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Exploration of Health Care Needs Among Sudanese Refugee Women

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Abstract

Many Sudanese refugees that have resettled in the United States have experienced severe trauma and loss during their migration, as well as physical, social, and psychological struggles in their continued adaptation to living in a new country. This study explored the healthcare needs of Sudanese women as they transition to living in the United States. Community-Based Collaborative Action Research (CBCAR) provided a framework for the study.

Qualitative descriptive design using focus groups was utilized to explore the healthcare needs of Sudanese Women. Eighteen women participated in the study, which consisted of five educational sessions that were immediately followed by five audio-taped focus groups. The educational seminars presented topics such as parenting skills, preventative health practices, childhood illnesses, and emotional well-being. Focus groups allowed for a confidential setting in which women were able to reflect on the information presented, as well as verbalize topics that they would like to receive more education on in the future.

Three themes were identified that reflected experience of Sudanese women. These included being pulled between two worldviews in ways of parenting and communicating with children, multiple difficulties maneuvering within the US health care system, and internal struggles in meeting emotional needs in their transition to living in the United States. This study may contribute to the empowerment of Sudanese women by providing them with a greater understanding and ability to maneuver within the US healthcare system. This partnering interchange may also increase nursing knowledge in offering culturally competent care to the Sudanese community and other refugee populations that have resettled in the United States.

Introduction

Due to a civil war between northern and southern Sudan from 1983-2005, millions of Sudanese have been forced to leave their homes and find refuge in nearby countries as they apply for refugee status. During their migration to countries such as Ethiopia, Kenya, and Uganda, the Sudanese are faced with devastating struggles such as starvation and sickness. Because of this, most resettled Sudanese refugees have experienced severe trauma and loss, as well as physical, social, and psychological struggles in their continued adaptation to living in a new country (Schweitzer, Greenslade & Kagee, 2007).

Purpose and Problem

The purpose of this study was to explore the health and illness concerns of Sudanese refugee women as they transition to living in the United States. Identifying specific health issues within this population will allow nurses and healthcare staff to provide more holistic care for the Sudanese, as well as educate health professionals in becoming more culturally competent for Sudanese refugee communities.

Research Questions

Our study was guided by 3 primary research questions. These questions were as follows: 1) What are the Sudanese refugee women's major health concerns for themselves and their family? 2) What are the barriers that Sudanese refugee women face in obtaining healthcare for themselves and their family? 3) What are Sudanese refugee women's perceptions of the interactions with healthcare providers and their ability to meet their healthcare needs?

Literature Review

History and Background of Sudanese Refugees

According to section 101(a) (42) of the Immigration and Nationality Act (INA), a refugee is "a person who is unable or unwilling to return to his or her country of nationality because of persecution or a well-founded fear of persecution on account of race, religion, nationality, membership in a particular social group, or political opinion" (United States Citizenship and Immigration Services, 2010, p.1). Within the past decade, there has been a great increase in the number of refugees and displaced persons around the world. In 2008 statistics, there were "approximately 14 million refugees, and an additional 23.6 million people [were] internally displaced" (Khawaja, White, Schweitzer & Greenslade, 2008, p. 489). Majority of these immigrants are fleeing situations that involve warfare and famine in which significant trauma is experienced (Khawaja et al., 2008). According to statistics from the United Nations High Commissioner for Refugees (UNHCR), refugees are scattered throughout the world, with more than 50% from Asia and 20% from Africa. Before resettlement, refugees live in widely varying conditions, ranging from well-established camps to makeshift shelters or living in the open. Since the early 1990s over 20,000 Sudanese, most from southern Sudan, have resettled to the US, with nearly 2,500 of them resettled in the KC metropolitan area (United Nations High Commissioner for Refugees, 2010).

Covering more than one million square miles, Sudan is the largest country in Africa. According to Kemp and Rasbridge's article (2001), the suffering is "large scale, with political and religious oppression, famine, flood, locusts, and warfare endemic" (p. 110). In Sudan, the country is essentially split between two religions: the Muslim north and the Christian south. When violence erupted between these opposing sides of the country in 1983, a civil war began that has taken over two million Sudanese lives within the past two decades. Due to war and drought, food shortages have occurred in the south leading to famines that add to the disparity of the country.

According to Schweitzer, Greenslade and Kagee (2007), nearly 5.5 million refugees have been forced to flee their homes and have either become internally displaced persons (IDP's) within the country's borders or are living in refugee camps in nearby states. Most refugees fled to neighboring states, such as Egypt, Kenya, Uganda and the Democratic Republic of Congo. After fleeing their homeland, many refugees will permanently reside in a new area within their nation, while others will apply for refugee status and be resettled in a new country. The most common countries for resettlement are Canada, United States, and Australia (Dormitorio, Sachs, Ali & Omar, 2008). During migration, the "majority of refugees reported being separated from their families, experiencing violence, witnessing murder of family or friends and being deprived of basic needs" (Schweitzer et al., 2006, p. 184).

Sudanese Cultural Values and Health Beliefs

Culture in Sudan varies greatly within each region of the country. Regarding language, the Sudanese people are diverse with each tribe having its own language and often several dialects within that language (Kemp & Rasbridge, 2001). English was the official language in Sudan until they gained independence in 1956 and it was replaced with Arabic by the northern Khartoum government (Kemp & Rasbridge, 2001). The written languages are *Dinka* and *Nuer*, but these tribal languages can only be read by those who have been through adequate schooling. Literacy rates are low among the Sudanese, and have dropped even lower during the civil war since schooling has been disrupted by warfare.

Health beliefs within the Sudanese culture are quite different between the northern Muslim and southern Christian areas of the country. For example, "almost 90% of women from northern Sudan have had genital cutting performed", whereas this practice is not as common among the Christians in southern Sudan (Kemp & Rasbridge, 2001, p. 111). The Sudanese have many alternative medical practices that are used as remedies for common sicknesses. For example, a widely used cure for migraine headaches is a chalky compound…that is rubbed over the head (Kemp & Rasbridge, 2001). Kemp's (2001) article provided multiple illustrations of the Sudanese people's remedies for a variety of illnesses, and it also states that, "even highly educated southern Sudanese may view this treatment as more effective than Western medications" (p. 112). As a result of chronic shortages of health care and medication in their homeland, it is not uncommon for

Sudanese to share over-the-counter medications and prescription drugs with one another if symptoms are similar (Kemp & Rasbridge, 2001).

A frequent finding in southern Sudan is the strong belief of the interconnectedness between health, cultural practices and spirituality. For example, "failure by a husband to meet the bridewealth obligation is believed to result in a family curse that may cause abortion or death of children in a marriage" (Onyango & Mott, 2011, p. 376). In Sudan, payment of bridewealth from the husband to the woman's relatives is a symbolic binding of the commitment between families that play a significant role in the normal functioning of the Sudanese social structures within the society (Onyango & Mott, 2011). Interestingly, southern Sudan has "one of the highest maternal mortality ratios in the world, estimated at 2,054 per 100,000 live births" (Onyango & Mott, 2011, p. 376). This is most likely due to abortion complications and failure of the woman to access appropriate healthcare during pregnancy and childbirth.

In southern Sudan, a woman is considered the property of her husband once she is married. Sudanese women are not allowed to make important decisions in the family because all authority belongs to the males, the women essentially have "no rights or voice in South Sudan" (Onyango & Mott, 2011, p. 382). Although the culture does not support physical abuse because of the woman's reproductive importance, a "husband can beat his wife if he discerns she is not listening to him" (Onyango & Mott, 2011, p. 382), illustrating that women have value more as a commodity rather than a person.

Because of the poor living conditions, the Sudanese people in Sudan typically do not receive any healthcare assistance unless they are severely ill, and even then, most will use traditional healers in an attempt to cure themselves. This type of healer will use herbs, cutting to release "bad blood", and sacrificing of animals to expel evil spirits in the home (G. Tanui, personal communication, February 2, 2012).

Sudanese Transitioning to Living in the United States

In her work with refugees at Jewish Vocational Services (JVS) in Kansas City, Gladys Tanui, BSN, provided some insight into the process of transitioning refugees from their homeland to the United States. "There is no specific time line between fleeing from their country to being resettled in a new country; some refugees have been in camps for several years, some even decades, before they are resettled. They have to apply with the UNHCR (The UN Refugee Agency) through their offices in the host countries, and this process may take several years to complete due to the large number of applications" (G. Tanui, personal communication, February 2, 2012). For 2012, the

United States will only accept 72,000 refugees, leaving millions of refugees left to struggle in their host countries (G. Tanui, personal communication, February 2, 2012).

As a result of the difficult migration process, millions of Sudanese have experienced instability as they live without critical resources, such as food and health care, for as long as two decades (Willis & Nkwocha, 2006). As noted above, refugees from Sudan that are accepted for resettlement into the US are primarily from southern Sudan. These refugees are composed of various minority ethnic groups fleeing religious and political persecution, warfare, and starvation (Kemp & Rasbridge, 2001). Due to warfare and extreme poverty, nearly all Sudanese refugees had limited access to health education and treatment prior to resettlement in the United States (Willis & Nkwocha, 2006).

Sudanese fleeing their country undoubtedly faced incredible stress, as they have endured the loss of loved ones and situations of extreme violence or trauma. Such emotional traumatic experiences can “challenge their sense of empowerment, identity and meaning in life” (Schweitzer et al., 2006, p. 180). Experiencing such trauma does cause the refugee population to be more vulnerable for poor adjustment in their transition to a new country, especially when combined with psychological stress.

Although agencies do the best they can to help the transition process, refugees are generally faced with language and cultural barriers that make it difficult for them to assimilate into the American society. Also, a huge factor in a refugee’s resettlement process is the cultural transition to a Westernized fast-paced society driven by technology (Willis & Nkwocha, 2006).

In the United States, southern Sudanese are confronted with a myriad of new cultural traditions and options as they transition into the American culture (Kemp & Rasbridge, 2011), but findings suggest that Sudanese people tend to avoid high risk behaviors within their new country. The Willis and Nkwocha (2006) article identifies that “refugees from Sudan are not engaging high risk behaviors known to impact health” such as smoking cigarettes and/or drinking alcohol. Also, “refugees report consistent use of safety behaviors, for example, seat belt use in the car, [and] concern about diet in the United States” (p. 31). As far as coping during their transitional period, consistent methods have been identified as refugees use religion, social support, cognitive reframing, and thinking of the future as ways to deal with their current stressors in life (Khawaja, White, Schweitzer & Greenslade, 2008).

Sudanese Issues of Health and Illness Upon Resettlement

Refugees face many barriers in their attempt to access healthcare, along with a health workforce with a generally low awareness of issues specific to refugees (Murray & Skull, 2005). Murray and Skull (2005) addressed several "hurdles to health" that make it difficult for refugees in Australia to receive adequate health care in their new country of resettlement. These identified hurdles included: economics and unemployment, cultural difference, language difficulties, an under-trained workforce, legal barriers, and the impact of current policies.

An article by Willis and Nkwocha (2006) identifies that health has been neglected in Sudanese refugees living in the US stating, "Sudanese refugee patients in a Minnesota health clinic had to be treated for a number of pre-existing conditions" (p. 20). Willis and Nkwocha (2006) also notes that for Sudanese refugees living in Nebraska, "nearly 40% [of refugees] do not have health or dental insurance, 20% have never visited a dental or eye care professional, and 11% have never been to a doctor" (p. 19). Furthermore, preventative health measures are rarely used in the Sudanese population, as demonstrated by nearly half of the female respondents never having had a clinical breast exam or pap smear performed. Willis and Nkwocha (2006) believe that the lack of understanding of HIV and AIDS, along with participating in preventative healthcare is most likely not taken advantage of due to financial constraint and a lack of education.

Studies suggest (Schweitzer et al., 2007) that the Sudanese refugees have experienced traumatic events that "may lead to an increased risk of psychological distress" and have left this population prone to emotional distress, symptoms of post-traumatic stress, anxiety and depression (p. 283). Schweitzer's article (2007) goes on to note that despite the hardships refugees have faced, reports of resettled refugees demonstrate that this population is extremely resilient and have high expectations for the future.

Theoretical Framework

Our study utilized the Community-Based Collaborative Action Research (CBCAR) framework which includes the tenets of participation, knowledge attainment, empowerment, and social action to create a positive change in the community (Velde, Williamson & Ogilvie, 2009). This framework allows both parties to actively participate in the study that results in knowledge attainment for both the researcher and participants. In Pavlish and Pharris' book on CBCAR (2010), the assumptions of this research method are defined. The following is a condensed version of assumptions incorporated within this research study:

1. Communities have the best insight into their own situations, and change within a population can be both transformational and unpredictable

2. For nurses, social justice is a mandate to identify and address inequalities and threats to human rights, freedoms, and capabilities
3. The purpose of research is to address inequalities and promote human flourishing
4. Patterns of health are recognized as nurses partner with communities and study the interactions between people and their environment.
5. Dialogue centered on significance gives rise to unforeseen learning and action potential

Methods

Research Design

A qualitative descriptive design using focus groups was used to explore the healthcare needs of Sudanese Women. This research method allowed for a thematic summary of Sudanese refugee women's experiences of health and illness concerns as they transition to living in the United States (Sandelowski, 2000).

Sample and Setting

The participants of this study were twenty women between the ages of 20-67 that participated in educational sessions and focus groups. These women have been in the United States for 7-16 years, and speak Dinka, Arabic, English, or a combination of these languages. All of the women in the study originated from villages in southern Sudan and were forced out of their homeland because of religious and racial persecution. They left due to fear for their safety and the safety of their family members. Many witnessed the murdering of loved ones. All of the women in this study migrated with their children and family members across multiple international borders to reach a place of refuge where they started a new life in countries of protection and applied for refugee status.

All participants were invited to five educational sessions. The sessions covered preventative health practices, women's health throughout the lifespan, childhood illnesses, parenting, and women's emotional well-being. These sessions were held on Saturday mornings in a designated room that was located in their church (agreed upon location by participants and researchers) they attended for Sunday services. Focus groups followed these educational sessions to elicit the helpfulness of the educational topic presented and to identify further educational needs. Focus groups were conducted in the same room that was identified as a private area. Childcare was also provided in another space within the church setting. Lunch was provided between the educational sessions and focus groups. All participants of the educational session were invited to join the focus group and were assured that their participation in the focus group was completely voluntary.

Data Collection

Data for the study was collected by means of descriptive demographics used so that the sample could be described for the study. Data collection also included observation participation (observation throughout educational sessions and focus groups), field notes (taken throughout the study), five educational sessions (sessions addressed healthcare topics chosen by the women), and audio-taped focus groups consisting of 7 to 13 women (conducted immediately after educational sessions). Prior to each of the focus groups, review of the consent for any new group participants was completed. An refugee woman was used during all study activities to translate between Dinka, Arabic, and English. All focus groups were audio-taped and transcribed into English with back translation.

Data Analysis

Qualitative content analysis was conducted on all six transcribed focus groups. In inductive content analysis, meaning units, codes, categories, and overarching themes are developed from all focus groups (Elo & Kyngas, 2007). Graneheim and Lundman (2004) identify that the goal of this type of analysis seeks to recognize the underlying meanings of the text. After the initial reading of the transcriptions, hand coding was completed to identify meaning units, and primary and secondary codes. Codes were then grouped into categories. Categories were condenses to form a specific pattern of meaning. Overarching themes were then developed that incorporated field notes and observations. Throughout the analysis and interpretation, debriefing was done with student and instructor to support the accuracy of the analysis and interpretation of all data.

Credibility and Trustworthiness

Focus groups were transcribed in English with back translation to ensure credibility, along with peer debriefing with co-investigators and student research colleagues throughout data collection and analysis and interpretation. Personal engagement in the study consisted of attending educational sessions and focus groups with the women, as well as participating in Sudanese church services. Also, personal reflective journals were kept by all members of the research team to support the trustworthiness of the findings (Lincoln & Guba, 1985).

Human Subjects Protection

Proposal for this study received approval by the university Institutional Review Board, and a verbal consent was read at the beginning of each focus group, which also explained that participants were able to leave or withdraw at any point in the study. Participants were assured that their confidentiality was protected at all times. All identifying information was removed to conceal the identity of the women.

Findings

Preliminary findings included Sudanese women's desire for a greater understanding in accessing healthcare. The findings identified three overarching themes as Sudanese women struggle with their transition to the living in the United States. 1) The first theme identified Sudanese women's experiences of being pulled between two worldviews in ways of parenting and communicating with children. 2) Secondly, the women experienced multiple difficulties maneuvering within the United States health care system. 3) The third theme identified the internal struggles of Sudanese women experience in meeting their emotional needs in their transition to living in the United States.

Theme 1: Sudanese women experience of being pulled between two worldviews in ways of parenting and communicating with children

The first theme consisted of two major categories:

Category 1: Conflicting beliefs of appropriate ways of interacting within family and community

During the focus group with of STD education, several of the women stated that they were not comfortable talking to their daughters about sex and self-hygiene, and it was common practice for the mothers to have relatives discuss personal issues with their daughters. A mother in the study gives an example of calling a friend and saying, "okay you are my aide, my daughter is doing this, I don't know if she's sleeping with somebody and maybe something's happening, could you come and talk to her?" Issues of privacy or sexual relations are typically not discussed with parents in the Sudanese culture. As a result of not having extended family living in the US, daughters are not being educated about normal sexual development, receiving information on sexual health, and being supported in making important sexual decisions. Left to feel that her only option was for her daughter to obtain this information from the clinic, one participant shared, "…you can talk to your daughter and let her go to the doctor for what's going on for her. We don't use the other thing [mothers talking to daughters about sexual practices], in my country, you don't talk to your daughter about it".

Category 2: Difficulties in raising Sudanese children in US culture.

As a result of the educational session on parenting, the study found that raising children in the United States has proved to be difficult for both parents and children because they are being pulled between two very different worldviews. Furthermore, Sudanese children are often better adapted to US culture which makes it challenging for parents to be a role model for their children. One woman describes how language is more difficult for her than her children by saying, "We speak broken English and when we want to say something to the system, we don't get our point across. While the child is just like speaking like this." Women felt that this disconnect between cultures has caused them to become more lenient with their children and more likely to 'give in' since the culture in America is not what they are accustomed to. Not knowing what else to do, one woman shares her dilemma, "So it's not because we blaming it on America or anything, but it's a stucking [stuck] between cultures. And also we give up so quick, that's another thing. Yea, we give up really quick."

Social norms according to the Sudanese culture have also presented struggles in raising Sudanese children in America. For example, women stated that in Sudan, children were taught to not make eye contact as a sign of respect to authority, but in America, the lack of eye contact is seen as disrespectful. One Sudanese woman, who came to America as an adolescent, shared this continued conflict as she described her experience, "So, if I'm talking to American like I'm talking to you I figure out that I have to look you in the eye. But if I'm talking like, right now I'm talking to my mother, I have to talk differently."

Theme 2: Sudanese women experiencing multiple difficulties in maneuvering within the US healthcare system

The second theme consisted of two major categories:

Category 1: Sudanese perception of interactions with US healthcare providers and payment options.

Information from the women suggested that American health care providers are not spending enough time with Sudanese patients for them to understand the information they are given, as well as additional education not being readily available for their use. Also, women feel that they are expected to know more about health care then they actually do, and this is why visits to the clinic only result in confusion and a large medical bill that most Sudanese are unable to pay. One woman states,

> Like in America the patient visit is like for ten minutes for every patient, but Sudanese or somebody who maybe don't…it's like…we don't have patient education…we don't know about, you know,

> anything. So when they go they want to limit that in 15 minutes and we have much to talk about, sometimes hard. And especially when you have an interpreter to interpret everything is like…it's terrible because they don't want to go more than that, so it's one of the problems too.

In their experiences with healthcare providers, women feel that the providers are not aware of the Sudanese culture and health providers are not listening to their concerns. From a financial aspect, the study found that the fear of receiving large medical fees prevents many Sudanese people from seeking care, and that most Sudanese families do not have health insurance or Medicaid to cover medical bills. This concern is demonstrated by one participant stating, "…you can be sick and sometime you don't want to go because you maybe inside you have a big problem when you go to the hospital they don't give you medicine and you come back with a big bill. So I think it's something too to make people don't go to the doctor".

Category 2: Healthcare knowledge needs of Sudanese women.

Sudanese women have a genuine desire for a greater understanding in the appropriate use of medications and vaccines. One woman gave an example of how she stopped taking her blood pressure medication because she felt that she didn't need it, but then she had to be hospitalized as a result of dangerous symptoms related to her hypertension. The women also wanted further information on preventative health screens such as pap smears and mammograms, STD's, childhood illnesses, women's health throughout the lifespan, and an understanding of how infections are spread. In speaking about infection, a participant states, "Because our concept in my community whoever is infected is related to hygiene. You think you are not clean enough." The women in the focus group were committed to provide health related information to other Sudanese women in their community. This was illustrated by the women's request, to receive all educational information provided during the research project to take back to their community, to educate other women on these health topics.

Theme 3: Sudanese women's internal struggles in meeting emotional needs in their transition to living in the United States

The third theme consisted of two major categories:

Category 1: Sudanese perception of mental health and emotional coping.

In Sudan, there were few resources available regarding mental health, so Sudanese people typically turned to God and family for support and help. Our findings reflected this as one participant stated,

> When we grown up back home there is no hospital. If you have mental problem there is nowhere you going to go to attend the medical [health facility] anywhere of [for] medication. So the way that you handle it is to pray to God to help you…So I think for me I understand it that way because if we were in America and you have a mental [problem] you will go to the hospital and they will help…. Us the only way that we have to help each other is the family praying and all of that.

Although mental health facilities such as ambulatory health centers are available for refugees in US, most Sudanese prefer to use prayer as a form of healing, and depend on God for help with their emotions. A Sudanese woman reiterated this by saying, "If you pray and you call God you will be okay in your mind…We believe in God and God help us." Women stated that they use their faith to cope with stress and tragedy, and it is difficult for them to consider alternatives to help in this process.

Sudanese women do not see traumatic life experiences as something that requires additional assistance to support coping skills. As one participant stated, "There are some countries like if you are stressed or traumatized, you need help. Like [people] from different [countries] they said, 'oh my brother was killed in front of me and I cannot get this image out of, you know, my mind, I need help with this'. But Sudanese we don't see these as a problem." Women explained that the view of mental health in their culture is 'someone that is crazy', so this causes Sudanese people to not want to be associated with mental health issues. The women explained that "…we define it like craziness and then when we don't think we are crazy, we don't think it applies to us." One participant gave an example of how the stress of her husband's death led to her forgetting to put her clothes on before leaving the house. It was only after this occurred that she realized how overwhelmed she was. Another woman elaborates on the Sudanese perception of mental health by saying,

> We don't believe in mental problems or emotional problems. I would think like whoever just like have an emotional problem is crazy. We are women of pride. I'm proud, I don't want to just like appear

> depressed or I did this or I did this because people are going to make fun of me. We are very close, we are very tight…we are strong, we don't give up, we don't get stressed, we don't cry, we don't do this. So all the time when you have mental problem or emotional problem you feel guilty. You feel like you didn't handle it right. You didn't handle the Sudanese way or the Dinka way, that's some of the problem.

Category 2: Additional stressful issues related to transition.

As a result of their inability to pay large medical fees, many Sudanese feel as if they are still living in Africa since they are unable to receive needed medical treatment. A participant states, "Lot of Sudanese they are like that, we don't go to hospital, what we going to do? Lot of refugee women and men they are here like that. You don't have any treatment, you are like in Africa." Women discussed that the financial struggle in America is almost worse than it was in Sudan, and that the financial stress of raising a large family in the United States makes their transition even more difficult.

Discussion and Conclusion

The purpose of this paper was to explore the healthcare concerns of Sudanese refugee women as they transition to living in the United States. The study was led by three primary research questions. The first research question concerning Sudanese women's major health concerns was addressed primarily in the second theme that identified multiple difficulties that Sudanese face as they maneuver within the US healthcare system. Our second research question was to identify the barriers that refugee Sudanese women face in obtaining healthcare for themselves and their family. This question was addressed by themes two and three, which concentrated on the difficulties encountered in seeking healthcare within the US healthcare and the internal struggles Sudanese women experience in meeting their emotional needs. Perception of interactions with healthcare providers, the third research question, was again addressed by theme two and three. Another major finding of this study identified the conflicts that Sudanese women face in communicating with and parenting their children and the continued pull between two worldviews. Sudanese women also expressed the internal conflicts of remaining strong in the face of multiple traumas and stress while also needing to be supported and comforted by members of their community. The women also shared how Sudanese cultural beliefs of infertility or being divorced increases stress and isolation as a result of the negative judgment imparted by family and community members.

Many of the barriers that Sudanese women identified in this study are consistent with previous qualitative studies with refugee populations. In a study by Schweitzer, Melville, Steel, and Lacherez (2006), findings suggested that social support played a significant role in mental health outcomes for Sudanese refugees that had faced trauma during migration. This was a similar finding in our study in that Sudanese women spoke of the importance of being able to share and trust other women within their community to gain support and comfort. Another study by Schweitzer, Greenslade, and Kagee (2007) had similar findings as it identified three themes that predicted Sudanese refugee's ability to cope during pre-migration from Sudan and post-migration in their host country. The attributing characteristics were religious beliefs, social support, and personal qualities. Murray and Skull (2005) conducted a study in Australia that identified barriers refugees face as they seek health care in a new country. Findings from their study recognized cultural differences, language difficulties, a workforce not trained in refugee health, legal barriers, and issues of economics and employment as the primary obstacles refugees faced in accessing health care. The outcomes from Murray and Skull's (2005) findings were similar to the findings from our study with the Sudanese refugee population in the Kansas City metropolitan area.

The CBCAR framework was utilized in this study by assessing the Sudanese community, acquiring data from observations and focus groups, and presenting the findings to the community to implement social action. Booklets were created on all information presented during the healthcare sessions so that women could have resources to use when educating other Sudanese women within their community.

The limitations of this study included hearing the health and illness concerns of only eighteen Sudanese women living in the Midwestern US that attended the educational sessions and focus groups. The women spoke of other healthcare information they desired but because of the time frame of the research these educational sessions could not be implemented within this study. These findings cannot be generalized to all refugee populations that have transitioned to the US since their history of pre-migration and migration may be very different. This study does provide a lens into the difficulties and health and illness concerns these particular refugee women have faced during their transition to living in the US. Even with these limitations, multiple positive results have occurred during this research. One positive outcome is that this study provided insight into the culture and struggles Sudanese women face during their resettlement. Women learned how they could access preventative health care services, and many of them followed through with well-women exams & mammograms. Also, women learned that they could utilize nurses in schools and clinics as a resource to talk to their daughters about issues of sexuality. Another benefit from this study is that women were able to verbalize the emotional stress that they have endured during their migration and transition to the United States.

This study may contribute to the empowerment of Sudanese women by providing them with a greater understanding and ability to maneuver within the US healthcare system. At the same time this partnering interchange increases nursing knowledge in offering culturally competent care to the Sudanese community and other refugee populations that have resettled in the United States. "By acknowledging the potential of refugees, health care professionals can develop interventions that empower women by maximizing their innate resources" (Baird, 2009, p.187).

References

Baird, M. B. (2009). Resettlement transition experiences among Sudanese refugee women (Doctoral dissertation, The University of Arizona, Apr. 09, 2009).

Dormitorio, I., Sachs, J., Moe, Z., Ali, M., & Omar, N. (2008). In *Sudanese Community*. (chap. Edmonton 2008 Cultural Profiles). Retrieved Jan. 04, 2012, from http://www.seniors council.net/Senior-diversity/

Elo, S. & Kyngäs, H. (2007). The qualitative content analysis process. *Journal of Advanced Nursing 62*(1), 107-115.

Graneheim, U.H. & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures, and measures to achieve trustworthiness. *Nurse Education Today, 24*, 105-112.

Kemp, C., & Rasbridge, L. A. (2001). East African cultures: part II, Sudanese. *Journal of Hospice and Palliative Nursing*, *3*(3), 110-120.

Khawaja, N. G., White, K. M., Schweitzer, R., & Greenslade, J. (2008). Difficulties and coping strategies of Sudanese refugees: A Qualitative Approach. *Transcultural Psychiatry*, *45*(3), 489-512.

Lincoln, Y.S. & Guba, E.G. (1985). Establishing trustworthiness (pp. 289-331). *Naturalistic Inquiry*. Sage: Thousand Oaks.

Meyer, M., Torres, S., Cermeno, N., MacLean, L., Monzon, R. (2003). Immigrant women implementing participatory research in health promotion. *Western Journal of Nursing Research*, 25(7), 815-834. doi: 10.1177/0193945903256707

Murray, S. B., & Skull, S. A. (2005). Hurdles to health: immigrant and refugee health care in Australia. *Australian Health Review*, *29*(1), 25-29.

Onyango, M. A. & Mott, S. (2011). The nexus between bridewealth, family curse, and spontaneous abortion among southern Sudanese women. *Journal of Nursing Scholarship*, *43*(4), 376-384.

Pavlish, C. P. & Pharris, M. D. (2010). *Community-Based Collaborative Action Research*: a nursing process*.* (Vol. 1, A. Sibley, Ed.). Sudbury, MA: Jones & Bartlett Learning.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23,* 334-340.

Schweitzer, R., Melville, F., Steel, Z., & Lacherez, P. (2006). Trauma, post-migration living difficulties, and social support as predictors of psychological adjustment in resettled Sudanese refugees. *Australian and New Zealand Journal of Psychiatry*, *40*(2), 179-187.

Schweitzer, R., Greenslade, J., & Kagee, A. (2007). Coping and resilience in refugees from the Sudan: a narrative account. *Australian and New Zealand Journal of Psychiatry*, *41*(1), 282-288.

United Nations High Commissioner for Refugees - Refugee Figures. *The UN Refugee Agency*. Retrieved Apr. 9, 2012, from http://www.unhcr.org/pages/49c3646c1d.html.

