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SELF REPORTED HEALTH PROMOTION BEHAVIORS OF INDIVIDUALS WITH
PSYCHIATRIC DISABILITIES IN A WEIGHT LOSS INTERVENTION

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Abstract

Introduction: Research shows that individuals with psychiatric disabilities, particularly those with schizophrenia, die on average 25 years earlier than the general population (Marder et al., 2004). Excess mortality is due primarily to cardiovascular disease but also from other comorbid conditions exacerbated by obesity. Limited income in combination with poor diet, lack of exercise, and psychiatric medications often contribute to obesity in individuals with psychiatric disabilities. **Purpose:** this study examines if individuals in a weight loss program report an increase in healthy eating and physical activity over time compared to those in a control group. **Methods:** scores from two subscales of the Health-Promoting Lifestyle Profile II (HPLPII) were administered at baseline, 3 months, 6 months and 12 months to individuals who were randomly assigned to a Psychiatric Rehabilitation Approach to Weight Loss program or a control group. Scores were analyzed using a repeated measure ANOVA. **Findings:** change in self-report of nutrition between the control and intervention groups did not significantly change over the course of the study. However, change in self-report of physical activity between the intervention and the control group was significant, with significant changes between baseline and three months, baseline and six months, but not between baseline and twelve months. **Discussion:** Participants in the Psychiatric Rehabilitation Approach to Weight Loss program reported increased physical activity, but reported no changes in nutrition compared to the control group. Further study is needed to determine if self-report of increased physical activity is confirmed with actual increase in activity.

Introduction

Of the numerous comorbid diseases that individuals with serious and persistent mental illness (SPMI) die from annually, the largest cause of natural death is cardiovascular disease (CVD) secondary to obesity (Hauswoltff-Juhlin et al., 2008). It is common for individuals with SPMI to be overweight, specifically those with schizophrenia; however, each year these numbers continue to rise above the accepted average. Additionally, a large number of individuals with mental illness are seen to be overweight when compared to overweight individuals in the general population, specifically 29% of men and 60% of women with SPMI are obese when compared to the general population (Allison et. al, 2000). It should be noted that many modifiable risk factors for CVD have been identified in this population such as obesity, smoking, hypertension, and hyperglycemia, yet antipsychotic medications also cause excess weight gain. In addition some antipsychotics cause sedation, leading individuals with severe psychiatric mental illness to be less inclined to exercise.

Individuals with severe mental illness, specifically those with schizophrenia, are known to exercise less due to the nature of their mental illness. Negative symptoms of schizophrenia such as

apathy and depression reduce motivation to be physically active. In addition individuals with schizophrenia are less likely to seek social activities and social interaction further reducing potential opportunities to be physically active (Hausswolff-Juhlin et al., 2008).

Individuals with serious mental illness, especially those with bipolar and schizophrenic disorders may have cognitive deficits. Common deficits include problems with attention, concentration and executive functioning that are needed for planning and executing healthy behaviors like exercising and preparing healthy meals. Since these disorders commonly emerge in late adolescence and young adulthood, knowledge and skills needed for selecting and developing healthy habits have not been established.

Generally individuals in this population are uninsured or under insured and live below the poverty line. Without adequate funds, it is difficult for individuals with serious mental illness to make healthy meal decisions. Often these individuals choose fast food or junk food, since these items are easy to access and relatively cheap. Consumption of food with little to no nutritional value is yet another factor contributing to obesity in this population.

Problem

Individuals with SPMI have higher levels of obesity, cardiovascular disease and die at an earlier age than individuals without serious mental illness. Many factors contribute to their increase in medical morbidity and mortality; lack of knowledge, lower income, availability of healthy foods and conducive environments for exercise. In addition medication used to treat individuals with serious mental illness often contribute to weight gain. Few weight loss programs have been evaluated to address the unique needs of this population.

Purpose

A current federally funded grant is examining Psychiatric Rehabilitation Approach to Weight Loss (Brown, 2006). This study followed people with SPMI for 12 months. As part of that larger study, self reported health behaviors were assessed at four times: baseline, 3 months, 6 months, and 1 year. Healthy behaviors are defined as health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management and measured with the Health-Promoting Lifestyle Profile Scale (Walker, Sechrist, Pender, 1987). The purpose of this study is to examine if individuals with serious mental illness who participated in a weight loss study reported engaging in more healthy behaviors, specifically physical activity and nutrition, over time.

Hypothesis

Individuals with severe mental illness who participate in a weight loss study will report an increase in the healthy behaviors nutrition and physical activity from baseline to 3, 6, and 12 months compared to individuals in the control group.

Literature Review

Several research studies focusing on the relationship between obesity and serious mental illness have been reported in the literature. The research studies use both quantitative and qualitative methods to describe this relationship and yield similar conclusions but cannot be assumed to establish causality. Farnam, Zipple, et al. (1999) were among the first to describe the health status of individuals with SPMI. Using mailed questionnaires, they found that these individuals did receive yearly medical checkups, but were below average for physical activity when compared to the general population. Additionally the individuals with SMI had increased risk factors such as smoking, poor diet, alcohol consumption, and drug use. Noting risk factors for multiple chronic illnesses within this population, Shen, Sambamoorthi, and Rust (2008) examined data from the national Medical Expenditure Panel Survey (MEPS) for adults living with chronic illnesses such as obesity and mental illness. They found that 25% of adults with obesity and physical illness also had a mental illness. The total expenditures for obese adults with physical illness and mental illness were \$9897 annually compared to expenditures of \$6584 for those with only physical illness.

Jones et al. (2004) studied the occurrence of chronic physical health problems in individuals with serious mental illness. Looking at Medicaid claims, they found that 74% in this population had at least one chronic physical problem and 50% of this population had at two chronic physical problems. Chronic pulmonary illnesses were noted as the most prevalent and the most comorbid. Using regression analysis, the researchers found that age, obesity, and substance abuse disorders were all risk factors in increasing chronic physical health problems in this population.

To assess the physical activity levels of individuals with SPMI, Daumit and Goldberg et al. (2005) examined the frequency of self reported physical activity in this population. They matched by age, gender, and race to data obtained from the National Health and Nutrition Examination Survey (NHANES II). They found a higher prevalence of obesity (46%; $p < 0.001$), less physically activity (49%; $p < 0.001$) in individuals with serious mental illness compared to the general population. Walking was the most common form of physical activity with 29% of this population reporting that it was their only form of physical activity in the past month.

The Health Promoting Lifestyle Profile (HPLP), the instrument used in the present study, was used by Holmberg and Kane (1999) along with the Denyes Self-Care Practices Instrument (DSCPI), Health Risk Appraisal (HRA), and Multidimensional Health Locus of Control Scale Form B (MHLC-B). They found that individuals with SPMI scored lower on all four of these scales and were less likely to perform self-care activities when compared to individuals without psychiatric disorders. Lack of self care, chronic illnesses such as obesity, and mental illness can all lead to poor quality of life.

Kolotkin and Corey-Lisle et al. (2008) looked at the impact of obesity on the quality of life in individuals with SPMI using the Impact of Weight on Quality of Life-Lite (IWQOL-Lite) a 31-item self-report measure consisting of five subscales: physical function, self-esteem, sexual life, public distress, and work. Data indicated that obese participants reported more impairment and lower IWQOL-Lite scores than nonobese participants ($p < 0.001$).

Pre-Post Research

Additional research studies investigate the effects of various interventions to lessen obesity in individuals with SPMI. Using a pre-post design these studies also assessed self-reports of health behaviors. Centorrino et al. (2006) looked at the effects of a weight loss study in individuals with SPMI. Twenty participants with schizophrenia or schizoaffective disorder who reported a weight gain of >4.5 kg and an increase in BMI of $>5\%$ since starting antipsychotic treatment were recruited for an intensive 24 week weight loss study. Participants were educated on diet, exercise, and counseling in weekly sessions which incorporated meal planning, and individualized fitness plans. While participants did not record self-reports of healthy behaviors, the participants were measured with a pre-test then monthly using the Quality-of-Life Questionnaire (QLS), Clinical Global Impressions (CGI), and Brief Psychiatric Rating scales (BPRS). Adverse effects of medications were measured using the Self-Report SF-36 Health Survey. Baseline followed by monthly tests of the QLS revealed no significant differences from baseline to end of the 24 weeks, while BPRS and CGI improved slightly within the first 6 months and remained stable. There were only minimal changes in ratings of neurological or other adverse effects. Data were analyzed using paired t-tests and average weight decreased by 6.0 kg (5.7%), and BMI decreased to 34.5 (by 5.7%). Blood pressures decreased from 130/83 to 116/74 (11% improvement), pulses fell slightly. Even under less intensive management for another 24 weeks, subjects regained only minimal weight (0.43 kg).

Chen et al. (2009) recruited 33 patients with schizophrenia and antipsychotic-related obesity in a 10-week multimodal weight control program. Participants were given pre-tests based on weight at baseline, then week 4, week 8, week 10 (end of the intervention), and post-test at week

12, week 24, and week 48. In addition to measuring weight, researchers also collected pre and post tests measured blood sugar levels, cholesterol levels, triglyceride levels, quality of life using the World Health Organization-Quality of Life-Brief version (WHO-QOL-BREF) scale, and mental health using the Positive and Negative Symptom scale (PANSS) and the Beck Depression Inventory (BDI). The intervention included nutritional counseling, exercise, and behavioral interventions to help reduce weight in these individuals. Data were analyzed using paired t-tests that indicated those in the intervention had a mean weight loss of 2.7 kg by the end of 12 months and a 1.1 decrease in BMI. Participants also showed significant improvements in WHO-QOL-BREF, PANSS, and BDI scores. The effectiveness of this weight loss intervention lasted up to 12 months in specific participants, indicating that a weight loss program targeted for individuals with SPMI can produce long term health benefits.

Control Group Research

Brown and Chan (2006) performed randomized control study with six weekly 50 minute sessions designed to promote health in individuals with serious mental illness. Subjects initially answered a basic health screening questionnaire, followed by the DINE questionnaire to assess diet and the GODIN questionnaire to measure frequency and intensity of physical activity prior to six weekly sessions of health education. Subjects gave self-reported ratings of their physical health, fitness and mental health on a Likert scale graded from 0 (very poor) to 10 (excellent) at baseline and after completion of the intervention. Researchers discovered that subjects in the intervention did report slight improvements in physical activity, increased fiber intake in their diets, an average weight loss of 0.9 kg, and self-reports indicated improved subjective well being in comparison to the control group.

Skouroliakou et al. (2009) recruited a total of 204 overweight subjects (63 without psychiatric disabilities and 141 individuals with SPMI) to participate in a weight loss study tailored for individuals with SPMI taking olanzapine. All participants with SPMI were recommended for the study by clinical psychologists and had been taking olanzapine for a minimum of one year with an average dosage of 8.96 ± 0.2 mg/d, while members from the general population were placed in a matched healthy/control group. During the 3 month nutritional intervention participants were screened to assess lifestyle, eating habits, physical activity, and food preferences. Individual food plans were designed for the participants by a registered dietitian and participants were given weekly food diaries to assess adherence to diet as well as receiving dietary and exercise counseling. Behavioral interventions included teaching basic nutritional principles, healthy recipes, cooking techniques, and grocery shopping skills. Participants were instructed to participate in light to

moderate intensity exercise daily for 30 minutes and to record this activity in their weekly exercise log. Data obtained at baseline and at three months were tested with independent *t* test to compare changes in body weight, fat mass, and waist circumference. The nutritional intervention produced significant decreases in body weight, BMI, fat mass, and waist circumference over the 3 month period with no difference in weight loss between the population with SPMI and individuals in the healthy control. The study shows that personalized nutritional interventions are effective in decreasing body weight, fat mass, and waist circumference in individuals with SPMI over 3 months.

Weber and Wyne (2006) performed a randomized placebo-controlled design to test the effectiveness of a cognitive/behavioral group intervention in 17 individuals with schizophrenia or schizoaffective disorder taking atypical antipsychotics. Weight, BMI, and waist-hip ratio, and blood sugars were measured pre and post intervention. The cognitive/behavioral intervention involved a one hour group session once a week for 16 weeks where participants learned strategies via role play, goal setting, motivational scaling, problem solving, etc. to promote risk reduction for developing diabetes. Participants also kept food and activity diaries. Data were analyzed using paired t-tests. Researchers found that participants in the cognitive/behavioral approach lost an average of 5.4 lbs compared to those in the control group who lost only 1.3 lbs. There was also a 2.9% change in BMI for the treatment group.

A prospective comparative analysis by Poulin et al. (2007) recruited 110 patients with schizophrenia, schizoaffective, or bipolar disorders in a behavioral weight control program to reduce antipsychotic induced weight gain. The 59 randomly assigned participants completed an 18 month intervention program involving dietary education and physical activity counseling, while 51 participants were assigned to a control group that did not receive the clinical intervention. Body weight, height, waist circumference, BMI, plasma lipid-lipoprotein profiles, and fasting plasma glucose concentrations at were collected at 11 intervals throughout the study. Additionally, serum concentrations of prolactin, thyrotropin-stimulating hormone (TSH), and glycated haemoglobin (HbA1c) were assessed at four times. The Clinical Global Impression scale (CGI), Brief Psychiatric Rating Scale (BPRS), and the Short Form (SF)-36 Health Survey were used to assess psychological health of the participants. Data indicated a significant increase in bodyweight (4.1%), BMI (5.5%), and waist circumference (4.2%) in the control group compared to a significant reduction in bodyweight (-3.5%), BMI (-4.4%), and waist circumference (-4.6%) for the experimental group at the end of the study. In addition, LDL cholesterol, triglycerides, total cholesterol, fasting blood glucose, and HbA1c showed significant decreases in the intervention group when compared to baseline. While there were no self-reports of health behaviors, this study

shows that a behavioral weight loss program can be effective for individuals with SPMI over 18 months.

Jay Lee et al. (2008) recruited 232 South Korean psychiatric patients who had a diagnosis of either schizophrenia or schizoaffective disorder and were also taking antipsychotic medications were randomly assigned to a 12-week weight management program. All participants had a body mass index (BMI) 25 kg/m² or greater. Researchers measured changes in body weight and BMI over the course of the study to determine the effectiveness of the weight control program. Participants in the intervention showed significant reductions in BMI (0.98 ± 1.01 kg/m², $p < .001$) and body weight (2.64 ± 2.75 kg, $p < .001$) compared to those in the control. Diet modification and compliance was the strongest indicator of weight loss for individuals with SPMI participating in this study.

Another study focusing on traditional weight loss practices recruited 53 individuals with schizophrenia from a veteran's hospital in Taiwan and randomly assigned them to a study group of 28 or a control group of 25. All participants had BMI greater than 27 and were taking clozapine. The study group was placed on a reduced calorie diet, cutting 200 to 300 calories per day for a period of six months. Participants also participated in regular physical activity burning a total of 600 to 750 kcal per week. Results found that compared to the control group, there was a significant decrease in BMI (5.4% reduction), waist circumference (3.3cm), as well as a decrease in triglyceride levels, Wu et al. (2007).

In addition to utilizing general weight loss practices, other researchers incorporated cognitive and behavioral interventions to help reduce and maintain weight loss in individuals with SPMI. Melamed et al. (2008) randomly assigned 59 individuals diagnosed with schizophrenia or schizoaffective disorder to a behavioral weight reduction intervention and control groups. In addition to behavioral modification, participants were given nutritional information and physical exercise to help reduce their body mass index (BMI). A 2x2 ANOVA was performed to compare the baseline, one, two, and three month BMI measures between the control and experimental groups. Data showed a significant weight reduction in the experimental group from one to three months when compared to the control group. Also, a significant improvement in self-report of quality of life was evident in the experimental group compared to the control group showing that a combination of behavioral and traditional weight loss methods are effective in reducing weight and improving quality of life in this population.

McKibbin et al. (2006) also performed a randomized controlled trial with 64 participants aged 40-81 and diagnosed with schizophrenia or schizoaffective disorder to test a lifestyle

intervention for older schizophrenia patients with type-2 diabetes. Participants were randomly assigned to 24 week diabetes awareness and training (DART) sessions where they had weekly weights, pedometers, healthy food sampling, and other strategies to implement behavioral changes. Physical activity was measured using an accelerometer worn around the waist and by participant self-reports on the Yale Physical Activity Scale (YPAS). Diet was measured using the Block Brief 2000 Revision of the Health Habits and History Questionnaire. Participants in the DART program showed significant reductions in BMI, weight changes (5%), waist circumference, and plasma triglycerides when compared to the control group. Analysis of diet indicated that participations in the intervention reduced their daily fat consumption from 2.8 servings to 1.7 servings, while the control group did not decrease their fat consumption from pre to post intervention. Additionally participants in the intervention reported an increase in total activity summary index as measured by the YPAS while individuals in the control decreased. Not only did this study reduce diabetes risk factors, it also produced healthier lifestyles for individuals with SPMI.

Cabassa et al. (2010) completed a systematic review of quality of lifestyle interventions for this population. Twenty-three articles were assessed that reported physical and health promotion outcomes of lifestyle interventions utilized in individuals classified with serious mental illness. After rating the studies using the Methodological Quality Rating Scale (MQRS) the researchers noted that the most effective interventions utilized behavioral techniques, such as goal setting, skills training, and motivational counseling to improve diet and physical activity levels. Of the studies included, all used anthropometric assessments, such as BMI or weight loss, to measure health outcomes as opposed to self-reports of health behaviors. Overall, specific lifestyle interventions targeted for individuals with serious mental illness can not only reduce weight and risk factors for diabetes, but enhance physical activity and nutrition, too.

In the larger federally funded grant *A Psychiatric Rehabilitation Approach to Weight Loss* (Brown, 2006) a randomized control designed was used to test a psychosocial rehabilitation weight loss program on weight reduction and health promotion behaviors in individuals with serious mental illness (Brown, Goetz, & Hamera, in press). Eighty-nine participants completed the Recovering Energy through Nutrition and Exercise for Weight loss (RENEW) program. RENEW uses evidence based weight loss strategies such as calorie deficits and daily physical activity as well as psychiatric rehabilitation through social support, goal setting, skill transfer training, and strategies to compensate for cognitive impairments in this population.

Participants in this randomized study attended weekly three hour sessions with active instruction and active participation in nutrition and physical activity and were given two meal

replacements per day. Over the next three months participants met monthly for a three hour session on active instruction and participation in nutrition and physical activity and received weekly phone support, but no meal replacements. Participants were also required to complete a 52 item questionnaire assessing self-reports of six health behaviors: health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management at baseline, three months, and six months. The intervention produced an average weight loss of 5 pounds in participants that was maintained at six months, illustrating that individuals with serious mental illness can benefit from diet and exercise programs and sustainably improve their health behaviors (Brown, Goetz, & Hamera, in press).

The present study examines the effects of a psychosocial weight loss intervention by assessing self-reports of healthy behaviors and focuses on the two specific health behaviors- physical activity and nutrition from the HPLPII. When assessing these self-reports at 3 months, 6 months, and 12 months there is expected to be an increase in healthy behaviors that occurs over time in the intervention group compared to the control group.

Methods

This study analyzes data from A Psychiatric Rehabilitation Approach to Weight Loss (Brown, 2006). A repeated measure ANOVA is performed to examine differences between the intervention and the control groups in self-reported nutrition and physical activity from the HPLPII at baseline, 3 months, 6 months, and 12 months.

