Development of a Plain Language Patient Education Book for Post Transplant Diabetes Mellitus

by

Lisa Joanne Orasanin
B.Sc.N. University of Victoria

A Project Submitted in Partial Fulfillment of the Requirements for the Degree of

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University of Victoria

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Abstract

Post transplant diabetes affects 8 to 36% of renal transplant recipients (Heisel, Heisel, Balshaw, & Keown, 2004; Hjelmesaeth, Midtvedt, Jenssen, & Hartmann, 2001; Kumar, Xio, Fyfe, Sierka, Heifets, & Moritz et al., 2005; Van Duijnhoven, Boots, Christiaans, Wolffenbuttel, & Van Hooff, 2001). A search for patient education material that relates specifically to Post Transplant Diabetes Mellitus (PTDM) revealed a paucity of patient information.

My purpose in this project was to create a relevant patient education book for renal transplant recipients. The perspectives that I used to inform the book included Jean Watson’s Model of Caring (1985) and the Cognitive Learning Theory (Bastable & Doody, 2006; Fleming, 2001; George, 2001). In the development of the book, the following factors were considered, the effects of health and low income on literacy, principles of adult education, plain language guidelines, readability level, and design and layout techniques. Several authors suggested that a grade six reading level for readability, large font, and ample white space be used in patient education materials. These recommendations were considered in the development of the book (Doak, Doak & Root, 1996; Eames, McKenna, Worrall, & Read, 2003; Eyles, Skelly, & Schmuck, 2003; Gal & Prigat, 2004).
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Currently, the Renal Transplant Program at St. Joseph’s Healthcare Hamilton (SJHH) has a paucity of written materials for patients experiencing post transplant diabetes mellitus (PTDM). In this report, I will outline the process of developing a plain language patient education book titled, “A guide for living with post transplant diabetes mellitus” (St. Joseph’s Healthcare Hamilton, 2007) for renal transplant recipients. This book will be used in conjunction with the education offered by the diabetes patient educator (DPE) and other health care professionals at SJHH. I will outline the theories and frameworks that informed the creation of this book, as well as steps taken for completion. I will address some of the ethical considerations that arose during the process of writing and doing the research for the book. In addition, I will detail the evaluative methods undertaken where I attempted to ensure incorporation of a variety of perspectives. Further, I will provide research to detail the health concerns that surround PTDM, the importance of written patient education material and my approach to the project. I will also discuss the affects of low income and literacy on overall health. Finally, I will present an outline of the plan to share this information with stakeholders.

Background

SJHH is a regional, renal transplantation centre in Southwestern Ontario performing approximately seventy kidney transplants a year (Ruaux, 2007). The Renal Transplant Clinic provides ongoing care for another seven hundred past recipients and their support persons (Ruaux). Patients can develop PTDM several years after transplantation. Therefore it is important to consider this when examining the program’s statistics.

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1 For the purposes of this paper, I refer to the “patient” alone. However, it is recognized that the patient may choose to have caregivers and/or support persons participating in his/her teaching-learning process.
2 The word “book” will refer to “A guide for living with post transplant diabetes mellitus” (St. Joseph’s Healthcare Hamilton, 2007).
3 The phrase “health care professional” refers to the physician, nurse, pharmacist, physiotherapist, occupational therapist, social worker, chaplain, or other allied health team members that assist the patient with chronic diseases such as renal failure or diabetes.
Several Canadian and American investigators report that between 8 to 36% of renal transplant recipients develop PTDM as a result of steroid and immunosuppressant therapy used to maintain optimal kidney function post transplantation (Heisel, Heisel, Balshaw, & Keown, 2004; Hjelmesaeth, Midtvedt, Jenssen, & Hartmann, 2001; Kumar, Xio, Fyfe, Sierka, Heifets, Mortiz, et al., 2005; Van Duijnhoven, Boots, Christiaans, Wolffenbuttel, & Van Hooff, 2001).

This particular group of patients did not have diabetes before transplantation. However, in the process of treating one disease (kidney failure), they acquired another chronic illness (diabetes). I discovered that statistics specific to the development of PTDM were not collected at SJHH. I reviewed the referrals to the diabetes service over a two year period and approximately 10% of transplant recipients developed PTDM. To complete this review, I compiled the DPE work sheets that indicated the renal transplant surgery was performed in 2005 or 2006. Then, I further sorted the worksheets into those persons with pre-existing diabetes, and those with PTDM. Sixty-seven renal transplant recipients were performed in 2005, and seventy-two in 2006. The total number of recipients who acquired PTDM immediately post surgery in 2005 and 2006 were fourteen.

I agreed with many authors that a patient’s quality of life is altered when diagnosed with this disease (Gross, Limwattanon, Mathees, Zehrer, & Savik, 2000; Maes, Kuypers, Messiaen, Evenpoel, Mathieu, & Coosemans, et al., 2001). I wanted to create a bridge that connected the verbal communication between the DPE and the patient in the form of a plain language teaching tool and take-home reference.
Current State of the Knowledge about PTDM

*Immunosuppression and PTDM*

Immunosuppression reduces the activation or efficacy of the immune system (Danovitch, 2005). Following a kidney transplant, it is common practice to deliberately induce immunosuppression to prevent the body from rejecting the transplanted organ (Danovitch). One of the most common immunosuppressives is regular administration of a steroid called prednisone (Khwaja, Asolati, Harmon, Melancon, Dunn, Gillingham, et al., 2004; Pascual, Quereda, Zamora, & Hernandez, 2004). However, prednisone has been shown to contribute to the development of PTDM (Danovitch). Alternate immunosuppressive medications used at SJHH include tacrolimus, sirolimus and cyclosporine. These immunosuppressants produce equivalent patient and graft survival, however, tacrolimus has proven to be more potent when used in equal volumes (Danovitch; Khwaja et al., 2004; Matas, Ramcharan, Paraskevas, Gillingham, Dunn, Gruessner, et al., 2001; Woodward, Schnitzler, Baty, Lowell, Lopez-Rocafort, Haider, et al., 2003). Tacrolimus has also been shown to increase the incidence of PTDM (Van Duijnhoven et al., 2001; Woodward et al., 2003). Sirolimus has recently been shown to cause hyperglycemia and new studies are being conducted to verify this fact (Crutchlow & Bloom, 2007; Ratain, Napoi, Knightly Moshier, Jiang, Fleming, Gajewski, et al., 2007).

Another immunosuppressant that increases the risk of PTDM is cyclosporine. However, it is not as commonly used and the incidence of PTDM is much lower when compared to tacrolimus (Boudreaux, McHugh, Canafax, Ascher, Sutherland, & Payne, 1987; Gourishankar, Jhangri, Tonelli, Wales, & Cockfield, 2004; Van Duijnhoven et al., 2001; Woodward et al., 2003).
Approximately 20% of renal transplant recipients have existing diabetes, leaving the remaining patients vulnerable to developing PTDM (Canadian Organ Retrieval Register (CORR), 2006). Variables such as age, race, ethnicity, and basal metabolic rate, history of hypertension and family history of diabetes are commonly identified as risk factors (Van Duijnhoven et al., 2001). In addition, the onset of PTDM is recognized as an increasingly common complication associated with poor graft and patient survival (Gourishankar et al., 2004; Roth, Milgrom, Esquenazi, Fuller, Burke, & Miller, 1989). In a Canadian study, Gourishankar et al. reported an incidence of PTDM of 9.8% with five independent clinical risk factors identified. They included older recipient age, deceased donor, hepatitis C antibody status, rejection episodes, and use of the immunosuppressant medication, tacrolimus. Furthermore, Miles et al. (1998) reported long term outcomes of increased risk of kidney failure in the transplanted kidney and/or death due to sepsis when a person developed PTDM.

**Importance of Glycemic Control**

According to the Canadian Diabetes Association (CDA) (2003), when blood glucose levels are over 12.0 mmol/L, viscosity of the blood may increase. This places extra stress on the heart, kidneys and smaller vessels. When blood glucose is not well controlled, the body must work harder to circulate the blood, thereby increasing the risk of complications such as acute kidney rejection (Miles et al., 1998). Since good glucose control is important in long term graft survival, any method of assisting with comprehension of diabetes management would contribute positively to a person’s quality of life (Danovitch, 2005; Gourishankar et al., 2004). This book is one method to provide the information required to assist with the management of PTDM.
Long Term Implications

Diabetes mellitus (referred to as diabetes in this paper) is a major cause of morbidity and death (Danovitch, 2005; Fallon, Gould, & Wainright, 1997; Miles et al., 1998). PTDM has been shown to produce the same long term complications and consequences as Type 1 and Type 2 diabetes (Kasiske, Vasques, Harmon, Brown, Danovitch, Gaston, et al., 2000; Miles et al.). Researchers have reported that patients with PTDM experience decreased allograft or kidney transplant survival (Boudreaux et al., 1987; Roth et al., 1989). The potential long term complications arising from diabetes are peripheral vascular disease, coronary artery disease, stroke, renal failure, blindness, neuropathy and erectile dysfunction (CDA, 2003; Danovitch). A book that describes how to prevent and delay complications can empower the person to improve his/her quality of life and longevity through lifestyle changes.

Importance of Written Material

In a review of studies examining memory, Kessles (2003), reported that 40 to 80% of the information provided by health care practitioners was forgotten immediately and 50% of the information that patients remember was recalled incorrectly. This is particularly true in some patients who develop PTDM. The emotional and psychological effect of steroids, immunosuppressants, organ transplantation and post surgical discomfort usually necessitates that the person receives repetitive educational sessions as well as reference literature (Prasauskas & Spoo, 2006). Several researchers report that renal transplantation is associated with a number of drawbacks such as constant risk of rejection, complex medication regimens with potential for pronounced side-effects and the need for ongoing medical supervision (Davis & Chesbro, 2003; Fallon et al., 1997; Kasiske et al., 2000).
Many of the studies I reviewed showed that patient education allayed anxiety, enhanced adjustment, adherence, and overall satisfaction with the quality of care and empowered patients in their relationships with health care professionals (Davis & Chesbro, 2003; Eames, McKenna, Worrall, & Read, 2003; Prasauskas & Spoo, 2006). Molzahn (1996) stated that transplant recipients were confronted with learning many survival skills such as monitoring physical parameters and medications. It is the responsibility of health care professionals to provide as many reinforcements as possible to enhance patient comprehension and ultimately, patient safety and longevity (Davis & Chesbro; Prasauskas & Spoo). The book can be used not only as a teaching tool during education sessions, but for reinforcement of information at times when the patient must make health decisions. A book cannot replace human contact. However, when used in conjunction with individual teaching, a health care provider can use this tool to help reinforce previously taught information.

