

“Pretty Radical from What I’ve Known”: The dissonance and distance underlying patients’
cognitive engagement with educational health information.

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Abstract

Patient education often aims to activate behaviours for health management. Assumptions of a fundamental desire for information and learning as a pre-requisite for self-management are countered by the fact that some patients refuse or selectively attend to health information. The complex and emotional context surrounding illness and disease may reduce the patient's openness or willingness to engage with information. Perceptions of a non-compliant, resistant or difficult patient are accompanied with little understanding of the underlying factors. The goal of this research was to explore the cognitive and emotional factors underlying the patient's readiness to learn or cognitively engage with information regarding diabetes management.

This study was conducted using Interpretative Phenomenological Analysis, which draws from the educational experiences of patients with diabetes and interprets their narratives within the context of existing research and theory. A maximum variation sample of 19 adults with Type II diabetes from a primary care clinic and a tertiary care hemodialysis unit participated in an interview.

Three main themes emerged: underlying incongruence in knowledge, thoughts and beliefs; relational talking; and negotiating control. Themes converged on the essence of 'distance' between the patient's lifeworld and the disease and its management. When considered in relation to cognitive dissonance and psychological distance theories, psychological adjustment and relational challenges were revealed. Adjustment involved reconciling difference and dissonance at various points during diabetes management. Distance also threatened the adjustment process and in some cases generated defensive reactions. Adjustment and relational challenges have a bearing on the early stages of the learning process. Differentiating the message according to concrete and abstract information may be more conducive to a staged learning process and offer a more tangible understanding of 'finding common ground' within patient-centered communication. These factors underlying readiness to learn have been reported by patients with diabetes and require further consideration for tailoring communication and education to support person-centred care and self-management.

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I have so many friends, co-workers and family who were always checking in on my progress. I appreciated the kind gentle nudges and your interest in "how I was doing." Thank you all!

I dedicate this to:

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Abbreviations, Glossary and Notes to the Reader

Hemoglobin A1c - a measure of blood glucose levels, commonly encountered in the health care setting and provided to the patients as an indicator of blood glucose control.

IPA: Interpretative Phenomenological Analysis - a research methodology based on hermeneutic phenomenology and described by Smith (1996), to capture idiographic subjective experiences. It is more thoroughly described in Chapter 3.

WHO: World Health Organization

ENREB: Education and Nursing Research Ethics Board – This is the Research Ethics Board within the University of Manitoba who are assigned responsibility for reviewing protocols for research conducted on humans by researchers associated with Education, Nursing, Kinesiology and Recreation Management, Extended Education, and Engineering.

HCP (plural: HCPs): Health Care Provider(s) – a generalized term encompassing the many types of professionally trained individuals providing health care within a medical setting (e.g., physician, nurse, dietitian, pharmacist etc.).

In addition to the list of abbreviations and glossary, the following points are offered to assist the reader. I will use the terms patient and participant in specific ways. The term patient will be used throughout this proposal to identify the individual as a learner with regard to a health issue, as opposed to individuals learning for other purposes. The patient may also be referred to as a research participant when discussed within the context of this study.

I have also used the term health care provider throughout most of this manuscript to avoid associating specific issues with a particular health provider. Reference to a specific

provider (e.g., physician or nurse) only occurs when it could not be avoided within the participants' quotes or where the research literature has focused on one particular health provider group.

Double quotations are also used where an excerpt is quoted verbatim from the literature. The quotes provided by the participants are mostly in the results chapter and also appear within double quotations. Throughout the discussion, I refer to certain terms or phrases used by the participants and these remain within double quotations. When referencing participants, I use a verbatim style to convey the interview contents and message. I have also used reproduced short excerpts from the interview transcripts (identifying myself, Gayle, and the participant pseudonym) to more adequately convey a message emerging from within the interaction.

Single quotations are used to emphasize concepts with specific terminology (e.g., 'cognitive machine') or where there terminology has undefined connotations (the 'difficult' patient). Concepts requiring emphasis are in italics.

Most of the manuscript is written in the third person, although I have chosen to write in the first person when I bring a personal perspective – such as in my personal foregrounding or where I present my philosophical paradigm (Chapter 3).

CHAPTER 1: Introduction

Patient education is frequently provided with the aim of modifying behaviours or activating and sustaining activities that will enable individuals to self-manage their health. A health deficit or uncertainty is assumed to generate a naturally occurring need for information and education and will prime the patient's interest and expectation for information and education (Case, Andrews, Johnson & Allard, 2005; Johnson, 2014). However, the complex and emotional context surrounding illness and disease may complicate or even hinder participation in various aspects of self-management, including an 'appetite' or willingness to engage with information. Most patients can recount an emotionally charged reaction to hearing a serious diagnosis or the range of emotions related to the ongoing and perhaps unsuccessful efforts to change or even maintain a particular health behaviour that has not previously been part of their lifestyle. This is the context within which patient education is occurring and may be the essence of problems related to interest, attentiveness and information processing. These problems may also stimulate perceptions that patients are resistant, non-compliant, and difficult. To better understand the patient and how these situations emerge, this research explores the cognitive and emotional factors underlying the patient's readiness to learn or cognitively engage with information related to managing a chronic health condition: diabetes.

Patient education aims to enable patients to understand and self-manage their health and/or medical conditions. In the case of diabetes, management and health outcomes are still not optimal. For example, the most recent Cochrane review of face-to-face diabetes education reported no differences from usual care, except among patients with higher baseline hemoglobin A1c levels and inadequate metabolic control (Duke, Colagiuri & Colagiuri, 2009). A bleak picture of diabetes education also emerges based on patient attendance. One study reported approximately

20% of patients within six months of a diabetes diagnosis participate in diabetes education (Cauch-Dudek, Victor, Sigmond & Shah, 2013) with a number of structural barriers reported (Temple & Epp, 2009). Rates of attrition from diabetes education services range from 4- 57% internationally, with Canada ranking among those with higher attrition rates. The barriers or challenges for not participating in diabetes education have received some attention over the last few years, but psychosocial and contextual variables still need further investigation (Gucciardi, 2012).

Inadequate management is also evident in rates of medication non-adherence; an ongoing concern given the numbers of medicine-related deaths and the increasing medication-related hospitalizations (Salvo & Cannon-Breland, 2015). Salvo et al. (2015) report only 50-70% of prescriptions are taken to pharmacy with fewer than 66% filled. They also report that among those who do have the medication from pharmacy, only 25-30% are taken as directed. Fewer than 50% of patients with chronic disease are following treatment correctly (Sabate, 2001) and less than one-half of patients who have been recommended insulin are using it (Sorli & Heile, 2014).

Despite the awareness of pathophysiology and development of medications and treatment strategies for diabetes, the rise in morbidity and mortality suggests a patient-focused approach is not integrated into effective management. The focus on glucose control needs to shift to a more holistic view that encompasses psychological, emotional and practical complexity of managing diabetes as it is impacted by activities of daily living (Nicolucci, Kovacs Burns, Holt, Comaschi, Hermanns, Ishii, ...Peyrot, 2013; Serrano-Gil & Jacob, 2010). While many of the authors exploring medication non-adherence note the importance of education, patient-centred approaches with active listening, coaching and supports appear to be more successful. Yet, few studies report on patient preferences, health care goals or patient reported health outcomes (Kuntz, Safford,

Singh, Phansalkar, Slight, Her... Hornbrook, 2014; Sorli & Heile, 2014) and therefore less is known about the patients' perspectives and experiences. Further, the cognitive and emotional dimensions have not been adequately described or operationalized, thus impeding further empirical investigation of communication, education strategies or counseling approaches that lead to greater learning and information acquisition.

Given the gap between knowing and doing, the World Health Organization (1998) challenges the health care system to a new way of thinking and approaching therapeutic patient education, by:

“debat[ing] whether it would be a waste of energy and of precious institutional resources to continue to condone inefficient educational practices for no reason other than that their own conventionally oriented teachers find such practices easy and convenient. They should consider whether it would be fair to expect their conventionally oriented teaching staff to implement, without help or guidance, educational programmes such as those proposed, and should provide for them a teacher training programme which they are required to take” (World Health Organization, 1998, p.2).

This observation tasks the system and health care providers with facilitating change through means that extend beyond the medico-centric, one-way delivery of information and the assumption that information is fixing the deficit in the self-management equation. Furthermore, current educational programs addressing management of chronic disease do not typically include educational methods or psychological supports, and need to consider the adaptation process as a point from which to initiate meaningful learning (World Health Organization, 2012).