Sample

The sample included adults age 21 to 65 that have a diagnosis of serious mental illness, a BMI greater than or equal to 25, and a stable weight with no change greater than 10 pounds in the past three months. Participants were recruited from four community support programs, three in the Kansas City area and one in Las Vegas, providing services to individuals with SPMI. The study was approved by the IRBs of the University of Kansas Medical Center and Touro University, Nevada. After complete description of the study to participants, written informed consent was obtained. Individuals were stratified by psychiatric medication risk for weight gain into high (olanzapine, clozapine, lithium), moderate (risperidone, chlorpromazine, quetiapine, valproate) and low/no (molinidone, ziprasidone, fluphenazine, haloperidol, aripiprazole) risk groups using guidelines from a consensus conference on antipsychotic drugs and obesity (American Diabetes Association, 2000) and randomly assigned to the intervention or control group. There were 47 participants randomly assigned to the intervention group and 42 to the control group. There were 35 (39%)

male participants, and the mean age was 44.6 (± 10.9). Racial distribution included 60% Caucasian, 34% African American, and 6% other races

Measure

The HPLP, was used to measure health behavior of participants. The HPLP was created in 1987 by three nurses, Walker, Pinder, and Sechrist (Walker et. al, 1987). This scale has been modified over time to measure frequency of self-reported health promoting behaviors. Healthy behaviors as defined by the HPLP scale include: health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management. The scale consists of a 52 item questionnaire relating to specific healthy activities. Responses are rated: never, sometimes, often, or routinely. This study focuses on the physical activity and nutrition subscales as assessed by the HPLPII. The scale has nine items relating to nutrition and eight items relating to physical activity. Five of the nutrition items relate to the food pyramid and specific serving sizes of food. They require participants to rate their adherence to the range of servings in each food group e.g. fruit, vegetable, carbohydrates, dairy, and fats per day. One item requires participants to be able to identify and read nutrition labels. Of the eight items that regard physical activity, three items require participants to report amounts of exercise per week. Two of the items suggest participants use equipment, such as a bicycle, for exercise.

The HPLPII scale has a high alpha coefficient of 0.919, signifying that items are measuring a similar construct. Additionally a t-retest r of 0.854 indicates stability of the scale. Another indication of validity of the HPLPII is the factor analysis of the six subscales: health responsibility, physical activity, nutrition, interpersonal relations, spiritual growth, and stress management. The HPLPII has been used in multiple studies, one example is the *Depression and Health-Promoting Lifestyles of Persons with Mental Illness* by Jensen and Decker et al. (2006). They found a total alpha coefficient of 0.92 and subscale alpha coefficients for stress management= (0.86), interpersonal relationships= (0.87), spiritual growth= (0.91), nutrition= (0.77), physical activity= (0.91), and health responsibility= (0.89).

Intervention

There were three phases to the intervention that included a 12-week intensive phase, 12-week maintenance phase, and a 6-month intermittent phase. During the intensive phase participants attended a three hour weekly session where they learned skills training, goal setting, participated in physical activity, and ate a nutritious lunch. The participants could also attend an optional one hour exercise session once or twice a week. During the intensive phase participants were given two meal replacements for each day of the week while they were learning portion sizes

for weight loss. During the maintenance phase (weeks 13-24), participants were instructed in transferring behavioral changes into habit patterns at the monthly 3-hours sessions. The participants continued to have the opportunity to participate in 1 hour exercise sessions once or twice a week and received weekly phone calls and newsletters in the mail. They also had the opportunity to participate in individualized grocery shopping training. The intermittent intervention occurred during weeks 25-52. Participants did not receive face to face contact but did receive feedback, reminders, and support to continue to adhere to behavioral changes through weekly phone calls and monthly newsletters.

Analysis

Data were collected from 2007 – 2009 and analyzed using SPSS X.0 software. Descriptive statistics were generated to describe the sample. The hypothesis was tested using a repeated measure ANOVA on the HPLPII subscales, nutrition and exercise.

Results

A total of 59 participants completed the study, 27 of which were in the control and 32 in the intervention. The primary psychiatric diagnoses of participants were schizophrenia spectrum disorders (n=31), bipolar disorder (n=14), and major depressive disorders (n=14). Fifty-eight (n=34) of the participants were female and the mean age for participants was 46.02 (\pm 10.55 SD). Ethnic/racial participants included 25 African Americans, 33 Caucasians, and 1 other group.

A repeated measure ANOVA with analysis of variance was performed to evaluate change over time in self-reports from HPLPII subscales, nutrition and physical activity, between participants in the control and intervention groups. There were 9 questions on nutrition yielding a possible range of scores from 9 to 36. There were 8 questions pertaining to physical activity yielding a possible range of scores from 8 to 32. Table 1 shows the means and standard deviations for individuals in the control and intervention groups for each testing period. The means for the nutrition subscale show small increases in both the intervention and control groups. Means for the physical activity subscale show improvements in physical activity for the intervention group at 3 and 6 months and little changes in the control group.

The time main effect from self-report of nutrition activities X the testing periods (time) were compared between the control and intervention group. Using the multivariate criterion of Wilks's lambda (Δ), change in self-reports of nutrition over time between groups was not significant, $\Delta = .94$, $F(3,55) = 1.09$, $p = .363$.

The time X group of self-report of physical activity were tested using the multivariate criterion of Wilks's lambda (Δ). The change in self-reports of physical activity over time was

significant, $\eta^2 = .83$, $F(3,55) = 3.83$, $p = .02$. Additional analysis was conducted to identify which time periods differed. From baseline to three months self-reports of physical activity were found to be significantly different between the control and intervention groups, $\eta^2 = .93$, $F(1,57) = 4.4$, $p = .04$. Similarly baseline to six months self-reports of physical activity between groups were also significant, $\eta^2 = .91$, $F(1,57) = 6.0$, $p = .02$. From baseline to 12 months self-reports of physical activity were not significant by group, $\eta^2 = .18$, $F(1,57) = .18$, $p = .68$.

Discussion

The findings show an increase in physical activity from baseline after 3 months of weekly intervention sessions and at 6 months after monthly intervention sessions but not at 12 months after there had been no face to face interventions for 6 months. Unlike the physical activity subscale of the HPLPII, the nutrition subscale did not show differences between the intervention and control groups at any of the testing times. This implies that participants in the intervention made more changes in physical activity than in their diet.

Before accepting this conclusion, other explanation for the lack of findings with the nutrition subscale of the HPLPII need exploration since approximately equal time was spent on both topics in the 3 hour intervention sessions. One possible explanation is the type of items in the nutrition subscale. Five of the nine items in the nutrition subscale focused on the food pyramid and serving sizes of food. This requires distinguishing between food groups and understanding what are serving sizes for each food group; a fairly complex task. For example "getting 5-11 servings of carbohydrates daily" requires understanding what carbohydrates are and that the number of serving needed depends on basic energy requirements and energy expenditure. In addition since most people eat more than once a day it is more difficult to calculate total daily intake. Items assessing physical activity were not as complex. For example "do stretching exercises at least 3 times per week" only requires the simple task of stretching with a minimal frequency and less cognitive effort on the part of the participant.

Another explanation for the increase in physical activity and lack of improvement in nutrition could have been that the information was learned but was too difficult to implement. Due to increased poverty levels in this population, participants may not have been able to purchase healthy foods, while exercise such as walking, dancing, running is free. Individuals with SPMI may not have access to nutritious foods in the neighborhoods where they live and lack transportation to go get to larger grocery stores with more selection and lower prices. Also, when eating out, participants may not have been able to obtain nutrition information about their food.

The improvement in self-report of physical activity must be tempered with the possibility that participants may have overestimated their actual activity or wanted to please or look good to the investigators. This reactivity effect occurs when subjects want to meet the perceived expectation of the researchers (Macnee, & McCabe, 2008). In addition, one study that used the UCLA Activity Score (Grimby scale) in which participants rated their levels of physical activity noted that a major disadvantage of the use of self-report scales is that although they give an impression of the level of physical activity, they do not provide details on duration, frequency, and energy expenditure. Therefore, it cannot be determined to what extent participants completed physical activity compared to their self-reports of activity (Wagenmakers et. al, 2011).

Furthermore, there is a tendency for people to overestimate time spent exercising. While reported physical activity can be used to make indirect measurements of energy expenditure, multiple validations of physical activity questionnaires indicate that individuals, especially those who are older and overweight, tend to overestimate their amounts of physical activity (Walsh et. al, 2004).

Results of this study were concurrent with such studies as Brown and Chan (2006) that resulted in weight loss as well as increases in physical activity for individuals with SPMI that participated in a weight loss intervention. Results of this study were also congruent with the Melamed et al. (2008) study implementing cognitive behavioral interventions that resulted in sustained weight loss in individuals with SPMI. While Daumit and Goldberg et al. (2005) examined self-reports of physical activity in individuals with SPMI, this study was the first of its kind that recorded participants self-reports of healthy behaviors throughout participation in a weight loss intervention.

Conclusion

Individuals with severe mental illness who participate in a weight loss study reported an increase in physical activity from baseline compared to individuals in the control group at 3 months and 6 months, but not at 12 months. There was no difference in self report of nutrition. Further study is needed to determine if self-report of increased physical activity is confirmed with actual increase in activity.

Table 1 Means (Standard Deviation) for total physical activity and nutrition subscales of HPLPII for intervention and control groups (N=59) at baseline, 3, 6, and 12 months

Subscales	Testing Periods			
	Baseline	3 Months	6 Months	12 Months
Nutrition				
possible range: 9 to 36				
Intervention	20.88 (4.34)	24.5 (4.42)	23.31 (5.25)	23.63 (4.56)
Control	20.6 (4.34)	22.9 (5.26)	22.07 (6.23)	21.78 (5.71)
Physical Activity				
Possible range: 8 to 32				
Intervention	16.66 (4.56)	20.47 (4.72)	19.97 (4.71)	18.19 (4.86)
Control	15.3 (5.07)	16.52 (4.96)	15.44 (4.99)	16.26 (5.16)

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PATIENT SATISFACTION FOR THE ADULTS WITH DOWN SYNDROME
SPECIALTY CLINIC

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Abstract

The Adults with Down Syndrome Specialty Clinic (ADSSC) was established in 2008 to better meet the unique needs of adults with Down syndrome due to many concerns regarding the health care that patients with Down syndrome receive. The purpose of this study was to assess the quality of care that the patients and families receive at this clinic and determine any additional resources that need to be incorporated into the patients' care. A satisfaction survey was developed and mailed to all of the patients (N=75) and 24 responses were obtained. The Likert scale questions were analyzed using weighted calculations and the written narrative responses were reviewed. There were six categories that were analyzed which include: ease of getting care, waiting, provider, nursing staff, all other staff, and facility. Overall, the patients were satisfied with the care that they are receiving at the ADSSC. However, two main concerns for the patients were better location of the facility and better parking. Many of these adults face difficulty finding services that can meet their individual needs. As a result of this study we hope to provide more access to resources as well as high quality healthcare to this population.

Introduction

There has been a growing concern of parents who have children with Down syndrome that their children do not receive adequate medical care once they reach adulthood. These patients were sometimes diagnosed prematurely with Alzheimer's disease. Other diseases that this population is predisposed to develop were either under-diagnosed or missed. Thus, facilities that specialized in the health care of adults with Down syndrome were established to provide specialized care to these individuals. Only two healthcare clinics with this specialty currently exist in the Midwest, one in Chicago and the other is in Kansas City at the University of Kansas Medical Center, Department of Family Medicine (Leshin, 2010).

Due to many concerns regarding the health care that patients with Down syndrome are receiving, Moya Peterson, PhD, ARNP developed the Adults with Down Syndrome Specialty Clinic (ADSSC) in 2008 to enhance their access to health care. This clinic operationalizes a unique health care model. The health care provider is a family nurse practitioner (Dr. Peterson) and other members of the interdisciplinary team include a registered dietician and a mental health nurse practitioner. Referrals are recommended as needed to specialized providers who are familiar with this population including a neurologist who works with dementia in Down syndrome and a cardiologist who works with adults with congenital heart defects. The most recent addition to the clinic is legal assistance (especially for guardianship issues) provided through the cooperation of the University of Kansas Law School.

A main concern for the providers of the ADSSC was whether the patients and families were satisfied with the health care that they are receiving and what can be done to improve their experiences. Thus, this study was conducted to assess the needs and level of satisfaction with care by the patients and families. Long-term goals of this facility include incorporating the medical home model that is solely focused on the advocacy for adults with Down syndrome and in the future, establish a "one stop shop" where adults with Down syndrome can receive all of their health care as well as social supports in one location.

Literature Review

Down syndrome occurs in about one in every one thousand births (Smith, 2001). Due to technological advances and improved health care strategies, individuals with Down syndrome are experiencing longer lives. The average life expectancy for adults with Down syndrome is the mid-fifties (Smith, 2001) with 40% surviving to age 60 and 13% surviving to age 68 (Rapp, 2005).

Health Concerns

There are several health concerns for adults with Down syndrome and often there is a lack of healthcare providers who are able and willing to assess these patients due to their complex health histories and lack of understanding of their adult healthcare needs. There is very little research on the health of individuals with Down syndrome as they age. Primary care physicians who care for many of these individuals are unaware of certain health conditions that adults with Down syndrome are more susceptible to such as pulmonary hypertension, hypothyroidism, osteoporosis, Alzheimer's disease, seizures, sleep apnea, gastroesophageal reflux disease, celiac disease and cataracts (Rapp, 2005).

Adults with Down syndrome have multiple physical impairments. This includes a higher prevalence of heart defects, muscle weakness and hypotonia, and low cardiovascular fitness. These impairments may contribute to a lower level of fitness and a diminished ability to complete daily activities. The high levels of inactivity are worrisome due to its association with obesity, type 2 diabetes, osteoporosis, and cardiovascular disease (Shields, Taylor, & Fernhall, 2010). Obesity is a common problem within this population. One study of individuals with Down syndrome found that 81% of the participants were overweight or obese (Carr, 2007).

When a patient declines, it is important to look at all possible causes and treat the cause if possible. Depression has been determined to be the predominant cause of changes in functioning for this population. In one study of 53 adults with Down syndrome, the patients were able to demonstrate improvement once treatment was initiated however about 11 of the individuals' condition progressively deteriorated and Alzheimer's disease was diagnosed. Four elements are focused on when a patient is diagnosed with Alzheimer's disease, which include: safety, stability (environment), social (emotions), and symptoms (Chicoine, McGuire, & Rubin, 1999). Safety is increasingly difficult to maintain as the patient declines and is often the chief reason that a patient will need to live in a long-term care or another type of group living facility. The patient should be as involved with his or her care as possible to maintain optimal functioning. Thorough assessments are essential to avoid a misdiagnosis of Alzheimer's disease.

Alzheimer's disease is more common in Down syndrome than in any other intellectual disability group and occurs at an earlier age in this population (Iacono, Torr, & Wong, 2010). Research has shown that the progression of Alzheimer's disease will happen earlier and more quickly with a presenting symptom of an abrupt decline in functioning for this population (Nevel, 2010). Adults are more likely to decline in function once the daily structure and support of cognitive and psychological aspects of educational programs are completed at age 21 years. Today, there are

relatively few opportunities for social interaction and a lack of employment regardless of the significant contributions of inclusion for persons with disabilities.

The “Health Care Guidelines for Individuals with Down Syndrome” is a widely accepted guideline for screening patients with Down syndrome for specific illnesses to which this population is predisposed (Smith, 2001). Often, an illness can be overlooked due to the limited communication skills of the patient and a provider may believe that the symptoms are due to Down syndrome instead of an illness that could be treated.

Social Activities

These adults have an active lifestyle and enjoy partaking in numerous activities. Within a study of 110 adults with Down syndrome sixty-five percent reported that work was the main activity outside of the home with a majority (65%) working in sheltered workshops and 23% employed at private enterprises. Ninety percent of adults reported watching television and listening to music at least daily. Just under half (45%) reported participating in sports with swimming being the most popular however only one third was regularly engaged in these activities (Carr, 2007).

These participants reported that friendship activities were infrequent but when occurring were with another individual with intellectual disabilities. Thirty-six percent of this sample group stated that they would like to marry, however none of the participants had actually done so. Over half of people with Down syndrome were said to make friends easily and eighty percent had at least one friend (Carr, 2007). In general, adults with Down syndrome have good health however weight issues are on the increase as in the population as a whole without Down syndrome.

The concept of “self-talk”, in which one talks out loud to oneself in order to direct behavior or problem solve, is frequently observed in adults with Down syndrome. Unfortunately, self-talk is often misconstrued as psychosis and the patients are given anti-psychotic medications. The Adult Down Syndrome Center at the Lutheran General Hospital determined that 81% of these patients participate in conversations with themselves or imaginary friends (McGuire, Chicoine, & Greenbaum, 1997). This mechanism is very common among these patients and is very helpful to them as tools for coping. The elderly and children without Down syndrome also partake in self-talk which can be due to social isolation or in children, a part of the process of developing higher thinking skills. Therefore, it is important to determine the root cause for self-talk and to initiate treatment only if needed.

Parents will continue to have an authoritative role in the lives of adults with Down syndrome and remain involved with the key decisions for employment and social activities. Over two-thirds of 30 to 35 year olds in one study remained in the care of their parents. Parents of this population act as a ‘layer of influence’ around the lives of their adult child either by acting as facilitators, such as

actively pursuing resources for the adult, or as gate-keepers, in which the parents will re-evaluate the expectations and goals of the adult as he or she develops (Docherty & Reid, 2009).

McGuire (2005) has developed a list of characteristics for adults with Down syndrome based on the hundreds of assessments that he has made during his practice at the Adult Down Syndrome Center at the General Lutheran Hospital. People with Down syndrome like to show affection and enjoy living in the moment. Adults with Down syndrome also tend to be very clean and tidy, similar to an obsessive-compulsive disorder, and are very particular about timeliness. Members of this population also prefer to take their time and may talk to his or herself to help cope with a problem or express his or her emotions. It is important to allow these individuals to have plenty of time to complete their tasks because they are very precise and want to focus on completing their job correctly. This population loves to dance and attend gatherings to socialize with others, which would involve a lot of hugging. They are sensitive to anger and want to resolve conflicts among individuals (McGuire, 2005).

An emphasis on the need for a healthy lifestyle for adults with Down syndrome is essential for greater wellbeing. Surprisingly, this population has not gained increased independence as they age due to two factors: parents' stress and the cognitive ability of the adult (Carr, 2007). Overall, adults in their middle years have vibrant lifestyles. Their health is reasonably good, many are employed, and they continue to be physically active. However, these individuals have limited levels of independence and social interaction.

Purpose

Our goal at the ADSSC was to ensure that the patients and families are provided with quality health care, have a voice in the plan of care and have access to the many services that they need. We then wanted to determine if we were meeting that goal in the first years after the establishment of the clinic. An evaluation on patient/family satisfaction was performed to gain insight on how we are currently providing care and services and how we might improve the care that patients and families receive at the ADSSC. We also wanted to know of any additional resources that need to be incorporated into the patient's care. The four goals of this study included:

1. Strengthen patient/family/professional partnerships through education, mentoring, technology, and financial investment to support family involvement at all levels of decision making
2. Enhance access and services received in the ADSSC
3. Address progression to adulthood by incorporating into practices and policies transition support for youth with disabilities

4. Build system capacity and sustainability

Methodology

Design and Measures

This study utilized an evaluation survey using quantitative and qualitative open-ended items via survey mailings. A survey was developed for the patients and families of the ADSSC to determine their level of satisfaction and to identify any needs that this population may have. The survey consisted of five open-ended questions and a twenty-one item questionnaire using Likert scales. The participants self-reported their own thoughts and feelings regarding this facility.

Ethical Considerations

The survey was reviewed by Institutional Review Board and it was determined not to be human subjects research because it is program evaluation research. A cover letter describing the study with the request to remain anonymous on the survey was included with the mailing. Adults with Down syndrome who were able to fill out the survey were free to do so or the family members could respond from their perspective of the care that they received from the facility.

Sample and Setting

Out of the 75 mailed surveys, twenty-four participants responded to the mailed survey for a 32% response rate. This is an average response rate since the typical response rate is 30% to 35% response rate for mailed surveys (White, 1999).

Within this sample, 20 were Caucasian, two were Hispanic, one was African American, and one was Asian. The age range was 18 years old to 56 years old while the mean age was 34.2 years old. All of the participants resided in either Kansas (69.2%) or Missouri (29.3%).

Data Analysis

The Likert scale data were analyzed using weighed calculations (the mean score of all responses) on a five point scale and the written comments were transcribed verbatim. After a content analysis, three themes were prominent which are: facility, provider care, and services. In general, the participants would like to see more services provided within the ADSSC. The facility had the most suggestions for improvements especially in regards to location, parking and cleanliness. The participants were the most satisfied with the provider care and made several comments pertaining to the level of the care that they received at the facility.

