts, the patient (manikin) has just arrived at the gynecology unit and complains of pain and nausea. The patient has an abdominal incision covered by a wound dressing. She had received 1½ L of intravenous fluid during the operation, with an estimated blood loss during surgery of half a liter. The patient was in the recovery unit for 2½ hr before admission to the gynecology unit and had a urinary catheter in situ with approximately 200 ml in the urine collection bag. She received pain relief immediately prior to transfer from the recovery unit but did not have a patient-controlled analgesia regimen in place because there was no pump available at the time.

Working Processes and Methods

In recognition of the benefits of SBL, pedagogical methods were chosen that focused on students as active participants in the learning processes. The methods included SBL in the skills proficiency and team-based simulation steps (described previously), where the latter comprised briefing, simulation scenario, and debriefing (Husebø, 2012). Adequate staff training and understanding of how to facilitate these steps was ensured prior to delivering the learning activities.

Assessment

It was essential to determine what was to be assessed, how to assess it, and the rationale for the assessment choices (Hiim & Hippe, 1998). Evaluation can be seen as having two interrelated functions, that is, formative and summative evaluation. The objective of formative assessment is to monitor student learning to provide ongoing feedback that can help students identify their strengths and weaknesses and target areas that need work, as well as to help faculty recognize where students are struggling

so that problems can be addressed immediately (Mahara, 1998). With this in mind, during the skill training and simulation scenario, faculty provide ongoing feedback to support achievement of students' learning objectives. Reflection on and about performance is a central part of the training sessions, and students should be encouraged to provide feedback of their SBL experiences (Husebø, O'Regan, & Nestel, 2015).

The students undertook summative assessment in the simulation laboratory before entering their surgical clinical practice. The goal of summative assessment is to evaluate student learning at the end of an instructional unit by comparing it against some standard or benchmark. To evaluate performance of nursing skills, the Model of Practical Skill Performance by Bjørk (1999), which consists of (a) substance and sequence, (b) accuracy, (c) fluency, (d) integration, and (e) caring component was applied to the assessment criteria.

The didactic model of relation is a structured, easy-to-follow didactic model, which appears to be applicable in most simulation-based courses in nursing education. The model emphasizes several critical components for learning with the intent of optimizing student performance during clinical practice.

Case Study 3: Collaboration for Practice: A Hearing Voices Simulation Workshop for Australian Nursing Students

Mental health is recognized as an integral component of a person's overall health (World Health Organization, 2015). However, the concept and experiences of mental illness can be challenging for nursing students to fully appreciate. One approach to prepare students for collaborative practice with healthcare consumers is to engage consumers of mental health services—those with lived experience of mental illness and mental health services and who are experts by experience—as curriculum consultants and as academics. The reported benefits of this approach include increased awareness of recovery from mental illness, reduction in stigma, and positively influencing attitudes (Byrne, Platania-Phung, Happell, Harris, & Bradshaw, 2015).

Increasing nursing students' understanding of voice-hearing can also be achieved by including consumers' lived experiences in learning and teaching approaches. Voices that are distressing or difficult to cope with may be experienced by some consumers of mental health services. To prepare students for practice, a hearing voices simulation (HVS), developed by Deegan (2006), an academic and consumer with lived experience, has been used in a number of nursing programs. The benefits

of HVS include awareness of voice-hearing experiences (Hamilton Wilson et al., 2009), decreased negative attitudes about people who have schizophrenia (Sideras, McKenzie, Noone, Dieckmann, & Allen, 2015), and empathy for those who hear voices (Orr, Kellehear, Armari, Pearson, & Holmers, 2013).

Collaboration and Development of the Hearing Voices Simulation Workshop

The HVS workshop, developed by Orr, Kellehear, Armari, Pearson, and Holmers (2013) was initially implemented at the University of Technology Sydney for 80 final year nursing students undertaking an elective subject in mental health nursing. It is a unique collaboration between mental health nursing academics and consumer consultants who were trained in the use of the HVS by Patricia Deegan. Mp3 players were purchased for program delivery to students, and the simulated voices audio-recording was copied onto the mp3s by the consumer consultants.

To complement HVS, the consumer consultants developed a 50-min presentation on voice-hearing experiences and coping strategies, and an overview of the aims of the HVS workshop. This presentation was recorded for students to view prior to HVS. Evaluation of this HVS workshop revealed it had increased students' awareness of voice-hearing experiences (Orr et al., 2013). Consequently, approval and funding was forthcoming from management to embed the HVS workshop in the core, final year mental health nursing subject for approximately 600 nursing students.

Implementing the Hearing Voices Simulation Workshop in a Large Core Subject

The workshop was conducted during one week in the scheduled tutorials in the final year mental health nursing subject. There were approximately 20 tutorials to manage, and staffing for each tutorial was increased to two academics, who were also mental health nurses. Consumer consultant-led training in the use of HVS was organized for academic staff prior to the student workshops.