Readiness to learn is a concept that materialized with Knowles, an adult learning theorist who characterized the adult learner and recognized subtle differences from younger learners. From

its theoretical grounding in psychotherapy and examining the unique characteristics of adults as learners, adult learning theory (andragogy) was adopted (Knowles, 1990). This theory posited that adults are driven by different motivators for learning, underpinned by a need and capacity for self-directed, experience-based learning, with a readiness to learn when one's life situation creates a need, and a problem-centred orientation to learning (Knowles, 1990; Knowles, Holton & Swanson, 2011). Drawing from cognitive theories of learning, andragogy considered the experiences of individuals and the internal mental processes that would guide or influence learning.

Thought processes are complex mental operations underlying emotions, beliefs and behaviours. People can modulate emotional responses and the way in which situations or stressors are appraised, thereby influencing subsequent behaviour (Kring & Sloan, 2010). This has particular relevance for the health context as patients encounter new information or a health deficit. An emotional response can influence one's receptiveness or ability to engage with information. A state of heightened anxiety or similar emotional arousal is associated with greater cognitive distraction - either voluntary or involuntary - and has an immense influence on understanding, motivation and learning as patients may not attend to important information (Bigdeli, 2010; Portnoy, 2010). Milewski and Chen (2010) found that lack of motivation to continue to engage with information may result from the extremely long disease management process and the ongoing challenges of self-management, resulting in feeling tired and not caring anymore. Thus, there may be significant, longitudinal differences in the daily and ongoing self-management of one's chronic illness or condition.

Understanding the complexity of the mental operations at work in learning and attention, and its variations among individuals and situations has enhanced knowledge and understanding of

behaviour control and regulation beyond the behaviourist perspective (Lazarus & Folkman, 1984). Moreover, recognizing the multiple stages and moderators in the learning that precedes and influences behaviour change has been suggested as a more feasible approach and important direction for patient education research (Adams, 2010). In fact, the process of gaining health competence may require a better understanding of factors such as the patient's recognition and acceptance of a health issue, its relevance and meaning to one's life, and the need for some kind of personalized action (Adams, 2010). Adams (2010) also proposed further investigation of influential or mediating factors within this unfolding process as there have been limited successes described in the research literature.

There is a great deal of health education literature that has focused on health education strategies for enhancing delivery of information and advice-giving rather than cognitive and affective factors that underlie learning, desire for information or information processing capacity (Albano, Crozet & d'Ivernois, 2008). The capacity for patients to be cognitively engaged in educational health information is an important first step for learning how to take a more self-directed and autonomous role in self-care. It is evident from the literature covering non-adherence and the experiences of health providers who have encountered the 'difficult' patient that other factors are influencing patient education and learning.

Conception of the Research

The choice of topic for this research was driven by my academic preparation and my experiences and interests. My foregrounding and methodological choices as the researcher must be made explicit and acknowledge potential biases and assumptions which may influence the study direction. This is regarded as a necessary feature of hermeneutic phenomenology and more specifically Interpretative Phenomenological Analysis (IPA), which frames this inquiry and will

be described in greater detail in Chapter Three (Brocki & Wearden, 2006; Dowling, 2007; Dowling & Cooney, 2012).

Researcher foregrounding. I have practiced as a clinical dental hygienist, a clinical instructor and most recently facilitating and conducting primary care research. In my earlier training, providing patients with information and education was a key component for preventing or treating oral conditions. This attitude carried over into my perspective regarding health management in general. I recall feeling that knowledge was the ‘missing link’ influencing a behaviour change that would enhance health. However over time, I have become more sensitive to the responses of the patients while discussing health behaviours. Patients who were ‘non-compliant’ or weren’t interested in the information, left me wondering what other factors were involved at an implicit level. There are several examples that have stuck with me. I was the clinical instructor for a dental hygiene student who presented in tears because her patient was angry when asked about his smoking history. I saw patients ignore instructions regarding oral care preparing for and following extensive gum surgery. Perhaps more striking, I had a relative choose to disregard advice to have a surgical repair to a heart valve, which soon escalated to a fatal complication. This latter situation was particularly troubling as this was a systemic problem and ultimately a choice between life and death. I imagined receiving a diagnosis would be met with a range of emotions. Anecdotally, friends and family have shared how a diagnosis was followed by a period of hearing nothing more. This left me with many questions around what this experience must be like and the subsequent instruction to change a behaviour such as one’s diet in order to manage an illness on a daily basis.

I believe I have held a certain degree of empathy for the struggles of patients with chronic illness, and have further reflected on my attitude toward the value of patient education and the

empowering quality of information and knowledge. How does patient education really fit into the ‘big picture’ as the patient sees and experiences it? Consequently, my perspective has changed over the years and I have become much more aware of the fact that despite best intentions, health care providers are often trying to ‘deposit’ information into the patient’s lifeworld. Is this how it is perceived by patients as well?

Summary and Research Purpose

Readiness to learn is a term borrowed from the education literature, but poorly conceptualized within the health care domain. Engagement, willingness, readiness are terms used in the literature to move learning and behaviour change forward however there is no operative understanding of the factors that may be influencing when engagement, willingness and readiness are lacking or not optimal. There has been very little literature around this phenomenon, particularly from the patients’ perspectives. Therefore this inquiry was seeking to better understand these circumstances as experienced and described by the patients themselves. Ultimately, the goal of this research was to conceptualize and describe readiness to learn or cognitively engage with health education by drawing from experiences as described by patients who are coping with a chronic condition: diabetes. More specifically, this research aimed to:

- 1) gain a better understanding of patients’ experiences with information and education within the healthcare encounter;
- 2) explore the situations encountered by patients where they felt more or less ready to learn;
- 3) identify and describe the patients’ self-reported factors related to the cognitive and affective dimensions of readiness to learn.

The ability and capacity for learning in the healthcare domain is indeed complex. This research focuses on cognitive and emotional factors and draws from educational theory which

proposes that educators deepen their understanding of the learner, including those who may be considered resistant. An inductive phenomenological inquiry is well-suited to develop knowledge and a theoretical framework around an implicit and under-developed concept such as readiness to learn within the healthcare domain. Phenomenology is a qualitative approach which seeks to explore multiple participant realities, their different perspectives and how they view their experiences and their world. In addition, IPA recognizes the naturally interpretive role of the researcher in the analytic process and therefore the analysis is a product of phenomenology and interpretation. Finally the findings are considered within the context of existing theories, concepts and constructs that may be related to readiness to learn. The synthesis of patients' reports and existing theory may have important implications for patient-centred health information and education. A better understanding of the patients' experiences and underlying factors affecting readiness for learning and engagement with health information will assist in customizing approaches for learning and extend beyond content and modes of delivery.

CHAPTER 2: Literature Review

The phenomenon of readiness to learn or cognitively engage with health education, as a precursor to learning and behavioural self-management, has not been conceptually or operationally defined in the literature. It is therefore difficult to narrowly explore the literature for evidence of its presence or influence on the learning process or subsequent behavioural outcomes. This review was guided by three main intentions: 1) exploring the positive and negative psychological factors influencing patient interactions with health education or counselling; 2) seeking the theories, concepts and constructs that may be related to readiness as a mental response to information or education; and 3) moving beyond the healthcare domain to bring a multi-disciplinary perspective.

The following literature review starts from a broad perspective by describing the historical evolution, context and common approaches to health education. The paradigmatic change to a patient-centred approach is relatively nascent, with still much to be learned about the ways in which it influences care, self-management and education. However, it is an important backdrop for considering various concepts and constructs that have been shown or hypothesized to impact communication, information exchange, information seeking and avoidance. This review focuses on mental constructs considered within educational approaches, in particular, the psychological prerequisites for learning. These are considered important influences on the learning process alongside a cognitive context influenced by coping, cognitive appraisal and information processing. This is not an exhaustive review of the literature but provides a selection of concepts and theories for a foundation upon which to begin conceptualizing readiness to learn.

