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Evaluating Self Care Practices of Children with Type 1 Diabetes Mellitus in Northern West Bank: A controlled Randomized Study Utilizing Orem- Self Care Theory

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Title: Evaluating Self Care Practices of Children with Type 1 Diabetes Mellitus in Northern West Bank: A controlled Randomized Study Utilizing Orem- Self Care Theory

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Abstract

Diabetes mellitus, a non communicable disease and a major public health problem. It is a chronic disorder of metabolism characterized by partial or complete deficiency of the insulin hormone. Diabetes which historically has been a phenomenon in older people, has now crept into the lives of young children.

Self– cared diabetes involves a complex set of tasks and the key to successful management of diabetes is adherence to these tasks. Diabetes self care education is a critical element of care for all people with diabetes and necessary to improve patient outcomes.

It has adopted an experimental approach to explore participants diabetes specific knowledge, self care practices, and observational self care practices checklist after attending a program. This is the first quantitative evaluation self care practices of Palestinian children with type 1 diabetes mellitus.

An experimental study design was used. The study started from January to August 2012. The study setting was the central diabetic clinics of PHC centers in Northern West Bank districts (Nablus, Tulkarem, Jenin, Tubas, Salfit, and Qalqellia). The total population was 203 patient, 20 patients from Jenin and Nablus were randomly assigned into the pilot testing and were excluded from the actual study. The rest of the population was 183 patients and assigned randomly into the experimental and control groups. Seven diabetic children withdrawn from the study, so the last sample was 176 participant, 91 subject in the experimental group and 85 subject in the control group. The investigator developed an instrument for collecting data, validity was tested by professional experts in diabetes mellitus and academic professions, Cronbach's alpha was strongly reliable (0.90).

The study was conducted in two phases; phase I pretest for both the experimental and control groups. The experimental group attended health education intervention, where the control group sought routine care. The intervention was conducted in 2 separate days, consisted of two discussion sessions about diabetes knowledge, and 3 demonstration sessions for insulin injection, blood and urine testing for sugar and/ or ketones. Also each participant received a booklet and a pamphlet on diabetic care during the intervention. After 3 months from intervention program phase II post test with the same tool was applied for both the experimental and control groups.

The scores of the study participants were tested by using descriptive and inferential statistics between both groups post test and between pretest and post test for experimental group. The data were analyzed using the statistical package for the social science (SPSS) 17.0 version, and the level of significance (α) was set at 0.05 for statistical analysis.

The findings showed that the mean scores of the experimental group at post test is higher than pretest for diabetes knowledge 1.94 post test and 1.61 pretest, self care practices 3.53 post test and 2.73 pretest, and observational self care practices checklist in insulin injection technique 3.45 post test and 2.56 post test, blood glucose test 3.68 post test and 2.84 pre test, urine test for glucose and /or ketones 3.39 post test and 2.07 pretest and hygiene care 1.89 post test and 1.54 pre test at a P value 0.05 after 3 months from the intervention. Also The mean scores of the experimental group at post test is higher than control group.

This indicate that the intervention program utilizing Orem's self care theory is effective in transferring diabetic children from wholly or partly compensatory to educative / supportive system to accomplish self care practices.

Orem theory can be utilized by nurses and / or educators when planning education programs for diabetic children. Diabetic patients need self care practices education and training from the professional team to transfer them from wholly compensatory or partially compensatory to educative to manage the diabetes. The diabetic health education intervention had a positive impact on the improvement of diabetes specific knowledge, self care practices and observational self care practices checklist.

العنوان: تقييم ممارسات العناية الذاتية عند الأطفال المصابين بمرض السكري من النوع الأول في شمال الضفة الغربية: دراسة عشوائية ضابطة مستعملا نظرية العناية الذاتية لأورم.

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الملخص

السكري من الأمراض غير السارية ويشكل مشكلة صحية كبيرة. وهو عبارة عن خلل مزمن في عمليات الأيض المتمثلة بنقص جزئي أو كلي لهرمون الأنسولين. السكري يعتبر ظاهرة مرضية عند الكبار ولكنه بدأ يزحف أيضا في الأطفال.

العناية الذاتية للسكري تتضمن مجموعة من المهام المكثفة، والمفتاح لإنجاح معالجة المرض هو الالتزام بهذه المهام. تعليم العناية الذاتية لمرضى السكري هو العنصر الأساسي في العناية لجميع المرضى المصابين بالسكري وكذلك ضروريا لتحسين نتائج المريض.