In the tutorial prior to HVS, students viewed the audio-visual recording on consumers' experiences and discussed the issues raised, and the academics addressed students' questions and concerns. In the following week's tutorials, the HVS workshop was conducted. The mp3s were distributed and the students were instructed on the use of the equipment. To create a life-like experience, students were asked to use earpieces and set the volume so that the voices were intrusive; suspend their disbelief and

imagine that they were actually hearing voices; resist the urge to discuss their voices with each other during the simulation; and listen to the voices until they finished. The students were instructed to seek the assistance of one of the two academic staff members if they felt distressed during the simulation.

The students listened to the simulation for 45 min while completing everyday activities in and outside the tutorial room. The recordings comprised sounds and voices, including derogatory comments. Initially all students completed a reading comprehension exercise in the tutorial room, then the group was divided into two groups to carry out the remaining activities, such as interacting with others at a café on the campus; asking for information from the library or student center; phoning a friend who was not aware that they were participating in the HVS; and participating in a discussion group in the tutorial room.

On completion of the simulation, all students returned to the tutorial room and the two academic staff facilitated a 40-min debriefing supportive of the students' experiences of the simulation. Each student had an opportunity to reflect on the simulation, with particular focus on how they felt and reacted during the range of activities. Discussions then focused on how the experience could inform their future nursing practice with consumers who hear voices, particularly the communication strategies that they might use.

Kolb's Experiential Learning Theory and the Hearing Voices Simulation

Kolb's (1984) theory of experiential learning (EL) underpins the student learning that takes place during the HVS workshop. Learning by experience is central to Kolb's (1984) theory, and the key components of the HVS workshop are consumers' experiences of voice-hearing and student learning through the experience of HVS. The cycle of learning described by Kolb (1984) includes four stages: a concrete experience, reflective observation, conceptualization, and active experimentation. The stages as applied to the HVS workshop are summarized below:

- i. A concrete experience, which comprises the consumer-led presentation on voice-hearing experiences followed by engaging in the hearing voices simulation while undertaking everyday activities;
- ii. reflective observation, which occurs during the large group debrief whereby the students review their experiences of the simulation and consider how they were affected emotionally, physically, cognitively, and behaviorally;

- iii. conceptualization whereby students analyze the reflective experience and form conclusions by considering what new ideas were learned, and consider what they might do differently when interacting with consumers who hear voices;
- iv. active experimentation whereby the students apply their learning to practice during 80 hr of subsequent facilitated mental health nursing clinical placement.

The HVS workshop provided students with the opportunity to develop knowledge about voice-hearing experiences and how it affects those who hear voices, enabling them to further develop the skills of therapeutic responding, necessary for graduate nursing practice.

Evaluation and Impact on Learners

The HVS workshop embedded as a learning activity within a core mental health nursing subject, was evaluated by the current cohort of students. This voluntary and anonymous university-based evaluation was completed by 40% of students enrolled in the subject. Students identified that overall the simulation increased their understanding of voice-hearing experiences, captured how it felt to hear voices, offered insight they had not previously acquired, and encouraged them to talk with consumers about their voice-hearing experiences during clinical placements.

Case Study 4: Trauma Simulations—Discerning Important Elements of Practice and Interrogating Pedagogies

For several years, students undertaking a critical care elective subject towards the end of their degree program have been offered a simulation experience focused on assessing and managing a trauma patient. The intent of the specific scenario was to combine all elements of skills practice, and clinical experiences of students who had undertaken the practicum, into a holistic rehearsal of caring for a trauma patient. Student numbers across five tutorial classes ranged from 20 to 25, comprising a total of approximately 125 students.

Simulation Preparation and Format

To orient the students to trauma management, a lecture followed by discussions of an in-class case study that focused on a patient in a car crash occurred the week prior. The subsequent simulation scenario connected to the preparatory work and featured a 30-year-old man who was riding the motorcycle (featured in the case

study) that crashed into the car. Students were provided with preliminary patient information: burn injuries to the right side, sternal bruising, lacerations and injuries to the left and right side of the body, helmet in situ, and that he was found 100 m from the motorcycle. After treatment at the scene, the motorcycle patient was transferred and admitted to an emergency department, where the simulation commenced. Up to eight students could participate in “active” roles (**Table S1**), while the remaining 18 or so were asked to observe the simulation. The practicalities of delivering the simulation resulted in the observer students being in the same room, separated visually by partitions. To enable observation of the simulation, live video feed (without audio) was set up.

The simulation commenced with the triage nurse (student) providing handover to a team of three registered nurses (RNs [students]), one in a team leader (TL) role. Students then performed a secondary patient assessment and proceeded to provide preliminary care. An academic took on the role of the medical officer (MO) and determined when to enter the scenario based on students’ progression in the simulation. The intent was to allow students to advance unaided through a head-to-toe but focused assessment, influenced by the “patient’s” vocal responses (another student, in the control room). In addition, the primary RN had to work with the TL and other RNs to manage the entire situation, including prioritizing and delegating tasks, gaining further information to assist with patient management, while also engaging and communicating with the team, patient, and relatives.