The Development of Patient Education

Cultural changes in society since the 1960s have influenced the development of patient education with a shift from a medico-centric approach to a focus on lifestyle changes and a more active role for the patient in decision-making and self-care (Glanz, Rimer & Lewis, 2002; Hoving, Visser, Mullen & van den Borne, 2010). The patient was once regarded as a more passive recipient of treatment in a medico-centric approach with information provided from a more medically-dominated authoritative position. Research in the 1980s emphasized active patient involvement in lifestyle changes as well as other variables such as quality of life as mediators to biomedical outcomes. With the shift to patient self-management, skill building took on greater importance (Hoving et al., 2010). The World Health Organization's (WHO; 1998) definition of therapeutic patient education reflected this change and drew attention to educational processes required to support the patient role in self-management as well as tailored support for emotional needs, personal adjustment, motivation and confidence building (Burke, Sherr & Lipman, 2014; Kawi, 2012). Patient education was no longer limited to knowledge transfer or dissemination but began to consider the need to develop patients' motivation, skills and confidence (World Health Organization, 1998) through teaching, counselling, guiding, supporting, advising and coaching (Yoon, Conway & McMillan, 2006).

Despite the development of a more holistic approach, health education has been criticized for still approaching disease management from a deficit model and assuming bio-medically accurate information will inform management goals and determine patient behaviours. Some argue that health goals are established by health care personnel rather than patients themselves, with medical power and authority still embedded in the actions of health organizations and care-providers (Scambler, Newton & Asimakopoulou, 2014). The WHO (1998) report on therapeutic

patient education suggested health care providers are mostly talking about the disease rather than providing self-management training, with less attention paid to the existential element of disease and the patient perspectives (Fredericks, Lapum, Schwind, Beanlands, Romaniuk & McCay, 2012; Johansson, Österberg, Leksell & Berglund, 2015).

The evidence-based practice paradigm has also been critiqued for inadequately considering the individuality of patients and the complexity of individuals (Maldonato, Piana, Bloise & Baldelli, 2010). Evidence generated through rigorous science within controlled environments may limit applicability to the diverse and complex needs of patients being treated in day-to-day practice (DiCenso, Guyatt & Ciliska, 2005). However, the increase in qualitative research since the 1990s, has elevated consideration of human complexity and the breadth of the patient experience (Maldonato et al., 2010). Despite more recent attention on psychological and social dimensions, there remains a need to examine learning processes and patients' strategies for acquiring self-management competence (Albano et al., 2008). Indeed, qualitative research is needed to gain the patients' perspectives and experiences, and will enhance understanding of personal capacity, including health literacy, educational background, level of existing knowledge, skills, beliefs, and attitudes. This diversity underlies a patient-centred approach and needs to be considered alongside psychological factors, cultural understanding and cognitive function as mediators to learning (Adams, 2010; Formosa, McInnes & Mandy, 2012).

The Diabetes Context

According to data reported by the Public Health Agency of Canada, in 2008/09, 2.4 million or 6.8% of the population had diabetes with the prevalence increasing by 70% from a decade earlier. From primary care data in 2012, the prevalence rate was estimated at 7.6% in the practice population with higher risk for co-morbidities such as cardiovascular and kidney disease

and lower self-rated health (Greiver, Williamson, Barber, Birtwhistle, Aliarzadeh, Khan...Katz, 2014).

Diabetes is a chronic and progressive disease with lifestyle behaviour modification considered a cornerstone for self-management, and health care professionals have a critical role in supporting self-management (Jones, Berard, MacNeill, Whitham & Yu, 2013). There is also growing evidence that the condition and complications can be prevented through a number of behaviours under the control of the patient. These include physical activity, healthy eating, tobacco control and weight management (PHAC, 2011), with even small changes in weight having significant benefits (Hux, 2016). However, the shift in self-care responsibility may also have disproportionately shifted responsibility. By emphasizing behaviours, an unbalanced message around the causes of diabetes may further contribute to stigmatizing the condition and sustaining the prevailing attitude that places the burden of blame squarely on the individuals (Hux, 2016). Furthermore, the clinical dynamics around diagnosis, treatment and outcome may contribute to an approach more aligned with the medical model than with one that is supporting behaviour changes for self-management (Vallis, 2015). The approaches and expectations surrounding the patient role have not yet been investigated as factors influencing the patient's attitude, capacity or readiness for learning.

There is concern regarding the number of individuals not achieving target hemoglobin A1c levels and the constant rise in diabetes morbidity and mortality. In addition to what is known about pathophysiology and internationally accepted treatment strategies, there is a need to understand the disparities in knowledge, attitude and effective practical action (Serrano-Gil & Jacob, 2010). The WHO (1998) reported that health care training is focused on diagnosis and treatment of chronic disease and results in too few health professionals educating patients.

However, diabetes is not easily managed by seemingly straightforward behaviour changes (Burke et al., 2014; Hux, 2016). Knowledge is not the only factor influencing glycemic control or health outcomes (Burke et al., 2014; Formosa et al., 2012) and confidence and motivation for self-management is not simply based on knowledge alone (Serrano-Gil & Jacob, 2010). In fact, a focus on self-care skills and measurable outcomes such as hemoglobin A1c have resulted in less attention to mediating variables or intermediate outcomes such as knowledge, beliefs, control or involvement in self-care (Hibbard, Stockard, Mahoney & Tusler, 2004). There are very few studies that have examined other confounding factors, in particular, the thoughts and emotions that influence learning as a dynamic and individualized process. Previous research has suggested a greater need for more holistic, patient-centred approaches, acknowledging the complexities of day-to-day diabetes management, addressing psychosocial and cultural aspects and nurturing skills, abilities, motivation and commitment (Burke et al., 2014; Formosa et al., 2012; Jones et al., 2013; Sapkota, Brien, Greenfield & Aslani, 2015).

Approaches to Health Education

Throughout the previously described evolution of patient education, various terms have emerged to reflect the systematic versus incidental nature of education and information exchange. Patient education still often refers to less formal education delivered in day-to-day health care encounters in hospital or in primary care. Across the literature, patient education is also referred to as patient instruction, teaching, and counselling thus suggesting the complex and varied nature of health education in clinical reality. Reviews (Albano et al, 2008; Lager, Pataky & Golay, 2010) have found a lack of description or characterization of patient education and teaching programs but suggest it be conceived as an integrated process of information and therapeutics, with educational processes and psychological interventions aiming to help patients

learn about their health. Health education now occurs in many different settings and across the continuum of care (Yoon et al., 2006). Clinical practice guidelines for diabetes define self-management education as a systematic process but also suggest that it refers to any education that provides the knowledge, skills and motivation to participate in decision-making and the application of skills (Jones et al., 2013). Whether a planned, systematic learning activity or less formal or incidental learning, this research considers all forms of delivery and exchange of educational health information. Thus, it is based on an assumption that for supporting self-management, there is a need for ongoing information exchange and support that is integrated into all health care settings (WHO, 1998) and across the care continuum.

The theories and concepts informing health education come from a large and diverse corpus of literature covering multiple disciplines including education, psychology and communication. Some of the most common theoretical approaches are introduced subsequently but focus on the cognitive context of learning and therefore limited to those that have theorized around cognitive elements, such as intention or motivation, and found to influence or mediate outcomes.

Behaviours and behaviour change. An important element of health reform has been the role of the informed, engaged consumer through improved education (Adams, 2010). Behaviour and lifestyle change remain the foci of health promotion and education (Glanz et al., 2002; Hoving et al., 2010) leaving a gap in understanding of how patient education has been experienced or how it has been compromised in moderating behaviour change. Health behaviour is the targeted objective and resounds throughout most definitions of health education. Green, Kreuter, Partridge and Deeds provide a widely-used definition: “any combination of learning

experiences designed to facilitate voluntary adaptations of behaviour conducive to health” (c.f Gochman, 1988, p.144).

Theories regarding barriers and facilitators within the behaviour change process have been influenced by the work of Lewin’s Health Belief Model (Glanz, et al., 2002). This long-standing theory is based on value-expectancy and individual perceptions of susceptibility and severity as well as beliefs or expectations about actions and outcomes. These collectively influence the likelihood of health behaviours (Glanz et al., 2002; Syx, 2008). Self-efficacy is the belief or conviction in one’s ability to execute a certain behaviour, which developed within social cognitive theory and was later added as a separate construct to the Health Belief Model (Glanz et al., 2002). Self-efficacy has been shown to be one of the most important indicators of motivation. For patients with diabetes, it is the greatest predictor of dietary self-care behaviours and associated with better metabolic control and treatment satisfaction (Nouwen, Ford, Balan, Twisk, Ruggiero & White, 2011). A second value-expectancy model is the Theory of Reasoned Action, which later became known as the Theory of Planned Behaviour. Central constructs are subjective norms and behavioural intentions associated with the decision-making process for behaviour change, with the addition of perceived behavioural control in a later version of the theory (Glanz et al., 2002). Both value-expectancy models present an important part of the behaviour change process. However with the focus on behaviour, the question remains whether these mental constructs are factors that similarly moderate the learning process and, in particular, one’s readiness to engage with the process.