Search for Existing Written Material

Wizowski, Harper, and Hutchings (2006) suggest contacting other health care organizations to determine whether there are existing written patient education materials available (p. 46). To begin my search, I telephoned the Canadian Diabetes Association. The staff confirmed that there was no material related to PTDM available from their organization. Following this, I telephoned the following Canadian organizations to confirm a lack of resources on PTDM. The Kidney Foundation of Canada, Canadian Organ Retrieval Register (CORR), Toronto General Hospital in Toronto, Ontario, the Trillium Gift of Life Network in Toronto, Ontario, and the Multi-Organ Transplant Unit at University Hospital in London, Ontario.

I then telephoned American representatives from the renal transplant units at the University of California in San Francisco, and the St. Joseph Hospital Kidney Transplant Center
in California. These centers did not have specific information on PTDM. Only the National Kidney Foundation provided information available in two pamphlets entitled, “Post transplant diabetes: What every patient needs to know” (2004), and “New onset diabetes: A guide for kidney transplant recipients” (2007). This literature is specific to the United States and a brief overview of the condition is provided in the pamphlets. My evaluation also determined that these handouts did not meet plain language guidelines, left out key messages and lacked flow (Davis & Chesbro, 2003; Houts, Doak, Doak, & Loscalzo, 2005; Prasauskas & Spoo, 2006; Wizowski et al., 2006). This lack of available literature was disturbing, but solidified my decision to fill a gap in services for renal transplant recipients.

Objective

My main objective in this project was to develop a plain language teaching tool (book) in order to enhance communication between the DPE and patients with post transplant diabetes mellitus. A secondary objective was to evaluate the content and use of plain language design principles in the book with members of the health care team and a small sample of patients.

The Education Process

When a patient develops PTDM, the DPE meets with the patient on the renal transplant unit. As part of the nursing and teaching process, the DPE develops a patient-centered relationship with the person during his/her hospital stay. Over several meetings, the DPE delivers information about PTDM using non-technical language in a relaxed setting. Patients (and with the patient’s permission, support persons) have many opportunities to pose questions, process information and learn new skills. However, no written material specific to PTDM is available to refer to after the DPE leaves and/or the patient is discharged. My current practice is to adapt Type 2 diabetes patient education material for home reference. Since print material supports
learning by reinforcing verbal information, use of this book could serve to augment the educational process in this program (Hainsworth, 2003; Lerner, Jehle, Janicke, & Moscati, 2000).

The research findings I reviewed showed that adult learners prefer to know why certain behaviors should be avoided to promote health (Canadian Public Health Association, 1999; Davis & Chesbro, 2002). I have thoughtfully chosen the material for the book based on best practices and patient preferences. Providing written material assists with the ability to look up information at home and can be shared with significant others (Lorig, 2001, 2003; Semple & McGowen, 2002; Sumner, Harper, Ginns, & Powers, 2005). If the DPE is unable to meet with family and caregivers, the book can be used as reinforcement for the patient and education of others. Well written materials can improve a patient’s ability to actively participate in his/her own health care (Nutbeam, 2000; Tankova, Dakovska, & Koev, 2001). Both the delivery of health care services and patient expectations has changed markedly over the decades. Patients are no longer kept in hospital for weeks after the initial diagnosis of diabetes and many are active participants in their own health care management. The book could be used to help solidify the verbal information given to improve the patient and caregiver knowledge base.

Approach to the Project

Figure 1 outlines the steps I used to complete this project. My planning group included my project committee at the University of Victoria as well as the members of the Diabetes Department and the Nephrology and Transplant Patient Education Committee at SJHH. I was also fortunate to obtain expert opinions from two Patient Education Specialists at Hamilton Health Sciences in Hamilton, Ontario.
Figure 1. Steps to developing the book, “A guide to living with post transplant diabetes mellitus” (SJHH, 2007)

1. Establish a planning group
2. Assess available materials
3. Identify the purpose and patient population
4. Decide on the content
5. Write the first draft in plain language
6. Apply clear design
7. Obtain feedback from the clinical team for accuracy
8. Obtain feedback from patients and significant others
9. Clarify changes with clinical team and patients when needed
10. Produce material
11. Use the material and notify other transplant centers for distribution
12. Consider new directions for dissemination of information such as the internet
13. Evaluate and revise material as new data emerges

Since my planning group was established, and the population identified, the next step was to perform a literature search. Some of the aspects such as rationale for the project, target population and health concerns have already been outlined in the introductory pages. The following discussion is the review of the research literature.

**Literacy**

In order to create a solid foundation for the book, I chose to investigate how literacy impacts written patient education material. A review of the literature revealed a plethora of disturbing information on literacy in Canada. According to the Adult Literacy and Life Skills (ALL) Survey (Statistics Canada, 2005), four out of ten Canadians or nine million people, age sixteen to sixty-five, struggle with low literacy. Considering those adult Canadians with low literacy, 15% have serious problems dealing with any printed materials and an additional 27% can only deal with simple reading tasks (Statistics Canada). The numbers become even more alarming for immigrants. According to the International Adult Literacy and Skills Survey (IALSS), 60% of immigrants show low literacy as measured by English comprehension, compared with 37% of native-born Canadians (Statistics Canada).

In the ALL Survey (2005), the minimum education required to be considered literate was a reading level of grade eight. This survey used five levels to categorize literacy. Level one included people who were unable to read and Level five were people who demonstrated a command of higher-order information-processing skills. People who did not achieve Level three were deemed to have low literacy. Level three consists of people who can use reading materials provided it is simple, clearly laid out and the tasks involved are not too complex.

Low literacy is found among all groups of people. A person’s educational grade level achievement is not an accurate gauge for reading ability (Canadian Public Health Association,
n.d.; Cotugna, Vickery, & Carpenter-Haefele, 2005). This is important to note since a person’s account of achieved grade level can often lead the educator to making assumptions about his/her ability to comprehend (French & Larrabee, 1999; Schwartzberg, 2002). Some people have lower literacy skills through no fault of their own, since education may not have been as available or necessary many decades ago (Baker, Gazmararian, Sudano, & Patterson, 2000).

At SJHH, renal transplantation is performed in people up to the approximate age of seventy, depending on health status and co-morbidities. This means special care must be taken to assess each person’s ability to read and understand the instructions regarding diabetes management (Canadian Public Health Association, 1998; 2002; Health Canada, 1999). Baker et al., (2000) in their study about the association between age and health literacy among elderly persons, showed that functional health literacy was markedly lower among older age groups. There remained some question whether this was a result of a decline in cognitive function or the quality of available education in the mid 1900s. There are numerous implications of this information for my practice as a DPE. For example, I need to be aware of the many factors that might contribute to a person’s ability to understand instructions regarding diabetes management.

French and Larrabee (1999) found that a person with an adequate literacy level has a higher knowledge score pertaining to diabetes management compared to a person with inadequate literacy scores. For French and Larrabee a reading level of grade eight or higher equated to an adequate literacy level. A patient who has to learn the intricacies of renal transplant management has the additional burden of learning about another health issue, PTDM. This can be stressful for any patient and might be unachievable for the person who cannot read or understand instructions well.
A patient can also mask his/her inability to read or understand by using such excuses as, “I forgot my glasses”, or “I have a headache”, or “Can I take this home to read later?” It can be embarrassing to admit to low literacy skills (Bass, Wilson, Griffith & Barnett, 2002). I have written the book for patients who can read English around a grade six level. It is beyond the scope of this project to provide alternate means of providing information about PTDM. However, some avenues to pursue in the future could include video presentations, audio tapes, and group education sessions.

Health and Literacy

In a review of the literature, I found that low literacy levels contribute to poorer health outcomes (Canadian Institute for Health Information (CIHI), 2004, 2006b; French & Larrabee, 1999; Schillinger, Grumbach, Piette, Wang, Osmond, & Daher, 2002; Serxner, 2000; Shalla & Schellenberg, 2001). Patient education material needs to be written so the majority of the population is able to comprehend the information and instructions (French & Larrabee). In a study by Wolf, Davis, Shrank, Neuberger, & Parker (2006), the researchers found that two-thirds of preventable adverse events were drug-related, and the majority of these were attributed to a lack of communication or comprehension. They concluded that reading level of text in medication guides should be reduced, summaries provided, and the scope of information limited. They predicted that these enhancements could increase the likelihood of proper use among people with limited literacy. This finding was echoed in a further study by Wolf, Davis, Tilson, Bass III, & Parker (2006). I incorporated these recommendations into the book. Readability, layout, font, and graphics will be covered in more detail in the readability section of this report.

It has been found that Type 2 diabetes patients with poor health literacy have worse glycemic control and higher rates of complications such as retinopathy than those with adequate
health literacy (Schillinger et al., 2002). Therefore, I wanted to make sure that the information presented in the book addressed glycemic control in a clear, understandable manner. Adequate glycemic control contributes to overall health when managing diabetes (CDA, 2003). I have included information on high and low blood sugar treatment as well as a list of resources to contact for help to assist the reader to base decisions on current CDA recommendations (SJHH, 2007, p. 87).

Low Income and Literacy

There is a direct correlation between low income status and literacy (CIHI, 2004; 2006a; 2006b; Federal Provincial, and Territorial Advisory Committee on Population Health, 1994; Federation of Canadian Municipalities, 2003; Rapheal, Bryant, & Curry-Stevens, 2004; World Health Organization, 1997). Shalla and Schellenberg (2001) clearly established a link between literacy and economic security, showing that Canadians with weaker literacy skills are more likely to be unemployed, work in lower-paying jobs and live in low income households. Compared to those who are literate, the findings from this study also point to a connection between economic security and the practice of literacy. Adults living in low income households receive less job-related training and education, and engage less frequently in activities (both on the job and in the home) that favor the development of literacy abilities (CIHI). Close to 50% of adults with low-level literacy live in low income households, compared with only 8% of those with high-literacy skills (Shalla & Schellenberg).

According to Statistics Canada (2006), compared to Ontario, a substantially higher proportion of the population in the city of Hamilton lives below the low income cut-off (18.8 % in the City of Hamilton versus 13.6 % in Ontario). This is true for all age groups but is worse for those aged seventy-five and over. The low income cut-off is defined as spending 20% or more on
food, shelter and clothing. These statistics tend to be reflected in the cross-section of people I meet in the Kidney and Urinary Program. This shows why it is so important to ensure the readability of the book is as low as possible for increased chance of comprehension. I discovered that many authors recommended the reading level be between grade six and grade eight and I have chosen to aim for the lower end of these suggestions (Cotugna et al., 2005; French & Larrabee, 1999; Gunning, 2003; Johnson & Stern, 2004; Paul, Redman, & Sanson-Fisher, 2003; Shah & Sill, 2007).