Results

Overall, the patients are satisfied with the care that they received at the ADSSC. The participants of the study generally felt that Dr. Moya Peterson, ARNP provided thorough care and was very compassionate with her patients. On a 1-5 point scale, this healthcare provider was rated as a 4.96 on listening and taking enough time with the patients. She also received a 4.92 on explaining treatments/procedures and providing appropriate advice and treatment. One participant stated:

The physician [health care provider] who cared for my Adult child was very helpful in our situation, and gave me the information I needed to go back to our regular physicians in our hometown, and I insisted on some changes in my adult child's medications and treatment that in turn helped with a two plus year ongoing serious health issue, which is now better controlled.

Another participant commented, "They seem to take a personal interest in the individual and are very timely in their response to the family and their needs". Nursing staff friendliness and helpfulness was rated as a 4.83 while all other staff friendliness and helpfulness was rated as a 4.77.

Two main concerns for the patients were better location of the facility and better parking. The ease of finding where to go was rated as a 3.87 and the neatness and cleanliness of the building was rated as a 4.19. The convenience of the facility's location was rated as a 3.63 (see Table 1 for a summary of the survey results).

The additional needed resources that were identified by the participants were therapists, especially a speech therapist and an occupational therapist. Also specialties such as cardiology, endocrinology, and audiology were also recommended to include as consultations for the patients. Other suggestions for additional services to offer at the ADSSC were a job coach and a social skills curriculum as well as a behavioral therapist to assist in the management of inappropriate behaviors.

Ninety-six percent of those who responded to the survey were 'very likely' to refer others to the ADSSC. There were several positive comments made in response to the open-ended questions. A participant stated, "I appreciate the caring atmosphere you provide patients and parents". Another participant responded that he/she liked best about the facility, "The fact that there is a 'Down Syndrome Clinic' is very encouraging. These medical problems for these children are not seriously addressed by many doctors".

Discussion

Many of these adults face difficulty finding services that can meet their individual needs. We would like to provide more access to resources and high quality of healthcare to this population.

There were several suggestions for services to provide at the ADSSC all of which would be very useful at this facility. Referrals are another option to provide patients and families with specialized care however one of the goals of this facility is to provide as many resources as possible for this population all housed in one location. Budgeting restraints may deter offering all of the suggested services however the most needed services will hopefully be established at this facility.

The lowest scores of the survey involved the facility's location and parking. Unfortunately, these items can not be managed by the care provider or the clinic. It is noted that in the near future the Department of Family Medicine, which is the home for the ADSSC, will be moving to a brand new state of the art facility. This new facility will also have improved parking availability. However, the fact of the location of the KU Medical Center with in the urban area of Kansas City will not be changed.

The care providers received the highest scores of the survey which is very promising. Care providers are the heart and soul of this clinic. The empathy and passion that providers and staff demonstrate to the patients and their families cannot be taught so it is crucial that all the members of the health care team be internally motivated and possess a compassionate and caring spirit for these patients and families.

Limitations

This study entailed only 24 responses which is a small sample size from which to draw conclusions. The participants were also obtained via mail which can prevent some participants from contributing. A majority of the sample (41.7%) responded that their last appointment was more than 12 months ago. The length of time since interacting with the facility can bias the accuracy of the responses that were given.

Conclusion

This satisfaction study on the ADSSC was very useful in determining the satisfaction level and changes that were recommended at the facility. Although not all of the suggestions can be implemented, the information is constructive for future practices. Families with adults with Down syndrome are experts in this syndrome because it is necessary. For this reason, their input is essential to this clinic. The providers at this facility would not be able to render the best care without providing the resources that the families need.

The unique needs of the adults with Down syndrome are still not well understood since there is little research on the health of this population as they age. It is critical to have health care providers that specialize in the needs of this population. Often, this population can be misdiagnosed simply due to misinterpretations. To alleviate these problems, a multidisciplinary team should be

utilized for the welfare of the patient. Specialists in specific fields such as audiology, nutrition, and social work would be very valuable for adults with Down syndrome to assist with their healthcare needs.

The ADSSC was established to provide specialized care to this population in the Midwest. It is important that our patients and families are satisfied with the care they have received. It is also important that the clinic, with its unique care model, continue to evolve, and offer additional services that the patients and families need. This is a first step in the evolution and development of this important facet for the health care of adults with Down syndrome.

Table 1 Summary of the Patient Satisfaction Survey

Category	Mean
Ease of getting care:	
Ability to get in to be seen	4.77
Hours Center is open	4.45
Convenience of Center's location	3.67
Prompt return on calls	4.36
Waiting:	
Time in waiting room	4.35
Time in exam room	4.39
Waiting for tests to be performed	4.19
Waiting for test results	4.14
Provider:	
Listens to you and your adult	4.96
Takes enough time with you and your adult	4.96
Explains what you want and need to know	4.92
Gives you appropriate advice and treatment	4.92
Nursing Staff:	
Friendly and helpful to you	4.83
Answers your questions	4.91
All Other Staff:	
Friendly and helpful to you	4.77
Answers your questions	4.80
Facility:	
Neat and clean building	4.18
Ease of finding where to go	3.91
Comfort and Safety while waiting	4.24
Privacy	4.29

Note. All values represent the mean score on a 1-5 Likert scale.

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BUILDING STUDENT RESOURCES FOR THE KANSAS CENTER FOR NURSING
SCHOLARSHIP & LEADERSHIP

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Abstract

The *Kansas Center for Nursing Scholarship & Leadership* (KCNSL) was recently created with the purpose of advancing nursing scholarship in Kansas through focused mentorship and broad-based collaboration. The Center is developing resources for nursing students, and stress management was identified as an area of need. High stress is common in nursing students and may negatively affect student success. The purpose of the study was to identify and describe sources of student stress and stress management strategies among nursing students. Senior nursing students from 13 pre-licensure baccalaureate nursing programs in Kansas were invited to participate in semi-structured interviews. A qualitative descriptive approach was used to describe the experience of student stress and strategies for stress management. Sources of stress among participants (n=2) included concern about studying for exams, balancing competing time commitments, and meeting deadlines. Stress management strategies included taking breaks, exercising, playing video games, smoking, and spending time with friends. Findings related to the stress experience and suggestions for stress management will be displayed on the KCNSL website as a resource for other nursing students.

Introduction

Problem

The present and future shortage of trained nurses poses a significant risk to healthcare. Duvall and Andrews (2010) estimate there will be a shortage of over one million nurses in the United States by 2020. Stress remains an inherent feature in nursing practice due to the challenging nature of the profession. It is likely this environment will not change. High workplace stress is a common reason nurses leave the profession (Fox & Abrahamson, 2009). Furthermore, O'Donnell (2009) found stress to be a significant risk factor for later attrition in nursing students. Stress in school and later occupational stress may be contributing factors to the nursing shortage. It is important to teach newly employed nurses how to effectively identify sources of psychological distress (Watson et al., 2009). Marshall (2011) found stress is associated with cardiovascular disease, suppresses immune function, and "may result in negative health consequences" (p. 136).

High stress remains a common health hazard nursing students experience while in school (Beddoe & Murphy, 2004; Gibbons, Dempster, & Moutray, 2008; Montes-Berges & Augusto, 2007; Murdock & Perlow, 2010; O'Donnell, 2009; Watson et al., 2009). Although several investigators have studied student stress, no studies have assessed Kansas pre-licensure students' perception of stress nor did they include a sample of students from the Midwest United States. This gap in knowledge should be investigated further, as stressors can vary based on geographic location. A survey of nurses working in rural acute care hospitals illustrated how the definition of nursing can change with respect to location. According to LeSergent and Haney (2005), "nurses in Canada's rural north find issues of nursing care stressful, because the meaning of nursing changes once one reaches the far north" (p. 321). Similar issues could be prevalent in other rural areas. LeSergent and Haney (2005) also noted that nursing in rural areas is stressful because "knowing your patient and their families because of the closeness of the community often leads to stress" (p. 321). A nurse working in rural Canada exemplified this sentiment:

These patients aren't just patients, they are friends, they are neighbors...there's a lot of emotions we deal with because of that, that makes nursing in the North particularly difficult, because at that point you have to separate yourself—am I going to be the relative here, or am I going to be the nurse, and it really takes some backbone to separate the two. (Moszczynski & Haney, 2002, p. 499)

Findings in rural areas of the United States, like much of Kansas, could be similar based on the student's familiarity with community members and systems of care. Little is known about how

pre-licensure nursing students in Kansas experience stress. Discovering what types of experiences that are stressful for students is vital to designing helpful stress management interventions.

The *Kansas Center for Nursing Scholarship & Leadership* (KCNSL) was recently created based on recommendations from the Kansas Association for Colleges of Nursing and other nurses from across the state. The purpose of the Center is to advance the development and dissemination of nursing scholarship in Kansas through focused mentorship and broad-based collaboration. The Center has a virtual location so that nurses across the state have access its resources. Currently, there are no resources specifically relevant to nursing students on the Center website. The researchers in this study are active participants in the Center and seek to create student-centered resources for the KCNSL.

Stress is a major problem pre-licensure students commonly encounter throughout their nursing education. Using findings from the literature and from this study about student stress in Kansas, stress management resources for nursing students will be added to the Center website. In order for stress management resources to be created for the Center, a general understanding of the stress experiences of Kansas nursing students must be identified. Incorporating study findings on the KCNSL website is a unique step in dissemination of findings.

Background

Definition of Stress

A clear definition of stress is vital when examining student nurses' perception of stress. However, there is a lack of literature that gives a definition of stress defined by nursing students. One study (Wheeler, 1997) concluded that "interpreting nurse stress research results may be problematic because globally there is a tendency of many published works not to provide clear working definitions of stress" (p. 713). Wheeler (1997) suggests "studies must offer clearer and more realistic definitions and models of nurse stress" (p. 713).

A review of literature exposed varying definitions of psychological stress. Cohen, Miller, & Rabin, (2001) define stress as "the experience of negative events or the perceptions of distress and negative affect that are associated with the inability to cope with them" (p. 7). Cohen, Janicki-Deverts, and Miller (2007) offer a similar description of stress "when an individual perceives that environmental demands tax or exceed his or her adaptive capacity" (p. 1685). These definitions illustrate coping ability and individual perception as components of stress, both of which are modifiable. Laszlo and Kopp (2009) used a model to quantify stress but failed to adequately define stress from the perspective of the sample population. Researchers (Newbury-Birch & Kamali, 2001) in England defined stress as, "a physical, mental, or emotional reaction resulting from an

individual's response to environmental tensions, conflicts, pressures, and similar stimuli" (p. 109). None of the definitions took into account the sample population's input on definition of stress. Furthermore, stress can have different meanings based on one's personal beliefs, which is why it is important to understand stress from the perspective of the sample population. Finding what constitutes stress to a Kansas nursing student could help in developing stress management resources.

Effects of Stress

Gaining acceptance into an accredited baccalaureate nursing program is difficult. In 2010, a total of 67,563 qualified applicants from baccalaureate and graduate nursing programs were denied entrance because of limited faculty and clinical resources (American Association of Colleges of Nursing, 2011). Gaining admission is only the beginning of school-related challenges, because successfully completing a nursing school curriculum is an arduous process for many students. Pre-licensure students are learning the fundamentals of a complex science through a rigorous academic course of study. Several studies confirm that nursing students experience high stress levels throughout nursing school (Beddoe & Murphy, 2004; Gibbons et al., 2008; Montes-Berges & Augusto, 2007; Murdock & Perlow, 2010; O'Donnell, 2009; Watson et al., 2009). Beddoe and Murphy (2004) suggest accumulating stress can "impede concentration, memory, and problem-solving ability . . . [and] may also diminish communication, interpersonal effectiveness, and empathy" (p. 305). Nursing students need to remain mentally sharp to achieve success in school, because a build-up of stress may have a negative effect on student success.

Student Stressors

Some nursing school stressors are relatively similar among programs. Key stressors nursing students experience can be classified as academic, clinical, and personal (Gibbons et al., 2008). Montes-Berges and Augusto (2007) found that "students suffer from high stress levels which have important economic, psychological and physical consequences both for themselves and the patients" (p. 165). Due to the inherent nature of these stressors, nursing schools are in an opportune position to help students manage stress. Stress reduction education can be implemented into nursing school curricula (Billingsley et al., 2007; Montes-Berges & Augusto, 2007).

Effects of Stress Management Interventions

Research has shown promising results with stress management interventions in the college student population. The interventions may be feasible to implement on a large scale. For example, investigators (Billingsley, Collins, & Miller, 2007) at a large Midwestern urban university found a

single 90-minute stress management workshop helped students develop a personal plan for managing stress and “the results of the workshop were overwhelmingly positive” (p. 51).

Using a randomized control group design, Winterdyk and colleagues (2008) examined the effects of mind/body interventions for college students living in a major urban center in western Canada. Students attended pre-and post-assessments and at least 4 of the 6 intervention sessions offered, each of which lasted approximately 60-minutes. Compared to control group participants, students in the experimental group reported (a) reduced self-reported psychological distress, (b) reduced anxiety, (c) reduced perceptions of stress, and (d) a positive influence in lifestyle behaviors.

Practicing meditation has been shown to effectively reduce stress in the college student population. A randomized controlled trial was conducted with a sample of undergraduates enrolled at a Roman Catholic university in California. The study examined how meditation management of stress interventions affected stress and well-being. Training meetings lasting 90-minutes each over an 8-week period (one meeting per week) were used to teach participants meditation-based stress-management techniques. Oman and colleagues (2008) found that the treatment group had lower levels of perceived stress and suggested that undergraduate students practicing integrated meditation will have reductions in perceived stress.

Gap in Literature

Although several studies have investigated nursing student stress, most have been conducted in urban areas. No studies have been conducted in the Midwestern United States, which has unique characteristics that may influence stress experiences and stress management strategies. Nursing schools in Kansas are located in both urban and more rural areas, so this study has the opportunity to discover new information about stress experiences and stress management strategies of nursing students in both urban and rural communities. Findings from this study may be useful in helping nursing students recognize and manage school-related stress, to foster success while in nursing school. The research report along with resources developed from this study will be disseminated on the KCNSL website, which serves as a unique approach to addressing student stress.

The Study

Purpose

The purpose of the research was to identify and describe sources of pre-licensure student stress and stress management strategies among students in Kansas. Study findings will be used to

develop nursing student-identified stress management resources for the KCNSL. Also, an aggregated description of stress experiences of Kansas pre-licensure nursing students will be included on the website.

Specific Aim

The specific aim of the research was to identify common school-related stress experiences and stress management strategies described by pre-licensure nursing students in Kansas.

Methods

A qualitative descriptive approach was used to describe the experience of student stress and strategies for stress management. Research from Sandelowski (2000) provided a methodological structure and helped guide the study. Semi-structured interviews lasting 15-30 minutes were conducted over the telephone to collect information from participants. The researcher took field notes during the interview and developed a narrative for each participant based on the responses from questions. Interview questions focused on stress experiences of the participant. A narrative for each interview was created describing the participant stress experiences and stress management strategies. Demographic information was collected to help describe the sample. Following explanation of the study through an introduction letter, oral consent was obtained from participants. After consent was obtained, data collection began. The research presented no more than minimal risk of harm to subjects and involved no procedures for which written consent is normally required outside the research context.

Methodological rigor.

Rigor was maintained throughout the research process. A consistent protocol in data collection ensured a similar interaction between interviewer and each interviewee. An audit trail was kept to ensure confirmability. The audit trail included detailed field notes from the interviews and completed demographic information sheets. Rich, thick descriptions from participants were taken to reflect the breadth of stress experiences. Member checks were utilized to ensure strong credibility. The preliminary findings from the data analysis were emailed back to the participants seeking their input concerning the accuracy, completeness, and interpretation of the data. Participants were asked to correct any inaccuracies of the data.

Data security

All information connected to participants was kept confidential. No information about individual participants was released to any outside parties. Pseudonyms were used to protect the privacy of the participants. All documents pertaining to the study were kept in a locked file cabinet

in the office of the principal investigator at the University of Kansas School of Nursing. All electronic information was stored on a flash drive, which was also stored in the locked file cabinet in the principal investigator's office when not in use. Only the researchers had access to the locked file cabinet. Data collection sheets contained no identifiable information about the participants.

Sample

A purposive sample of senior pre-licensure nursing students currently attending a Kansas baccalaureate nursing program was the primary participant selection criterion. Inclusion criteria included: (a) currently a senior nursing student, (b) currently attending an accredited (Commission on Collegiate Nursing Education or National League for Nursing Accrediting Commission) pre-licensure BSN program, and (c) currently expecting to graduate in Spring 2011. An email was sent to each dean of baccalaureate nursing school with a pre-licensure program in Kansas (13) along with a letter of introduction. After administrative approval, the Deans disseminated an email and a letter of introduction to nursing students who met inclusion criteria. The first eligible participant to respond from each school was chosen for the sample. Of the 13 Kansas Deans that were emailed, 9 agreed to email those students who met inclusion criteria in their respective school. A total of two nursing students participated in the study (n=2), Don and Mandy. Participants were between the ages of 20-25 when interviewed.

Data Analyses

The researchers read and re-read the narratives and formed themes from the data. Common phrases from field notes and narratives were highlighted. The researchers compared notes and narratives collected from participants and identified commonalities. Simple, broad themes reflecting the experiences of the participants were formed. Previous stress research has been criticized for failing to define a working definition of stress. The current study avoided this problem by directly asking participants their definition of stress. A common definition of stress was developed based on responses to the question, "What is your definition of stress?"

Don's narrative.

Don is a non-Hispanic Caucasian male student attending a pre-licensure nursing program in Kansas. He is expecting to graduate in the spring of 2011 with a Bachelor of Science in Nursing degree. He has no prior post-secondary degrees, is single, unemployed, and has no children. Don is fulfilling clinical coursework in a critical care setting.

When asked to define his definition of stress, he took some time to think about the question and responded, "anything that causes me to worry." Don has many stressors, including: finishing projects, completing clinical hours, studying for exams, applying for jobs, saving money, studying

for the state board licensure exam, and making time commitments to school. Most of these stressors are directly related to nursing school. When questioned about what causes him the most stress, he claimed studying for exams is the source of most of his stress.

Don uses both healthy and unhealthy behaviors for managing stress. Healthy coping was defined as “responding to a psychological and physical challenge by recruiting available resources to increase the probability of favorable outcomes in the future” (Kent et al., 2010, p. 227). When questioned about ways he manages his stress, he replied, “smoking cigarettes, eating snacks, procrastinating, playing video games, working out, watching TV, complaining, and drinking alcohol.” Don finds that smoking cigarettes best reduces his stress. He went on to say, “Smoking a cigarette takes all my cares away for a few minutes. It’s like a mini vacation.”

As a senior nursing student, Don feels that access to an online voiceover PowerPoint (VOPP) lecture about coping strategies and ways to prevent stress would have been helpful to have upon entering nursing school. He emphasized the importance of making the strategies relevant to nursing students.

Mandy’s narrative

Mandy is a non-Hispanic Caucasian female student attending a pre-licensure nursing program in Kansas. She is expecting to graduate in the spring of 2011 with a Bachelor of Science in Nursing degree. She has no prior post-secondary degrees, is single, and has no children. She is currently employed as a nurse technician and works an average of 12 hours per week. Mandy is fulfilling clinical coursework in a critical care setting.

Mandy’s definition of stress is, “anything that puts demands on you.” She believes that the stressor must be something significant to her in order to cause stress. For example, if one does not care about a potential stressor, then no stress will accrue. Mandy experiences both physical and emotional stress. A major stressor is the significant amount of time she must devote to nursing school along with meeting deadlines. She spoke of these stressors and graduation stating, “The amount of information we have to learn and getting things done on time [is stressful]. The fact that nursing school takes up most of your life (*sigh*) it’s hard to find personal time. The most stressful thing about graduating is all the accountability and responsibility you have as a nurse.” Of her many stressors, Mandy claimed that meeting deadlines is her greatest source of stress.

Unlike Don, Mandy’s stress management strategies were mostly healthy. Her stress management activities included: spreading work out so she does not have to do everything at once, not putting things off and procrastinating, spending time with her friends and fiancé, having a

movie or game night, and taking breaks from studying. Mandy feels she has not procrastinated as much, which has proven to be her best stress management strategy.

