CUIDAR DE QUEM CUIDA: A IMPORTÂNCIA DA ASSISTÊNCIA DE ENFERMAGEM ÀS MULHERES CUIDADORAS DE CRIANÇAS COM DEFICIÊNCIA.

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Objetivo: prestar assistência de enfermagem às mulheres cuidadoras de crianças com deficiência, a fim de avaliar riscos para o desenvolvimento de DM. Método: Trata-se de um estudo de campo com características quantitativa e qualitativa (de caráter descritivo e analítico), onde foram desenvolvidos três mutirões de saúde. Foram averiguados os seguintes parâmetros das mesmas: relação cintura-quadril (RCQ), glicemia capilar pós-prandial (GCPP) e pressão arterial (PA). Todos os dados coletados, foram analisados e apresentados em média, desvio padrão/erro e número de dados. Os valores onde p<0.05, foram considerados significantes. Resultados: Os dados obtidos nesse estudo revelam que uma parte considerável das cuidadoras atendidas nos mutirões de saúde possuem alterações de PA, GCPP ou RCQ. Conclusões e Implicações para a Prática: Cuidadores de crianças com deficiência possuem diversos fatores de risco para o desenvolvimento de DM. Campanhas como essa são de extrema importância, pois contribuem com a prevenção de patologias e aumentam a qualidade de vida das pessoas. Dessa forma, o presente estudo permite que os profissionais de enfermagem, através do poder transformador do trabalho, possam colaborar com a mudança de vida e de saúde dos menos favorecidos.

palavras-chave: crianças com deficiência, cuidadoras, enfermagem, diabetes mellitus

CUIDAR DE QUIEN CUIDA: LA IMPORTANCIA DE LA ASISTENCIA DE ENFERMERIA A LAS MUJERES CUIDADORAS DE NIÑOS CON DISCAPACIDAD.

Objetivo: Brindar atención de enfermería a mujeres cuidadoras de niños con discapacidades para evaluar los riesgos para el desarrollo de la DM. Método: Este es un estudio de campo con características cuantitativas y cualitativas (de carácter descriptivo y analítico), donde se desarrollaron tres grupos de salud. Se investigaron los siguientes parámetros: relación cintura-cadera (RCC), glucemia capilar posprandial (GCPP) y presión arterial (PA). Todos los datos recopilados se analizaron y presentaron en promedio, desviación estándar / error y número de datos. Los valores donde p <0.05 fueron considerados significativos. Resultados: los datos obtenidos en este estudio revelan que una parte considerable de los cuidadores atendidos en las unidades de atención de la salud tienen cambios de BP, GCPP o WHR. CONCLUSIONES E IMPLICACIONES PARA LA PRÁCTICA: Los cuidadores de niños con discapacidades tienen varios factores de riesgo para el desarrollo de la DM, que son extremadamente importantes porque contribuyen a la prevención de patologías y aumentan la calidad de vida de las personas. Así, el presente estudio permite a los profesionales de enfermería, a través del poder transformador del trabajo, colaborar con el cambio de vida y salud de los menos favorecidos.

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CARING FOR THOSE WHO CARE: THE IMPORTANCE OF PROVIDING NURSING CARE TO WOMEN CARING FOR DISABLED CHILDREN.

Objective: To provide nursing care to females, who are caregivers of children with disabilities, and to assess the presence of risk factors for developing DM. Method: This was a field study where three health initiatives, focusing on the caregivers, were conducted. The following parameters of the caregivers were recorded: blood pressure (BP), postprandial capillary glucose (PPCG) and waist-to-hip ratio (WHR). All of the collected data were analyzed and results with p values of <0.05 were considered significant. Results: It was observed that a considerable portion of the caregivers displayed alterations in all of the evaluated parameters (risk factors). Conclusions and Implications to the practice: Caregivers of children with disabilities have been shown to possess risk factors for the onset and progression of DM. Health initiatives are beneficial to these caregivers, because they educated the population about self and preventive care. Thus, the present study highlights an area of nursing that focuses on and attempts to improve the the health and quality of life for the underprivileged.

key words: children with disabilities, caregivers, nursing, diabetes mellitus

CUIDAR DE QUIEN CUIDA: LA IMPORTANCIA DE LA ASISTENCIA DE ENFERMERÍA A LAS MUJERES CUIDADORAS DE NIÑOS CON DISCAPACIDAD.