Shillinger et al. (2002) found that inadequate health literacy may contribute to the disproportionate number of diabetes-related problems among disadvantaged populations. Since Hamilton is home to a larger number of low income people, I have surmised that this translates into a higher percentage of the population that may develop diabetes-related complications.

It is apparent that together low literacy and low income adversely affect health. By aiming for a lower threshold of a grade six reading level, I considered these factors when designing the book to give people who may be at a disadvantage an opportunity to be participants in their own health outcomes. In addition, there is no cost to patients for the book.

Frameworks for the Project

The concept of learning is complicated and multifaceted (Fleming, 2001). For example, Joyce and Weil (1996) present 80 different models and theories of learning. As a result, it was difficult to decide what framework was the most appropriate for the development of the book. Recently, several authors have presented their interpretations of what theoretical perspectives can inform print materials (Fleming, 2001; Wilson, Mood, Risk, & Dershaw, 2003). Some theories and models explored include Cognitive Learning Theory (Braungart & Braungart, 2003; Wilson & Williams, 2003), Orem’s Self-Care Deficit Theory (Braungart & Braungart, 2006; Orem,
1971; Taylor, 2002, Taylor, Renpenning, Genden, Neuman & Hart, 2001), Humanistic Learning Theory (Braungart & Braungart, 2003), Health Promotion Model (Becker, 1990; Jayne, 1996; Richards & Sayward, 2006), Health Belief Model (Prohaska & Lorig, 2001; Richards & Sayward), Self-efficacy Model (Clark & Dodge, 1999; Prohaska & Lorig), and Watson’s Model of Caring (Glasgow & Morris, 2005; Watson, 1985, 1990, 1999, 2005). It became clear to me during this review that the manner in which written material is conceptualized and developed does not always fall neatly into one framework.

My purpose in this project was to help each person affected by PTDM to acquire knowledge about living with the condition. I was unable to find a single theoretical approach that fit all of the requirements of the book. Therefore, I decided to merge two perspectives by integrating the appropriate concepts from each. I chose to combine aspects from Jean Watson’s (1985) Model of Caring with particular sections from the Cognitive Learning Theory (Bastable & Doody, 2006; Fleming, 2001).

Watson’s Model of Caring

Watson’s Model of Caring is a broad conceptual model that guides human care concepts in the nursing profession (Jesse, 2006; Glasgow & Morris, 2005; Watson, 1985, 1999, 2005). The metaparadigm concepts, human being, health, nursing, and environment meld with the basic theme that caring is central to the professional discipline of nursing (Walker, 1996; Watson, 1990). Without Watson’s theory, the book may have lacked the human touch that I believed was needed for a truly collaborative learning experience. I studied elements of her model and integrated them into the language, style, and layout for a more interactive and collaborative experience.
**Carative factors.** Watson’s theory (1985) is based on the action of caring. Caring is relayed throughout the book with the use of wording, relevant information, and presentation. Part of Watson’s theory (1985) addresses ten carative factors. For the purposes of the development of the book, the seventh was the most relevant. There is a list of the ten carative factors located in Appendix A. In the seventh carative factor, Watson states that engaging in a genuine teaching-learning experience is essential to the caring approach (Jesse, 2006).

Watson (1985) describes the interaction between nurse and patient as fundamental. She also claims that the goal of the nurse is to help the patient explore the meaning of his/her health-illness experiences. It is important to note the book is a tool to be used by the DPE as an adjunct to patient teaching. This book is not intended to replace the relationship that is formed between a health care provider and patient. Rather, the book provides a hard copy of health issues discussed during the nurse-patient relationship.

Watson (1985) also describes the patient’s subjective world by the openness to self-discovery, participative learning and accessing external resources. I have applied these tenets to the approach for the book. I took into consideration the possible social, cultural, economic, and emotional perspectives the person might experience when developing PTDM. I then applied these concepts to the book so he/she might find answers to some common health concerns that surface in this population. I have compiled a list of the common health issues addressed by patients over my tenure as a DPE and put them in a format to be shared with others. I will discuss the cultural approach later in the paper.

**Assumptions.** There are several assumptions that underpin the foundation of the caring-healing paradigm (Watson, 1985, 1990). The first one that applies to this project is that caring results in the fulfillment of certain human needs. When people agree to surgery that places a
foreign organ in their bodies, many emotions might surface such as excitement, fear, guilt and apprehension. These emotions can be augmented by the additional diagnosis of PTDM. My goal is for the patient to read the book and feel comforted with the knowledge that the diabetes team cared enough to address some of the common issues he/she has encountered. This is also why patient feedback was so important to the foundation of this book.

The second assumption of this paradigm is that caring can promote health and personal/family growth (Watson, 1985, 1990). Many of the issues addressed in the book pertain not only to physical concerns, but emotional and financial. Through my research for this project, I have learned that connecting with the reader through conversational language, and distilling information can assist with comprehension, buy-in, and potential behavioral changes that benefit health.

The third assumption is that caring develops human potential while still allowing the person to choose the best action for him/her at that given point in time (Watson, 1985, 1990). I have ensured that the language in the book does not demand certain behaviors of the reader. The information is suggestive, but does not place guilt. I have purposely minimized references to the potential complications of diabetes so the reader is not inundated with negative messages that might hinder behavior change. The resulting discussion of this decision is outlined in the evaluation section.

The final assumption that I would like to discuss is that caring is central to nursing (Watson, 1985, 1990). Watson (1999, 2005) has created her entire paradigm around this belief and it is thought to be the essential component to the nursing profession (Rawnsley, 2000; Reed, 2000). I have threaded messages throughout the book that offer a list of health care providers
with whom the reader can speak to address areas of concern. I believe this shows the reader the book is not meant to be the final word.

*Humanistic value system.* Watson (1985) emphasized a humanistic value system as the foundation of the philosophy. I integrated several of these values into the book. The first is recognizing the power of humans to grow and change (Watson). I wrote the language to emphasize the positive yet realistic behaviors expected with diagnosis of PTDM. For example, when I outlined some suggestions for increased activity, I provided a list of realistic activities for the average person. This book is aimed at the person who has been dealing with the chronic disease of renal failure. In some instances, the person may not be feeling well enough to be physically active. In many cases, the person received hemodialysis or peritoneal dialysis treatments regularly and his/her stamina was severely limited. Most health care professionals understand that incorporating activity into the patient’s life can be challenging. The suggestions for activities in the book are gardening, taking the stairs, or doing housework. It would be unrealistic to list jogging as a doable activity for this population. I also graded the level of activity for people who use insulin according to the intensity. This is so the reader can personally judge the type, intensity and duration of the activity that aids in the prevention of hypoglycemia.

The second value outlines how the nurse can try to understand how a patient is perceived as well as how the patient experiences illness (Watson, 1985). I omitted the word “must” and ensured the language was not all-encompassing. An example of this is, “Some people feel all of these symptoms. Some people do not feel any.” (SJHH, 2007, p. 23). If the statement read, “these are the symptoms of hypoglycemia” it could leave readers concerned if they do not exhibit any signs, or think they must have all of the signs listed before treating a low blood sugar.
The final value is the emphasis on self-care and recognizing the nurse as a co-participant (Watson, 1985; Watson & Smith, 2000). No health care provider can dictate or ensure behavior change. The person who has developed PTDM is in control of his/her own behavior. I want the message in this book to relay that the reader has the support of the nurse and health care provider, but ultimately, it is his/her decision to learn how to manage diabetes. An example of this integration is in a “remember” box where I state, “there are many members of the team who can help” and, “your diabetes nurse supports you as you learn new skills” (SJHH, 2007, p. 6). By using the term “your” diabetes nurse, I am personalizing the message that the reader has someone to call for questions.

Watson (1985, 1999, 2005) outlines the nurse/patient relationship as the nurse attempting to enter into and stay within the other’s frame of reference where together, they join in a mutual search for meaning. The person is viewed as whole and complete, regardless of illness or disease. Messages of hope, encouragement, and collaboration are threaded throughout the pages. I placed emphasis on the fact that the person has done nothing to induce development of PTDM and that it happened because of an unfortunate side-effect of the immunosuppressive medications. I wrote the book to contribute toward this nursing goal and addressed many of the common questions that I have compiled during my tenure as a DPE. The reader has a factual account of knowledge and behaviors that are specific to his/her health issue. The person can then elaborate on any additional concerns that are outside the scope of the book during his/her meeting with the health care professional. This enables the health care professional to learn more about what specific perspectives of health and healing is important to this person. I believe it will also help with revisions to future publications.
Cognitive Learning Theory

I chose to blend some of the concepts of Cognitive Learning Theory with Watson’s (1985) Model of Caring. This enabled me to incorporate the self management approach to health in the development of the book. A person may spend a short period of time with a DPE and an even shorter time with a physician therefore, self management can contribute to overall health (Gucciardi, Smith, & DeMelo, 2006). Safe diabetes management requires skills in many areas such as diet, medication, and activity (CDA, 2003). This can be a steep learning curve and overwhelming to some people and caregivers. Cognitive Learning Theory outlines the many ways that a learner absorbs information and how it can be best presented.

Dimensions of learning. Overall, the Cognitive Learning Theory is concerned with the learner’s perceptions, thoughts, memory and ways of processing and structuring information (Bastable & Doody, 2006; Fleming, 2001; George, 2001). Developers of the theory propose three dimensions of learning; cognitive (knowledge and information), affective (attitudes and values) and psychomotor (skills and performance) (Bastable & Doody; Rankin, Duffy Stallings, & London, 2005). The belief is that learning in these three areas results in a change in behavior. I believe that if the concepts are integrated with a more human approach, such as Watson’s Model of Caring, it can lead toward empowerment through knowledge.

Cognitive domain. The cognitive domain is the process of gaining knowledge and facts (Bastable & Doody, 2006). This can be done using written material to present facts so the reader may consider this information at the time of reading or to return to later. It is essential to provide current, evidence based information for the appropriate acquisition of knowledge. As Rankin et al. (2005) suggest, words such as “define”, “list”, “match”, “sort”, “outline” and “compare” should be used to achieve the knowledge component (p. 203). I created learning activities
throughout the book to help the reader exercise his/her cognitive abilities. An example of one activity is, “Here are 3 blood sugar tests using a meter. Check the one that is the best number for a target blood sugar” (SJHH, 2007, p. 19).

**Affective domain.** The affective domain is the ability of the person to develop an appreciation of the benefits and value of the information. The research results I found showed that written materials did not facilitate this aspect of learning. Instead, written material helped support verbal communication (French & Larrabee, 1999; Gunning, 2003; London 1999). However, some techniques are used in written materials to help the reader achieve this domain of learning. Rankin et al. (2005) wrote that writing objectives that contain words such as “describe”, “arrange”, “choose”, “practice” and “label” fall into the affective domain (p. 203). I have applied this idea when writing the objectives for the book in order to facilitate assessment of a patient’s retention of the information. These are specific, measurable behaviors that outline exactly what is expected of the reader.