اعتمدت الدراسة طريقة البحث الإجرائي للتعرف على المشاركين الأطفال المرضى من ناحية المعرفة بمرض السكري، ممارسات العناية الذاتية، وممارسات العناية الذاتية التطبيقية بالمشاهدة بعد حضورهم البرنامج المقترح. هذا أول عمل تقييمي كمي لممارسات العناية الذاتية بين الأطفال الفلسطينين المصابين بالنوع الأول من مرض السكري بالاعتماد على نظرية أورم للعناية الذاتية.

استخدم الباحث الدراسة الإجرائية. امتدت الدراسة من كانون ثاني إلى تموز من عام 2012. مكان الدراسة عيادات السكري المركزية في مدن شمال الضفة الغربية حيث أحصي 203 طفل تنطبق عليه مواصفات الدراسة. أجريت دراسة إرشادية على 20 منهم من مراجعي عيادة نابلس وجنين وتم اختيارهم بشكل عشوائي وتم إقصاؤهم من الدراسة الفعلية، لذلك أصبح مجتمع الدراسة 183 طفلا، وقد تم تقسيمهم عشوائيا إلى مجموعة تجريبية ومجموعة ضابطة. المجموعة التجريبية تلقت تدريبا في حين لم تتلق المجموعة الضابطة إلا الرعاية الروتينية. انسحب سبعة أطفال من الدراسة لأسباب غير محددة حيث أصبحت 176 طفلا . تمت الدراسة على مرحلتين، المرحلة الأولى تم فيها الاختبار القبلي والتدريب والمرحلة الثانية تم فيها الاختبار البعدي بعد 3 شهور من انتهاء التدريب. تكون التدريب من محاضرتين عن مرض السكري، و 3 جلسات تطبيقية في إعطاء الأنسولين، قياس السكر في الدم، وقياس السكر والكيتون في البول ، وتم توزيع كتيب ومنشور عن السكري للمشاركين في التدريب. تم عرض التدريب في يومين منفصلين بواقع أسبوع بينهما.
استخدم الباحث مقياس صممه لجمع المعلومات ومقارنة أداء أفراد الدراسة على الاختبارات القبلية والبعدية للمجموعتين. وقد قام الباحث بالتحقق من صدق وثبات أدوات الدراسة.

وللتحقق من نتائج الدراسة استخدم الباحث برنامج التحليل الإحصائي (SPSS) نسخة 17 ، والدلالة الإحصائية عند مستوى ($\alpha = 0.05$) .

أظهرت نتائج الدراسة إلى وجود فروق ذات دلالة إحصائية عند مستوى (α= 0.05) في المعرفة المحددة بمرض السكري، ممارسات العناية الذاتية، وممارسات العناية الذاتية المشاهدة لصالح المجموعة التجريبية بعد مضي 3 شهور من انتهاء التدريب. معدل العلامات للمجموعة التجريبية في الاختبار البعدي أعلى من الاختبار القبلي حيث كانت بالنسبة للمعرفة بمرض السكري في الاختبار 1,94 في الاختبار البعدي بينما كانت 1,61 في الاختبار القبلي، أما بالنسبة للممارسات العناية الذاتية فكانت 3,53 في الاختبار البعدي بينما كانت 2,73 في الاختبار القبلي ، وفيما يختص بممارسات العناية الذاتية المشاهدة فكانت بالنسبة لطريقة إعطاء الإنسولين 3,45 في الاختبار البعدي و 2,56 في الاختبار القبلي ، وفحص السكر في الدم 3,68 في الاختبار البعدي و 2,84 في الاختبار القبلي و فحص السكر في البول فكان 3,39 في الاختبار البعدي و2,07 في الاختبار القبلي والعناية بالنظافة 1,89 في الاختبار البعدي و 1,54 في الاختبار القبلي. وكذلك كان معدل العلامات للمجموعة التجريبية اكبر من معدل المجموعة الضابطة.

وهذا يدل على أن البرنامج التعليمي باستخدام نظرية أورم فعال في نقل أطفال السكري من معتمدين أو شبه معتمدين على الاخرين إلى مستقلين لانجاز ممارسات العناية الذاتية.

وبينت الدراسة إمكانية إستخدام التمريض نظرية أورم عند التخطيط للبرامج التعليمية للأطفال المصابين بالسكري وأن مرضى السكري بحاجة لتعليم وتدريب على ممارسات العناية الذاتية من فريق مهني لنقلهم من مرحلة الاعتماد على الاخرين إلى الاعتماد على أنفسهم لضبط السكري عندهم وبينت كذلك أن التدريب له تأثير ايجابي على المعرفة بمرض للسكري وممارسات العناية الذاتية.

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Chapter I

Introduction

1.1 Introduction

Diabetes mellitus, a non communicable disease and a major public health problem. It is a chronic disorder of metabolism characterized by partial or complete deficiency of the hormone insulin (Wong D., Hockenberry M., Wilson, 2011). Diabetic patients not only suffer from diabetes mellitus symptoms, but also from acute and chronic complications that cause a disability or malfunction.

