UNIVERSIDADE DE SÃO PAULO ESCOLA DE ENFERMAGEM DE RIBEIRÃO PRETO

SHEBRENA ANGELA BELLE

Prototype of an educational technology about appropriate diet for

patients with chronic kidney disease

Ribeirão Preto

2020

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Prototype of an educational technology about appropriate diet for

patients with chronic kidney disease

Dissertation presented to the University of de São Paulo at Ribeirão Preto College of Nursing to obtain the title of Master of Science, Nursing Graduate Program in Public Helath

Line of Research: Education, Educational Technology, Teaching Training, Health and Nursing

Advisor: Profa. Dra. Rosangela Andrade Aukar de Camargo

Ribeirão Preto

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DEDICATION

This dissertation work is dedicated first to my beloved husband whose love for me and confidence in my abilities, encouraged and supported me.

Then to my children Michael and Michaela.... my adorable treasures, I hope that this will help you to appreciate the value of hard work.

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ABSTRACT

BELLE, S. A. Prototype of an educational technology about appropriate diet for patients with chronic kidney disease 2020. Dissertation (Master in Health Sciences)
Ribeirão Preto College of Nursing, University of São Paulo, Ribeirão Preto, 81 pp.

Introduction: Chronic kidney disease is a worldwide public health problem. If consideration should be given to the effect that this disease has on individuals, families, society and the country's economy, the urgency of patient education as a form of health promotion will be clearly understood. Patient education is key to the management of such conditions and a proactive approach to dealing with renal disease should be engaged. Chronic kidney disease describes the gradual loss of kidney function which, once established, tends to progress to end-stage renal failure and imminent death. Nursing care for patients with this condition include a number of areas of which patient education is paramount. In Guyana, the Georgetown Public Hospital Corporation alone has established that there are over five hundred people with chronic renal disease. Approximately 70% of patients with chronic kidney disease at this Hospital are readmitted frequently and their disease condition degenerates rapidly. Objective: To construct a prototype of educational technology for adult patients with chronic kidney disease. Methods: This was a study that used a methodological approach in three phases: Analysis & Diagnosis; Instructional Planning with Content systematization; and Didactic Drawing with Choice of illustration and Writing content. After gaining approval from the ethical committee of the Georgetown Public Hospital Corporation, hospitalized patients with chronic kidney disease and their families who were willing to be participants of this research during the period October to November 2019, were invited with their consent, to complete a questionnaire for the researchers to gather biographic and socioeconomic data. The number of participants was thirty, twelve were patients and eighteen were relatives. The majority of patients and relatives were female (58.3% and 61.1%), most of them were married. This was complemented with interviews where the participants shared their health education needs relating to their disease condition. Interviews were recorded and transcribed verbatim. From the themes that arise out of the interviews, along with the review of relative scientific literature, a prototype of an educational material for patients with chronic kidney disease was constructed as well as engaging design and layout artists and advertising professionals. Results: A prototype of a booklet for patients with chronic kidney disease

and their caregivers was developed. Its selected theme came from interviews with the patients and their relatives. At the end, the prototype contains eight pages on the appropriate diet for patients with chronic kidney diseases. The contents were subdivided into steps so that educational guidelines were organized and could be discussed with patients and relatives. Conclusion: It is supposed that this prototype of educational technology will serve as a stimulus to the improved health of patients with chronic kidney disease through knowledge construction followed by self-care. It is anticipated to be a teaching technology for nurses and students who work on the clinical area to encourage the target population to take responsibility for their health maintenance when not hospitalized. Future work will examine the effectiveness of the implementation of this educational booklet.

Keywords: Educational Technology; Diet; Chronic Kidney Disease; Health Education; Nursing.

RESUMO

BELLE, S. A. Protótipo de uma tecnologia educacional sobre dieta apropriada
para pacientes renais crônicos 2020. Dissertação (Mestrado em Ciências da Saúde)
Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo, 81pp.

Introdução: a doença renal crônica é um problema de saúde pública mundial. Se for levado em consideração o efeito que esta doença tem sobre os indivíduos, famílias, sociedade e economia do país, a urgência da educação do paciente como forma de promoção da saúde será claramente compreendida. A educação do paciente é fundamental para o manejo de tais condições e uma abordagem proativa para lidar com a doença renal deve ser adotada. A doença renal crônica é compreendida como a perda gradual da função renal que, uma vez estabelecida, tende a progredir para insuficiência renal em estágio terminal e morte iminente. Os cuidados de enfermagem para pacientes com essa condição incluem várias áreas nas quais a educação do paciente é fundamental. Na Guiana, apenas no Georgetown Public Hospital Corporation há mais de quinhentas pessoas com doença renal crônica em tratamento. Aproximadamente 70% dos pacientes com doença renal crônica neste hospital são readmitidos com frequência e sua doença avança rapidamente. Objetivo: construir um protótipo de tecnologia educacional para pacientes adultos com doença renal crônica. Métodos: trata-se de um estudo que utilizou uma abordagem metodológica em três fases: análise e diagnóstico; planejamento instrucional com sistematização de conteúdo; e desenho didático com escolha de ilustração e conteúdo de escrita. Após obter a aprovação do comitê de ética da Georgetown Public Hospital Corporation, os pacientes internados com doença renal crônica e seus familiares que se dispuseram a participar desta pesquisa no período de outubro a novembro 2019, assinaram o termo de consentimento livre e esclarecido, e responderam a um questionário sociodemográfico. O número de participantes foi de trinta, sendo doze pacientes e dezoito parentes. A maioria dos pacientes e familiares era do sexo feminino (58,3% e 61,1%), a maioria casada. Este foi complementado com entrevistas nas quais os participantes compartilharam suas necessidades de educação em saúde relacionadas à sua condição de adoecimento. As entrevistas foram gravadas e transcritas na íntegra. Em segundo lugar, a partir dos temas que surgiram das entrevistas, junto com a revisão da literatura científica relativa à temática selecionada, um protótipo de um material educacional para pacientes com doença renal crônica foi construído, envolvendo artistas de design e layout e profissionais de publicidade. Resultados: foi desenvolvido um protótipo de cartilha para pacientes com doença renal crônica e seus cuidadores. Ao final, o protótipo contém oito páginas sobre a dieta adequada para pacientes com doenças renais crônicas. Os conteúdos foram subdivididos em passos para que as diretrizes educacionais fossem organizadas e pudessem ser discutidas com pacientes e familiares. Conclusão: supõe-se que este protótipo de tecnologia educacional servirá de estímulo à melhoria da saúde do paciente com doença renal crônica por meio da construção do conhecimento seguido do autocuidado. Prevê-se que seja uma tecnologia de ensino para enfermeiros e alunos que atuam na área clínica para estimular a população-alvo a se responsabilizar pela manutenção da saúde quando não estiver internada. O trabalho futuro examinará a eficácia da implementação deste livreto educacional.

Palavras-chave: Tecnologia Educacional; Dieta; Doença Renal Crônica; Educação em Saúde; Enfermagem.

RESUMEN

BELLE, S. A. Prototipo de tecnología educativa sobre dieta adecuada para pacientes renales crónicos 2020. Dissertação (Máster en Ciencias de la Salud) -Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo, 81pp.

Introducción: la enfermedad renal crónica es un problema de salud pública mundial. Si se tiene en cuenta el efecto que tiene esta enfermedad en las personas, las familias, la sociedad y la economía del país, se comprenderá claramente la urgencia de la educación del paciente como forma de promoción de la salud. La educación del paciente es clave para el manejo de tales condiciones y se debe involucrar un enfoque proactivo para tratar la enfermedad renal. La enfermedad renal crónica describe la pérdida gradual de la función renal que, una vez establecida, tiende a progresar hasta una insuficiencia renal terminal y una muerte inminente. La atención de enfermería para pacientes con esta afección incluye una serie de áreas en las que la educación del paciente es primordial. En Guyana, solo la corporación de hospitales públicos de Georgetown ha establecido que hay más de quinientas personas con enfermedad renal crónica. Aproximadamente el 70% de los pacientes con enfermedad renal crónica en este hospital son readmitidos con frecuencia y su condición de enfermedad degenera rápidamente. Objetivo: construir un prototipo de tecnología educativa para pacientes adultos con enfermedad renal crónica. Métodos: este fue un estudio que utilizó un enfoque metodológico en tres fases: análisis y diagnóstico; Planificación instruccional con sistematización de contenidos; y Dibujo didáctico con elección de contenido de ilustración y escritura. Luego de obtener la aprobación del comité de ética de la corporación de hospitales públicos de Georgetown, los pacientes hospitalizados con enfermedad renal crónica y sus familias que estuvieron dispuestos a ser participantes de esta investigación durante el período de octubre a noviembre de 2019, fueron invitados con su consentimiento, a completar un cuestionario. Para que los investigadores recopilen datos biográficos y socioeconómicos. El número de participantes fue de treinta, doce eran pacientes y dieciocho eran familiares. La mayoría de pacientes y familiares eran mujeres (58,3% y 61,1%), la mayoría de ellos casados. Esto se complementó con entrevistas donde los participantes compartieron sus necesidades de educación para la salud relacionadas con su condición de enfermedad. Las entrevistas fueron grabadas y transcritas textualmente. En segundo lugar, a partir de los temas que surgen de las entrevistas, junto con la revisión de la literatura científica relativa, se construyó un prototipo de material educativo para pacientes con enfermedad renal crónica, además de involucrar a artistas del diseño y maquetación y profesionales de la publicidad. Resultados: se desarrolló un prototipo de folleto para pacientes con enfermedad renal crónica y sus cuidadores. Su tema seleccionado provino de entrevistas con los pacientes y sus familiares. Al final, el prototipo contiene ocho páginas sobre la dieta adecuada para pacientes con enfermedades renales crónicas. Los contenidos se subdividieron en pasos para que las pautas educativas se organizaran y pudieran ser discutidas con pacientes y familiares. Conclusión: se supone que este prototipo de tecnología educativa servirá como estímulo para la mejora de la salud de los pacientes con enfermedad renal crónica a través de la construcción de conocimiento seguida del autocuidado. Se prevé que sea una tecnología de enseñanza para enfermeras y estudiantes que trabajan en el área clínica para incentivar a la población objetivo a asumir la responsabilidad de su mantenimiento de salud cuando no esté hospitalizada. El trabajo futuro examinará la efectividad de la implementación de este folleto educativo.

Palabras clave: Tecnologia Educacional; Dieta; Enfermedad renal crónica; Educación para la salud; Enfermería.