**Psychomotor domain.** The psychomotor domain refers to focusing on developing skills that demonstrate application of the cognitive and affective domain. Glasser (1965) divides skill learning into three phases, the cognitive phase, the fixation phase and the autonomic phase (Gleit, 1998). In the first phase, the reader tries to understand the broad picture of what the task or skill involves (Gleit). The content of written material can certainly relay this type of message (Houts et al., 2005). An example of the psychomotor domain in the book is on page 33 subtitled, “If your blood sugar is less than 5.0 mmol/.” This part continues on to detail the exact steps to take when treating a low blood sugar.

Fixation involves mastery of the steps through practice. Writing clear instructions is one method used to attain fixation. The activities and super quiz in the book can help the reader
assess his/her knowledge. The DPE can use this tool to identify any gaps in knowledge. The reader could use the book as a reference when practicing the steps described.

Reaching the autonomic phase means that the skill can be performed without conscious attention (Boyd, Graham, Gleit, & Whitman, 1998). Written material can help since “this phase involves a gradual period of time, perhaps years” (Glasser, 1965, p. 182). Since a patient might not be able to access an educator to review the steps in a timely manner, written material can serve as a reminder of how to perform the skill.

I believe the application to the book of the basic tenets of the Cognitive Learning Theory in combination with Watson’s Model of Caring (1985), satisfies the intellectual, behavioral and human aspect of teaching and learning. While the Cognitive Learning Theory has been researched and tested for efficacy and receptiveness with much success, the Model of Caring can add the human touch that is often missing in health literature (Boyd et al., 1998; Glasser, 1965).

I created an image (Figure 2) that depicts the intertwining of the Cognitive Learning Theory with Watson’s Model of Caring (1985). The patient is represented in the middle of the visual model indicating he/she has access to all of the aspects of a caring, healing, teaching and learning approach. The dimensions of learning are shown with a broken line to represent the opportunity to move through the cognitive, affective, and psychomotor domains freely. The process for developing written patient education materials surrounds the patient and his/her ability to absorb the information with a wavy line. This depicts the nurse’s responsibility to attend to readability factors such as formulas, wording, relevance, personalization, and content flow. This also includes font, graphics, behavioral objectives and evaluation for effectiveness.

Finally, the outermost circle shows the overall concept from Watson’s Model of Caring (1985) through caring, healing, teaching and learning. The wavy line between the patient and
these tenets continues the idea of fluidity in the relationship between the patient and the nurse. The dotted lines between the four concepts indicates the ability to move back and forth through each aspect, recognizing that situations change and may need a new approach.
Figure 2. Visual diagram of Watson’s (1985) Model of Caring with Cognitive Learning Theory
Behavioral Objectives

In order for patient education literature to have meaning, behavioral objectives are recommended (French & Larrabee, 1999; Rankin et al., 2005). A behavioral objective refers to the intended result of instruction, not the process of instruction itself (Barlow, Bancroft, & Turner, 2005; Bastable & Doody, 2006; French & Larrabee, 1999; Rankin & Duffy Stallings, 1996). A good behavioral objective describes who does what, when, and how the information is presented. It is a specific map of exactly who will present the information, in what format, in what period of time, and with what method (Rudd, 2002). When objectives are clearly stated, readers know their roles and expectations therefore they can concentrate their energy on learning (Anderson & Funnel, 2000; Gucciardi et al., 2006; Rankin et al., 2005; Rudd).

It became evident that the book required behavioral objectives in order for the reader to understand why he/she would want to read further. I performed a literature search to learn how to write behavioral objectives so they would be best understood by both the reader and the health care professional. I discovered that using specific language to describe what was expected of the reader was important for both the reader and writer to measure learning (Bastable & Doody, 2006; Mager, 1997). Some examples of the terminology suggested are “to write”, “to solve”, “to list” and “to state” (Bastable & Doody, p. 297). These are measurable outcomes that both the reader and teacher can use to evaluate his/her progress (Doak, Doak, & Root, 1996). The language that Bastable (2003) recommends one should avoid using included “to know”, “to understand”, and “to realize” (p. 297). She argues the reason behind this suggestion is that it is difficult to measure how much a person knows, understands, or realizes.

Watson (1985) does not use the words “behavioral objective” to guide the learning process. She calls these “ends-in-view” because she believes that the nurse cannot plan what a
patient will learn. There are often inadvertent learning experiences from a planned lesson. Watson’s Model of Caring is supported by the basic value of self-care that indicates the nurse’s goal is to promote independence. Behavioral objectives outline what the patient can expect to learn. However, the person can seek further clarification or additional time with the DPE to expand on these objectives. For the purpose of this discussion, I will use the term “behavioral objective”.

**Characteristics of a Behavioral Objective**

Robert Mager (1997) wrote that the three important characteristics of behavioral objectives are performance, condition, and criterion. He defines performance as describing what is expected of the learner and what kinds of behaviors the teacher will allow as acceptable. The behavioral objectives in the book outline exactly what information the reader can expect to learn. Each topic is divided into parts and concentrates only on the information that pertains to that topic.

Condition is the situation under which the behavior will be observed or what performance is expected to occur (Bastable, 2003; Mager, 1997; Maier-Lorentz, 1999). I wrote each behavioral objective to match an evaluation tool or quiz at the end of each chapter. For example, “After reading this section, you will be able to pick the part of the body that makes insulin” (SJHH, 2007, p.11) goes with “The Matching Game” (SJHH, 2007, p. 17).

The final criterion is how well the learner must be able to perform the behavior to be considered competent. I wrote each behavioral objective so the patient can read the expectations required to be considered competent in the task or knowledge base. An example is, “After reading this part you will be able to put the steps for how to manage low blood sugar in the correct order” (SJHH, 2007, p. 29) matches “The Right Steps” (SJHH, 2007, p. 41).
RUMBA is a common approach to writing behavioral objectives. RUMBA stands for: realistic and reasonable; understandable, measurable, behavioral (behavior that can be observed), and achievable (Doak, Doak, & Root, 1996; Winslow, 2001). I ensured that each of the behavioral objectives followed these guidelines. All of the behaviors described in the book are necessary to keep the person safe. An example of this is reading how to recognize the signs and symptoms of a low blood sugar. I employed plain language techniques and readability guidelines to make each behavioral objective clear. Instead of using medical jargon such as “hypoglycemia”, I used the phrase, “low blood sugar”.

It also became evident that if I was including behavioral objectives, it was important to implement an evaluative component to the book. This led me to create a post test for each section of the book that specifically addressed each behavioral objective. I decided to use a variety of puzzles, word finds, and fill in the blanks so the reader was not limited to one type of format. I also created a final super quiz that consisted of multiple choice questions and incorporated the key messages of the entire book.

The behavior is observable in that once the reader has completed the post test activities he/she can identify weaknesses and review the chapter. The DPE can also ask the patient to demonstrate or voice the information from the book to show competency.

Plain Language Guidelines

Once I decided on the theoretical perspectives to inform my thinking about patient education and, therefore, the development of the book, I considered adult learning principles and the application of plain language guidelines such as readability level and formulas, design and layout techniques (Davis & Chesbro, 2003). I will discuss each of these areas individually.
Readability Formulae

I compiled data about diabetes management after renal transplantation and employed readability tools to ensure that my initial goal of creating a useful patient education book would attain recommended literacy levels of grade six to grade eight. Readability formulas are objective tools that estimate the reading difficulty of a passage (Beaver & Luker, 1997; Meade & Smith, 1991; Serxner, 2000; Wilson & Williams, 2003). It is important to note that none of the available formulae consider factors such as format, layout, complexity of the subject, or reader interest (Wilson & Williams).

Some of the readability formulae include the Simple Measure of Gobbledygook (SMOG), Fry, Flesch, the Maine Area Health Education Center (AHEC) assessment checklist, and Gunning FOG (Beaver & Luker, 1997; Flesch, 1948; Fry, 1968; Gal & Prigat, 2004; Gunning, 1969; Wilson & Williams, 2003). Research has shown that these tools are considered to be highly correlated when used on the same sample. In addition to their validity, they are also considered to be quick and easy to use (Beaver & Luker; Cotugna et al., 2005; Foltz & Sullivan, 1996; Meade & Smith, 1991; Sand-Jecklin, 2007). Researchers do caution users not to overemphasize reading level scores and overlook other factors that can affect the ability to read such as motivation, interest, needs, culture, acute versus chronic illness, physical limitations, and cognitive limitations (Beaver & Luker; Meade & Smith; Sand-Jecklin). In addition, they recognize the margin of error might be as much as two reading grade levels (Foltz & Sullivan; Meade & Smith; Sand-Jecklin).

I analyzed the book at the beginning, middle and end stages of development using the FOG Readability Index. I took passages from the three places in the book to check readability. These passages were located at the beginning, middle and end of the book to ensure a broad
spectrum of representation. Appendix B depicts the initial draft result, Appendix C, the mid draft result and Appendix D, the final draft. The initial drafts showed a reading level between grade nine and eleven. It was evident some changes were required so with attention to trimming larger words and shortening sentences, I was able to lower the reading level to grade six. The Patient Education Specialists in the Hamilton area use the FOG Readability Index since they have found this to be the most accurate tool to assess the patient education materials that are developed. Taking into account the possibility of a two grade error margin, the book still remains within recommended guidelines of between grade a six and grade eight reading level (Paul et al., 2003; Wilson & Williams, 2003).

Readability

Readability and reading level are equally as important, but entirely different concepts. Readability is the ease with which readers are able to understand the text. Thus, a person reading at the eighth grade level may be able to recognize all the words in a brochure but may have difficulty understanding the content because of the way it is written (Eames et al., 2003; Estey, Musseau, & Keehn, 1994; Johnson & Stern, 2004; Singh, 2003). There are several different aspects, in addition to writing style, that affect readability such as wording, layout, font and graphics (Eames et al.). I will address each aspect individually.

Wording. In order for patient education handouts to be readable, they must be relevant, personalized, and the content should flow in a sensible manner (Comerford Freda, 2005; Mumford, 1997; Sand-Jecklin, 2007; Wilson & Williams, 2003). Several researchers revealed that terminology is important to comprehension, and medical jargon should be avoided whenever possible to enhance material readability (Cotugna et al., 2005; Estey et al., 1994; French & Larrabee, 1999; Gal, & Prigat, 2004; Lake, Speed, Brookes, Heaven, Adamson, & Moynihan,
2007; Sand-Jecklin). I changed several of the words to more acceptable and understandable terms. Some examples were changing “physician” to “doctor” and “glucose” to “sugar”.