As the scenario progressed, the patient reacted to medications, deteriorated, and required advanced life support measures, including endotracheal intubation, the latter performed by the MO (academic).

After approximately 15 min, the scenario ended, students “de-rolled,” and a 25- to 30-min facilitated debriefing began using open-ended questions to trigger reflection about practice, communication, and leadership. Another phase of simulation followed, with other students taking on roles to care for the same patient after transfer to the intensive care unit. Similar issues with patient deterioration unfolded; students had to again prioritize patient care, while working as a team, responding to the “patient,” and interacting with the relatives.

This scenario was offered (and refined) over a number of years, and students reported they felt engaged in the learning, were able to “walk in the shoes” of the nurse or relative, and could appreciate the time-critical nature in recognizing and responding to a patient who was deteriorating (Kelly, 2014).

Collaboration With Other Disciplines for Greater Insights About Pedagogy

In 2013, I (MK) invited four colleagues from the Faculty of Education to view these simulations to provide additional perspectives about the pedagogical approaches in use. These colleagues provided different and broader viewpoints about what and how students might be learning in simulation, and the applicability for practice. At this time, the pedagogy of simulation was an emerging area of interest. The opinions from experts in other disciplines both corroborated and tested assumptions about student learning in simulation. A simple yet critical first question put to the researcher group was “What is being simulated?” (Hopwood, Rooney, Boud, & Kelly, 2014). From this platform, other problematics arose, which elicited rich discussion and thought about what was occurring and for whom in the simulations. Particular focus was directed to two elements: the large and culturally diverse student cohorts, and the experience for those observing simulations.

Initial seed funding through education enabled some of these questions to be interrogated through observational research methods. During simulations the following year, the four research colleagues, positioned at different viewpoints in the simulation laboratory, described how students in their various roles engaged in the activities. A number of theoretical frameworks to account for student learning were raised during subsequent discussions and analysis of the research data.

To start, Hopwood et al. (2014) advocated that simulation enabled learners to engage in sociomaterial (Schatzki, 2012) as well as sociocultural performances (Gherardi & Perrotta, 2014). For example, students initially considered the manikin as a technical or plastic person, prodding the arm to determine how real it felt. As the scenario unfolded, interactions with the manikin became clinically based, as in giving medications and assessing pupil responses, to finally taking on a human patient body as students demonstrated therapeutic touch while offering empathic responses (Hopwood et al., 2014). Such examples illustrate how simulation can trigger emotional engagement in the learning as participants interact with each other and with materials or environmental artifacts. Further, as the simulation unfolded and students become immersed in the scenario, the manikin moved from being a plastic person in the bed to a patient with whom students interacted in meaningful ways. Vocal responses from the manikin were key to this relationship-building process. Without voice, the plastic body may remain just that, rather than being incorporated into the doings and sayings of (simulated) practice.

Further discussions among the research group presented the notion that simulation, through embodied

performances, can help novice nurses adapt and respond to the changing nature and demands of work (within the scenario), in effect to become agile learners—to seek out opportunities to learn and make judgments about their learning (Rooney, Hopwood, Boud, & Kelly [2015] anonymized for blind review). This in turn may enable agile learners to become agile practitioners upon graduation, engaging in socially established and recognized actions, sayings, and doings (Rooney et al., 2015).

Areas for Further Investigation

One further area of interest for this research group relates to those who observe simulations. As noted earlier, due to large student cohorts and the pragmatics of providing simulations within existing resources, students may be in the observer role for a substantial part of the time. While the learning potential in observing simulations is acknowledged (O'Regan, Molloy, Watterson, & Nestel, 2016), many are now focusing on ways to maximize engagement for these participants so they become agile observers and become more attuned to the professional roles and responsibilities of the RN. A critical component in assisting students to make sense of simulation events for clinical practice is linking the connections during the debriefing. The expertise of the debriefer and the debriefing approach are important in this regard as students highly rated these components of simulation in the context of making clinical judgments about patient care (Kelly, Hager, & Gallagher, 2014).

Overall Discussion

The rapid uptake of simulation in the preparation of entry-level practitioners is testament to the powerful impact of this learner-centered approach to understanding practice. The journey of becoming a healthcare practitioner is amplified after graduation as nurses begin to fully contextualize their course experiences with episodes of patient care. The transformation from novice to advanced beginner (Benner, 1984) requires clinical experiences that change the student's capacity to act in complex situations. The aims are to shift the typical predominant focus on skill formation towards noticing the salient features of situations and responding and relating to patients and each other in meaningful ways. Students are required to learn skills of perception and action and form what Merleau-Ponty (1969) called a style of comportment in which they learn to adjust to the dynamics and possibilities of a particular situation. The actions and responsibilities of being a nurse or a doctor form a habitus (Bourdieu, 1990) of skills, expectations, perceptual

acuity, and actions, which, over time, create the foundation for skilled, embodied nursing and medical practice (Merleau-Ponty, 1969).