LIST OF FIGURES

Figura 1 - Outline of the study steps	
Figura 2 - Booklet cover and back cover	53
Figura 3 - Page 3 to 5 of the booklet	54
Figura 4 - Page 6 to 8 of the booklet	54

LIST OF TABLES

Tabela 1 - Characteristics of the sample – Patients	39
Tabela 2 - Characteristics of the sample – Relatives	.41
Tabela 3 - Frequency themes from interviews – patients	41
Tabela 4 - Frequency themes from interviews – relatives	41
Tabela 5 - Literature relevant to appropriate diet and chronic kidney disease	.45

LIST OF ABBREVIATIONS

СКD	Chronic kidney disease
EERP-USP	University of São Paulo at Ribeirão Preto College of Nursing
eGFR	glomerular filtration rate
KDIGO	Kidney Disease Improving Global Outcomes
PTSD	Posttraumatic Stress Disorder
SCDNT	Self-Care Deficit Nursing Theory
USP	Universidade de São Paulo

Presentation	18
1. Introduction	21
1.1 Theoretical Framework	27
2. Objectives	30
3. Method	32
3.1 Local	32
3.2 Participants	33
3.3 The booklet construction process	33
3.3.1 Research Instruments	35
3.3.2 Procedure for Collection of Data	35
3.4 Data analysis	36
3.5 Ethical considerations	36
4. Results	38
4.1 Analysis & Diagnosis	38
4.1.1 Study Context	38
4.1.2 The findings from the interviews	39
4.1.2.1 Themes from interviews	43
4.2 Instructional Planning	44
4.2.1 The findings from Literature Review	44
4.2.2 Instructional Planning	50
4.3 The Prototype - Didactic Drawing	51
5. Discussion	56
6. Conclusion	63
6.1 Contributions/Recommendations	64
7.Bibliographic References	66
Attachments A	72
Appendix A	78
Apendix B	80

Sumário

Presentation

Presentation

God's plan is abways the best.

Sometimes the process is painful and hard. But don't forget that when God is silent, SCe's doing something for pou. Anonymous

I am accomplishment driven Shebrena Belle. I am a Registered Nurse who functioned in this capacity for five years. In my tenure as a Registered Nurse, I cared for adult patients with acute and chronic medical conditions; children with surgical conditions pre and post operatively and patients in the Intensive Care Unit. Not only was I able to conduct patient care but I managed the staff and other resources on the unit for whichever shift I worked and always made time for health promotion in the form of patient and family education; this was a challenge since the unit was constantly understaffed and had a heavy patient load. I am a Registered Midwife who managed pregnant women in their antenatal period, during labour and delivery and post-delivery. This was one of the highlights of my profession because it gave me an opportunity to participate in what I believe is the miracle of life. I was also privileged to conduct numerous sessions of patient and family education in the areas of obstetrics and neonatology. I am presently married with two children ages five and two and work full time as a Nursing Tutor who teach, monitor and evaluate students classroom and clinical performances. It is a challenge to work full time, be a full time parent and a student nevertheless I have good family support. I generally treat others the way I desire to be treated and look for positivity in all things. I strive daily to be the best version of myself through self-evaluating and correcting actions and activities that did not work well. I encourage persons to achieve their goals.

My professional interest as a Nursing Educator was birthed out of my passion to help my fellow man and the invaluable experienced I have gained in both my professional and educational development. My holistic development in this profession was piloted by the value system imbedded in me by my parents, teachers and mentors, and my desire for being of service to others.

Philosophy

• There is one Supreme Being who deserve my obedience.

- Family and health are priority.
- Helping others makes this world a better place.
- Education is the key to a world of opportunity.

Goal

Help nurses to realize that they are important, what they do is vital in achieving health for all and nursing is not limited to the patient's bedside.

Introduction

1. Introduction

Chronic kidney disease (CKD) is a worldwide public health problem that affects 13% to 19% of the world population with increasing prevalence and adverse outcomes, including progressive loss of kidney function, cardiovascular disease and premature death. Diabetes and hypertension account for over 2/3rd of the cases of CKD globally (KDIGO, 2013; VIVEKANAND et al., 2013; GLASSOCK et al, 2017; SAFARPOUR et al., 2020). It was not possible to estimate the prevalence of chronic kidney disease patients in Brazil due to the heterogeneity of studies (MARINHO et al, 2017). No studies were found to estimate the prevalence of CKD in Guyana.

In Guyana, the Georgetown Public Hospital Corporation alone has established that there are over five hundred people with chronic renal disease. Evidence suggests that this number has been increasing steadily between the periods 2016 to 2017. In addition, records of the monthly nephrology unit register have revealed that approximately 70% of patients who are hospitalized and discharged on treatment subsequently return within a short time period. Informal interview with some of the patients revealed that many of these patients lack knowledge about their disease condition and hence a catastrophic result in non-compliance to medication, diet, non-involvement in care and treatment and self-care deficit. About 80% of persons with this disease condition at the Georgetown Public Hospital Corporation fall within the age range of 25 - 50 years old (GEORGETOWN PUBLIC HOSPITAL CORPORATION, 2019).

Kidney Disease Improving Global Outcomes (KDIGO) in their Clinical Practice Guidelines for Evaluation and Management of CKD developted a universal definition of chronic kidney disease that is applied to patient populations throughout the world (KDIGO, 2013). CKD is defined as abnormalities of kidney structure or function, present for greater than 3 months with specific implications for health. This is defined as a glomerular filtration rate (eGFR) less than 60 mL/min/1.73 m2 or one or more markers of kidney dysfunction including albuminuria, urine sediment abnormalities, electrolyte and other abnormalities owing to tubular disorders, abnormalities detected by histology, structural abnormalities detected by imaging and history of kidney transplantation (KDIGO, 2013; CHARLES & FERRIS, 2020). In USA, age has the highest correlation with low eGFR (eGFR <60 mL/min/1.73 m2), and chronic kidney disease has the highest prevalence in individuals over the age of 60 years (CHARLES & FERRIS, 2020).

According to Levey et al. (2011), the worldwide rise in the number of patients with CKD and consequent end-stage renal failure necessitating renal replacement therapy is threatening to reach epidemic proportions over the next decade, and only a small number of countries have robust economies able to meet the challenges posed.

Soyibo et al. (2011) posited that patients with CKD have high rates of healthcare utilization, morbidity and mortality. Managing the economic and clinical burden of CKD will be a significant challenge for the healthcare system (CHARLES & FERRIS, 2020). The burden of CKD/ESRD-specific and CKD/ESRD-related complications are major reasons for accessing the healthcare services. Additionally they stated that the financial burden of CKD in the Caribbean region cannot be sustained by most, if any, of the countries (SOYIBO et al., 2011).

Patients of CKD are required to follow oppressive management that is complex and difficult to understand. Comprehensive management of CKD patients includes dietary modification, fluid management, appropriate medication and renal replacement therapy. This comprehensive patient care is pivotal in slowing the progression and complications of CKD (AGGARWAL et al., 2018, p.166).

If consideration should be given to the effect that this disease has on individuals, families, society and the country's economy, the urgency of patient education as a form of health promotion will be clearly understood. In light of its benefits to all the before mentioned groups, patient education can never be an overrated view (AGGARWAL et al., 2018). Reflecting on the issue, patient education is key to the management of such conditions and a proactive approach to dealing with renal disease should be engaged. Caution must be taken in placing people on dialysis too early when there are other procedures which can be employed. If patients with this condition have regular monitoring and treatment of their blood glucose and blood pressure, the need for dialysis may be eliminated (CHARLES & FERRIS, 2020).

In this way, Bēta (2014), posited that each individual's health is a social, economic and personal development resource regardless of age, gender or cultural criteria. Health maintenance or prevention measures largely depend on the educational work that can be viewed not only in the perspective of nurses' work, but also in the general context of the implementation of common public health strategy. Every individual's personal interest is also an important factor. Patient education as a

process of interaction is topical in the context of any disease or prevention case. Quite often after arriving at health care institutions, especially hospitals, some patients feel overwhelm because of their lack of understand of what is happening. The role of a nurse as an educator here is very significant. She transfers to the patient a certain amount of appropriate and understandable information, reduces information deficit about the coming steps, promotes emotional stability and prevents the formation of cognitive dissonance. The patient's safety and well-being are created by a welcoming attitude and favourable atmosphere at various levels of patient care, when the patient's health problems or discomforts are understood. In general, it can be described as a part of the treatment process service.

Bēta (2014) also stated that patient education is an important but a complex issue. Nurses and doctors recognize the need for patient education. In the greatest number of cases the information that is important for the patient for the time being is outlined verbally or visualized, less focus is put on the secondary education aspects that are currently not in sight. The overall view of the situation is more important because an educated patient is more engaged in solving problems, improving their health status, and future prevention measures. Educated, empowered patients and their relatives are active participants in maintaining health, forming an educated society. The nurses understanding of the educational process plays an important role in the evaluation. Has the patient understood what was said? What causes difficulties for a patient? Should the educational process be repeated? These issues include both the feedback, identifying the patient's level of understanding and integration of reflection in society, in the educational process.

There are wide varieties of factors that affect patient education. Some of them are common to nurses worldwide. Farahani et al. (2013), posited that the major theme extracted in this study was inappropriate organizational culture, which includes eight categories. The categories are not putting value on education, non-professional activities, physician-oriented atmosphere, conflict and lack of coherence in education, inappropriate communication skills, and ignorance of patient's right in education, lack of motivation and rewarding system in the organization, and poor supervision and control.

In a study on strategy for improving patient education, Marcus (2014), stated that the best practices we identified suggest goals providers should strive for when educating patients verbally. Providers should be empathetic and pay attention to patients' fears. Practices like using concrete instructions may be considered common sense, but may be difficult to achieve unless one focuses on doing so. Effective patient education practices need to be learned and reinforced by staff educators in order to become part of the everyday provider care environment.

Patient education is admitted as a necessary to CKD care, with evidence that CKD education improves patient knowledge, self-management (NARVA et al., 2016). Lamentably, a new evidence produced by Chu et al. (2020) suggests that significant deficits persist in patient awareness of CKD, even among those with the highest risk for moving forward to kidney failure. Taking data from the National Health and Nutrition Examination Survey (NHANES) the researchers estimated patients' awareness of their kidney disease, evaluated by the question "Have you ever been told you have weak or failing kidneys?" stratified by the individual risk for progression to kidney failure. Around half of the NHANES participants with moderate or high risk for progression to kidney failure were unaware of their kidney disease. Besides, the degree of CKD awareness was unchanged during the 18-year study period. They propose many reasons for low CKD awareness: asymptomatic disease, health care providers' limited knowledge of current guidelines, and fearof inciting unwarranted stress in patients with low-risk CKD. Others have suggested other level factors: limited incentives for education, challenges in describing CKD and CKD risk, and poor access to decision support tools (NARVA et al., 2016). Advancing CKD awareness requires educational interventions not only at the individual and community level but also at the provider level.

Schrauben et al. (2020) found that objective kidney disease knowledge is likely necessary, but not sufficient for self-care and may depend on the level of health literacy. Perceived kidney knowledge may offer a novel target to assess patients at risk for poor self-care, and be used in targeted educational interventions.