United States Citizenship and Immigration Services – Immigration and Nationality Act. (2010). *U.S. Citizenship and Immigration Services*. Retrieved Apr. 25, 2012, from http://www.uscis.gov.

Velde, J., Williamson, D. L., & Ogilvie, L. D. (2009). Participatory action research: practical strategies for actively engaging and maintaining participation in immigrant and refugee communities. *Qualitative Health Research, 19*(9).

Willis, M. S. & Nkwocha, O. (2006). Health and related factors for Sudanese refugees in Nebraska. *Journal of Immigrant and Minority Health*, *8*(1), 19-33.

Is There an App For That? Developing an Evaluation Rubric for Apps for Use with Adults with Special Needs

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Abstract

With the rise of mobile technology, there are now thousands of applications (apps) at our fingertips. Many apps could potentially enhance the lives of adults with special needs, but there lacks an evaluation tool and central repository of apps for this population. A tool that was developed for evaluation of apps by teachers for the classroom was adapted by the researchers for use in this population. The purpose of this study was to find apps that enhance the lives of adults with special needs and validate a tool for evaluation of their usefulness through a pilot study. Selected apps were evaluated using a tool adapted to address such issues as cost, benefits of use, ease of use, alteration, and application to the population. A pilot group of 10 parents, siblings, and caregivers of adults with special needs were recruited for this study. Those recruited reviewed predetermined apps and used the adapted evaluation tool to review the apps. Based on this process, recommendations were made for apps that were useful for adults with special needs and recommendations were made for continued development of the evaluation tool. Findings helped identify applications that adults with special needs can use to enhance their lives and assist families in finding and evaluating applications. An expanded study is being planned based on the results of this study. It is anticipated that this will result in adaptation of the tool and then retesting with a larger participant number. The goal is to publish the tool and the results for these apps as well as others on a public access website so that family and caregivers can use it to evaluate apps that are appropriate for use by their adults with special needs.

Introduction

The world entered a new era with the introduction of the iPod and iPad technology. The touch technology reinvented how computing is done and the size of the machines rapidly changed where and when people are able to access technology. However, the impact that it has had on special needs populations and education is only beginning to be recognized. More and more projects are being done to take the ease and engagement that the iPod/iPad offer to enhance learning in students of all types. Remarkable advancements have been seen in the interaction/communication of non-verbal people as the iPod/iPad has given them the abilities to interact with the world around them. The breadth of vocabulary and abilities that some students with autism have acquired but previously were unable to express has stunned educators. There are many instances where educators have taken these tools and made extraordinary progress with individual students with special needs. Parents are beginning to engage their children at earlier ages in these technologies to increase or augment their child's learning. Word travels quickly on the Internet when an application (app) is found that assists children in learning or communicating through news stories and websites dedicated to this topic.

However, adults with special needs have different requirements for their learning. The emphasis in their lives may not be the mastering of math skills or reading skills as with school children. Their needs are more geared toward obtaining or the adaptation of daily living skill, ways to keep lists so that they may complete appropriate tasks, or learning to communicate so that they can successfully function in society. The apps for these types of skills are very limited when compared with traditional educational apps (math, reading, etc.).

With hundreds of apps being published on a daily basis the research team endeavored to find some of these apps and develop a tool that will assist parents, siblings, caregivers, and the adults with special needs evaluate an app and determine whether not it is useful for their adult or themselves. Some apps are free, some are inexpensive and some are quite costly. With adults with special needs having limited funds, the app purchases must be made carefully and judiciously so that money will not be spent only to find out that the app is not useful to them.

The goal of this study is to pilot an evaluation rubric for applications with parents or siblings of adults with special needs. The research team endeavored to develop a rubric that can give insight to the apps' strengths and weaknesses so that purchasers of the apps can know what app will best assist their adult in living a full, independent life. A secondary goal is to discover apps that can assist adults with special needs in reaching that full, independent life.

Literature Review

With the revolutionary changes in technology, the use of technology with special needs adults has become increasingly relevant. Unfortunately, the focus is largely on the use of new technologies with the special needs children, not adults. The literature on the use of technology with special needs adults is scanty, prompting the need for more research on this topic. While there is no literature on the use of "apps" in the special needs adult population, there is some literature on other types of technologies and their use in this population.

The overarching purpose of these assistive technologies is to increase the independence of adults with disabilities. Storey (2010) outlines the use of assistive technology in the realm of independent living using "smart" technology. These technologies include a wide variety of assistive tools to aid in the independence of individuals in their home setting from controlling appliances to monitoring the safety of the individual (Storey, 2010). While some of the technology requires specific devices, many of them can be used with computers, tablets, and smart phones. Using this technology, adults with disabilities have the potential to live nearly independently, with as little technology as a smart phone or tablet which are readily available and becoming increasingly more affordable in our society. This technology can assist the adult on many levels dependent on what the adult needs to function. Webcams can monitor them in their household and smart phones with GPS capabilities can track their movements in the house or outside of their home making it a safe environment for them to function and live. Alarms on phones can alert the adult when it is time to complete an activity or to take a medication. Emergency response systems can be notified wirelessly when needed. There are also a variety of telemedicine or telehealth programs that can be accessed from their homes.

Time management is an issue for many adults regardless of whether or not they have special needs and many adults use one of the multiple scheduling programs that are available online. Special needs adults can also find programs that allow the schedules to include picture cues to assist in tasks and then allows them to complete the tasks in a timely manner regardless of their skill level in reading. There are few homes today that do not have a number of remote controlled devices and an adult with special needs home is no exception. Televisions, music systems, vacuums, window shades, lights, garage doors and thermostats are all examples of what can be controlled from a remote and many times from a smart phone application.

Smart phones, iPods and tablets have also become a technological medium for augmentative and alternative communication (AAC). This type of technology is used by many adults with moderate to severe language impairments as a way to allow them to communicate with the world around them (Cheslock, Barton-Hulsey, Romski, & Sevcik, 2008). It has long been thought that AAC devices would not be useful for adults who lack speech due to the perception that the adults are “too old to improve their language and communication skills” (Cheslock et al., 2008, p. 376). The authors debunk this idea through a case report. With the technological mediums of smart phones and tablets for AAC use, the opportunities and access to AAC software are becoming more extensive. As research emerges using the iPad it has been found that people that were thought to have a limited vocabulary and communication actually have an extensive vocabulary that they are just unable to express. When they are provided a medium to express their thoughts and feelings, they are able to do so very well, regardless of age or when the technology was introduced.

Smart phones and tablets also have the ability to assist adults with disabilities in learning life skills through computer-based instruction (CBI) and computer-based video instruction (CBVI). According to Ayres and Cihak (2010), this type of instruction can improve the acquisition of life skills. Ayres and Cihak set out to determine the advantages of using CBVI for specific life skills and focused on learning and generalization of the skills being taught. The authors determined that it is important that skills taught in this mode are functional for the learner to benefit (Ayres & Cihak, 2010).

As previously mentioned there is new research and anecdotal records being revealed daily on the impact of the iPad on the lives of people with special needs. USA Today (2011) notes that the reasons that the iPad is so successful with this population is because they are lightweight, mobile, can be easily tailored to the needs of the user and gives the sense that the user is “plugged in” to a greater community that is high tech and oblivious, many times, to their particular disabilities. The touch screen also makes using the iPad easier for those who struggle with fine motor skills and dexterity. The iPad is engaging and draws the user into its functions with vibrant colors and interactivity.

Walker (2011) states that there are 566,165 apps currently for the iOS (Apple operating system) and on average 775 new apps are submitted to Apple daily. He states that 15 billion apps have been downloaded from the Apple Store in the past three years. The most common apps are those in the gaming category, however, there are over 40,000 educational apps. When adding the reference tools, utilities, news and other apps that are commonly used in educational settings, the number exceeds 166,000 apps. It was in the midst of those numbers Walker began to formulate a rubric for the quick but accurate evaluation of apps for teachers. He determined from his research that there were six characteristics of an app that were important to teachers that he included in the rubric (Walker, 2011). They were a) curriculum connections, b) authenticity, c) feedback, d) differentiation, e) user friendliness and f) motivation. Under curriculum connections, the teachers wanted reinforcement of the topics of interest when the student is not engaged in direct instruction. They wanted some correlation to a targeted skill or concept that was being taught. The authenticity criterion addresses the quality of the experience for the learner using the app. Walker defined authenticity in terms of the engagement of the student in real learning problems that help them connect the theory to real life. The feedback given by the apps needed to be constructive and timely to the learner. Differentiation concerns the ability to target specific skills and tailor the level of difficulty for the particular learner. User friendliness was defined as the ease of use of the app and the learning curve and support that was needed to effectively use the app. Finally, the last criterion is motivation. Does the app motivate the student to its use? A good app is of no use, he states, if the students are bored with it and do not use it. One interesting point that Walker makes is that price, in general, does not assist in the decision making process. There are good apps that are free and bad apps that are expensive.

Walker took these characteristics and needs and designed a rubric (Appendix A) to allow teachers to grade the apps that they currently use and to allow a standardized language so that teachers could communicate with each other about apps that work and those that do not. The rubric included the six domains described above and allowed ratings of 1-4 for each domain. He tested the rubric with teachers but has not been able to establish a cut score for an app. It is highly dependent on the user and the teacher's purpose for the app. He does state that he thinks most good apps score a "4" in at least four of the six categories. He has continued to gather data using this rubric. Permission was obtained from him to adapt his rubric to the particular needs of the adults with special needs population. (Appendix B) During the adaptation process, Walker's rubric was used as the base. Some domains were changed to better suit the needs of the special needs population as opposed to use in the classroom. In changing the domains, new scoring criteria had to be adapted to match the new domains and to better suit the population.

The long-term goal is that functionality and independence can be achieved for adults with disabilities using apps on devices such as smart phones and tablets. This pilot study will prepare for a larger study that will determine if the rubric created will assist parents and siblings as well as other caregivers choose apps that will allow the adult with special needs to function in a more independent environment. The final outcome is that the rubric will be used on a web based site that is available to the public to assist them in making choices on hardware and apps that will allow their adults to reach their fullest potential.

Methodology

This study was submitted and approved by the Institutional Review Board for Human Subjects. The participants included 10 adults who were either parents or siblings of an adult with varying degrees of special needs. Participants were selected using a combination of purposive and convenience sampling. They were asked to participate in the study and their willingness to complete the evaluation form implied consent. The adults were required to speak English and be of sufficient technological savvy to manipulate through the apps. The researchers provided the hardware and the apps and were available to the participant during the evaluation period if assistance was necessary. The participants were asked to evaluate six different apps using the evaluation tool created by the researchers (Appendix C). They were provided with a form to complete ratings on each app, scoring the app in each domain, and then answering a few short answer questions about the usefulness of the app and the tool. (Appendix D) The apps that were evaluated included the following: Counting money, Proloquo2go, iDress, Tap to Talk, Touch and Learn, and Telling Time. Two of the apps are alternative and augmentative communication apps (Proloquo2go and Tap to Talk). The rest of the apps are aimed at activities of daily living. The entire evaluation period for the participant averaged 15-20 minutes. The completed evaluations were anonymous with no personal information or identifying factors.

The evaluation forms were compiled and the comments examined for content and themes. Also, the scores on the apps were compiled, averaged, and evaluated against the scores that the research team hypothesized they would receive. For example, the research team hypothesizes that Proloquo2go will score highly with those adults that have communication issues but may show weakness in application and cost.

Results

Table 1 depicts the average scores of the evaluated apps. A total of ten participants completed the worksheet (Appendix D). Among the participants, four were siblings, five were parents, and one caregiver of adults with special needs. Table 1 depicts the averages of the scores collected for each app and respective domain. The scoring range for each domain ranges from 1-4. Higher average scores depict positive feedback for that specific app and domain. The individual scores for the apps were as follows: Counting Money ranged from 2.4-3.8 with an average of 2.86, Proloquo2Go scores ranged from 1.6-2.7 with an average of 2.34, Touch and Learn scores ranged from 1.7-2.8 with an average of 2.4, iDress for Weather scores ranged from 1.9-3.2 with an average of 2.67, Telling Time scores ranged from 2.3-3.2 with an average score of 2.65, and TaptoTalk scores ranged from 2.4-3.0 with an average score of 2.58.

With regard to the short answer question portion of the worksheet, the results were as follows: 100% of respondents answered “Yes” to the question “Do you think any of these apps would be helpful to your adults?”; 80% of respondents answered “Yes” to the question “Do you think that your adult could use any of these apps?”; 89% of respondents answered “Yes” to the question “Do you think other adults that you know would benefit from these apps?”; 100% of respondents answered “Yes” to the question “Do the apps seem applicable to you for use with adults with special needs?”; 88% of respondents answered “No” to the question “Are you aware of any other apps we should investigate?"; 80% of respondents answered "Yes" to the question "Do you or someone in your family own an iPad or iPod?"; and 80% of respondents answered "Yes" to the question "Do you think this tool adequately evaluated the apps and gives you the information you would need to make a decision on the app's use for your adult?".

Discussion

The overall scores showed a very positive outlook on the use of apps for this population. As expected, cost did play a factor with less expensive apps scoring much higher in the "Cost" domain than the more expensive apps. It was anticipated that Touch and Learn would be a low scoring app and indeed it had one of the lower average scores. iDress for Weather scored lower than was anticipated, however, when examined more closely, it scored higher than 3 in three domains. This is Walker's criteria for a good app. This would support the hypothesis that this app would be useful for this population. It would also appear that the feedback domain may be the least useful. It was not applicable in the AAC apps and scored low in the iDress app but should not have been seen as a fault in the app.

The responses to the short answer questions identified that most felt that adults with special needs could benefit from apps such as those used in this study. However, very few of the participants were aware of any other apps for use in this population, indicated the limited use of this technology in this population. One person noted that had this technology been available for his sibling when it was younger it would have been helpful, but now he has dementia and it was doubtful that he could use the technology. Most of the families did have access to devices that could use these applications, so for most, the purchase of a device to run an app is not an issue. There was concern by participants that this tool may not be appropriate for AAC apps and that different domains may need to be established for communication apps. From the information gathered and the responses to the questions on the questionnaire (Appendix D), it can be concluded that the evaluation tool is useful and beneficial for the adults with special needs population, but does need further adaptation and testing. This study also demonstrated that many families have the technology available but are unaware of apps that would potentially assist their adults.

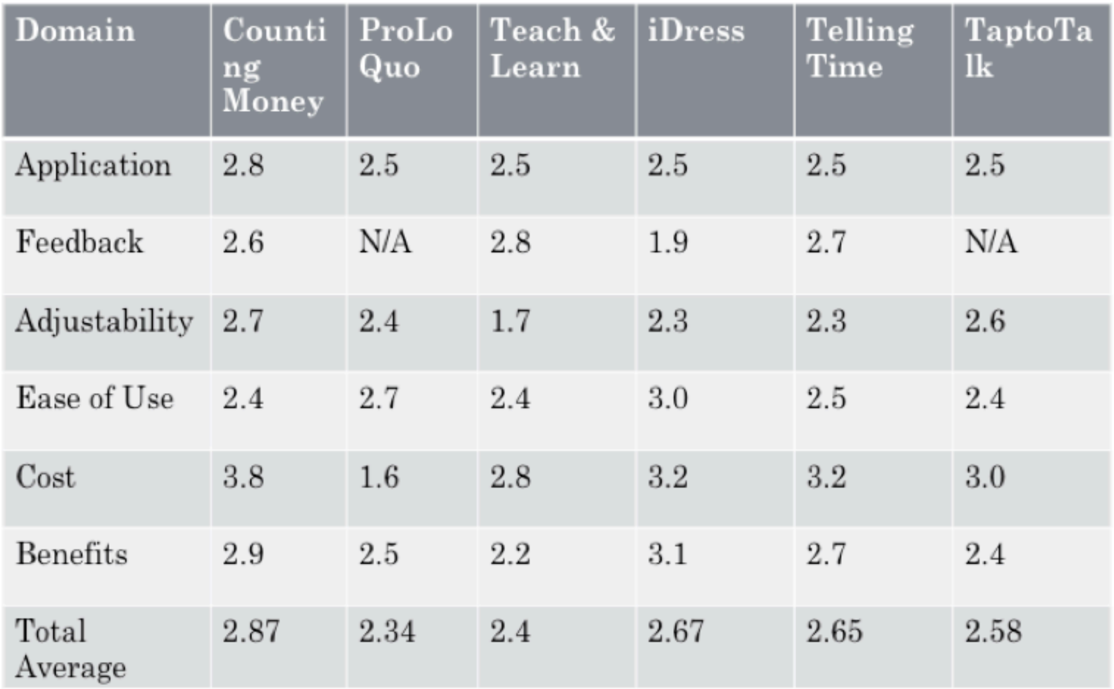
Conclusion

It can be concluded that this evaluation tool can be utilized effectively by care providers, but needs to be further adapted. A larger sample size will be used in the following study as well as including adults with special needs to participate.

Initial dissemination of apps, such as iDress, has already been achieved on a Facebook site developed for the Adults with Down Syndrome Specialty Clinic at The University of Kansas Medical Center.

This pilot study, however, has established the need for this information for families and adults with special needs and for a tool to assist families in these decisions.

Table 1



Domain	Counting Money	ProLoQuo	Teach & Learn	iDress	Telling Time	TaptoTalk
Application	2.8	2.5	2.5	2.5	2.5	2.5
Feedback	2.6	N/A	2.8	1.9	2.7	N/A
Adjustability	2.7	2.4	1.7	2.3	2.3	2.6
Ease of Use	2.4	2.7	2.4	3.0	2.5	2.4
Cost	3.8	1.6	2.8	3.2	3.2	3.0
Benefits	2.9	2.5	2.2	3.1	2.7	2.4
Total Average	2.87	2.34	2.4	2.67	2.65	2.58

*Costs: Counting Money $0.99, Proloquo2Go $189.99, Touch & Learn Free, iDress for Weather $1.99, Telling Time $0.99, TaptoTalk $39.95

Appendix A Evaluation rubric for IPod apps (Walker, 2010)

Evaluation Rubric for IPod Apps

Domain	1	2	3	4
Curriculum Connection	Skill(s) reinforced in the app are not clearly connected to the targeted skill or concept	Skill(s) reinforced are prerequisite or foundation skills for the targeted skill or concept	Skill(s) reinforced are related to the targeted skill or concept	Skill(s) reinforced are strongly connected to the targeted skill or concept
Authenticity	Skills are practiced in a rote or isolated fashion (e.g., flashcards)	Skills are practiced in a contrived game/simulation format	Some aspects of the app are presented an authentic learning environment	Targeted skills are practiced in an authentic format/problem-based learning environment
Feedback	Feedback is limited to correctness of student responses	Feedback is limited to correctness of student responses and may allow for student to try again	Feedback is specific and results in improved student performance (may include tutorial aids)	Feedback is specific and results in improved student performance; Data is available electronically to student and teacher
Differentiation	App offers no flexibility (settings cannot be altered)	App offers limited flexibility (e.g., few levels such as easy, medium, hard)	App offers more than one degree of flexibility to adjust settings to meet student needs	App offers complete flexibility to alter settings to meet student needs
User Friendliness	Students need constant teacher supervision in order to use the app	Students need to have the teacher review how to the use the app on more than one occasion	Students need to have the teacher review how to the use the app	Students can launch and navigate within the app independently
Student Motivation	Students avoid the use of the app or complain when the app is assigned by the teacher	Students view the app as "more schoolwork" and may be off-task when directed by the teacher to use the app	Students will use the app as directed by the teacher	Students are highly motivated to use the app and select it as their first choice from a selection of related choices of apps

http://learninginhand.com/storage/blog/AppRubric.pdf
Created by Harry Walker – Johns Hopkins University
10/18/2010
Please contact for permission to use hwalker@bcps.org

Appendix B Email correspondance with Harry Walker seeking permission to adapt rubric

From: Moya Peterson [mailto:MPETERSO@kumc.edu]
Sent: Thursday, February 09, 2012 5:38 PM
To: Walker, Harry C.
Subject: your evaluation for iPod apps

Sir- I am an assistant professor at the University of Kansas School of Nursing and School of Medicine. I have established an Adults with Down Syndrome Specialty Clinic. A student and myself are attempting to find and evaluate apps on the iPad and iPod touches that my patients would benefit from as well as be able to inform parents and other providers of apps that are established that could assist them in their activities of daily living. We have used your evaluation tool as a pattern but have changed it somewhat to fit our particular needs. I have attached this tool to this email. I just wanted to make sure that we had your permission to do this. We were thrilled to find your tool, as there is very little in the literature about this. We thought it valuable and it provided the only suggestion to develop the tool that we wanted.

Please feel free to email me any questions you may have. Thank you for consideration of this matter. We will be anxious to hear back from you.

Moya Peterson, PhD, APRN

From: Harry Walker
Sent: 2/10/2012 10:15:22 AM
To: Moya Peterson

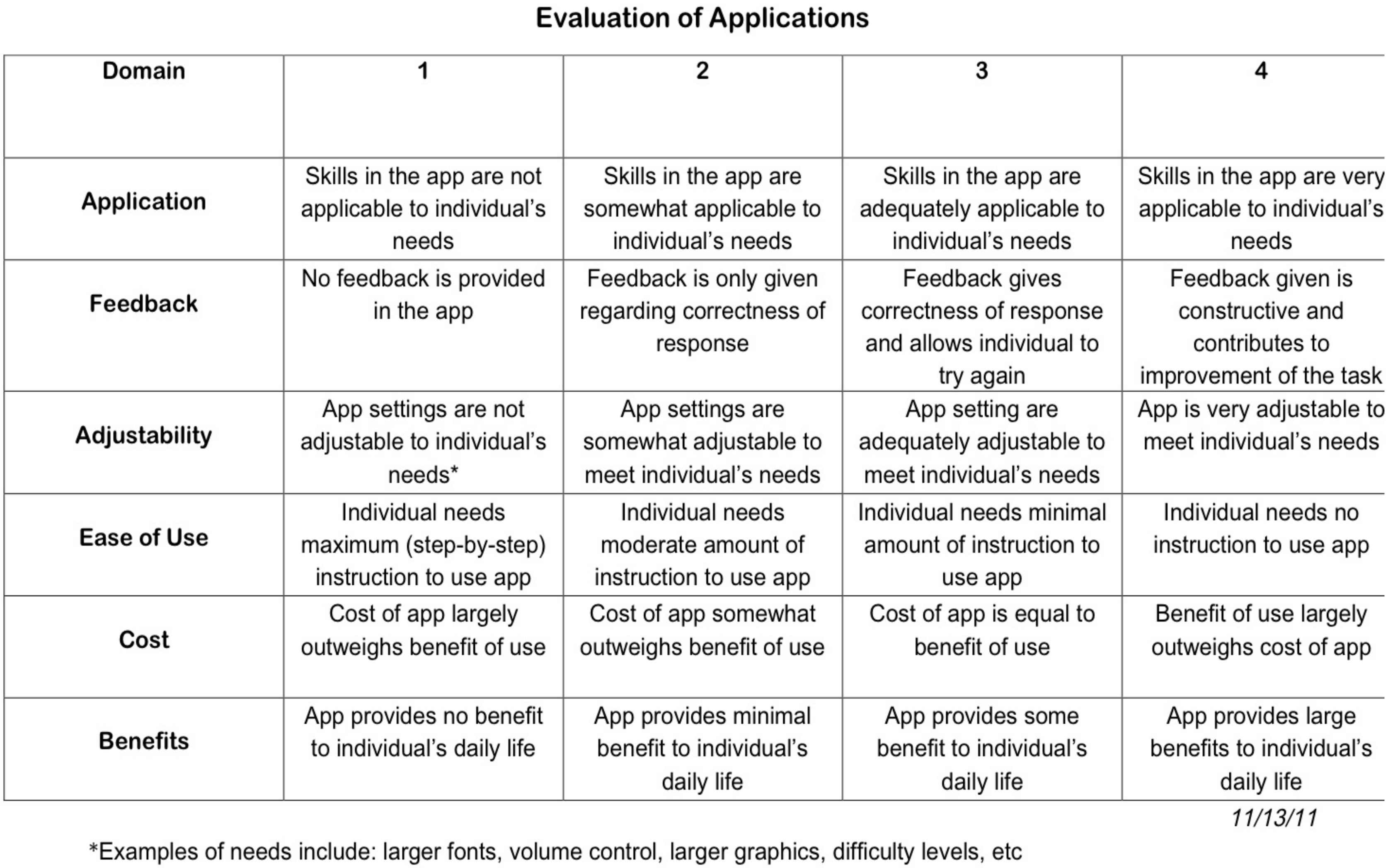
Hi Moya,

I'm glad you found the rubric to be useful. You have permission to use the rubric as described in your email. I will likely be in touch sometime in the coming month to ask for formalized feedback as part of my dissertation research at Johns Hopkins. I hope you will be able to participate. Best of luck in your efforts to get mobile devices in the hands of your patients.

You might also want to check out our blog - http://iteachthererforeipod.blogspot.com It has resources, articles, etc., related to IPods, Mobile 1 to1 and BYOT. Feel free to share with like minded folks. There is also a link to an article I wrote for the Journal of Special Education Technology about the rubric. The background material may help in your work.

Regards,
Harry Walker

Appendix C Evaluation of Application



Evaluation of Applications

Domain	1	2	3	4
Application	Skills in the app are not applicable to individual's needs	Skills in the app are somewhat applicable to individual's needs	Skills in the app are adequately applicable to individual's needs	Skills in the app are very applicable to individual's needs
Feedback	No feedback is provided in the app	Feedback is only given regarding correctness of response	Feedback gives correctness of response and allows individual to try again	Feedback given is constructive and contributes to improvement of the task
Adjustability	App settings are not adjustable to individual's needs*	App settings are somewhat adjustable to meet individual's needs	App setting are adequately adjustable to meet individual's needs	App is very adjustable to meet individual's needs
Ease of Use	Individual needs maximum (step-by-step) instruction to use app	Individual needs moderate amount of instruction to use app	Individual needs minimal amount of instruction to use app	Individual needs no instruction to use app
Cost	Cost of app largely outweighs benefit of use	Cost of app somewhat outweighs benefit of use	Cost of app is equal to benefit of use	Benefit of use largely outweighs cost of app
Benefits	App provides no benefit to individual's daily life	App provides minimal benefit to individual's daily life	App provides some benefit to individual's daily life	App provides large benefits to individual's daily life

11/13/11

*Examples of needs include: larger fonts, volume control, larger graphics, difficulty levels, etc

Appendix D Questionnaire

1. Please score each app in each domain using the rubric attached.

DOMAIN/APP	Counting Money	Proloquo2go	Teach and Learn	iDress	Telling Time	TapToTalk
Application						
Feedback						
Adjustability						
Ease of Use						
Cost						
Benefits						

2. Do you think any of these apps would be helpful to your adult?
3. Do you think that your adult could use any of these apps?
4. Do you think other adults that you know would benefit from these apps? How?
5. Do the apps seem applicable to you for use with adults with special needs?
6. Are you aware of any other apps we should investigate?
7. Do you or someone in your family own an iPad or iPod? If no, have you thought about the purchase of one or such technology that is similar?
8. Do you think that this tool adequately evaluates the app and gives you the information you would need to make a decision on the app's use for your adult?

References

Ayres, K., Cihak, D. (June, 2010). Computer- and video-based instruction of food-preparation skills: acquisition, generalization, and maintenance. *Intellectual and Developmental Disabilities*, *48*(3), 195-208. Retrieved from http://www.aaiddjournals.org.proxy.kumc.edu:2048/doi/full/10.1352/1944-7558-48.3.195

Cheslock, M.A., Barton-Hulsey, A., Romski, M., Sevcik, R.A. (October, 2010). Using a speech-generating device to enhance communicative abilities for an adult with moderate intellectual disability. *Intellectual and Developmental Disabilities*, *46*(5), 376-386. Retrieved from http://www.aaiddjournals.org.proxy.kumc.edu:2048/doi/abs/10.1352/2008.46%3A376-386

Storey, K. (December, 2010). Smart houses and smart technology: Overview and implications for independent living and supported living services*. Intellectual and Developmental Disabilities*, *48*(6), 464-469. Retrieved from http://www.aaiddjournals.org.proxy.kumc.edu:2048/doi/abs/10.1352/1934-9556-48.6.464

Walker, H. (2011). Evaluating the effectiveness of apps for mobile devices. *Journal of Special Education Technology*, 26(4). 59-66.

Williams Boyd, A. (2011, September 11). Adapting to the iPad, called education's 'equalizer'. *USATODAY.* Retrieved from http://yourlife.usatoday.com/parenting-family/special-needs/story/2011-09-11/Adapting-to-the-iPad-called-educations-equalizer/50362426/1

THE RELATIONSHIP BETWEEN NURSING CHARACTERISTICS AND PAIN CARE QUALITY

Elaine Davis, KU BSN Student
Nancy Dunton, PhD, Faculty Advisor

Abstract

The purpose of this study is to examine relationships between unit-level nursing characteristics (e.g. RN education, certification, RN hours per patient day) and hospital characteristics (e.g. Magnet designated, academic institution) with the unit average of patients' self-rated perception of pain and pain care quality. The study is a correlational analysis of cross-sectional data from the National Database of Nursing Quality Indicators® (NDNQI) combined with data on pain care quality. The sample was a convenience sample that covered 170 hospitals across the U.S. with 725 reporting units. . The study found significant clinical relationships, although weak, between several variables. Strong relationships included: patient's average pain rating and nursing care hours per patient day; average pain and having pain medications available when needed. The strongest relationship was between percent pain relief and having pain medications available when needed. The study's findings that no significant differences presented across various unit types reinforce the point that pain is pervasive. Pain is also unique to each individual's subjective experience. Therefore, each patient's plan of care should be individualized, patient-centric, and unique to his or her experience.