Diabetes mellitus was classified to type 1 diabetes mellitus which is previously encompassed by the terms insulin dependent diabetes or juvenile-onset diabetes, and type 2 diabetes mellitus which is previously encompassed by the term non insulin dependent diabetes mellitus (ADA, 2008).

Type 1 diabetes is classically a disease of the young but can occur at any age; onset is generally rapid and presentation acute. Causation in the majority of cases is an auto-immune process which destroys the insulin-producing pancreatic beta cells. Both genetic and environmental factors have been implicated as important factors in the initiation of the auto-immune process, with viruses often acting as a trigger (British Medical Association (BMA), 2004). Type 2 diabetes is the most common type of diabetes, accounting for 90 % of all cases of diabetes, and is frequently undiagnosed, with perhaps as many as half the number of individuals who have this type of diabetes being unaware of their condition (BMA, 2004). Although type 2 diabetes has characteristically been thought of as a condition affecting the middle-age and elderly, it is increasingly being detected in younger people, including children. Onkamo P., Vaananenet S., Karavenen M. and Tuomilehto J., (1999) indicated that globally the incidence of diabetes in children and adolescents is increasing. A recent study published in the journal of Pediatrics found that 96% of children who have diabetes are under the age of 10 years, have diabetes mellitus type1 (ADA, 2006).

In Palestine, the population is young where 48.2% are under 18 years old at year 2010; the study target children between 10 -18 years which was 25% of the total

Palestinian population for same year (Palestinian Central Bureau of Statistics (PCBS), 2011).

At year 2010 the total of new diabetic registered cases under 25 years were 206 in West bank while at 2009 the total new cases were 171 (MOH, 2011). The incidence rate of diabetes mellitus among children; for the age group 0-4 years was 2.3% for males and 3.5% for females, 5 -14 years 12.7% for males and 15.9% for females, 15 - 24 years for males 24.0% and 28.9% for females (Ministry of health report (MOH), 2011).

Most of Children with type 1 diabetes mellitus are treated and followed up by diabetic clinics at MOH primary health care centers. Each diabetic clinic have only one physician and one nurse, many of these clinics specify one day / week to serve diabetic children for checking fasting blood sugar and insulin delivery.

Guidelines for improving the care of diabetic patients by ADA (2007) stated that diabetic patients must be changing their life styles including eating habits and self care along with taking diabetes medicine to have a regular and balanced blood sugar level.

Self – care diabetes involves a complex set of tasks and the key to a successful management of diabetes is adherence to these tasks. It is generally agreed that the basis of a diabetes education program should include: a) self-monitoring of blood glucose, b) nutrition, c) exercise, and d) taking medications as directed (Gagliardino and Etchegoyen, 2001).

The nurse as a member of the health care team must be involved in self-management of diabetic children. Nurses responsibilities are numerous, educating the children to the best of their ability to understand their condition in such a way that they know enough about their management and self-care in order to change their life-style (Wong et al, 2011).

This study was guided by Orem's self care theory. Orem's theory of self-care holds that self care is a learning activity, the main premise of this theory states that promotion of self-care contributes to the individual's self-maintenance and promotes health-care well being (Orem, 1985; Orem D., Renpenning K., Tylor S., 2003). According to Orem self-care nursing system theory, three systems exist; (i) Wholly

compensatory, nurse or guardian provides client total care; (ii) partially compensatory system where the nurse or guardian and patient share responsibility for the care; and (iii) educative- development system where the client has primary responsibility for personal health with nurse or advocate as a consultant (Orem et al, 2003). The literature available focuses on DM type 1 with limited local studies on the self care practices or utilizing Orem self care theory.

The aim of this study was to evaluate self care practices among Palestinian's children with type 1 diabetes mellitus, before and after diabetic educational intervention program.

1.2 Problem statement

Diabetes mellitus (DM) is a common, chronic, metabolic syndrome characterized by hyperglycemia as a cardinal biochemical feature (Alemzadeh and Ali, in Nelson 2011).

Diabetes is largely a self-managed disease and the patient's role is complex and demanding. Education is the key to the successful management of diabetes and is central to clinical management (Silverstein J., Klingensmith G., Copeland K. 2005; Swift, 2009). Achieving a balance between insulin levels, food intake and energy expenditure are cornerstones of clinical management. Diabetes requires extensive self-management and frequent high-quality educational input and support (Saudek C., Derr R., Kalyani R., 2006).