In a study by Mayer (2004), it was concluded that all of the participants preferred a book that was easy to read. Even people with higher reading levels liked simple material. This solidified my decision to make the terminology as basic as possible. Mayer stated that patient education materials should focus on all components of readability, including typography, and ensure that people can read the typeface and font size clearly. People and their caregivers are usually challenged by the stress of diagnosis, the physical deficits of the medical problem or disease and shorter hospital stays in which to grasp the information (Lorig, 2003; Singh, 2003; Winslow, 2001). I believe that attending to the presentation makes the book easier to read and more relevant to the reader.

Relevance. The process of finding only the pertinent information and wording for the general public was challenging. The purpose of the book was to create a reference tool for the patient who developed PTDM so many of the common questions were answered. There were many interesting pieces of information that I wanted to cover however it became clear that I could not include everything. One example is that I wanted to include a conversion chart that explains a hemoglobin A1c (a measure of a patient’s blood sugar average over three months), which is shown as a percentage, and it’s relationship to blood glucose, which is shown as mmol/L. Patients often confuse the blood sugar reading on their glucometer with the percentage value of a hemoglobin A1c and I have found that a conversion chart helps them understand more clearly. I was not able to create a satisfactory duplicate of the conversion chart, so I elected to omit it from the book and I will revisit this idea for future revisions.
I threaded some of the most important facts throughout the book as a review. For example, blood sugar targets are mentioned three times in the book to reinforce the guidelines recommended by the CDA (2003). This is an important message that is integral to blood sugar management and therefore highly relevant.

Personalization. The messages in the book are personalized by including the reader in the conversation. Some examples are, “How do I get rid of used lancets and needles?” (SJHH, 2007 p. 69) and “This book helps you learn how to control diabetes” (SJHH, p. 1). This employs the technique of writing in an active voice and conversational style that research has found to increase readability (Doak, Doak, & Root, 1996; Eames et al., 2003; Lake et al., 2007; Lewis & Newton, 2005; Wilson & Williams, 2003).

Content flow. I chose the content based on recommendations by the CDA (2003), personal experience, and documented patient concerns. I discovered that following the rules of grammar and syntax were important to improve readability as well as reliability of the content. The reader might question the content if there were errors in grammar and use of words (Comerford Freda, 2005; Eames et al., 2003; Lake et al., 2007; Lewis & Newton, 2005; Wilson & Williams, 2003). I took the time to carefully read each part and look for grammatical errors, use of the same descriptive words, and flow. I rearranged parts based on the logical order of reading. For easy reference, I have included an index that informs the reader about where to locate the specific part he/she might be interested in covering for easy reference. I also began the book with a brief outline of how the content is laid out and instructions on how to use the book. Several stakeholders have reviewed the book and I have made some additional revisions, a process I will outline in the evaluation section of the paper.
**Layout.** The aspects of layout that improve the readability of patient education material are the use of white space, text spacing, organization, and visual appeal (Anderson, Satterfield, German, & Anderson, 1996; Beaver & Luker, 1997; Doak, Doak, & Root, 1996; French & Larrabee, 1999; Gal & Prigat, 2004; Johnson & Stern, 2004). In a review of numerous patient education leaflets, I noted the use of these layout techniques and chose to implement the recommended aspects of layout for the book. I ensured ample white space, line spacing of 1.5 lines and wide borders. I also followed the suggestion by Gal and Prigat to limit the number of characters to between 30 and 50 per line. They also suggested avoiding “widows” or short words such as “I” at the end of a row. This is based on the premise that sentences should not start at the far right-hand side of the page (Gal & Prigat).

Sand-Jecklin (2007) surmised that the learner had to believe he/she could read the teaching material since a page of solid text may, just by its imposing appearance, discourage the reader. In this book, there is ample white space and the large font increases the readability for those with visual impairments.

Doak, Doak, and Root (1996) recommended that content be broken up by short, clear headings. Lists should be separated into chunks, each with subheadings. I applied these recommendations throughout the book by ensuring each change in topic began with a new chapter or “part”. The behavioral objectives indicate a new subject and the activities delineate the end of a subject. This technique helps the reader to find the beginning and end to a part. I was cognizant of these layout techniques to make it easier for the reader to follow the flow of information and de-clutter the learning experience.

**Font.** Research has shown that Serif Font, Times, Times Roman and Arial are easier to read than other more showy fonts such as Helvetica, Universal, and Geneva (Beaver & Luker,
Although some researchers recommend using a 12 to 14-point font, I chose to use Arial in a 16-point font based on a patient survey conducted by Paula Eyles, Clinical Nurse Specialist in Patient Education, in the Kidney and Urinary Program (Beaver & Luker; Doak, Doak, & Root, 1996; Eyles, 2007; Fisher, 1999; Kubba & Phil, 2000). This survey showed that seventy percent of people preferred a size 16-point font for patient education literature. Results of this survey are shown in Appendix E.

It is also recommended that no more than six font styles be used in one document, that both upper and lower case be used, and that unnecessary capitals and italics be avoided. Key points can be underlined, bolded or larger font, or shown in color for emphasis (Beaver & Luker, 1997; French & Larrabee, 1999; Gal & Prigat, 2004; London, 1999). I chose to use only one font and drew the reader to important sections through use of font size, bolding and boxing messages.

*Graphics.* Graphics play an important part in relaying a message with simplicity and appeal (Eyles et al., 2003; Lewis & Newton, 2005; Mayer, 2004). Doak, Doak, and Meade (1996) suggest using illustrations not to decorate, but to teach. The message should be instantly clear. The use of captions offers an additional teaching opportunity. I chose to use both hand drawn and photographic illustrations to make a visual connection to the information on the page. For example, the target is connected with the recommended target blood sugar levels and is repeated three times throughout the book for emphasis. Repetitions of certain graphics relay an instant message that supports the text. Due to financial restrictions, only the front cover can be printed in color, therefore, I am not able to use color to emphasize graphic messages. The illustration on the front cover is explained in detail in the section of this paper titled “Ethno-cultural Considerations”.
I also made revisions to the pictures shown for the final book based on evaluations from stakeholders. This included more use of photographs of real people to relay messages instead of cartoon images. The evaluations were important for gaining a variety of perspectives.

Evaluation

It is suggested in step seven in the approach to the project (Figure 1) that obtaining feedback from the clinical team for accuracy is important (Wizowski et al., 2003). Some of the many health care professionals that assist with diabetes management include physicians, DPEs, dietitians, pharmacists, occupational therapists, physiotherapists and social workers. In an effort to create patient education material that included all of these disciplinary perspectives, I sent the first printed draft of the book to a sample of stakeholders with an evaluation sheet to complete. These allied health team members reviewed the book for content and presentation. An example of the checklist for patient education material evaluation form is found in Appendix F. I have outlined the results from the checklist for patient education material evaluation form in Appendix G.

I was also fortunate to be mentored by Paula Eyles, Clinical Nurse Specialist, Patient Education at SJHH, Hamilton, Ontario. Two of her colleagues, Lindsay Wizowski and Theresa Harper, both Patient Education Specialists, at the Hamilton Health Sciences Centre reviewed the book from a readability perspective. Wizowski and Harper, along with their colleague, Tracy Hutchings, authored a book titled, “Writing health information for patients and families: A guide to creating patient education literatures that are easy to read, understand and use” (Wizowski et al., 2006). They were given the checklist for patient education material evaluation (see Appendix F) as well as the Suitability Assessment of Materials (SAM) scoring sheet (see Appendix H) with
instructions for use (Doak, Doak, & Root, 1996; Wizowski et al.). The results from the SAM scoring sheet are detailed in Appendix I.

SAM is an evaluation tool that has been validated with 172 health care providers from several ethno-cultural communities (Doak, Doak, & Root, 1996). The communities included South-east Asian, Native American, and African American as well as students and faculty from the University of North Carolina School of Public Health and Johns Hopkins School of Medicine (Doak, Doak, Miller, & Wilder, 1994). Doak, Doak, and Root state that, “the application of SAM can pinpoint specific deficiencies in an instruction that reduce its suitability” (p. 49). I used this tool during the development of the book in order to correct any deficiencies that were noted by the evaluators. A complete description of the steps used to implement the SAM evaluation tool is outlined in Appendix J. I used SAM along with the checklist developed by Wisowski et al. (2006) since the SAM assessment tool has been validated on a large scale (Doak, Doak, & Root). The checklist developed by Wisowski et al. has not been validated through research. My rationale was to strengthen the validity of the evaluations performed by the experts.

Researchers recommend that if possible, patients who are going to be using the materials should be involved in the revision process (Gal & Prigat, 2004; Singh, 2003). After a random selection from DPE records, I contacted five patients who had developed PTDM over the past two years. I had no previous contact with any of the patients selected. I spoke with each patient by telephone to explain the project and ask if he/she would be willing to review the book and return it with suggestions. Each of the patients agreed and several stated they were honored to be asked for their opinions. I sent a package that included an instruction sheet, the book, “Tell us what you think” feedback form (see Appendix K), and a self addressed, stamped envelope.
Response

I sent copies of the book for review to a total of sixteen allied health team members, physicians and Patient Education Specialists. In addition, the project supervisor, Rosalie Starzomski, and two committee members, Anita Molzahn and Paula Eyles, were sent copies. Ten colleagues, three patients, and all three committee members responded. One of the patients completed the “Tell us what you think” evaluation sheet, and two others responded by telephone. I attempted to contact the remaining two patients who agreed to evaluate the book by telephone however, was unsuccessful. I spoke with some respondents to clarify a few of the suggestions and made changes based on what I have learned about readability, literacy, layout, and comprehension of patient education materials.

Five reviewers suggested that explanations of hemoglobin A1c be included in the final version. This is a blood test to show overall glycemic control over a three-month timeframe. Since this omission was an oversight on my part, I have included this section in the final copy.

Two physicians requested the potential complications of diabetes be more forcefully written. In the initial drafts I had placed the complications near the front of the book. However, the more I read about the principles of adult education I realized this was not an appropriate method of communicating information (Lewis & Newton, 2005). Generally, adults do not respond to negative messages, but prefer positive reinforcement to develop empowerment (Anderson & Funnell, 2000; Barlow et al., 2005; Bull, Holt, Kreuter, Clark & Scharff, 2001). The information included in the book is for reference only and may be verbally explored in more detail by the health care professional during the consultation visit with the patient.

The two physician reviewers also commented on the low reading level and suggested I develop a second version with a higher level of reading difficulty. I would entertain this
suggestion for future development. However, patients with higher reading abilities might still find this book useful during times of stress, such as after a renal transplant. Gal and Prigat (2004) found that reading levels dropped by as much as five grades when a person is exposed to stressful situations.