The literature on haemodialysis patients' non-compliance identifies a range of reasons for this behaviour. Inadequate education about the illness and illness management (BAIRWA et al. 2012; CONSTANTINI, 2006; KRESPIA et al. 2004; ALLEN et al. 2011) and the desire for more control over an unpredictable chronic illness (LEGGAT, 2005; QUINNAN, 2007; AGGARWAL et al., 2018) are commonly cited explanations for dialysis patients' non-compliance. Lack of family support and the complexity of treatment regimens are other commonly cited reasons for non-compliance (SAFARPOUR et al., 2020).

The causal pathway connecting educational status and CKD incidence is complex. Previous studies found that low educational attainment was associated with un-healthy modifiable behaviours including smoking, poor diet, and sub optimal physical activity (LANTZ et al., 2010; RASK et al., 2009; TRIPATHY et al. 2020).

For Nava et al. (2016) patient education is associated with better patient outcomes, but a range of barriers prevents widespread implementation of comprehensive education for people with progressive kidney disease. The obstacles to education include the complex nature of kidney disease information, low baseline awareness, limited health literacy and numeracy, limited availability of CKD information, and lack of readiness to learn. For providers, lack of time and clinical confidence combine with competing education priorities and confusion about diagnosing CKD to limit educational efforts. At the system level, lack of provider incentives, limited availability of practical decision support tools, and lack of established interdisciplinary care models inhibit patient education.

Despite these barriers, innovative education approaches for people with CKD exist, including self-management support, shared decision-making, use of digital media, and engaging families and communities. New educational approaches are being developed through research and quality improvement efforts, but challenges to evaluating public awareness and patient education programs inhibit identification of successful strategies for broader implementation. However, growing interest in improving patient-centred outcomes may provide new approaches to effective education of people with CKD (NARVA et al. 2016, p. 698).

A Systematic review about educational interventions with people with CKD stages 1 to 5 in community and hospital settings found 26 studies (12 trials, 14 observational studies) involving 5,403 participants were included. Interventions were multifaceted, including face-to-face teaching (26 studies), written information (20 studies), and telephone follow-up (13 studies). Twenty (20) studies involved 1-on-1 patient/educator interaction and 14 incorporated group sessions. Nine (9) studies showed improved outcomes for quality life, knowledge, and self-management; nine (9) had improved clinical end points; and two (2) studies showed improvements in both patient-reported and clinical outcomes. Characteristics of effective interventions included teaching sessions that were interactive and workshops/practical skills; integrated negotiated goal setting; involved groups of patient, their families, and a

multidisciplinary team; and had frequent (weekly or monthly) participant/educator encounters (LOPEZ-VARGAS, 2016).

Technology as a set of knowledge and practices related to products and materials that define therapeutics and work processes, as well as constitute tools to perform actions on health promotion (AGGARWAL et al., 2018). The technologies are classified into Educational Technologies (devices for measuring the processes of teaching and learning), Care Technologies (devices for measuring the processes of care) and Management Technologies (devices for measuring the processes of management in the various health stems) (MANIVA et al., 2018).

Technology is as a socio-cultural artefact, a product of human needs. For Bannell et al. (2016, p. 67):

Technologies are, therefore, cultural artefacts, a product of cultural needs. Through the development and deployment of artefacts that embody intentions and desires, human beings gain control over their needs. Artefacts become mediators of human relations with the world and enhance cognitive abilities upon acting as technical and psychological tools.

Educational booklet is a technology widely used as the first generation of selfdirected learning media. However, during their preparation, readability for the target group, presence of simple pictures and diagrams, boldfacing important words and phrases, including up-to-date information, and using reliable sources have to be considered (KHORAMI et al. 2011).

According to Hoffmann and Warrall (2004) printed educational materials conduce positively in the communication process, furthermore maximize adherence to the treatment and decision-making capacity, as they provide trustworthy information, enable portability, flexibility, patient feedback and increase the instruction verbalized.

In this proposal, the researcher suggests the construction of an educational technology in the form of a booklet, to empower patients with chronic kidney disease through education, with the objective of decreasing hospital readmissions and promoting longevity.

We advocate health education with patients and families in managing chronic diseases is a significant nursing duty with any age and at any setting. Health care systems should give closed attention to such concern. Many adult and older adult with chronic illness can effectively manage their conditions through health information.

Health education equips them to be involved actively in self-care and disease management decisions.

1.1 Theoretical Framework

For this study, the researcher will analyse the Social-Constructivism Pedagogy Theory developed by Paulo Freire, and the Self-Care Deficit Theory developed by Dorothea E. Orem for effecting integration. This analysis will provide the theoretical foundations for proposing the two theories that will be integrated to assess the relationship between empowerment through effective patient care education and patient self-care.

Freire's Social-constructivism pedagogy theory influenced a new conception of empowerment, a key health promotion concept. Empowerment leads to social changes, and it is a result of the acquisition of knowledge related to discursive, cognitive and procedural capabilities (ROZENDO et al., 2017). In education, empowerment occurs in a context of dialogical learning.

Educators, patients and families are subjects of an educative process, and opportunities for knowledge created with the participation of everybody (FREIRE, 2008; WALLERSTEIN, 2003).

Nel (2014) states, that according to Freire, true education is a liberating and active educational process, which allows people to become genuinely engaged with the learning material and responsible for understanding the material.

Theoretical studies conclude that involving students or patients as active participants in decision-making processes such as student evaluation or personalized care plans respectively, contributes to acknowledging the other as an active subject in the construction of their own history (ROZENDO et al., 2017).

Freire's theory assumes that despite having the same learning experience, each individual will base their learning on the understanding and meaning personal to them; learning is an active, not a passive, process and depends on the individual taking responsibility to learn (NICOLAIDES & FERNANDES, 2008). Through dialogue, nurses and patients learn together and act on their duty to uncover what is going on and transform the life.

The Self-Care Deficit Nursing Theory (SCDNT) emphasized on establishing the nursing perspectives regarding human and practice (SHAH et al., 2015). Orem's theory

provides a positive frame of reference about nurses, patients and the interactions between nurses and patients; it provides communication, structure, and focus (THE UNIVERSITY OF TENNESSEE AT CHATTANOOGA, 2016). The model interrelates concepts in such a way as to create a different way of looking at a particular phenomenon. The theory is relatively simple, but generalizable to apply to a wide variety of patients.

The structure of the SCDNT theory comprises of three related parts: (1) theory of self-care; (2) the theory of self-care deficit; and (3) the theory of nursing system (SHAH et al., 2015).

The theory of self-care includes self-care, which is the practice of activities that an individual initiates and performs on his or her own behalf to maintain life, health, and well-being; and self-care agency. The human ability that is "the ability for engaging in self-care," conditioned by age, developmental state, life experience, socio-cultural orientation, health, and available resources; therapeutic self-care demand. Which is the total self-care actions to be performed over a specific duration to meet self-care requisites by using valid methods and related sets of operations and actions; and selfcare requisites, which include the categories of universal, developmental, and health deviation self-care requisites (SHAH et al., 2015).

The structure and content of Orem's SCDNT has been developed and refined over the past two decades. The theory of nursing systems describes how the patient's self-care needs will be meet by the nurse, the patient, or by both. Patients with decreased self-care abilities in activities have frequent hospitalizations and a decreased quality of life (HAGRAN & FAKHARANY, 2015).

SCDNT model assumes that human beings require continuous, deliberate inputs to themselves and their environments in order to remain alive and function according to their capacity (GEORGE, 2011; TOMEY & ALLIGOOD, 2006). People are distinct individuals, as such each patient is unique.

Based on the two theories, it will be assumed that improved patient self-care is largely dependent on the relationship between patient and nurse and the patient and their family. An increased in a patient's self-care abilities can enable a patient to have a better control of their life; as patients who follow their treatment regimen and take better care of themselves are expected to have improved functional capacity in order to improve their quality of life (BRITZ & DUNN, 2010). Communication is key to positive health results, particularity for patients with low literacy skills.

Objective

2. Objective

To construct a prototype of educational technology for adult patients with chronic renal disease.

Method

3. Method

This study used a methodological approach with in two steps: building a prototype of an educational material for patients with chronic kidney disease (POLIT & BECK, 2012). According to Oliveira et al. (2014, p.619) "the construction of the booklet involved scientific knowledge and teamwork, as well as engaging design and layout artists and advertising professionals".

The intent of this research is to explore the effectiveness of creating an educational booklet for patients with chronic kidney disease and their relatives, with the aim that the introduction of this new stimulus will improve self-care of patients.

3.1 Local

Georgetown Public Hospital Corporation is Guyana's largest specialist care hospital. It is located in the capital city of the country. This hospital opened in 1938, and was initially state owned but for the past twenty years, it corporatized and managed by a board. It has a bed capacity of 576.

Being the country's largest hospital, all specialized care and training are offered here. It has a maternity unit with specialist obstetricians, gynaecologist, paediatricians, oncologist and trained nurses along with ancillary staff. It also has an operating theatre. The hospital has a functioning main operating theatre where surgeries are performed.

There is an emergency unit, an intensive care unit, a Caribbean heart institute, burn care unit, high dependency unit and a diabetic foot care centre. Other clinical wards found in this establishment are male and female surgical, male and female medical, medical and surgical paediatric wards and an infectious disease ward. Additional services include a high-risk maternity clinic; medical, surgical, paediatric and psychiatric outpatient services; pharmacy, bio-medical department, laboratory x-ray and plaster of pairs department. All these facilities come under the umbrella of the Guyana's Ministry of Health.

Patients with chronic kidney disease are managed at the male and female medical wards. When there is an excess of patients with this condition, the hospital had reserved one room on the male surgical ward and one room on the female surgical ward with a bed compliment of six each. From 2016 to present, six of these rooms are now being utilised exclusively for patients with chronic kidney disease. The age of patients with this condition previously admitted to the Georgetown Public Hospital was

predominantly 60 years and over. Presently, about 80% of these patients are between the ages of 25-50 years old. In addition to this, 70% of these patients are readmitted in a short time period at the Georgetown Public Hospital.

3.2 Participants

This sampling approach helped the researcher to select participants who provided useful and invaluable information that may allow the researcher to develop a more detail understanding of the phenomenon. This approach gave the researcher the ability to intentionally select the sample size as opposed to a random selection. As such the researcher targeted data that provided relevant information for the research.

The sample pool for the research consisted of patients and patients who were readmitted at the Georgetown Public Hospital Corporation who were diagnosed with CKD.

The sample size included of all patients and their relatives who were willing to be participants of this research, during the period October to November 2019. The number of patients and relatives that were interviewed depended on code saturation.

Excluded was patients with CKD who only attend clinic and were not admitted to the clinical unit, patients on the unit with CKD who were unresponsive, patients who just returned from dialysis center and were too weak and exhausted to give quality feedback, nurses on the unit who were just relieving the shift.