Introduction

Almost one-half of all Americans report pain as their primary reason for seeking treatment, making pain the most common reason to see a physician in the United States (Turk & Dworkin, 2004). Pain is a subjective experience that has the potential to negatively affect a hospital patient's ability to function, quality of life, physical recovery, immune function, stress, and satisfaction with care. Pain is distinctive in that it is universal, yet unique to each individual's own experience. Additional factors to consider that may affect the patient's perceptions and reactions to pain include culture, religion, and tolerance. Besides the negative physiological and psychological effects pain has on the individual, it can also be a burden financially. The costs of treatment, missed work, and costs associated with short or longer term disability are all factors that must be considered (Turk & Dworkin, 2004).

The purpose of this study is to examine relationships between unit-level nursing characteristics (e.g. RN education, certification, RN hours per patient day) and hospital characteristics (e.g. Magnet designated, academic institution) with the unit average of patients' self-rated perception of pain and pain care quality.

Research Questions

The study addressed 4 research questions.

1. Do hospital characteristics have an effect on pain care quality?
    a. Teaching status
    b. Magnet designation
    c. Number of staffed beds
2. Do staffing characteristics have an effect on pain care quality?
    a. Total nursing hours per patient day
    b. Percent of nursing hours supplied by RNs (skill mix)
    c. Average RN educational attainment
    d. Mean national specialty nursing certification
    e. RN education
    f. RN specialty certification
3. Does the availability of pain treatments have an effect on pain care quality?
    a. Does having pain medications available when needed have an effect on pain are quality?
    b. Does having alternative treatments available, in addition to pain medications, have an effect on pain care quality?
4. Does the quality of patient-nurse communication have an effect on pain care quality?
    a. Does patient self-rating of effectiveness of pain medication for pain control have an effect on pain care quality?
    b. Do nurses' beliefs of patient's pain reports have an effect on pain care quality?
    c. Does patient rating of level of the healthcare team's inclusion of patient in pain control decisions have an effect on pain care quality?

Literature Review

QIs are becoming a more important way for researchers and health care organizations to assess and measure the effectiveness and satisfaction of care being provided. There is a need to develop a consensus quality measure of the quality of pain management. Interestingly, recent studies have found paradoxical results indicating that patients who report significantly high pain ratings concurrently report high satisfaction ratings. A research project conducted by Susan Beck et al. (2010) investigated possible reasons for this finding. The research project investigated whether current QIs inadvertently measure factors such as caring behaviors, staff responsiveness to requests for pain medications, bedside manner; or patient factors such as expectations that pain cannot be relieved or will vary, not wanting to get anyone in trouble; patient satisfaction with pain management. The study found that patients do not appear to distinguish between the actual effectiveness of their pain management and the setting in which care is provided. This has serious implications for the health care practitioner, especially nursing staff, because it shows that environmental factors affect the patient's overall judgment of how effectively their pain is managed.

A second research project assessed the relative effectiveness of different quality improvement strategies. The study was undertaken because many quality improvement strategies (QIs) have fallen short (Scott, 2009). Findings from the study established that the failure of many QIs can be attributed to the lack of application of evidence-based practices. This occurs because the practices have been applied before sufficient research has been performed to validate their effectiveness. Not only is this poor practice, but it is also wastes resources while risking patient harm (Scott, 2009). The study also found QIs directed from the provider or patient level had both stronger evidence of efficacy and larger effect sizes than strategies conducted from the manager or policy maker level. Effective QIs included clinician directed audit and feedback cycles, clinical decision support systems, specialty outreach programs, chronic disease management programs, continuing professional education based on interactive small-group case discussions, and patient-mediated clinician reminders. Ineffective QIs included continuous quality improvement programs, risk and safety management systems, public scorecards and performance reports, external accreditation, and clinical governance. The findings from Scott's study can be applied to this research project because they highlight specific, evidence-based procedures necessary to effectively manage pain.

Several additional studies reinforce the current failure of the medical system to adequately manage patient's pain. A study by Gordon, Pellino, and Miaskowski et al. (2002) looked at pain data collected over a 10 year period and found that pain intensity ratings remained high over the 10 year period. Not only does this mean that our healthcare system is not working to effectively manage pain, but also that our QIs and assessment standards, which were put in place to help make improvements, are ineffective (Gordon et al., 2002). This failure to effectively manage pain is happening despite quality guidelines that have been released by the Agency for Health Care Policy and Research, the American Pain Society, as well as the Joint Commission (Gordon et al., 2002).

A second pain prevalence study conducted in a large Canadian teaching hospital revealed 31.5% of the patients surveyed reported being in moderate-severe pain (≥4/10) with 11.4% of patients reporting severe pain levels (≥7/10). Results of pain levels over the past 24 hours revealed similarly poor results with 76.3% reporting pain scale ratings of moderate to severe pain (≥4/10) and 47.3% reporting severe pain (≥7/10). The results also showed the patients' pain affected various aspects of their quality of life such as mood, walking ability, relationships, sleep, and enjoyment of life (Sawyer, Haslam, Robinson, Daines, Stilos, 2008). The results of these two studies are representative of a body of research that finds current pain management is sub-optimal. As the providers of bedside care, nurses can become leaders to improve of pain care quality by implementing evidence-based practice.

The significance of the role nursing plays in the drive to improve pain management is evident in the findings of a final study, which highlights the relationship between nursing staffing and positive patient outcomes (Seago, Williamson, & Atwood, 2006). The study explored the relationship of quality outcomes, such as failure-to-rescue from medication errors and decubitus ulcers with nursing process measures such as pain management, teaching, and physical care; and nursing structural measures such as RN staff hours, skill mix, direct care total staff hours. Results of the analysis found that as the total hours of nursing care per day and skill mix (i.e. more hours of care provided by an RN) increased, so did all patient satisfaction measures, including satisfaction with pain management (Seago et al., 2006). Thus, the results draw support the need for further research into the relationship between staffing variables and QIs. This study is based in that tradition and examines examine the relationships between nursing workforce characteristics and effective pain management.

In summary, the literature found that effective pain management was related to adequate and skilled nursing staff, effective evidence-based pain care management practices and assessment. However, the literature showed that our current system frequently fails to provide effective pain management. This was evident in the high rates of pain and lack of improvement in pain management over time. Thus, more research is needed to indentify ways to improve pain management.

Methods

The study is a correlational analysis of cross-sectional data from the National Database of Nursing Quality Indicators® (NDNQI) combined with data on pain care quality from a study by Dr. Susan Beck. Clinical significance was assessed using a linear regression in the SPSS software system.

Sample

The sample was a convenience sample that included 170 hospitals across the U.S. with 725 reporting units. NDNQI® data came from the annual RN Survey. Participating unit types included: medical, surgical, combined medical-surgical, step down, rehabilitation, and post-partum. Pain care quality from the Beck study was collected at the patient level across all participating units over the course of April 2011. The Beck study participants were screened for eligibility by three questions before consent was obtained and the survey administered. To meet the eligibility criteria, patients had to be age 19 or older, understand and respond in English, and have experienced pain or taken any medication for pain in the past 24 hours.

Measures

The Donabedian quality model was the conceptual framework for this study, in which the quality of care is influenced by the structure and processes of health care. For the purposes of this research structure of care was defined as the supply, skill mix, education, and certification of the nursing staff as well as hospital characteristics such as Magnet designation and teaching status. Structural data were obtained from the NDNQI® database. Specific indicators of nursing assessment and interventions were taken from responses to the Beck Pain Study Questionnaires, found in Appendix A. Descriptive statistics for the measures included in this study are presented in Table 1, Figures 1 and 2, and Table 2.

Analysis

To describe the sample, descriptive statistics were run on each variable for both the total of all units and unit type. Next, correlation matrixes were run using SPSS Version17.0, by the total of all units and by unit type. The correlations were assessed for statistical significance using a p value of 0.05 or less. Finally, four regressions were run in SPSS using the general linear model. A regression was run using the structure and process measures (i.e. staffing and hospital characteristics) against two separate dependent variables: mean rate of pain and percent relief from medications.

Results

Research Question 1: Do hospital characteristics have an effect on pain care quality?

There were several significant ($p \leq .05$) correlations between the pain care quality items and hospital characteristics, although most were of small magnitude (Table 3). Among the six pain care quality items there were three significant correlations: two with Magnet status, and one with unit type. All three correlations were below .10. Table 4 presents multivariate regression results for

Average Pain During Past 24 hours. The only hospital characteristic having a significant effect on pain level was Teaching Status. While the effect size was small, the regression coefficient indicated that pain scores were lower in teaching hospitals and academic medical centers.

Research Question 2: Do staffing characteristics have an effect on pain care quality?

There were significant correlations between Average Pain Score and three nursing characteristics: total nursing hours per patient day, percentage of nursing care hours supplied by agency staff, and unit average RN age (Table 3). The regression presented in Table 4 confirmed these associations, although the effect sizes were small. Pain scores were higher on units with lower nursing care hours per patient day (B = -0.157), more hours from Agency staff (B = 0.060), and on units with lower average RN age (B = -0.077).

Research Question 3: Does the availability of pain treatments have an effect on pain care quality?

The strongest beta value reported in Table 5 was between Having Pain Meds Available and % Pain Relief (0.221). This indicates that a one standard deviation increase in pain medication availability was associated with a 0.221 increase in the standard deviation for pain relief. Having Pain Medications Available was also significantly associated with Average Pain in 24 hours, (beta value = -0.146) as reported in Table 4. These variables have an inverse relationship; and thus, by increasing pain medication availability by one standard deviation, average pain in the past 24 hours would decrease the average pain score by 0.146 of a standard deviation.

Other variables (Table 5) that were found to have statistically significantly regression coefficients ($p < 0.05$) but were not clinically significant (B values < 0.5) included:

- % Pain Relief with alternative pain management approaches
- % Pain Relief with healthcare team involved patient in decisions controlling pain

Research Question 4: Does the quality of patient-nurse communication have an effect on pain level?

The effects of patient-nurse communication on Average Pain in the Past 24 Hours are presented in Table 4 and on Percent Pain Relief are presented in Table 5. Nursing factors related to lower Average Pain scores included:

- Healthcare team involved patient in decisions controlling pain (B = -0.95)
- Nurse suggested alternative pain treatment (B = -0.42)

The same two nursing factors associated with a higher percentage of pain relief.

Discussion

Interestingly, the data reported in Table 2 showed no significant difference between unit type and average rate of pain or percent pain relief (p values of .145 and .371 respectively). This finding is of importance to nursing practice and to the field of pain management and the healthcare system as a whole. Pain should be treated effectively across the spectrum of healthcare regardless of unit type or healthcare setting. Healthcare workers must always remember that pain is subjective. Healthcare workers must always remember that pain is subjective. Therefore, the patient's description and rating of his or her pain is always what providers should assume pain to be and treat accordingly.

Having pain medications available when needed had the strongest association with percent pain relief. Pain medication availability was also clinically significant with average rating of pain. These findings have important clinical implications for pain management. Nursing staff must make frequent pain assessments and offer pain medication(s) in a timely manner. This requires nursing knowledge of the patient's medication administration record (MAR) in order to reference available scheduled and PRN medications. Additionally, nursing staff must reassess after each pain medication administration in order to gauge effectiveness. If the nurse finds that the pain medication(s) are not adequately relieving the patient's pain level, the nurse must advocate to the physician for a dosage or medication adjustment. Proper charting of initial pain assessment, interventions, and reassessment are also necessary. In order to help remind nursing staff to frequently assess for pain, flowsheets or pop-up reminders in the electronic charts can be utilized.

In addition to having pain medication(s) available, the model showed that nursing care hours per patient day had a clinically significant effect on average pain levels The data showed that as nursing care hours per patient day increased, patients' average pain ratings decreased. These findings are translatable to nurse staffing ratios; namely that with increased staffing, better pain management occurs. This finding correlates with the results discussed in the literature review highlighting the relationship between nurse staffing and positive patient outcomes (Seago et al., 2006).

Within the data set the term "nursing care hours" encompassed RNs, LPNs, and unlicensed assistive personnel rather than RNs alone. Therefore, these data show that a meaningful influence on pain reduction can come from all levels of nurse staffing. A possible explanation for the effect generated by LPNs and UAPs (who cannot administer medications) is through their communication of patient needs to the RN or other licensed staff member, who then administers available pain medication(s). All in all, as the drive for improved pain management gains momentum, hospital and unit staffing matrixes must begin to reflect improved nurse staffing

Limitations

This study had two limitations. First, while there were statistically significant relationships between various pain measures and nursing indicators, the relationships were fairly weak and had limited clinical significance. The statistical significance can be attributed to the study's large sample size. Second, data were collected from a convenience sample in which larger hospitals and teaching hospitals were over-represented, thus, limiting the generalizability to all hospitals in the United States.

Conclusion

Nearly 50 percent of Americans present to healthcare institutions with pain as their main complaint. (Turk and Dworkin, 2004). The study's findings that no significant differences presented across various unit types reinforce the point that pain is pervasive. Pain is also unique to each individual's subjective experience. Therefore, each patient's plan of care should be individualized, patient-centric, and unique to his or her experience.

Without proper pain management a patient's ability to function, quality of life, physical recovery, immune function, level of stress and satisfaction can suffer. The literature review discussed previously reported that the keys to effective pain management included an adequately staffed and skilled nursing workforce as well as effective assessment tools and pain care protocols. However, our current healthcare system is failing to meet these objectives.

This study found significant clinical relationships, although weak, between several variables. Strong relationships included: patient's average pain rating and nursing care hours per patient day; average pain and having pain medications available when needed. The strongest relationship was between percent pain relief and having pain medications available when needed.

Implications for Nursing

Several nursing implications can be drawn from these results. Timely, thorough, and appropriate pain assessments are the duty of each and every nurse staff member. Appropriate pain medication administration, documentation, and reassessment are also essential to improve pain management. A second implication is the necessity of appropriate staffing matrices for all nursing staff (RNs, LPNs, unlicensed assistive personnel) to increase care hours per patient day.

Current practices and the healthcare system as a whole are failing to effectively manage patient's pain. This failure is captured by evidence in the literature such as high rates of pain and poor improvement in pain management over time (Gordon et al, 2002), (Sawyer et al., 2009). Nurses, as the providers of bedside care, have the potential to be leaders in pain care quality improvement. Not only must nurses push for continued research into the field of pain management, but they must also be leaders at the bedside to implement best practice guidelines.

References

Beck, S.L., Towsley, G.L., Berry, P.H., Lindau, K., Field, R.B., Jensen, S. (2010). Core aspects of satisfaction with pain management: cancer patients' perspectives. *Journal of Pain Symptom Management, 39*(1), 100-115.

Gordon, D.B., Pellino T.A., Miaskowski, C., et al. (2002). A 10-year review of quality improvement monitoring in pain management: recommendations for standardized outcome measures. *Pain Management Nursing, 3*(4), 116-130.

Sawyer, J., Haslam, L., Robinson, S., Daines, P., Stilos, K. (2008). Pain prevalence study in a large Canadian teaching hospital. *Pain Management Nursing, 9*(3), 104-112.

Scott, I. (2009). What are the most effective strategies for improving quality and safety of health care? *Internal Medicine Journal 39*(6), 389-400.

Seago, J.A., Williamson, A., & Atwood, C. (2006). Longitudinal analyses of nurse staffing and patient outcomes: more about failure to rescue. *Journal of Nursing Administration, 36*(1), 13-21.

Turk, D.T., Dworkin, R.H. (2004). What should be the core outcomes in chronic pain clinical trials? *Arthritis Research and Therapy, 6*(4), 151-154.

Appendix A Beck Pain Study Questionnaire

These questions ask about how your pain has been in the past 24 hours.

1. Please rate your pain on the average during the past 24 hours from 0 no pain to 10 pain as bad as you can imagine.
2. How much of the time did you experience pain that was severe during the last 24 hours? (Note: Only read percentages if needed to distinguish categories and confirm responses)
   ____ (0) not at all
   ____ (1) rarely (<5% of the time)
   ____ (2) occasionally (5 to 25% of the time)
   ____ (3) intermittently (26 - 50% of the time)
   ____ (4) frequently (more than 50% of the time)
   ____ (5) constantly (all the time)
   ____ (99) Patient Refused
3. Were you given any medication for pain in the past 24 hours?
   ____ (0) No (Go to question 5)
   ____ (1) Yes (Go to question 4)
   ____ (2) Don't Know (Go to question 5)
   ____ (99) Patient Refused (Go to question 5)
4. If yes, in general, how much relief have pain treatments or medications provided? Please answer from 0 (no relief) to 100% (complete relief).
   0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

The following questions ask about your perceptions of how your pain was managed **by your nurse during the past 24 hours**. Please answer honestly. Please indicate how much you agree or disagree with each statement on a scale from 1 (strongly disagree) to 6 (strongly agree) following each item.

5. My nurse believed my reports about my pain.
   ____ (0) strongly disagree
   ____ (1) moderately disagree
   ____ (2) slightly disagree
   ____ (3) slightly agree
   ____ (4) moderately agree
   ____ (5) strongly agree

____ (99) patient refused

6. I had pain medication available when I needed it.

____ (0) strongly disagree

____ (1) moderately disagree

____ (2) slightly disagree

____ (3) slightly agree

____ (4) moderately agree

____ (5) strongly agree

____ (99) patient refused

7. In addition to medications, my nurse suggested approaches to help manage my pain. (Examples are positioning my body, thinking about other things, deep breathing exercises, relaxation, and massage, or using heat or ice).

____ (0) strongly disagree

____ (1) moderately disagree

____ (2) slightly disagree

____ (3) slightly agree

____ (4) moderately agree

____ (5) strongly agree

____ (99) patient refused

8. My nurse discussed side effects of the pain medications with me.

____ (0) strongly disagree

____ (1) moderately disagree

____ (2) slightly disagree

____ (3) slightly agree

____ (4) moderately agree

____ (5) strongly agree

____ (99) patient refused

9. The pain medications worked well to control my pain.

____ (0) strongly disagree

____ (1) moderately disagree

____ (2) slightly disagree

____ (3) slightly agree

____ (4) moderately agree

____ (5) strongly agree

___ (99) patient refused

The next question is about **your health care team**, the doctors, nurses and therapists who are taking care of you.

10. My healthcare team involved me in decisions about controlling my pain.

____ (0) strongly disagree

____ (1) moderately disagree

____ (2) slightly disagree

____ (3) slightly agree

____ (4) moderately agree

____ (5) strongly agree

____ (99) patient refused

Table 1 Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
Magnet	725	0	1	0.43	0.50
TeachID	725	1	3	2.36	0.69
Percent of RNs with National Certification	725	0E-11	100	13.88	13.88
Percent of All Hours from Agency	725	0	23	0.74	2.19
Percent of RNs with BSN or Higher	725	0E-12	100	45.50	18.79
Total Nursing Care Hours per Patient Day	725	5.58	17.91	9.22	1.74
Gender	725	0	1	0.57	0.23
Age	725	27.67	87.50	61.28	9.02
Healthcare Team Involved Pt with Decisions	725	1	6	4.83	0.81
RN Offered Alternative Approaches	725	1	6	4	1.08
Pain Meds Available When Needed	725	2.67	6	5.41	0.59
RN Believed Pain Reports	725	2	6	5.57	0.49
Percent Pain Relief	723	0.20	1	0.72	0.13
Average Pain in 24 hrs	725	1	10	6.11	1.24
Unit Type Designation	725	2	61	5.32	7.02

Figure 1 Average Pain Rating in past 24 hours.

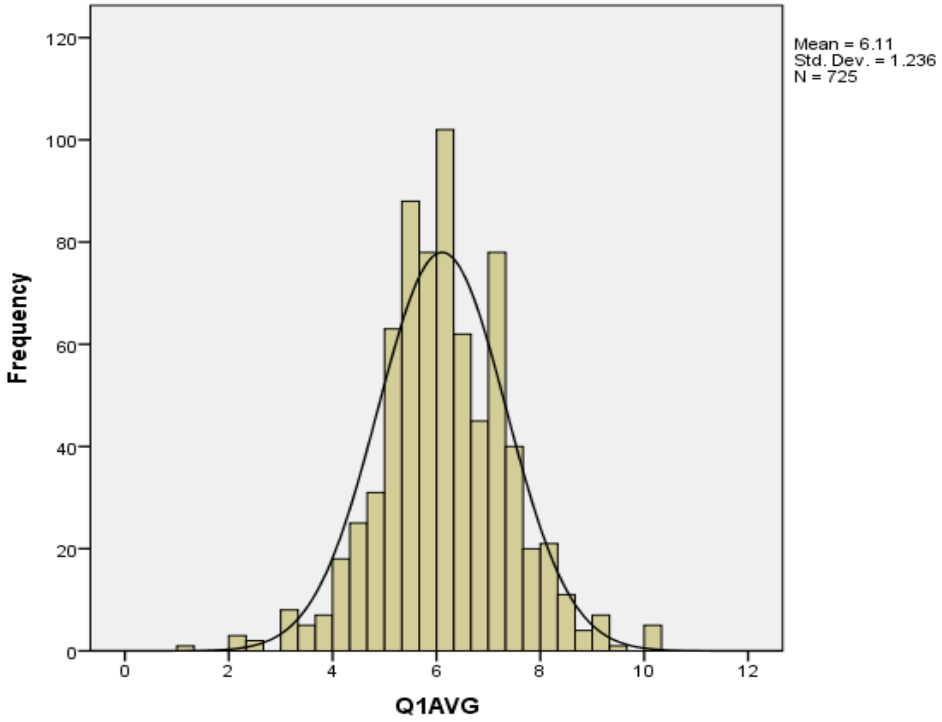


Figure 2 Percent Pain Relief.

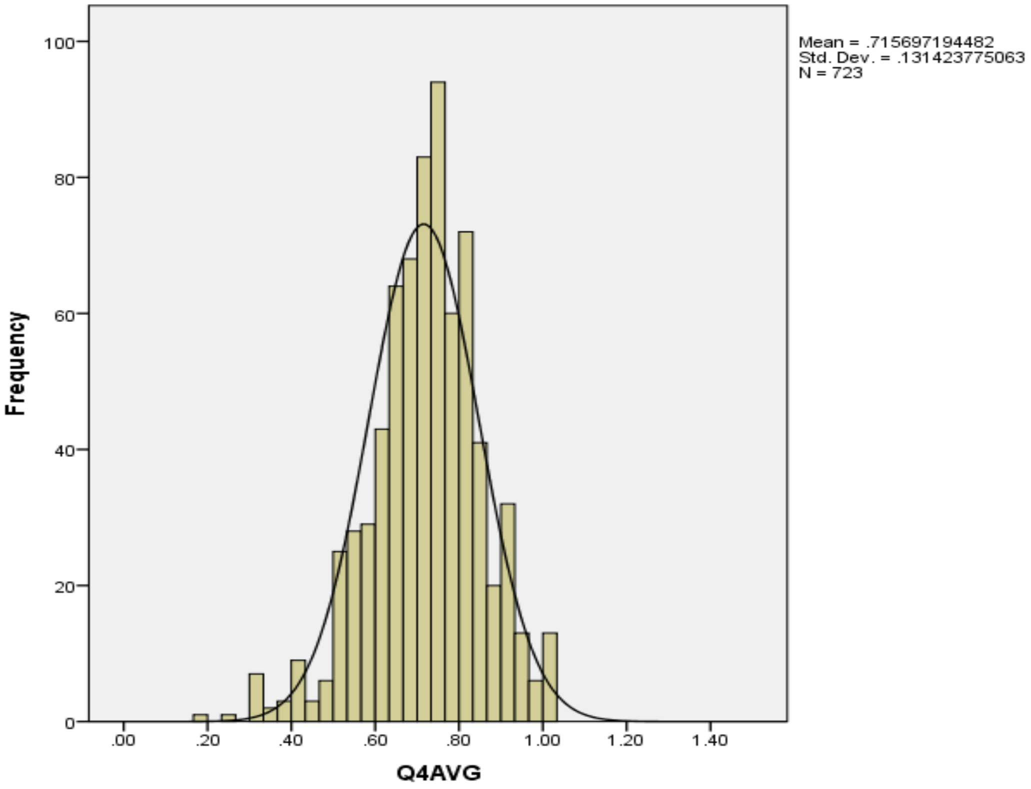


Table 2 Descriptive Statistics, by Unit Type

*Unit Type Designation		N	Minimum	Maximum	Mean	Std. Deviation
Step Down	% Pain Relief	128	0.20	1.00	0.70	0.16
	Avg Pain 24 Hrs	128	3	10	6.08	1.17
Medical	% Pain Relief	170	0.30	1.00	0.72	0.13
	Avg Pain 24 Hrs	170	2	10	6.13	1.40
Surgical	5 Pain Relief	150	0.35	1.00	0.73	0.11
	Avg Pain 24 Hrs	150	3	10	5.92	1.09
Med/Surg	Pain Relief	237	0.30	1.00	0.71	0.13
	Avg Pain 24 Hrs	238	3	10	6.31	1.17
Rehab	Pain Relief	35	0.37	1.00	0.73	0.14
	Avg Pain 24 Hrs	36	1	8	5.61	1.42
Critical Access	Pain Relief	3	0.65	0.90	0.78	0.13
	Avg Pain 24 Hrs	3	4	7	5.72	1.30

Table 3 Correlations

		Avg Pain in 24 Hrs	% Pain Relief	RN Believes Pain Reports	Pain Meds Available	RN-Suggested Alternatives	Involved Pt with	Age	Sex	% RNs with National	% RNs with BSN or Higher	% All Hours from Agency	Total Nursing Care Hours	Teach ID	Magnet	Unit Type Designation
Avg Pain in 24 Hrs	Pearson Correlation	1	-.250**	-.143**	-.220**	-.142**	-.203**	-.095*	.051	-.084*	-.016	.091*	-.187**	-.071	-.071	-.080*
	Sig. (2-tailed)		.000	.000	.000	.000	.000	.010	.169	.024	.672	.014	.000	.055	.055	.031
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
% Pain Relief From Treatments	Pearson Correlation	-.250**	1	.208**	.297**	.192**	.234**	-.075*	.057	-.016	-.022	.004	.023	.007	.005	.046
	Sig. (2-tailed)	.000		.000	.000	.000	.000	.044	.127	.672	.549	.906	.538	.844	.900	.219
	N	723	723	723	723	723	723	723	723	723	723	723	723	723	723	723
RN Believes Pain Reports	Pearson Correlation	-.143**	.208**	1	.569**	.262**	.411**	-.100**	-.030	.048	-.102**	-.135**	-.004	.009	.077*	.025
	Sig. (2-tailed)	.000	.000		.000	.000	.000	.007	.421	.194	.006	.000	.919	.815	.039	.506
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Pain Meds Available When Needed	Pearson Correlation	-.220**	.297**	.569**	1	.275**	.437**	-.016	.028	.026	-.057	-.110**	.070	-.017	.045	.062
	Sig. (2-tailed)	.000	.000	.000		.000	.000	.671	.447	.481	.127	.003	.059	.644	.229	.094
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
RN Suggested Alternative Approaches	Pearson Correlation	-.142**	.192**	.262**	.275**	1	.406**	-.027	.026	.021	-.079*	-.100**	.087*	.021	.018	.057
	Sig. (2-tailed)	.000	.000	.000	.000		.000	.466	.479	.567	.033	.007	.019	.581	.637	.122
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Healthcare Team Involved Pt in Decisions	Pearson Correlation	-.203**	.234**	.411**	.437**	.406**	1	-.070	-.024	.053	.006	-.088*	.100**	.002	.084*	.022
	Sig. (2-tailed)	.000	.000	.000	.000	.000		.060	.512	.154	.874	.017	.007	.952	.023	.562
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Age	Pearson Correlation	-.095*	-.075*	-.100**	-.016	-.027	-.070	1	.016	-.007	-.093*	-.042	.070	.183**	.001	.103**
	Sig. (2-tailed)	.010	.044	.007	.671	.466	.060		.675	.845	.012	.264	.058	.000	.976	.006
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Sex	Pearson Correlation	.051	.057	-.030	.028	.026	-.024	.016	1	-.007	-.015	-.038	-.054	.091*	.032	-.003
	Sig. (2-tailed)	.169	.127	.421	.447	.479	.512	.675		.844	.690	.307	.146	.015	.391	.944
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725

Table 3 Correlations (Cont'd)

		Avg Pain in 24 Hrs	% Pain Relief	RN Believes Pain Reports	Pain Meds Available	RN Suggested Alternatives	Involved Pt with	Age	Sex	% RNs with National	%t RNs with BSN or Higher	% All Hours from Agency	Total Nursing Care Hours	Teach ID	Magnet	Unit Type Designation
Percent of RNs with National Certification	Pearson Correlation	-.084*	-.016	.048	.026	.021	.053	-.007	-.007	1	.094*	-.076*	.035	.041	.140**	.172**
	Sig. (2-tailed)	.024	.672	.194	.481	.567	.154	.845	.844		.012	.040	.352	.269	.000	.000
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Percent of RNs with BSN or Higher	Pearson Correlation	-.016	-.022	-.102**	-.057	-.079*	.006	-.093*	-.015	.094*	1	.000	.103**	-.297**	.188**	-.079*
	Sig. (2-tailed)	.672	.549	.006	.127	.033	.874	.012	.690	.012		.994	.006	.000	.000	.033
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Percent of All Hours from Agency	Pearson Correlation	.091*	.004	-.135**	-.110**	-.100**	-.088*	-.042	-.038	-.076*	.000	1	.079*	-.002	-.167**	-.050
	Sig. (2-tailed)	.014	.906	.000	.003	.007	.017	.264	.307	.040	.994		.034	.958	.000	.177
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Total Nursing Care Hours per Patient Day	Pearson Correlation	-.187**	.023	-.004	.070	.087*	.100**	.070	-.054	.035	.103**	.079*	1	-.019	.017	-.015
	Sig. (2-tailed)	.000	.538	.919	.059	.019	.007	.058	.146	.352	.006	.034		.613	.638	.695
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
TeachID	Pearson Correlation	-.071	.007	.009	-.017	.021	.002	.183**	.091*	.041	-.297**	-.002	-.019	1	-.082*	.032
	Sig. (2-tailed)	.055	.844	.815	.644	.581	.952	.000	.015	.269	.000	.958	.613		.028	.387
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Magnet	Pearson Correlation	-.071	.005	.077*	.045	.018	.084*	.001	.032	.140**	.188**	-.167**	.017	-.082*	1	-.062
	Sig. (2-tailed)	.055	.900	.039	.229	.637	.023	.976	.391	.000	.000	.000	.638	.028		.094
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725
Unit Type Designation	Pearson Correlation	-.080*	.046	.025	.062	.057	.022	.103**	-.003	.172**	-.079*	-.050	-.015	.032	-.062	1
	Sig. (2-tailed)	.031	.219	.506	.094	.122	.562	.006	.944	.000	.033	.177	.695	.387	.094	
	N	725	723	725	725	725	725	725	725	725	725	725	725	725	725	725

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

Ta**ble 4** Dependent Variable: (Q1 Avg) Average Pain during past 24 Hrs

Independent Variables	**Unstandardized Coefficients B**	**Standardized Coefficients Beta**	**Significance**
Q5 AVG Believed Pain Reports	-0.012	-0.005	0.916
Q6 AVG Pain Meds Available	-0.307	-0.146	0.001
Q7 AVG Alternative Approaches	-0.049	-0.042	0.281
Q10 AVG Involved with Decisions	-0.145	-0.095	0.025
Q11 AVG Age	-0.011	-0.077	0.035
Q12 AVG Gender	0.298	0.056	0.115
Total Nursing Care Hrs Per Pt Day	-0.111	-0.157	0.000
Magnet	-0.105	-0.042	0.255
Teaching Hospital	-0.137	-0.076	0.044
% of All Hrs from Agency	0.034	0.060	0.101
% RNs with BSN or Higher	-0.002	-0.032	0.397
% RNs with National Certification	-0.004	-0.043	0.242
Unit Type Designation	-0.009	-0.053	0.145

Notes: R Square=0.120 Adjusted R Square=0.104

Table 5 Dependent Variable: (Q4 Avg) % Pain Relief

Independent Variables	**Unstandardized Coefficients B**	**Standardized Coefficients Beta**	**Significance**
Q5 AVG Believed Pain Reports	0.007	0.026	0.565
Q6 AVG Pain Meds Available	0.050	0.221	0.000
Q7 AVG Alternative Approaches	0.011	0.091	0.021
Q10 AVG Involved with Decisions	0.015	0.091	0.033
Q11 AVG Age	-0.001	-0.067	0.066
Q12 AVG Gender	0.033	0.058	0.101
Total Nursing Care Hrs Per Pt Day	0.000	-0.003	0.935
Magnet	0.000	-0.001	0.980
Teaching Hospital	0.003	0.015	0.691
% of All Hrs from Agency	0.003	0.050	0.175
% RNs with BSN or Higher	3.728E -005	0.005	0.890
% RNs with National Certification	0.000	-0.032	0.385
Unit Type Designation	0.001	0.033	0.371

Notes: R Square=0.012 Adjusted R Square=0.104

The Relationship Between Sleep and Night Eating on Weight Loss in Individuals with Severe Mental Illness

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Abstract

Introduction: Insomnia and night eating is associated with weight gain in individuals with Severe Mental Illness (Palmese, et al., 2011). Poor sleep, night eating, and psychiatric medications may hinder weight loss which, in turn, can sustain obesity in individuals with psychiatric disabilities.