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INTRODUCTION

The concept of work is a historical process, which has evolved concomitantly with changes in the production of goods, organization of society and knowledge of humans. Consequently, work has economic, ideological, political, philosophical and sociological characteristics. In the present day, the professional life of an individual plays a fundamental role in the identity formation and well-being of the person. Thus, a thorough understanding of the meaning of work becomes critical when trying to understand the behavior of the people when they are at work.

Regardless of the circumstances (i.e. religious, philosophical or progressive humanization, anthropological-phenomenological and biological), all lives deserve respect, and this a commonality of researchers on the subject. Indeed, the right to life is the most fundamental of all human rights. Thus, being rational, social and spiritual, humans manage to live in societies or communities that favor the emergence of socialization and work. However, regardless of global location, all walks of human life are affected by illness. This makes humans dependent on attaining basic needs, and ultimately disrupting their social and professional realities.

Nursing is a profession that focuses on the science of providing care. However, if nurses only place emphasis on the scientific aspects of the discipline, then nursing would become impersonal and pragmatic. It is an inevitable fact that scientific data must be utilized in this profession, however, patient care, as well as the relationship between the nurse and patient are fundamental to nursing care. Consequently, sensitivity as necessary characteristic for nurses.

It should be pointed out that the work of the nurse not only requires knowledge about proximate causes, but also demands that nurses reflect about more diverse causes, which guides
the nurse to a philosophy, establishes a way of life and puts their knowledge at the disposal of the patient. As a consequence, nursing has an intense commitment to human relations, and has a significant impact on human health and life\textsuperscript{3,5}.

In order to work with the community, health professionals must first dissociate themselves from training that is incapable of articulating the theory of practice. Despite the discussions revolving around the need to include people with disabilities, currently health services and professionals are not sufficiently prepared for treating this population and their respective caregivers. In fact, the National Policy on the Health of Persons with Disabilities has indicated that training human resources personnel, especially nurses, on how to properly serve the patients and their caregivers should be made a priority\textsuperscript{6}. In the present field study, the risk of female caregivers of disabled children developing Diabetes mellitus (DM) was investigated, with the intention of improving the quality of life of the caregiver and their dependent(s).

Diabetes mellitus (DM) is a metabolic disease that can exert lasting effects throughout the body, including the kidneys and cardiovascular system. In fact, damage to the cardiovascular system can be severe, having the potential to substantially reduce the quality of life of people affected by the disease. Characteristics often associated with the metabolic syndromes include: dyslipidemia, insulin resistance, hypertension, obesity, inflammation, oxidative stress, endothelial dysfunction, as well as others, all of which can damage the cardiovascular system\textsuperscript{7}. Furthermore, DM-mediated cardiovascular damage (i.e. micro- and macrovascular diseases), can result in the development of retinopathies, nephropathies, neuropathies, as well as coronary, cerebrovascular and peripheral arterial diseases, which when not properly managed can lead to lower limb amputations\textsuperscript{8}. Thus, it is evident that all of these complications can impair the health and quality of life of the individuals who have the disease.
Considering that caregivers of children with disabilities are often exposed to most of the previously described DM risk factors, projects that stimulate the prevention, detection and control of DM for this population are extremely important and necessary. The present study, through an Extension Project of an ongoing Research Project at Universidade Paulista (UNIP), sought to create health efforts that tend to the needs of female caregivers of children with disabilities, from the Associação Beneficente Comunidade de Amor Rainha da Paz, Santana de Parnaíba, a city of São Paulo/Brazil, with an emphasis on the prevention, detection and control of DM.

**OBJECTIVE**

Assess the risk of developing DM in female caregivers of children with disabilities, and provide nursing care to these individuals.

**MATERIALS AND METHODS**

This was a field study with quantitative and qualitative characteristics (descriptive and analytical).

The research was carried out at the Associação Beneficente Comunidade de Amor Rainha da Paz, located in the metropolitan region of São Paulo, Brazil. It is a non-profit organization, founded in 2001, with the mission of assisting disabled people in Santana de Parnaíba and other regions, such as: Tatuí, Cotia, Caieiras, Mairinque, Araçariguama, Pirapora do Bom Jesus, Franco da Rocha, Francisco Morato, Barueri, São Paulo, Osasco, Carapicuíba, Jandira, Cajamar and Itapevi. Additionally, the organization achieves its goals through workshops, therapeutic consultations and social activities, and currently serves about 400 disabled children/adolescents.