As research subjects, they were required to sign the Terms of Free and Informed Consent form (APPENDICE 1).

3.3 The booklet construction process

The construction of this booklet entailed the use of a five-phase process (REBERTE et al., 2012). Work conducted between the periods January 2019 to September 2020 via a methodological approach. The phases employed were:

- ✓ Phase 1 Analysis & Diagnosis
- ✓ Phase 2 Instructional Planning (Content systematization)
- ✓ Phase 3 Didactic Drawing (Choice of illustration and Writing content)
- Phase 4 Validation of booklet by nurses
- Phase 5 Validation of booklet by patient and family

This research was developed until Phase 3.

Brydon-Miller et al. (2003) argue that the main presupposition of this method is the

construction of knowledge in collective and participatory ways, in order to find a solution for a problem that needs to be studied. The solution found can produce positive reflexes for people, community, and society.

Phase 1 - Analysis & Diagnosis

At first, this phase included the observation of the studied context, the discussion of the problem by the researcher and advisor and the analysis of the reviewed literature. Also, this phase was based on the needs of patients with CKD and their relatives. Patients with CKD and their relatives were invited by the researcher to participate in the interviews. Participants were able to express their doubts and educational needs. The use of these resources permitted the identification of the participants own requirements, and promoted an active contribution in the elaboration of contents. All interviews were tape recorded and transcribed verbatim.

Phase 2 – Instructional Planning (Content systematization)

In this phase a literature review was conducted by consulting the international databases to actively involve them in the process of selecting the information for the booklet. The researcher organized the information in a systematic way for a smooth flow of content.

Phase 3 – Didactic Drawing (Choice of illustration and Writing content)

In this phase, images were selected from electronic pages and patients with their consent. These images provided a visual illustration of the various content area that were addressed in the booklet.

Equally, textbooks were accessed in order to find quality illustrations. Didactic images were selected and used as the basis for elaboration of the illustrations, a work performed by a graphic designer.

In the third phase, a prototype, the preliminary content was developed with attention given to the information considered as essential. Content was simplified in order for it to be easily read and understood by patients and family. This content was edited to improve grammar and clarity. The development of this phase was based on the criteria previously established for the whole booklet construction process, easy reading and content clarity.

3.3.1 Research Instruments

Questionnaire (APPENDICE 2) and interview were the instruments selected by the researcher, as these are very effective method of gathering information from the participants.

The questionnaire is economical and it allowed for the researcher to interact with a large number of participants relatively easy. The responses provided to the various questions by respondents were statistically analyzed. According to Adamson et al. (2004) a well designed and validated questionnaire produce data of immense value to Health Services Research, which could be further enhanced by their use within a qualitative interview.

The researcher conducted interviews with participants, this gave the researcher the opportunity to ask questions to follow up and clarify responses. Only one question guided the interviews, the researcher asked the participants what they would like to learn about chronic kidney disease. When it was necessary the researcher explained more and ask other relative questions. According to Kvale (1996) the main task in interviewing is to understand the meaning of what the interviewees say. Interviews are very useful for getting the story behind a participant's experience, and can be used to pursue in-depth information around the topic (McNAMARA, 1999).

3.3.2 Procedure for Collection of Data

Questionnaires and interview techniques were used for the research as they allowed the researcher to interact with participants and provided for more accuracy in the data collection process.

The researcher first sought permission from the Georgetown Public Hospital Corporation for permission to invite patients with chronic kidney disease and their families to participate in an interview with the researcher.

Initially, the participants expressed their doubts and educational needs. At the end of the interviews, the participants evaluated the approach. The use of these resources permitted the identification of the participants' own requirements, and promoted an active contribution in the elaboration of contents. All interviews were tape recorded and transcribed verbatim. These data were used to guide the elaboration of the topics of the booklet and its contents. The elaboration of the content was based on scientific literature in order to guarantee reliability.

3.4 Data analysis

The information which came from the interviews was organized and read in sequence. The parts with significant speeches were selected and classified in a table. The sociodemografic data from interviews were analyzed by descriptive statistics.

3.5 Ethical considerations

Participation in this study were voluntary and confidential after signing of informed consent. The researcher sought to ensure that consent was given by all participants prior to their involvement in this process. Participants were made aware of this research and of the strict confidentiality in which the researcher will treat all information provided by the participant.

This study was approved by the Institutional Review Board of Guyana and the Georgetown Public Hospital Corporation before it was conducted (ATTACHMENT 1). Research subjects signed the Terms of Free and Informed Consent form.


4. Results

A prototype of a booklet for chronic kidney patients was developed whose selected theme came from interviews with the patients and their relatives. At the end, the prototype contains 8 pages on the appropriate diet for patients with chronic kidney diseases. The contents were subdivided into steps so that educational guidelines were organized and could be discussed with patients and relatives.

Below we present the results of the path taken in this construction with the selected topics that were demanded by patients and relatives and the findings from the literature in which the contents of the booklet prototype on the appropriate diet for patients with chronic kidney disease were selected.

The Figure 1 shows the outline of the steps taken in the study and their results, which we will detail below.



Figure 1 – Outline of the study steps, Georgetown, Guyana, 2020.

4.1 Analysis & Diagnosis

4.1.1 Study Context

The experiences of the patients at Georgetown Public Hospital Corporation encouraged the researcher to develop a booklet for patients with kidney failure. With the analysis and diagnosis, it was possible to identify the theme that patients and their families would like to know about the disease.

Performing an analysis in the literature on educational technology at national level for adult patients with CKD, no technology was found in booklet format.

Patients with CKD are managed in the male and female medical wards at the Georgetown Public Hospital Corporation. When there is an excess of patients with this condition, the hospital had reserved one room on the male surgical ward and one room on the female surgical ward with a bed compliment of six each for these patients. From 2016 to present, six of these rooms are now being utilised exclusively for patients with chronic kidney disease. There is presently a shortage of nursing staff, which makes it challenging for patients and relatives to have constant education sessions. The relatives are allowed to visit patients twice daily for half an hour and one hour respectively. When the relatives are absent, the patients interact with nursing or medical staff only when nursing or medical care is necessary.

From analysis of the situation, the researcher propose to construct an educational booklet, which the researcher believe will be an excellent strategy to support patient care. Using the booklet, the nurse can give verbal guidance to patients and relatives while the patient is hospitalized. The booklet will then be given to patients and relatives to take home on discharge. With this, the patient and relatives have a written document to use as a guide at home to assist in their self-care when there is no nurse present.

4.1.2 The findings from the interviews

The number of participants was 30 (12 patients and 18 relatives). The majority of patients and relatives were female (58.3% and 61.1%), most of them were married. The demographic characteristics of the sample are presented in Table 1 and Table 2.

		n= (%)	
	25 – 31 years old	1 (8.3%)	
4.00	31 – 35 years old	1 (8.3%)	
Age	36 – 40 years old	3 (25 %)	
	41 – 45 years old	1 (8.3%)	
	46 – 50 years old	6 (50%)	
Cander	Male	5 (41.6%)	
Gender	Female	7 (58.3%)	

Table 1. Characteristics of the sample - Patients, Georgetown, Guyana, 2020.

	Fast Indian	7 (58 3%)
	Afro Guyanese	1 (33 3%)
Ethoioity	Amorindian	4 (33.378)
Eunicity		0 (0%)
	Chinese	0 (0%)
	Mixed race	1 (8.3%)
	Single, never married	2 (16.6%)
	Married/Common law	10 (83.3%)
Marital status	Widowed	0 (0%)
	Divorced	0 (0%)
	Separated	0 (0%)
.How many people in the home	One	0 (0%)
	Two	2 (16.6%)
	Three	2 (16.6%)
	Four	4 (33.3%)
	Five	3 (25%)
	Six	6 (50%)
	Seven	0 (0%)
Primary language	English	12 (100%)
	Nursery	0 (0%)
Highost dograa	Primary	5 (41.6%)
nighest degree	Secondary	7 (58.3%)
	Tertiary	0 (0%)
	Employed for wages	0 (0%)
	Self-employed	3 (25%)
	A homemaker	3 (25%)
	A student	0 (0%)
Are you currently	Retired	0 (0%)
	Unable to work	4 (33.3%)
	Out of work and looking for work	2 (16.6%)
	Out of work but not currently looking for work	0 (0%)
	Less than \$40,000	0 (0%)
Total combined family income	\$40,999 - \$60,000	0 (0%)
	\$60,999 - \$80,000	4 (33.3%)

\$80,999 - \$100,000	3 (25%)
\$100,999 - \$120,000	0 (0%)
More than \$120,000	4 (33.3%)
Don't know	1 (8.3%)
Chose not to answer	0 (0%)
Hindu	5 (41.6%)
Muslim	1 (8.3%)
Christian	6 (50%)
Other	0 (0%)
Yes	10 (83.3%)
No	0 (0%)
Not sure	2 (16.6%)
	\$80,999 - \$100,000 \$100,999 - \$120,000 More than \$120,000 Don't know Chose not to answer Hindu Muslim Christian Other Yes No Not sure

Table 2. Characteristics of the sample - Relatives, Georgetown, Guyana, 2020.

		n= (%)
4.00	25 – 31 years old	6 (33.3%)
	31 – 35 years old	3 (16.6%)
Aye	36 – 40 years old	1 (5.5%)
	41 – 45 years old	2 (11.1%)
	46 – 50 years old	6 (33.3%)
Condor	Male	7 (38.8%)
Gender	Female	11 (61.1%)
	East Indian	10 (83.3%)
	Afro Guyanese	7 (38.8%)
Ethnicity	Amerindian	0 (0%)
	Chinese	0 (0%)
	Mixed race	1 (5.5%)
	Single, never married	8 (44.4%)
Marital status	Married/Common law	10 (83.3%)
ivianiai sialus	Widowed	0 (0%)
	Divorced	0 (0%)

	Separated	0 (0%)
How many people in the home	One	0 (0%)
	Two	2 (11.1%)
	Three	3 (16.6%)
	Four	6 (33.3%)
	Five	6 (33.3%)
	Six	1 (5.5%)
	Seven	0 (0%)
Primary language	English	18 (100%)
	Nursery	0 (0%)
High oct do groo	Primary	4 (22.2%)
nignest degree	Secondary	12 (66.6%)
	Tertiary	2 (11.1%)
	Employed for wages	11 (61.1%)
	Self-employed	5 (27.7%)
	A homemaker	1 (5.5%)
	A student	0 (0%)
Are you currently	Retired	0 (0%)
	Unable to work	0 (0%)
	Out of work and looking for work	1 (5.5%)
	Out of work but not currently looking for work	0 (0%)
	Less than \$40,000	0 (0%)
	\$40,999 - \$60,000	0 (0%)
	\$60,999 - \$80,000	4 (22.2%)
Total combined family income	\$80,999 - \$100,000	4 (22.2%)
rotal combined family income	\$100,999 - \$120,000	0 (0%)
	More than \$120,000	9 (50%)
	Don't know	1 (5.5%)
	Chose not to answer	0 (0%)
	Hindu	8 (44.4%)
Dellaisse (see the	Muslim	9 (50%)
Religious family	Christian	1 (5.5%)
	Other	0 (0%)
		A

To be committed to your religious teachings	Yes	18 (100%)
	No	0 (0%)
	Not sure	0 (0%)

4.1.2.1 Themes from interviews

During the interviews, the researcher inquired of patients and their relatives about knowledge needs as it related to chronic kidney disease. The tables below are a representation of the frequency of responses we collected from participants.