As a senior nursing student, Mandy feels that access to an online resource that connects students together would have been helpful to have upon entering nursing school. It would be helpful in connecting with others who are experiencing the same transition. Students could share advice on common problems encountered in school (i.e. hard classes, where to buy books). When questioned about the possibility of interacting with resourceful seniors she suggested, "Connecting with seniors is good because they have the most experience but any connection on any level is helpful because you can learn ways to deal with stress to get through school easier."

Findings

The participants shared many of the same demographic characteristics. Both participants were non-Hispanic Caucasians with no prior post-secondary degrees. Also, they were single with no children.

High stress, especially related to school, was common in the sample. However, the participants only had two stressors in common: the large amount of time one must devote to school, and meeting deadlines. The two participants shared no similar stress management strategies. Procrastination was an interesting behavior between the two participants. Don utilized procrastination as a stress management strategy, whereas Mandy avoided procrastination as it contributed to her stress. This highlights a fundamental difference in the way the two manage stress.

Although the sample size was limited, we created an aggregate definition of stress based on the responses to the question, "What is your definition of stress?" As defined by the participants, "Anything that causes worry or puts demands on one," described stress.

Discussion

The findings in this study support prior research that high stress is common in nursing students. Stressors students experienced were not caused by clinical sources, which is in opposition to previous studies. This finding could be attributed to the level of clinical experience in the students because of their progression in school. Participants likely had competent clinical abilities, which did not contribute to their stress. Common stressors, time commitments to school and meeting deadlines, in the participants support previous findings. For example, Montes-Berges and Augusto (2007) identified "time pressure" (p. 163) as a common stressor nursing students experience.

Current literature lacks a description of stress defined by nursing students. We developed a definition, albeit from limited responses, which can help future researchers understand stress from a student perspective. We offer a simple definition of stress compared with the literature. Prior definitions include exceeding demands on an individual, which is also present in the definition based on participants' responses. Although coping abilities is a component in some definitions of stress, the participants did not perceive this as relevant in their definition. Our definition uses a broad sense of environment, "anything", but is congruent with an existing definition of stress regarding "environmental tensions, conflicts, pressures, and similar stimuli" (Newbury-Birch & Kamali, 2001, p. 109).

The most significant limitation of the study was the lack of participants. This gives a limited perspective on student stress experiences and stress management strategies. Transferability of findings remains weak because of the small sample size. Thirteen schools were invited to participate; nine of which chose to participate and still only two responses were received. Reasons for why schools chose to not participate remain unknown. For the schools that did participate, we offer two explanations for the low number of responses. First, timing of recruitment may have attributed to the low sample size. The email from deans to students calling for volunteers was sent in mid-March/early-April. Many students graduate in May and take the NCLEX-RN exam soon after graduation, leaving little time for extra activities such as volunteering in a research study. Second, high stress in the study population may have prevented students from volunteering. Participating in research may have been perceived as an added stressor and therefore a low priority. Reasons for refusal may be more complex and other explanations are possible. We could have addressed this by asking participants the question, "Why did you choose to volunteer for this study?" Future research examining reasons nursing students participate in research is needed.

Recommendations

The KCNSL should create a resource for their website helping connect students with each other to facilitate communication. This intervention could help students better manage stress. An open discussion board available to students and a link to upload videos are some specific examples. We also recommend the Center create a voiceover PowerPoint (VOPP) about coping strategies and ways to prevent stress. The VOPP must be relevant and feasible to students. To make strategies feasible to most students, the VOPP (Appendix A) should not include expensive interventions such as getting a massage every day or taking frequent vacations. These techniques may be effective at reducing stress, but are unrealistic for the average student to afford. Stress management strategies

found in this study should be included in the VOPP. Recommendations for stress management strategies should focus on *healthy* coping techniques.

Nursing professors have some control over student stress because meeting deadlines was found to be a common stressor. We recommend nursing professors collaborate to ensure deadlines for class (i.e. tests, projects) are spaced appropriately to reduce student stress. To facilitate dissemination of findings, nursing school deans should place a link on their school's website that directs users to the Center's student resources.

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Human Subjects Approval

The research presented in this study was approved by the University of Kansas Medical Center Institutional Review Board and the Fort Hays State University Institutional Review Board.

Appendix A

Content Outline for Stress Management Voiceover PowerPoint (VOPP)

- I. Introduction
 - A. Background on VOPP
 - 1. What study this information came from
 - 2. How it was obtained
 - B. Definition of stress defined by Kansas nursing students
- II. Effects of Stress
 - A. On academics
 - B. On clinical abilities
 - C. On personal life
 - D. On working RNs
- III. Potential Stressors
 - A. Immense time devotion to school, meeting deadlines, graduation, NCLEX, finding employment, saving money, studying for exams
- IV. Healthy Stress Management Strategies
 - A. Not procrastinating, exercise, spending time with friends, taking breaks from studying, game night, movie night
- V. Non-healthy Stress Management Strategies
 - A. Eating, smoking, drinking alcohol, complaining, TV, video games
- VI. Recommendations for Identifying and Managing Stress

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EXPLORING BARRIERS TO EXCLUSIVE BREASTFEEDING AMONG
ADOLESCENT LATINA WOMEN

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Abstract

American adolescent mothers typically have low rates of exclusive breastfeeding. Currently, Hispanics make up the largest ethnic group in the U.S., have high fertility rates, bear their children at younger ages, and also have low rates of exclusive breastfeeding. These factors put adolescent Latina mothers at higher risk for not exclusively breastfeeding; however, there is a lack of research about exclusive breastfeeding in this population. This study examines the attitudes and barriers to exclusive breastfeeding in a sub-sample of adolescent Latinas who are part of an ongoing larger qualitative exploration of barriers to exclusive breastfeeding.

Pender's health promotion model frames the study in which enrollment is currently taking place in a large city in the Midwest. An exploratory descriptive approach is being performed using semi-structured, in-person interviews conducted in either English or Spanish with the use of the ARSMA-II to identify participants' acculturation levels. Tape-recorded interviews are transcribed verbatim. Spanish transcripts are translated to English for analysis. Inductive content analysis is being performed by hand. For this sub-study, the results are then interpreted in relation to Pender's Health Promotion Model in a case analysis fashion.

One 16 and one 17-year-old mother comprised this case analysis. Acculturation scores suggest that the younger teen is more acculturated than the older teen. Findings were consistent with concepts of Pender's model. The largest difference between the two cases was the amount of school support each received, with one teen getting ample support while lack of support hindered the other in providing breast milk. Findings are consistent with previous adolescent breastfeeding research regarding support.

Introduction

Breastfeeding support and promotion in the United States has become an increasingly important component of the advancement of maternal and infant health. It has been known throughout history that human breast milk is the best choice for infant nutrition. The immunologic benefits provided to infants are numerous and the health benefits for the mother are plentiful. Accordingly, the federal health initiative, Healthy People 2020 (2010) and the Department of Health and Human Services goal is to raise rates of exclusive breastfeeding to 46.2% at 3 months and 25.5% at 6 months. This ongoing initiative is supported by many organizations such as the American Academy of Pediatrics (2005) and the World Health Organization (n.d.), which both recommend exclusive breastfeeding for at least the first 6 months of life.

Despite increased knowledge of breastfeeding health benefits and public health initiatives, exclusive breastfeeding in the United States is still falling short from the recommended goals. The Breastfeeding Report Card – United States (CDC, 2010) reported that among infants born in 2007, 75% ever breastfed. It went on to say that 33% of infants were breastfed exclusively through 3 months and only 13.3% of infants were breastfed exclusively through 6 months.

Among various maternal age groups, adolescent mothers have the lowest rate of breastfeeding initiation, continuation, and exclusivity (Feldman-Winter & Shaikh, 2007; Wambach & Cole, 1999; Wambach & Koehn, 2004). For example, the National Immunization Survey (CDC, 2010) found that among infants born in 2007 to women under the age of 20, only 59.7% ever breastfed as compared to 69.7% of women age 20-29, and 79.3% of women over the age of 30. While this national database contains information regarding the rates for both exclusive breastfeeding for the general population and the rate of breastfeeding in adolescents, the rates of exclusive breastfeeding amongst adolescents is not enumerated.

Hi-lighting the disparities in breastfeeding rates among teenage mothers is important because of the high number of teen-age pregnancies and births. In 2008, approximately 434,758 infants were born to adolescents between the ages of 15 and 19 in the United States (Martin et al., 2008). The teen birth rate in the United States is currently the highest of all industrialized nations in the world (Feldman-Winter & Shaikh, 2007) making it not only a large social, but economic problem as well. Another demographic group of importance in the United States is the Hispanic population. It has been estimated that with zero net international migration, the Hispanic population will gain 6.7 percentage points, from 14.3% in 2010 to 21.0% by the year 2050. As the largest and fastest growing minority in the United States, the unique issues surrounding the health of their communities needs to be addressed. Furthermore, Hispanics have the highest level of

fertility relative to all other racial and ethnic groups (Ortman & Guarneri, 2009 & Hernandez, 2006), compounding the importance to focus on the health of mothers and infants of Hispanic origin.

With regard to breastfeeding, results of the National Immunization Survey (CDC, 2010) indicated that of Hispanic or Latino children born in 2007, 80.6% were ever breastfed. Further, they found that 46% breastfed to 6 months but only 24.7% breastfeeding to 12 months. At 3 months, only 33.4% of Hispanics were found to be exclusively breastfeeding and only 13.4% were exclusively breastfeeding at 6 months. While the numbers of Hispanics initiating any breastfeeding is well above the national averages, the rates at both 6 and 12 months are still considerably below the Healthy People objectives, and the rates of exclusive breastfeeding fall below the Healthy People targets.

As a whole, Hispanic women begin bearing children at an earlier age than other ethnic groups (Hernandez, 2006; Sussner, Lindsay, & Peterson, 2008). This has contributed to many adolescent Hispanics being faced with the important decisions surrounding infant feeding. With the rapid increase occurring in the Hispanic population and the increased level of fertility amongst the population, it is imperative that the practices surrounding the issue of exclusive breastfeeding be explored. These distinctive characteristics make exclusive breastfeeding promotion a significant priority for this population. Therefore, the purpose of this research is to examine the attitudes and barriers to exclusive breastfeeding in a sub-sample of adolescent Latinas who are part of a larger qualitative exploration of barriers to exclusive breastfeeding in Latino mothers.

Review of Literature

In order to understand this research it is important to describe first the framework that was chosen for the parent study. Along with this framework the existing knowledge base regarding the benefits of breastfeeding, the effect of acculturation on breastfeeding and factors influencing adolescent breastfeeding choices and experiences will be portrayed.

Theoretical Framework

The theoretical framework used as the guide in this study is Pender's health promotion model (Pender, Murdaugh, & Parsons, 2006). According to Schlickau and Wilson (2005) this model is a comprehensive perspective that integrates both behavioral science and nursing to explain the behaviors related to health promotion (See Appendix A for figure). Breastfeeding is considered a health-promoting behavior because it is consistent and continuous and has positive health effects for both infant and mother. Furthermore, the model is appropriate for use in breastfeeding

research and maternity practice because nurses are able to influence and support mothers in this health behavior.

Pender's health promotion model is comprised of three major constructs: individual characteristics and experiences; behavior-specific cognitions and affect; and behavioral outcomes. The model represents a framework that is designed to explain the complex decision that individuals face when engaging in health promoting behavior. The first component, individual characteristics and experiences, is comprised of both prior related behaviors and personal factors, which include biological, psychological, and socio-cultural. Those factors influence the future behavior and for the most part are not modifiable factors. The behavior-specific cognitions and affect consist of factors that are divided into two main categories: those that are perceived and those that are influences. The model looks at the perceived benefits of action, perceived barriers to action, perceived self-efficacy, and the activity-related affect. Interpersonal influences that are able to affect the health promoting behavior include family, peers, and providers. Support available, role models, and also societal norms may also influence the behavior. The different options available, aesthetics, and the characteristics of the demand are components of the type of situational influences that one may have. Those factors all have an impact on the commitment to the plan of action. Lastly, the model is made up of the behavioral outcomes. Here the model looks at the immediate competing demands (low amount of control over) and preferences (high amount of control over) that may inhibit and hinder or help to continue to promote the health promoting behavior.

Self-efficacy is a central concept of this model because it is based upon the belief that an individual takes an active role in determining and maintaining individual health behaviors. This model also takes into consideration not just the behavior specific cognitions but individual characteristics and experiences that includes: biological conditions of age and gender; psychological factors or self-esteem, self-motivation, and personal competence; and the sociocultural factors of race/ethnicity, acculturation, education, and socioeconomic status (Pender et al., 2006; Schlickau & Wilson, 2005).

The ten determinants of behavior within the health promotion model have been found to mimic the same factors that affect breastfeeding promotion and support. For this reason, the concepts and relationships found will assist in providing a meaningful approach to this particular research and the creation of interventions in the future (Schlickau & Wilson, 2005).

This model has been used successfully in many studies regarding adults and, more recently, in studies involving adolescents. An integrative review of research in the use Pender's model in adolescent studies suggested that the model is appropriate for adolescent research (Srof & Velsor-

Friedrich, 2006). For example, it was determined that the underpinnings of social cognitive theory presented in Pender's model, made it an appropriate framework to use as a predictor of health-promoting behavior. However, the linear nature of the Pender's model was seen as a possible barrier to understanding the complexities of relationships for the adolescent. The previous research with adolescents and the model have been primarily focused on chronic illness cases. Therefore, the concept of imitation (role-modeling) that plays such a large part in breastfeeding support and decision making does not exist (Srof & Velsor-Friedrich, 2006).

Health Benefits of Breastfeeding

Breastfeeding has been found to be an optimal source of nutrition for both newborns and their mothers. Benefits for the mother include more rapid return to the pre-pregnant uterus size, a decrease in postpartum bleeding, and a decrease in menstrual blood loss. Many women also find that they are able to get back to their pre-pregnancy weight much quicker. Infants have shown better cognitive development, and a decrease in the incidence/severity of common infections (respiratory tract, otitis media, diarrhea, urinary tract, necrotizing enterocolitis, and pneumonia). Increased childhood obesity and diabetes rates are related to not breastfeeding (Gill, 2009; Hernandez 2006; Schlickau & Wilson, 2005). Hispanics have the largest proportion of overweight children according to the 2002 Pediatric National Nutritional Surveillance Survey (REF), which makes breastfeeding in this population even more desirable.

Acculturation

"Acculturation is the process of adapting to a new culture and adopting the values, beliefs, attitudes, and practices of the 'new' or dominant culture" (Gill, 2009, p. 245). It occurs when groups of individuals from different cultures come in contact with each other and is a multidimensional process (Jimenez, Gray, Cucciare, Kumbhani, & Gallagher-Thompson, 2010). Gill found that the number of Hispanic mothers that initiate breastfeeding of their children is higher than those of other women; however, the rates for exclusive breastfeeding at 3 and 6 months still fall below the Healthy People goal. The decision to breastfeed was determined prior to giving birth in the majority (63%) of Hispanic women. It was also found that of those women, foreign-born, were more likely to make the decision to initiate breastfeeding or exclusively breastfeed than their counterparts that were born in the United States.

Ethnic and racial differences in United States breastfeeding rates may be related to acculturation and the role of immigrant status (Gill, 2009; Sussner, Lindsay, & Peterson, 2008). Gill described research showing that Hispanics that are more likely to initiate breastfeeding have closer ties to their cultural beliefs, traditions, and practices; immigrant mothers were more likely to

initiate breastfeeding than their American-born counterparts (Gill, 2008). For every year that a Hispanic mother resided in the United States, there was a 4% decrease in the odds of breastfeeding. There was also a negative correlation to exclusive breastfeeding when English was being spoken in the home. "Research has shown that as the degree of acculturation increases for Mexican American women, the rate of initiation of breastfeeding decreases" (Hernandez, 2006, p. 320). For most Hispanic women, breastfeeding is the cultural norm; however, they perceive bottle-feeding as the norm for American women, and thus, believe it to be superior.

Adolescents and Breastfeeding

Infants of adolescent mothers are at a significantly greater risk for infant mortality, morbidity, and developmental delays due in large part to the social and economic disadvantages faced (Mossman, Heaman, Dennis, & Morris, 2008). Prematurity, small for gestational age, and a risk for less than optimal maternal-infant attachment are more likely amongst infants born to adolescent mothers. Research has shown that breastfeeding has been found to be of great benefit to combat these problems by providing the appropriate micronutrients and helping in promoting the maternal-infant closeness (Nelson, 2009). Breastfeeding can also aid in offsetting some of the economic burden that adolescent mothers face (Wambach & Cole, 1999).

When looking at the adolescent mother's history, it was found that those who were breastfed as infants had a much more positive view of breastfeeding than those that had not been breastfed as infants (Mossman et al., 2008; Nelson, 2009). In the study by Mossman et al., it was also found that significantly more mothers who initiated breastfeeding were breastfed themselves, and the majority that planned to breastfeed the longest had decided that prior to pregnancy or during the first trimester. It was also found that the majority had a partner supportive of their decision to breastfeed.

Attitudes of the adolescents' peer group, partner, and family also were reported as having a large influence on the decision to breastfeed (Mossman et al., 2008). In one study, 70% of high school females of a middle class background identified embarrassment as a major barrier to breastfeeding (Swanson, Power, Kaur, Carter & Shepherd, 2005). Other issues that have been found to have significant impact on adolescent breastfeeding outcomes include: breastfeeding support from the teens' mother, boyfriend, and friends, fatigue, the concern of being tied down, body image perception, breast exposure, medical complications, pain, breastfeeding knowledge, school/work, perceived barriers, anxiety, and difficulties with positioning and latch on (Mossman et al, 2008; Nelson, 2009; Wambach & Cohen, 2009).

Method

Design

The parent study from which this study originates is still in progress. The study, using Pender's theoretical framework as the guide, uses an exploratory descriptive design. Data are collected using formal interviews, a qualitative acculturation measurement tool, and a demographic survey. This report focuses on the findings from the adolescent participants in the study. A case study analysis approach was used because thus far only two adolescents have participated in the study.

Sample Criteria

Adolescent Latina mothers of infants up to 6 months of age were eligible for participation. To qualify, mothers must have been between the ages of 16 and 20 years old, and currently breastfeeding or have breastfed to two weeks of age. The infant must have been a singleton full-term infant of greater than 37 weeks of gestation. Mothers could be English-speaking, bi-lingual, and/or Spanish speaking.

Setting and Procedures

Participants were recruited at an academic medical center's pediatric outpatient clinic, a clinic that serves low-income families, and a community-based project that supports a diverse group of families between October 2010 and present. Candidates were identified during well-baby visits by a pediatric nurse practitioner and a physician assistant at the hospital clinic. At the others sites, subjects were identified by patient advocates and various types of health care workers. Individual interviews were conducted in the outpatient clinic or in the participant's home. A bi-lingual research assistant conducted all interviews and recorded field notes throughout the interview and asked clarifying questions, if necessary. Participants were provided with a token gift for participation in the study (e.g. photograph holder, infant toy) and their parking fee reimbursed if interviewed at the clinic setting. The institutional review board approved the study in its entirety. There were no legal, social, physical or psychological risks anticipated for the participants. Confidentiality of the subjects was assured and informed consent laws regarding minors were followed. Informed consent procedures were done prior to data collection for all participants. The institutional review board recognizes adolescent mothers as emancipated minors so additional parental consent was not necessary.

Data Collection

Upon admission to the study, participants were asked in which language (English or Spanish) they were most comfortable. The consent was read in the language requested and any questions were answered prior to beginning the interview. Participants were informed that at any time they were able to decline answering a question and that withdrawal from the study may occur at any time without any further ramifications. Demographic data were collected (See Appendix B) in order to accurately portray those involved.

The selected language was also used for the audio-recorded interviews. Two digital tape recorders were used to ensure technological reliability. Interviews took place on a mutually (investigator and participant) agreed upon date, time and location. The setting was private, quiet and comfortable. Interviews lasted about one hour. Semi-structured interviews were based on open-ended questions (See Appendix C) developed by the investigator and were based on concepts in Pender's health promotion model (See Appendix A). Additional questions more specific to the adolescent mother were also included (See Appendix D) when appropriate. Throughout the interview probing questions were used to clarify statements or solicit more detailed information when needed. Observations regarding the participant's mannerisms, affect, body language, and voice inflections were also recorded.