Wizowski and Harper returned the SAM assessment form with “superior” scores of 86% and 81% respectively. Wizowski stated the book was, “interactive, easy-to-read, positive, and helpful”. She also wrote the book was, “A good resource, especially for people with limited general literacy, English as a second language, and low health literacy”. Harper’s comments were similar in content. She wrote, “I think this book is fabulous – you have done a terrific job; especially for those patients with limited literacy”. A letter of support from Theresa Harper, Patient Education Specialist, at the Hamilton Health Sciences Centre, Hamilton, Ontario is shown in Appendix L.

Five respondents questioned the meaning of the front cover. They stated they were unsure how the cover related to PTDM. I chose to use a concept that depicted abstract people trying to join hands in a circle around the Canadian flag to show unity and national affiliation. Diabetes is a growing epidemic (CDA, 2003), and it is my intent to promote collaboration. The pictures throughout the book show real people in situations that relate to the topic of each section. I wanted the cover to be different than the usual patient education material and catch the reader’s attention. I will explain this in more detail in the section of this paper titled “Ethno-cultural Considerations”.

I received two suggestions to include family and caregivers in the book. One respondent said, “How could you better attend to the needs of family and significant others in this book?”
According to the proposal outline, family and caregivers were not the target audience. I would entertain the idea of writing another resource in future endeavors.

One of the patient evaluation responses was returned with the comment that he had been switched from tacrolimus to sirolimus in an effort to control his blood sugars\textsuperscript{4}. This change in treatment did not have the intended results to help with blood sugar management for this particular patient. This indicates that sirolimus might not be as neutral to glycemic control as initially indicated. In a conversation with a transplant physician about this concern, he said there are new preliminary studies that point toward similar glycemic concerns with sirolimus. I searched for more current articles and found several that are showing adverse glycemic affects with the use of sirolimus (Crutchlow & Bloom, 2007; Ratain et al., 2007). I elected to include sirolimus on page five of the book where I list the medications that can increase blood sugar based on this new information. I will continue to search the literature for more information on this topic and revise as needed.

I found this collaborative relationship between the stakeholders to be valuable. I believe it was important to have a variety of perspectives to make the book more useful to all disciplines and particularly patients. The response from these stakeholders was more than I had expected and I was pleased that each reviewer took the time to carefully read this lengthy book. This displayed a collaborative effort and genuine caring of what the patient is given as reference materials. I look forward to a continued relationship with the health care professionals and patients as I continue to make future revisions. In addition, patients will have the opportunity to evaluate the book on an ongoing basis since the form “Tell us what you think” is located at the end of each book (Appendix K).

\textsuperscript{4} The respondent identified himself on the evaluation sheet by writing his name. This was not solicited.
Effectiveness

Although it is beyond the scope of this project to evaluate the effectiveness of the book, I plan to assess for revisions on an annual basis to include the most recent research based evidence for best practices. In the diabetes department at SJHH, all patient education material is revised at least every two years. Once patients and allied health team members start to use this material, there might be some new suggestions that arise. At the time of revision, I will take the same steps as described above in contacting all of the stakeholders for comments and concerns. I will examine these suggestions for validity and applicability and make revisions in each new edition.

Ethical Considerations

There are many different ethical considerations related to patient education. It is helpful to consider ethical principles, as well as the concepts of moral agency and relational ethics to examine these considerations. Although the perspectives intersect with one another, I will present each one separately.

Basic Principles of Ethics

The ethical principles that apply to the development of the book are autonomy, nonmaleficence and beneficence (Nelson, 2006; Rodney, Burgess, McPherson, & Brown, 2004). Autonomy is a person’s right to make his/her own decision regarding a medical treatment and health care service based on full disclosure of his/her condition, and full awareness of what to expect as a result of medical treatment (Jurchak, 1990; Nelson; Rodney et al.). Rodney, Burgess et al. (2004) state that, “human beings have the ability to act voluntarily based on information” (p. 62). Further, Gleit (1998) describes autonomy as intentionality, made up of two parts; the idea of a thought or an intention, and acting on the intention. This means that a person may intend to do something, but never take action. However, when an action is coupled with the
intent to perform the action, the action becomes intentional. The content of the book provides evidence based information. The person now has the choice to use this information to help (or not help) manage his/her condition and avoid complications thereby applying the principle of autonomy.

In ethical discussions, the principles of nonmaleficence and beneficence are often combined (Rodney, Burgess et al., 2004). Whereas nonmaleficence emphasizes “to do no harm”, beneficence means “to do good” (Nelson, 2003, p. 27). To ensure that patients benefit, I provide current, accurate information keeping the best interest of the patient in the forefront (Nelson, 2003; Robinson, 2005; Rodney, Burgess et al., 2004). The content of the book is based on current evidence and there is a section where the most commonly asked questions are answered. The answers are based on the *Canadian Diabetes Association 2003 Clinical practice guidelines for the prevention and management of diabetes in Canada* (CDA, 2003). These guidelines are the national standards of practice developed in order to ensure the principles of nonmaleficence and beneficence are considered in the treatment of diabetes. New guidelines were announced at the CDA National Conference in Vancouver, British Columbia on October 27, 2007. They will be published in the May 2008 edition of the clinical practice guidelines, but are in effect immediately. These new guidelines affect target blood sugar levels so I have made the necessary revisions in the final version.

In most projects, the principle of confidentiality applies. However, for this project the protection of privileged information was a minor issue. I randomly chose five names from the DPE patient files. Patients and caregivers were asked to volunteer to review the book and gave anonymous feedback using a written evaluation form. Once the assessment package was labeled
and mailed, all contact data were destroyed. The feedback form was returned with no identifying marks. There was no method to discern the identity of the respondent.

French and Larrabee (1999) recommend that when evaluating educational material to distribute, a related ethical issue that providers must consider is unbiased accuracy. Commercially prepared pamphlets are considered to be potentially biased for promoting a product, drug, or procedure and may not fully disclose all information a consumer should know (French & Larrabee). The diabetes department receives numerous pamphlets developed by pharmaceutical companies to distribute to patients. I wanted to ensure this book did not serve any commercial interest. This book is for the patient, with no intent for profit. The book was not funded or influenced by any commercial product. There are no references to any product mentioned in the book to avoid conflict of interest issues.

*Moral Agency*

The characteristics that are generally used to define moral agency include, autonomy, rationality and self-interest (Sherwin, 1992). The basis of moral agency is that people make their own choices (Taylor, 1992). This also presumes equality, and does not consider the “power over” relationships such as parent-child or nurse-patient (Baier, 1994; Rodney, Brown, & Liaschenko, 2004). I examined the book from the perspective of moral agency that led me to ponder the “power over” relationship between nurse-patient or health care profession-patient. My goal for this book was to provide the necessary information for a patient who was required to learn about a new and complicated health issue in a short period of time.

I re-read the book with special attention to the issues that patients have disclosed to me as a DPE. I mentioned earlier that for the sake of readability, literacy, and brevity, I was required to remove some information that was initially included. Some of the information removed included
a broad description of costs of diabetes related supplies, a chart that outlined each insulin and oral antihyperglycemic agent, and an A1c conversion chart. I have not changed my opinion regarding the pertinence of this information. However, the data regarding adult patient education and readability strongly support this decision to omit the material (Boyd et al., 1999; Davis & Chesbro, 2003; Doak, Doak, & Root, 1996).

The “Tell us what you think” evaluation form (Appendix K) at the back of each book will allow for further consideration of new ideas that are patient based. This means that the patient can choose to use the book and choose to make comments on the content.

Knowledge shapes our ability to be moral (Audi, 1997). As nurses, we are held accountable for our actions, recognizing that we cannot change what we do not know. I received an evaluation from a patient who stated that “I was changed from tacrolimus to sirolimus, that was supposed to help my blood sugars. My diabetes got worse.” I have been reading and collecting data on PTDM for several years. The articles I have read claim that prednisone, tacrolimus, and cyclosporine were the offending agents for hyperglycemia. Recent data have come to my attention about the potential glycemic affects of sirolomus (Crutchlow & Bloom, 2007; Ratain et al., 2007). In the final draft, I have added this medication to the list of immunosuppressants that may increase blood sugar. This draws attention to the amount of change to practice in short periods of time within the health care profession.

Relational Ethics

In order to behave in an ethical manner, our actions as health care providers are based on knowledge and justness, whereas relational ethics is acting in ways that lead to positive interactions with others without being sure that we are right (Bergum, 2004; Olithuis, 2000). It is our inner moral compass that drives us to take care of our families, colleagues, and patients. A
book cannot enter into a relationship with a patient. However, the information contained within the pages, as well as the way it is presented, can create the basis for a trusting relationship with the health care professional. This is done by relaying accurate information that is pertinent to the patient’s condition. The health care professional can also ensure the book is introduced at the appropriate time in the patient’s recovery phase so as not to overwhelm the patient.

Three themes that pertain to relational ethics are environment, embodiment, and mutual respect (Dillon, 1992). I have attended to the environment by creating a detailed, readable and pertinent book for the patient to read (or not read) on his/her terms. Embodiment is the attempt to heal the split between mind and body (Bergum, 2004). This is of particular relevance to this book since the patient may have lofty expectations for a complication-free surgical experience that have been dashed with the development of PTDM. The majority of the book deals with information on the physical changes and requirements for diabetes management. However, I have included two sections called, “Your feelings” and “Community resources”. In this book, I have described some of the feelings that arise with a diagnosis of PTDM. The book also contains contact information for other community resources that can help patients seek their own information or assistance. A book cannot engage in a relationship but attention to these topics show the patient that there is more to diabetes management than the physical needs.

Ethno-cultural Sensitivity

Apart from First Nations Peoples, Canada is a country settled by immigrants. Our ethno-cultural diversity is celebrated through holidays, ceremonies, manner of dress and language. Ethno-cultural sensitivity is important when writing patient educational material. It is important when writing patient education materials that special attention is given to cultural sensitivity (Weintraub Baliski, Fink, Choe, & Litwin, 2003).
Admittedly, I found this aspect of the process of writing the book to be difficult. I had to make decisions to include or exclude references to certain foods, practices and attitudes. I acknowledge my bias as a Caucasian, middle class, female. I had to dampen my automatic assumptions based on personal history, experience and comfort levels. It was challenging to include one ethno-cultural community without excluding another. I began incorporating food references such as “naan bread”, “tabouli” and “pad thai” but soon realized I was excluding many other ethno-cultural communities when making these few references. Health Canada (2007) has just published a new Canada’s Food Guide for Aboriginal peoples titled, “Eating well with Canada’s Food Guide: First Nations, Inuit, and Métis”, with the promise of ethno-cultural communities to follow. I believe this is the most respectful and thorough approach since it can be given to the patient by the dietitian during a nutrition consult. I attempted to include references to aspects other than food but found the same concern arose regarding exclusion.