Purpose: The study examined the relationship of sleep and avoidance of night eating on weight loss in individuals who participated in the Psychiatric Rehabilitation Program for Weight Loss.

Question: Will self-report of the frequency of getting enough sleep and avoidance of night eating predict weight loss?

Design: This secondary analysis focuses on data from participants in a weight loss intervention group (N=34) after 3 month of intervention.

Methodology: Sleep and night eating scores from the Pender Health-Promoting Lifestyle Profile-II and total score of the Night Eating Questionnaire, respectively, served as predictor variables. Changes in body weight from baseline to 3 months was the criterion variable.

Findings: No significant correlation (.354, p=0.24) was found between the Night Eating Questionnaire score and weight loss while report of sleep and weight loss were correlated (-3.44, p=0.05). Because scores on participants' perception of getting enough sleep and total score for the Night Eating Questionnaire were intercorrelated (-.507, p=0.09) and because only scores from 12 participants on the Night Eating Questionnaire were available, a bivariate regression was performed on weight loss and frequency of getting enough sleep. The frequency of getting enough sleep that accounted for weight loss was low (R^2= .119).

Discussion: Self- report of getting enough sleep is a poor predictor of weight loss. Future studies examining weight loss in this population should use a more robust measure of sleep, and an increased sample size

Introduction

Obesity is a rising concern in the United States of America. Data from The National Health and Nutrition Examination Survey in 2007-2008 shows that approximately 34.4% of American adults over the age of 20 are overweight, and another 33.9% are obese (Flegal, Carroll, Ogden, & Curtin, 2010). Individuals with severe mental illness (SMI), like schizophrenia, are not exempt from the rising trends in obesity. On the contrary, these individuals are more likely to be overweight or obese than the general population. Only 27% of the general population, compared to the 42% of a group of individuals with schizophrenia are considered obese, with a Body Mass Index (BMI) ≥ 27 (Marder et al., 2004). Risk factors for weight gain in individuals with SMI, specifically schizophrenia, are numerous including resources and knowledge deficits about a healthy diet, weight promoting anti-psychotic drugs, disruption in sleep and night eating.

Antipsychotic medications have numerous side-effects. The adverse effects of typical antipsychotics medications are severe in nature and include extrapyramidal symptoms, neuroleptic malignant syndrome, and agranulocytosis. A new classification of antipsychotics medications referred to as atypical antipsychotics, cause fewer of these severe adverse effects but come with their own side effects which can include insomnia, metabolic syndrome and weight gain.

Emerging research shows a relationship between chronic lack of sleep and hyperphagia as well as chronic lack of sleep and weight gain (Chaput, Klingenberg, & Sjödin, 2010; Koban, Sita, Le, & Hoffman, 2008; Palmese et al., 2011). Sleep loss can cause a transient state of insulin resistance, which may develop to type 2 diabetes mellitus (DM), when associated with overweight and obesity (Gutierrez & Willoughby, 2010). Sleep loss is also thought to increase appetite due to reduced levels of leptin, a hormone that is secreted from fat cells. When leptin levels are increased, as with high body fat mass and recent feedings, appetite is decreased and energy use is increased. When leptin levels are decreased which follows sleep loss, appetite may consequently increase. Another hormone that affects weight and is influenced by sleep is ghrelin, which is secreted by the stomach when there is an energy deficit to the body. In contrast with leptin, when ghrelin levels are *high*, individuals are more likely to feel an increase in hunger and have an increased appetite and consequently increase food consumption (Gutierrez & Willoughby, 2010).

Night Eating Syndrome (NES) is another condition that hinders weight loss in individuals with SMI. The condition, which was first coined by Dr. Albert Stunkard in 1955, is defined by: eating a minimum of one quarter of daily caloric intake late in the evening or at night after the evening meal; nocturnal awakenings with ingestions at least two times per week; distress or impairment of functioning; and awareness of the eating episode. Other sources also include insomnia, morning and daytime anorexia, feelings of guilt after nighttime eating, and carbohydrates as the majority of nighttime foods as part of diagnostic criteria (Allison et al., 2010; American Psychiatric Association, 2000; Stunkard, Grace, &

Wolff, 1955). Studies by Palmese et al. (2011) and Lundgren et al. (2010) found that overweight individuals with severe mental illnesses were at a high risk for Night Eating Syndrome. The pattern of intake in NES, and its association with insomnia puts the psychiatric population at great risk for weight gain especially when coupled with the appetite and sleep altering side effects of psychiatric medications.

Problem

Individuals with psychiatric disabilities die on average 25 years earlier than the general population (Marder, et al., 2004). Excess mortality is primarily by cardiovascular disease but also is influenced by other comorbid conditions such as diabetes, hypertension and obesity. Preliminary research shows a relationship between sleep and obesity which may interfere with weight loss. The relationship between poor sleep and night eating may play a role in success or failure of weight loss interventions in individuals with SMI.

Purpose

Recovering Energy through Nutrition, Exercise and Weight Loss (RENEW) (Brown, Goetz & Hamera, 2011) is a project designed to meet the weight loss needs of the underserved population of individuals with SMI. A goal of this project was to examine the efficacy of a maintenance and support program in achieving long-term weight loss in the SMI population. The purpose of this secondary review of data from RENEW, supported by the National Institute of Mental Health, is to examine if avoidance of night eating and self-report of sleep predicts weight loss.

Research Question

Will self-report of the frequency of getting enough sleep and avoidance of night eating predict weight loss?

Literature Review

Although Dr. Albert Stunkard first introduced NES in 1955, research on the topic experienced a period of relative latency for nearly half a century before researchers began to give critical attention to the disorder within the last decade and a half. The review of the literature focuses on the relationship between NES, sleep and weight loss in the general population and then summarized research with individuals who have sever mental illness.

A study by Gluck, Venti, Salbe, & Krakoff (2008) examined the prevalence of nighttime eating and its effect on weight change. Participants (N=160) were admitted to a clinical research unit where they were provided a personalized weight-maintaining diet for three days prior to testing. During the final three days at the inpatient clinic, participants had free access to special vending machines for 23.5 hours per day in addition to core condiments, beverages, breads and spreads. These vending machines were stocked with foods that had a high hedonic rating based on participant responses to an 80-item food preference questionnaire. Participants were instructed to eat whatever they wanted and whenever they wanted as long as all vended items were consumed in the vending room. In this study, participants that had food intake from the vending machines between 2300 and 0500 were considered nighttime eaters (NEs).

At baseline, in the 45 NE participants, and 99 non NE participants there was no differences between the NEs and the non-NEs groups in body weight, percentage body fat, or BMI. On average, NEs had caloric intake of ≈15% (±3) between the hours of 2300 and 0500 and 61.5% of these calories came from carbohydrates. Individuals with NE gained significantly more weight from baseline to follow-up (3.4 lbs. ± 1.8). However individuals with NE increased body weight 3.1% per year from baseline compared to the 1.5% change in non-NEs (*P*= 0.04).

Wantanabe, Kikuchi, Tanaka, & Takashashi (2010) investigated the association between short sleep duration and elevated BMI and obesity in a sample of 35,247 Japanese men and women in a longitudinal study. Self-administered questionnaires were given at baseline and again at a one year follow-up period. Obesity was defined as BMI ≥ 25 per the International Obesity Task Force proposal of adult obesity in Asians. Of the original sample, data sets for 34,852 participants were complete and used for data analysis. Researchers report 20,023 non-obese men at baseline, compared to 1,171 new cases of obesity at 1 year follow-up. BMI was found to be significantly greater in participants who reported sleep in a range of <5 hours and up to 7 hours of sleep when compared to those with 7-8 hours of sleep. Linear regression analysis showed that among men, sleep duration less than 6 hours was associated with weight gain and obesity compared with men who had 7-8 hours of sleep. Also among men, sleep duration greater than 9 hours was associated with weight gain, relative to 7-8 hours of sleep. There was no relationship between short sleep duration and weight gain and obesity at a 1 year follow-up in women.

Rao, Blackwell, Redline, Stefanick, Ancoli-Isreal, & Stone, (2009) used a cross-sectional, observational study design to explore the association between slow wave sleep (stage 3 and 4 sleep; SWS) and BMI in 2745 men ≥65 years. Researchers focused on SWS because previous research found insulin resistance after selective SWS deprivation (Tasali, Leproult, DA, & Cauter, 2008). Data were collected from single night in-home sleep studies using unattended polysomnography. Researchers found that SWS and BMI are negatively related, independent of total sleep duration; when SWS decreased, BMI significantly increased. The odds of obesity (BMI ≥ 30) were 1.4 times higher in participants in the lowest SWS quartile (0 to < 3.8% Total Sleep Time) when compared to participants in the highest SWS quartile (>16.7% Total Sleep Time). There was also an inverse relationship between SWS and waist circumference. There was no significant association between SWS and percentage total body fat or waist-to-hip ratio.

Rogers, Dinges, Allison, Maislin, Martino, O'Reardon, & Stunkard (2006) compared sleep in women with NES (n=15) with women in a control group (n=14) using polynomnographic and sleep questionnaires. Sleep and food diaries were also distributed to study participants during this 1- week outpatient study. The questionnaires included the Pittsburgh Sleep Quality Index (PSQI) and Multivariable Apnea Risk Index (MAP) to assess sleep quality and sleep disturbance; the Morningness- Eveningness Scale to indicate circadian preference; the Epworth Sleep Scale (ESS) to assess daytime sleepiness levels; and finally the Beck Depression Inventory to evaluate possible differences in depression between the NES group and the control group.

Participants with NES consumed food during nighttime awakenings while participants in the control group refrained from post- awakening food consumption. Participants with NES reported longer time falling asleep, shorter sleep duration, reduced sleep quality and increased sleep medication on the PSQI compared to the control group. On the MAP index, the NES group reported more daytime sleepiness compared to the control subjects (p=0.003). Despite no significant difference in circadian preferences, between the two groups, the NES group had reduced non-REM stage 2 and 3 sleep time compared to control group. This contributed to reduced Total Sleep Time as well as reduced sleep efficiency in the NES group.

Cappuccio and colleagues (2008) conducted a meta-analysis of 36 studies on short sleep duration and obesity in children and adults to examine the relationship of sleep duration and obesity in children and adults. Research studies were taken from Medline, Embase, AMED, CINAHL and Psychinfo. This yielded a large total sample size of 603,519 from 22 population samples in 17 different short sleep studies. Seven of 11 pediatric population samples reported a significant positive association between short duration of sleep and obesity. However, unlike studies in children, all of the studies in adults revealed a consistent and significant negative association between hours of sleep and BMI (Cappuccio et al., 2008). This is the first systematic review of research focused on short sleep studies and weight. The meta-analysis demonstrates that there is consistent data of having increased odds of being a short sleeper in the obese adult population.

Since the meta analysis by Cappuccio et al. (2008), two subsequent studies report no relationship between NES and percent weight loss. Grave, Calugi, Ruocco & Marchesini (2011) tested the effect of NES diagnosis on weight loss outcome in obesity. The intervention group was comprised of 27 women who were diagnosed with NES and had a BMI of ≥ 40 or BMI range of 30-40 and two or more medical comorbidities. Non-NES individuals were matched on gender, age, and BMI made up the control group. The 21-day treatment included: a low calorie diet; 30 min of bicycle exercise per day, and two 45-min sessions of calisthenics per week. Psycho-educational groups helped participants reduce their speed of eating. Data gathered at baseline and at a 6-month follow-up period showed that 51.4% of participants with baseline diagnosis of NES no longer met diagnostic criteria at follow-up. The percent weight loss between individuals with NES and those without NES diagnosis did not differ at 6-month follow-up.

In a sample of 68 overweight (BMI ≥25) and obese (BMI ≥30) individuals with SMI, Lundgren et al. (2010) found that night eating was not associated with BMI. Researchers suggest that the lack of association may be attributed to the restricted BMI range, and recommend that future studies included individuals with NES of all weight ranges.

Night eating in individuals with serious mental illness

Lundgren, et al. (2006) studied the prevalence of NES in a psychiatric population and its relationship to antipsychotic medication use. A sample of 399 participants from psychiatric outpatient clinics at the University of Pennsylvania, and the University of Minnesota were screened using the Night Eating Questionnaire (NEQ), and those who scored above 20 points (of a possible 56) were selected for further evaluation and the Night Eating Syndrome History and Inventory (NESHI) was used for NES diagnosis. Subjects were diagnosed with NES if one of two criteria were met: evening hyperphagia or ingestion of food after nocturnal awakening that occurred three or more times per week. More than half,121 participants, of the 205 participants that scored above 20 points on the NEQ were available for the follow-up. Of the 121 participants, 49 were diagnosed with NES, while 28 had sub-threshold NES and the 44 participants were not diagnosed with NES. The positive predictive value of the NEQ with a cutoff of 20 was 40%, but increased to 60% when the cutoff score was 38.

Lindgren and colleagues (2006) also found that a greater proportion of participants with NES were prescribed atypical antipsychotic medications than those without the syndrome (38% versus 30.8%, respectively; $\chi 2= 6.24$, df=2, p=0.04). These medications include aripiprazole, olanzapine, quetipine, risperidone, and ziprasidone. Furthermore, researchers also found that there appeared to be no difference in the percentage of participants using weight-promoting agents versus other antipsychotic medications. Researchers reported a positive relationship between NES and BMI. NES is five times higher (Wald=13.3; $p<0.001$) in obese participants (BMI ≥ 30) than in normal weight participants with psychiatric disabilities. In addition, overweight participants were 2.5 times (Wald=3.5; p=0.06) more likely to meet NES criteria than normal-weight participants.

RENEW (Brown, Goetz, & Hamera, 2011) is a weight loss program that includes a 12-weeks intensive intervention, followed by a 12-weeks maintenance phase and finally 6 months of intermittent supports. During the intervention, participants receive individualized diet plans, dietary education, 30-45 minutes of moderately intense activity 3-5 days per week, as well as frequent contact between professionals and other participants. Resources that were provided to the participants include two main-meal replacements per day. In order to promote physical activity, exercise equipment and tracking devices also were provided throughout the study.

Brown, et al. (2011) examined the efficacy of the RENEW intervention in a randomized controlled trial of 89 individuals with SMI who were completing the maintenance phase. The intervention group had an average weight loss of 5.3lbs at three months, with one participant loosing as much as 34.5lbs. At six months, the average weight loss from baseline was 4.4lbs in the intervention group. The average weight of the control group did not vary significantly at three and six months: 0.1lb weight gain and 0.1lb weight loss, respectively.

Methods

The present secondary data analysis from the Recovering Energy through Nutrition, Exercise and Weight Loss intervention will examine the relationship of NES with sleep and its effect on weight loss.

Sample

Participants from the original study were recruited from four community support programs with services to individuals with severe mental illnesses (SMI). Three of these programs were based in the Kansas City area and one program was based out of Las Vegas. A written informed consent was obtained from participants after a complete description of the study was given to those who were recruited. The study protocol was approved by the institutional review boards of the University of Kansas Medical Center and the University of Missouri-Kansas City. Participants were stratified on the use of typical and atypical antipsychotic medications and randomly assigned to the control group.

In this secondary data analysis of RENEW, only data from participants in the original intervention group from baseline to three months was analyzed. The sample included 34 adults (female=19, male=15) with psychiatric diagnoses of Bipolar Disorder, Schizophrenia Spectrum Disorder, Major Depressive Disorder (n=10, 18, 6, respectively). The average age of participants was 44.9 (range 19-64, SD= 11.85). The majority of the population is Caucasian/White (n=20), but also included African American/Blacks (n=13) and Multi-Racial (n=1) individuals as well.

Measures

The Health Promoting Lifestyle Profile II (HPLPII) was developed in 1987 to measure health behavior of participants (Walker, Sechrist, & Pender, 1987). The 52-item survey measures six dimensions of health behavior: Self-Actualization, Health Responsibility, Exercise, Nutrition, Interpersonal Support and Stress Management. One of seven items on the Stress Management subscale, asks participants to indicate the frequency they “Get enough sleep” and is ranked as “Never= 1, Sometimes= 2, Often= 3, or Routinely= 4.”

Walker & Hill-Polerecky (1996) reports the stability of the HPLPII with a three-week test-retest stability coefficient of 0.892. The alpha reliability coefficient for the total scale is 0.943 which indicates that items are measuring a similar construct. Jensen, Decker and Andersen (2006) also found a strong relationship among items on the HPLPII, with a Cronbach’s alpha of 0.92, and a Cronbach’s alpha of 0.86 on the Stress Management subscale.

Behavioral and psychological symptoms of Night Eating Syndrome (NES) are measured with the Night Eating Questionnaire (NEQ) (Allison et al., 2008). The most current version of the 13-item self-report NEQ measures nocturnal ingestions, evening hyperphagia, morning anorexia, and mood/sleep. Each item is scored from 0-4 with a total score ranging from 0-52.

The NEQ internal consistency reliability score (alpha= 0.70) is acceptable and correlates with evening caloric intake percentage, number of nocturnal ingestions, morning hunger, disturbed eating attitudes and behaviors, sleep quality, mood and perceived stress (Vander Wal, 2012). A positive predictor value (PPV) measures the likelihood that someone has NES. The scale has a PPV of 72.7% with a total questionnaire score of greater than 30. When the cutoff is lowered to 25, the PPV drops to 40.7%. Although the NEQ is a well-recognized measure to screen for NES, it does yield a high number of false positives among obese samples.

Participant weight was measured as an average of three digital readings from a Seca Platform scale, model 707. Participants were instructed to wear regular clothing, and asked to remove shoes prior to stepping on the scale.

Demographic data collected from participants included: age, gender, weight, ethnicity, education, psychiatric diagnoses, psychiatric medication use and shift work. Primary psychiatric diagnosis was based on criteria from the Diagnostic and Statistical Manual of Mental Disorders (DSM) – IV (American Psychiatric Association, 2000) and retrieved from chart data.

Procedures

Measures were administered individually to participants who completed the questionnaires and weight going from station to station in large rooms. Both the HPLIII and NEQ were read to participants compensate for reading difficulties.

Data Analysis

This secondary data analysis uses data collected from the HPLPII sleep item, total scores from the NEQ, and weight difference from baseline to three months. Descriptive statistics of scores was computed using SPSS.

Multiple regression was to be computed with weight as the dependent criterion variable and total score from the NEQ and frequency of getting enough sleep from the HPLPII as independent predictor variables.

Results

The mean sleep score from the HPLPII was 3.08 on a scale of 1-4. Scores from the Night Eating Questionnaire ranged from 4-24 with a mean of 16.3. Participants had a wide range of weight loss scores ranging from losing 34.5lbs to gaining 7.5lbs (M= -6.75, ± 10.34). Table 1 shows the ranges, means, and standard deviation for the HPLPII, NEQ, and weight loss.

Correlations were calculated among measures are shown in Table 2. A significant negative correlation of -.344 (p=.05) was found between self-report of getting enough sleep per the HPLPII and weight loss at three months (N=34) while the correlation of between NEQ and weight loss was not significant (R=.354, n=12).

A bivariate regression was calculated to determine how much sleep accounted for weight change. Results from the regression show a low R^2 of .119, indicating that sleep accounts for very little weight change.

Discussion

This is the first study of its kind to look at sleep as a predictor variable for weight loss in individuals with severe mental illnesses. This secondary data analysis assessed the relationship between sleep and night eating on weight loss in individuals in a weight loss program. Analysis of data show that there is a significant negative correlation between weight loss and self-report of getting enough sleep however self-report of sleep only predicted 12% of the variance in weight loss. There were too few participants who completed the NEQ at 3 months to determine if avoidance of night eating predicted weight loss.

The Heath Promoting Lifestyle Profile II asks about participants' perception of sleep from the past month. Scores from HPLPII sleep item ranged from 1-4 (possible range 1-4). The obtained mean value of 3.08 suggests that participants, as a whole, felt as though they were 'often' getting enough sleep. The findings in this study are not supportive of the literature that identifies a relationship between insomnia and NES (Palmese, et al., 2011).

Limitations of this study include a small sample size, and the use of measures that were inadequate in testing the hypothesis. The small obtained range of total score from the Night Eating Questionnaire was low (0-24) with the possible score ranging from 0-52. The positive predictive value of the NEQ is 62% using a cutoff score of 25 in a psychiatric population (Allison, et al., 2008). Per these guidelines, none of the participants in the present study met criteria for Night Eating Syndrome. Using a two-stage assessment of NES might provide better data, for example using the NEQ as a screening tool, and the Night Eating Syndrome History and Inventory to confirm diagnosis. Another limitation of this study is measuring sleep with a one-item question from the HPLPII. The sleep item asked participants to rate how often they got enough sleep in the past month.

In future studies, a more robust measure of sleep such as the Pittsburgh Sleep Quality Index would provide a larger range of sleep scores while measuring various aspects of sleep. Using both subjective and objective sleep data can also enrich future studies. We would also propose using a prospective study design so that sleep can be measured at regular intervals while participants were enrolled in a weight loss intervention to see if the two variables fluctuated equally.

Conclusion

Individuals with severe mental illness are at a great risk for many health issues including those conditions that are exacerbated by overweight and obesity. Compounding health deficits are problems of use of psychiatric medication, poor sleep and night eating. We found that sleep accounts for very little weight change, and is therefore a poor predictor of weight loss as it was measured in this study. Future studies are needed to further investigate the nature of these factors and determine if improving sleep would have any beneficial effects on weight loss maintenance in this population.

Table 1 Means, Standard Deviations and Obtained Ranges for HPLPII Sleep Item, NEQ, and Weight Loss

	Possible Range	Mean	Standard Deviation	Obtained Range
“Get enough sleep” from HPLPII at 3 months	0-4	3.08	.90	1-4
Night Eating Questionnaire	0-52	16.3	6.01	5-24
Weight Loss*	Not limited	-6.75	10.34	(-34.50)-(+7.50)

*3 month weight subtracted from baseline weight

Table 2 Correlations between weight loss and report of getting enough sleep, NEQ, and weight loss at three months

	NEQ Score	Weight Loss at 3 months
"Get enough sleep" at 3 months	-.507	-.344*
NEQ Score	--	.354

* Correlation is significant at the 0.05 level

References

Allison, K. C., Lundgren, J. D., O'Reardon, J. P., Geliebter, A., Gluck, M. E., Vinai, P., . . . Stunkard, A. J. (2010). Proposed diagnostic criteria for night eating syndrome. *Int J Eat Disord, 43*(3), 241-247. doi: 10.1002/eat.20693

Allison, K. C., Lundgren, J. D., O'Reardon, J. P., Martino, N. S., Sarwer, D. B., Wadden, T. A., . . . Stunkard, A. J. (2008). The Night Eating Questionnaire (NEQ): Psychometric properties of a measure of severity of the Night Eating Syndrome. *Eating Behaviors, 9*(1), 62-72.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (Revised 4th ed.).

Brown, C., Goetz, J., & Hamera, E. (2011). Weight Loss Intervention for People With Serious Mental Illness: A Randomized Controlled Trial of the RENEW Program. *Psychiatric Services, 62*(7), 800-802.

Cappuccio, F. P., Taggart, F. M., Kandala, N. B., Currie, A., Peile, E., Stranges, S., & Miller, M. A. (2008). Meta-analysis of short sleep duration and obesity in children and adults. *Sleep, 31*(5), 619-626.

Chaput, J. P., Klingenberg, L., & Sjödin, A. (2010). Do all sedentary activities lead to weight gain: sleep does not. *Current Opinion in Clinical Nutrition & Metabolic Care, 13*(6), 601-607. doi: 10.1097/MCO.0b013e32833ef30e

Flegal, K. M., Carroll, M. D., Ogden, C. L., & Curtin, L. R. (2010). Prevalence and trends in obesity among US adults, 1999-2008. *JAMA: Journal of the American Medical Association, 303*(3), 235-241. doi: 10.1001/jama.2009.2014

Gluck, M. E., Venti, C. A., Salbe, A. D., & Krakoff, J. (2008). Nighttime eating: commonly observed and related to weight gain in an inpatient food intake study. *American Journal of Clinical Nutrition, 88*(4), 900-905.

Grave, R. D., Calugi, S., Ruocco, A., & Marchesini, G. (2011). Night eating syndrome and weight loss outcome in obese patients. *International Journal of Eating Disorders, 44*(2), 150-156. doi: 10.1002/eat.20786

Gutierrez, J., & Willoughby, D. S. (2010). Slimming slumber? How sleep deprivation manipulates appetite and weight. *Nutrition Today, 45*(2), 77-81.

Jensen, L. W., Decker, L., & Andersen, M. M. (2006). Depression and health-promoting lifestyles of persons with mental illnesses. *Issues Ment Health Nurs, 27*(6), 617-634. doi: 10.1080/01612840600642919

Koban, M., Sita, L. V., Le, W. W., & Hoffman, G. E. (2008). Sleep deprivation of rats: the hyperphagic response is real. *Sleep, 31*(7), 927-933.

Lundgren, J. D., Allison, K. C., Crow, S., O'Reardon, J. P., Berg, K. C., Galbraith, J., . . . Stunkard, A. J. (2006). Prevalence of the night eating syndrome in a psychiatric population. *American Journal of Psychiatry, 163*(1), 156-158.

Lundgren, J. D., Rempfer, M. V., Brown, C. E., Goetz, J., & Hamera, E. (2010). The prevalence of night eating syndrome and binge eating disorder among overweight and obese individuals with serious mental illness. *Psychiatry Res, 175*(3), 233-236. doi: 10.1016/j.psychres.2008.10.027

Marder, S. R., Essock, S. M., Miller, A. L., Buchanan, R. W., Casey, D. E., Davis, J. M., . . . Shon, S. (2004). Physical health monitoring of patients with schizophrenia. *The American journal of psychiatry, 161*(8), 1334-1349. doi: 10.1176/appi.ajp.161.8.1334

Palmese, L. B., Degeorge, P. C., Ratliff, J. C., Srihari, V. H., Wexler, B. E., Krystal, A. D., & Tek, C. (2011). Insomnia is frequent in schizophrenia and associated with night eating and obesity. *Schizophrenia Research, 133*(1-3), 238-243.

Rao, M. N., Blackwell, T., Redline, S., Stefanick, M. L., Ancoli-Israel, S., & Stone, K. L. (2009). Association between sleep architecture and measures of body composition. *Sleep, 32*(4), 483-490.

Rogers, N. L., Dinges, D. F., Allison, K. C., Maislin, G., Martino, N., O'Reardon, J. P., & Stunkard, A. J. (2006). Assessment of sleep in women with night eating syndrome. *Sleep, 29*(6), 814-819.

Stunkard, A. J., Grace, W. J., & Wolff, H. G. (1955). The night-eating syndrome; a pattern of food intake among certain obese patients. *Am J Med, 19*(1), 78-86.