The Revised Acculturation Rating Scale for Mexican Americans (ARMSA-II) (See Appendix E) was used to quantify the participant's level of acculturation. The scale, which consists of 30 items, is made up of two subscales that measure Mexican orientation (MOS) and Anglo orientation (AOS). Within the overall scale there are four factors that assess: (1) ethnic interaction; (2) language use and preference; (3) cultural heritage and ethnic behaviors; and (4) ethnic identity and classification. Items were scored on a Likert scale from 5 (*extremely or always*) to 1 (*not at all*). Evidence for internal consistency of the Anglo orientation subscale (coefficient alpha of .83) and the orientation towards the Mexican culture (coefficient alpha of .88) has been obtained (Jimenez et al., 2010).

Data Analysis

The sample demographics were characterized using descriptive statistics. The data obtained from the ARMSA-II was computed into a single linear score. This occurred by subtracting the mean MOS from the mean AOS. The resulting score could then be placed along a continuum that represented the participant's level of acculturation from very Anglo oriented (a high score) to very Mexican oriented (a low score) (Jimenez, et al, 2010). Acculturation scores were used to characterize the sample.

The tape recordings from the interviews were professionally transcribed into the language in which the interview was conducted. Transcripts in Spanish were then translated into English. Another researcher then validated the translation by spot-checking a third of the interview narratives in order to look for discrepancies; any discrepancies were discussed until consensus was reached.

General Data Analysis Procedures

For the larger sample of the study, field notes and verbatim audiotape transcripts were the basis for inductive qualitative content analysis; with the individual interview treated as a separate unit during the initial analysis. An interview was first read through several times prior to beginning the analysis. Once familiar with the text, notes and headings were written in the margins in order to describe the content. The first level of data analysis occurred by creating meaning units, “a constellation of words or statements that relate to the same central meaning” (Graneheim & Lundman, 2003, p. 106). The units were then condensed into condensed meaning units and finally into codes. The coded data were aggregated into themes that were created to link the underlying meanings together from the categories (Graneheim & Lundman, 2003).

Adolescent Data Analysis

A case analysis process was used for approaching the data collected from the smaller sub-sample of adolescents. Codes obtained from the general analysis of the data; verbatim narrative, statements, and themes from the adolescent cases were compared to and linked to the concepts and relationships of the Pender model. The two adolescent cases were analyzed separately allowing codes and themes to emerge independently. The two cases were then compared and contrasted looking for any overarching similarities or differences in barriers to exclusive breastfeeding amongst these two case studies.

Trustworthiness

Taking several supplementary steps ensured the reliability of this study (Elo & Kyngäs, 2007). An additional bilingual research assistant validated the translations of the interviews. As noted previously, spot-checking a third of the narrative to look for discrepancies between the meanings of the Spanish and English translations were conducted. This process helped ensure that the data were true to the original meaning of the interviews.

The research assistant conducting the interviews was appropriate because of her professional experience as a nurse, background working with the Latino population and ability to speak Spanish. In addition to listening carefully to the interview, the research assistant also observed how the questions were answered. This provided additional contextual information for

interpretation as well as clarification during the interview if there was an area of ambiguity. At the conclusion of the interview, the research assistant also summarized the content asking the participant(s) to verify and add any additional information if they felt it was necessary.

During the data analysis each member of the team performed independent coding of the data. Data coding was then mutually examined for the purpose of comparison, detection of patterns, and to identify themes, as well as search for rival explanations. The data were compared and contrasted until a mutually agreed upon analysis was ultimately achieved.

Results

The following section presents findings of the case analysis and is organized by Pender Model constructs. Additional comparison of the two cases is found in the Table.

Individual Characteristics and Experiences

Two female adolescent Latinas aged 16 and 18 years old both single but in committed relationships (with their infants father) participated in the study. Infants were roughly the same age and both were born by spontaneous vaginal birth. Demographic data demonstrated that both young women were born in Mexico; however, immigrated to the United States (participant one 3.5 years and participant two 11 years ago). Currently both lived with their parents and were attending their local public high school prior to, during, and after their respective pregnancies. The infant's fathers were also active in the infant and teens' lives. Participant one was very confident in her ability to breastfeed prior to her delivery. She stated that she was "100% confident" and physically "fine" to feed her infant. On the other hand, participant two stated that she was "scared and [I] wasn't really that confident" to breastfeed her infant. In fact, she was worried that the infant would hurt her, especially since she had a difficult time with the latch.

An acculturation score was calculated from the Revised Acculturation Scale for Mexican Americans – II score for both participants (See Appendix E). Participant one scored a -2.61 acculturation mean score. This is classified as a Level 1, which represents a "Very Mexican Orientation". Participant two scored a 0.73 acculturation mean score. This is classified as a Level 3, which represents "Slightly Anglo Oriented Bicultural". Participant two reported that she was not comfortable writing in Spanish, associated with both Anglos and Mexican, and did not have any contact with Mexico. Whereas participant one reported that she was most comfortable reading, writing and thinking in Spanish. In addition, she mainly associated only with Mexicans and did have frequent contact with Mexico.

Behavior-Specific Cognitions and Affect

Both adolescents were adamant in their belief that breastfeeding is healthier than formula and that it promotes physical and mental development. Participant one commented on breast milk's ability to help combat childhood illnesses while participant two pointed out the benefits on the infant's metabolism and that it is much less expensive than formula. Both adolescents also reported that their respective families were very supportive.

Both participants commented that they would have preferred taking their infants to school; however, neither school would allow that to occur. Participant one had a very supportive school environment. They provided her with a room to pump, access to cold storage for her expressed milk, and flexibility amongst the staff with her schedule. She said, "I have plenty of milk" and was "very happy" to be breastfeeding. Participant two did not have a supportive school environment. In the beginning they were; however, when the time came, they were unable to follow-through and provide a pumping location, access to cold storage, and the needed flexibility within her day without penalty. Despite those factors, she stressed that she would have liked to have breastfeed longer and more frequently. Unfortunately, she believed that she "wasn't producing enough milk" and was advised to discontinue breastfeeding due to antibiotic use for bronchitis.

Despite having different experiences, both adolescents commented on the connection made while breastfeeding and the intimate bond that was created between mother and child. Participant one commented on the infant's desire for closeness while participant two said it was "a really cool experience."

Both participants stressed the importance of support and were incredibly fortunate to have a familial support system behind them all the way. Mother's were the largest influence in making the decision to breastfeed and participant one mentioned that her mother informed her that she did not have a choice. Her boyfriend stated that breastfeeding was "tradition" in Mexico. In addition, participant one had the support of her school and teachers to help her continue breastfeeding. Participant two increased her confidence as she took classes biweekly for the month after delivery to gain experience with breastfeeding. As noted previously, she was advised by her health care provider to discontinue breastfeeding due to antibiotic use for bronchitis, an example of negative support given that most antibiotics are compatible with breastfeeding.

Behavioral Outcome

While participant two was unable to exclusively breastfeed, she was able to supplement formula with breast milk; however, participant one was able to exclusively breastfeed for six weeks. Comparison of the two participants revealed that both implicated school as a competing demand. Participant two also struggled with time management. Participant one was much more committed

to exclusive breastfeeding, largely in part to her role modeling: "Well, if my grandmother breastfed 11 babies, why wouldn't I breastfeed 1!" Participant two had intended to be more committed but her school and health situation greatly hindered her decisions.

Discussion

The results of the two interviews add to previous research regarding breastfeeding in the adolescent and Latina populations respectively. Few studies solely focus on adolescent Latinas, and the promotion of positive breastfeeding behaviors is important amongst this vulnerable population.

Participant one and two were both first time mothers with differing levels of initial confidence surrounding breastfeeding. Both were born in Mexico. According to Schlickau and Wilson (2005), mothers that migrated from Mexico had a greater chance of breastfeeding than their counterparts born in the United States. Their findings also supported that acculturation level does affect breastfeeding decisions. When looking at ARMSA-II scores, participant one was much less acculturated, and reported that she mainly used the language of her homeland country. Sussner et al. (2008) found that mothers that almost exclusively used their native language had two times the odds of initiating breastfeeding. Participant two's acculturation score also supported the literature, in that a higher score is negatively associated with all phases of breastfeeding (Gill, 2009). Despite wanting to breastfeed and believing that it was best, she was scared and not as confident. Even after going to classes, she still supplemented with formula. Her commitment level did not match that of participant one's.

Mossman and Lee-Dennis (2009) found that breastfeeding decisions and outcomes were significantly influenced by support from the adolescent's mother, boyfriend, knowledge and additional perceived barriers. Both participant one and participant two were very confident in their decision to breastfeed, despite, differing views on their initial ability. Participant one spoke much more of her family's influence and role modeling and was confident from the start.

Both adolescents were adamant in their belief that breastfeeding is healthier than formula and that it promotes physical and mental development; which is consistent with the previous literature (Nelson, 2009; Wambach & Koehn, 2004). Nelson also noted; however, that despite the adolescents belief, it is not always strong enough to influence their actions such as with participant two.

Dallas (2009) found a strong relationship between positive and consistent involvement by the adolescent father and the child's cognitive development and well-being. Both interviews revealed that the infants' fathers were active in the lives of both the infant and teen. Adolescent mothers that were able to maintain positive relationships with the fathers had a greater likelihood of providing their children with better preventative health care (Gill, 2009).

Participant two commented that she "wasn't producing enough milk" and was advised to discontinue breastfeeding due to antibiotic usage for bronchitis. These may be examples of areas that

could be targeted by culturally relevant interventions. Gill (2009) found that many Hispanic women supplemented breast milk with formula because they did not feel like they were producing enough milk. In another study, adolescents described needing to put the baby's needs first and discontinuing breastfeeding helped them feel like they were doing this (Nelson, 2009). By frequently weighing the infants, mothers were able to see that their babies were gaining weight from the breast milk intake (Gill, 2009).

The teens in this study experienced both ends of the spectrum with regards to school support. Both girls had a great desire to return to school and finish and this factor played an important role in their ability to continue with breast milk. These findings supported the literature that school can be a pivotal point in either continuing breastfeeding or having to stop all together (Wambach & Cohen, 2009).

Both adolescents made the connection between breastfeeding and a special infant bond or closeness that developed. The literature suggests that this is a common finding and is usually considered one of the most important considerations when choosing whether or not to breastfeed. Wambach and Cohen (2009) discovered that closeness and bonding was reported by 65% of the adolescents in their study as a positive of breastfeeding. Adolescent mothers are at an increased risk for poor infant attachment, so breastfeeding is an important way to help promote and nurture the bond between infant and child. Both mothers seemed very comfortable with their decisions and showed no evidence of poor infant attachment that may be directly related to the breastfeeding.

Adolescent parents, despite their limited financial resources and social support, rely heavily on their families of origin as their primary sources of parenting assistance (Dallas, 2009). The teens' mothers were reported to be the largest influence in making the decision to breastfeed and that supports Sussner et al. (2008) findings that attitudes, beliefs, and practices related to feeding are strongly influenced by older family members such as mothers and grandmothers.

Participant two increased her confidence as she took her postnatal classes at WIC, which is consistent with Gill (2009) and Sussner et al. (2008) findings that stressed the importance of postpartum support to promote and encourage breastfeeding. They found that classes correlated with higher initiation, duration, and exclusivity. Not all new mothers are familiar with the resources available in their community so it is important that the information is shared. For participant two, attending the WIC classes gave her the needed confidence to be able to breastfeed.

In summary, even while having a small sample, this study was comprised of two very different perspectives from adolescent Latinas. Each participant's story was able to enrich the data to provide additional viewpoints giving a more comprehensive and balanced analysis of the study.

Limitations

The study has some limitations since the results represent preliminary findings in an ongoing study. The study sample was smaller than anticipated due to slow enrollment in the larger study and lack of teen participants in the overall study sample. Conducting research with this age group presents multiple issues with participants' availability to interview including, but not limited to: transportation, school schedule and demands, child-care, and the unwillingness to participate in a study. The case analysis characterizes the outcomes of only two adolescent Latinas; therefore, the small sample size prohibits generalizing the findings to other groups of adolescent Latina mothers and the general population.

Implications for Nursing Practice and Research

This project will help to increase the knowledge base surrounding adolescent Latinas and the barriers to breastfeeding. It will also be able to add culturally relevant information to assist in the design of future research. Findings from this research are consistent with previous research; however, interventions still have not been created. This research supports the necessity of specific interventions that target the adolescent population. In particular, interventions are needed related to support during the school day, such as pumping location, cold storage facilities, and flexibility. Future research will test the effectiveness of these interventions in this vulnerable population.

In addition to information regarding breastfeeding, this project adds increased validity for the use of Pender's health promotion model with the adolescent population. The model appears to be applicable for framing research questions as well as the potential for developing theory-based interventions for practice.

Conclusions

There are three primary conclusions that can be gathered from this case analysis: (1) the findings of the two interviews support earlier published research. Adolescent breastfeeding success can be influenced by school support, confidence, acculturation, family, and peers; (2) the findings were consistent with the concepts identified in Pender's health promotion model; and (3) Pender's model appears to be an appropriate framework to use with the adolescent population, most likely due to focus on self-confidence, but also the concepts that reflect the social milieu within which the adolescent mother nurtures her infant.

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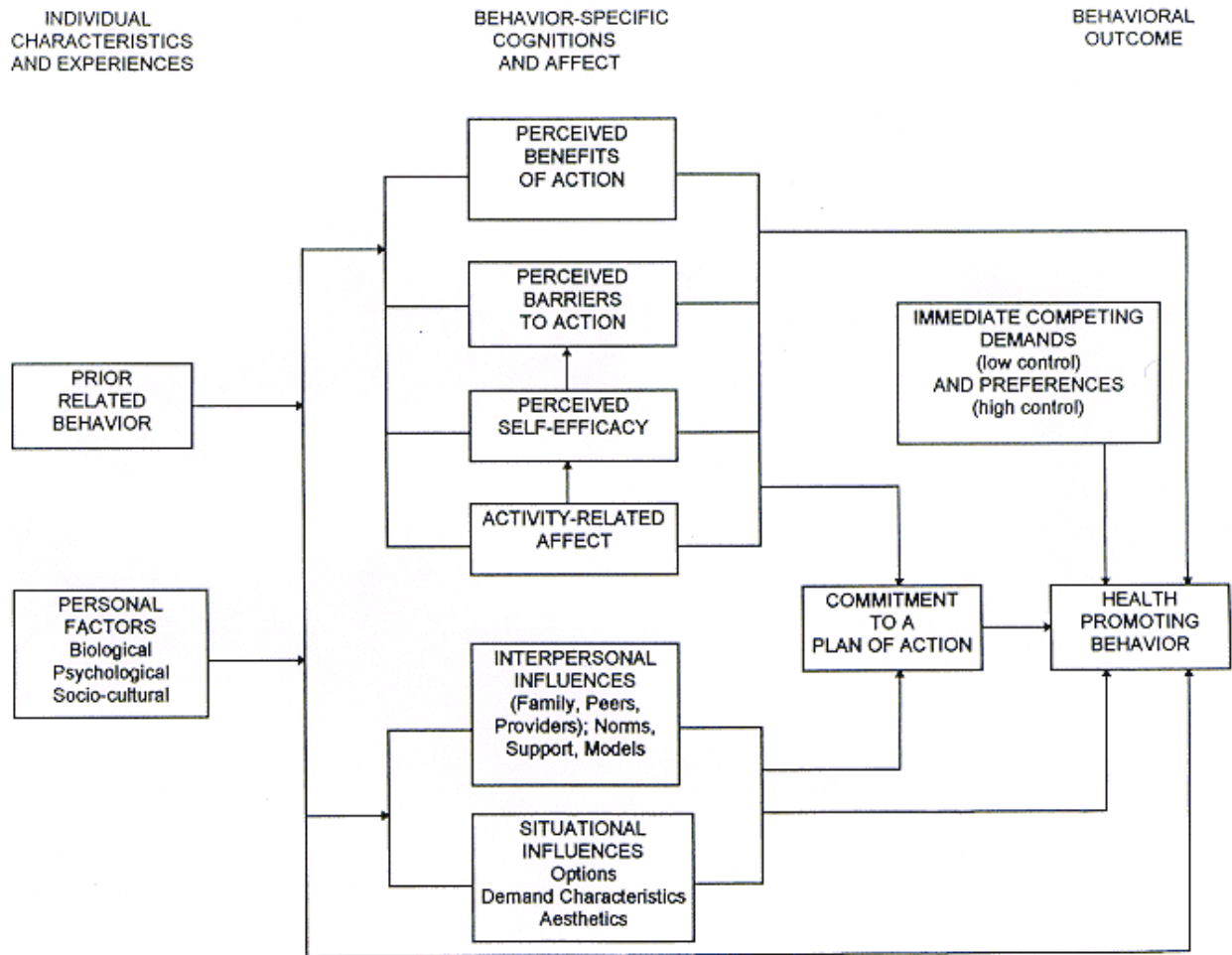
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TABLE 1 COMPARISON OF PENDER MODEL CONSTRUCTS AND CONCEPTS BY INTERVIEW

Construct/Concept	Interview One	Interview Two
Individual Characteristics and Behaviors		
Prior related behavior	Not applicable	Not applicable
Personal Factors		
Personal biological factors	18 years old Single (committed relationship) Infant 13 weeks at interview 3.7kg at delivery – spontaneous vaginal birth	16 years old Single Infant 4 months old on 4/27/11 6lbs 13 oz - spontaneous vaginal delivery
Personal psychological factors	“100% confident” “fine” physically	“scared and I wasn’t really that confident I could do it” Difficulty with latch
Personal socio-cultural factors	Acculturation score: -2.61 (low acculturation, high Mexican orientation – very Mexican oriented) Senior at a public high school	Acculturation score: 0.73 (level 3 – slightly Anglo-oriented, bicultural) Junior at a public high school
Cognitions and Affect		
Perceived benefits of action	Breastfeeding is healthier than formula and promotes physical and mental development	Breastfeeding is healthier than formula and promotes physical and mental development Less expensive than formula
Perceived barriers to action	Unable to take infant to school Daycare periodically gives breast milk and formula	Unable to take infant to school School does not allow adequate time, space, and storage for milk expression Lack of milk production

Activity-related affect	“very happy” to breastfeed Enjoys the infant’s desire for closeness	Breastfeeding “was a really cool experience” Enjoys the connection made with infant
Interpersonal influences	“tradition to breastfeed” in Mexico My mother told me I had to breastfeed School/teacher support	Encouraged by family and peers WIC classes Lack of school/teacher support
Situational influences	School resources for milk expression	Lack of resources at school for milk expression Antibiotic usage
Behavioral Outcomes		
Commitment to a plan of action	“Well, if my grandmother breastfed 11 babies, why wouldn’t I breastfed 1!”	“I would have continued to breastfeed him” if the school provided more resources and antibiotics were not taken
Immediate competing demands and preferences	Attending school Maintains milk expression schedule	Attending school Time management
Health promoting behavior	Maintained exclusive breastfeeding for 6 weeks Continues to express milk and breastfeed when possible	Unable to exclusively breastfeed Still believes it to be the best option

APPENDIX A PENDER'S HEALTH PROMOTION MODEL



Revised Health Promotion Model

NOTE: FROM HEALTH PROMOTION IN NURSING PRACTICE (5TH ED., P. 50) BY N.J. PENDER, C.L. MURDAUGH, AND M.A. PARSONS. UPPER SADDLE RIVER, NJ: PEARSON EDUCATION, INC. © 2005.

APPENDIX B DEMOGRAPHIC FORM

Please answer or check (X) in the blank regarding your personal information.