Simulation presents an opportunity for students to begin to learn and develop a nursing habitus or medical habitus, enabling them to rehearse the "skilled know-how" required for competent practice. The opportunity to experience and act in a range of complex clinical situations through simulation enables healthcare students to rehearse and refine the skills and holistic practices of their discipline. Simulation also facilitates the development of an understanding of a clinical situation requiring specific responses and professional interactions while fostering the growth of professional identity.

Commonalities across the four case studies include the collaborative processes used to develop and ratify scenarios through the engagement of educators with clinicians and consumers, and basing case studies on actual patient experiences. Simulation offers specific opportunities for participants to develop or refine therapeutic and other communication skills regardless of the scenario context and content. Experiential learning and learning by experience underpins each of the case studies, as students are afforded opportunities to become attuned to their professional roles through activities that closely align with practice. Understanding what may be expected of them in the clinical setting and anticipating what may happen next in patient "situations" is highly valued by students and novice nurses (Kelly et al., 2014). Ensuring simulation scenarios are informed by relevant pedagogical frameworks ensures a solid foundation for learning experiences that have meaning and high impact on subsequent practice and patient care.

Conclusions

Irrespective of the context or country, the case studies described in this article reflect the commitment of each author to enabling co-production of knowledge with students through simulation by engaging with peers and consumers, and basing scenarios on authentic cases. The importance of embedding relevant pedagogical frameworks into the planned simulation experience and articulating with preparatory materials offers students the opportunity to engage in more meaningful ways in learning about their own and others' practice.

Clinical Resources

- The Association for Simulated Practice in Healthcare: <http://www.aspih.org.uk/>

- The Australian Society for Simulation in Healthcare: <http://www.simulationaustralasia.com/divisions/about-assh>
- Keepwell Ltd – Arana Pearson, Director and Principal Trainer – Hearing Voices Program: <http://www.zoominfo.com/p/Arana-Pearson/257833992>
- Pat Deegan – Hearing voices curricula; Common Ground (recovery from mental health): <https://www.patdeegan.com/>
- The Society in Europe for Simulation Applied to Medicine: <http://www.sesam-web.org/>
- The Society for Simulation in Healthcare: <http://www.ssih.org/>

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web site:

Figure S1. The didactic model of relation, modified after Hiim and Hippe (1998, p. 99). Reproduced with permission.

Table S1. Roles and Scope of Actions in the Critical Care Trauma Simulation

HEALTH POLICY AND SYSTEMS

Reducing Preventable Hospitalizations With Two Models of Transitional Care

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Abstract

Purpose: Transitional care is an emerging model of health care designed to decrease preventable adverse events and associated utilization of health care through temporary follow-up after hospital discharge. This study describes the approaches and outcomes of two distinct transitional care programs serving different populations: one is provided by master's-prepared clinical nurse specialists (CNS) with a chronic disease self-management focus, another by physicians specializing in palliative care (PPCs). Existing research has shown that transitional care programs with intensive follow-up reduce hospitalizations, emergency department (ED) visits, and costs. Few studies, however, have included side-by-side descriptions of the efficacy of transitional care programs varying by healthcare providers or program focus.

Design: This is a retrospective cohort study comparing the number of ED visits and hospitalizations in the 120 days before and after the intervention for patients enrolled in each transitional care program. Each program included post-hospitalization home visits, but included differences in program focus (chronic disease vs. palliative), assessment and interventions, and population (rural vs. urban). Data from participants in the CNS program (September 2014 to December 2014) were analyzed ($n = 98$). The average age of participants was 69 years and 65% were female. Data were collected from patients from the PPC program from September 2014 to April 2015 ($n = 71$). Thirty participants died within 120 days after the intervention and were excluded; the remaining 41 were included in the analysis. Participants had an average age of 81 years and 63% were female.

Methods: For the CNS program, a secondary analysis of existing data was performed. For the PPC program, a review of patient charts was done to collect data on encounters. A Wilcoxon matched-pairs signed-rank test was performed to test for significance.

Findings: Patients in the CNS intervention had significantly fewer ED visits ($p < .005$) and hospitalizations ($p < .005$) in the 4 months after the intervention than in the 4 months before the intervention. Patients in the PPC program had a nonsignificant reduction in ED visits ($p = .327$) and a significant reduction in hospitalizations postintervention ($p = .03$).

Conclusions: Both transitional programs have value in decreasing rehospitalizations. The CNS intervention also significantly reduced ED visits for their target population. Further study with randomized controlled trials is needed to allow for a better understanding of the healthcare workforce best fitted to enhance transitional care outcomes. Future study to examine the cost savings of each of the interventions is also needed.

Clinical Relevance: Transitional care programs have the potential to prevent unnecessary utilization of health care at the critical periods of transition that leave patients vulnerable to adverse events and poor outcomes.