Tasali, E., Leproult, R., DA, E., & Cauter, E. V. (2008). Slow-wave sleep and the risk of type 2 diabetes in humans. *PNAS : Proceedings of the National Academy of Sciences, 105*(3), 1044-1049.

Vander Wal, J. S. (2012). Night eating syndrome: a critical review of the literature. *Clin Psychol Rev, 32*(1), 49-59. doi: 10.1016/j.cpr.2011.11.001

Walker, S. N., & Hill-Polerecky, D. M. (1996). *Psychometric evaluation of the Health-Promoting Lifestyle Profile II*. Unpublished manuscript. University of Nebraska Medical Center.

Walker, S. N., Sechrist, K. R., & Pender, N. J. (1987). The Health-Promoting Lifestyle Profile: development and psychometric characteristics. *Nurs Res, 36*(2), 76-81.

Watanabe, M., Kikuchi, H., Tanaka, K., & Takahashi, M. (2010). Association of short sleep duration with weight gain and obesity at 1-year follow-up: a large-scale prospective study. *Sleep, 33*(2), 161-167.

Examining Nurse Leader/Manager-Physician Communication Strategies: A Pilot Study

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Abstract

A shared goal of all health care providers is to provide safe and quality care (IOM, 1972). In order to provide this there needs to be an understanding of how the communication of that care is delivered (IPEC, 2011). After a literature review we found no existing studies that described specific communication strategies used by nurse leaders to navigate nurse-physician communication and collaboration. Therefore, in this study we sought to gain initial insight from nurse leaders about how they were able to successfully navigate effective communication and collaboration with physicians. This pilot study used a qualitative approach to generate nurse leader/manager-reported strategies, using an interview guide developed from a literature review of the nurse-physician communication and collaboration literature. A convenience sample of six nurse leaders/managers at a large, Midwestern hospital was interviewed. Five themes, teamwork, respect, being direct, building relationships and role modeling were generated from the interview responses that provide initial direction for understanding effective nurse-physician communication.

Introduction

Communication is power. With that power there is the potential to change lives in more ways than one. Through proper and efficient communication people are brought together, ideas are exchanged and in health care lives can be saved. A shared goal of all health care providers is to provide safe and quality care (IOM, 1972). In order to provide this there needs to be an understanding of how the communication of that care is delivered (IPEC, 2011).

Background

Nurse physician communication and collaboration is a key component in reducing medical errors and improving patient outcomes (Robinson, Gorman, Slimmer, & Yudkowsky, 2010; Farahani, Sahragard, Carroll, Mohammadi, 2011; Baggs, Schmitt, Mushlin, & Mitchell, 1999). The Inter-Professional Education Collaboration Expert Panel has established that inter-professional team competencies are key to improving nurse-physician communication (2011). The panel stated that professional hierarchies created by demographics and professional differences create a dysfunctional environment for working together and communicating (IPEC, 2011). This panel included sponsors from the following inter disciplinary organizations: American Association of Colleges of Nursing, American Association of Colleges of Osteopathic Medicine, American Association of Colleges of Pharmacy, American Dental Education Association, Association of

American Medical Colleges, and Association of Schools of Public Health. Therefore it is important learn how to give efficient feedback and receive information to function effectively as a team in the hospital (IPEC, 2011). As will be described below, satisfaction with nurse-physician communication is likely to improve nurse job satisfaction and retention. However, as will be discussed in more detail below, no study examines communication strategies used by nurse leaders to successfully navigate relationships with physicians. After a review of selected relevant literature, the study's method, sample, findings, and limitations will be discussed.

Literature Review

During the literature review several studies were found to support the idea of improving patient outcomes by improving communication and collaboration between interdisciplinary teams. Nurses and physicians expressed how patients benefited when team members came together to compare patient data and problem solve (Robinson, et al, 2010). Also collaborative medical teams have been shown to have a favorable impact on staff morale and patient satisfaction (Farahani, et al, 2011). Furthermore, medical ICU nurses' reports of collaboration were associated positively with patient outcomes (Baggs, et al 1999).

The review also found that increased job satisfaction was a factor that correlated with improved interdisciplinary collaboration. Over 60% of the variance in nurses' job satisfaction was explained by the combination of practice environment factors and RN/MD communication, providing compelling evidence of the importance of the work environment for nurses' job satisfaction (Manojlovich, 2005; Rosenstein, 2002; Zangaro & Soeken, 2007). Three outcomes were identified from RNs/MDs collaborating: improved patent care, maximizing information and plan of care, and feeling better in the job which related to a pleasant work atmosphere and learning (Baggs & Schmitt, 1997).

Further information gained from the literature review was strategies already in place to improve communication. One tool used is known as SBAR, which stands for situation, background, assessment and recommendation. SBAR is used during change of shift and in critical situations as a way to break down exactly what information you need to give when calling the physician or to use when transferring information between providers. It has been shown to improve safety, and quality of care, while improving communication (Beckett & Kipinis, 2009). Some physicians have given feedback about the recommendation portion and not wanting a medical recommendation from a nurse before they have assessed the patient so some places have turned recommendation into, "I need you to come assess now," instead of, "this is what I recommend we do." (Woodhall, Vertacnik,

& MacLaughlin, 2007). This tool is also used between providers during hand off of care at the end of a shift.

Another tool used for improving communication is the electronic medical record (EMR). The EMR was developed to improve patient outcomes and make charting more legible. However studies show that a lack of documentation and narrative notes can lead to harmful outcomes (Green & Thomas, 2008). In addition, the EMR cuts back on face-to-face communication between nurses and physicians, which can lead to misunderstandings about orders (Robinson, et al, 2010). After the literature review was completed it was determined that no existing studies had described specific communication strategies used by nurse leaders to navigate nurse-physician communication and collaboration confirming a need for this study.

Purpose

In this study we want to gain initial insight from nurse leaders about how they were able to successfully navigate effective communication and collaboration with physicians. The research question is: What are the strategies used by nurse managers for positive collaboration with physicians?

Methods

This pilot study uses a qualitative approach to generate nurse leader/manager-reported strategies. We used an interview guide developed from a literature review of the nurse-physician communication and collaboration literature. A convenience sample of six nurse leaders/managers at a large Midwestern hospital was interviewed. The interview process lasted about 30-45 minutes per subject. Notes were taken at each interview for reference during the thematic analysis. Each interview began with an introduction of the interviewer, preview of the study, and goals. The following are the questions each participant was asked during their interview.

- What type of unit do you work on: nurse to patient ratio, number of patients, and number of residents rounding on unit per day?
- What type of educational preparation do you have for your current job position?
    - Length of time in current positions, other leadership positions, and overall nursing experience?
- How do you define communication and collaboration?
- How can you tell when interactions between RNs/MDs are collaborative? (Baggs & Schmitt, 1997)

- How would you describe the organizational culture where you work? (Manojlovich, & DeCicco, 2007)
    - What are your key values and your organizations key values?
- What communication strategies do you personally use to work effectively with physicians?
    - When a conflict arises how do you solve it without tension?

Results and Discussion

After analyzing all of the responses given during the interviews recurring ideas and words were identified. Several themes were then generated that provide initial direction for understanding effective nurse-physician communication and collaboration. The five established themes from the interviews are: teamwork, respect, being direct, building relationships, and role modeling.

Teamwork

One of the most repeated words used by all six managers in regards to positive communication and collaboration was teamwork. When the nurse and physician work together for the shared common goal then positives outcomes are gained. Specifically "teamwork" was cited by all manages as a key value to the organizational cultures of their individual units. As Nurse Manager A stated, her definition of collaboration is " Working together as a team with a common goal in mind". As Manager B puts it, " Interactions are collaborative when both sides work to be collegial and focus is on the outcome." Manager C states that the relationships are so well established on the unit that, " The nature of the unit is empowering, there is not a subordinate relationship between physicians and nurses." When the nurses and physicians work together with effective communication for the shared common goal of positive patient care then positives outcomes are more likely to be gained.

Respect

The second most common word or ideal used by the managers was respect. When asked the question what are strategies you use for effective communication? All six managers replied with the word respect somewhere in their answer. The following quotes are examples of how to establish that respect. Nurse Manager C stated in response to how to handle conflict, " First be respectful and use a close door policy, handle the resolution off the unit separate from the patient care area." Manager D stated, " Don't use a demeaning attitude and remain positive during the collaboration to keep the attitude of the conversation positive by having mutual respect." Manager B says that to solve a conflict, “Apologize, hear the other party out, take ownership, and come back when cooled off to resolve the issue. Remain calm, cool and collective and always have ownership of your mistakes.” When all of the parties involved feel respected collaboration and communication will remain positive and therefore effective.

Being Direct

When asked the question about what strategies are used during collaboration a statement or idea used by five out of the six managers was “be direct”. Manager D repeated several times during his interview to, “be clear and concise, know the information beforehand.” Manager B stated, “ Use objective data only and keep it short and to the point”. Manager A stated, “ Be direct with expectations of the outcomes you want as to avoid the potential for conflict to arise”. Overall the idea was that the physicians are busy and are receiving multiple contacts from different interdisciplinary team members therefore go into the conversation with all the background information and be direct. Then the conversations will usually have a more positive outcome for all parties involved, including the patient.

Building Relationships

A very common theme from five of six managers was to build a relationship with the physician in order to obtain a more positive collaboration. As Manager E put it, “The use of small talk is key to building a relationship I simply listen to what they have to say and if something in their personal life is said, I feed off that.” Manager F stated, “On our unit we hold a new resident orientation where all the residents and nurses get a chance to meet and mingle and build a relationship before they even begin working with our patients.” Manager A said in response to how to build a relationship, “ Build relationships on personal levels and have multiple conversations with the same physician, that way both parties become familiar with one another.” When collegial relationships are established trust is built and then effective communication and collaboration is able to come with ease.

Role modeling

During the interviews another question was asked that was not officially listed on the guide but was brought up during each interview. It was how does your unit provide resources to new hires on how to establish communication/ collaboration skills with the physicians? All six managers responded with the same phrase or idea, role modeling. They all discussed how the new hires are paired with preceptors who role model proper communication and collaboration skills with physicians. Therefore, over the course of their orientation the new hires see and then practice with their preceptors the skill of communication and collaboration.

Limitations

For this pilot study the limitations include sample size, type of hospital, and the fact that only nurse managers were interviewed. As this was a pilot study, only nurse managers were interviewed. In addition, all participants were from the same hospital. The hospital is large and a teaching institution. Larger sample sizes may have revealed other responses or themes. In addition, there may be differences in responses from managers at community-based hospitals in contrast to teaching hospitals. Last, only one part of the nurse manager-physician dyad was interviewed, the nurse manager.

Direction for Future Research

In order to gain more information on how to have positive communication and collaboration between the different disciplines with in health care, there will be a need for further studies that include interviewing other disciplines. Specifically, it will be important to study physician's perspectives on communication with nurses. It would also be valuable to interview other disciplines with direct patient care since the current health system utilizes multiple professions to provide care. In order for patient outcomes to be positive there needs to be positive communication among all of the professions.

Second, nurses at other hospitals such as non-teaching institutes and community hospitals should be interviewed. There may be differences in how physicians and nurses interact in other agencies. At teaching institutes there is always an attending, fellow, and resident at the hospital for face-to-face communication. At some smaller community hospitals the physician goes home at night and the nurses have to call or page them. This can create a barrier to effective communication that was not explored during this study.

It will also be insightful to interview nurses with different educational backgrounds and different roles such as DNP, MSN, BSN and ADN, as well as expert nurses compared to new graduate nurses to see the variation between education and experience. This would help determine if education or experience has an effect on the communication and collaboration skill development of nurses. The question would focus on whether more experience leads to a better development of communication skills and more time to build relationships with physicians in order to have a more positive outcomes with collaboration.

Conclusion

In conclusion the need for studying communication and collaboration has the potential to have a huge impact on patient care. When the communication is effective the care will more likely be effective. When all parties involved know what they need to do and the interventions are carried out appropriately more lives will be saved. This study was able to give insight in strategies for positive communication/collaboration between nurse managers and physicians, as well as how to gain these skills and then what to do when the collaboration is not positive in order to then make it positive. All of these approaches will provide valuable information to newly graduated nurses, physicians and other ancillary staff who deal with direct patient care.

References

Baggs, J.G., & Schmitt, M.H., (1997). Nurses' and resident physicians' perceptions of the process of collaboration in a MICU. *Research in Nursing & Health*, 20, 71-80.

Baggs, J.G., Schmitt, M.H., Mushlin, A.I, Mitchell, P.H., Eldredge, D.H., Oakes, D., &

Hutson, A.D., (1999). Association between nurse-physician collaboration and patient outcomes in three intensive care units. *Critical Care Medicine, 27*, 1991-1998.

Beckett, C.D., & Kipinis, G. (2009) Collaborative communication: Integrating SBAR to improve quality/patient safety outcomes. *Journal of Healthcare Quality, 31*(5), 19-27.

Green, S.D., & Thomas, J.D., (2008) Interdisciplinary collaboration and the electronic medical record. *Pediatric Nursing, 34*(3), 225-228.

Farahani, M.A., Sahragard, R., Carroll, J.K., & Mohammadi, E., (2011). Communication barriers to patient education in cardiac inpatient care: A qualitative study of multiple perspectives. *International Journal of Nursing Practice, 17*, 322-328.

Institute of Medicine (IOM), (1972). Educating for the health of team. Washington, D.C.: National Academy of Sciences.

Interprofessional Education Collaboration Expert Panel (IPEC), 2011. Core Competencies for Interprofessional Collaborative Practice: Pre-publication recommendations. Washington, D.C.

Manojlovich, M. (2005). Linking the practice environment to nurses' job satisfaction through nurse-physician communication. *Journal of Nursing Scholarship, 37:4*, 367-373.

Manojlovich, M., & DeCicco, B., (2007). Healthy work environments', nurse-physician communication, and patients' outcomes. *American Journal of Critical Care, 16*, 536-543.

Robinson, F.P., Gorman, G., Slimmer, L.W., & Yudkowsky, R., (2010). Perceptions of effective and ineffective nurse-communication in hospitals. *Nursing Forum, 45*, 206-216.

Rosenstein, A.H., (2002). Nurse-Physician relationships: Impact on nurse satisfaction and retention. *The American Journal of Nursing, 102*, 26-34.

Woodhall, L.J., Vertacnik, L., & MacLaughlin, M. (2008). Implementation of the SBAR communication technique in a tertiary center. *Journal of Emergency Nursing, 34*(3), 314-317.

Zangaro, G.A., & Soeken, K.L. (2007). A meta-analysis of studies of nurses' job satisfaction. *Research in Nursing & Health, 30*, 445-458.

Comparison of Personal, Health and Family Characteristics of Children With and Without Autism

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Abstract

Today it is reported that one in 88 children in the U.S. has been diagnosed with autism spectrum disorder (ASD), with rates continuing to rise. Early diagnosis and intervention are imperative, as well as a systematic way to identify characteristics of children that put them at risk for ASD as well as associated comorbidities. Few studies have examined whether the health status of the child or the type of health insurance impacts the diagnosis and intervention. The aim of this study is to examine and compare the personal (child), family, and health status characteristics of children (< 18 years) with autism with a matched sample (age and gender) of children without autism as reported in the National Health Interview Survey (NHIS): 2009. A descriptive, exploratory study with secondary analysis was performed using data from the NHIS: 2009. Frequencies, chi-square, and ANOVA were used in data analysis. In this study there was a higher proportion of children with autism residing with biological, adoptive, and step parents. The study also reveals that children with autism have a significantly ($p<.05$) higher incidence of specific comorbidities such as developmental delays, learning disabilities/ADHD, and seizures, a higher number of health care visits, as well as lower average family health status scores. Identifying characteristics that are common among children with autism will help identify other health problems associated with ASD, create a systematic way to identify potential risks, and serve as a baseline for early intervention programs.

Introduction

The Centers for Disease Control and Prevention (CDC, 2012) reports that one in 88 children in the U.S. has been diagnosed with autism spectrum disorder (ASD), and rates continue to rise (CDC, 2012). Early diagnosis and intervention are imperative, as well as a systematic way to identify characteristics that put children at risk for ASD and other comorbidities. Few studies have examined whether the health status of the child or the type of health insurance impacts the diagnosis and intervention. The overall aim of this study is to examine and compare the personal (child), family, and health status characteristics of children (< 18 years) with autism with a matched sample (age and gender) of children without autism as reported in the National Health Interview Survey (NHIS): 2009.

Andersen's Model of Health Service Utilization (1995) is used as the guiding framework for the study (See Figure 1). Anderson's theory posits that predisposing characteristics impact enabling characteristics, and enabling characteristics impact need characteristics. The review of the literature will be based on the variables identified as part of the guiding framework. For the purpose of my study the predisposing characteristics include child and family demographics and personal characteristics. For the enabling characteristics insurance and income were included because they remain unsupported by any studies found in the literature. For the need characteristics the health status of the child and the health status of all members of the family were included, as well as the child's specific diagnoses and types of health care visits.

Figure 1. Theoretical Framework adapted from Andersen's Health Service Utilization Model

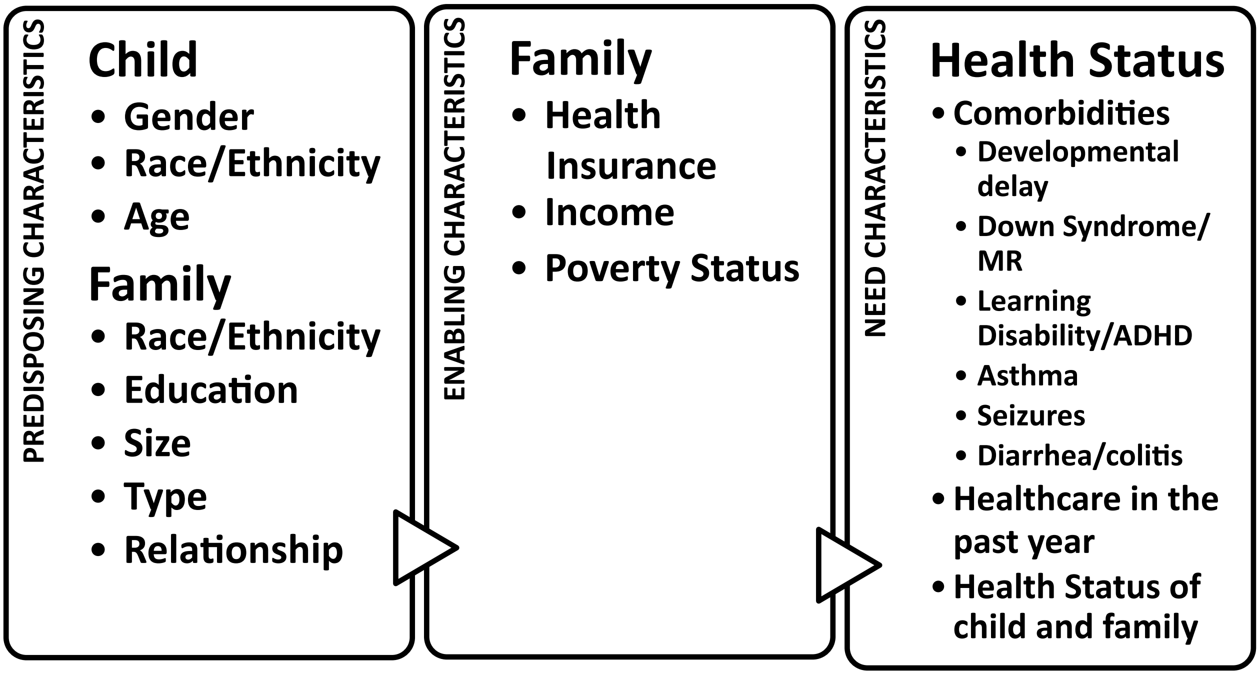

Figure 1. The individual determinants of the Health Service Utilization Model served as a guiding framework for the study. Adapted from Revisiting the Behavioral Model and Access to Medical Care: Does it matter? Andersen R.M. (1995), *Journal of Health and Social Behavior*, 36, p 7.

Literature Review

Predisposing Characteristics

Gender. Little is known about the specific characteristics that put children at risk for ASD. However, there have been consistent findings amongst researchers and clinicians that males are more likely than females to be diagnosed with ASD. One comprehensive review of 43 studies found the average male to female to population ratio for autism to be 4.2:1 (Fombonne, 2009). A recent study in 2012 conducted by the CDC found that the prevalence of ASD among boys is 1 in 54, making boys five times more likely than girls to have ASD. (CDC, 2012).

Race. Substantial research between the association of race and ASD is lacking. In examining the associations of ASD with socioeconomic factors, Thomas et al. (2011) found that the incidence of autism was higher among white and Asian children, than in Black and Hispanic children. However, when they controlled for income, there was no association between race and prevalence of ASD. Previously, there have been other studies that found Latino children have lower prevalence of ASD (Croen, Grether, Hoogstrate, & Selvin, 2002; Liptak et al., 2008). Mandell et al. (2009) found that later diagnosis of ASD is associated with minority race and ethnicity status.

Parental education. Rai et al. (2012) conducted a population-based study to compare demographics of children with an autism spectrum disorder (ASD) and their families compared to a matched sample of children without ASD and their families. Study findings revealed that families with lower prenatal household income and parents who held manual and unclassified occupations put children at greater risk for ASD (Rai et al., 2012). They also found no association between education of parents and diagnosis of an ASD. The conflicting and unclear results of multiple studies illustrate the need for more research to gain better insight into the effect demographics have on the diagnosis of ASD.

Enabling Characteristics

Health insurance. According to the Autism Society of America (ASA) the cost of ASD for an individual over their entire lifespan is approximately 3.2 million dollars (ASA, 2007). Health insurance coverage for the different therapies that are beneficial to children with ASD varies from state to state. Insurance coverage depends on the state's stance on the effectiveness of the therapies. For example, some states, like Pennsylvania and Arizona, have Blue Cross Blue Shield coverage for a certain therapy called applied behavioral analysis, but have a per year cap that limits how much can be spent on the therapy and specifies the ages for when coverage stops (Atlantic Information Services, 2008).

For example, in Kansas, there has been no requirement that private insurance cover any services that are used to provide autism therapies. However, a law recently passed in Kansas gives state employees coverage for ASD therapies that are deemed medically necessary. This law, however, also has a cap of $36,000 a year until age seven and $27,000 a year until age 19 (Autism Votes, 2011). Currently, the Kansas Senate is working on passing a bill that will broaden the current state employee plan that covers treatments for ASD to all state-regulated group plans (Autism Votes, 2012). Additionally in Kansas, there is an autism waiver given by Medicaid that will give needed support for families for their child to receive early, intensive intervention for autism. This could decrease overall costs of therapies in life by two-thirds (ASA, 2007). Without insurance, children who have ASD may not be seen by a qualified health care provider and their diagnosis of ASD may not occur until years later. Early diagnosis and intervention is imperative for the success of children diagnosed with ASD and without insurance to cover early doctor visits these children may not receive necessary care for them to reach their full potential.

Income. The relationship between socioeconomic status and ASD is unclear and few studies have supported any association between the two. Thomas et al. (2011) studied the diagnosis of ASD in children and examined the correlation with median income. According to the study findings, as income increased the incidence of ASD diagnosis increased. This relationship could be attributed to children from families with higher socioeconomic status were diagnosed at an earlier age and had a higher number of evaluations. The prevalence of children with ASD with incomes < $30,000 was 7:1; for incomes $30,000 to $60,000 was 9:1; for incomes $60,000 to $90,000 was 13:4; and for incomes > $90,000 was 17:2. The investigators also found that children in families with higher income have a higher incidence of mild and severe impairment associated with ASD; however, children with moderate impairment did not follow the same trend with income (Thomas et al., 2011). These findings could lead one to think that having higher income would result in increased access to care which could play a role in diagnosis and interventions.

Need Characteristics

Comorbidities. Developmental delays in social skills, behavior, and cognitive skills are the most pronounced symptoms in children with ASD. These delays begin to appear between eighteen months and three years of age. The severity of developmental delays varies with each child, and signs and symptoms appear at different ages. Developmental delays cannot be treated pharmacologically but instead are treated by behavior therapy and educational interventions. These therapies do not cure ASD but instead help the child in the areas of speech and behavior so that they may be “mainstreamed” into schools with other children (KidsHealth, 2011).

Mental retardation is the most common comorbidity seen in children with ASD. However, the 4:2 male to female ratio declines as mental retardation increases. One study (Yeargin-Allsopp et al., 2003) found that the male to female ratios in children with ASD among three to ten year olds were 6.7:1 among children without intellectual disability; 4.4:1 in those children with IQs from 50–70, and 1.3:1 among those children with IQs less than 20 The findings reveal that as the severity of mental retardation in children with ASD increases, the likelihood of having mental retardation is just as common in females as it is in males despite males having higher incidence of ASD.

Three other comorbidities found commonly in children with ASD are epilepsy (seizures), sleep disorders (insomnia and waking in the night), and GI disorders. Epilepsy is found in about one-third of children diagnosed with ASD. In a study in California, it was found that children with autism have almost three times more chance of mortality from epilepsy than children with epilepsy without autism (Pickett et al., 2011). Sleep disorders are more common among children with ASD than normally developed children and can aggravate their autism symptoms (Siversten et al., 2011). Another study (Adams et al., 2011) found that 70% of the children with ASD had gastrointestinal (GI) issues and symptoms compared to 28% of the children with normal development. The investigator hypothesized that GI symptoms may exacerbate ASD symptoms.

Health status. No studies could be found that examined the health status characteristics of children with ASD. Similarly, no studies were found on whether there are differences between the health status of the members of families who have children with autism and those that do not. Further research is needed to see if a diagnosis of ASD results in differences in the health status of the child as well as their family members.

Research Questions

The limited research that is available on child, family, and health status of the child with ASD serves as the basis for this study. Two research questions will be explored: (a) What are the child, family, and health status characteristics of the children with autism spectrum disorder (ASD) as reported in the National Health Interview Survey (NHIS, 2009)?; and (b) Using a stratified random sample based on age and gender, are there differences in the child, family, and health status characteristics between children with ASD and children without ASD?

Methods

This exploratory study used a secondary analysis of National Health Interview Survey (NHIS): 2009 to compare children with autism with a matched sample (age and gender) of children without autism. The NHIS is conducted annually by the National Center for Health Statistics. The interviewers visit 35,000-40,000 households across the country and collect data about 75,000-100,000 individuals (NHIS, 2011). The NHIS is a survey conducted by personal interviews that covers a wide range of health topics including information about children with autism.

Sample

From the NHIS: 2009, 112 children (< 18 years) were identified with ASD. Children without ASD (*n* =112) were randomly selected from the remaining children (*n*=10,997) and matched based on gender and age by year.

Measures

The predisposing measures that were used from the NHIS: 2009 for the child was child's *age* by year (*range* = 1-11), *gender* (male = 1; female = 2), *child/family race* (white = 1; African American = 2; American Indian/Alaskan native = 3; Asian = 4; all other races= 5); and *child/family ethnicity* (all Hispanic groups = 1; nonHispanic = 0). Other family characteristics included *family size* (the number of family members living in the household) and highest *education* of the household (less than high school =1; high school or GED = 2; some college/vocational/no degree = 3; BS or higher degree = 4). Other family characteristics that were examined were *relationship* to the child (biological/adoptive/step parents = 1; grandparent = 2; aunt/uncle = 3; brother/sister = 4; other = 5) and *family type* (single = 1; parents married or cohabitating = 2; single parent with other adult with child = 3).

The enabling measures included *income* categories ($0-$34,999 = 1; $35,000 – 74,999 = 2; $75,000 – 99,999 = 3; $100,000 or greater = 4) and *ratio of income to poverty* (less than 1.00 = 1; 1.00-1.99 = 2; 2.00-3.99 = 3; 4.00 and over = 4). *Insurance type* was operationalized into eight categories (no insurance = 0; Medicare = 1; Medicaid = 2; private insurance = 3; military coverage = 4; State/government sponsored plan = 5; Medicare/private = 6; Medicare/Medicaid = 7; Medicare/military = 8).

The need variables included *comorbidities*, *health care visits in the past year*, and *health status* of the child and family. Identified from the literature, the *comorbidities* included were developmental delay, Down's Syndrome/mental retardation, learning disability/ADHD, asthma, seizures, and diarrhea or colitis in the past year and were operationalized as yes = 1 and no = 0. *Health care visits* in the past year (yes= 1; no = 0) included well child visits to physician, nurse practitioner/physician assistant visits; mental health specialist or physician visit for emotional/behavioral problems; other physician specialist visit; emergency room/department visits; home care visits, and flu shot in past year.

The *health stat*us of the child (worse = -1, same =0, better = 1) and the *health status of the family* members ranged from one (poor) to five (excellent). An average was created by multiplying the number of family members who reported each response respectively from one to five, summing the total across each response and dividing by the number of family members. The average ranged from one (poor) to five (excellent).

Data analysis

Frequency statistics using SPSS 18.0 were used to answer the first research question: What are the child, family, and health status characteristics of the children with autism spectrum disorder (ASD) as reported in the NHIS: 2009. For the second research question, *Analysis of Variance* (ANOVA) and *Chi Square* statistics were used to determine if there were differences in the child, family, and health status characteristics between children with ASD and children without ASD.

Results

There were 224 children equally divided between children with ASD and children without ASD in the matched sample obtained from the NHIS: 2009. The results for the first research question, 'what are the child, family, and health status characteristics of children with autism?' are reported in Tables 1 through 3. There is a higher incidence of ASD in males and as one would expect the majority (79%) of our sample were males, predominately white children and parents (76% and 80%, respectively), and one-fifth of the children (22%) were Hispanic. The majority (92%) of the children with autism had either a biological, adoptive or step parent report their ASD in the survey, and 56% of the children had parents who were either married or cohabitating. Approximately two-fifths (41%) of the children with ASD had parents with an education of a bachelor's degree or higher (See Table 1).