Table 3. Frequency themes from interviews - patients, Georgetown, Guyana, 2020.

Themes	n=12 (%)
Functions of the kidney	5 (41,6%)
Causes of Renal Failure	7 (58,3%)
Stages of Renal Failure	3 (25%)
Symptoms of Renal Failure	4 (33,3%)
Medications used	5 (41,6%)
Fluid Intake	3 (25%)
Diet	5 (41,6%)
Catheter and Fistula care	7 (58,3%)
Is Disease curable?	1 (8,3%)
Life expectancy with disease	4 (33,3%)
Organ Transplant	9 (75%)

	Table 4.	Frequency	y themes	from	interviews	- relatives,	Georgetown,	Guy	/ana,	2020
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Themes	n=18 (100%)
Functions of the kidney	1 (0,5%)
Causes of Renal Failure	10 (55,5%)
Stages of Renal Failure	7 (38,8%)
Symptoms of Renal Failure	7 (38,8%)

Medications used	16 (88,8%)
Fluid Intake	10 (55,5%)
Diet	16 (88,8%)
Catheter and Fistula care	12 (66,6%)
Is Disease curable?	10 (55,5%)
Life expectancy with disease	6 (33,3%)
Organ Transplant	8 (44,4%)

Most of the relatives wanted to know about diet and medication, and the most of the patients choose organ transplant (75%).

4.2 Instructional Planning

To create the booklet, it was necessary conduct a literature review to construct the contents, as well as built a plan to describe all the steps and objectives of the booklet. The review and plan follows.

4.2.1 The findings from Literature Review

Two electronic databases used for literature search process included PubMed and Google[™] Scholar. Keywords and Boolean combinations for the search included diet, hemodialysis and Chronic Kidney Disease. The publishing time for the literature was set between the year of 2016-2020, and all were published in English. The literature search returned 121 initial records. The investigators evaluated and selected the records following a two-step procedure. Firstly the relevancy of the literature was checked through the title/abstract and those relevant ones were kept in the data set. Their full-texts were retrieved from online archives of the university library. Secondly, the content of the full-texts were read through to further determine the relevancy of the literature. The inclusion criteria of literature included 1. Focusing on diet by Chronic Kidney Disease. 2. The type of the article could be either research report or review. Other types of literature such as personal opinion, learning practice report, editorial report were excluded. As a result, a total of nine (9) articles were included in final data analysis (Table 5).

No.	Title - Author Year Country	Purpose (Aim)	Participants	Results
1	Diet and Chronic Kidney Disease, Holly Kramer (2019) USA	This article reviews the potential mechanisms whereby several key characteristics of the typical Western diet may impact kidney disease incidence and progression.		dietary factors are important for determining the workload of each individual nephron. In the setting of CKD and reduced working nephron number, each individual nephron is already at risk for hemodynamic injury. High intake of animal protein and egg yolks combined with low intake of fruits and vegetables is extremely conducive for nephron injury, and mechanisms of injury are not duplicative. Although a modified DASH diet is encouraged for patients with CKD, more studies are needed to determine the benefits and risks of vegetarian diets in this population. Clinicians should consider the dietary patterns, traditions, and culture of their patients when providing dietary advice and utilize medical nutrition therapy services to guide their patients to a healthier diet
2	The low-protein diet for chronic kidney disease: 8 years of clinical experience in a nephrology ward Ivano Baragetti, Ilaria De Simone et	This study provides a report of real-world nutritional management of CKD patients to confirm the value of the guidelines through a	299 CKD Stage 4 patients followed for 70 months in collaboration with a skilled nutritionist. The patients included 43 patients on a controlled protein	eGFR was higher in CPD patients than in UPD and LPD patients $(21.9 \pm 7.4 \text{ mL/min}/1.73 \text{ m}^2)$ versus $17.6 \pm 8.00 \text{ mL/min}/1.73 \text{ m}^2$ and $17.1 \pm 7.5 \text{ mL/min}/1.73$ m ² ; P = 0.008). The real daily protein intake was

Table 5 – Literature relevant to appropriate diet and chronic kidney disease, Georgetown, Guyana, 2020.

	(2020)	analysis of our	0.8 g/kg/day	than in LPD and CDP
		clinical	[estimated	patients
	Italy	experience with	glomerular	$(0.80 \pm 0.1 \text{ g/kg/day versus})$
		renal nutrition.	filtration rate	0.6 ± 0.2 and
			(eGFR) 20–	0.63 ± 0.2 g/kg/day;
			30 mL/min/1.73	P = 0.01). Body mass
			m ² body surface	index (BMI) was stable in
			(b.s.)], 171	the LPD and CPD groups
			patients on an	but decreased from
			LPD 01	$28.3 \pm 4.52 \ 10$ 25.4 ± 2.04 kg/m ² in the
			85 patients on an	UPD group ($P < 0.001$)
			unrestricted	The renal survival of UPD.
			protein diet	LPD and CPD patients
			(UPD) who were	was 47.1, 84.3 and 90.7%,
			not followed by	respectively, at 30 months
			our nutritionist	(P < 0.001), 42.4, 72.0 and
			(LPD and UPD,	79.1%, respectively, at
			eGFR	50 months (P < 0.001) and
			<20 mL/min/1.73	42.4, 64.1 and 74.4%,
			m² b.s.).	respectively, at 70 months
				(P < 0.001). The LPD
				patients started dialysis
				hearly 24 months later than
				the UPD patients. Diet was
				of dialysis [-67% of PR
				reduction (bazard
				ratio = 0.33 : confidence
				10000, 000, 0000, 000000000000000000000
				together with a reduction in
				BMI.
0				
3	Impact of Dietary	10 discuss the		Current clinical guidelines
	Restrictions in CKD	adherence to a		notassium intake to
	on Clinical	low-notassium		prevent and treat
	Outcomes: Benefits	diet and the		hyperkalemia in patients
	of a Plant-Based	impact of dietary		with CKD. However. the
	Diet	restrictions on		traditional low-potassium
		adverse clinical		diet is complex and can
	Clegg, D. J.,	outcomes.		counteract the benefits of a
	Headley, S. A., &			plant-based diet, with only
	Germain, M. J.			modest evidence to
	(2020)			support the rationale for
				these dietary restrictions.

4		The purpose of	Participants were	The study findings provide
	Perceptions on	this study was to	purposively	awareness for nutritionists
	Adherence to	explore the	selected at renal	and other healthcare
	Dietary	perceptions about	clinics/dialysis	providers about CKD
	Prescriptions for	adherence to	units at national	patients' and caregivers'
	Adults with Chronic	dietarv	referral hospitals	views and feelings
	Kidnev Disease on	prescription	in Kenva. Studv	concerning renal diets.
	Hemodialvsis: A	among adults	participants were	Both patients and
	Qualitative Study.	with CKD on	52 patients and	caregivers are in
	, , , , , , , , , , , , , , , , , , ,	hemodialvsis and	40 family	agreement that diet
	Okovo Opivo, R.,	their family	caregivers (42	prescriptions are beneficial
	Nvawade, S. A.	caregivers.	males and 50	for health and wellbeing of
	McCaul. M.		females) aged 20	the patient. However, there
	Nvasulu. P. S.		to 69 years.	are mixed messages to the
	Lango, D. B., Were			patients and caregivers
	A Nabakwe F C			who have challenges with
	Bukania, Z. N., &			management and
	Olenia, J. M.			acceptability of the
	(2020).			prescriptions. Most of them
	()			therefore make un-
	Kenva			informed dietary decisions
				that lead to consumption of
				unhealthy foods with
				negative outcomes such
				as metabolic waste
				accumulation in the
				patients' bodies negating
				the effect of dialysis and
				undermining the efforts of
				the healthcare system in
				CKD management.
5	Dietary interventions	This review	Randomised	Dietary interventions have
•	for adults with	evaluated the	controlled trials	uncertain effects on
	chronic kidney	benefits and	(RCTs) or quasi-	mortality, cardiovascular
	disease.	harms of dietary	randomised	events and ESKD among
		interventions	RCTs of dietary	people with CKD as these
	Palmer. S. C.	among adults	interventions	outcomes were rarely
	Maggo, J. K.	with CKD	versus other	measured or reported.
	Campbell. K. L.	includina people	dietarv	Dietary interventions may
	Craig, J. C.	with end-stage	interventions	increase health-related
	Johnson, D. W.	kidnev disease	lifestyle advice.	quality of life, eGFR, and
	Sutanto. B.	(ESKD) treated	or standard care	serum albumin. and lower
	Ruospo. M., Tona.	with dialvsis or	assessing	blood pressure and serum
	A., & Strippoli. G. F.	kidnev	mortality	cholesterol levels.Based
	(2017).	transplantation.	cardiovascular	on stakeholder
			events, health-	prioritisation of dietarv
			related quality of	research in the setting of
			life. and	CKD and preliminary
			biochemical.	evidence of beneficial

anthropomorphic, effects on r	sks factors for
and nutritional clinical outc	omes, large-
outcomes among scale pragn	natic RCTs to
people with CKD. test the effe	ects of dietarv
intervention	s on patient
outcomes a	re required.
6 Potassium Binders Stimulate Sodium ziro	onium
for Hyperkalemia in awareness that	and patiromer
Chronic Kidney hyperkalemia is a have been	found to be
Disease-Diet potentially life-	d tolerable in
Renin-Angiotensin- threatening clinical trial	and are viable
Aldosterone System complication of	to SPS for the
Inhibitor Therapy chronic kidney manageme	nt of
and Hemodialysis disease (CKD)	ia in patients
The management with CKD	
Palmer B F of CKD requires	
(2020) balancing the	
benefits of	
specific	
treatments which	
may exacerbate	
the potential for	
hyperkalemia	
with the risks of	
hyperkalemia	
itself	
7 Phosphorus testing novel The develo	oment of more
Regulation in targets that may potent inhib	itors should be
Chronic Kidney inhibit intestinal forthcomine	ı. but it is
Disease. transport of important to	emphasize
phosphorus to that there w	, vill alwavs be a
achieve better place for ph	osphate
Suki, W. N., & phosphate binders to b	lock the
Moore, L. W. control. passive abs	sorption of
(2016).	for people with
advanced (KD.
Furthermor	e. protecting
and monito	ring bone
health shou	ld also aid in
controlling	serum iP as
CKD advan	ces.
8 This review Several line	s of evidence
Salt, water and summarizes	support to a
nephron: existing and new pathogenic	
Mechanisms of literature and and low-wa	role of high-salt
	role of high-salt
I action and link to I discusses I common in	role of high-salt ter intake, the general
Action and link to discusses common in hypertension and complex multi-	role of high-salt ter intake, the general 17 in the
action and link to discusses common in hypertension and complex multi- population, chronic kidney organ effects of genesis of I	role of high-salt ter intake, the general <u>17</u> in the TTN and CKD.