1. What is your age? _____ years
2. What is your family's country of origin?
_____ Mexico
_____ Puerto Rico
_____ Central America (Please specify): _____
_____ Cuba
_____ Guatemala
_____ South America (Please specify): _____
_____ Other
3. Where were you born? _____
4. Where were your parents born? _____
5. How long have you lived in the United States? _____
6. What is your preferred language spoken in your home? _____
7. What is the language you read in? Spanish _____ English _____ Both _____
8. What is the language you write in? Spanish _____ English _____ Both _____
9. What is your marital status?
_____ Married _____ Divorced
_____ Widowed _____ Separated
_____ Single _____ Living with partner
10. What's your highest level of completed education?
_____ Grade school _____ High school
_____ Partial college _____ Bachelor's degree
_____ Graduate degree _____ Other (Please specify): _____
11. What is your yearly family income? (circle)
 - a. \$10,000 or less
 - b. \$10,001 to \$25,000
 - c. \$25,001 to \$40,000
 - d. \$40,001 to \$55,000
 - e. \$55,001 to \$70,000
 - f. over \$70,000
 - g. N/A

12. Date of your baby's birthday: (mm/dd/yy) _____
13. Type of delivery: ____ vaginal ____ Cesarean Section (c/s)
If you had cesarean section, write reason why _____
14. Baby's gender(sex): _____ Male _____ Female
15. Baby's birth weight: _____
16. Number of weeks gestation when the baby was delivered? _____ weeks
17. Have you returned to work after childbirth? ____yes ____no
18. How do long do you plan to breastfeed your baby? _____

APPENDIX C INTERVIEW GUIDE (BASED ON PENDER'S HEALTH PROMOTION MODEL)

1. General breastfeeding beliefs, perceived benefits, and perceived barriers.
 - a. Tell me about your experiences of breastfeeding?
 - b. What do you believe about breastfeeding?
 - c. Did you have different beliefs about breastfeeding before you began to breastfeed?
 - d. Do you see benefits or positives to breastfeeding?
 - e. Do you see difficulties or problems with breastfeeding?
 - f. Do you have role models (family member or close friends) that have breastfed or you have seen breastfeed?
 - g. If so, did they influence you (or help) you make the decision to breastfeed?

2. Personal confidence and self-efficacy beliefs that impact breastfeeding.
 - a. How do you believe someone becomes confident or feels that they can breastfeed?

 - b. How confident or sure of yourself did you feel about breastfeeding when you began breastfeeding?

 - c. How did you feel about your overall physical ability to breastfeed when you began to breastfeed?

 - d. How did you feel about your overall emotional ability to breastfeed when you began to breastfeed?

 - e. Are these the same feelings that you have now about your ability to breastfeed?

 - f. How do you feel about yourself since you are or have breastfed?

 - g. Do you feel that your relationship with your baby is different since you are or have breastfed?

 - h. Do you feel that your relationship with significant others has changed since you are or have breastfed?"

3. Decisions to exclusively breastfeed
 - a. How did you make the decision to only breastfed your baby?

 - b. What helped you to make the decision to only breastfed your baby?

 - c. What has continued to help you make the choice to only breastfeed your baby?

- d. Has your current lifestyle helped you to continue to only breastfeed your baby?
- e. Has school or work influenced you to continue to only breastfeed your baby?
- f. Is there a particular person or people in your life that has made it easier for you to only breastfeed your baby?
- g. Has there been anything in your life that has made it more difficult to only breastfeed your baby?
- h. Has there been any person in your life that has made it more difficult to only breastfeed your baby?
- i. Are there benefits or positives to only breastfeeding your baby?
- j. Are there drawbacks or negatives to only breastfeeding your baby?
- k. Have there been changes in your life since starting to breastfeed and continuing to only breastfeed your baby?

OR

- 4. Decisions to mix breastfeeding and formula feeding
 - a. How did you make the decision to feed your baby both breast milk and formula?
 - b. Was there anything in your life that helped you make the decision to use formula along with breastfeeding your baby?
 - c. Has school or work influenced your decision to use formula along with breastfeeding your baby?
 - d. Is there a particular person or people in your life that has influenced your decision to use formula along with breastfeeding our baby?
 - e. Has there been anything in your life that has made it more difficult to give formula along with breast milk to your baby?
 - f. Has there been any person in your life that has made it more difficult to give formula along with breast milk to your baby?

- g. Are there benefits or positives to giving your baby formula along with breast milk?
- h. Are there drawbacks or negatives to giving your baby formula along with breast milk?
- i. Have there been changes in your life since starting to give both breast milk and formula to your baby?

OR

- 5. Decisions to stop breastfeeding and use formula
 - a. How did you make your decision to use only formula to feed your baby?
 - b. Was there anything in your life that happened as you made the decision to use formula only?
 - c. Was school or work influenced your decision to use formula only?
 - d. Is there a particular person or people in your life that has influenced your decision to use formula only?
 - e. Has there been anything in your life that has made it less difficult or easier to use formula only?
 - f. Has there been any person in your life that has made it less difficult or easier to give formula only?
 - g. Are there benefits or positives to giving your baby only formula?
 - h. Are there drawbacks or negatives to giving your baby only formula?
 - i. Have there been changes in your life since starting to use formula only to feed your baby?
- 6. Is there anything else that you would like to tell be about your breast feeding experiences, use of both breast-feeding and formula, or formula only that I did not ask you?

APPENDIX D

Breastfeeding Questions for Adolescents Participant #___; Date: _____

I. Education Probes – to be used during the collection of demographic information (record below):

- Demographic Item #9 – marital status: What is your living arrangement now?
(live alone, live with own family, other arrangement)

- Demographic Item #10: If participant indicates they completed grade 7-8 or Grade 9-12: What grade in school did you complete or partially complete?

- Were you pregnant while in school? ___Yes, ___ No.
- Do you plan on returning to school? ___ Yes ___ No
- If you did continue with school while pregnant...
 - What services were available to assist with your pregnancy? Prenatal classes; breastfeeding classes, parenting classes; other health education
 - Were any of these available before your pregnancy?

II. Include the following questions in the interview where appropriate – suggested places are indicated in parentheses. Breastfeeding and continuing school:

- What were some of the difficulties at school with breastfeeding exclusively or partially? (interview questions 3-e; 4-b, 4-c; 5c)
- Were there any services available to you at school to assist with breastfeeding? (interview questions 3-e; 4-b, 4-c; 5c)
- If so, what type(s) of services? Examples below:
 - Were there breast pump supplies?

- Room set aside for pumping?
- Was there cold storage provided? A refrigerator?
- Flexibility with class schedule?
- How did these services impact your decisions regarding infant feeding?
- If more services/facilities were made available, would you have made a different decision regarding infant feeding?
- What type of child care did you utilize while you attended school?

III. Influence of father if he is in the picture: Include with 3-h; 4-d; or 5 -d

- Is the father involved with the care of your baby?

Appendix E

REVISED ACCULTURATION RATING SCALE FOR MEXICAN AMERICANS (ARSMA-II)

Response Options:

1 = not at all, 2 = very little/not very often, 3 = moderately, 4 = much/very often, 5 = extremely often/almost always

Items:

1. I speak Spanish.
2. I speak English
3. I enjoy speaking Spanish.
4. I associate with Anglos.
5. I associate with Mexicans (*specific*) and/or Mexican (*specific*) Americans
6. I enjoy listening to Spanish language music
7. I enjoy listening to English language music
8. I enjoy Spanish language TV.
9. I enjoy English language TV.
10. I enjoy English language movies.
11. I enjoy Spanish language movies
12. I enjoy reading in Spanish (e.g., books).
13. I enjoy reading in English (e.g., books).
14. I write in Spanish (e.g., letters).
15. I write in English.
16. My thinking is done in the English language.
17. My thinking is done in the Spanish language.
18. My contact with Mexico (*specific*) has been
19. My contact with the USA has been...

20. My father identifies himself as "Mexicano" (specific)
21. My mother identifies herself as "Mexicano" (specific)
22. My friends while I was growing up were of Mexican (specific) origin
23. My friends while I was growing up were of Anglo origin.
24. My family cooks Mexican (specific) foods
25. My friends now are of Anglo (specific) origin
26. My friends now are of Mexican (specific) origin.
27. I like to identify myself as an Anglo American
28. I like to identify myself as a Mexican American
29. I like to identify myself as a Mexican (specific).
30. I like to identify myself as an American.

FAMILY CAREGIVER STRAIN AND RESIDENT DISTRESS IN THE
DEMENTIA POPULATION OF NURSING HOME FACILITIES

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Abstract

End-of-life care in the U.S. is increasingly provided in nursing homes (NHs), and over half of all NH residents have some degree of cognitive impairment. Given the prevalence of this cognitive decline, there is a surprising gap in research related to the management of distress in this patient population and their family caregivers. Symptoms of distress vary based on multiple factors (e.g., pain, cognitive status, type of caregiver) and can be masked in the cognitively impaired due to communication difficulties. The purpose of this study was to examine whether resident and family caregiver distress and strain are different among three NH resident groups based on diagnoses: (a) Alzheimer's, (b) other dementia disorders, and (c) non-cognitive diagnoses. This exploratory study was a secondary analysis of data collected from a longitudinal study examining end-of-life care in NHs. The sample was comprised of 1,282 pairs of NH residents and their family caregivers from two Midwestern states. Caregiver and resident distress and strain were measured with the *Caregiver Strain Index* and the *Family Memorial Symptom Assessment Scale Global Index*, respectively. ANOVA procedures were used to test for differences among the groups, and follow-up tests were conducted using *Duncan/Dunnett's T3* tests. Findings indicated significant decreases in distress ($F_{(2,1267)} = 34.16, p < .001$) and strain ($F_{(2,1267)} = 10.08, p < .001$) among cognitively-impaired residents from those who were cognitively intact. No significant differences were found in caregiver distress or strain based on the cognitive status of their loved one. It is uncertain whether the reported differences are attributable to communication difficulties of the cognitively-impaired residents or whether they are experiencing less distress and strain. Research in other geographic locations using larger samples are needed to provide further insight.

Introduction

Nursing homes are of ever increasing occurrence in American culture as the population ages. Currently, 20% of all deaths occur in nursing homes, and this number is expected to increase to 40% by the year 2020 (Forbes, 2001). With death such an integral part of nursing home culture, there are surprising gaps in research regarding quality end-of-life care in the nursing home setting. Most research to this point has focused on patients with cancer diagnoses or on those in the hospital setting. Thus the research always is not applicable because patients with long-term, non-cancer diagnoses usually present differently, having periods of instability intermixed with periods of stability, with death frequently occurring abruptly. Demographic characteristics and comorbidities of the

nursing home population lead to increased vulnerability of nursing home patients, both to physical and emotional stress and trauma.

Over half of all nursing home residents have some degree of cognitive impairment (DeVellis, Hanson, Henderson, Reynolds, & Steinhauser, 2008). Distress or pain in a patient with Alzheimer's or other dementia diagnoses must be evaluated with different measures than for those with no cognitive impairment. For example, pain assessment must rely on other expressions like fidgeting, grimacing, or 'crying out' if the patient's cognitive disorder prevents reliable verbal reports. Up to this point, research related to patients with cognitive impairment has centered on pain management rather than overall patient distress and strain. Looking more closely at the strain and distress experienced by nursing home residents that are cognitively impaired and comparing them to those that are not impaired will allow us to identify if there is inadequate pain management among this group. Strain and distress may be harder to measure due to the communication challenges and memory lapses that occur with cognitive impairment, and so may be undertreated. However, in recent years there has been as an increase in medical studies involving this population, as well as improvement in the development of pain assessment tools specifically geared to geriatrics and the cognitively impaired. Effort is being made to qualify dementia patients for end-of-life care instead of waiting for them to meet Medicare's current required prognosis of six months or less to live. This will assist in improving comfort measures for this patient group, who may remain in the advanced stages of their disease for many years before passing (Diwan, Hougham, & Sachs, 2004).

Research examining caregiver role strain for cognitively-impaired individuals has mainly focused on those who care for their loved one at home, and not on families of residents residing in the nursing home setting. Family caregivers of the cognitively impaired face unique challenges related to the change in personality and outbursts frequently experienced by this patient group, and this type of stressor exists whether the patient is cared for at home or in alternative settings. Many family caregivers of this patient group report feeling as though they are "on duty" 24-hours a day, and a high degree of guilt is not uncommon (Diwan et al., 2004, p.798). Comparing caregiver strain and distress for families of cognitively-impaired patients to families of the non-cognitively impaired will help to identify if there is a lack of the appropriate caregiver support among this group.

Purpose

The purpose of this secondary analysis is to examine whether resident distress and the corresponding family caregiver strain differ among patients with varied cognitive status. The following research questions will be explored: (a) is there a difference in the number of resident strain symptoms and amount of associated distress reported among three diagnostic groups of residents (Alzheimer's, other dementia, and no dementia), and (b) is there a difference in the number of caregiver strain symptoms and the amount of distress reported among the Alzheimer's, other dementia, and no dementia residents?

Background

Many studies have examined pain management in older adults with cognitive impairment, along with caregiver role strain for family members acting as the primary providers for these people. Literature has demonstrated clear differences in pain reporting and management based on the cognitive status of the individual, focusing primarily on the patients' inability to express pain in a way their caregiver can understand (Ferrell et al., 1995). Additionally, caregiver role strain has been shown to be unique in many ways for those family members who must face their loved one's cognitive impairment instead of or in addition to their physical challenges.

Pain Management. Improperly managed pain in older adults is considered to be a pandemic across nursing homes in this country, with chronic pain estimates ranging from 40% to 80% of all residents (Forbes, 2001). Pain is difficult to identify and manage in older adults with all forms of diagnosis, but it is of little surprise that it is even more challenging consistently to identify pain from among approximately half of these residents who are suffering from some degree of cognitive impairment (DeVellis et al., 2008). Several factors are attributed to the difficulty in identifying pain in older adults: (a) the use of pain assessment instruments that have not been validated for the elderly population, (b) difficulty in establishing consistency of care in nursing homes, (c) higher incidence of side effects related to pharmacology for this age group, and (d) a fear of using analgesics due to heavy scrutiny of these facilities by state and federal authorities (DeVellis et al., 2008; Ferrell, 1995).

Pain usually is reported verbally by the residents; however scales designed for patients who are unable to communicate verbally typically look for pain associated non-verbal symptoms or cues such as fidgeting, grimacing, and verbal outbursts (DeVellis et al., 2008). These symptoms or cues obviously can be difficult to interpret and measure consistently at times. However, the increased interest in the topic and a required focus on

pain management mandated by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has led to the development of more varied pain assessment measures. Encouragingly, several studies have shown that 83% of cognitively-impaired residents with pain could complete at least one of the self-assessed, non-verbal pain scales (e.g., horizontal visual analogue scale with anchors of “no pain” and “worst possible pain”; Rand Coop Chart with facial expressions indicating degree of pain; or the pain thermometer visually indicated increasing pain) (Ferrell et al., 1995). For those patients unable to complete any kind of self-reported pain assessment, the Minimum Data Set (MDS) 3.0 includes a non-verbal provider assessed pain intensity scale guide that measures groaning, sighing, restlessness, withdrawal, crying and immobility (Quality Partners of Rhode Island, 2006). The next step will be to convince those in charge of policy making for nursing home facilities that such scales are needed in addition to the traditional self-reported 0-10 pain scale in order accurately to assess pain in the cognitively-impaired.

There is a social myth that pain is a normal part of aging, but the importance of measuring pain accurately cannot be under-estimated. A 2010 study focusing on pain and memory in adults showed that persistent pain can lead to an exacerbation of cognitive dysfunction even in those who are cognitively intact, let alone those individuals who are cognitively impaired (Brown, 2010). Further motivation to identify pain in these residents as early as possible is the fact that the declined functioning of residents suffering from cognitive impairment make them more likely to acquire additional painful conditions such as pressure ulcers and contractures (Brown, 2010).

Unfortunately, studies examining pain management have consistently found pain to be under-detected in all nursing home residents, especially those with cognitive impairment. A 2004 study examining analgesic provision in a nursing home in the United Kingdom found that prescriptions of opioid and non-opioid analgesic decreased as cognitive impairment increased (Barr, Briggs, & Closs 2004). Similarly, a measure of daily pain in nursing home residents taken as part of a 2004 study in the United States found that 3.7% of those surveyed with normal cognitive status reported daily pain that was excruciating at least once in the last week. In contrast, caregivers reported that those with cognitive impairment had this level of pain only one-fourth as often (Kabumoto, Mor, Roy, Teno, & Wetle, 2004). A 2010 analysis of the Resident Assessment Instrument (RAI) data used to collect information about residents for Minimum Data Set (MDS) reporting focused on pain in communication-impaired dementia residents. The study reported that residents with

impaired communication were less likely to have their pain rated as moderate to extreme, and less likely to receive the wide range of medications available per week when compared to those residents with no impairment (Brown, 2010). They also found in examining the RAI pain ratings that some residents who were experiencing pain never received any analgesic treatment (Brown, 2010).

A 2008 study (DeVellis et al., 2008) examined disparities in pain management based on level of cognition. Despite the fact that there was no variation between the groups in diagnoses likely to cause pain, they found that 80% of cognitively intact residents received some pain medication throughout the study, versus only 56% of residents with severe cognitive impairment. Similarly, a 2005 study (Jarland & Nygaard, 2005) looking at pain revealed that nurses were likely to over-estimate pain in cognitively intact patients as only 47% of this patient group self-reported pain versus the 67% described as being in pain by their nurses. In contrast, analgesics given as needed (PRN) were bestowed to 33% of cognitively-intact patients, 27% of cognitively-impaired patients, and 12% of demented patients, showing that those with dementia diagnoses were less likely to receive PRN medications.

Caregiver Strain. Caregiver role strain results from a wide variety of factors related to both the patient and the caregiver. Personal orientation, or an individual caregiver's self-perception, has a large impact on the stress one experiences; but for nearly all, caring for a loved one with a dementia diagnoses leads to a high degree of strain (Goodman, Steiner, & Zarit, 1997). The symptoms specific to dementia of behavioral changes, decreased communication skills, decreased ability to perform one's own activities of daily living, and declining motor function lead to a high degree of strain for their caregiver, who often feels they no longer are able to recognize the person they love within the disease-defined characteristics of the patient they now care for (Annerstedt, Elmstahl, & Grafstrom, Samuelsson, & Samuelsson, 2001). The *Caregiver Strain Index* defines three dimensions of strain for the caregiver: role, personal, and emotional (Diwan et al., 2004). Role strain can include having to make adjustments to normal routine, losing personal time, and taking time off work. Personal strain can include financial hardships, sleep disturbances, and physical challenges of care (Diwan et al.). Emotional strain, which includes changes in the personality of their loved one and upsetting behaviors such as incontinence or memory loss, is most prominent among caregivers of cognitively-impaired family members. Researchers have found that problem behaviors related to the patient,

specifically patient functional limitations, predict both personal and role strain (Diwan et al.).

Along these lines, a 2010 study (Ito, Miyamoto, & Tachimori, 2010) examining caregiver burden used a multiple linear regression model to predict the burden on caregivers. Results supported that there was a positive relationship between behavioral and psychological symptoms of dementia (BPSD) such as aggression, screaming, and low activities of daily living (ADL) levels with reported caregiver burden. They recommended that the effectiveness of training designed to decrease BPSD in dementia patients should be examined as a possible method to decrease this elevated caregiver strain.

Burden of responsibility experienced by family caregivers of dementia sufferers was examined effectively in a qualitative study in Sweden in 2001. The study showed that 100% of caregivers felt a “heavy burden” early on in the process, particularly before a diagnosis was made (Annerstedt et al., 2001). The quality of the relationship between the caregiver and dementia patient had an effect on the caregiver’s stress as the disorder progressed. Those that described themselves as having been on poor terms with their loved one before the dementia experienced more ambivalence towards the decline, less sympathy, less guilt, and emotional distance (Annerstedt et al.). Those that had a close relationship suffered more strain as they watched their relationship change. One caregiver described the difficulty of his wife’s dementia as “not being able to reach her any longer...to talk to each other...to get contact” (Annerstedt et al., p.29).

More research is needed on caregiver role strain specific to family members whose loved one is in a nursing home or assisted living facility rather than at home. Examination of the differences in caregiver strain across cognitively impaired and cognitively intact residents needs to be explored, as well as additional research comparing other indicators of resident distress besides pain management in these same groups.

Methods

Design

This study was a secondary analysis of data from the NINR-funded “Impact of Quality End-of-Life Care in Nursing Homes” Study, a longitudinal study examining end-of-life care in nursing homes. The primary study used a multi-level structural equation model to examine both the personal resident/family factors and the facility-level factors such as staff communication and palliative care practices that contribute to quality of end-of-life

care for residents. The purpose of this secondary analysis was to examine whether resident distress and family caregiver strain differ among patients of varied cognitive status.