In the ASD sample, slightly more than one-third (38%) reported incomes between $35-75,000 but 28% reported incomes less than $35,000. About one-third (32%) reported incomes that were 2-3 times the poverty level and less than one-fifth (18%) reported income to poverty ratios less than 1.00. The majority of the families (60%) reported having private insurance but 17% reported they had no insurance (See table 2).

A majority of the children with ASD reported a diagnosis of developmental delay (73%) or a learning disability or ADHD (85%). Children with ASD had an average of 3.66 (range 0-8) office visits within the past year, and 79% had a well-child checkup. Within the past year, 60% of the sample had been seen by a mental health professional or physician for behavioral or emotional problems and 91% were seen by a physician specialist for comorbidities. For the health status scale of -1 (worse) to 1 (better), children with ASD reported their health status stayed about the same (M=.27). The families of children with ASD reported "good to very good" health (M=6.35) across all family members that included the child diagnosed with ASD (See Table 3).

Table 1 Predisposing Characteristics of the Child and Family Comparing Child with/without Autism

Predisposing Characteristics	**Children without Autism (*n*=112)**		**Children with Autism (*n*=112)**		**Statistic**
Child	***n***	**%**	***N***	**%**	**X^2**
Gender (males)	88	78.6	88	78.6	NS
Hispanic	29	25.9	25	22.3	NS
Race					NS
White	75	67	85	75.9	
Black	22	19.6	18	16.1	
Indian American	1	.9	1	.9	
Asian	8	7.1	4	3.6	
Multiple Race	6	5.4	4	3.6	
	M (SD)	***Range***	***M (SD)***	***Range***	***t-test***
Age	9.62 (4.52)	1 to 17	9.63 (4.52)	1 to 17	NS
Family	***n***	**%**	***N***	**%**	**X^2**
Relationship to Child					7.79
Parent-biological, adoptive, or step	95	84.8	103	92.0	p= .10
Grandparent	11	9.8	6	5.4	
Aunt/uncle	3	2.7	1	.9	
Brother/sister	3	2.7	2	1.8	
Family type					NS
Single parent w/ child	26	23.2	18	16.1	
Parents married or cohabitating w/ child	48	42.9	63	56.3	
Single parent w/ other adult w/child	38	33.9	31	27.7	
Parent Hispanic	30	26.8	23	20.5	NS
Parent Race					NS
White	80	71.4	89	79.5	
Black	24	21.4	17	15.2	
Asian	7	6.3	4	3.6	
All other	1	.9	2	1.8	
Highest Education of Household					NS
Less than High School	8	7.1	7	6.3	
HS or GED	27	24.1	16	14.3	
Some college, vocational, AA	44	39.3	43	38.4	
BS or higher	33	29.5	46	41.1	
	M (SD)	***Range***	***M (SD)***	***Range***	***t-test***
Family size	3.97 (1.22)	2-8	3.98 (1.32)	2-9	NS

Key: NS = Non-significant

Table 2 Enabling Characteristics of the Child and Family Comparing Child with/without Autism

Enabling Characteristics	**Children without Autism (*n*=112)**		**Children with Autism (*n*=112)**		**Statistic**
	n	**%**	***N***	**%**	***X*²**
Income					NS
0-34,999	30	26.8	31	27.7	
35,000-74,999	33	29.5	42	37.5	
75,000-99,999	18	16.1	12	10.7	
100,000 or greater	24	21.4	22	19.6	
Ratio of income to poverty status					NS
<1.00	17	15.2	20	17.9	
1.00-1.99	19	17.0	20	17.9	
2.00-2.99	36	32.1	36	32.1	
4.00 and over	31	27.7	27	24.1	
Insurance Type					NS
None	23	20.5	19	17.0	
Medicare	2	1.8	2	1.8	
Medicaid	12	10.7	10	8.9	
Private	70	62.5	67	59.8	
Military coverage	1	.9	2	1.8	
State sponsored/Gov.	3	2.7	8	7.1	
Medicare/private ins. /military	1	.9	1	2.7	
Medicare/Medicaid	0	0	3	.9	

Key: NS= Non-significant

Table 3 Need Characteristics of the Child and Family Comparing Child with/without Autism

Need Characteristics	**Children without Autism (n=112)**		**Children with Autism (n=112)**		**Statistic**
Health Status	**n**	**%**	**N**	**%**	**X^2**
Diagnosis					
Developmental delay	4	3.6	82	73.2	114.83**
Down Syndrome/MR	1	.9	24	21.4	23.82**
Learning disability/ADHD					
Asthma	15	13.4	95	84.8	114.32**
Seizures	18	16.1	25	22.3	NS
Diarrhea or colitis in past	0	0	7	6.3	7.23*
year	1	.9	6	5.4	NS
Talked to Health Professional in past year					
NP/PA	1	.9	0	0	NS
Mental Health professional/MD	9	8.0	67	59.8	66.99**
MD specialist	83	74.1	102	91.1	11.21*
Health care in past year					
Well-child checkup	87	77.7	88	78.6	NS
ER/ED visit	16	14.3	27	24.1	NS
Home Care	0	0	10	8.9	10.47*
Flu shot	33	29.5	37	33.0	NS
	M	***Range***	***M (SD)***	***Range***	***t-test***
Number of office visits in past year	2.06 (1.45)	0 to 7	3.66 (2.55)	0 to 8	5.78**
Child health status in past year (response options: -1=worse, 0=same, 1=better)	.16 (.42)	-1 to 1	.27 (.50)	-1 to 1	1.74 *p* = .08
Average family health status score (response options: (1=poor health, 2=fair health, 3=good health, 4=very good health, 5=excellent health)	4.16 (.79)	2.33-5	3.65 (.79)	1-5	4.2**

Key: **p<.001; *p<.01; NS= Non-significant

For the second research question, the differences between children with autism and a matched sample of children without autism were explored. Primarily there were no significant (*p*<.05) differences between groups among the predisposing child or family characteristics (e.g. race, parent race, family type, and highest education of household). Although not significant (*p*=.10), there was a higher proportion of children with autism whose biological, adoptive, or step parent were the primary interviewee (See Table 1). For the enabling characteristics, there were no significant (p<.05) differences between the two groups on income, income/poverty ratio, or insurance type (See Table 2).

For the need characteristics shown in Table 3, children with autism reported a significantly higher incidence of diagnosis of developmental delay (p<.001), Down Syndrome/mental retardation (p<.001), learning disabilities/ADHD (p<.001), and seizures (p<.01). Children with autism also reported a significantly higher number of visits to MD and Mental Health professionals for emotional or behavioral problems (p<.001), physician specialist for other comorbidities (p<.01), and home care visits (p<.01). Children with autism had on average 1.66 more office visits per year than children without autism. The average health status for the families of children with autism was significantly lower (M=3.65) than families of children without autism (M=4.16). Children with autism reported a slightly higher but insignificant health status than children without autism (See Table 3).

Discussions and Conclusions

Although there were no significant differences amongst the chosen predisposing characteristics, the trend toward more children with autism being reported by biological, adoptive, or step parents was an unexpected finding. This could be attributed to the notion that parents are more "in tune" to their child's behavior and perhaps notice ASD symptoms more quickly. Previous studies have not reported significant associations between socioeconomic status and diagnosis of ASD, which is similar to the findings in this study.

Findings from this study showed the majority of the sample had private insurance. However, what cannot be ascertained from the data collected in the NHIS is if the private insurance provides coverage for the costly treatments required for children with ASD. There were several significant differences for the incidence of comorbidities between the children with and without ASD. Other studies, such as the one conducted by Siversten et al. (2011), suggested that sleep disorders such as insomnia and waking in the night are prevalent among children with ASD. Because the NHIS did not collect data on sleep disorders, it was not possible to explore this in this study.

Even though only a small percentage (6%) of children with ASD reported having seizures, no children from the sample of children without ASD reported any seizure activity. However, this may be a sampling issue as only 1% of the total number of children without autism in the NHIS reported seizure activity. Findings about the increased incidence of developmental delays and learning disabilities are not surprising given that ASD is often associated with intellectual disabilities and difficulties in motor coordination.

As expected children with ASD had more visits to see a mental health professional or physician for emotional and behavioral problems. Given that ASD is characterized by varying difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors as defined by Autism Speaks (2005-2012), it would be expected that they would have more mental health professional visits. In the past year, children with autism made, on average, about one and one half more visits to their physician's office than children without ASD, which may not be surprising given their accompanying comorbidities.

Results like these are important for health care professionals to know because as the incidence of ASD rises, more and more of these children will be seen in our clinics and hospitals. It is important for health care professionals to know the signs and symptoms of ASD so that they may work toward a diagnosis and begin the imperative early intervention programs for the child. It also is important for the health care providers to be knowledgeable about other diagnoses associated with ASD and other common features in order to intervene early and prevent complications from the comorbidities. Knowing families with a child diagnosed with ASD may experience changes to their own health that lowers their general health status will help the health care professionals give more holistic and family-based care that could benefit the family and the child. More research is needed to address the issues surrounding the health status of the child with autism and the health status of their families.

The study findings helped identify other health problems associated with ASD. The findings from this study could, in the future, help to provide direction to identify characteristics specific for autism that will help create a systematic way to identify potential risks for autism and corresponding comorbidities. It also may serve as a baseline for early intervention for health problems associated with ASD.

Limitations

Limitations to this study are that the small sample of children with autism in the NHIS: 2009 may not be representative of the population. The number of children with ASD was one in 102 in this sample that is a lower rate when compared to the current estimates by the CDC, (2012). Additionally, a secondary analysis does not include all variables, such as sleep disorders and specific insurance coverage benefits that are necessary for risk identification.

References

Adams J.B., Johansen L.J., Powell L.D., Quig, D. & Rubin, R.A. (2011). Gastrointestinal flora and gastrointestinal status in children with autism-comparisons to typical children and correlation with autism severity. *BMC Gastroenterology, 11,* 2-6. DOI:10.1186/1471-230X-11-22

Andersen, R.M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36, 1-10.

Atlantic Information Services. (2008). The AIS report on Blue Cross and Blue Shield plans. Retrieved from: http://www.autism-blog.com/lawsuits-against-blue-cross-blue-shield

Autism Society of America. (ASA, 2007). Facts and Statistics. Retrieved from: *http://www.autism-society.org/about-autism/facts-and-statistics.html*

Autism Speaks. (2005-2012). What is autism? What is autism spectrum disorder? Retrieved from: *http://www.autismspeaks.org/what-autism*

Autism Votes. (2011). Summary of Kansas Autism Insurance Reform Law: Senate Substitute House Bill 2160 - Introduced by the LEPC. Para. 2. Retrieved from: *http://www.autismvotes.org/site/c.frKNI3PCImE/b.4425759/k.B84C/Kansas.htm*

Autism Votes (2012). The Senate is Returning Kansas! Urge Them to Move HB.2764. Retrieved from: *http://www.autismvotes.org/c.frKNI3PCImE/b.8056667/k.1F4A/The_Senate_is_Returning_Kansas_Urge_Them_to_Move_HB2764/siteapps/advocacy/ActionItem.aspx*

Centers for Disease Control and Prevention. (2012). CDC estimates 1 in 88 children in United States has been identified as having an autism spectrum disorder. *Press Release.* Retrieved from: *http://www.cdc.gov/media/releases/2012/p0329_autism_disorder.html*

Croen, L.A., Grether, J.K., Hoogstrate, J. & Selvin, S. (2002). The changing prevalence of autism in California. *Journal of Autism and Developmental Disorders, 32,* 209–211. Retrieved from*: http://web.ebscohost.com.proxy.kumc.edu:2048/ehost/pdfviewer/pdfviewer?sid=b4fafdad-ac55-439e-9720-dba94267a704%40sessionmgr110&vid=2&hid=112*

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research, 65*, 592-593. DOI: 10.1203/PDR.0b013e31819e7203

KidsHealth. (2011). Autism and other pervasive developmental disorders. 1-2. Retrieved from: *http://kidshealth.org/parent/medical/learning/pervasive_develop_disorders.html#*

Liptak, G.S., Benzoni, L.B., Mruzek, D.W., Nolan, K.W., Thingvoll, M.A., Wade, C.M., & Fryer, G.E. (2008) Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. *Journal of Developmental and Behavioral Pediatrics, 29,* 156-157. DOI: 10.1097/DBP.0b013e318165c7a0

Mandell, D.S., Wiggins, L.D., Carpenter, L.A., Daniels, J., DiGuiseppi, C., Durkin, M.S., … Kirby, R.S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99,* 493–496. DOI:10.2105/AJPH.2007.131243

National Center for Health Statistics. (2009). National health interview survey. Retrieved from: *http://www.cdc.gov/nchs/nhis/nhis_2009_data_release.htm*

Pickett, J., Xiu. E., Tuchman, R., Dawson, G., & Lajonchere, C. (2011). Mortality in individuals with autism with and without epilepsy. *Journal of Child Neurobiology, 26,* 932-934. DOI: 10.1177/0883073811402203.

Rai, D., Lewis, G., Lundberg, M., Araya, R., Svensson, A., Dalman, C., Carpenter, P., and Magnusson, C. (2012). Parental socioeconomic status and risk of offspring autism spectrum disorders in a Swedish population-based study. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*, 467-476. DOI: 10.1016/j.jaac.2012.02.012

Sivertsen, B., Posserud, M.B., Gillberg, C., Lundervold, A.J., Hysing, M. (2011). Sleep problems in children with autism spectrum problems: a longitudinal population-based study. *Autism, Volume 15(3)* 2-3. DOI: 10.1177/1362361311404255

Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., Brimacombe, M. (2011 Aug). The association of autism diagnosis with socioeconomic status. *Autism,* 6-9. doi: 10.1177/1362361311413397

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg N., Boyle C., & Murphy, C. (2003). Prevalence of Autism in a US Metropolitan Area. *The Journal of the American Medical Association, 289,* 51-53. DOI: 10.1001/jama.289.1.49

Association Between Obstructive Sleep Apnea and Postoperative Adverse Events

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Abstract

Purpose

Adults with obstructive sleep apnea (OSA) arouse from sleep repeatedly due to hypoxemia and hyerpcapnea. General anesthesia, analgesics, and sedatives may interfere with these arousals and, thus, increase adverse events. Therefore, the purpose of this study is to compare postoperative recovery scores in adult surgical patients with and without diagnosed OSA. Significant differences in postoperative recovery scores between these groups may suggest an opportunity to improve patient care in the postoperative environment.

Methods

We performed a retrospective electronic data review to compare postoperative recovery scores in two matched cohorts of patients admitted to a large urban medical center between November 2009 and July 2011 for procedures requiring anesthesia. OSA and non-OSA cohorts were matched based on gender, age, and type of surgical procedure. We collected data regarding patients' post-anesthesia recovery scores in four categories: oxygen saturation, respiration rate, blood pressure, and level of consciousness.

Results

Our cohorts included 61 people with an ICD-9 code for OSA and 55 people who did not have an OSA diagnosis. We noted no significant differences in mean post-anesthesia recovery scores between the two cohorts in each of the four categories. We did find a significant difference ($p = .05$) between the number of assessments the OSA cohort received ($M = 5.80$, $SD = 2.52$) and the number of assessments the non-OSA cohort received ($M = 4.87$, $SD = 2.62$). We also found that the OSA cohort's mean initial scores upon arrival to the post-anesthesia care unit (PACU) were significantly better for respiration ($p = .05$) and level of consciousness ($p = .03$) than were the non-OSA cohort's scores.

Conclusions

While the OSA cohort received better initial recovery scores upon arrival to the post anesthesia care unit (PACU), they had a higher number of assessments overall, indicating that they spent more time on the PACU before discharge. Numerous explanations exist to explain these results, indicating a need for further research.

Introduction

Obstructive sleep apnea (OSA) is a sleep disorder in which partial or complete cessation of breathing occurs five times or more per hour of sleep, lasts ten seconds or more, and causes a reduction in oxyhemoglobin saturation of four percent or more from baseline (Kryger, Roth, & Dement, 2005). It is the most common breathing disorder during sleep, and it is estimated that OSA is prevalent in two to four percent of the general population (Hiestand, Britz, Goldman, & Phillips, 2006) and is as high as 24% in surgical patients (Chung, Ward, Ho, Yuan, Kayumov, & Shapiro, 2007). However, 93% of women and 82% of men with moderate-to-severe OSA have never been diagnosed (Young, Evans, Finn, & Palta, 1997).

Adults with OSA arouse from deep sleep repeatedly due to hypoxemia (i.e., deficiency of oxygen in arterial blood) and hypercapnia (i.e., increased concentration of carbon dioxide in blood). These arousals serve as a protective mechanism in that they restore muscle tone to the airway so that the apneic event ends and breathing resumes. In adult surgical patients, general anesthesia, opioid analgesics, and sedative agents may interfere with these arousals and increase the risk of respiratory (Lakdawala, 2011), cardiac (Namtvedt et al, 2011), and neurologic complications (Liao, Yegneswaran, Vairavanathan, Zilberman, & Chung, 2009).

Gupta, Parvizi, Hanssen, & Gay (2001) found that OSA patients undergoing hip or knee replacement had a higher rate of adverse postoperative outcomes. Almost one-third of the OSA patients in Gupta and colleagues' study experienced a serious respiratory or cardiac complication. Moreover, the OSA patients in this study had significantly higher unplanned intensive care unit (ICU) admissions and longer lengths of stay (LOS). In another study, Liao, Yegneswaran, Vairavanathan, Zilberman, & Chung (2009) agreed that OSA patients have an increased incidence of postoperative complications, with the most common being oxygen desaturation due to respiratory complications. Liao and colleagues found that the majority of complications occurred after patients were transferred out of the post-anesthasia care unit (PACU) and that a significantly greater number of OSA patients required additional monitoring. Their study also showed a signifncatly higher rate of ICU admissions for the OSA group.

From these studies one can glean that general anesthesia, analgesics, and sedatives may interfere when one has been diagnosed with OSA, and, thus, there may be an increase in adverse events. Therefore, the purpose of this study is to compare postoperative recovery scores in adult surgical patients with and without diagnosed OSA. Significant differences in postoperative recovery scores between the OSA and non-OSA groups may suggest an opportunity to improve patient care in the postoperative environment.

Methods

We performed a retrospective matched cohort study of patients admitted to a large urban medical center between November 2009 and July 2011 for a procedure requiring anesthesia. While previous studies have examined the incidence of adverse postoperative events in OSA patients, they have spanned the entire postoperative period. In contrast, we focused on the immediate postoperative period while patients were still in the PACU. Following Human Subjects approval, we obtained de-identified data from a proprietary database of patient records.

Sample

From the de-identified data, we created two cohorts. The first consisted of patients who had ICD-9 code 327.23 for OSA (n=61); the second cohort were matched on criteria that included age, sex, and type of surgical procedure. In order to control for differences in post-anesthesia recovery due to length of sedation, we selected surgical procedures based on the typical time required to complete the surgery. These procedures included: (a) arthroscopy, knee or shoulder; (b) ligamentous reconstruction, knee; (c) endoscopy, wrist; (d) percutaneous skeletal fixation of femoral fracture; (e) treatment of fractures, femoral, fibular, tibular, ulnar; (f) arthroplasty, knee or acetabulum; (g) laparascopy, hernia repair; (h) neuroplasty; (i) laminotomy; and (j) cholecystectomy. Exclusion criteria included all surgical procedures involving the upper airway (e.g. tonsillectomy and uvulopalatoplasty) as these procedures may have been used to cure OSA. As well, it is estimated that 77% of people with a BMI greater than 35 have OSA (O'Keefe & Patterson, 2004). Therefore, we excluded these subjects from our non-OSA cohort.

Measures

We collected data based on the postoperative recovery scores that patients received upon arrival to the post-anesthesia care unit (PACU). These data included respiration, blood pressure level of consciousness, and oxygen saturation, and each was scored on a scale from zero (absent), one (abnormal), and two (normal). The categories for each assessment had varying definitions and are shown in Table 1.

Table 1 Category Score Definitions for Respiration, Blood Pressure, Level of Consciousness, and Oxygen Saturation Assessments

Assessment	2 (Normal)	1 (Abnormal)	0 (Absent)
Respiration	coughs and deep breaths	dyspneic	apneic
Blood Pressure	±20 mmHg	±20-50 mmHg	±50 mmHg
Level of Consciousness	awake	arousable on calling	nonresponsive
Oxygen Saturation (SpO_2)	> 94%	92-94%	< 92%

Note: Blood pressure indicates difference from pre-anesthesia baseline

Other data that were collected regarding the recovery scores included: (a) comprehensive first recovery scores (range=0 to 10); (b) comprehensive last recovery scores (range=0 to 10); and (c) first and last recovery scores for each of the four assessments (respiration, blood pressure, level of consciousness, and oxygen saturation). To derive the first and last scores for each of the four assessments, we recoded the absent (0) or abnormal (1) scores to one (abnormal) and recoded the normal (2) scores to zero (normal). While in the PACU, patients were assessed at 15-minute intervals or more frequently if nurses deemed it necessary. Consequently, the total number of assessments each patient received was used as a proxy variable for length of time patients remained in the PACU since the data set did not include length of stay in the PACU.

Data analysis

We used *Student's paired t-test* and *Pearson's chi-square* to test differences in means and frequencies between the OSA and non-OSA groups. Alpha was set at 0.05. A *priori* power analysis (Cohen, 1988), with an alpha set at .05 and power at .80, indicated we needed a sample size of 64 paired observations for a moderate effect size.

Results

The OSA cohort (*n*=61) had 54% men and 46% women. The non-OSA cohort (*n*=55) had 55% men and 46% women The non-OSA cohort sample could be matched on age category and gender but in six cases there was missing data for the subject with a corresponding surgical procedure code. The average age was 62 years (*range* = 25 to 89) for the OSA cohort and 62 years (*range*= 23 to 89) for non-OSA cohort. We found no significant differences between the two groups in sex, age, language, marital status, or race. See Table 2 for all demographic data.

Table 2 Demographic Data Comparing the OSA and non-OSA Cohorts

Demographic	**OSA** ***n (%)***	**Non-OSA** ***n (%)***	X^2	***p***
Patients	61	55		
Sex				
Male	33 (54)	30 (55)	.002	.96
Female	28 (46)	25 (46)		
Age categories				
<45	7 (12)	7 (13)	.923	.92
45-54	9 (15)	5 (9)		
55-64	13 (21)	13 (24)		
65-74	24 (39)	23 (42)		
75 or greater	8 (13)	7 (13)		
Race				
White	54 (89)	41 (75)	5.372	.07
Black	7 (12)	11 (20)		
Other	0	3 (6)		
Language				
English	50 (82)	43 (78)	.261	.61
Other	11 (18)	12 (22)		
Marital Status				
Married	37 (61)	39 (71)	1.507	.68
Divorced	7 (12)	4 (7)		
Widowed	8 (13)	5 (9)		
Single	9 (15)	7 (13)		
	M (SD)	*M (SD)*	*t-test*	*p*
Age in years	61.92 (12.85)	62.27 (14.58)	-.14	.89

Note: Some categories may not add up to 100% due to rounding.

We examined the mean score of all assessments for each patient in each category, as shown in Table 3. There were no significant differences between the OSA and non-OSA cohorts on the mean scores for the four assessments: respiration, blood pressure, level of consciousness, or oxygen saturation.

Table 3 Mean Scores and Ranges by Assessment Category for the OSA and non-OSA cohorts

Category	OSA	Non-OSA	*t*	*p*
Respiration				
Mean (SD)	1.83 (.38)	1.85 (.24)	.381	.70
Range	.00-2.00	1.00-2.00		
Blood Pressure				
Mean (SD)	1.92 (.19)	1.92 (.21)	-.081	.94
Range	1.25-2.00	1.00-2.00		
Level of Consciousness				
Mean (SD)	1.49 (.39)	1.46 (.36)	-.549	.58
Range	.33-2.00	.67-2.00		
Oxygen Saturation				
Mean (SD)	1.89 (.26)	1.96 (.11)	1.766	.08
Range	1.00-2.00	1.50-2.00		

We also examined the patients' comprehensive scores on arrival to the PACU (their first recovery score) and on discharge from the PACU (their last recovery score), as depicted in Table 4. These scores included five categories that are typically assessed in the PACU, not just the four assessments for which we had separate data. These five categories were summed to create the recovery score; therefore, the maximum total score possible is 10. There were no significant differences between cohorts for these scores.

Table 4 First and Last Comprehensive Recovery Scores Differences between OSA and Non-OSA Cohorts

	OSA	Non-OSA
First Recovery Score*		
Mean (SD)	8.21 (1.51)	8.14 (1.31)
Range	3-10	3-10
Last Recovery Score*		
Mean (SD)	9.67 (.61)	9.64 (.52)
Range	7-10	8-10

Note: Includes five parameters measured in PACU *Non-significant differences between cohorts.

In comparing patients' first and last scores upon arrival to the PACU, we looked at whether they had a normal (0) or an abnormal score (1) in each of the four assessment categories as detailed in Table 5. We found that the OSA cohort had a higher percentage of normal first scores than did the non-OSA cohort in each category except for oxygen saturation where they had an equal percentage of normal scores. The OSA cohort had significantly higher or better scores on arrival to the PACU than the non-OSA group in respiration and level of consciousness. As expected, we found no significant differences between the two cohorts on the last scores before discharge from the PACU since all patients must achieve a minimum score before discharge.

Table 5 First and Last Scores (Normal vs. Abnormal) on Four Assessment Scores between OSA and Non-OSA cohorts

	OSA *n (%)*		**Non-OSA** *n(%)*		X^2		*p*	
	First	Last	First	Last	First	Last	First	Last
Respiration								
Normal	49 (80)	57 (93)	35 (64)	54 (98)	4.034	1.575	.05*	.21
Abnormal	12 (20)	4 (7)	20 (36)	1 (2)				
Blood Pressure								
Normal	57 (93)	60 (98)	47 (85)	52 (95)	1.990	1.264	.16	.26
Abnormal	4 (7)	1 (2)	8 (15)	3 (5)				
Level of Consciousness								
Normal	25 (41)	41 (67)	12 (22)	41 (75)	4.891	.750	.03*	.39
Abnormal	36 (59)	20 (33)	43 (78)	14 (25)				
Oxygen Saturation								
Normal	54 (89)	56 (92)	49 (89)	54 (98)	.151	2.399	.70	.12
Abnormal	7 (12)	5 (8)	5 (11)	1 (2)				

Note: "Normal (2)" recoded to 0; "Abnormal (1)" or "Absent (0)" recoded to 1. Some categories may not add up to 100% due to rounding. * Denotes significance at the p ≤ .05 level

Since we did not have information about the length time patients spent in the PACU, we used the number of times patients were assessed (*range*=1 to 12) as a proxy measure for time. Three of the non-OSA and none of the OSA patients were assessed only once before discharge from the PACU. Six of the non-OSA patients and six OSA patients received two assessments. One of the non-OSA patients and two of the OSA patients received the maximum number of 12 assessments. We then examined the total count of assessments by category, which can be seen in Table 6. On average, there were significant differences (p = .05) between the cohorts, with the OSA group receiving significantly more assessments in the categories of respiration, blood pressure, and level of consciousness than the non-OSA subjects. For an unknown reason, the patients in both cohorts received fewer assessments of oxygen saturation. Even though the number of assessments for the non-OSA cohort was lower, it was not significant (p=.06).

Table 6 Mean Number of Assessment Scores by Category between OSA and Non-OSA Cohorts

Category	**OSA**	**Non-OSA**	***t***	***p***
Respiration				
Mean (SD)	5.80 (2.51)	4.87 (2.62)	-1.951	.05*
Range	2-12	1-12		
Blood Pressure				
Mean (SD)	5.80 (2.51)	4.87 (2.62)	-1.951	.05*
Range	2-12	1-12		
Level of Consciousness				
Mean (SD)	5.80 (2.51)	4.87 (2.62)	-1.951	.05*
Range	2-12	1-12		
Oxygen Saturation				
Mean (SD)	5.38 (2.58)	4.46 (2.47)	1.933	.06
Range	1-12	1-12		

* Denotes significance at the p ≤ .05 level

Discussion

Patients in the OSA cohort had significantly better scores on arrival to the PACU than did non-OSA patients in two categories: respiration and level of consciousness. This finding is counterintuitive to what we expected and warrants further study to determine the factors that cause OSA patients to have better initial outcomes following anesthesia. Even though OSA patients arrive to the PACU with significantly better scores in respiration and level of consciousness, the patients in the OSA group received significantly more assessments of respiration, level of consciousness, and blood pressure. This finding may indicate that the OSA patients remained in the PACU longer than the non-OSA patients, which may indicate a longer recovery time. Alternatively, nurses may have conducted more frequent assessments of the OSA patients due to anticipated or actual adverse events.

Implications

This study suggests that OSA patients may have a higher risk for adverse events following anesthesia than do non-OSA patients, even though their initial scores on arrival to the PACU were not significantly different. Our findings highlight the importance of assessing OSA patients frequently and watching them closely following anesthesia. It is important for nurses to avoid assuming that OSA patients' high initial PACU scores mean that their recoveries will be uneventful, particularly in light of findings that OSA patients have a higher risk for adverse events than do non-

OSA patients for up to five days post-anesthesia (Gross et al, 2006). Moreover, many patients with OSA remain undiagnosed. Given our study findings, it is important for nurses to recognize the risk factors for OSA and closely monitor post-anesthesia patients who fit the criteria for OSA for adverse events.

Limitations

This study has several limitations, many of which are due to the limitations of conducting a secondary data analysis. First, while the patients in the non-OSA cohort did not have an ICD-9 code for OSA, they may have had undiagnosed OSA. We did not have the data to determine if these patients had risk factors for OSA. Thus, it is likely that some of the patients in our non-OSA cohort did have OSA. This information certainly illuminates another area for research: examining records of undiagnosed patients who have risk factors for OSA and comparing their outcomes with patients who do not have risk factors for OSA.