	Qian Q. (2018).	water intake and role of arginine vasopressin in this process, as well as the potential clinical significance of non-osmotic sodium storage pool and rhythmicity of urine sodium excretion.	
9	Dietary protein intake and chronic kidney disease Ko, G. J., Obi, Y., Tortorici, A. R., & Kalantar-Zadeh, K. (2017)	To review the effect of protein intake on incidence and progression of CKD and the role of LPD in the CKD management.	Actual dietary protein consumption in CKD patients remains substantially higher than the recommendations for LPD. Notwithstanding the inconclusive results of the 'Modification of Diet in Renal Disease' (MDRD) study, the largest randomized controlled trial to examine protein restriction in CKD, several prior and subsequent studies and meta-analyses appear to support the role of LPD on retarding progression of CKD and delaying initiation of maintenance dialysis therapy. LPD can also be used to control metabolic derangements in CKD. Supplemented LPD with essential amino acids or their ketoanalogs may be used for incremental transition to dialysis especially on nondialysis days. The LPD management in lieu of dialysis therapy can reduce costs, enhance psychological adaptation, and preserve residual renal function upon

		transition to dialysis
		Adherence and adequate
		protein and energy intake
		should be ensured to avoid
		protein-energy wasting.

The consultation of the literature allowed the updating and construction of knowledge on the theme, and required a reflection on the selection of the content to give reliability to the information that would be included in order to fill the knowledge gap of the participants, with valorization of the advancement of science on the subject.

4.2.2 Instructional Planning

An instructional plan was elaborated to guide the production of the prototype by the webdesigner. This professional was hired to produce the booklet together with the researcher. All selected images from the internet are freely open to access.

Theme/ Topic: Prototype of An Educational Technology About Appropriate Diet For Patients With Chronic Kidney Disease

Responsible Persons: Shebrena Belle and Rosângela Aukar Andrade de Camargo

Location Identification: Georgetown Guyana

Target Audience: Adult patients with chronic kidney disease and their caregivers.

Main Goal: Build educational technology in a booklet format for adult patients with chronic kidney disease.

Specific Objectives:

- Explore common factors that affect the delivery of patient education about chronic kidney disease.
- Explore areas about the disease essential for patients and family knowledge.
- Construct a prototype of a booklet with scientific information of patient and caregivers need.

Content:

- Importance of using a chronic kidney disease diet
- Deciding on foods with less salt and sodium
- Choosing foods with the right amount and type of protein
- Selecting foods with reduced phosphorus content
- Choosing foods with the right amount of potassium

Strategy: Booklet

Development:

The booklet was divided into four steps to follow:

Step 1 – patients are introduced to foods with less salt and sodium, to help control their blood pressure.

Step 2 – proteins that support protection of the kidney will be presented along with their ideal amounts.

Step 3 – the consequences of phosphorus for the kidney are presented, as well as foods that have reduced phosphorus content will be presented.

Step 4 – consequences of increase potassium for the kidney, as well as helping to choose foods that have a good amount of potassium.

The planning consisted of reflecting on what is the best food for a person who has kidney failure, as well as how a booklet can facilitate this learning.

4.3 The Prototype - Didactic Drawing

After selecting the contents of each booklet topic, the information was typed in Microsoft Office FrontPage, saved them in a file called Booklet content in the researcher's personal microcomputer, choosing and capturing the necessary media and saving them in a named file. Then, the script was prepared to be presented in booklet form and in four different steps. In the didactic design, instructional planning was refined with respect to form and appearance, as well as content.

With the plan and script in hand, as well as with the selection of the content, the booklet prototype was produced. Below we present the Booklet.

Cover page – this page displays a representation of the kidneys surrounded by foods that appears fresh and healthy. This is intended to visually stimulate the patients and send a mental message that they need to care for their kidneys by consuming appropriate foods.

Page 1 – here we see the picture with the appearance of a healthy kidney indicates that the researcher we will be addressing kidney health.

Page 2 – this page has two pictures; the first depicts the kidneys being held up as precious gems. This picture was placed there to remind the patients that their kidneys are extremely important for the sustenance of their lives. The second picture indicates that healthy foods are necessary for the support of your kidneys.



Figure 2 - Booklet cover and back cover, Georgetown, Guyana, 2020.

Page 3 – the footsteps are meant to imply that your choice to adhere to an appropriate diet can be as simple as taking little steps.

Page 4 – the picture here complements the protein information presented beside it. It also stimulates the patients imagination concerning meal preparation in that meals do not have to be dull.

Page 5 – this page talks about food with high and low levels of phosphorus. The patients will understand that they can get low levels of phosphorus from cans but the picture will encourage them to choose fresh fruits in preference to canned foods.

Figure 3 - Page 3 to 5 of the booklet, Georgetown, Guyana, 2020.



Page 6 – here this picture says that the right choice of fruit blend can constitute the correct potassium levels for the patient's dietary intake.

Page 7 – the points here are highlighted in various colours individually to capture the attention of the patient that there are different signs to look out for.

Page 8 – the picture on this page is to let the patient understand that they are also responsible for the planning and implementation of their care.

Figure 4 - Page 6 to 8 of the booklet, Georgetown, Guyana, 2020.



Discussion

5. Discussion

This research developted a prototype of a health education technology, a booklet for adults living with CKD and their relatives/caregivers, anticipating that it will educate and empower them to practice self-care measures to maintain optimum health while living with the disease condition. According to Moura et al (2019), health education is an important tool for the socialization of knowledge, health promotion and disease prevention, with a view to the construction and incorporation of practices that aim at changes in behaviors harmful to health through subject empowerment.

CKD is a global threat to health in general and especially for developing countries in particular, because therapy is expensive and life-long. Chronic kidney failure is a permanent condition. CKD is well managed by haemodialysis. The number of patients undergoing haemodialysis is steadily increasing. Haemodialysis is usually administered three times a week in a dialysis center or clinic. These patients and families need to know about the home care management of haemodialysis to prevent complications, which will increase their life expectancy and help them to lead a near normal life. Different studies showed the importance of proper knowledge about home care management such as Dietary management Fluid management, Care of oral cavity, Prevention of infection and skin care, Safety measures to prevent bleeding tendencies, Care of dialysis Access- AV fistula and catheters, Emergency care and First aid. Providing an information booklet will help the haemodialysis patients to care for themselves at home (NEENA & GAJANAND, 2020).

The development of a booklet with accurate and scientific information for a positive behavioral change could be realized with the participants of this study. The research began with an assessment of the context where the educational technology will be implemented. Patients and relatives of both sex, diverse literacy levels and socio-economic background were engaged. There was found an intense readiness for health education information to aid in their health status maintenance. In a similar study, Watts et al. (2016) stated that patients with Posttraumatic Stress Disorder (PTSD) reported a strong preference to receive information about treatment options. They expressed interest in also learning about PTSD symptoms. The patients preferred information presented in a booklet format. In this way, Mansouri et al. (2019) compared the interactive multimedia and booklet methods at the time of discharge on

the quality of life of kidney transplant patients. They found that both methods had positive impacts on the quality of life emotional, fatigue and uncertainty/fear domains.

Literature supports the significance of research conducted in a collaborative method. According to Archambault et al. (2018) patient engagement can improve emergency medicine research by helping researchers select meaningful outcomes, increase social acceptability of studies, and design knowledge translation strategies that target patients' needs. It was therefore indispensable to have participation from target audience in the process of this educational booklet development.

In a study by Bragagnollo et al. (2020) in which an educational technology on Spotted Fever was developed, the authors carried out a diagnostic analysis of the knowledge on the topic with the target population of the study to identify the real needs. Similarly Dorneles et al. (2020) who aimed to build an animated infographic on permanent health education, the authors also carried out a diagnostic analysis with the target population in the form of brainstorming; the authors claim that this moment was essential for educational technology to really reach its goal.

When there is a balance between the researcher's ideas and the target audience involvement, it allows for the researcher to get clear insight of the felt and expressed health education needs to be addressed, and makes the technology user appropriate. Furthermore, Forsythe et al. (2019) posited that engagement can support more relevant research through better alignment with patients' and clinicians' realworld needs and concerns. Concerning the participation of target audience (CKD patients and their care givers) in this research, it involved them contributing by verbally expressing their knowledge needs regarding their disease condition. This was instrumental in arriving with themes, and guided the selection of a priority topic for the booklet. Similarly, Doria et al (2018) stated that their contributions are not treated as research data, but instead they help make decisions that shape the research process.

Participants were equally interested in information about diet and organ transplant. Gluba-Brzózka et al. (2017) posited that healthy diet is highly important, especially in patients with CKD. Proper nutrition provides the energy to perform everyday activities, prevents infection, builds muscle, and helps to prevent kidney disease from getting worse. With the aim of preventing the disease from worsening and the fact that it is very challenging to secure an organ donor for kidney disease, the researcher opted to fill the educational gap for diet since this information if utilized can promote kidney health and suspend the need for an organ donor.

Moura et al. (2019) goes on to posit that printed material, such as manuals, brochures, folders and booklets, constitute viable tools for information and awareness of children and adolescents, allowing the young people and their families a later reading, serving as a guide in cases of doubts and helping in everyday decision-making. Charles and Ferris (2020) also stated that handbooks for health care, guidelines, information leaflets and booklets are able to promote expressive outcomes for the participants of educational activities. Informed choices can only be made when persons are furnished with the appropriate information to make those decisions. The situation at the Georgetown Public Hospital where there is a shortage of nurses can be assisted with the implementation of a booklet use. Figueiredo et al. (2019) said that the elaboration of printed technologies (such as a notebook) is intended, among other aspects, to facilitate the assistance provided by health professionals, and help the community to better understand its health-disease process and to consciously seek out the paths to be followed for its recovery.

These studies show that it is essential to consider previous knowledge and doubts of users in the elaboration of educational technology added to this is the relationship between the quality of educational material and the use of principles and defined forms of elaboration (VERASZTO et al., 2016; BONILLA et al., 2018; CRUZ et al., 2019).