Sample and Setting

The sample included 1,282 resident/family caregiver pairs from 88 nursing homes in two Midwestern states. A target of 100 participating nursing homes was randomly selected from an initial sampling strategy that generated 180 facilities that met the criteria of the parent study. The criteria for inclusion were: free standing nursing facilities, not hospital based, and at least 60 beds per facility.

Family caregivers were recruited for residents that had died in the nursing home in the past month. Resident/caregiver pairs per institution ranged from 8 to 25, with a mean of 15. The nursing home residents were divided into three groups based on three diagnoses: Alzheimer's disease ($n=246$; 19.5%), other dementia disorders ($n=439$; 34.9%), and all other non-cognitive diagnoses ($n=575$; 45.6%).

Measures

Caregiver Strain and Distress. *Caregiver strain* and *distress* were measured using the *Caregiver Strain Index* (Robinson, 1983; Thorton & Travis, 2003). The index was comprised of two scales looking first at strain and then at associated distress, designed to determine the degree of challenge experienced by family caregivers while their loved one was in a nursing care facility. Reliability (*Cronbach's alpha* .86) and construct validity have been demonstrated (Robinson, 1983).

Caregiver Strain was measured using 13 questions addressing the issues of sleep disruption, physical challenges, emotional challenges, less time for self, adjustment of work schedules, financial strain, adjustment of family routines, changing of personal plans, inconveniences, other demands on time, upsetting behaviors, changes seen in the resident, and overwhelming feelings. Item responses were 'yes' or 'no' with a value of one given for each yes response. Questions were formatted as follows: In caring for the resident, was your sleep disturbed? Scores across the thirteen items were summed to create a scale. Scores ranged from 0 (no strain) to 13 (highest strain).

Caregiver Distress was similarly structured with 13 questions addressing the same items as those identified for caregiver strain, but through follow-up questions asking for the amount that the caregiver was distressed or bothered by each area of strain. For example: In caring for the resident, how much did your sleep disruption distress or bother you? Response options were: 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), or 4 (a

great deal). Scores were summed across the 13 items and ranged from 0 (no distress) to 52 (most distress).

Resident Strain and Distress. *Resident strain* and *distress* were measured using the Family Memorial Symptom Assessment Scale Global Distress Index [MSAS_GDI] (Kornblith et al., 1994; Hickman, Tilden, & Tolle, 2001). The two scales were designed to evaluate the stress experienced by the residents of the participating nursing homes, considering their three diagnoses groups. The MSAS-GDI has demonstrated reliability and validity (Portnoy et al., 1994; Viet & Ware, 1983). Strain was measured through an 11-item scale with one point given for each positive response to questions addressing experience of sadness, worry, irritability, nervousness, lack of appetite, lack of energy, feeling drowsy, constipation, dry mouth, difficulty breathing, and pain. Questions were formatted as follows: Did the resident seem to feel sad in the last week of his or her life? If a response of yes was given, one point was added to the resident strain scale. Scores then ranged from 0 (no strain) to 11 (most strain). Similarly, resident distress was measured through the examination of the same issues, but with questions addressing how often the stress was experienced, and how much the experience seemed to distress the resident. For example: How often did the resident seem sad? Responses included 0 (never), 1 (rarely), 2 (occasionally), 3 (frequently), or 4 (almost constantly). Also how often did feeling sad seem to distress the resident? Responses included 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), and 4 (very much). Final scores then ranged from 0 (no distress) to 60 (most distress).

Procedures

After an initial sampling strategy using public lists of nursing facilities generated 180 eligible nursing homes in two Midwestern states, 100 nursing facilities were randomly selected to be included in this study. Based on average death rates and a desire to encourage enrollment, inclusion criteria was a minimum of 60 beds for the homes. Once selected, the facilities received a letter describing the study, and a telephone call to answer any questions and to seek consent. Facilities that decided to participate selected a staff member to serve as site coordinator for monthly reports. Contact information for resident and family caregivers was obtained from the site coordinator, and family caregivers were contacted by phone to give consent and complete the surveys.

Data Analysis

The following research questions were explored: (a) Is there a difference in the number of resident strain and distress symptoms reported among the Alzheimer's, other dementia, and other non-cognitive diagnoses groups, and (b) Is there a difference in the number of caregiver strain and distress symptoms reported in the Alzheimer's, other dementia, and other non-cognitive diagnoses groups? Analysis of Variance (ANOVA) procedure was performed by selecting for each dependent variable (resident strain and distress, and caregiver strain and distress). A one-way layout ANOVA looks at one treatment factor at two or more levels, and quantifies the differences in mean among the levels. ANOVA assumptions are that the treatment effects are additive and errors are random, independently distributed, follow a normal distribution, and have a mean of zero with constant variance. Correlation analysis also is done on random samples with normal distribution to determine whether two variables are associated. The correlation coefficient is a number between -1 and 1 which indicates the degree to which a change in one variable leads to a change in the other. The correlation coefficient is statistically significant only if there is a less than 5% probability you would have reached the same result with a true correlation coefficient of zero. This is indicated by a p value of $<.05$.

ANOVA procedures were used to test for differences among the three nursing home resident diagnostic groups: Alzheimer's disease, other dementia disorders, and all other non-cognitive diagnoses. Follow-up tests were conducted using Duncan and *Dunnett's T3* tests based on whether the assumption for homogeneity of variance was met or not met, respectively.

Results

Our sample was comprised of 1,282 resident/family caregiver pairs. Mean age of family caregivers and involvement in the residents' lives are outlined in Table 1, as well as other demographic information of both the resident and family caregiver. Our sample residents and caregivers were predominantly female, non-Hispanic white, and Protestant. The largest resident age group was 85 years and older; and nursing homes were the primary location of death.

Means and standard deviations for caregiver strain, caregiver distress, resident strain, and resident distress can be found in Table 2. Caregiver strain and distress were analyzed to determine if statistical differences existed between our three resident diagnostic groups. Testing the assumption of equal variances, or that the three groups would have equal slopes if plotted independently, there were non-significant ($p = .19$ and

.34) findings for caregiver strain and distress, respectively, confirming that we met the assumption for equal variances. The ANOVA revealed non-significant ($p = .46$ and $.75$) differences for the means of both caregiver stress and strain, respectively, among the three resident diagnostic groups.

Resident strain and distress were examined to determine if differences for these measures existed between our resident diagnostic groups. The homogeneity of variance test resulted in significance ($p = .03$ and $.00$) for resident strain and distress, respectively, indicating the assumption of equal variances had been violated. The overall *F test* for the ANOVA among the three resident diagnoses groups revealed significant differences for both resident strain and distress (See Table 2). Follow-up tests using the *Dunnett's T3* showed that for resident strain the Alzheimer's group ($M = 4.85$) was significantly ($p < .01$) lower than the other dementia group ($M = 5.10$) and all other non-cognitive diagnoses group ($M = 5.52$). For resident distress, the *Dunnett's T3* test revealed significant ($p < .01$) differences between all groups: Alzheimer's ($M = 4.21$), other dementia ($M = 5.54$), and all other non-cognitive diagnoses groups ($M = 6.68$).

Discussion

Resident strain and distress are important measurements for improving quality end-of-life care. This especially is true but more difficult to quantify in those with cognitive impairment, due to communication difficulties and personality changes that make it difficult to identify varying degrees of agitation. The use of self-assessed, non-verbal scales, as well as caregiver-assessed scales, can help more accurately to measure strain and distress for this group. Pain management has been studied extensively in the cognitively impaired population, but other variables such as sadness, lack of appetite, and fatigue need to be examined as well.

Caregivers face unique strain and distress when caring for a loved one with Alzheimer's or other dementia disorder. The change in personality of their loved one, when combined with the physical challenges of caregiving, can be overwhelming. There has been a fair amount of research on this topic when the caregiver and the patient live together, but more research is needed to examine how the cognitive decline of the patient affects caregiver strain and distress when the patient lives in a nursing home.

Our study found no significant difference in caregiver strain or distress based on diagnoses of Alzheimer's, other dementia disorder, or non-cognitively impaired residents. This was a surprising finding as we anticipated increased strain and distress for

the caregivers due to the particular characteristics that impact residents who have cognitive disorders such as personality change, volatility, communication impairment, and low ability to perform ADL's independently. In examining the caregiver strain and distress means, the caregivers for the Alzheimer's residents reported lower strain and distress even though the findings were non-significant. The lack of significant variance could be due to the successful use of non-verbal assessment measures providing comfort to residents, personal attributes of the caregivers, or simply a true lack of variability in the strain and distress between caregivers for those with cognitive impairment and caregivers of those without. Also these findings were reported for residents who had recently passed away, and it could be that strain and stress for the family caregivers during the resident's end-of-life experiences were about the same regardless of type of cognitive impairment level of the resident.

However, the findings revealed significant difference in resident strain and distress based on diagnoses groups. For resident strain, the significant variances existed between the Alzheimer's group and the other non-cognitive diagnoses groups, as well as between the dementia and the other non-cognitive diagnoses groups. For distress, significant variance existed between all three diagnoses groups. Strain and distress was much higher for residents in their last days of life for those who were cognitively intact than for those who were not. This may be that they were more able to express this to their loved ones or it may have been due to the fact that the family caregivers had clearer communication from these residents.

Results of this study can be used to anticipate lower visible strain and distress among residents who are cognitively-impaired. Nursing care should be adapted to consider the possibilities of why this is occurring. It is possible these patients are truly experiencing less strain and can manage better with less medication geared towards reducing anxiety and pain towards the end of life. Other possible explanations for this decline in strain and distress also should be considered. If these cognitively-impaired residents are simply less able to express their strain verbally, effort must be made on the part of healthcare providers to attempt to measure strain in other ways, such as through non-verbal, caregiver-provided assessment scales.

Summary

In summary, symptoms of strain and distress can vary based on multiple factors, and may be difficult to assess in those with cognitive impairment. Findings of this study revealed that: (a) caregiver strain and distress did not significantly vary between caregivers

whose loved one is cognitively-intact and those whose loved one is cognitively-impaired, and (b) resident strain varied significantly between the Alzheimer's group and the other non-cognitive diagnoses groups, as well as between the dementia and the other non-cognitive diagnoses groups. Resident distress showed significant variance between all three diagnoses groups. The limitations of this study include the racial and gender homogeneity of our sample. Additionally because this research was conducted in the Midwest, it cannot be generalized to other areas of the U.S. Findings should be confirmed through further research in more diverse sample and in other geographic locations.

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Table 1 Demographic Characteristics of the Sample by Diagnostic Group

Characteristic	Diagnostic Groups			Total (N=1,282)
	Alzheimers (n=246)	Other Dementia (n=383)	Non-Cognitive (n=653)	
Family Caregiver	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)
Age	65.95 (10.25)	63.26 (11.20)	62.88 (10.75)	63.58 (10.85)
Involvement	3.55 (0.62)	3.54 (0.63)	3.56 (0.61)	3.55 (0.62)
	%	%	%	%
Gender (Female)	71.1	73.1	69.5	70.9
Race (Non- Hispanic White)	98.4	99.0	99.1	98.9
Employed	47.6	56.4	56.7	54.8
Religion (Protestant)	76.3	73.6	73.8	74.2
Resident	%	%	%	%
Age				
<65	0.8	0.5	1.9	1.3
65-74	3.3	4.0	9.0	6.4
75-84	30.5	28.0	27.4	28.2
>85	65.3	67.5	61.8	64.2
Gender (Female)	69.3	69.7	65.8	67.7
Race (Non-Hispanic White)	98.7	98.1	98.9	98.6
Religion (Protestant)	75.2	75.7	73.5	74.5
Place of Death (NH)	91.1	88.8	84.8	87.2

^aScale of 1-4; Higher score=more involvement

Table 2 Resident and Caregiver Stress and Strain by Diagnostic Groups

	Diagnostic Groups			ANOVA
	Alzheimer's	Other Dementia	Non-cognitive	<i>F Value</i>
	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	(<i>p</i>)
Caregiver Strain	5.26 (3.17)	5.58 (3.38)	5.52 (3.29)	.78 (.46)
Caregiver Distress	12.20 (8.70)	12.77 (9.24)	12.44 (8.97)	.29 (.75)
Resident Strain	4.85 ^a (2.01)	5.10 ^b (2.16)	5.52 ^{ab} (2.21)	10.08 (<.001)
Resident Distress	4.21 ^c (4.77)	5.54 ^c (6.05)	7.74 ^c (6.68)	34.16 (<.001)

^aAlzheimer was significantly different from other Non-cognitive diagnoses

^bOther dementia was significantly different from other Non-cognitive diagnoses

^cAll diagnostic groups were significantly different from each other

COMPLEMENTARY THERAPY/CARE TO RELIEVE PEDIATRIC CANCER-
THERAPY RELATED SYMPTOMS IN THAILAND

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Abstract

Patients undergoing treatment for cancer, whether it includes chemotherapy and/or radiation, experience many side effects that are linked to the treatment. The specific purposes of this study were to examine (a) what Thai parents report they do to help alleviate symptoms that the child experiences during cancer therapy; and (b) what categories of dependent care and/or complementary therapies were those methods reported. Orem's self-care/dependent-care concept was used to guide the analysis of the care pediatric patients received. Secondary analysis was done of data collected from a larger study at the National Children's Hospital in Thailand. The sample included children ages 5-17 years ($N=100$). Of the 100 patients, 71 were male and 29 female; while 75 patients were 5-11 years old, and 25 patients 12-17 years old. Cancer diagnoses can be divided into the following: 63% leukemia, 12% nervous system tumors, 10% solid tumors, 6% lymphoma, and 9% Other. The 34-item Therapy-Related Symptom Checklist for Children (TRSC-C) was used to record patients' symptom occurrence/severity (0, no symptom; 4, "A whole lot"); and the Symptom Alleviation: Self-Care Methods (SA:SCM) tool was used to identify methods parents used to alleviate chemotherapy-related symptoms. To address the study purposes, descriptive data and content analyses were done. Symptom occurrence of 16 symptoms were reported by 45% or more of patients; and mean severity "2", or "Quite a bit" of the top five reported symptoms included hair loss, nausea, vomiting, fever, loss of appetite. Of the six categories of self/dependent-care methods/complementary therapies, all were found useful; and, Diet/nutrition/life-style and Mind/Body Control were the most utilized. Assessing patient/parent-reported symptoms and use of self/dependent care and complementary therapies help Thai families cope during pediatric cancer treatments.

Introduction

Being diagnosed with cancer can be extremely devastating to a patient and their loved ones. Not only does cancer affect the patient physically, but it also affects all aspects of their life psychologically, emotionally, and spiritually. The diagnosis of cancer in a pediatric patient can be even more devastating. The incidence of pediatric cancer is more common than expected. Statistics show that one in 330 individuals younger than 20 will be diagnosed with cancer yearly (Berg et al., 2009). Although treatment can be effective, cancer still takes many lives. According to the American Cancer Society [ACS], cancer is the leading cause of disease related death in children (2010). The cancer patient will undergo long, extensive treatments to try and put their case into remission. Treatment advances have allowed 80% of pediatric patients diagnosed with cancer to live five

years or more compared to less than 50% in the 1970s (ACS, 2010). Pediatric cancer treatment may include chemotherapy, surgery, and/or radiation. Even though treatment is beneficial, many pediatric patients experience side effects as a direct result of their treatment according to the ACS (2010). The ACS also claims that treatment-related “late effects” may not appear until months or even years later. The side effects have a lasting impact on the quality of life of these patients, and it may be difficult to manage these symptoms in children (Baggott et al., 2004). But without knowing the specific symptoms children are experiencing, knowledge and resources cannot be directed to help overcome these side effects. An assessment of patient and parent self-reports of symptoms during treatment cycles allows care providers to effectively manage the side effects that may impair their therapy (Williams et al., 2006a,b; 2008; 2010; In press).

Conceptual Framework

This study uses Orem’s Self-Care Theory to guide the data collection and analysis. Orem defines self-care as the “voluntary regulation of human functioning and development that is necessary for individuals to maintain life, health, and well-being” (95). As children cannot always care for themselves as they grow up, the parents/caregivers help care for the children and monitor the children’s self-care needs which Orem refers to as dependent care (Williams et al., 2006a; 2010; In press). As children with cancer experience side effects of cancer treatment, parents/caregivers can implement dependent care strategies for their children. The term complementary therapy is commonly used in this study to identify methods parents/caregivers take to alleviate the symptoms. Complementary care and therapies are “care modalities or self-care used as adjuncts to mainstream medical care such as chemotherapy, as provided in a cancer clinic.” Various methods are used and these have been classified into categories by Williams et al. and co-investigators (2006; 2010, p.38; Piamjariyakul et al., 2010). Complementary care and therapies have also been referred to as “integrative therapies” (Wesa et al., 2008).

Purposes

The specific purposes of this study were to examine (a) what Thai parents report they do to help alleviate symptoms that the child experiences during cancer therapy; and (b) what categories of dependent care and/or complementary therapies were those methods reported.

Literature Review

A computer-based search was completed with the databases CINAHL and PubMed to locate research from the past 15 years that has been done on cancer treatment in children, and the side effects experienced as a result of treatment. The research reports were analyzed to determine

symptoms that patients exhibited and what, if any, methods were used to alleviate these symptoms. The focus was directed towards dependent care methods utilized by the parents of cancer patients.

Symptom prevalence and type were measured during a year-long period by Collins et al. (2000) to determine what pediatric patients were experiencing. The study involved 159 children between the ages of 10-18 who had a current or prior diagnosis of cancer. Symptom occurrence was verified by a 30-item instrument used to measure the prevalence, severity, and distress of symptoms. Of the 30 symptoms, patients experienced an average of 12.7 various symptoms. Pain was the most prevalent symptom patients suffered from with an 84.4% occurrence. Overall, the most common symptoms, which were reported by more than 35% of participants, were lack of energy, pain, drowsiness, nausea, cough, lack of appetite, and psychological symptoms including sadness, worry, and irritability. Symptoms that led to the greatest distress in patients included difficulty swallowing, insomnia, mouth sores, hair loss, skin changes, and vomiting. The study concluded that children ages 10-18 are capable of self-reporting their symptoms and that the usage of validated tools can help determine the quality of life in children who are ill.

Symptom monitoring of 11 children ages 2-18 years with cancer who were inpatients at a Midwestern medical center was explored by Williams et al. (2006a). The study utilized the Therapy-Related Symptom Checklist (TRSC) adult version (Williams et al., 1997; 2001) to measure symptom occurrence and severity based on report from the parent and/or caregiver. Data indicated the most common symptoms experienced included fatigue, nausea, eating, fever, pain, and hair loss. Another tool was used to determine what dependent care methods were used to alleviate the symptoms, and if the methods were effective. Some examples of dependent care strategies utilized were distraction, massage, nose sprays, mouth rinses, and vitamins. Dependent care strategies were found to be beneficial to alleviate symptoms. Furthermore, the methods used to alleviate symptoms can be sorted into two categories: diet/nutrition/lifestyle modifications and mind/body control. The study showed a wide range of symptoms manifested in children with cancer, and many methods, either general or symptom-specific ones, that were used to alleviate these symptoms.

Level of activity in patients undergoing chemotherapy, radiation, and/or surgery may be decreased due to treatment. Between 2005 and 2007, Winter et al. (2009) studied the activity level of 80 patients, ages 5-18 years during cancer treatment, as compared to 45 healthy controls. Level of activity was measured using a Step Activity Monitor that patients were instructed to wear for seven days during hours when they were awake. They found that the patients were significantly less active and participated in short bouts of activity rather than sustained or continuous activity over a long period or distance. Physiological factors were found to contribute to the lack of activity

including nausea and general fatigue, and a low self-confidence in one's capability. They concluded that although rest and recovery are important aspects of cancer treatment, it is also important to adapt interventions to each patient's needs and activity levels during and after treatment.