As countries throughout the world face increases in aging populations and chronic conditions, healthcare reform in recent years has focused on ways to increase quality while decreasing costs and improve care coordination and information sharing through electronic health records (Berwick, Nolan, & Whittington, 2008). A key area of focus is on individuals with complex needs moving between multiple specialties and settings, also called care transitions. Care transitions are defined as a change in the setting of the provision of care, which most commonly refers to movement from the hospital to the community, but can also include other shifts, such as a move to long-term care (Coleman, 2003).

Transitions are significant as a time of increased risk for adverse events that contribute to higher rates of healthcare utilization and spending (Forster, Murff, Peterson, Gandhi, & Bates, 2003). In a study of all Medicare beneficiaries hospitalized from 2003 to 2004, nearly one fifth were readmitted within 30 days, 34% were rehospitalized within 90 days, and 67% within 1 year, with only 10% of these readmissions likely to have been planned (Jencks, Williams, & Coleman, 2009). The estimated cost of these rehospitalizations was about \$17 billion in 2004, and the Medicare Payment Advisory Commission (MedPAC) estimates that up to two thirds of these readmissions may be preventable (MedPAC, 2007).

As a response to these challenges facing the healthcare system, advance practice nurses (APNs) were the first to develop and study transitional care, an empirically supported method to reduce readmissions post-hospitalization (Verhaegh et al., 2014). Transitional care is defined by Naylor, Aiken, Kurtzman, Olds, & Hirschman (2011, p. 747) as:

A broad range of time-limited services designed to ensure health care continuity, avoid preventable poor outcomes among at-risk populations, and promote the safe and timely transfer of patients from one level of care to another or from one type of setting to another.

This care serves a distinct but complementary role to other services in its time-limited nature and specific focus on managing the adverse outcomes of transitions.

With the provisions of the Affordable Care Act (ACA), many new financial incentives exist for hospitals to develop programs to reduce hospital readmissions. The ACA created the Hospital Readmission Reduction Program, which beginning in 2013 penalized hospitals for higher than expected all-cause readmission rates within 30 days of discharge (Tilson & Hoffman, 2012), initially targeting select diagnoses of heart failure, pneumonia, and acute myocardial infarction. In 2015, the additional diagnoses of chronic obstructive pulmonary disease, total

hip arthroplasty, and total knee arthroplasty were added (Centers for Medicare and Medicaid Services, 2014). As of 2015, penalties for excess hospitalizations have been increased to 3% of base payments by Medicare, and readmissions for these diagnoses are also treated as an indicator of the quality of a hospital's care and are publicly reported and available to consumers. The ACA also created the Community Based Care Transitions Program, which tests models to improve care transitions for high-risk Medicare beneficiaries from inpatient care to other settings. The program began in 2011 and plans to spend \$500 million over 5 years to reduce readmissions and document measurable savings (Tilson & Hoffman, 2012).

Due to these emerging incentives, in recent years many models of delivery have been examined to determine the most effective ways to deliver transitional care (Naylor et al., 2014). The most consistently tested models of transitional care are the Care Transitions Intervention (Gardner et al., 2014) and Transitional Care Model (TCM; Naylor et al., 2014). Studies of the TCM, as applied to cognitively intact older adults (Naylor et al., 1994, 1999), patients with heart failure (Naylor et al., 2004), and cognitively impaired older adults (Naylor et al., 2014), have consistently shown reductions in readmissions, emergency department (ED) visits, and costs of care. For example, in the randomized controlled trial on heart failure (Naylor et al., 2004), the program led to an average savings of \$4,845 per patient.

Other models have varied greatly by intensity, healthcare providers involved, constellation of services provided, and approach to care. The intensity of programs ranges from providing a single follow-up phone call (Dudas, Bookwalter, Kerr, & Pantilat, 2001; Kind et al., 2012) to multiple home visits over an extended period of time (Naylor et al., 2004). The majority of transitional care programs in the literature are multidisciplinary teams with care directed by APNs (Naylor et al., 1999), while other models rely primarily on registered nurses (Kwok, Lee, Woo, Lee, & Griffith, 2008; Yu et al., 2015), pharmacists (Dudas et al., 2001), social workers (Watkins, Hall, & Kring, 2012), and physicians (Reese, Hicks, McWilliams, Britton, & McKean, 2003). Models expanding the focus from chronic disease self-management have focused on palliative (Lukas, Foltz, & Paxton, 2013) and restorative care (Courtney et al., 2009).

Systematic reviews of this body of research have found key elements common to successful transitional care programs. In a systematic review of 21 transitional care programs, Naylor and colleagues (2011) found that the nine programs that effectively reduced admissions utilized nurses as the manager of care, and six of those programs included in-person home visits. The programs that

reduced readmissions for at least 6 to 12 months also emphasized patient self-management and connected acute and primary care providers. Another recent systematic review of 26 randomized controlled trials of transitional care interventions found that only high-intensity models were effective in reducing short-term (30 days or less) readmissions (Verhaegh et al., 2014). Similarly to the above study, programs that included a home visit within 3 days, care coordination by a nurse, and communication between the acute and primary care providers were the most effective in reducing hospitalizations.