Accordingly, studies carried out in Brazil (BENEVIDES et al., 2016; MOURA et al., 2017), Venezuela (MACHADO et al., 2016), United States (WANG et al., 2016) and Italy (GIGANTESCO et al., 2019) worked with Educational Technology obeying scientific criteria and seeking to know the target population adopted strategies with the potential to gather knowledge modifiers for the teaching-learning process.

To establish a sense of direction, the researchers developed a study plan called instructional planning. The instructional planning for the current study was built in a systematic way to understand the scenario in which we were inserted, facilitating the choice of the approach and type of action for transformation practice and consequently reality, looking to build a creative, consistent and innovative (BRAGAGNOLLO et al., 2020).

The systematic structure of this study plan permitted identification of what was important and the creation of clear goals in relation to the booklet construction process. Planning was essential for the researcher to keep track of the booklet development progress. Prospective difficulties were identified and adequate preparation was made to address these difficulties. For example, the graphic designer that initially designed the booklet did not do so satisfactorily and a second designer had to be engaged. This incurred an added cost and time. Since there was a plan in place, there was room for flexibility at this juncture.

For this project the researcher utilized the Social-Constructivism Pedagogy Theory developed by Paulo Freire, which assumes that acquisition of knowledge leads to empowerment. (ROZENDO et al., 2017). The content present scientifically proven information that addresses the knowledge needs of the target population which the researcher anticipates will help the target population to attain precise knowledge about an appropriate diet for their disease condition through dialogue with the nurse. It also utilizes Self-Care Deficit Theory developed by Dorothea E. Orem which assumes that humans require continuous, deliberate inputs to themselves to remain alive and function. (GEORGE, 2011; TOMEY & ALLIGOOD, 2006). Information when disseminated to the target population by the nurse through dialogue, is expected to empower them to be confident enough to exercise self-care when they are discharged. Since they will be given the booklet to take home for referencing these patients will feel a sense of responsibility for the management of their personal health.

The contents covered that subsidized the construction of the educational booklet included several themes involving aspects related to healthy food for people living with chronic renal failure. Maintaining a balanced and healthy diet is considered care that contributes to health promotion, being fundamental to maintaining physical and emotional health. Such health practice improves people's quality of life, decreasing the mortality rate and increasing treatment adherence, which are directly linked to the improvement of the immune system (WORLD HEALTH ORGANIZATION, 2004).

There was concern and attention in carrying out a translation of the technical and scientific language into a language accessible to the population, seeking to facilitate understanding and understanding mainly for those with less health literacy. The development of a booklet as educational material based on educational needs and with the participation of the target population was a strategy fundamental in this study. So it is expected that this technology can favor quality of life and contribute to health prognosis (JESUS et al., 2020).

According to Razera et al. (2014), the script is an indispensable tool because it allows a previous assessment by specialists in relation to the quality of the material

developed, so it must be well detailed so that the professionals responsible for the production know exactly what they want.

In addition, in order to build a booklet, account must be taken of the illustrations in an attempt to attract attention and help understanding of the subject. There is a consensus that health education material should be written in a simple way, with a lower reading level and that makes it possible to transmit accurate information. The illustrations must be attractive with clear communication of the purpose of the educational material (HOFFMANN; WARRALL, 2004). In addition, images must achieve a high level of attention and interest in reading the material with acceptance of the population at different levels of education (JONES et al., 2011).

Many times visual images serves as a means of improving person's interpretation of information that they read. It also stimulates the desire to read. In the booklet prototype presented in this study, visual images accompanied each step of diet that was dealt with. Arujuna et al. (2018) in a similar study posited that the use of photograph booklets containing simple and relevant images to support the consent process for dermatologic surgery improves patients' understanding, expectations, and experience of skin surgery.

It is supposed that this prototype of educational technology will contribute to the improved health of patients with chronic kidney disease through knowledge construction followed by self-care. It is anticipated to be a teaching technology for nurses and students who work on the clinical area to encourage the target population to take responsibility for their health maintenance when not hospitalized.

In the construction of booklet prototypes, there is always a need for a follow-up study to determine the effects of their use. According to Santerre-Theil et al. (2018) to meet parents' needs, a communication guidance booklet was developed. This communication tool responds to a significant unmet need faced by parents carrying a genetic predisposition to cancer. Future studies are needed to assess how the information from the parent's genetic test result impacts the child's development, health behaviors, and relationship with the parent. This booklet prototype when presented to the respective personnel will have to be approved and implemented. It will also take further study to assess the effects of the usage of this educational booklet. Zubkoff et a.I (2016). In a similar study stated that the resultant PTSD patient decision aid is a booklet that describes the causes, symptoms, and treatments for PTSD. Future work will examine the effects of use of the PTSD decision aid in clinical practice.

Khodambashi et al (2017) stated, we developed a prototype and drug ontology to support reasoning about drug interactions. We evaluated individual performance in finding information, understanding the drug interactions, and learning from the provided information in the prototype compared to using patient information leaflets (PILs). We concluded that interactive visualization of drug information helps individuals find information about drugs, their side effects and interactions more quickly and correctly compared to using PILs. In the didactic drawing – prototype aspect of this study, significant efforts were placed on the insert of images relative to the information presented in the booklet with the intention that these images will give the user a richer understanding of the booklet content.

Thus, the importance of materials and educational activities, such as the one developed in this study, comes to collaborate with the increase of information for self-care measures to maintain ideal health while living with chronic kidney disease, empowering them in the search for self-care (LIMA et al., 2018).

This elaboration built with the subjects forms the set of captured ideas that reflect on facilitating instruments in the development of educational technologies with renal patients in treatment. We believe it will be this prototype to be accepted and renewed by many who believe and make efforts to innovate care.

Conclusion

6. Conclusion

Health education is an essential part of patient care. Patient education is not only an important aid by which patients can better understand their questions, concerns, and needs regarding kidney disease care addressed, but also a crucial pathway to make sure patient participation in selfmanagement of CKD risks. Patient education can help with better patient outcomes. Among most patients, barriers to education include the complex nature of kidney disease information, limited availability of CKD information, and lack of readiness to learn.

This study constructed a prototype of educational technology about appropriate diet for adult patients with CKD.

CKD is a major cause of morbidity and mortality globally and locally. In Guyana, this disease condition contributes to shortened life expectancy of patients; the health care institution and the government by extension is financially overburdened with the cost of care for this large amount of patients when the finance can go to other avenues that greatly need it.

The problem is the constant readmission to hospital of patients with CKD. We hope if nurses use the booklet and patients and families are knowledgeable of the disease and its management, patient care will be improved. There will be a delay in the rapid onset of the disease progression, because patients will assume more responsibility for their own health. Nurses will experience satisfaction from the effective use of resources and improved communication between themselves client and families. The economic burden of the country will be reduced. The confidence of the general populace in the health system in terms of post diagnosis treatment will be improved.

In addition, there is a consensus on the verbal guidance with writing as more effective for health education, which increases patient understanding and promotes better recovery. I thought to address diet first and present a prototype of a booklet, because filling the educational gap for diet will deliver information that, if utilized can promote kidney health and suspend the need for an organ donor. The absence of this type of teaching material was found in Guyana. This prototype can be followed by a series of booklet capturing the other themes in a future study. It is supposed that this prototype of educational technology will serve as a stimulus to the improved health of patients with chronic kidney disease through knowledge construction followed by self-care. It is anticipated to be a teaching technology for nurses and students who work on the clinical area to encourage the target population to take responsibility for their health maintenance when not hospitalized. Future work will examine the effectiveness of the implementation of this educational booklet.

6.1 Contributions/Recommendations

The successful implementation of this booklet will see a resolution of the problem by patients and their families being able to take better care of themselves at home, patients with the disease condition enjoying longer life without end stage complications. Nurses will have a manageable patient population, and will be able to conduct care without being exhausted and making care errors that can harm the patients. The hospital and by extension the government having a decrease in the financial burden since there will have decrease in the number of patients being readmitted. The general health of the population with this disease condition will be improved and they will live the best possible quality of life with their chronic condition.

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7.Bibliographic References

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Attachments

Attachments A

Ministry of Public Health Guyana Institutional Review Board

<u>Research Proposal Form</u> (Must be submitted typewritten with each proposal)

Date Received by Board: (office use)

Please complete all sections of this Form

1. Title of Project: Construction and validation of an educational technology for patients with chronic kidney disease

2. Investigators:

Primary investigator (PI): Shebrena Belle

Tel No.: 592 626 6859

Address:150 Cato Street, Agricola. Georgetown

E-mail: shebrenabelle@gmail.com

Collaborators/Supervisor Name: Rosangela Andrade Aukar de Camargo

Contact Information: Tel No.: +55 16 982336305

Address: 340 Rua J, Ribeirao Preto (SP). Brazil. CEP: 14033-014

Sponsors/Agencies/Organization: University of Sao Paulo at Ribeirao Preto, College of Nursing

Contact Information: Tel No.: +55 16 3315-3381

Address: 3900, Bandeirantes Ave, Ribeirao Preto (SP). Brazil. CEP: 14040-92

3. Expected dates of:

Sample collection/field work: July 8th to July 26th 2019

4. Purpose and objective of project.

To construct and validate an educational technology for adult patients with chronic renal disease.

5. How many subjects will be used? Not more than 12, depending on code saturation.

6. Who are being recruited and what are the criteria for their selection?

The sample pool for the research consist of patients and patients who are readmitted at the Georgetown Public Hospital Corporation, between the ages of 25 and
50 years old, who were diagnosed with chronic renal disease by a physician, and their families, as well as nurses working on the unit who manages the patients. The sample size will consist of all nurses, patients and their families who are willing to be participants of this research.

7. How are subjects being recruited? If with written materials, attach a copy. If verbally state exactly what they will be told, by whom, and when and where this will occur. Subjects will be recruited by way of written document.

8. Describe the study methodology and procedures. Include details of all medical devices or tests, interviews, questionnaires, or use of medical records.

Research Design

The intent of this research is to explore the effectiveness of creating and validating an educational booklet for patients with chronic kidney disease and their families, with the aim that the introduction of this new stimulus will improve self-care of patients.

The booklet construction process and validation

The construction of this booklet and validation will entail the use of a five phase process. Work will be carried out in the period January 2019 to September 2020 via a methodological approach. The phases employed are as follows:

Phase 1 – Content systematization

Phase 2 – Choice of illustration

Phase 3 – Writing content

Phase 4 - Validation of booklet by nurses

Phase 5 - Validation of booklet by patient and family

The main presupposition of this method is the construction of knowledge in collective and participatory ways, in order to find a solution for a problem that needs to be studied. The solution found can produce positive reflexes for people, community, and society (Brydon-Miller et al, 2003).