The primary purposes include: providing therapies and treatments, as well as promoting social assistance to these poor special needs children and their families, free of charge for a
predetermined amount of time. Patients can receive therapeutic assistance in the fields of occupational therapy, physiotherapy, speech therapy, psychology, nutrition, hippotherapy, pet therapy, dentistry, nursing, and pediatric neurology. Moreover, the families receive social and psychological assistance through projects aimed at assisting them.

Since 2013, UNIP Alphaville campus, has been developing multidisciplinary activities in conjunction with the Associação Beneficente Comunidade de Amor Rainha da Paz through Extension Projects, which are part of a larger research project entitled: "Effectiveness of multidisciplinary care in individuals with multiple disabilities in Santana de Parnaíba – SP" (Ethics committee #21327013.2.0000.5512). The main project requires students, who are under the guidance of UNIP professors, to develop activities, during the school year, related to biomedicine, nutrition, physical education, biology, physiotherapy, psychology, aesthetics and nursing. Annually, the project receives proposals for new activities and/or improvements to activities conducted during the previous year. Furthermore, these activities are carried out with children and adolescents with disabilities and/or their caregivers, who attend the Association.

The advisor of the present study is a UNIP professor and is the researcher responsible for the nursing portion of the main research project. She is also the advisor of the nursing technician at the Association who conducted the present field study, who is also seeking to attain a Bachelor's Degree in Nursing from UNIP and is the person who carried out the present field study. Since the focus of the teacher and student is nursing care for this population, only the data related to the nursing area are presented.

For this study, the data presented were collected during three health care initiatives (one in 2015 and two in 2016), where the following parameters were evaluated in female caregivers of children with disabilities: blood pressure (BP), postprandial capillary glycemia (PPCG), and waist-to-hip ratio (WHR).
With regards to BP, values above 130/90 mmHg were considered abnormal. The PPCG has been used to predict the onset and/or for assessing the severity of DM, and values above 126 mg/dL were considered to be abnormal. The WHR has been shown to be an indicator for the development of metabolic syndromes, cardiovascular diseases and breast cancer, and for this study values above 0.85 were considered to be abnormal. It is worth noting that the female caregivers, who participated in the study, did not necessarily participate in the collection of all the parameters. As a result, the total number of participants for each parameter evaluated are different.

The Extension Project was approved by the UNIP research ethics committee and the caregivers that participated in the study agreed to the conditions set forth in the Informed Consent Form.

The data recorded during the three data collection periods were analyzed using the GraphPad Instat 3 program. Results were considered significant when the p values were <0.05.

RESULTS

The present study assessed the risk of female caregivers of children with disabilities developing DM, towards the goal of providing nursing care to these individuals and their families. The study took place at the Associação Beneficente Comunidade de Amor Rainha da Paz, located in the metropolitan region of São Paulo, which specializes in providing multi-professional assistance to children and adolescents with disabilities and their families. To that end, nurses worked with these women, and evaluated BP, PPCG and WHR during three events, which took place between 2015 and 2016. The first event was held in May of 2015, the second in May of 2016 and the third in October of 2016, which amounted to 8 days of data collection. In total, data was collected from 182 women, which corresponds to roughly 22.75 women per day, with ages ranging from 16 to 53 years.
As shown in Table 1, once all of the blood pressure data was collected, two groups were formed for data analysis. One group contained caregivers that had a systolic blood pressure of $<130$ mmHg and a diastolic blood pressure of $<90$ mmHg, and the other group included caregivers that had a systolic blood pressure of $>130$ mmHg and a diastolic blood pressure of $>90$ mmHg. In total, 136 women participated in the blood pressure measurement portion of this study, and it was determined that 14 participants (~10%) had increased systolic and diastolic blood pressures, which is a considerably high percentage.

Table 1. Blood Pressure Data.