The Transtheoretical Model (often referred to as the Stages of Change model) developed by Prochaska and Velicer in 1997, achieved widespread use in health behaviour education as it characterized people in different stages and proposed integrating change processes from across

psychotherapeutic approaches. The focus is on the intrinsic aspects of change, such as levels of motivation and intention that affect an individual's progress through the change process (Glanz et al., 2002; Prochaska & Norcross, 2010; Syx, 2008). The Stage of Change model has important implications for this research as it recognizes the varying stages or levels of readiness. This is a widely used theory and instrument for refining counselling according to stages of readiness. The earliest stages (from pre-contemplation to contemplation) remain the most difficult aspects of behaviour change to address. Despite the focus on defined behaviour changes, there remains a lack of understanding and research exploring the underlying factors influencing stage transition (Ryan, Lynch, Vansteenkiste & Deci, 2011) therefore also hindering the development of a more comprehensive approach to facilitating and tailoring health education efforts.

The concept of Patient Activation also draws from both self-efficacy and stage of change theories, where the individual is thought to move through stages in becoming effective self-managers. Notably, it is not linked to a specific behaviour change but conceptualized as part of the broader concept of patient engagement, providing a broader assessment of an individual's ability to manage behaviours as well as his/her willingness and ability to take action or seek out health information (Fowles, Terry, Xi, Hibbard, Bloom & Harvey, 2009; Hibbard & Greene, 2013). Measures of Patient Activation are also used to tailor communication and support behavioural change (Hibbard & Mahoney, 2010). They have been used in studies which revealed the diversity among patients in terms of their personal factors influencing change and the degree to which an individual believes in and is able to play an active role in self-management behaviours (Hibbard et al., 2004; Hibbard & Greene, 2013; Hibbard & Mahoney, 2010). Although one study (Hibbard & Greene, 2013) looked at tailoring support or coaching to encourage action, further evidence is needed to support strategies to increase the participation of

less activated patients (Hibbard & Greene, 2013; Woodard, Landrum, Amspoker, Ramsey & Naik, 2014) and potentially develop psychometric measures that include elements of cognitive and motivational constructs (Smith, Curtis, Wardle, von Wagner & Wolf, 2013). While most of the studies with the Patient Activation Measure have referred to terms such as openness, willingness, engagement, beliefs, mind sets and confidence, it remains unclear how activation relates to readiness for learning as a latent factor within the process of behaviour change.

The previously described models of behaviour change have been criticized for their assumption that individuals have the ability and conscious mindfulness to understand and act in a logical, reasoned way in order to address a behaviour as a volitional act. Anecdotal evidence suggests that reactions, particularly those attached to emotions commonly encountered in health care, are not always logical or reasonable. In fact, behaviour change requires self-discipline, personal resolve and readiness before strategies are considered (Elder, Ayala & Harris, 1999). Cognitive processing capability has been more closely considered in relation to the Theory of Reasoned Action and specifically with regard to the individual's capacity to manage decisions or tensions and the manner in which this capacity evokes different cognitive processing pathways. This dynamic will be described later in the chapter and in relation to emotions and coping, and the neuroscientific basis underlying information processing.

As mentioned previously, the focus on behaviour or the 'behaviouristic touch' has been noted among various approaches to health education (Friberg & Scherman, 2005), with less attention paid to underlying issues or causes for behaviours (Brouse, Basch & Kubara, 2005). Friberg and Scherman (2005) caution that the emphasis on the behavioural models risks reverting the educational focus and goals to traditional meanings of compliance. Without an understanding of underlying issues, challenges or personal convictions required to initiate and

sustain change, the counsellor conveys a lack of interest in the patient's lifeworld (Friberg & Scherman, 2005) and many of the most influential factors related to the individual's behaviour(s).

Cognitive and affective elements are key considerations for translating medical evidence to the complexity of an individual and their lifestyle (Burke et al., 2014) and for addressing the burden of the disease and quality of life (Kawi, 2012). The behaviour change theories previously presented are based on psychological and behavioural research (Hoving et al., 2010) and demonstrate a more comprehensive approach. The increasingly greater inclusion of cognitive and affective elements is also evident in the WHO definition of health literacy, which considers motivation or 'mind sets' in addition to the behavioural skills required for promoting health (Smith et al., 2013). Furthermore, an integrative theoretical framework of psychological constructs for behaviour change research developed and validated by a large team of experts (Cane, O'Connor & Michie, 2012; Michie, Johnston, Abraham, Lawton, Parker & Walker, 2005), outlines fourteen domains within the behaviour change process. An important outcome from this synthesis of behaviour change models is that knowledge and skills are only two of the influencing factors, and knowledge was not found to be the important source of variance. Notably, several cognitive and affective domains (e.g., memory, attention, intention, social influence, beliefs) were revealed to provide more comprehensive coverage of the influences on behaviour, with some of the common constructs relating to the individual's capacity, beliefs, identity and levels of influence and motivation (Cane et al., 2012). While this framework is limited to select theories of behaviour change, it has brought an important focus on the process of change and the breadth of domains and constructs underlying behaviour change.

A common theme from theories and approaches regarding self-management and behaviour change is the important but less emphasized role of cognitive and emotional factors such as beliefs, attitudes and fear. Such underlying thoughts and emotions appear to be instrumental moderators for translating medical evidence and behaviour change counselling to the complexity of the patient's lifeworld. Indeed, affect has been found to have an influence on health related behaviours such as medication adherence (Broadbent, Donkin & Stroh, 2011) and general levels of activation, whereby patients are less open to new ideas, information and change (Hibbard & Mahoney, 2010). Other empirical evidence suggests emotional responses shape one's perceptions of his/her condition, which in turn affects self-care behaviours (Furler, Walker, Blackberry, Dunning, Sulaiman, Dunbar & Young, 2008). Yet, less is known about how specific thoughts and emotions emerge within the patients' experiences, and how they might influence readiness to engage with information.

Patient-centred approach. The concept of patient-centred care is derived from Carl Rogers, who marked a unique departure from psychotherapeutic approaches by introducing person-centred (later called client-centred) therapy. In this approach, he placed responsibility upon the patient whom he felt could consciously and rationally participate in reconciling incongruence between a desired or symbolized self and the experienced or actual self. Through empathic but non-prescriptive guidance from the counsellor, clients expanded upon emotion and awareness, which fostered more effective information processing toward the goal of self-actualization (Prochaska & Norcross, 2010).

During this time, Engel's (1977) biopsychosocial model also urged a more comprehensive view of health and illness. He argued against a definitive boundary marking the difference between health and disease and proposed an approach that would take into account the

cultural, social and psychological context within which health or illness is experienced by the patient (Engel, 1977). This brought attention to personal constructions of disease and illness and the impact on one's functioning and equilibrium. This philosophy was reflected in research where scientific and medically accurate descriptions and approaches to disease were being supplemented with the experiential and phenomenological aspects of disease and illness. Consequently, the focus on individual's conceptions and sense making emerged and became evident in approaches more closely associated with psychoanalysis (Gochman, 1988).

Patient-centred care is an approach that considers the unique, individuality of each patient and respectfully responds to his or her values, needs and preferences. A primary objective is to gain an understanding and value the patient's unique way of perceiving and experiencing his/her situation (Constand, MacDermid, Dal Bello-Haas & Law, 2014; Pelzang, 2010). The patient is considered in terms of biological, psychological and social needs rather than just signs and symptoms of illness from the narrow perspective of biophysiological systems or problems (Mead & Bower, 2000; Pelzang, 2010; Smith, Dwamena, Grover, Coffey & Frankel, 2011; Stewart, Brown, Weston, McWhinney, McWilliam & Freeman, 1995). It is an approach that disrupted the authoritative health care paradigm (Fredericks et al., 2012) and promoted greater equality in dialogue and decision-making (Glanz et al., 2002; Hoving et al., 2010), with the aim of expanding the patients' role in their health and empowering them to self-manage (Pelzang, 2010; Yoon et al., 2006).