Weintraub et al. (2003) stated that people are empowered to learn and retain the information better if it is culturally appropriate. In addition, it can encourage positive behaviors and model behaviors and skills. Many of the people who develop PTDM are from high risk groups, Asian, South Asian, African, and Hispanic descent (CDA, 2003). Hamilton, Ontario is home to 154,660 recent immigrants, defined as those who landed in Canada after 1985. The city has a total population of 655,060, therefore, twenty-four percent of Hamiltonians are considered immigrants (Citizenship and Immigration Canada Data, 2006). The proportion of immigrants in Hamilton remains above that of Canada but below that of Ontario (Citizenship and Immigration Canada). Almost one quarter of Hamilton’s population is foreign born, thus a variety of languages are spoken (Citizenship and Immigration Canada Data). Although it is beyond the
scope of this project to address translation into the most commonly used languages, it is certainly something to consider for the future.

French and Larrabee (1999) stated that a lack of cultural sensitivity in written education materials may reduce readability for some groups. I took into consideration the many ethno-cultural communities within the Hamilton area when writing this book. The front cover is an original composition that relays a circle for unity, a maple leaf to indicate a Canadian publication and unidentifiable people of varied genders and cultures trying to touch hands. Genders are broadly represented by skirts and pants with the knowledge that in some ethno-cultural communities, either men or women wear robes. There are no distinguishable marks on the faces of the persons on the front cover to represent a specific ethno-cultural community, but color is represented by a darkened head.

In the revised final draft of the book, I have included realistic photos of people from several different ethno-cultural communities. Seven of the completed evaluation forms mentioned the lack of reference to diversity of communities. I took this feedback and added new pictures in order to attend to this important aspect of patient education material. If funds are available in the future, I will develop a full color version.

Dissemination of Information

I believe that information is for sharing. The book has been printed at SJHH and is posted on the website. Patients may print the book from this website at no charge. I would like to see patients, regardless of geographical location, benefit from the information in this book. I have made plans to share the book with the transplant centers at London Health Sciences Centre and Toronto General Hospital. I will approach the Kidney Foundation of Canada and the CDA to
inquire about making this information more readily available to Canadians. Should I receive any other requests, I will be willing to share this information.

The book will be used in the SJHH Transplant program and has the approval of the diabetes team, patient education specialist, nephrologists, renal transplant nurse representative, dietitian, occupational therapist, physiotherapist, pharmacist, and social worker.

I recently presented a poster titled “Patient education: The process of writing a book for people with post transplant diabetes mellitus“, at the Canadian Diabetes Association National Conference in Vancouver in October. I attended the poster session and spoke to a many people about my approach and steps taken to complete this project. I will also be presenting at the Best Practices Open House at SJHH in November to generate further discussion. I plan to write an article for a peer reviewed journal on the process of developing this book in order to share my learning experience with other educators.

Limitations

I have acknowledged throughout this paper that a book cannot create or maintain a relationship with a patient. I created this book to fill a gap in available literature for patients who develop PTDM. The book is not meant to replace the individual assessment, teaching and collaboration of the nurse-patient relationship. Although this book is more comprehensive than the patient education material that I was able to find, there are still aspects of diabetes management that I would have liked to include. Some of these are detailed instructions on glucometer and insulin pen use, an insulin and medication chart, and an A1c chart. There were numerous reasons why I did not include this information, including the wide variety of diabetes related products with differing instructions. These can be addressed in future revisions to the book.
Another limitation is the restriction on printing costs. This allows for only the front cover to be printed in color. If fiscal restraints improve, I will address this for future editions.

I want to acknowledge that of the sixteen health care professionals and five patients who agreed to review the initial draft, only eight and two, respectively, responded. I would have liked a wider range of perspectives to strengthen the collaborative effort. Once the book is in active use, the “Tell us what you think” evaluation form will allow for more patient feedback. I can also solicit more opinions from health care professionals at a future date.

Future Considerations

I would like to review the book in one year to evaluate its effectiveness, usability, and acceptance. This evaluation would include a literature search for any new data or practice issues that arose over that period of time. I will collect more data regarding the suspicion of Sirolimus contributing toward PTDM. I would like to send the book to a larger group of health care professionals and patients to gain a wider perspective.

The length of this book might have detracted from a higher response from the stakeholders. The patients that I telephoned to evaluate this book had developed PTDM one to two years prior. Perhaps the responses will improve when a patient is newly diagnosed with PTDM.

I believe there some improvements that could be made from a cultural perspective. I have attended to some of these, but should funds become available for a full color version, I would look for more diverse pictures that could truly represent our diverse population.

I believe a future endeavor could include creating a book in this format that is specific to Type 2 diabetes. Although there are more patient education materials currently available for this
segment of the population, I have not found one that covers the basic needs of a newly diagnosed patient.

Summary

Education is the key to empowering people with any chronic disease (Schatell & Witten, 2006). In the process of receiving treatment for one chronic disease (renal failure) some people develop another (diabetes). It is my goal to help people cope with the daily requirements of diabetes management through education.

During my four years as a DPE for the renal transplant program, I identified PTDM as an area that needed more attention and resources. This began with my realization that potential renal transplant recipients were not as informed about the chance of developing diabetes as necessary. I began to meet with all people in the pre transplant work-up phase and noticed the available written patient education material did not answer many of the questions recipients had about the specifics pertaining only to PTDM. I started to explore PTDM, adult education, literacy, plain language techniques and how to create effective patient education material. This resulted in a compilation of information that patients might need to learn in order to manage PTDM. I then sent a draft to the health care providers that were specialists in their field to check for accuracy and appeal. I also sent copies to patients who agreed to review the contents. I incorporated the feedback from all of these sources into the published draft. I plan to continue to evaluate the book on a yearly basis to maintain current standards of diabetes management.

I have a particular interest in patient education and how information is disseminated. I would like to continue to learn more about adult learning styles and how to create effective patient education materials. I believe that melding my twenty years of experience as a nurse with the knowledge of adult education can result in a realistic perspective of patient needs.
Prior to undergraduate studies, I did not realize that I had integrated the theory of caring into my practice. It is through these years of higher education that I have learned to recognize my true desire to help patients as a basic tenet of my practice of nursing. It is no longer sufficient just to help people endure the health issues that arise. I want to make changes to the current approach to nursing practice to improve the lives of patients and their families.
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*AJN, 103*(3), 118-119.

Education and Counseling, 17*, 153-158.

Diabetes mellitus after renal transplantation: As deleterious as non-transplant-associated


designed by nurses. *Journal of Advanced Nursing, 26*(5), 985-999.


Tomey & M. R. Alligood, (Eds.), *Nursing theorists and their work* (pp. 189-211). St. Louis, MI: Mosby Inc.


Appendix A
Watson’s ten carative factors

1. The formation of a humanistic-altruistic system of values.
2. The instillation of faith-hope.
3. The cultivation of sensitivity to one’s self and to others.
4. The development of a helping-trusting relationship.
5. The promotion and acceptance of the expression of positive and negative feelings.
6. The systematic use of the scientific problem-solving method for decision-making.
7. The promotion of interpersonal teaching-learning.
8. The provision for a supportive, protective, and corrective mental, physical, sociocultural, and spiritual environment.
9. Assistance with the gratification of human needs.
10. The allowance of existential-phenomenological forces.

Appendix B

FOG Readability Index. Performed on initial draft, September 2007

I randomly chose 3 paragraphs from the front, middle and back of the book. This example is from a passage on page 32.

Summary of the method

1. Count about 100 words. Stop at nearest sentence end. 111

2. Count the number of sentences. 10

3. Count the number of hard words (three syllables or more)
   Do not count verb forms in which the third syllable is merely the ending. 14

4. Find the average number of words per sentence

   \[
   \frac{\text{Number of words}}{\text{Number of sentences}} = \text{Average sentence length}
   \]

   Number of words = Average sentence length 11.1

5. Find the percentage of hard words.

   \[
   \frac{100 \times \text{number of hard words}}{\text{Number of words}} = \text{Percent of hard words}
   \]

   100 X number of hard words = Percent of hard words 12.61%

6. Find the grade reading level.

   \[
   \frac{\% \text{ of hard words} + \text{average sentence length}}{\text{Sum}} = \text{Sum}
   \]

   % of hard words + average sentence length = Sum 9.49

   Sum X 0.4 = grade reading level

The above example is only one type of Readability Index that is available. Other indices are described in the literature.

Adapted from Canadian Public Health Association (1998). Creating plain language forms for seniors: A guide for the public, private and not-for-profit sectors. Ottawa, Canada: Author
Appendix C

FOG Readability Index. Performed on second draft, October 2007

I randomly chose 3 paragraphs from the front, middle and back of the book. This example is from a passage on page 32.

Summary of the method

1. Count about 100 words. Stop at nearest sentence end. 110

2. Count the number of sentences. 11

3. Count the number of hard words (three syllables or more) 9
   Do not count verb forms in which the third syllable is merely the ending.

4. Find the average number of words per sentence

   \[
   \frac{\text{Number of words}}{\text{Number of sentences}} = \text{Average sentence length} \quad 10
   \]

5. Find the percentage of hard words.

   \[
   \frac{100 \times \text{number of hard words}}{\text{Number of words}} = \text{Percent of hard words} \quad 8.18\%
   \]

6. Find the grade reading level.

   \[
   \frac{\% \text{ of hard words} + \text{average sentence length}}{\text{Sum}} = 7.27
   \]

   \[
   \text{Sum} \times 0.4 = \text{grade reading level}
   \]

The above example is only one type of Readability Index that is available. Other indices are described in the literature.

Adapted from Canadian Public Health Association (1998). Creating plain language forms for seniors: A guide for the public, private and not-for-profit sectors. Ottawa, Canada: Author
Appendix D

FOG Readability Index. Performed on final draft, November 2007

I randomly chose 3 paragraphs from the front, middle and back of the book. This example is from a passage on page 76.

Summary of the method

1. Count about 100 words. Stop at nearest sentence end. 103
2. Count the number of sentences. 9
3. Count the number of hard words (three syllables or more) 4
   Do not count verb forms in which the third syllable is merely the ending.
4. Find the average number of words per sentence
   \[
   \text{Number of words} \div \text{Number of sentences} = \text{Average sentence length} \quad 11.44
   \]
5. Find the percentage of hard words.
   \[
   \frac{100 \times \text{number of hard words}}{\text{Number of words}} = \text{Percent of hard words} \quad 3.9%
   \]
6. Find the grade reading level.
   \[
   \frac{\% \text{ of hard words} + \text{average sentence length}}{\text{Sum}} = \text{Sum} \quad 6.13
   \]
   \[
   \text{Sum} \times 0.4 = \text{grade reading level}
   \]

The above example is only one type of Readability Index that is available. Other indices are described in the literature.