Continued study of the effective elements of transitional care is needed to provide a strong evidence base for cost-effective programs as hospitals develop evidence-based practices to reduce readmissions. While transitional care using a variety of providers and models of care has been widely studied (Naylor et al., 2011), few studies offer a side-by-side snapshot of the effectiveness of different types of transitional care or examine care by different providers (Jeangsawang, Malathum, Panpakdee, Brooten, & Nityasuddhi, 2012).

The purpose of the current study was to describe the interventions and effectiveness of two dissimilar intensive home visiting programs providing transitional care to distinct populations at two medical centers in a small rural state. The programs differ by providers, with one headed by master's-prepared clinical nurse specialists (CNS), the other by physicians. They also vary in focus, with the APN-directed program focusing on chronic disease self-management, and the physician-led program focusing on palliative care and managing complex chronic conditions. The programs will be described in depth and patient outcomes will be evaluated by a retrospective study comparing the number of ED visits and rehospitalizations in the 120 days before and after the transitional care interventions.

Based on the current strength of the evidence supporting the use of APNs in providing transitional care, the APN-led program is expected to be effective in reducing healthcare utilization. As physician-only transitional care programs have not been widely studied, mixed results are predicted for this program based on previous study of palliative-focused transitional care.

Methods

Study Design

This is a retrospective descriptive study of patients who received one of two transitional care interventions: a CNS-led transitional care model and one led by physicians specializing in palliative care (PPC). The study used a pre-post single-patient design without controls. The

CNS program was evaluated using a secondary analysis of existing data. A chart review of encounters data for the patients of the PPC intervention was also utilized for data collection.

CNS-Led Program

Setting. The CNS program is based in a small rural community hospital in a town surrounded by a rural area in a small rural state. The median household income is \$50,221 for this county and 13.9% of citizens live below the poverty level (U.S. Census Bureau, 2015a).

Clinicians. The providers of CNS program are three master's-prepared CNS. They previously acted as the CNS for the Emergency, Intensive Care, and Medical/Surgical Departments of the hospital, and each have more than 35 years of clinical experience in these areas. They each have been trained in the University of Pennsylvania Transitional Care Nursing Program.

Participants. Patients in the CNS program were patients of one of six primary care practices from the surrounding community of the hospital. Each nurse collaborates with two primary care providers (PCPs) with the goal of enhanced coordination and communication and facilitating patients' willingness to accept the intervention.

Exclusionary criteria included those with severe dementia who were unable to participate in self-management teaching, those who had a behavioral health issue as their primary diagnosis, those who did not have risks for rehospitalization, or those who lived in a long-term care facility. Patients who were not generally involved but were not as a rule excluded were those who were receiving home health services or were on hospice.

Program organization. Referrals generally came from the inpatient huddle with the case management nurse, but requests were also taken from collaborating PCPs and nursing homes. Visits began in the hospital, the first hospitalization day if possible, and continued daily until discharge. The goals of hospital visits were to establish contact, introduce patients to the transitional care program, and request that they would allow a home visit. The first home visit occurred 24 to 48 hr post-hospitalization, with a goal of initiation before the first office visit with the patient's PCP. Patients were seen at home or in a rehabilitation facility.

The initial assessment included a complete problem list and list of medications, risk factors for rehospitalization, details of medication management, and a physical examination. Social support systems, patient

understanding of their treatment plan, and self-management learning needs were also assessed. Goals were created for a safe transition home and a follow-up plan of care. Interventions included medication reconciliation, review of discharge instructions, chronic disease self-management education, and evaluation of necessary services like housing, food, and transportation. The CNS may also have gone to primary care or other appointments with program participants to facilitate communication and common goals of care.

Visits generally occurred once per week for the first 4 weeks, then biweekly, with an average of 2 to 3 months until discharge. Some patients were only seen once and discharged if their goals were met or they did not want further visits. The transitional care nurses were available by phone during weekday office hours. Patients were discharged when goals for follow-up and disease self-management were met and the CNS was confident that they would follow through with the plan created. A further description of the origin of the program and case studies of patients enrolled in the program was provided by Fels et al. (2015).

PPC-Led Program

Setting. The PPC program was based in an academic medical center in the principal city of a metropolitan area in a small rural state. The median household income is \$63,989 in this county, with 11.2% of citizens living below the poverty level (U.S. Census Bureau, 2015b).

Clinicians. The clinicians providing care were two physicians with specialization in internal medicine and palliative care who had 26 and 10 years of experience in these fields. They concurrently acted as the medical directors of a sub-acute rehabilitation or long-term care facility and a hospice program, respectively. Both PPC clinicians had previous experience providing house calls to patients in their own practices. While a multidisciplinary team was not a formal aspect of the program, the physicians may have coordinated with home health agencies, including palliative care and hospice services.