As stated earlier, the problem is the constant readmission to hospital of patients with chronic kidney disease. When nurses use the booklet and patients and families are knowledgeable of the disease and its management, patient care will be improved. There will be a delay in the rapid onset of the disease progression, because patients will assume more responsibility for their own health. Nurses will experience satisfaction from the effective use of resources and improved communication between themselves client and families. The economic burden of the country will be reduced. The confidence of the general populace in the health system in terms of post diagnosis treatment will be improved.

Phase 1 – Content systematization

In this phase interviews will be conducted with, patients and their family, to actively involve them in the process of selecting the information for the booklet. The researcher will organize the information in a systematic way for a smooth flow of content. This phase will be based on the needs of patients with chronic kidney disease and their families. Patients with chronic kidney disease and their families will be invited by the researcher to participate in the interviews. Participants will be able to express their doubts and educational needs. The use of these resources will permit the identification of the participants own requirements, and promote an active contribution in the elaboration of contents. All interviews will be tape recorded and transcribed verbatim.

Phase 2 – Choice of illustration

In this phase, images will be selected from electronic pages and patients with their consent. These images will provide a visual illustration of the various content area that will be addressed in the booklet.

Equally, text books will be accessed in order to find quality illustrations. Didactic images will be selected and used as the basis for the elaboration of the illustrations, a work to be performed by a graphic designer.

Phase 3 – Writing content

In the third phase, the preliminary content will be developed with attention given to the information considered as essential. Content will be simplified in order for it to be easily read and understood by patients and family. This content will be edited to improve grammar and clarity. The development of this phase will be based on the criteria previously established for the whole booklet construction process, easy reading and content clarity. Phase 4 - Validation of booklet by nurses

In phase four, a draft of the content for the booklet will be given to nursing staff (experts in this area) at the chronic kidney disease unit of the Georgetown Public Hospital Corporation for the purpose of assessment and validation.

Phase 5 - Validation of booklet by patients with chronic renal disease

In this final phase, a draft of the content for the booklet will also be issued to a group of patients diagnosed with chronic kidney disease at the Georgetown Public Hospital Corporation and their families for interpretation and validation.

Sampling Design and Methods

The research will use a purposeful qualitative sampling approach. This sampling approach will help the researcher to select participants who will provide useful and invaluable information that may allow the researcher to develop a more detail understanding of the phenomenon. This approach will give the researcher the ability to intentionally select the sample size as opposed to a random selection. As such the researcher will target data that would provide relevant information for the research.

Sample Size

The sample pool for the research consist of patients and patients who are readmitted at the Georgetown Public Hospital Corporation, between the ages of 25 and 50 years old, who were diagnosed with chronic renal disease by a physician, and their families, as well as nurses working on the unit who manages the patients. The sample size will consist of all nurses, patients and their families who are willing to be participants of this research, during the period July – August 2019. The number of patients and families that will be interviewed will depend on code saturation.

Exclusion will be patients with chronic kidney disease who only attend clinic and are not admitted to the clinical unit, patients on the unit with chronic kidney disease but are unresponsive, patients who just returned from dialysis center and are too weak and exhausted to give quality feedback, nurses on the unit who are just relieving the shift. Research Instruments

Questionnaire and interview are the instruments selected by the researcher as these are very effective method of gathering information from the participants.

The questionnaire is economical and it allow for the researcher to interact with a large number of participants relatively easy. The responses provided to the various questions by respondents will be statistically analyzed and validated by specialists. According to Adamson, Gooberman-Hill, Woolhead, Donovan (2004) a well-designed and validated questionnaire produce data of immense value to Health Services Research, which could be further enhanced by their use within a qualitative interview.

The researcher will also conduct interviews with participants as the researcher will have the opportunity to ask questions to follow up and clarify responses. Only one question will guide the interviews, the researcher will ask the participants what they would like to learn about chronic kidney disease. If it is necessary the researcher can explain more and ask other relative questions. According to Kvale (1996) the main task in interviewing is to understand the meaning of what the interviewees say. Interviews are very useful for getting the story behind a participant's experience, and can be used to pursue in-depth information around the topic (McNamara, 1999).

Procedure for Collection of Data

Questionnaires and interview techniques will be used for the research as they would allow the researcher to interact with participants and will provide for more accuracy in the data collection process.

The researcher would first seek permission from the Georgetown Public Hospital Corporation for permission to invite patients with chronic kidney disease and their families to participate in an interview with the researcher.

Initially, the participants can express their doubts and educational needs. At the end of the interviews, the participants will be able to evaluate the approach. The use of these resources will permit the identification of the participants own requirements, and promote an active contribution in the elaboration of contents. All interviews will be tape recorded and transcribed verbatim. These data will be used to guide the elaboration of the topics of the booklet and its contents. The elaboration of the content will be based on scientific literature in order to guarantee reliability.

Some information related to public services available for patients with chronic kidney disease will be included in the booklet, and the reliability will be confirmed by phone or e-mail. Data analysis

The information coming from the interviews will be submitted to thematic content scrutiny (Bardin, 2011). Thus, in the pre-analysis, the information will be carefully organize and read in sequence, during the material exploration process. The parts with significant speeches will be selected, when the treatment will be conducted, the inference and the interpretation of results, which allowed the final construction of thematic categories.

9. What is known about the risks and benefits of the proposed research? Do you have any additional opinions on this issue?

There is no known risk of the proposed research. The benefits are longevity for patients; satisfied health care providers; decrease financial burden on the Ministry of Public Health and the state by extension.

10. What discomfort or incapacity are subjects likely to endure as a result of their participation?

There are no perceived discomfort, and there will be no incapacity for participants.

11. What provisions are made to protect confidentiality? Who has access to coded and uncoded data?

Data will remain anonymous by using numbers instead of names. The researcher and supervisor will have access to data.

12. How much time will a subject have to dedicate to participating? Participants will have to dedicate not more than 20 minutes of their time to participate.

13. What are plans for future use of data or samples, beyond what is already described? Probably a cohort study.

14. How will <u>informed consent</u> be obtained? If by written forms, please attach copies. If informed consent will be verbal, state who will be involved and provide a written statement of information that will be given to subjects, and to nurses or other intermediaries.

By written forms.

15. Do you agree to provide a statement of significant findings (not more than one page in laypersons terms) to the MOPH Committee when writing your paper/thesis, and to copy such information to participants who request it? Yes I agree.

16. If the study is a part of your requirement for training, list the members of your supervisory committee and their affiliated institutions:

17. I certify that this statement is true. I agree to submit any subsequent changes in study design that bear on living subjects to the IRB for review. I will report to the IRB any concerns brought to me by the study participants about their roles or treatment in the project.

Signed: Shebrena Belle Date 21st June, 2019

(Principle Investigator)

Date jun/21/2019

(Supervisor/Other)

Please submit seven (7) completed forms along with seven (7) copies of the Study Proposal and other relevant documents printed three (3) weeks prior to the Statutory Board meeting which is the 2nd Saturday of every month to:

Dr. Shamdeo Persaud, CMO Chairman, IRB/Ethical Review Committee Ministry of Public Health, Guyana Lot 1 Brickdam, Stabroek GEORGETOWN Guyana

Tel: 592 226 1224 Fax 592 225 6271 E-mail: <u>cmoguyana @gmail.com</u> or <u>cmo@health.gov.gy</u> <u>msmith@health.gov.gy</u>

Appendix

Appendix A

Form of Consent

This informed consent form is for patients diagnosed with chronic kidney disease and their family who we are inviting to participate in a research titled "Construction and validation of an educational technology for patients with chronic kidney disease.

I am Nurse Shebrena Wilson-Belle who work at the Georgetown School of Nursing. I am also a student at the University of Sao Paulo and am doing a research on chronic kidney disease which is non-communicable.

Chronic kidney disease is now a worldwide health problem and it is affecting the Guyanese population in a negative way. Many persons with this condition are admitted many times at the Georgetown Public Hospital Corporation, and their ailment worsens quickly. My research supervisor and I would like to find a solution to this issue and we believe that you can help us by answering a few questions on a questionnaire followed by a short interview that will not exceed 15 minutes. We want to create an educational booklet for persons living with this ailment.

You are being invited to take part in this research because we understand that your contribution is very important in guiding us concerning what information we put into this booklet.

You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me.

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this Hospital will continue and nothing will change.

During the interview, I will sit down with you in a comfortable place at the Hospital. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except my supervisor and me will access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape.

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. However, we do not wish for this to happen. You do not have to answer any question or take part in the interview if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

There will be indirect benefit to you, therefore your participation is likely to help us find out more about how to take care and treat chronic kidney disease in your community

This research being done on your ward may draw attention and if you participate you may be asked questions by other patients in your room. I will not be sharing information about you to anyone except my supervisor. Information about you will have a number on it instead of your name.

You will not be provided any incentive to take part in the research.

I have read the foregoing information/ it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant _____

Signature of Participant _____

Date _____

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant and the individual has had the opportunity to ask questions, I confirm that the individual has given consent freely.

Print Name of witness _____

Thumb print of participant

Signature of witness _____

Date _____

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

Apendix B

Questionnaire

Dear participant, I kindly invite you to answer eleven questions that will take less than five minutes of your time. The objective of this survey is to obtain background information relative to your social and economic status to aid in the construction of an educational booklet for patients living with chronic kidney disease.

The responses obtained will be used to guide the structure of this booklet and will remain anonymous.

To answer questions, please check the box next to the response that best suite you.

Thank you very much for your contribution which will enhance the construct of this educational booklet.

1.	What is your age? 25-30 years old	years old □ old □	36-40 46-50 years) years old □ old □
2.	What is your gender? Male □ Female □			
3.	Please specify your ethnicity. East Indian Afro Guyanese	Amerindian 🛛	Chinese 🛛	Mixed race $\ \square$
4.	What is your marital status? Single, never married Widowed	Married/Comr Divorced □	non law relati Se	onship □ parated □

5. How many people are currently living in your household, including yourself?

6. What is the primary language spoken at home?

7. What is the highest degree or level of school you have completed? If currently enrolled, highest degree received.

Nursery Secondary		Primary □ Tertiary □		
8. Are you currently Employed for A student Out of work a Out of work b	? wages □ □ nd looking for ut not currentl	Self-employed Retired work y looking for work	A homemaker □ □ Unable to work	

9. What is your total combined family income for the past 12 months, before taxes, from all sources, wages, public assistance/benefits, help from relatives, alimony, and so on? If you don't know your exact income, please estimate.

Less than \$40,000	\$40,999 - \$60,000 🛛	\$60,999 - \$80,000
\$80,999 - \$100,000	\$100,999 - \$120,000 🛛	More than \$120,000
Don't know	Chose not to answer D	

- 10. What religious family do you belong to or identify yourself most close to? Hindu □ Muslim □ Christian (Catholic protestant or any other Christian denominations) □ Other, I am not religious (please specify) □
- 11. Do you consider yourself to be committed to your religious teachings? Yes
 No No Not sure