There is a lack of consensus around the meaning and measurement of patient-centred care (Constand et al., 2014; Scholl, Zill, Härter & Dirmaier, 2014; Smith, DuHamel, Egert & Winkel, 2010). A recent review (Scholl et al., 2014) found the definition of patient-centredness yielded 15 distinct but interrelated dimensions. A patient-centred approach appears to have a positive

influence on a number of patient outcomes, although there is some inconsistent evidence of its effect on health outcomes (Scholl et al., 2014). Earlier research has found the movement toward greater patient-centred care has not been without implementation challenges. Roter and Hall (2006) reported that during patient education and counselling, physicians spent most of the time talking and in 50% of cases, education was providing factual information. Few medical visits include motivational strategies (Moran, Bekker & Latchford, 2008) and there has been overall low agreement on goals and strategies for patient care (Heisler et al., 2003).

Communication. A common theme interwoven through the literature around health education, self-management and behaviour change is the person-centred approach enabled by communication (Scholl et al., 2014). In fact, communication is considered one of the most valued dimensions by patients and is the most consistently defined component of patient-centred care across various models (Constand et al., 2014). With the emergence of a more patient-centred communication style, variables other than just the delivery of information are being explored and considered. There is increasing interest in tailoring health education by using patient-centred processes and strategies to enhance learning and overcome psychosocial and cultural barriers (Albano et al., 2008). The relational aspect of effective communication is also fundamental to supporting the exchange of ideas and improving the practitioner's understanding of the patient's primary concerns, emotions, perspectives and illness experiences (Falvo, 2011; Roter & Hall, 2006; Stewart et al., 1995).

A message reiterated in the communication literature is the need to examine variations in personal, psychosocial and situational variables that may moderate communication processes and effects (Han, Collie, Koopman, Azarow, Classen, Morrow, Michel, Brennan-O'Neill & Spiegel, 2005; Roter & Hall, 2006). Constand and colleagues' (2014) review of the communication

component within person-centred care revealed information sharing and an effective learning environment were necessary to support patient-centred care. They also found that an essential step to tailoring information was in recognizing information uptake and patient receptiveness based on patient needs. Unfortunately, the identifiers or markers for patient needs were largely objective observations such as alertness or hearing loss (Constand et al., 2014) rather than awareness of the cognitive and affective factors influencing the interaction.

The limitation of the research around health communication is in the foci on information content and modes of communication, and less consideration of psycho-emotional issues that may mediate information processing and understanding. The predominant method for researching communicative interaction is through interactional analysis, which is dependent upon explicit utterances to reflect patient communicative styles and personal characteristics (Street Jr, 1991). Interactional analysis has not explored patients' perspectives, inner thoughts or feelings. The patient may experience an array of psychological reactions that result in less affective expression. For example, silence and avoiding disclosure are common symptoms related to trying to manage one's self-concept and identity and avoid appearing needy, vulnerable or weak (Parrott, 2009). Less expression may also have deeper roots. Traumatic stress symptoms related to breast cancer have been shown to result in difficulty interacting with health personnel. These patients were limited in their ability to actively participate in the medical encounters, were less likely to fully attend to or focus their attention within the encounter, assimilate information or navigate the encounter to meet their informational needs (Han et al., 2005). Some patients do not think of the medical interaction as a place where their personal distress or weaknesses can be discussed (Street, Makoul, Arora & Epstein, 2009). There is also often significant unease associated with the medical exam itself and the loss of personal and

physical privacy, which undermines confidence to participate fully in the medical exchange (Parrott, 2009).

There is a lack of research trying to understand a patient's reluctance to discuss self-care for diabetes management. This has been studied in other chronic illnesses and the ability to communicate and express concern and problems may be a barrier to successful self-care. A recent study examining some of the factors underlying reluctance found patients were not discussing their self-care because they did not want to feel judged, were shameful, guilty, embarrassed, in denial or had fear of diabetes and potential complications (Beverly, Ganda, Ritholz, Lee, Brooks, Lewis-Schroeder,... Weinger, 2012). This resulted in almost one-third misrepresenting or withholding information. Yet many of these individuals were struggling with self-care, and experiencing more emotional stress, depressive symptoms and lower quality of life (Beverly et al., 2012).

The patient-centred approach underpins this research regarding health education. Patient-centred care and communication reject the isolated focus on disease and attend to the psychological and social aspects of patients' illnesses by incorporating their perspectives. A common thread among various approaches to patient-centred care is information and education and awareness of implicit affective elements such as the patient's readiness to learn, values and attitude, and confidence (Fredericks et al., 2012). Communication is an enabling component of patient-centred clinical care directed toward assessment and treatment planning. But, does it bear similarity or parallel the approach required for patient-centred education? A more in-depth exploration is required to understand the patient-centred learning environment and the cognitive and affective factors influencing and supporting learning capacity in various situations and at various times.

Information seeking and avoidance. Information seeking is another variable that may mediate the capacity for self-management and indicate engagement in the change process. Research in this area has increasingly considered the factors influencing information avoidance, with attention from a diverse range of disciplines, but mainly led by communication and psychology scholars (Afifi & Weiner, 2004). Information seeking is an independent, active or purposeful behaviour of the patient (Anker, Reinhart & Feeley, 2011; Lambert & Loiselle, 2007), however largely operationalized in terms of type and amount of information, sources used and actions implemented. Various personal and contextual factors have been found to influence health information seeking (Lambert & Loiselle, 2007). The benefits of acquiring information and practical issues related to sources or processes have been the foci within information seeking discourse and have been based on the assumption that individuals will seek or at least pay attention to information as a basic human desire for learning (Case et al., 2005). This assumption has not been adequately explored and little is known about the factors underlying a desire for information.

Information avoidance within the health care context has increasingly received attention over the last decade (Anker et al., 2011; Case et al., 2005; Johnson, 2014; Lambert & Loiselle, 2007) with evidence that patients utilize nuanced approaches to avoidance. This ranges from a more passive abstinence or guarded disposition toward information to actively avoiding information and purposefully ignoring the threat (Lambert & Loiselle, 2007; Afifi & Weiner, 2004). Selective exposure is also an emerging area in the literature and has yet to be more completely explored. Unfortunately, current research approaches have used forced exposure rather than providing opportunity for the users to exercise preference for exposure (Hastall & Knobloch-Westerwick, 2013). Strategies enabling an exposure preference serve as a means for

individuals to self-regulate emotions and fear (Afifi & Weiner, 2004; Lambert & Loiselle, 2007), providing some indirect evidence of factors influencing readiness. Longo, Schubert, Wright, Lemaster, Williams and Clore (2010) also report a temporal dimension with information overload having an initial paralyzing effect. However, as life events unfolded over time, a shift occurred in patient attitude and his/her desire to seek out information. In fact, the adjustment process may also be a determinant of the kinds of information needed (Mulcare, Schofield, Kashima, Milgrom, Wirth, Bishop & Wheeler, 2011). Among cancer patients, the passage of time offered an opportunity to move through stages - 'being traumatized,' 'taking it on,' and 'taking control' – all requiring different kinds of information and support (McCaughan & McKenna, 2007). However, a very different scenario has been suggested among patients with diabetes where a more active lifestyle change for daily self-management must be carried out alongside managing emotional or psychological effects (Milewski & Chen, 2010). Milewski and Chen (2010) posit that lack of motivation to continue to engage with information may result from the extremely long disease management process and the ongoing challenges of self-management resulting in feeling tired and not caring anymore.

With the varying changes and demands for self-management, patients may experience periods of being more open to information as well as periods of blocking (McCaughan & McKenna, 2007). There is a greater likelihood for avoidance when the consequences are uncontrollable, when individuals feel unable to cope with the information or it is too difficult to understand or interpret (Sweeny, Melnyk, Miller & Shepperd, 2010). Personal beliefs, attitude toward change or recommended action, salience, experience and unpleasant emotions are related to information avoidance (Anker et al., 2011; Lambert & Loiselle, 2007). In addition, earlier research found that purposefully and chronically elevated uncertainty was a coping

mechanism in the face of poor prognosis. This phenomenon is referred to as ‘optimistically uncertain’, where uncertainty serves to sustain hope and optimism. This finding also drew greater attention to the competing factors, emotional context and stimuli vying for cognitive attention and potentially limiting a rational and mindful approach expected of individuals in their engagement with information (Afifi & Weiner, 2004). There is a need to gain a greater understanding of why people do not seek health information and how to address people without information or motivation to engage with information (Kim, 2015).