Participants. Participants in the PPC program may have been patients of any PCPs but lived in the surrounding communities of the academic medical center. There were no exclusions based on the patients' participation in home health, hospice, or living at long-term care facilities, and they did not have to be previously hospitalized to receive the service.

Program organization. Sources for referrals to the PPC program included the patient's PCP, hospitalists,

specialist physicians, hospital case manager, home health professional, or family member. The urgency of the referral was discussed with the referring source and the timing of the visit was planned accordingly. Hospitalized patients were not seen by the PPC program physician prior to discharge. PPC visits were made wherever the patients resided, including home, residential care settings, and nursing facilities.

At the first visit, immediate needs were assessed. There was not a standardized assessment applied to each patient. Interventions included treatment of acute illness, disease management, symptom management, medication management, home safety, goal clarification, advance care planning, and referrals to a higher level of care. The physicians prescribed medications or other interventions directly or made recommendations to the patient's PCP. For selected home-bound patients with life-limiting illnesses for whom clinic burdens were overly burdensome, PPC program physicians took on the role of PCP.

The number of home visits varied from 1 to 19; the mean number of visits was approximately 3. The PCP office remained the point of contact for the patient and family throughout the PPC program involvement in the case, and office staff facilitated communication with the PPC program physician as needed. Discharge from the program occurred when the objectives of the PPC intervention had been met. Consultation was available during business hours Monday to Friday. See **Table 1** for summaries of the two interventions.

Analysis

Data from participants in the CNS program (September 2014 to December 2014) were analyzed. Patients who died before the end of this 120-day period were removed from the data pool before the researchers received the data. Data were collected from patients in the PPC program from September 2014 to April 2015, a longer period due to fewer participants in the program at a given time.

Patients' age and sex were collected. The outcome variables examined were the number of hospitalizations and ED visits 120 days before and after the interventions began. For the PPC program, data were also collected regarding date of death. A Wilcoxon matched-pairs signed-rank test for nonparametric data was performed to test for significance. Means were reported rather than medians due to several medians being zero.

Ethics

The University Committees on Human Subjects approved the research project. Research certification from the academic medical center was obtained to access

Table 1. Descriptive Comparison of the Two Transitional Care Programs

CNS	PPCs
Led by a team of three clinical nurse specialists with expertise in inpatient care and training in transitional care.	Led by two physicians with expertise in internal medicine and palliative care.
Small rural community hospital.	Academic medical center in small city in metropolitan area.
Focus on chronic disease self-management.	Focus on managing complex chronic illnesses, palliative care.
Hospital based, daily patient visits during hospitalization.	Community based, no visits during hospitalization.
Standardized assessment and home visit schedule.	No standardized assessment or home visit schedule.
Patients seen at home or acute rehabilitation facility, not if living at long-term care facility.	Patients seen at home or long-term care facility. Patients may be on hospice or receiving home health care.
Patients on hospice or receiving home health care usually excluded.	
Patient mean age 69 years.	Patient mean age 81 years.

Note. CNS = clinical nurse specialists; PPCs = physicians specializing in palliative care.

patient charts, and approval was obtained from the medical center’s Nursing Research Committee.

Results

Patient Characteristics

For the CNS intervention, data were collected from 98 participants from the secondary data source. The average age of participants was 69 years and there were slightly more females than males (65% female). For the PPC intervention, a chart review of 72 participants was completed; 32 of these participants died within 120 days after the intervention and thus were excluded from the analysis. The remaining 40 that were included had an average age of 81 years and 63% were female.

Hospital and ED Utilization

CNS program. The mean number of hospitalizations was 1.03 per patient in the 120 days before the intervention and 0.21 per patient after the intervention. Mean ED visits per patient were 0.93 in the preintervention period and 0.22 postintervention. A Wilcoxon signed-rank test indicated that there were significantly fewer hospitalizations in the 4 months after the intervention than in the 4 months before the intervention ($p < .005$). This was also true for ED visits ($p < .005$).

PPC program. Patients in the PPC program had a mean of 0.72 hospitalizations in the 120 days before the intervention and 0.34 in the postintervention

Table 2. Outcomes of Emergency Department Visits and Hospitalizations for Clinical Nurse Specialists (CNS) and Physicians Specializing in Palliative Care (PPCs)

Outcomes	Transitional care programs					
	CNS (n = 98)			PPCs (n = 41)		
	Mean before	Mean after	p	Mean before	Mean after	p
ED visits	0.93	0.22	<.005	0.67	0.28	.33
Inpatient stays	1.03	0.21	<.005	0.72	0.34	.03

period. The mean number of ED visits was 0.67 preintervention and 0.28 postintervention. A Wilcoxon signed-rank test for significance showed that there were significantly fewer hospitalizations postintervention ($p = .03$) and that the reduction in ED visits was not significant ($p = .327$). See **Table 2** for a summary of the results.