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>SYSTOLIC $&lt; 130$ mmHg</td>
<td>$114.90 \pm 0.80$ (122)</td>
</tr>
<tr>
<td>SYSTOLIC $&gt; 130$ mmHg</td>
<td>$144.28 \pm 3.09$ (14)***</td>
</tr>
<tr>
<td>DIASTOLIC $&lt; 90$ mmHg</td>
<td>$74.34 \pm 0.74$ (122)</td>
</tr>
<tr>
<td>DIASTOLIC $&gt; 90$ mmHg</td>
<td>$92.85 \pm 2.44$ (14)**</td>
</tr>
<tr>
<td>TOTAL NUMBER OF PARTICIPANTS</td>
<td>136</td>
</tr>
</tbody>
</table>

***p<0.0001 Systolic $< 130$ mmHg vs. Systolic $> 130$ mmHg. **p<0.001 Diastolic $< 90$ mmHg vs. Diastolic $> 90$ mmHg. Tukey test - level of significance p < 0.05.

Another important parameter assessed during the health initiatives was PPCG. In total, 122 women participated in the PPCG portion of this study. For this assessment, the data were organized into three groups, based on glucose concentration values: $< 99$ mg/dL, 100 to 126 mg/dL and $> 126$ mg/dL. As shown in Table 2, despite not collecting the blood under fasting conditions, 16 women (~13%) had glucose concentrations above 126 mg/dL ($172.12 \pm 14.37$, n = 16).

Table 2. Postprandial Capillary Glycemia Data

The third DM risk factor screened for in the caregivers was WHR. This parameter has been employed as a risk indicator for heart and metabolic diseases. As shown in Table 3, 182 women participated in this portion of the study. From this sample, 40 women presented values above 0.85 (0.87 ± 0.002) and 21 presented values above 0.90 (0.93 ± 0.005).

Table 3. Waist-to-hip ratio data

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>VALUE</th>
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<tbody>
<tr>
<td>&lt; 0.85</td>
<td>0.78 ± 0.006(74)</td>
</tr>
<tr>
<td>0.86 TO 0.90</td>
<td>0.87 ± 0.002(40)**</td>
</tr>
<tr>
<td>&gt; 0.91</td>
<td>0.93 ± 0.005(21)**</td>
</tr>
</tbody>
</table>

**p<0.001 < 0.85 vs. > 0.86. Tukey test - level of significance p < 0.05**

DISCUSSION

In total, data was collected from 182 women – caregivers. It is important to note that the Association attends to about 400 children and adolescents with disabilities; however, not all of the caregivers were able to participate in the study, since some needed to work to support their homes. Furthermore, some of these children with disabilities are unaccompanied during their therapies and rely on the transportation granted by the local governments or through the Association. Upon arriving at the association these patients are then are assisted by employees...
and/or volunteers. Typically, the patients are scheduled to attend the Association daily, three times per week, or once per week. Before treatments are initiated at the Association, a multiprofessional team screens each patient, and determines the best course of action. Thus, considering the circumstances of some of the patients and caregivers and the flow of care at the Association, being able to sample a large portion of the total population (182 caregivers of ~400 children/adolescents) is encouraging and likely a good representation of the entire population. However, it is worth mentioning that their participation in the three health parameter evaluations was different, which is evidenced by the total number of participants for each parameter.

With regards to BP, 136 women participated in the blood pressure measurement and about 10% had increased BP, which is a considerably high percentage. An individual is considered hypertensive when their systolic blood pressure has a value that is \( \geq 140 \) mmHg and a diastolic value that is \( \geq 90 \) mmHg. Due to the fact that, in most cases, this pathology is asymptomatic, the diagnosis and treatment is often neglected\(^9\).

While a variety of factors contribute to elevated BP (i.e. increased body weight, sedentary lifestyle, unhealthy lifestyle, genetic predisposition), stress is probably a factor that nearly all of the caregivers experience on a regular basis\(^{10}\). Stress triggers systemic hypertension by increasing adrenaline, noradrenaline and cortisol hormone levels, thus increasing the risk of developing cardiovascular complications\(^9,10\).

However, the effects of stress are difficult to investigate because this factor is a personal experience that proceeds from different directions and affects everyone differently. It is also multi symptomatic, presenting physical, behavioral and/or clinical symptoms, ranging from wheezing, restlessness and irritability to a reduction of income and/or employment, loss of vitality, as well as many others\(^9,10\).
For these female caregivers, stress can be attributed to the various situations these women regularly face, such as long hours of paid and/or unpaid work (household chores). One inference, that can be taken away from that, is that female caregivers of children with disabilities dedicate most of their time taking care of their dependents, and not caring for themselves. Thus, initiatives like this study, promote self-care, and provide knowledge about their limitations. Additionally, and perhaps more importantly, these initiatives increase the consciousness these women have with regards to their health and the continued care they must provide to their dependent(s).