Adult learning theory. Adult learning theory (andragogy) gained broader understanding among educators due largely to the work of Malcolm Knowles in the late 1960s. He was one of the first theorists to distinguish between adult and childhood or pre-adult learners (Knowles et al., 2011). Several ideologies evolved from a more detailed characterization of adult learners. A more holistic view of the learner considered the influence of mind, body, emotions, social and spiritual context in the learning endeavour (MacKeracher, 2004). Contrary to the ‘cognitive machine’ concept where information is acquired, processed and stored, learning is seen as a process, valuing not only what is learned but cognitive, affective and psychomotor domains for the way it is learned (Spencer & Jordan, 2001). Bloom and his associates framed educational objectives around three domains of learning: cognitive, affective, and psychomotor (Krau, 2011). Notably, behaviour is a key learning outcome but occurs alongside cognitive development (i.e., intellectual ability and skill) and affective development with changes in attitudes and values (Knowles et al., 2011). Bloom’s taxonomy considered the need to move beyond simpler learning tasks and integrate content knowledge into more complex thinking and problem-solving processes and skills (Dettmer, 2006).

Among adult learning theories, it is evident that the learning process involves more than content or communication channels and is dependent upon inner drives, interpersonal energy, and constitutive and transformative dimensions of individualized sense-making and learning (MacKeracher, 2004). Adult learning theories have emphasized motivation and mastery orientation over task or performance orientation. The emotional context for learning has also been a more recent focus in research despite its longstanding presence in educational scholarship. In particular, anxiety within the educational context has shown to have a curvilinear relationship (i.e., Yerkes Dodson effect) with lower learning occurring at the high and low ends of anxiety and arousal (Titsworth, Quinlan & Mazer, 2010). Numerous studies have found negative affect is correlated with stress, psychological distress, and influences withdrawal whereas positive affect is associated with greater behavioural flexibility, broadened attention, motivation and engagement (Saklofske, Austin, Mastoras, Beaton & Osborne, 2012).

The health care context can be an emotionally charged experience. There is ample literature suggesting patients with diabetes or other chronic diseases encounter and suffer with psychological sequelae, from depression to anxiety to fear (Beverly et al., 2012; Milewski & Chen, 2010; Nicolucci, Kovacs Burns, Holt, Comaschi, Hermanns, Ishii,...Peyrot, 2013). While learning theory recognizes the important influence of affect, it has received less attention with regards to learning in the health care environment. In particular, there is very little literature that has examined the patient's perspectives, experiences or self-reported thoughts and feelings that may impact on one's openness or willingness to engage with health information.

Psychological Prerequisites for Learning

Within the education literature, anxiety has been explored as a significant factor for self-regulation or personal control among learners. Investigations of emotions and beliefs that support

self-regulated learning are not new as there has been a long-standing awareness that emotion impacts learning. Emotions and stress have been found to affect learning, memory and cognitive processing (Bridge, Chiao & Paller, 2010; Zoladz, Clark, Warnecke, Smith, Tabar & Talbot, 2011), which in turn, affect a range of tasks including problem solving and judgment (Clare, 2007). Additionally, the beliefs in one's effort, ability and a mastery orientation have been found to impact self-regulation and are also considered part of the cognitive process for self-regulation (Svinicki, 2010). This is supported by other studies and theorists who promote the idea that learning needs to occur in a safe environment (Bigdeli, 2010; Clapper, 2010), and positive emotions are related to successful educational experiences (Mudge, Priesmeyer & Grinnan, 2009). Similarly, positive emotion among individuals in psychotherapy encourages exploratory introspection, helps to broaden thought-action repertoires and fosters openness to interventions (Lewandowski, D'Iuso, Blake, Fitzpatrick & Drapeau, 2011). Alternatively, too much anxiety or emotional stress influences mental, physical and social decline and has a significant influence on learning, information processing and memory (Bigdeli, 2010). Titsworth et al. (2010) also found an anxiety-inducing learning environment required students to engage in higher levels of 'emotion work' and careful management of displayed emotion, which resulted in lower levels of motivation and use of more avoidant coping strategies.

Readiness to learn. Throughout this review, attention has been drawn to the influence of thoughts and emotions and their impact on learning. This relates back to the concept of readiness to learn proposed within Knowles' conceptualization of the adult learner. Within andragogy (i.e., theory and principles related to adult learning), it was assumed that readiness to learn developed from a need, but largely based on role development and experiences in adult development and life circumstance. A second assumption was that adults had different

orientations to learning, which were more likely to be problem-centred and resulting from an experienced inadequacy that has prompted a desire to satisfy a curiosity (Knowles, 1990). Furthermore, the history leading up to and following andragogical theory has a common theme related to the concept of a learner's *dispositional* readiness to learn. Even earlier theorists from the behaviourist tradition, believed there was a law of readiness or the circumstances that support a disposition or feeling toward learning. Later, Maslow (c.f., Knowles, 1990) considered a more holistic approach with an emphasis on various human needs supporting self-actualization. The need for safety or the extent to which one is not psychologically impaired by fear was formulated as one of the fundamental elements in the growth process.

Within the discipline of education, it was also recognized that learning was contingent upon a balance between 'power' and 'load' of the individual learners and particularly evident in adult learners who were trying to balance multiple responsibilities (Clapper, 2010; Hiemstra, 1991). McCluskey's Theory of Margin was based on a formula to determine a load-to-power ratio, which brought greater awareness to the implications of imbalance and the need for educators to consider the role of multiple demands among adult learners (Hiemstra, 1991). This theory was not intended to suggest that adults have a reduced ability for learning, but it is important that the learner first regard the content as essential and meaningful (Clapper, 2010) and internal resources, self-concept, goals and personal expectations are optimized to foster internal power (Hiemstra, 1991).

The research literature around readiness to learn mostly targets developmental growth and change, particularly periods of developmental transitions experienced by children and adolescents. Very little research has further examined the factors influencing readiness to learn among adults. Over time, greater attention has been drawn to the requisite state of cognitive

readiness, i.e., the circumstances or self-actualization deficit underlying a curiosity and subsequent need to engage with and attend to information and education. This intuitively resonates with life transitions or health challenges related to managing diabetes or another chronic health condition. However, there is a dearth of literature examining mental readiness to engage with health information, but may be a fundamental starting point for emotionally and behaviourally managing a health issue.

The concept of readiness to learn is not a well-developed notion within the health education literature. Motivation to receive and process information is one of the necessary pre-requisites for gaining the knowledge required for executing behaviour (Adams, 2010). Readiness may in fact be the initial point in a process supporting self-management, by first recognizing the patient's perspective regarding relevance, acceptance and capacity to address the health problem and further gauged by attitude, motivation and inclination (Adams, 2010). However, there are few means for assessing the cognitive and emotional context as it influences or mediates the need for patient specific learning and information exchange for a health issue.

Readiness to learn is a term that has surfaced within the medical literature, largely from nursing. Authors have emphasized the importance of assessing and recognizing readiness to learn in order to implement a more effective teaching process (Bastable, 2003; Beagley, 2011; Falvo, 2011; O'Connor, 2005; O'Shea, 2001; Redman, 2004; Rosenal, 1992; Tiivel, 1997). However, readiness has been considered in terms of observable evidence and with little direction on how to assess the latent aspects of readiness. Tiivel (1997) described readiness to learn in terms of physiological considerations such as decreased energy related to illness and recovery but also suggested it may be affected by states of grief, denial, fear, anger, and depression. Others have suggested readiness is related to motivation, capability (e.g.,

intellectual, physical and learning), energy and whether the individual is willing and able to participate (Bastable, 2003; Rosenal, 1992). However, the conditions that comprise ‘willing and able’ as well as the underlying emotional and psychological factors of readiness to learn are not clearly operationalized. The concept of readiness has not yet been addressed in terms of the psychological variables that motivate or inhibit openness or receptiveness to engaging with health information. The emotional encounter with a diagnosis resonates with patients but with primarily anecdotal evidence of how difficult it was to process and cognitively participate in the exchange. Previous research has suggested a need to further investigate whether screening patients for readiness and establishing ‘psychotypes’ will better determine engagement with information and education and predict successful understanding and behaviour change (Adams, 2010).