Appendix E

Results of patient survey collected in the Kidney and Urinary Program and Diabetes Program from May to September 2007

Patients were given a sentence to read in 3 font styles each displayed in a 14 and 16-point size. After reading all 6 options, patients were asked to check the font size and style they preferred most. Convenience sample (n = 139).

Font Collation
Kidney and Urinary Program

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<th>Font Size / Font Style</th>
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<th>CAHS Diabetes Clinic</th>
<th>KFP</th>
<th>RTU</th>
<th>Peritoneal</th>
<th>Home Hemo</th>
<th>Hemo CAHS</th>
<th>Hemo SJH</th>
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<td>20</td>
<td>7</td>
<td>24</td>
<td>22</td>
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Total selected 14: 43
Total selected 16: 96
Appendix F

Checklist for patient education material

Use these criteria to assess existing patient education materials or guide you in developing new materials.

<table>
<thead>
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<th>Content</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
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</thead>
<tbody>
<tr>
<td>Does the title relate to the content?</td>
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<td></td>
</tr>
<tr>
<td>Is the purpose of the material clearly stated?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the content reflect current clinical practice?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the content include all essential information about the topic?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the content divided into sections?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the information organized in a logical, easy-to-follow sequence?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is a table of contents used when there are many pages?</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Is the material free from bias and commercial endorsement?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Writing Style</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the material written in plain language?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Is the writing style personal and conversational?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clear Design</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the format suitable for the way patients will use the material?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the font style simple and easy to read?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the font size increase from body text, subheadings to headings?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are upper and lower case letters used, not all capitals?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the line length comfortable, between 50 to 70 letters?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the text left justified, without hyphens?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is white space used around margins and between sections of text?</td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Are important points emphasized with bold or a box?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is dark ink used on light, non-glare paper?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the use of color emphasize and not distract from the message?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illustrations</td>
<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>---------------</td>
<td>-----</td>
<td>----</td>
<td>-----</td>
</tr>
<tr>
<td>Do illustrations have simple, clear lines without distracting details or shading?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do illustrations have clear captions and labels?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do illustrations show people, activities and objects that are realistic, positive and culturally acceptable to patients?</td>
<td></td>
<td></td>
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<tr>
<td>Are body parts shown within the context of the whole body?</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Process of Development</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has the content been reviewed by the clinical team?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has the material been tested with patients and families?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has the material been reviewed by a Patient Education Specialist?</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

# Appendix G

## Results from checklist for patient education material

*(n = 10)*

<table>
<thead>
<tr>
<th><strong>Content</strong></th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the title relate to the content?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the purpose of the material clearly stated?</td>
<td>10</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Does the content reflect current clinical practice?</td>
<td>8</td>
<td>2</td>
<td>(don’t know)</td>
</tr>
<tr>
<td>Does the content include all essential information about the topic?</td>
<td>8</td>
<td>2</td>
<td>(don’t know)</td>
</tr>
<tr>
<td>Is the content divided into sections?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the information organized in a logical, easy-to-follow sequence?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is a table of contents used when there are many pages?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are important points emphasized or summarized?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the material encourage interaction with the reader?</td>
<td>10</td>
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<tr>
<td>Does the material encourage patients to take an active role in their health care?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are patients directed to others sources of information or support if needed?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the material free from bias and commercial endorsement?</td>
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<table>
<thead>
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<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the material written in plain language?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the average sentence length about 10 words?</td>
<td>9</td>
<td>1</td>
<td>(wrote ½ &amp; ½)</td>
</tr>
<tr>
<td>Are medical and technical words and abbreviations defined?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the material written mostly in the active voice?</td>
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<td></td>
</tr>
<tr>
<td>Is the tone of the writing positive?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the writing style personal and conversational?</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Clear Design</strong></th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the format suitable for the way patients will use the material?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the font style simple and easy to read?</td>
<td>10</td>
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</tr>
<tr>
<td>Does the font size increase from body text, subheadings to headings?</td>
<td>6</td>
<td>4</td>
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</tr>
<tr>
<td>Are upper and lower case letters used, not all capitals?</td>
<td>10</td>
<td></td>
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</tr>
<tr>
<td>Is the line length comfortable, between 50 to 70 letters?</td>
<td>10</td>
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<tr>
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<td></td>
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<tr>
<td>Is white space used around margins and between sections of text?</td>
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<td></td>
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</tr>
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<td>Are bullets used to present lists?</td>
<td>10</td>
<td></td>
<td></td>
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<tr>
<td>Are important points emphasized with bold or a box?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is dark ink used on light, non-glare paper?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the use of color emphasize and not distract from the message?</td>
<td>2</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>
### Illustrations

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do illustrations have simple, clear lines without distracting details or shading?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do illustrations have clear captions and labels?</td>
<td>7</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Do illustrations show people, activities and objects that are realistic, positive and culturally acceptable to patients?</td>
<td>9</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Are body parts shown within the context of the whole body?</td>
<td>9</td>
<td>1</td>
<td></td>
</tr>
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### Process of Development

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has the content been reviewed by the clinical team?</td>
<td>9</td>
<td></td>
<td>1 (don’t know)</td>
</tr>
<tr>
<td>Has the material been tested with patients and families?</td>
<td>7</td>
<td></td>
<td>3 (don’t know)</td>
</tr>
<tr>
<td>Has the material been reviewed by a Patient Education Specialist?</td>
<td>3</td>
<td></td>
<td>7 (don’t know)</td>
</tr>
</tbody>
</table>

### SAM Scoring Code:
- 2 points for superior rating
- 1 point for adequate rating
- 0 points for not suitable rating
- N/A if the factor does not apply to this material

<table>
<thead>
<tr>
<th>Factor to be rated</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. CONTENT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Purpose is evident</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Content about behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Scope is limited</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Summary or review included</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. LITERACY DEMAND</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Reading grade level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Writing style, active voice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Vocabulary uses common words</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Context is given first</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Learning aids via “road signs”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. GRAPHICS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Cover graphic shows purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Type of graphics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Relevance of illustrations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) List, tables, etc. explained</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Captions used for graphics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. LAYOUT AND TYPOGRAPHY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Layout factors</td>
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<td></td>
</tr>
<tr>
<td>b) Typography</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Subheads (“chunking”) used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. LEARNING STIMULATION MOTIVATION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Interaction used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Behaviors are modeled and specific</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Motivation – self-efficacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. CULTURAL APPROPRIATENESS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Match in logic, language, experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Cultural image and examples</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total SAM score: __________________

Total possible score: __________________, Percent score: ________________ %

Appendix I

Results using the Suitability Assessment of Materials (SAM) scoring sheet
(n = 2)

<table>
<thead>
<tr>
<th>Factor to be rated</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. CONTENT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Purpose is evident</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>b) Content about behaviors</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>c) Scope is limited</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>d) Summary or review included</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>2. LITERACY DEMAND</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Reading grade level</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>b) Writing style, active voice</td>
<td>2/2</td>
<td>-suitable for general public including low literacy</td>
</tr>
<tr>
<td>c) Vocabulary uses common words</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>d) Context is given first</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>e) Learning aids via “road signs”</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>3. GRAPHICS</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| a) Cover graphic shows purpose          | 1/0   | -illustration is confusing
- not sure about the significance of cover |
| b) Type of graphics                     | 1/1   | -cartoons more suitable to children                |
| c) Relevance of illustrations           | 2/2   | -nice in the fruit & veg section                   |
| d) List, tables, etc. explained         | 2/2   | -tests well introduced                             |
| e) Captions used for graphics           | 1/no answer |                                           |
| 4. LAYOUT AND TYPOGRAPHY                |       | -very well done                                    |
| a) Layout factors                       | 2/2   |                                                    |
| b) Typography                           | 2/2   |                                                    |
| c) Subheads (“chunking”) used           | 2/2   |                                                    |
| 5. LEARNING STIMULATION MOTIVATION      |       | -very well done                                    |
| a) Interaction used                     | 2/2   | -excellent                                         |
| b) Behaviors are modeled and specific   | 2/2   |                                                    |
| c) Motivation – self-efficacy           | 2/2   |                                                    |
| 6. CULTURAL APPROPRIATENESS             |       | -this is hard to do overall. I would say this is for a youthful, white audience |
| a) Match in logic, language, experience | 2/1   |                                                    |
| b) Cultural image and examples          | 1/1   |                                                    |

Total SAM score: **38 (86%)/44 and 36 (81%)/44**

Additional comments: Superior rating; I think this book is fabulous – you have done a terrific job; especially for those patients with limited literacy
Appendix J

Steps to using Suitability Assessment of Materials (SAM) scoring sheet to evaluate patient education material

To use SAM, follow the six steps below:

1. Read through the SAM factor list and the evaluation criteria.
2. Read the material (or view the video) you wish to evaluate and write brief statements as to its purpose(s) and key points.
3. For short instructions, evaluate the entire piece. For long instructions, select samples to evaluate.
4. Evaluate and score each of the 22 SAM factors.
5. Calculate total suitability score.
6. Decide on the impact of deficiencies and what action to take.

The factors that are rated on the SAM scoring sheet are:

1. Content
2. Literacy demand
3. Graphics
4. Layout and typography
5. Learning, stimulation, motivation
6. Cultural appropriateness

Refer to Appendix H for the list of areas examined under each factor using the SAM scoring sheet.

Appendix K

Tell us what you think…

After reading this book, please respond to the following statements. Your answers and comments will help us improve the information.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The words are easy to read.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Comments</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>The information is easy to understand.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Comments</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Reading this information was helpful.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Comments</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>The information answered my questions.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>List other questions you have:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would recommend this information to other people with this problem.</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Comments</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

I would have liked MORE information about:

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

I would have liked LESS information about:

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
Other comments and suggestions:

__________________________________________

__________________________________________

__________________________________________

Thank you very much.

Please return this form to:
Paula Eyles, Patient Education
Room G 622
St. Joseph’s Hospital
50 Charlton Avenue East
Hamilton, Ontario L8N 4A6

You can mail this form in or bring it back with you to a follow-up visit. Ask a member of the health care team to put it in the inter-hospital mail for you.
Appendix L

Letter of support from Theresa Harper, Patient Education Specialist, Hamilton Health Sciences, Hamilton, Ontario

November 5, 2007

Dear Lisa:

I reviewed your booklet *Diabetes after Kidney Transplant* – it is excellent!

You have done a wonderful job, taking into consideration all of the important concepts in developing patient education materials that are easy to read, understand and use. Future patients and their families are fortunate that this booklet will be available to them.

If I had to say one thing to improve, it would be the cover. I am not sure what it means. It must have meaning to this population, so it could be my ignorance at fault.

I am looking forward to hearing how the patients responded to all of the information and interactive pieces.

Sincerely,

Theresa Harper
Patient Education Specialist