Despite cancer treatment's effects on patients currently undergoing therapy, patients also experience effects from treatment in the future. Berg et al. (2009) studied 25 patients between the ages of 10-17 who had cancer treatment at least two years prior. It was determined that pain and fatigue led to many activity restrictions in children who survived cancer. Performance restrictions were found such as impaired ability to lift heavy objects, climb stairs, walk one block, and perform self-care activities. Of the 25 patients, 92% ($N=23$) reported lower extremity symptoms, cognitive deficits, fatigue, and psychosocial issues. Lower extremity symptoms involved pain and numbness; cognitive deficits involved memory or attention problems; fatigue led to decreased activity tolerance; and psychosocial issues involved depression and fights with peers. The data clarified that the participants experienced symptoms that affected their participation in everyday activities which may impair their ability to experience proper development. Self-management was found to be beneficial and contributed to increased engagement in self-care, participation in chores, and increased mobility. The results confirmed that self-management may enhance the ability of patients to adapt and accommodate the future effects of treatment in order to maintain activity in their day to day lives.

Rheingans (2008) focused on the most distressing symptoms reported by pediatric patients. The study was conducted using surveys from 509 pediatric hematology/oncology nurses across the United States. The survey was based on the most distressing symptoms that pediatric oncology patients experienced according to the literature. It was used to assess nurses' views on patient symptoms experienced and distress due to these symptoms, and what interventions nurses used to treat patient symptoms. Pain was the most commonly reported symptom, and the least common was trouble sleeping. Nurses reported an average of 12.7 interventions that they used to treat each symptom. Interventions that were found helpful included art therapy, deep breathing, distraction, humor, imagery, massage, music therapy, and acupuncture. The most useful nursing intervention was emotional support for both the patient and family. This study emphasizes taking a holistic approach to effectively manage patient symptoms, including pharmacologic and non-pharmacologic methods. Rheingans concluded the usage of nursing interventions found successful in evidence-based research provided the best patient care for symptom management, in addition to pharmacologic interventions.

In summary, the literature includes many studies that have been done to analyze the multitude of symptoms experienced by children with cancer in response to treatments. It can also be said that many studies have looked at how quality of life is affected by these effects and determined nursing interventions are beneficial in addition to pharmacologic methods to relieve symptoms. The aim of this study will further analyze symptoms experienced during cancer treatment and what self-care and dependent-care methods have been used by parents/caregivers, and deemed successful to alleviate symptoms.

Methods

Design

This study is a secondary analysis of data collected for a larger study done in Thailand by this student's faculty mentors. IRB approval was obtained initially at the University of Kansas Medical Center, and then also at the study setting, the Queen Sirikit National Children's Hospital located in Bangkok, Thailand. To participate in the honors practicum this student also had to obtain KUMC-IRB approval as well as a Conflict of Interest clearance.

Subjects were included in the larger study if they: (a) had a diagnosis of cancer; (b) received two or more rounds of treatment; (c) were under 18 years of age; and (d) parent consent was obtained. The sample included children ages 5-17 years ($N=100$). Of the 100 patients, 71 were male and 29 female; while 75 patients were 5-11 years old, and 25 patients 12-17 years old. Cancer diagnoses can be divided into the following: 63% leukemia, 12% nervous system tumors, 10% solid tumors, 6% lymphoma, and 9% Other.

Instruments

The Therapy-Related Symptom Checklist-Child (TRSC-C), a patient/parent self-report tool, was used to gather information on symptom occurrence and severity experienced during cancer treatment (Williams et al. 2008; 2010; In press). The TRSC-C was used to measure symptom severity on a 5-point scale, "0" (no symptom), "1" (a bit), "2" (quite a bit), "3" (a lot), and "4" (a whole lot). Higher scores on the checklist indicate the symptoms were more severe. The checklist includes "kid-friendly" terms to help the child (and parent) understand the symptoms. The TRSC-C has 34 symptoms that have been identified by clinical experts and the literature. There was space at the bottom of the checklist also for parents and/or patients to add additional symptoms. Since the tool was used in Thailand, the Thai version was developed using Miller's (2001) translation and back-translation methods. A Cronbach's alpha coefficient of .90, and good construct validity have been reported on the TRSC-C (Williams et al., 2008; 2010).

The Symptom Alleviation: Self-Care Methods (SA:SCM) was another tool used in this study. The parent and/or caregiver were able to report what methods were used to control symptoms reported on the TRSC-C. Furthermore, the tool allowed the parents/caregivers to determine if the method was useful or not to alleviate the symptoms. Also it measured how often on a scale of 0 (not done) to 4 (done very often) the methods or strategies were used.

Parents also completed the demographic form. The nurse data collector completed the Health Form that included diagnosis, treatments, and other health data based on the medical record.

Data Analysis

To address Purpose 1, the dependent care and self-care methods on the SA:SCM that were used to alleviate symptoms reported on the TRSC-C were analyzed descriptively. That is, the symptom alleviation methods used for each symptom reported were tallied and percentages were obtained. To address Purpose 2, the six categories of complementary care methods (Williams et al., 2006a,b) were used: Diet/nutrition/life-style changes; mind/body control; biologic treatment; herbal treatment; taking prescribed medications; and other methods (Williams et al., 2006a,b; 2010a). Content analysis was done of the responses (Polit & Beck, 2008) before the classifications into categories were done.

Results

Sample Characteristics

Parents of 100 children with cancer who were 17 years old or younger were included in the sample. Of the 100 children, 71 were males and 29 were females. Seventy-five children were below 11 years old while 25 were between 12-17 years old. Table 1 shows the breakdown of diagnoses. Sixty-three children and adolescents had diagnoses of leukemia; 12 had diagnoses of nervous system tumors; 10 had diagnoses of solid tumors, such as Wilm's tumor or rhabdomyosarcoma; 6 had diagnoses of lymphoma such as Hodgkin's; and 9 had other diagnoses including cancer of the liver, ovary, kidney, and retinoblastoma. Ninety-five percent of the respondents identify themselves with the Buddhist religion.

Symptoms and Dependent Care Strategies Reported

In a separate report (Piamjariyakul et al. 2010), the occurrence and severity of symptoms reported on the TRSC-C are shown (Table 2). The table shows the 34 items into the seven TRSC-C subscales or clusters developed by Williams et al. (2010; In press). Overall, in terms of symptom occurrence, 45% or more of the sample reported 16 symptoms [hair loss (95%), nausea (79%),

vomiting (75%), fever (71%), loss of appetite (65%), weight loss (64%), irritable (63%), cough (61%), sore mouth (59%), pain (53%), sweating (52%), feeling sluggish (49%), depression (49%), afraid (49%), constipation (47%), and headache(46%)). In terms of symptom severity, it is noted that the calculations included “0”, which means that mean severity was actually one point higher, if only those reporting the symptom were calculated. Nine symptoms with mean severity above “1” were loss of appetite, nausea, vomiting, weight loss, hair loss, irritable, fever, and sweating.

Table 3 presents the six categories of dependent-care methods and complementary therapies that the parents/caregivers reported they used to help alleviate each of the 34 symptoms listed on the TRSC-C. The six categories include: Diet/nutrition/life-style changes; mind/body control; biologic treatment; herbal treatment; taking prescribed medications; and other methods. Also the option of “Do Nothing” was reported for some symptoms as the parent/caregiver did nothing in response to the symptom. Of the six categories of dependent-care methods and complementary therapies, all were found useful. The two most common categories were diet/nutrition/life-style changes and mind/body control.

Diet/nutrition/life-style changes included adding flavoring to food items, changing the variety of foods, providing small frequent meals, and offering soft or liquid diets. Mind/body control involved massage, sponge baths, providing words of encouragement, allowing more periods of rest, and varying activities. Biologic treatment included use of vitamins while herbal treatment relied on such things as ginger ointment, “violet flower”, and coconut oil. Other methods reported by some parents/caregivers include following up with the doctor and providing mouth care. Prescribed medications were also used to alleviate symptoms including anti-emetics for nausea, Xylocaine for sore mouth, inhaler for shortness of breath, Paracetamol for fever and pain, and laxatives for constipation.

Discussion

This study suggests that children with cancer experience many symptoms as a result of cancer treatment. The TRSC-C was effectively used for parents/caregivers to report symptoms their child experienced. The parents and caregivers were also able to use the SA: SCM to identify dependent-care methods and complementary therapies used to alleviate symptoms. The five most reported symptoms were hair loss, nausea, vomiting, fever, and loss of appetite. Nausea was the most reported symptom in all children (79%) after hair loss (95%). An adult study confirmed the most frequent symptoms reported included hair loss, fever, nausea, vomiting, numbness of fingers and toes, fatigue, and difficulty sleeping (William et al., 2000). In comparison, the most frequent five symptoms were confirmed in children.

A survey of nurses done by Rheingans (2008) indicated nurses' interventions were effective to manage symptoms. The nurses reported pain most frequently followed by difficulty sleeping. The nurses found interventions useful including emotional support, play therapy, relaxation, and education for parents regarding therapies. In comparison, other methods besides pharmacological interventions were found effective to overcome symptoms as in this study.

Parents and caregivers used a variety of methods to alleviate the symptoms children exhibited. Dependent-care strategies and complementary therapies were extremely helpful to manage symptoms. Diet/nutrition/life-style changes and mind/body control were the two most effective categories. A study done on Thai adult cancer patients indicated useful self-care methods including food flavoring to enhance taste, massage, mouth rinses for sore mouth, and medicines that were prescribed to control pain, nausea, and difficulty sleeping (Piamjariyakul et al., 2010). These methods were also used by the parents/caregivers to relieve symptoms in their children.

Parents and caregivers have found many additional dependent-care strategies and complementary therapies to combat the secondary effects of treatment. In this study the parents resorted to methods such as adding flavor to foods, massage, and play. A study on pediatric cancer patients determined methods used to alleviate symptoms, and indicated many care strategies were effectively used such as distraction, massage, mouth rinses, and rest periods (Williams et al., 2006). In summary, there are many similarities in reliable dependent-care strategies and complementary therapies that can be used to overcome secondary effects of cancer treatment.

Implications for Nursing

Children experience a variety of symptoms during cancer treatment. These symptoms may greatly influence the child's quality of life, which is also dependent upon preventive or reactive methods patients and/or their parents take in response to the symptoms (Baggott et al., 2004). Even though pharmacologic methods have commonly been used to manage symptoms, nurses have found interventions to be useful in alleviating these symptoms as well (Rheingans et al., 2008). Rheingans found pediatric cancer patients were able to manage their symptoms better when nurses encouraged family involvement and provided education to manage symptoms. Other advanced practice nurses using the Stetler model of evidence-based practice (Polit & Beck, 2008) have used a symptom checklist as basis for patient education and symptom management of oncology patients as well (Williams et al., 2011). Pediatric oncology nurses need to be knowledgeable and well-educated in order to assist family members to cope with the diagnosis of cancer and the side effects of therapy (Williams et al., 2006; 2010b; In press).

In conclusion, it cannot be ignored that assessing patient and parent-reported symptoms is extremely important to identify what symptoms children experience secondary to cancer treatment. The TRSC-C can be used to help monitor symptoms. In addition, the SA:SCM will allow parents/caregivers to report what dependent-care methods and complementary therapies have been useful. The combination of pharmacologic and non-pharmacologic methods provides the best, well-rounded care for the cancer patient. The usage of dependent-care and complementary therapies may help Thai families cope during pediatric cancer treatment.

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THERAPY-RELATED SYMPTOM CHECKLIST-CHILDREN (TRSC-C)

Name: _____ ID # _____ Date: _____
 Age: _____ Gender: Male _____ Female _____

PLEASE **IDENTIFY** below THE PROBLEMS YOU HAVE HAD **IMMEDIATELY**
AFTER AND SINCE YOUR LAST TREATMENT. PLEASE CIRCLE HOW SEVERE
THE PROBLEM WAS ACCORDING TO THE FOLLOWING SCALE:

0=NO SYMPTOM 1 = A LITTLE BIT 2 = QUITE A BIT 3 = A LOT 4 = A WHOLE LOT

EXAMPLE	CIRCLE HOW SEVERE				
	0	1	2	3	4
Pain	0	1	2	3	4
Loss of Appetite [Not feeling hungry; Eat less; Not feel like eating]	0	1	2	3	4
Nausea [Feel like throwing up; Upset stomach; Stomach hurts]	0	1	2	3	4
Vomiting [Throwing up]	0	1	2	3	4
Weight Loss [Losing weight; Feel skinnier]	0	1	2	3	4
Sore Mouth [Mouth hurts; Hurts to eat]	0	1	2	3	4
Difficulty Swallowing [Hard to swallow; Hurts to swallow]	0	1	2	3	4
Sore Throat [Throat hurts]	0	1	2	3	4
Jaw Pain [Jaw hurts; Hurts to chew or yawn]	0	1	2	3	4
Cough [Coughing much]	0	1	2	3	4
Shortness of Breath [Hard to breath; Breathe fast]	0	1	2	3	4
Feeling Sluggish [Feel very tired; Feel lazy]	0	1	2	3	4
Depression [Feel sad a lot; Cry more]	0	1	2	3	4
Difficulty Concentrating [Hard to think; Hard to pay attention]	0	1	2	3	4
Difficulty Sleeping [Hard to go to sleep; Hard to stay asleep]	0	1	2	3	4
Fever [Feel very hot; High temperature]	0	1	2	3	4
Bruising [Dark spots on skin; Bruise easily]	0	1	2	3	4
Bleeding [Bloody nose; Bleeding from cuts, scratches, or when brushing teeth]	0	1	2	3	4
Hair Loss [Hair falling out; Losing hair]	0	1	2	3	4
Skin Changes [Skin feels dry or red; Skin feels different]	0	1	2	3	4
Pain [It hurts]	0	1	2	3	4
Numbness in Fingers and Toes [Tingling fingers/ toes; fingers/ toes "falling asleep"; Fingers/ toes feel cold]	0	1	2	3	4
Constipation [Hard to "poop"]	0	1	2	3	4
Sweating	0	1	2	3	4
Itching [Want to scratch skin]	0	1	2	3	4
Hard to urinate [Hard to "pee"]	0	1	2	3	4
Afraid [Feel nervous; worried]	0	1	2	3	4
Headache [Head hurts]	0	1	2	3	4
Irritable [Feel upset easily; get mad easily]	0	1	2	3	4
Agitation [Feel restless; can not stay still]	0	1	2	3	4
Tripping or Falling	0	1	2	3	4
Other (List)	0	1	2	3	4
Other (List)	0	1	2	3	4
Other (List)	0	1	2	3	4

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Table 1 Distribution of Diagnosis

Diagnosis	Frequency	Percent	Cumulative
Leukemias			
Acute Leukemia	1	1	1
ALL	58	58	59
Leukemia	2	2	61
ANLL	2	2	63
Lymphomas			
Hodgkin Disease HD	1	1	64
Hodgkin Lymphoma Stage 3	1	1	65
NHL	2	2	67
T-Cell Lymphoma	1	1	68
HLH-EBV	1	1	69
Nervous System Tumors			
Neuroblastoma	10	10	79
Ganglioneuroblastoma	1	1	80
PNET	1	1	81
Solid Tumors			
Wilm's Tumor	1	1	82
Rhabdomyosarcoma	4	4	86
Germ Cell Tumor	3	3	89
Endodermal Sinus Tumor	1	1	90
Mixed Germ Cell Tumor	1	1	91
Others			
Ca Liver	1	1	92
Ca Ovary	2	2	94
Immature Teratoma Rt Ovary	1	1	95
Retinoblastoma	3	3	98
Sarcoma Rt Kidney	1	1	99

Table 2 Distribution of Symptoms and Severity (N=100). Source: Piamjariyakul et al. (2010)

Distribution of Severity Scores (%)	0	1	2	3	4	Mean(SD)	% Occurrence
1. N/V, Eating, Fatigue-Other							
Loss of Appetite	35	24	25	13	3	1.25 (1.158)	65
Nausea	21	38	31	7	3	1.33 (0.985)	79
Vomiting	25	36	29	7	3	1.27 (1.014)	75
Weight Loss	36	35	21	5	3	1.04 (1.024)	64
Feeling Sluggish	51	24	19	6	0	0.80 (0.953)	49
Hair Loss	5	11	26	38	20	2.57 (1.085)	95
2. Behavior, Cognition-Other							
Depression	51	23	21	3	2	0.82 (0.999)	49
Difficulty Concentrating	78	9	9	3	1	0.40 (0.853)	22
Pain	47	25	19	8	1	0.91 (1.036)	53
Irritable	37	20	25	12	6	1.30 (1.251)	63
Agitation	77	7	9	4	3	0.49 (1.020)	23
Headache	54	19	20	6	1	0.81 (1.022)	46
Afraid	51	20	21	5	3	0.89 (1.091)	49
3. Oropharynx							
Sore Mouth	41	33	21	3	2	0.92 (0.961)	59
Difficulty Swallowing	70	19	7	4	0	0.45 (0.796)	30
Sore Throat	65	24	5	6	0	0.52 (0.847)	35
4. Fever, Neuropathy, Motor							
Fever	29	29	32	8	2	1.25 (1.029)	71
Bruising	65	17	14	4	0	0.57 (0.891)	35
Bleeding	68	20	9	2	1	0.48 (0.822)	32
Numbness of Fingers/Toes	67	22	7	4	0	0.85 (1.095)	33
Tripping/Falling	63	21	10	6	0	0.59 (0.90)	37
5. Skin, Other							
Skin Changes	57	23	13	5	2	0.72 (1.006)	43
Itching	58	20	18	3	1	0.69 (0.94)	42
Sweating	48	15	22	11	4	1.08 (1.228)	52
Cough	39	39	16	5	1	0.90 (0.916)	61
6. GI, GU-Other							
Jaw pain	92	4	4	0	0	0.12 (0.433)	8
Constipation	53	22	14	9	2	0.85 (1.095)	47
Hard to urinate	87	9	3	1	0	0.18 (0.52)	13
7. Shortness of Breath, Other							
Shortness of Breath	64	18	14	4	0	0.58 (0.878)	36
Difficulty Sleeping	64	20	12	3	1	0.57 (0.891)	36

TRSC scale : severity 0-4 : "0", None; "1", A bit; "2", Quite a bit; "3", A lot; "4", A whole lot;
 % Occurrence : % report of presence of symptom

Table 3 Symptoms Reported and Self-Care Methods Used

Symptoms Reported	A	B	C	D	E	F	G
1. Taste Change	20	4	0	0	0	1	8
2. Loss of Appetite	50	4	3	0	1	0	3
3. Nausea	27	6	1	1	2	31	6
4. Vomiting	19	7	0	0	3	39	7
5. Weight Loss	35	0	3	0	2	1	16
6. Sore Mouth	10	0	0	0	13	37	4
7. Difficulty Swallowing	19	0	0	0	5	1	3
8. Sore Throat	16	1	0	0	9	1	6
9. Jaw Pain	4	0	0	0	0	1	6
10. Cough	23	1	0	0	4	40	4
11. Shortness of Breath	0	16	0	0	9	4	5
12. Feeling Sluggish	0	32	0	0	0	2	12
13. Depression	0	42	0	0	0	0	3
14. Difficulty Concentrating	0	14	0	0	0	0	6
15. Difficulty Sleeping	0	24	0	0	0	0	9
16. Fever	0	51	0	0	14	60	0
17. Bruising	0	10	0	0	3	12	7
18. Bleeding	0	20	0	0	5	8	2
19. Hair Loss	0	38	0	1	0	1	40
20. Skin Changes	1	23	0	1	1	4	11
21. Pain	0	19	0	0	3	12	7
22. Numbness in Fingers and Toes	0	23	0	0	0	1	7
23. Constipation	35	0	0	0	0	14	3
24. Dizzy	2	0	0	0	0	12	2
25. Diarrhea	3	0	1	0	5	24	5
26. Sweating	0	36	0	0	0	0	5
27. Itching	0	10	0	0	0	25	5
28. Hard to Urinate	6	1	0	0	1	0	2
29. Afraid	0	40	0	0	0	0	1
30. Dry Mouth	30	1	0	0	29	2	3
31. Headache	0	9	0	0	1	22	3
32. Irritable	0	48	0	0	0	0	3
33. Agitation	0	5	0	0	0	0	5
34. Tripping or Falling	0	14	0	0	1	1	5
35. Other	0	2	0	0	2	0	0

Self-care methods, by complementary care categories : A. Diet/Nutrition/life-style; B. Mind/Body Control; C. Biological Treatment; D. Herbs; E. Other; F. Prescribed Medicine; G. Do Nothing

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