Readiness to learn has also been equated to the ‘teachable moment’ based on the assumption that information need is likely to arise in reaction to a stimulus related to a life change or a perceived threat to well-being, such as with an illness diagnosis (Timmins, 2006). A diagnosis and need for managing a condition may generate a learning need and often patient education is approached in terms of what needs to be changed and not how the change is integrated into one’s life and sense of self (Berglund, 2014). The teachable moment has been conceptualized as an opportunity for instruction and/or learning to stimulate patient actions and behaviours (Cohen, Clark, Lawson, Casucci & Flocke, 2011).

Although relevant across many teaching and learning situations, the teachable moment is a construct with unique challenges in the health care environment. While health behaviour change goals are often the targets for patient education, the interactions are fairly unpredictable as they are constructed through a dynamic, social interaction (Lawson & Flocke, 2009). The

factors that lead to the teachable moment cannot be predicted but tend to be opportunistic (Cohen et al., 2011). Cohen et al.'s (2011) study found cases of teachable moments followed a pattern whereby the provider was building on the patient's concerns and linking the concern to a modifiable health behaviour and motivating that behaviour. Thus, these moments centre on the patient's salient issue(s). This was evident among a range of conditions, with health events that ranged in personal intensity for the patient (Cohen et al., 2011). Recent research has also found that the link to a patient's salient issue was of primary importance as otherwise providing information was found to have a negative effect and changes were worse than if no discussion occurred (Flocke, Clark, Antognoli, Mason, Lawson, Smith & Cohen, 2014). There is still insufficient evidence supporting particular events or timing of interventions for advancing the teachable moment phenomenon. However, psychological factors are important elements for creating these learning opportunities and require further investigation (Lawson & Flocke, 2009).

Motivation.

“...there is simply no change without movement and no movement without motivation.”
(Ryan et al., 2011, p. 199)

Autonomous motivation and volition reflect one's intrinsic or internalized source of goals and interest. This is important for most psychotherapeutic approaches and recognized to be part of a process of successful change when the client becomes actively engaged (Ryan et al., 2011). As a key precursor to change, motivation has been more closely examined and found to be based on attitudes and beliefs (King, Currie & Petersen, 2014), but also influenced by other internal constructs such as psychological adjustment and personality traits as well as external factors or supports within one's environment (Lequerica & Kortte, 2010). In counselling, it is important to identify the energy behind change, for instance, the impetus or reasons for embarking and sustaining the change process. Researchers have suggested that the sequential movement from

intention to behaviour change is not well predicted by the stage of change model and there is insufficient attention to the qualitative differences in why change is pursued. Furthermore, self-efficacy perceptions and beliefs have been considered in relation to distal behaviour change goals but neglected in the research regarding self-efficacy for participating in therapy (Ryan et al., 2011) with a similar conclusion to be drawn for health education.

As a key construct in the therapeutic process, there is a need to understand and appropriately work with varying levels of motivation including resistance (Holdsworth, Bowen, Brown & Howat, 2014). Resistance can be an unconscious defense and the therapeutic process involves exploring the nature of this resistance and the role it serves (Ryan et al., 2011). In psychotherapy, a true measure of amotivation is not evident until participants fail to show for appointments or drop out of therapy. At this point, Ryan et al., (2011) point out that a latent level of disengagement was occurring much earlier and further add: “In so many outcome studies, those who are not motivated or considered ‘ready’ for treatment are ‘already gone,’ a screening luxury the typical practicing counselor or clinic staff member does not have” (p. 196).

Contemporary approaches to counselling value the client volition and motivation, which largely remain part of the theory and application of psychotherapy and counselling. Indeed, many clients are not motivated from the start and may even express fear, ambivalence, despair which compromise embarking upon and persisting with progress toward change. Initial motivation, sustaining motivation and fostering engagement are instrumental and central tasks for most psychological counselling approaches (Ryan et al., 2011).

Therapeutic engagement. Cognitive constructs and emotions have been discussed within the context of behaviour change and skills for self-management. The more specific concept of engagement has been a relevant issue across disciplines with increasing interest in the

process variables involved in and leading to the patient's therapeutic effort. Most research around engagement has stemmed from family therapy and substance abuse where motivation and resistance are very likely to be key issues (Holdsworth et al., 2014). This provides a relevant context from which to explore potential factors underling readiness to engage with health education and information.

While there has been growing recognition of therapeutic engagement as an influential factor for treatment outcomes, there remains inadequate critical exploration or consensus on what engagement means or its determinants (Bright, Kayes, Warrall & McPherson, 2015). While some scholars suggest that engagement should constitute any efforts the individuals make toward change (Holdsworth et al., 2014), the literature generally refers to engagement in terms of the resulting outward behaviours and actions (Bright et al., 2015). However, throughout the literature there is ongoing reference to constructs such as emotional involvement, commitment (Lequerica & Kortte, 2010), expectations, beliefs, attitude, receptiveness, willingness, self-efficacy, a hopeful stance, conviction and confidence (King et al., 2014). Lewandowski et al. (2011) found a number of studies had operationalized therapeutic involvement as engagement based on experiences but also considering the individual's capacity to concentrate and accept the thoughts and emotions associated with therapy. This was much more focused on the therapeutic processes and in-depth exploration of thoughts and feelings regarding therapy. According to Lequerica and Kortte's (2010) review, motivation is best understood as the precursor to engagement, which is ultimately the energy expended at the interface of person and environment.

The evolving conceptualization of engagement suggests a growing awareness of its role within the therapeutic process, but also that it is multifaceted and encompasses multiple domains (King et al., 2014; Lequerica & Kortte, 2010; Mastergeorge, 2009). Scholars have begun to

further differentiate between being engaged *in* and engaged *with* (King et al., 2014) or procedural and substantive engagement with the latter analyzing the emotional investment in learning and extending beyond sheer willingness to participate (Mastergeorge, 2009). Bright et al. (2015) further add that engagement is co-constructed through interactions and therefore considered in terms of the act of engagement, occurring through an internal state but expressed through observable behaviours.

Engagement has not generally been differentiated from participation and involvement, which has further contributed to disagreement in how engagement is conceptualized, leading some to also believe that these terms have contributed to a conflated definition (Holdsworth et al., 2014). Tetley argues that cognitive aspects such as readiness and motivation, commitment and attitude conflate treatment engagement; they may predict engagement but are not factors as it is the manifest active participation that defines engagement (Tetley, Jinks, Huband & Howells, 2011). This has maintained the focus on the behavioural dimension of engagement (King et al., 2014; Tetley et al., 2011) a perspective that is also evident in the health education literature (Gruman, Rovner, French, Jeffress, Sofaer, Shaller & Prager, 2010; Serrano-Gil & Jacob, 2010).

The imprecision in defining and operationalizing engagement in the research literature hampers measurement, theory building and scientific discourse, and the potential to nurture engagement as part of the process of behaviour change (Bright et al., 2015). It is also important to note that the concept of engagement is more frequently based on clinician and researcher perceptions and viewpoints, which has targeted client amenability, resistance, responsiveness or readiness (Bright et al., 2015). Two measures of engagement included in a review found that patients and providers rated engagement differently, which puts reliability and validity into question. The questionable measures along with the lack of qualitative methods to obtain an in-

depth understanding of the patient's perspectives suggest a gap and a need for future research to explore patient experiences (Holdsworth et al., 2014).

Coping and Information Processing Pathways – A Theoretical Framework

This research mainly draws from three theoretical perspectives, each recognizing the emotional and cognitive processes influencing one's reactions. Coping Theory and Personal Construct Theory and theories regarding information processing provide a broad theoretical perspective but highlight the value of a personalized process and experiential knowledge and emotions underlying a response that substantiates readiness for learning.

Coping theory. Understanding the coping process is a fundamental framework within which to consider the ways cognition and emotion influence the capacity to process information and engage with health education generally. Stress and anxiety have been central to the work of many psychology theorists (Lazarus & Folkman, 1984). Early researchers focused on the physiology of stress and stress reactions, which later resonated with coping theorists who recognized the intrapersonal struggles to manage stress (Lazarus & Folkman, 1984). The 1950's saw the emergence of findings that revealed differences among individuals and marked a departure from behaviourist approaches. Research began to consider a more complex mediating process between a stressor and a resultant performance (Lazarus & Folkman, 1984).