We also did not have information regarding interventions patients may have received in the PACU, such as oxygen, anti-hypertensives, pressors, or pain medications. These interventions would affect results from assessments and, if used, may help explain why the OSA group had significantly better scores in respiration and level of consciousness on arrival to the PACU than did the non-OSA group. Moreover, since the OSA patients had a known diagnosis, it is possible that their anesthetic procedure differed in some way from the non-OSA group. For instance, the anesthesiologist may have used a different type or concentration of sedative or may have kept the OSA patients in the operating room longer. We also do not know the post-anesthesia protocol for OSA patients. They may be required to remain in the PACU longer so nurses can continue to assess them. It is also possible that some of the OSA patients used CPAP following anesthesia as part of their recovery.

Finally, our *a priori* power analysis (Cohen, 1988), with an alpha set at .05 and power maintained at .80, indicated we needed a sample of 64 paired observations for a moderate effect size. With only 61 OSA and 55 non-OSA patients in the study with usable data, the study may be under-powered. Also, the process for retrieving data from the electronic health record that was used for this study is still under development and has some usability issues that may have affected the data we collected.

References

Chung, F., Ward, B., Ho, J., Yuan, H., Kayumov, L., & Shapiro, C. (2007). Preoperative identification of sleep apnea risk in elective surgical patients, using the Berlin questionnaire. *Journal of Clinical Anesthesia, 19*, 130-134.

Cohen J. (1988). *Statistical Power Analysis for the Behavioral Sciences*. Hilldale, New Jersey: Lawrence Erlbaum Associates Publishers.

Gross, J. B., Bachenberg, K. L., Benumof, J. L., Caplan, R. A., Connis, R. T., Coté, C. J., . . . & Yu, S. (2006). Practice guidelines for the perioperative management of patients with obstructive sleep apnea: A report by the American Society of Anesthesiologists Task Force on perioperative management of patients with obstructive sleep apnea. *Anesthesiology, 104*, 1081-1093.

Gupta, R. M., Parvizi, J., Hanssen, A. D., & Gay, P. C. (2001). Postoperative complications in patients with obstructive sleep apnea syndrome undergoing hip or knee replacement: A case control study. *Mayo Clinic Proceedings, 76*, 897-905.

Hiestand, D. M., Britz, P., Goldman, M., & Phillips, B. (2006). Prevalence of symptoms and risk of sleep apnea in the US population: Results from the national sleep foundation sleep in America 2005 poll. *Chest, 130*, 780-786. DOI: 10.1378/chest.130.3.780

Kryger, M., Roth, T., & Dement, W. (2005). *Principles and practice of sleep medicine*. Philadelphia, PA: Elsevier Saunders.

Lakdawala, L. (2011). Creating a safer perioperative environment with an obstructive sleep apnea screening tool. *Journal of PeriAnesthesia Nursing, 26*, 15-24.

Liao, P., Yegneswaran, B., Vairavanathan, S., Zilberman, P., & Chung, F. (2009). Postoperative complications in patients with obstructive sleep apnea: A retrospective matched cohort study. *Canadian Journal of Anaesthesia, 56*(11), 819-828. doi: 10.1007/s12630-009-9190-y

Namtvedt, S. K., Randby, A., Einvik, G., Hrubos-Strom, H., Somers, V. K., Rosjo, H., & Omland, T. (2011). Cardiac arrhythmias in obstructive sleep apnea (from the Akershus Sleep Apnea Project). *American Journal of Cardiology, 108*, 1141-1146. doi:10.1016/j.amjcard.2011.06.016

O'Keefe, T. & Patterson, E. J. (2004). Evidence supporting routine polysomnography before bariatric surgery. *Obesity Surgery, 14*, 23-26. doi:10.1381/096089204772787248.

Young, T., Evans, L., Finn, L., & Palta, M. (1997). Estimation of the clinically diagnosed proportion of sleep apnea syndrome in middle-aged men and women. *Sleep, 20*, 705-706.

Challenges Associated with Partnering with Sudanese Refugee Women in Addressing Their Health Issues

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Abstract

Civil war in Sudan has displaced refugees all over the globe. A community-based collaborative action research project (CBCAR) took place over one year between university researchers and southern Sudanese refugee women. The purpose of the study was to define the process of partnering with Sudanese refugee women to address their health needs. CBCAR requires equal participation from researchers and participants and is divided into six cyclical phases: partnership, dialogue, pattern recognition, dialogue on meaning of pattern, transforming insight to action, and reflecting on evolving pattern. Challenges from this project were examined from the perspectives of the researchers and the participants. The main challenges associated with conducting a CBCAR project between researchers and refugee women included: misunderstandings and differing expectations of research outcomes, language barriers, and cultural differences. Despite the challenges, this project led to increased knowledge for participants and researchers and improved health outcomes for the refugee women. This study demonstrates how CBCAR is a useful method to partner with refugees to address their health needs.

Introduction

At the beginning of 2011, there were 10.4 million refugees of concern in the world (United Nations High Commissioner for Refugees (UNHCR, 2012). Commonly confused with immigrants, who choose to leave, or internally displaced persons, who are displaced within their own countries, a refugee is a person who,

> Owing to a well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinions, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country (International Organization for Migration (IOM), 2004).

Refugees are forced to flee their home countries for many reasons, including economic, social, violent, ethnic and religious concerns. They are not safe in their home states, and often unwelcome in surrounding areas, foreshadowing a dim future for the well-being of themselves and their kin.

As a continent, Africa is responsible for large numbers of refugees in different regions. The UNHCR budget for humanitarian programs in Africa in 2010 totaled 1.2 billion US dollars (UNHCR, 2012). However, without funding for these programs, many Africans would be deprived of the most basic needs like food, water, shelter, and also denied health services and education (UNHCR, 2012). Africa faces major challenges with population growth combined with scarcity of resources. For too many Africans, seeking refuge within, or elsewhere abroad, is not optional, but mandatory.

Sudan is an eastern African country that has been plagued with civil war for more than three-fourths of its existence as a country (U.S. State Department, 2012). The two most heightened periods of violence were in 1956-1972 and 1983-2004 (IOM, 2011). It is estimated that 2 million Sudanese lives were lost from the second war and effects from famine (IOM, 2011).

Differences in culture and religion, as well as social, economic and political issues, have divided Sudan since the southern half gained independence from the United Kingdom in 1956 and the northern half gained independence from Egypt in 1956. Arab-led Khartoum government failed to keep promises to southerners to create a federal system, which led to a rebellion by southern army officers (U.S. State Department, 2012). Ongoing conflict can be largely attributed to effort of northern government to unify the country along the lines of Arabism and Islam, despite the opposition of the predominantly Christian southerners (U.S. State Department, 2012). Over 90% of the population of South Sudan identifies themselves as Christian (U.S. State Department, 2012). The Sudanese Christian community is "disproportionately represented in the resettled populations globally" (Schweitzer, et. al., 2006, p. 180).

Providing social peace, religious freedom, and economic opportunities, the United States is a distant, yet common, destination for Sudanese refugees not migrating into neighboring countries. Between the years of 2000 and 2007, the U.S. received an average of 3,108 Sudanese refugees per year, with the highest percentage being in the age range of 25-39 years (IOM, 2011). The Sudan-born population in the U.S. has grown from a census estimated 19,800 in 2000, to about 42,000, according to the American Community Surveys (IOM, 2011). Of these Sudanese immigrants and refugees living in the United States, 36.9% are women (IOM, 2011).

In 2011, the people of South Sudan voted, by overwhelming majority, to secede from the North (U.S. State Department, 2012). Official results were announced on February 7, 2011 (U.S. State Department, 2012). On July 9, 2011, South Sudan declared independence and emerged as a new state.

Review of Literature

Research has already examined the experiences of resettled Sudanese refugees. A study of resettled Sudanese refugees in Australia, using five questionnaires through a structured interview process, found that each of the 63 participants had experienced trauma in some form, the most common being separation from family, the murder of a family member or friend, lack of food and water, lack of shelter, torture, and rape, respectively (Schweitzer, Melville, Steel, & Lacherez, 2006). Gender was a significant demographic variable, with women overall experiencing more anxiety and depressive symptoms than men (Schweitzer, et. al., 2006). It was also noted that the most common post-migration problems were "concerns about family not living in Australia, difficulties in employment, and difficulties adjusting to cultural life in Australia" (Schweitzer, et. al., 2006, p. 185). This study illustrates how the traumatic pasts of Sudanese refugees effect their adaptations to new environments.

Pavlish (2012) describes her experiences conducting a CBCAR with East African refugees. She used a former refugee as her interpreter. After receiving approval from community stakeholders, focus groups were conducted to assess and analyze refugee women's perspectives on their health situations. Pavlish found that the refugee women perceived health as broader than physical concerns. As a result, health programs were planned to address the "social, economic, and political contexts" for the refugee women (Pavlish, 2012, p. 46). The primary challenges that arose from Pavlish's study included: expanding refugee women's health agenda, changing social norms, and improving refugee women's daily lives.

An ethnographic study by Baird & Boyle, (2011) researched the influences to the health and well-being of 10 refugee women from the Dinka tribe of South Sudan who were resettled with their children to the United States. The authors identified three main themes within this research that included liminality: living between two cultures, self-support: standing on our own two legs, and hope for the future.

Liminality, or living between two cultures proved to be a big challenge in the refugee women's transition from Sudan to America (Baird & Boyle, 2011). The Dinka women experienced pressure to keep cultural traditions, such as patriarchy, which are not commonly practiced in the United States (Baird & Boyle, 2011). The most challenging aspect of balancing two cultures for the women was "raising their Dinka children in the 'American way'" (Baird & Boyle, 2011, p. 4). Participants experienced frustration when some of their children, influenced by western culture, began using recreational drugs or having premarital sex. These activities caused concern and conflict for these mothers because they are not aligned with their South Sudanese Christian culture.

The second theme was the women's ability to "stand on their own two feet" in America (Baird & Boyle, 2011, p. 4). This was a big difference from the Sudanese culture in which they were accustomed to the husband being responsible and providing for the wife and children. The women's ability to become financially independent in America gave them a sense of pride as well as "bargaining power" with their husbands (Baird & Boyle, 2011, p. 5). Gaining financial independence aided in the resettlement process for the refugee women.

The final theme recognized in this study was hope for the future. For this community, being relocated to America was a means to "strengthen and secure future generations" (Baird & Boyle, 2011, p. 5). All of the participants expressed a desire to return to Sudan, after gaining education and skills in America, to help those in need. This study found that staying linked to their Dinka community in America and back in their homeland was "vital to the positive adjustment of the refugee women" (Baird & Boyle, 2011, p. 5). Clearly this population did not come to America to put behind their past, but to find hope for the future.

There are many lessons to be learned from doing research with culturally and ethnically diverse groups, especially when working with translators and interpreters. In order to ensure cultural competence with transcultural research, researchers may have to "make adaptations to the usual processes of translation/back-translation when appropriate to the cultural context and the specific situations" (Jones & Boyle, 2011, p. 109). Having trustworthy relationships among the researchers, translators, and interpreters, as well as between the interpreters and participants is imperative for achieving credible study results (Baird, 2011). Strategies for strengthening relationships with translators and interpreters include, but are not limited to: planning for adequate time and funding for the translation process, describing the qualities of the ideal translator, arranging meetings and interviews with potential translators, and planning time for mutual teaching between the researcher and the translator (Jones & Boyle, 2011).

Sudanese refugees face many challenges when resettling in different countries. Commonly, these challenges center on finding employment in a new country, balancing a different culture with their native Sudanese roots, and providing support and stability to family and friends in Sudan.

Purpose

The purpose of this study was to identify the challenges associated with conducting a community-based collaborative action research project (CBCAR) with Sudanese refugee women to address their health issues. This paper presents part of a larger study that explored the process of partnering with Sudanese refugee women to address their health issues.

Methods

Theoretical Framework

A community-based collaborative action research framework (CBCAR) using qualitative methods was used in this study to capture the challenges the refugee women faced in resettlement. CBCAR is a "relationship-based research process that requires partnered planning, sustained commitment, equitable benefits, and a common desire to address structural health barriers" (Pavlish and Pharris, 2012, p. xii). Using a CBCAR model, researchers can move forward with projects and turn findings into impactful action on a group of individuals or a community. CBCAR requires meaningful relationships, as the participants take equal part in the projects as the researchers. With the goal of social change, CBCAR is unique because the areas of research arise from people within communities or settings where transformation is needed, and research runs its own course instead of following a formula (Pavlish and Pharris, 2012, p. 5).

Design and Setting

This CBCAR study was conducted between January 2011 and December 2011. Five educational seminars and focus groups were held in the Sudanese Community Church in Kansas City, Missouri. These sessions were open to all women in the southern Sudanese refugee community from different tribes. The sessions were held on Saturdays and included babysitting and lunch. A sixth focus group focused on thematic confirmation and action planning.

Focus groups were used in this study to capture the perspectives of the refugee women. Focus groups are designed to facilitate "carefully planned discussion" in a "permissive and nonthreatening environment" (Owen, 2001, p. 652). This approach to qualitative research is a viable option when working with refugee women because "focus groups do not discriminate against people who cannot read or write" and can provide a "safe environment" for participants to share their thoughts and feelings "without fear of criticism" (Owen, 2001, p. 653).

All focus groups were audio-recorded. Each audio-recorded focus group was transcribed and back-translated. A refugee woman from Sudan who was trained and certified as an interpreter, interpreted the educational sessions and focus groups from English into Dinka and Arabic and back into English again. The educational seminar topics, chosen by the women, were preventative health, sexually transmitted diseases, childhood illnesses, parenting skills, and women's psychological stress. Students and members of the research team made participant observations, kept extensive field notes, and maintained reflective journals during the entire research process.

Student Involvement

I joined the research team in May 2011 as an undergraduate nursing student as a part of my honor's project. I was introduced to the Sudanese community, along with the two other students who joined the team, at a Sunday morning church service in July 2011, approximately halfway through the project. In preparation for participation in this study, I made participant observations at the Jewish Vocational Services (JVS), a refugee resettlement agency, and Samuel Rodgers Health Center, a community safety-net clinic that serves refugees. I was particularly interested to learn about the local resources to assist refugees in their transition to America. I attended the last educational seminar on women's stress and was present for the final focus group concerned with confirmation of themes. I participated in the research process by making observations and taking field notes at the last two sessions. The main focus of my investigation was to identify the challenging aspects of participating in a CBCAR research study with refugee women.

Recruitment

Recruitment methods included advertisement at church service and word of mouth. Women who participated in the South Sudan Women for Change Committee (SWCC) recruited friends and family members to the sessions and arranged transportation.

Data Analysis

Inductive qualitative methods were used to analyze the transcribed focus group data and field notes. Each researcher read and coded the transcripts separately, then met together to discuss and recurring patterns and themes. Data was entered into NVIVO (9.0), a qualitative data software management program, and organized into the six components of the CBCAR framework: partnership, dialogue, pattern recognition, dialogue on meaning of pattern, transforming insight to action, and reflecting on evolving pattern (Pavlish and Pharris, 2012).

Results

A total of twenty Sudanese refugee women between the ages of 21 and 67 participated in the year-long study. The majority of the women spoke Dinka as their primary language and two of the women spoke only Arabic. The average number of sessions attended by a participant was 3.4. Most of the women were mothers and brought their children to the sessions.

Partnership

The first phase of CBCAR is establishing a partnership between researchers and participants. This is achieved by “creating a trusting and meaningful bond between the community and the research team” (Pavlish and Pharris, 2012, p. 17). The partnership for this study started with a meeting in the church with 11 women and the lead researcher to develop a list of health topics. Students and members of the research team were introduced to the community at a church service to establish trust.

Dialogue

The data from this study came from the dialogue of the focus groups. As Pavlish and Pharris (2012) describe how “engag[ing] in authentic dialogue with people very different from ourselves” allows us to “see the world more fully” (p. xix). In the focus groups, participants were able to share how their experiences with resettling to the United States had affected their health needs. During the focus group about women’s stress, the women shared that their community does not "talk to older women about anything because of respect. [The older women] think [they] are weak if [they] bring [their] problems to them." Other women expanded on the pressure to keep their Sudanese culture in America, and "if [they] lower [themselves] down to not follow the culture, [they] have low self-esteem." Dialogue helped researchers to understand the perspectives of the refugee women.

Pattern Recognition

Creating themes is a useful tool in qualitative research as a way to "link the underlying meanings together in categories" (Graneheim & Lundman, 2003, p. 107). When working with transcripts, researchers use coding as a way to analyze data. Graneheim and Lundman (2003) explain how "a code can be assigned to…discreet objects, events and other phenomena" and should be "understood in relation to the context" (p. 107). In this CBCAR study, coding was used to identify themes and patterns from the transcribed dialogue. Multiple themes were found, such as: roles and power, finding common meaning, misunderstandings of the research outcomes, and parenting children in America.

Dialogue on Meaning of Pattern

CBCAR recognizes that both the community and research team should come together to discuss meaning of patterns from the dialogue, and that "findings should be collaboratively and carefully analyzed so it can be understood by all audiences" (Pavlish and Pharris, 2012, p. xx). This was achieved during the final focus group in which the researchers met with the women to share identified patterns and themes that had been analyzed.

Transforming Insight into Action

CBCAR is defined as "a relationship-based research process with the goal of social change and impactful action" (Pavlish and Pharris, 2012, p. 5). This study had great positive impact on the lives of this group of refugee women. The women organized themselves into a group they called the South Sudanese Women for Change Committee (SWCC), and are currently working on attaining a 501(c) 3 to become a non-profit organization. The women's health seminar had immediate positive reactions, as 5 out of the 13 women in attendance at the first session on well-woman health obtained a mammogram for the first time. The SWCC has formed a partnership with Heart to Heart International in Kansas City. Two shipments of medical supplies will be sent to South Sudan to aid family members and loved ones abroad. On World Health Day, Saturday April 7, 2012, the SWCC presented Heart to Heart with the new South Sudan flag at the Global Distribution Center. The SWCC is also planning a community health event with Heart to Heart spring 2012.

Reflecting on Evolving Pattern

The final step of CBCAR involves evaluating actions and considering new questions (Pavlish and Pharris, 2012). In this process of dissemination, challenges with the process of conducting a CBCAR with Sudanese refugee women to address their health issues were examined. Challenges for both researchers and participants were identified in this study.

Challenges for researchers

There were many challenges associated with this study that reflect a partnership of two completely different cultures. The first of which was an issue of collaboration. Researchers expected participants to take more responsibility for the project and initiative to organize themselves. Punctuality was an issue, as educational seminars sometimes did not get started until over an hour after the decided scheduled time. This was sometimes due to the more relaxed 'African culture', lack of communication among participants, and not reminding each other of the meetings, as well as limited transportation for participants. Not getting started on time pushed back researchers' schedules and limited the time allocated for focus group dialogue as the babysitter's schedule and church contract also needed to be respected.

One of the definitive features of CBCAR is equal involvement between the researchers and the community, which proved to be a complicated task. There was inconsistency in the number of participants each session due to competing events such as Southern Sudan Independence Day celebrations and a memorial service. Some of the women were unable to attend sessions because they were at home making food for the events. The interpreter and many women traveled back to Sudan for several weeks around this time, which delayed the group meetings. Constant efforts were made to engage the women to share responsibility for the group. Women were encouraged to identify topics and communicate with other members to remind them of group meeting dates and times. Lack of communication within any research study is a major concern that may have affected the outcomes of the study.

There were many obvious dialogue challenges, as participants did not speak the same language as researchers. For the language barrier, an interpreter was required to interpret English, Arabic, and Dinka. This alone required more time and increased the odds of participants' statements and opinions to be taken out of context or misunderstood by researchers. The women who did speak English had thick accents, and were hard to understand. Another challenge with the focus group dialogue was the matter of sharing subjects that would not normally be socially acceptable to discuss in the South Sudanese culture. For example, it was brought up in discussion that it is acceptable for a young Sudanese widow to move in with her brother-in-law, who will take over responsibilities of caring for the woman and her children. This topic was not discussed in depth, as an elder Sudanese woman said something in Dinka to the interpreter telling her to move to another subject.

Elder women kept younger women in line by enforcing cultural codes when discussing sensitive educational topics, such as reproductive health and sexually transmitted infections. This was also seen when an elder woman interjected during conversation about discrimination in America towards black Africans, advised the interpreter to change subjects. Traditionally, it is taboo for the women to admit to being depressed or overwhelmed with anxiety, which was noted in the women's stress seminar.

Challenges for participants

One challenge with this partnership, from the perspective of the refugee women, was misunderstandings of what the group meetings would accomplish. Participants had different expectations of researchers. Several of the women believed that they would be trained to become a Certified Nurse Assistant (CNA) and thus acquire job skills as a result of participating in these sessions. One woman stated that she wanted the sessions "to be more like a training, so when we graduate from here we can have like license or certificate." Participants requested certificates at the last session, and received certificates of completion of the study, but not certification of clinical skills, as they had expected

At the conclusion of the action planning session, several participants stayed to discuss their "frustration and disappointment" with the project. During this session, one woman stated her expectations of the researchers to "buy the medicine and go to help some people" in Sudan. She was dissatisfied with the project as she thought the project would raise money to fund their family and friends in Sudan. These misunderstandings may cause distrust between the participants and researchers and lead to difficulty in future partnerships.

Another big challenge for the participants was the issue of gossiping. The CBCAR focus groups had to remain confidential despite being in a culture with a lot of gossip. Most refugees are isolated from the American society and must rely on each other for support. A participant shared how the Sudanese women "don't tell all of the secret" because of "gossip going on…that's why people keep things to themselves." Another participant shared how Sudanese gossip is worse than American gossip. These cultural tones may have prevented the women from feeling comfortable to share information during the focus groups.

Discussion

In summary, university researchers and South Sudanese refugee women were able to work together to identify health issues. Similar to the results of Schweitzer's (2006) study, concerns about family still in Sudan, difficulties with seeking employment, and conflicts adjusting to new cultural values and beliefs outside of Sudanese tradition all posed challenges during the resettlement process for Sudanese refugees. Participants wanted to attain job skills from the seminars to help with employment. One of the graduate nursing students on the research team, who was also an immigrant to the United States, noted that refugees have a different outlook on adapting to American culture than immigrants. She explained that she chose to come to the United States, but refugees do not. This student speculated that refugees who are forced to live in the US might be "resistant to learn things" in the US because they have the expectation they will return to their homeland. This sense of temporariness may have affected the results of the study.

This study showed that developing a trusting partnership with the community is essential for CBCAR. In this study, similar to Pavlish's study (2012), a refugee was used as an interpreter for the focus groups, which proved to be a positive link between researchers and participants. The theme of "hope for the future," from Baird and Boyle's ethnographic study (2011) also emerged from the CBCAR project. Participants were very focused on helping their family abroad, and as a result, were able to partner with Heart to Heart International to send medical supplies to South Sudan.

Implications for Nursing

This study has many implications for nurses and other healthcare professionals. Refugees face many challenges with America's health system. As a nurse it is very important to practice with cultural competence and an open mind and to take the time to understand what the patient has experienced, because it makes a big difference not only in his/her care, but the way he/she experiences living in the United States.

Conclusions

In conclusion, this CBCAR study demonstrated the importance of partnering with refugees to address their health issues. There were many challenges with this partnership for both the researchers and participants. The main challenges included misunderstandings, differing expectations, language barriers, and cultural differences. However, even with these multiple challenges, participants have taken initiative to transform insight into action when addressing health issues for themselves and their community.

References

Baird, M. (2011). Lessons learned from translators and interpreters from the Dinka tribe of southern Sudan. *Journal of Transcultural Nursing.* 22(2), 116-121. DOI: 10.1177/1043659610395764

Baird, M. & Boyle, J. (2011). Well-being in Dinka refugee women of southern Sudan. *Journal of Transcultural Nursing.* Xx (x), 1-8. DOI: 10.1177/1043659611423833

Graneheim, U. & Lundman, B. (2003). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nursing Education Today, 24, 105-112.

International Organization for Migration (IOM). (2011). *IOM Glossary on Migration, International Migration Law Series.* Retrieved from http://www.iom.int/jahia/Jahia/about-migration/key-migration-terms/lang/en#refugee

International Organization for Migration. (2011). *Migration in Sudan: A Country Profile 2011.* 15-136. Retrieved from http://www.iom.int/jahia/Jahia/sudan

Jones, E. & Boyle, J. (2011). Working with translators and interpreters in research: Lessons learned. *Journal for Transcultural Nursing.* 22 (2) 109-115. DOI: 10.1177/1043659610395767

Owen, S. (2001). The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients. *Journal of Advanced Nursing.* 36 (5), 652-658.

Pavlish, C. (2012). CBCAR: Insights Developing. In C. Pavlish & M. Pharris, *Community-Based Collaborative Action Research: A Nursing Approach* (pp. 31-55). Sudbury, MA: Jones & Bartlett.

Pavlish, C. & Pharris, M. (2012). *Community-Based Collaborative Action Research: A Nursing Approach.* Sudbury, MA: Jones & Bartlett.

Schweitzer, R., Melville, F., Steel, Z., & Lacherez, P. (2006). Trauma, post-migration living difficulties, and social support as predictors of psychological adjustment in resettled Sudanese refugees. *The Royal Australian and New Zealand College of Psychiatrists.* 179-187.

United Nations High Commissioner for Refugees (UNHCR). (2012). *Refugees in South Sudan.* Retrieved from http://data.unhcr.org/SouthSudan/country.php?id=251

U.S. State Department. (2012). *Bureau of African Affairs.* Retrieved from http://www.state.gov/r/pa/ei/bgn/5424.htm

Complementary Therapy to Relieve Pediatric Cancer Therapy-Related Symptoms in the USA

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Abstract

Children undergoing treatment for cancer often receive chemotherapy or radiation therapy and may experience many symptoms linked to these treatments. This study examined complementary therapies and self-care or dependent-care methods used by pediatric patients and parents to alleviate symptoms during cancer treatments. The specific purposes of this study were to assess symptoms and the complementary therapies and self-care or dependent-care methods used by pediatric patients and parents during cancer treatments. Orem's self-care/dependent-care concept was used to guide the analysis of the care pediatric patients received. Secondary analysis was done on data collected from a cross-sectional, multi-site study in the Midwestern and Southwestern USA. The sample included 92 parents of children ages 1-17 years old; 52% were females; 16 were less than 5 years old; 53 were 5-11 years old, and 23 were 12-17 years old. Of the cancer diagnoses reported, 56% had leukemia and 44% had other cancer types. The 30-item Therapy-Related Symptom Checklist for Children (TRSC-C) was used to record patients' symptom occurrence and severity on a 5-pt scale (0, no symptom; 4, "A whole lot"). The Symptom Alleviation: Self-Care Methods (SA:SCM) tool was used to identify methods parents used to alleviate therapy-related symptoms. To address the study purposes, descriptive data and content analyses were conducted. Symptom occurrences of 19 symptoms were reported by 40% or more of the patients and had a mean severity of "2" or "Quite a bit." The top five symptoms included nausea, feeling sluggish, hair loss, loss of appetite and vomiting. Of the six categories of self-care or dependent-care methods and complementary therapies, four were found useful; herbal treatments were not mentioned. The two categories most utilized were Prescribed Medications and Mind Body Control. Assessing patient-reported and parent-reported symptoms and the use of self-care and dependent-care methods and complementary therapies help parents cope and help their children.

Introduction

According to the American Cancer Society (ACS, 2011), cancer is the leading cause of disease-related death in children aged 0-14 years. In fact, about 11,210 children in the United States under the age of 15 will be diagnosed with cancer in 2011 (ACS, 2011). Childhood cancer rates have been rising slightly for the past few decades (ACS, 2011). However, with improved efficacy of cancer treatment, the 5-year survival rate for childhood cancers has increased to 80% overall (ACS, 2011). More types of cancers are being treated with chemotherapy and radiation at high or sustained dosages. The research program of Dr. Phoebe D. Williams deals with the increased concerns about symptoms during treatment and patients' reactions. The initial (pilot) and subsequent studies examined symptom occurrence and severity as monitored and reported by parents and caregivers of children and adolescents during chemotherapy and radiation therapy. The pilot study also focused on ways parents helped to alleviate symptoms through self-care or dependent care. Williams' research findings showed that systematic assessment through patient/parent self-reports of symptoms during treatment cycles allows care providers to more effectively manage early conditions that threaten successful therapy (Williams et al., 2006). In 2012, a calibrated instrument, the Therapy-Related Symptom Checklist for Children (TRSC-C) was developed for use by patients/parents to "self-report" the occurrence and severity of symptoms during pediatric cancer treatments (Williams et al.. 2012).

Purpose

The purpose of this research was to examine during pediatric cancer treatments: (a) what parents of children in the USA report they do to help alleviate symptoms during cancer therapy; (b) what complementary (dependent) care categories are reported.

Conceptual Framework

The concept of self-care by Orem (1995) was used to guide the data collection and analysis. Self-care is defined as the "voluntary regulation of human functioning and development that is necessary for individuals to maintain life, health, and well-being" (p. 95). Parents or caregivers care for their children and monitor their self-care needs because many children cannot always care for themselves, which Orem refers to as dependent care (Williams et al., 2006). Parents and caregivers implement dependent care strategies with their child during cancer treatments.

Complementary care is a term used to describe the methods parents and caregivers use to alleviate the symptoms caused by cancer therapy. Complementary Care and Therapies, as used in this study: are "care modalities or self-care used as adjuncts to mainstream medical care, as provided in a cancer clinic" including chemotherapy (Williams et al,, 2006; 2010, p. 38) and are also called "integrative therapies" (Wesa et al., 2008). Various methods are used are classified into six different categories by Williams et al. and co-investigators (2006; 2010, Piamjariyakul et al., 2010).

Literature Review

An Internet database search using CINAHL and PubMed helped the student locate pediatric oncology treatment research from the past 15 years. The research supports the theory that parents play a crucial and an integral part of their child's treatment process during cancer therapy. When a child is diagnosed with cancer, often parents become overwhelmed with new stressors and do not feel as though they are adequately caring for their child and themselves. The focus of the literature review was directed towards: (a) parental coping and dependent care methods utilized by parents of children with cancer, and (b) symptom monitoring and management during pediatric cancer treatments.