The PPCG was measure and 122 women participated. The data demonstrated that ~13% of women had glucose concentrations above 126 mg/dL and were considered to be at a higher risk for developing DM. The American Diabetes Association (ADA) considers fasting blood glucose values above 100 mg/dL as hyperglycemic, and values above 126 mg/dL, on two separate occasions, indicative of DM\textsuperscript{11}. However, these values differ when blood glucose is measured in the postprandial capillary. For example, if the PPCG is above 126 mg/dL, the individual will require special attention, since this is indicative of considerable insulin intolerance.

Additionally, the WHR parameter has been employed as a risk indicator for heart and metabolic diseases and our results indicate that ~33% of the study participants are at a high risk for developing cardiovascular and/or metabolic diseases. According to the ADA, the risk of developing DM increases considerably when the WHR exceeds 0.85, and becomes extremely concerning when it exceeds 0.90, since it has been correlated with a high rate of comorbidity\textsuperscript{11,12}. The altered WHR may, at least partially, contribute to the elevated BP and PPCG values.

Epidemiological data has provided evidence that DM is a growing worldwide public health concern. It was estimated that in 2015, about 415 million people, from 20-79 years of age, had DM.
age, would be diagnosed with DM, which corresponds to 8.8% of the world population, and that by 2040 this number would reach 642 million. It is important to note that about 75% of these cases will involve people who reside in developing countries, such as Brazil\textsuperscript{13}.

Factors that have been associated with the increased prevalence of DM, include: rapid urbanization, epidemiological transition, nutritional transition, sedentary lifestyle, excess weight, growth and age, and each plays a specific role in disease onset and patient survival. In addition, less than satisfactory health care system performance, and poor public and health professional awareness about the disease and its insidious onset, results in only about 46% of DM cases being detected. All these factors promote the development of complications, especially in developing countries\textsuperscript{14}. Success in controlling the disease and consequently reducing its complications has been linked to the development of partnerships and campaigns aimed at the prevention, detection and control of DM\textsuperscript{15}.

Since this extension project is part of a larger multiprofessional health care research project, it was possible to refer the caregivers, who presented abnormal test results, to other health professionals, thus allowing for follow-up evaluations and more regular monitoring, on a case by case basis.

Furthermore, the results of this study further justify the importance of these health initiatives, which, in this study, disseminated knowledge about the prevention, detection and control of DM. If properly implemented and put into practice, these initiatives could stimulate a reduction in the number of DM cases. It was also found that female caregivers of children with disabilities, possessed risk factors, which could make them more prone to the onset and progression of DM. Through education and proper therapies, it is the job of the nurses to help individuals who run the risk of developing or have been diagnosed with DM, so as to directly improve the quality of life the patient, which will translate into better care for their dependents.
CONCLUSIONS

Work is critical for the subsistence of human beings, and nursing, a profession that provides care to others, assists the community by increasing the quality of health and life of the individuals they treat.

The present study was carried out at a non-profit organization, in Sao Paulo, Brazil, and focused on female caregivers of children and adolescents with disabilities, who attend the Association. The objective of the study was to evaluate whether risk factors for developing DM (elevated BP, PPCG and WHR) were present in these caregivers.

The data showed that a considerable portion of the caregivers, that participated in this study, presented with altered/abnormal BP, PPCG and/or WHR values. Additionally, there were women in the study who have not yet manifested changes in these parameters, but still are at risk for developing DM. Health efforts, like the one carried out in this study, are extremely important for the effective prevention, detection and control of diseases, since through these initiatives it is possible to guide patients have previously been diagnosed with the disease, and to educate those who are asymptomatic to seek preventative care. Moreover, by monitoring the health of the caregivers more closely, the nurse can seek preventive actions, administer treatments and avoid future complications of the disease.

It is the job of the nurse to improve the quality of life of the patients, and their families through humanizing care, which is the reason this profession attracts sensitive, socially committed individuals. Consequently, through a direct improvement in the health of the caregiver will indirectly benefit the quality of care received by their dependent(s).
REFERENCES