Discussion

This study documents the characteristics of two very different approaches to transitional care and despite these differences gives empirical support for each program’s ability to reduce hospitalizations. One difference in outcomes is that the CNS program also showed a statistically significant decrease in ED visits, while the PPC program did not. While a direct comparison between the programs cannot be drawn due to multiple differences in patient populations, providers, and program structures, it is possible to explore the differences and characteristics

of each program and comment on ways they may have contributed to the success of each program.

One clear difference is seen in the patient population, with the PPC program having an older population. A likely contributor to the increased age of the PPC participants is the palliative expertise of the providers and that individuals needing at-home physician visits are more likely to be homebound and at the end of life. Previous study of an at-home palliative care consulting program provided by nurse practitioners similarly showed a decrease in hospitalizations but not ED visits postintervention, and concluded that increasing on-call availability may improve the program's ability to reduce ED visits (Lukas et al., 2013). While there is evidence that palliative care reduces healthcare utilization at the end of life (Smith, Brick, O'Hara, & Normand, 2014), there is mixed evidence that palliative care effectively reduces ED visits (DiMartino, Weiner, Mayer, Jackson, & Biddle, 2014). Since it is not known how the ED visits for PPC patients would have progressed without the intervention, further study with randomized controls is needed to determine whether it prevented increased utilization.

Another key difference is the providers' training and scope of practice. Nursing traditionally has taken on the role of care coordination and developed skill sets in this area, which may be why previous studies of transitional care provided by master's-prepared APNs have yielded similar results of reductions in ED visits and hospitalizations (Naylor et al., 2011, 2014). There has been very little study of physician-only transitional care for comparison to the PPC program outcomes (Reese et al., 2003). Previous study of differences between nursing and physician approaches to care have found that nurses are more oriented toward rule-based or protocol-oriented care (McDonald, Waring, Harrison, Walshe, & Boaden, 2005). This difference is apparent in the design of the two programs: while the CNS program used a comprehensive assessment applied to each patient and a standardized visit schedule, the PPC program left the assessment and visit schedule open to their discretion. The structured nature of the CNS program, which identified patients during hospitalization and had a set schedule of visits, may be a contributor to the success of the CNS program at reducing ED visits and hospitalizations. It is unclear, however, whether a structured program would improve PPC program outcomes, as its flexibility may be necessary to coordinate overlapping visits with other providers, such as home health.

Another factor is the region, with the CNS program being in a more rural area with more limited resources and a population with a lower income and challenges to social determinants of health. The results of the CNS

program are particularly significant given the variation of the socioeconomic status of their patients and the nurses' own reports of managing social determinants of health.

Limitations

One methodological limitation of the study is the absence of a randomized controlled design, limiting the ability to conclude that the intervention directly led to the outcomes. Especially for PPC program patients with complex conditions who may have been declining more rapidly, a control arm would have been helpful. Control groups with similar illness trajectories would make it more clear whether utilization was prevented and whether the intervention was the driver of the decrease in postintervention hospitalization.

The restrictions of the CNS program to exclude those receiving home health care and hospice care (a compromise made with local home health agencies to get community buy-in and to prevent duplication of services), those with cognitive impairment, and those with primary mental health diagnoses may have left out some key groups at risk for rehospitalization (Callahan et al., 2015; Piraino, Heckman, Glenny, & Stolee, 2012), which limits the generalizability of the findings.

The wide variety of differences between the two programs and their patient populations also limits a direct comparison of the two programs' effectiveness. Risk adjustment was a potential option for direct comparison, but it was felt that it would not adequately account for the complexity of differences between the two patient populations. Future study with programs with more similar patient populations may give a clearer picture of the most effective components of transitional care.

Another limitation is that data on cost were not collected, which limits the ability to draw a conclusion that the programs have reduced costs. An assumption is made that fewer ED visits and rehospitalization decrease costs; however, further research with cost data could determine whether the programs were cost effective by comparing the cost of salaries and support of the clinicians with the cost of healthcare utilization.

Conclusions

Despite these limitations, this study shows the potential for a variety of transitional care programs to decrease unnecessary utilization of health care at the critical periods of transition that leave patients vulnerable to adverse events and poor outcomes. A potential criticism of

transitional care is that it creates yet another layer of provider hand-offs, further complicating care, leading to the question of whether adding extra providers is necessary or beneficial. Perhaps improved primary care would eliminate the need for transitional care. This study contributes to the growing body of evidence that in our currently fragmented health-care system, there is a critical need for transitional care programs that bridge a gap and prevent unnecessary and costly utilization of ED services and hospitalizations.

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Clinical Resources

- The Care Transitions Intervention: <http://caretransitions.org/>
- ConsultGer: <https://consultgeri.org/geriatric-topics/transitional-care>
- Nurses Improving Care for Healthsystem Elders: <http://www.nicheprogram.org/>
- Transitional Care Model: <http://www.transitionalcare.info/>

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