Parental Care during Pediatric Cancer Treatments

A study participant in the Flury et al. (2011) qualitative study explained, "caring for a medically fragile child at home is equal to a full time job" (p.2). Parents have to keep children under surveillance 24 hours a day for severe side effects and it takes a toll. Parents in this study were interviewed about their experiences of taking home their sick child for the first time after the diagnosis and what new tasks they were facing 4 to 7 weeks later. Hospital stays, reduced to a minimum (due to the ability to place central intravenous lines and give chemotherapy at home and have specialized home care services) force parents to abruptly come to terms with their child's life-threatening illness and begin taking on an overwhelming amount of new duties involved in caring for a sick child.

According to the study by Flury et al. (2011), parents of children with cancer need information about treatment and condition as well as contact with the medical staff on a regular basis. They need training and support for home health work. When parents first learn of their child's diagnosis, they are confronted with a lot of information both written and oral. The first weeks at home are the most challenging. They are given instruction for many new considerations and dependent care and complementary care methods including administration of medication and symptom management. Health care professionals can provide better discharge teaching for parents of newly diagnosed children with cancer about potential problems and solutions.

Findings in the study by James, Keegan-Wells, Hinds et al. (2002) done in the USA showed parental caregiving of ill children led to negative physical and emotional health of parents. This was a descriptive, exploratory study of 151 parents who were actively involved in the care of their sick child. They answered 6 open-ended questions on the *Care of My Child with Cancer* survey. Content analysis of 1,280 responses showed two types of actual assistance were found to be most helpful by parental caregivers: timely education about their child's health status from Health Care Providers and emotional support from family members, friends and others. Findings provided ideas for future interventions to ease the workload of parents of children with cancer. Examples of helpful topics included ways of monitoring the patient's medical status, and maintaining other roles and activities outside the home.

Symptom Monitoring and Management during Pediatric Cancer Treatments

Rheingans (2008) conducted a study using surveys from 509 pediatric oncology nurses in the United States, focused on the most distressing symptoms experienced and reported by pediatric patients. The survey was used to assess nurses' views on patient symptoms experienced, the distress symptoms caused, and what interventions were used to treat patient symptoms. Pain was the most commonly reported symptom and trouble sleeping was the least common. Nurses' distress was greatest with trouble sleeping and the least with hair loss. The study found nurses use an average of 12.7 interventions including emotional support, art therapy, deep breathing, distraction, humor, massage, music therapy and acupuncture. Symptom management is typically led by the administration of pharmacologic agents, but this study emphasizes the importance of non-pharmacologic agents and providing a more holistic approach through other interventions.

In the study by Baggott et al. (2004), a questionnaire was mailed to 1,000 pediatric oncology nurses asking about their practices for advising patients and their families about self-care measures and reporting of adverse symptoms. The survey had three domains: advice about symptoms for which it is appropriate to initiate self-care prior to calling for professional advice, consensus self-care interventions recommended for common symptoms, and advice on when to call immediately for professional assistance. An analysis of 135 valid responses showed consensus that nurses were recommending similar self-care interventions for eight common adverse symptoms (constipation, weight loss, fatigue, pain, infection, nausea, mouth sores and bleeding) and advice for when patients should promptly report to health care providers.

The study by Berg et al. (2009) used semi-structured interviews with 25 cancer survivors (8 to 18 years of age) to investigate the late effects of childhood cancer on participation and quality of life. It concluded many survivors experience lower quality of life scores, as measured by the Pediatric Cancer Quality of Life Inventory, and are less likely to participate in vigorous leisure activities due to late effects of the disease or effects of the chemotherapy and radiation therapy. These included lower extremity pain and numbness, memory and attention deficits, fatigue and depression. These patients needed to be offered self-management and self-care strategies to cope with ongoing symptoms.

In the pilot study by Williams et al. (2006) the Therapy-Related Symptom Checklist (TRSC-C) child version was given to parents/caregivers of 11 children and adolescents (12 to 18 years). Findings showed that the most common symptoms were feeling sluggish (fatigue), pain, hair loss, sore mouth, vomiting, loss of appetite, weight loss, fever, constipation-- and nausea which was reported by all children. In this study, Williams and co-investigators suggested that healthcare providers need to assist patients and family members to cope with the side effects of therapy; moreover, systematic assessment through a caregiver-report (or a child self-report) checklist could help with both identification and prioritization of symptoms needing intervention. The TRSC-C assists parents and healthcare providers in monitoring the symptoms experienced by pediatric oncology patients.

The study found that symptoms were physiological, psychological and social in nature. Pediatric oncology nurses should be knowledgeable about child development and be able to identify their patients' symptoms and treat them adequately to improve their quality of life. Ignored side effects can lead to anxiety toward treatment and create unsuccessful outcomes. Pediatric oncology nurses need tools to help parents gauge their child's symptom occurrence and severity, and methods to alleviate them.

In the instrument development study by Williams et al. (2012), data were collected from 385 children 5-17 years old with cancer at 5 university-affiliated oncology clinics across the USA (central, western, eastern, southeastern). Parents used the TRSC-C to report symptom occurrence and severity during chemotherapy, radiation therapy and combined CT/RT. The study calibrated the 30-item TRSC-C; "kid-friendly" terms (shown in Figure 1) were used to monitor symptom occurrence and severity during chemotherapy, radiation therapy, or combined CT/RT. The study showed the TRSC-C, with psychometric properties of excellent reliability and validity, improves communications among patients, parents, clinicians and others. It allows self-report of symptoms and shared decision-making and is a quality tool to improve quality of life of pediatric oncology patients.

Methods

Design

The larger study was a cross-sectional, descriptive study by Dr. P.D. Williams conducted in the USA and in Thailand; IRB approvals were obtained at all sites. Secondary analysis of data collected in the Midwestern and Southwestern USA was done for this report to address the research purposes. In order for the honors student to participate in this research, she had to obtain *KUMC-IRB approval* as well as a *Conflict of Interest* clearance.

Instruments

The Therapy-Related Symptom Checklist-Child, TRSC-C (Williams et al., 2012), a patient/parent self-report tool, was used to gather information on symptom occurrence and severity experienced during cancer treatment. Parents used the 30-item TRSC-C to record patients' symptom occurrence/severity on a 5-pt scale: "0" (no symptom), "1" (a bit), "2" (quite a bit), "3" (a lot), and "4" (a whole lot). Scores of "2" or more indicate symptoms were more severe. The TRSC-C also had a space at the bottom of the checklist for parents and/or patients to report additional symptoms (not listed on the TRSC-C) they might be experiencing. A Cronbach's alpha coefficient of .91 (indicating good internal consistency reliability), and good content and construct validity have been reported on the TRSC-C (Williams et al., 2012).

Another tool used in the study was the Symptom Alleviation: Self-Care Methods (SA:SCM) tool. Self-Care Methods, in this study, may include complementary care and therapies to relieve symptoms. The SA:SCM was used to identify methods parents used to alleviate therapy-related symptoms as reported on the TRSC-C. The tool also measured whether the method was found useful or not in alleviating symptoms. It measured how often methods or strategies were used, as well. A "0" indicated "not done" and a "4" indicated "done very often." Williams et al. (2012b) have reported a Cronbach's alpha coefficient of .72 on the SA:SCM.

Parents also completed the Demographic form. The Health and Other Data form was completed by the Nurse Clinician; she also rated the child's condition and activity (functional status) using either the Lansky scale (5-15 years) or the Karnofsky scale (16-17 years).

Data analysis

To address the study purposes, data on parents' dependent care methods were content analyzed by this student. The researcher, on each of the 25 symptoms made a tally in tabular format of all the reported parental alleviation methods-- or their complementary care responses to the Symptom Alleviation: Self-Care Methods (SA: SCM) tool. These responses were classified into six categories (Williams et al, 2006; 2010), namely: (a) Diet, Nutrition, and Life-style change; (b) Mind Body Control; (c) Biologic Treatment; (d) Herbal Treatment; (e) Other methods; and (f) Taking Prescribed Medications. The categories were clear for most of the methods used; only a few responses needed clarification by the Mentor. Symptom alleviation methods used for each symptom reported were finally counted and reported in Table 2.

Results

Sample Characteristics

The parents of 92 pediatric oncology patients were included in the sample. The ages of their children ranged between 1 and 17 years old; 52% were females. Sixteen were less than 5 years old, 53 were between the ages of 5-11 years old, and 23 were between the ages of 12-17 years old. Of the 92 children, 56% had diagnoses of leukemia and 44% had Other cancer types including nervous system tumors, Wilm's tumor, rhabdomyosarcoma, retinoblastoma, lymphoma, and cancers of the liver, ovary and kidney.

Symptom Occurrence and Severity Reported

The occurrence and severity of symptoms reported on the TRSC-C are shown in Table 1. The table consists of 30 items clustered into the 7 TRSC-C subscales (Willams et al., 2012a). Overall 40% or more of the sample reported 19 symptoms [nausea (80%), feeling sluggish (80%), hair loss (80%), loss of appetite (74%), vomiting (72%), irritable (69%), pain (61%), weight loss (58%), headache (52%), agitation (47%), depression (46%), constipation (45%), bruising (42%), fever (41%), afraid (41%), tripping and falling (40%), skin changes (40%), sweating (40%) and difficulty sleeping (40%)]. The typical mean severity of the symptom was "2" or "Quite a bit." It is noted also that the larger study (Williams et al. 2012b) found that the TRSC-C scores were significantly related to patients' functional status, as rated on the Lansky-Karnofsky scale.

Complementary or Dependent Care Method Reported

The six categories of complementary or dependent-care methods that parents/caregivers reported on the SA:SCM tool are shown in Table 2. The six categories are: A. Diet, nutrition, and life-style changes; B. mind body control; C. biologic treatment; D. herbal treatment; E. other methods; and F. taking prescribed medications. Each of the 30 TRSC-C symptoms is listed in the first column of Table 2 and the number of times each complementary therapy method was used to alleviate each symptom was listed under the categories A, B, C, D, E, or F. For example, the symptom "Feeling sluggish" occurred commonly—47 parents reported using B. Mind-Body Control, while 1 parent reported using F. Prescribed Medications. It should be noted that parents/ caregivers had the option of reporting "Do Nothing" (E), if that was in fact how they marked their response on that symptom. Of the six categories of self-care or dependent-care methods or complementary therapies, four were found useful; herbal treatments were not mentioned.

The two most common categories were (a) taking prescribed medications and (b) mind/body control. Findings in prescribed medications category included taking anti-emetics such as Zofran for nausea, laxatives for constipation, Xylocaine for a sore mouth, and pain relievers such as Tylenol or Oxycodone. Examples of parental (dependent) care methods in the mind/body control category included providing reassurance, rewards; holding, hugging and saying "I love you"; playing and talking with mom; sleeping; and using a heating pad. The most common findings in the Other category included nutritionist consult; mouth care, ice chips, magic mouthwash, and throat spray.

Discussion

The study findings showed that the TRSC-C is a tool that health care professionals can use to help all parents, but especially those with newly diagnosed children, to observe and report the occurrence and severity of their child's symptoms -- and relay the information to health care providers during treatments. By also gathering the information on the SA: SCM, a list of ways to relieve symptoms were found, and these can be shared with parents in their efforts to relieve symptoms during their child's chemotherapy or radiation therapy. When parents first learn of their child's diagnosis, they are confronted with much information, both written and oral (Flury et al., 2011). Moreover, the findings in the James et al. (2002) study showed that parental caregiving of ill children led to negative physical and emotional health of parents. However, timely education from Health Care Providers about their child's health status and ways to monitor it was of the greatest assistance to them.

The study by Baggott et al. (2004) showed that nurses recommended to parents similar self-care interventions for 8 common adverse symptoms (constipation, weight loss, fatigue, pain, infection, nausea, mouth sores, and bleeding), and advised that they should promptly report these to health care providers. The study by Berg et al. (2009) found cancer patients needed to be offered self-management and self-care strategies to cope with ongoing symptoms from the late effects of the treatments for childhood cancer. This is information that can be documented with the TRSC-C and the SA: SCM tools, as shown in this study.

The Williams et al. (2006) pilot study of parents of 11 children and adolescents with cancer showed the TRSC-C is a tool that improves communications among patients, parents, clinicians and others by allowing for self-report of symptoms and shared decision-making to relieve symptoms. The checklist uses terms that a child would use to express discomfort and this allowed for more accurate reporting of symptoms, as shown in this study.

As mentioned, the TRSC-C was an effective tool for parents and caregivers to report symptoms their child experienced, and the SA: SCM was an effective way to help them identify dependent-care methods and complementary therapies used to alleviate symptoms. The five most reported symptoms were nausea, feeling sluggish, hair loss, loss of appetite and vomiting; the first 3 were most reported by the children, each at 80%. Another children's study confirmed the most common symptoms included hair loss, nausea, vomiting, and loss of appetite (Williams et al., 2012b).

Parents and caregivers used dependent-care strategies and complementary therapies to alleviate many of the symptoms children exhibited. Using prescribed medications and mind/body control were the most effective categories. A study completed on Thai pediatric cancer patients indicated that the complementary therapy category Diet, Nutrition, and Lifestyle" was most common, followed by the category Mind Body Control (Shanberg & Williams, 2010). Common methods in the first category as used by Thai parents included adding flavoring to food items, changing the variety of foods, providing small frequent meals, and offering soft or liquid diets. Examples of specific methods used in the Mind/body control included massage, sponge baths, providing words of encouragement, allowing more periods of rest, and varying activities (Shanberg, Williams & Piamjariyakul, 2011). Comparing the results from studies done in Thailand and the United States suggests that international collaboration is feasible to study symptom monitoring and ways to manage symptoms during chemotherapy and radiation therapy. The patients experienced similar symptoms, yet cope differently.

According to Rheingans (2008), symptom management by nurses was typically done through the administration of pharmacologic agents. The study also emphasized the importance of using non-pharmacologic agents and providing a more holistic care. It discussed the use of interventions such as emotional support, art therapy, deep breathing, distraction, humor, massage and music therapy, which are all classified in the B. Mind/body category on the SA:SCM tool (Williams et al., 2006; 2012b).

In conclusion, the study found that dependent (parental) care helped manage symptoms. Moreover, assessing patient/ parent-reported symptoms and parents' use of dependent care methods or complementary therapies during pediatric cancer treatments also helped parents cope when they knew that they were helping their children.

Implications for Nursing

Nurses and other care providers can enhance care during treatments through assessments with a symptoms checklist. They also can advise parents on ways to alleviate their children's symptoms. Pediatric oncology nurses should be knowledgeable about child development and be able to identify their patients' symptoms and treat them adequately to improve their quality of life. Ignored side effects can lead to anxiety toward treatment and create unsuccessful outcomes.

Acknowledgements

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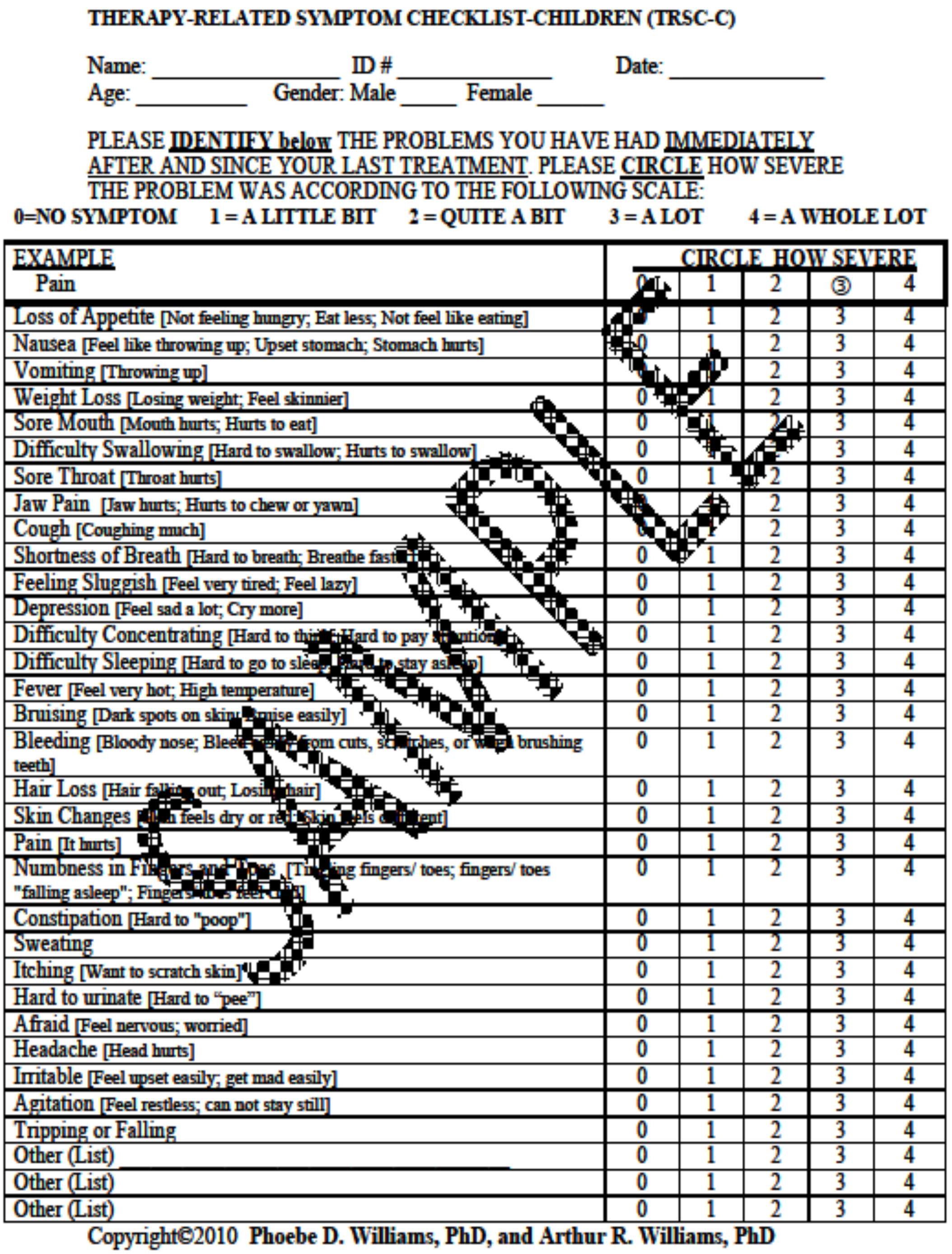
Figure 1 Therapy-Related Symptom Checklist-Children (Williams et.al, 2012)



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

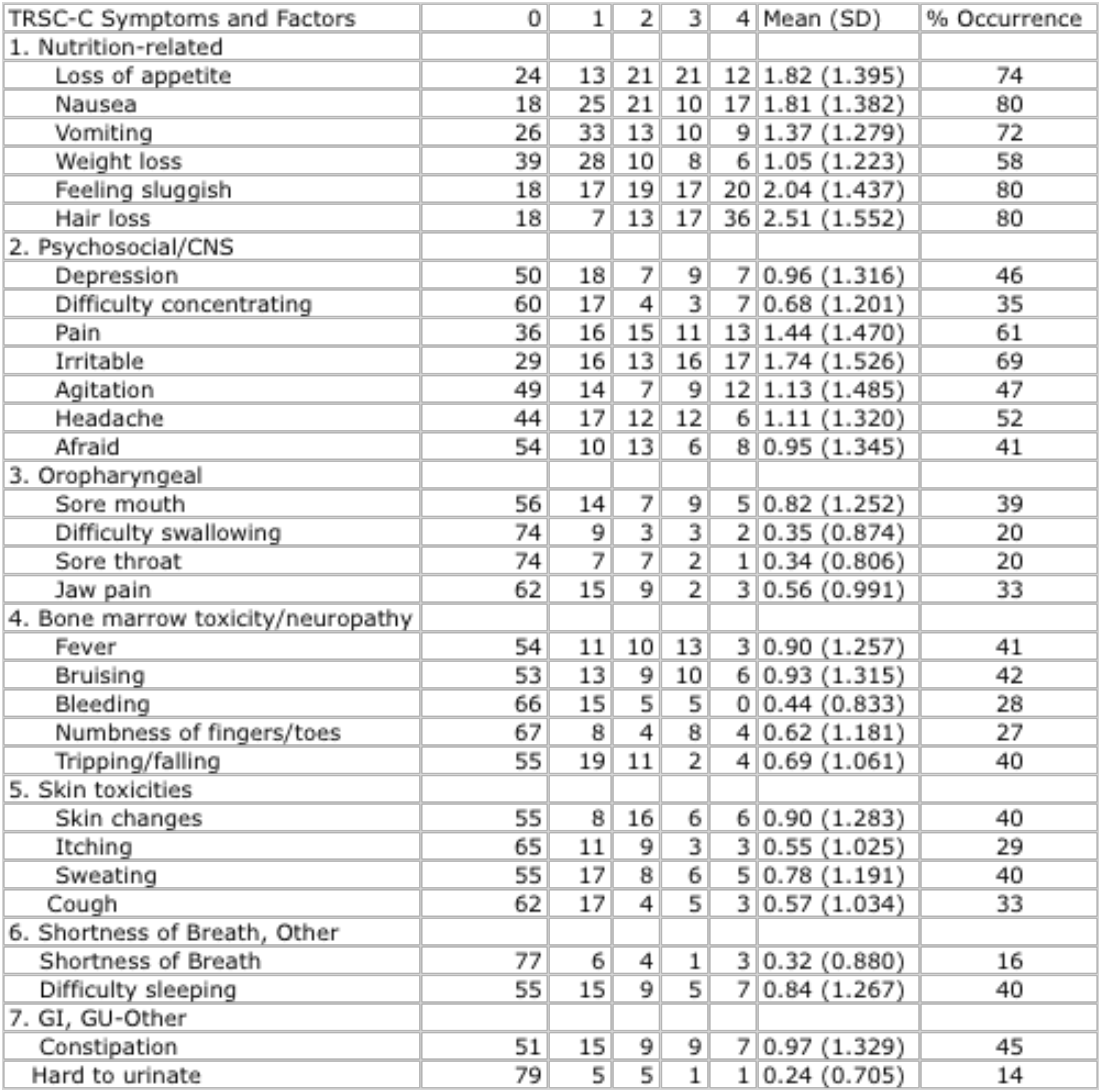
Name: ________________ ID # ____________ Date: ____________
Age: _________ Gender: Male _____ Female ______

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				
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; Bleed easily 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

Table 1 Distribution of Symptoms and Severity on the TRSC-C (*N*=92)



TRSC-C Symptoms and Factors	0	1	2	3	4	Mean (SD)	% Occurrence
1. Nutrition-related							
Loss of appetite	24	13	21	21	12	1.82 (1.395)	74
Nausea	18	25	21	10	17	1.81 (1.382)	80
Vomiting	26	33	13	10	9	1.37 (1.279)	72
Weight loss	39	28	10	8	6	1.05 (1.223)	58
Feeling sluggish	18	17	19	17	20	2.04 (1.437)	80
Hair loss	18	7	13	17	36	2.51 (1.552)	80
2. Psychosocial/CNS							
Depression	50	18	7	9	7	0.96 (1.316)	46
Difficulty concentrating	60	17	4	3	7	0.68 (1.201)	35
Pain	36	16	15	11	13	1.44 (1.470)	61
Irritable	29	16	13	16	17	1.74 (1.526)	69
Agitation	49	14	7	9	12	1.13 (1.485)	47
Headache	44	17	12	12	6	1.11 (1.320)	52
Afraid	54	10	13	6	8	0.95 (1.345)	41
3. Oropharyngeal							
Sore mouth	56	14	7	9	5	0.82 (1.252)	39
Difficulty swallowing	74	9	3	3	2	0.35 (0.874)	20
Sore throat	74	7	7	2	1	0.34 (0.806)	20
Jaw pain	62	15	9	2	3	0.56 (0.991)	33
4. Bone marrow toxicity/neuropathy							
Fever	54	11	10	13	3	0.90 (1.257)	41
Bruising	53	13	9	10	6	0.93 (1.315)	42
Bleeding	66	15	5	5	0	0.44 (0.833)	28
Numbness of fingers/toes	67	8	4	8	4	0.62 (1.181)	27
Tripping/falling	55	19	11	2	4	0.69 (1.061)	40
5. Skin toxicities							
Skin changes	55	8	16	6	6	0.90 (1.283)	40
Itching	65	11	9	3	3	0.55 (1.025)	29
Sweating	55	17	8	6	5	0.78 (1.191)	40
Cough	62	17	4	5	3	0.57 (1.034)	33
6. Shortness of Breath, Other							
Shortness of Breath	77	6	4	1	3	0.32 (0.880)	16
Difficulty sleeping	55	15	9	5	7	0.84 (1.267)	40
7. GI, GU-Other							
Constipation	51	15	9	9	7	0.97 (1.329)	45
Hard to urinate	79	5	5	1	1	0.24 (0.705)	14

TRSC-C scale severity 0-4: 0 = None, 1 = A bit, 2 = Quite a bit, 3 = A lot, 4 = A whole lot
% Occurrence = % reported of presence of symptom

Table 2 Symptoms Reported on the TRSC-C and Self-Care Methods Used

Symptoms reported	**A**	**B**	**C**	**D**	**E**	**F**
Taste change	34	0	0	0	0	1
Loss of appetite	14	1	4	0	1	21
Nausea	4	4	0	0	0	62
Vomiting	4	2	0	0	1	49
Weight loss	6	2	4	0	1	15
Sore mouth	0	0	0	0	10	16
Cough	1	3	0	0	5	5
Sore throat	2	1	0	0	5	4
Difficulty swallowing	0	0	0	0	7	1
Jaw pain	0	1	0	0	1	15
Shortness of breath	0	5	0	0	0	1
Numbness fingers/ toes	0	2	0	0	0	6
Depression	0	17	0	0	6	3
Difficulty concentrating	0	7	0	0	0	1
Fever	0	3	0	0	3	26
Bruising	0	13	0	0	15	0
Bleeding	0	4	0	0	8	1
Hair loss	0	9	0	0	0	0
Skin changes	0	17	0	0	0	0
Afraid	0	34	0	0	0	1
Difficulty sleeping	0	6	0	0	1	10
Pain	0	8	0	0	0	44
Constipation	4	0	0	0	0	31
Hard to urinate	0	0	0	0	0	1
Tripping/falling	0	19	0	0	0	3
Sweating	0	14	0	0	0	0
Itching	0	15	0	0	0	15
Irritable	0	27	0	0	0	5
Agitation	0	14	0	0	0	3
Feeling sluggish	1	47	0	0	8	1
Other:						
Dizzy	0	10	0	0	3	0
Diarrhea	6	0	1	0	0	5
Dry mouth	9	5	0	0	0	7
Headache	3	10	0	0	0	35
Totals	88	300	9	0	75	388

Self care methods, by complementary care categories: A = Diet, Nutrition, and Life-style, B = Mind Body Control, C = Biological Treatment, D = Herbal Treatment, E = Other, F = Prescribed Medications (Williams et al. 2006).

References

ACS, American Cancer Society : childhood cancer. Available at http://www.cancer.org/cancer/cancer in children. Accessed October 27, 2011.

Baggott, C., Dodd, M., & Kato, P. (2004). A survey of self-care and dependent-care advice given by pediatric oncology nurses. *Journal of Pediatric Oncology Nursing*, *21*(4), 214-222.

Berg, C., Neufeld, P., Harvey, J., Downes, A., & Hayashi, R.J. (2009). Late effects of childhood cancer, participation, and quality of life of adolescents. *OTJR: Occupation, Participation, and Health*, *29*(3), 116-124.

Flury, M., Caflisch, U., Ullman-Bremi, A., & Spichiger A. (2011). Experiences of parents with caring for their child after a cancer diagnosis. *Journal of Pediatric Oncology Nursing*, published online 13 April 2011, DOI:10.1177/1043454210378015.

James K, Keegan-Wells, D., Hinds, P.S., Kelly, K.P., Bond, D., Hall, B., Mahan, R., Moore, I.M., Roll, L., & Spekhart, B. (2002). The care of my child with cancer: Parents' perceptions of caregiving demands. *Journal of Pediatric Oncology Nursing*, *19*(6), 218-228.

Rheingans, J. (2008). Pediatric oncology nurses' management of patients' symptoms. Journal of Pediatric Oncology Nursing. *25*(6), 303-311.

Shanberg, R., & Williams, P.D., (2010): Complementary therapy to relieve pediatric cancer therapy-related symptoms in Thailand. Poster presented at *Mind and Heart Honors Conference*, Kansas City, KS, Nov.

Shanberg, R.,Williams, P.D., & Piamjariyakul, U. (2011). Complementary therapy and care to relieve pediatric cancer therapy-related symptoms in Thailand. *The Journal of BSN Honors Research*, *4*(1). http://archie.kumc.edu/handle/2271/987.

Wesa, K., Gubili, J., Cassileth, B. (2008). Integrative oncology: complementary therapies for cancer survivors. *Hematology Oncology Clinics of North America*, *22*(2), 343-353.

Williams, P.D., Schmideskamp, J., Ridder, E.L., Williams, A.R. (2006). Symptom monitoring and dependent care during cancer treatment in children: pilot study. *Cancer Nursing*. *29*(3):188-197.

Willams, P.D., Lopez, V., & Chair, S. et al. (2010). Symptom monitoring and self-care practices among oncology adults in China. *Cancer Nursing, 33*(3):184-193.

Williams, P.D., Williams, A.R., Kelly, K.P., et al. (2012): A symptom checklist for children with cancer: Therapy-Related Symptom Checklist-Children (TRSC-C). *Cancer Nursing*, *35*(2):89-98.

Williams, P.D., Dobos, C., Piamjariyakul, U., Slaven, A., Geiseking, A., Connor, R., & Williams, A.R. (2012). Symptom monitoring and dependent care during cancer treatments of children and adolescents (poster). *Western Institute of Nursing Research Conference*, Portland, OR, April.