Diabetes self- care education is a critical element of care for all people with diabetes and is necessary in order to improve patient outcomes (Funnell M., Brown T., Childs B., Haas L., Hosey G., Jensen B., Maryniuk M., Peyrot M., Piette J., Reader D., Siminerio L., Weinger K., Weiss M., 2011).

For children with diabetes, it will help them to take responsibility for their self - care and make their needs known to those who care for them at home and school settings or environment.

Diabetes type 1 incidence is increasing every year among the children in Palestine (MOH report, 2012). Therefore, this study is to evaluate self care practices among

Palestinian's children, with type 1 diabetes mellitus, before and after diabetic educational intervention program.

1.3 Justification of the study

Managing children's diabetes successfully requires continuous education and encouragement of parents and children (Curtis and Hagerty, 2002).

A Study applied in New Zealand to evaluate diabetes self-management education program is conducted, participants showed improvement in attitudes toward their own ability to manage their diabetes; in diet, physical activity, and foot care; and in hemoglobin A1c levels 3 months after the end of participation (Silva M., Clinton J., Appleton S. and Flanagan P., 2011).

Diabetes is one of the most medically complex of the chronic conditions to manage. Yet the trend in health care today is for each person with diabetes to assume most of the self-care management of this condition within the home environment. The intricate regime for diabetes self-care management is based on the individual being able to correctly read, assimilate, and problem solve the multitude of diabetes educational materials including the pathophysiology, medication dosage adjustments, symptomology treatment and risks, dietary substitutions, and exercise physiology (Tones, 2002).

The rationale for examining self care practices among type 1 diabetes mellitus children are important to manage diabetes mellitus, performing daily activities and to prevent long term complication.

Children don't know the importance of self care practices, if they weren't guided and followed up by diabetic educational interventional program. Thus teaching self care utilizing Orem's self care theory is important to avoid acute and long term complications of diabetes mellitus.

Attempting to achieve a goal of near normal blood sugar requires individuals to remain diligent with their daily diabetes management regimen, which includes testing blood glucose levels, administering insulin, managing nutrition, and adjusting therapy for physical exercise or in anticipation of special circumstances (Lorenz, 2003).

In a study by Chin M., Cook S., Jin L., Drum M., Harrison J., Koppert J., Thiel F., Herrand A., Schaefer C., Takashima H. and Chin S. (2001) found that 40% of health care providers believed that their patients were not able to make the changes in

Chapter VI

Conclusions and recommendations

6.1 Conclusions

Self care educational program based on Orem's theory for children with type1 diabetes mellitus increases patient's self care agency to meet therapeutic self care demands including diet control, exercise, medication taking and personal hygiene and safety practices. Giving knowledge that is congruent with the person's needs can bring about better practice. Nursing for self care development would make the patients to be active participants in their own self care practice.

Overall, the findings met the hypothesis and were consistent with the Orem's self care theory for evaluation of the diabetic health education program for children with type 1 diabetes mellitus. The information about the diabetic health education program of self care for children with type 1 diabetes can be helpful in Palestine.

6.2 Recommendations

1. Recommendation for families and schools community

- Encourage children in self care practices education programs as soon as possible since diagnosis of diabetes mellitus .
- Ensure good understanding of the self care practices to the children.
- The majority of the mother's are the main caregivers of the diabetic child. If mothers are encouraged to join the education program this can encourage them to assist in the supervision of the diabetic child.
- The school community has a role to play in assisting and overseeing diabetic children during school hours. There is a need for the school community to be made aware and educated on diabetes. This will help pupils and teachers to understand diabetes and the treatment so that diabetic children don't feel ashamed of his or her diabetes.

2. Recommendation for health care providers and staff in PHC

- The health providers can be trained to provide relevant diabetic interventions based on self care theory.
- They could invited diabetic children to a day program to educate them on diabetes and self care practices.

3. Policy and management

We suggest the following recommendations for policy makers and managers:

- Interventions or patient education for children with type 1 diabetes mellitus should incorporate the concept of self care in their design and implementation. Moreover, support based interventions to groups rather than individuals.
  - Development of manuals on self care and audiovisual aids will help health provider to educate the children.
  - A variety of diabetes knowledge and self care multimedia should be provided for all patients.
  - The multimedia for taking care of patient with diabetes should be revised and updated overtime.

4. Need for continued research

- Replication of this study in various settings and adding other outcomes measures (such as HbA1c) would be suggested in further studies.
- Some participants found it difficult to disclose their personal circumstances or difficulties. A qualitative research study is required to clarify their individual needs.
- A long term follow- up study of the effectiveness of the educational program in diabetes should be done.
- Additional studies need to be done such as age, gender, health literacy, measurement of compliance to prescribed treatment, frequency of acute complications and hospitalizations, rate of school absenteeism and health care costs in diabetes are other aspects which need investigations.