The basic premise of coping theory is that individuals appraise stress encounters, which then stimulates various responses along a continuum between problem and emotion-focused responses. Other coping theories have expanded upon Lazarus and Folkman's work resulting in a large volume of literature related to coping in many domains, including health care. As the coping literature has matured, 100 coping assessments and 400 ways or categories of coping have been developed. This has prompted development of a hierarchical structure to map out

coping processes. However, problem and emotion-focused coping have remained as higher order adaptive processes to categorize the numerous ways in which individuals respond to stress (Skinner, Edge, Altman & Sherwood, 2003). Lazarus and Folkman also described the problem and emotion-focused coping continuum in terms of more specific responses, ranging from confronting the problem, accepting responsibility, seeking information and social support, to distancing or detaching and escaping or avoiding the problem or circumstance (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986; Lazarus & Folkman, 1984). Coping appraisal was also thought to be influenced by psychological variables, circumstances, time and personal resources. This shifted the thinking from causal reference to fixed personality traits or operant conditioning. In fact, empirical evidence was reportedly overwhelming in support of an appraisal process shaping responses over traditional non-cognitive models such as reinforcement and arousal (Lazarus & Folkman, 1984).

Cognitive appraisal and construal. The mediating process of cognitive appraisal and personal construal is the phenomenon of interest for this research study as thoughts and emotions have been shown to have important influences in education, communication and information processing. Construal and appraisal are based in constructivist philosophy foundational to psychoanalytical assessment, which seeks to understand how an individual uniquely comprehends or construes the world and to identify possible distortions. Reducing one's inner constraints and enhancing individual capacity and power to act is frequently the starting point toward a psychotherapeutic goal (Ryle, 1975). The central assumption in Personal Construct Theory is that people strive to make sense of their world and construct the meaning of their lives by devising their own personal theories or construct systems. Each of the constructs is a representation of a personally developed model of an individual's lifeworld. These constructs are

the ways in which people view or construe the events around them in order to differentiate, integrate and predict their surroundings. Construal is based on beliefs and hypotheses stemming from individual experiences and may be based on idiosyncratic or broadly shared theories that inform how one views or construes the lived experience (Caputi, 2012; Fransella & Bannister, 1977). Although not immutably fixed, reality is represented by an individual's grasp of it and his/her unique experiences (Ryle, 1975). This is particularly relevant to person-centred care, which focuses on the experiences of individuals and their individualized needs, concerns, beliefs and health goals.

Information processing. Further examination of the coping appraisal process has resulted in two proposed processes: primary and secondary appraisal. Primary appraisal refers to what the individual perceives to be at stake in the stressful encounter (Folkman et al., 1986). In secondary appraisal, the individual evaluates coping options, what might be done, and the likelihood of an expected outcome considering one's ability to apply the behaviour (Lazarus & Folkman, 1984). Scholars interested in information processing have also proposed dual-process models of cognitive functioning, with unconscious and conscious levels of brain activity. A dual process model of information processing is based on a conceptual integration of theories and theoretical debate around the cognitive processing functions experienced by individuals on an ongoing and regular basis. Numerous theorists have agreed there are two modes or systems at work in cognitive processing. Humans are thought to have more evolved, higher order cognitive functions that work to produce responses, i.e., immediate 'fast-binding' perception as well as slower purposeful learning with evidence of neuro-physiological differences (DeWall, Baumeister & Masicampo, 2008; Smith & DeCoster, 2000).

The important differentiation for these two systems is in pre-conscious or automatic responsiveness versus the need for analytical conscious processing. For example, a more conscious level of brain activity is required when first learning to ride a bicycle. After prolonged use, the knowledge and know-how stored in memory enables one to ride a bicycle with ease and with less intentionality. A more conscious and vigilant approach is required for a complex performance such as riding a bicycle while navigating a busy traffic intersection. According to Dual Process theories, the knowledge stored in memory allows one to preconsciously carry out a certain perfunctory level of performance while more consciously attending to that which is novel and unexpected (Smith & DeCoster, 2000).

The persuasive appeal literature also draws largely from classic and contemporary theories of information processing. The Elaboration Likelihood model is frequently encountered in the persuasion and communication literature and suggests multiple psychological process changes are operating based on the level of elaboration (i.e., thoughtful consideration or scrutiny) on the information communicated. The central route of information processing is used when there is high motivation and ability to think about a message and assess information, however, requiring a higher level of energy, time and mental effort. Peripheral processing occurs when the message carries little interest or there is less ability to examine or process the information. It also assumes people have limited resources and cannot expend equal effort in processing all messages (Kim & Nan, 2012; Petty & Cacioppo, 1986). To account for reactive as well as thoughtful, logical information processing, research began to look beyond content and quality of messages and more toward the level of involvement of the receiver, based on intrinsic importance or personal meaning (Petty & Cacioppo, 1986). Thus, less elaboration of a message may be due to attitude, personal relevance, distraction, available cognitive resources (i.e., load or multiple

tasks) and existing knowledge. The Heuristic Systematic Model introduced by Eagly and Chaiken (Chaiken & Trope, 1999) bears a great deal of conceptual similarity to the Elaboration Likelihood Model but emphasizes concurrent processing (Kim & Nan, 2012). These theories became the centre of attitude research and have been applied to real-world contexts in health communication. The significance of these theories is in the description of how information processing is compromised and the situations contributing to lower processing or selective attention. This may be a particularly salient consideration for health education or information within the emotional context of health management.

Dual process models consider the role of cognitive capacity in terms of available processing time, task-relevant background knowledge and attentional resources. As such, processing is more susceptible to distraction and lessened attention resulting in an automatic response based on experiential cues (Smith & DeCoster, 2000) and difficulty integrating new information (DeWall et al., 2008). Given adequate time for the slow rule-based processing, a more thoughtful goal-oriented response may ensue. The automatic system has difficulty integrating larger diverse sets of information (e.g., the role of the conscious controlled system) but excels at processing simpler discrete pieces of information. Each serves an adaptive function because they have complementary contributions (DeWall et al., 2008). DeWall et al., (2008) contend that conscious processing is responsible for logical reasoning and therefore, cognitive overload will impair this ability. Similarly, Lavie's Load theory (Lavie, Hirst, De Fockert & Viding, 2004) has explored the role of selective visual attention and found cognitive control has a direct role in altering distracter interferences, but efficiency is a dual-task coordination function of working memory and cognitive control, both originating in similar regions of the brain.

Availability of these resources and the intensity of the stimulus that requires attention will affect the efficiency of selective attention.

The Strength Model of Self Control developed by Baumeister and colleagues (Baumeister, Vohs & Tice, 2007) also suggested processing modes can be impacted by a limited intrinsic resource or ‘energy’ and will alter one’s responses to meet expectations, rules or priorities. It further hypothesizes that thought control, emotion control, impulse control and task performance all share the same intrinsic resource (Baumeister et al., 2007). When these resources are depleted, logical reasoning and other controlled cognition processes (i.e., slow-learning or ‘rule-based’ processing modes) are compromised (Baumeister et al., 2007). Emotion regulation operates under similar principles suggesting that when mood or emotional repair is required, it may take precedence and impact efforts for regulation and self-control (Tice & Bratslavsky, 2000).

Cognitive influences on affect and emotions, particularly with regard to attentional control and information processing, is supported by empirical neuroscientific evidence. Neuroscience researchers report to have mapped neural systems associated with fear and anxiety and attentional selection as part of a complex neural circuitry (Ptak, 2012). The amygdala has been at the centre of studies examining functions related to attentional vigilance, encoding memories, and initiating approach and avoidance responses (Lazarus & Folkman, 1984). Future research is suggested to understand the affective constructs and the functions of emotions that may mediate message processing leading to behaviour changes. It is also suggested that future research seek to identify the ways in which variables can have an impact on persuasion, why messages may be weak or strong or why certain variables influence information processing (Kim & Nan, 2012).

A purposeful change in behaviour might suggest one has taken a problem-focused approach for managing a health condition. However this is not always the response to a health problem. Based on the emotional context of the health care setting and the challenges in self-managing a chronic health condition, coping theories have offered insight regarding the mediating processes of cognitive appraisal. A more in-depth analysis of the appraisal process reveals a number of variables and a great deal of complex interplay within the cognitive and emotional appraisal process, which may affect information processing and a general readiness for the patient to learn or participate in information exchange.

Summary

The evolution of patient education has resulted in an increasingly greater role expected of patients in self-management, representing a shift from a medico-centric approach to one that considers the active engagement of the patients (Glanz et al., 2002; Hoving et al., 2010). However, the shift toward more self-management, especially among patients with diabetes, has created an educational focus on behaviour change (Glanz et al., 2002; Hoving et al., 2010; Jones et al., 2013). While this is immensely important for managing diabetes and other chronic illnesses, the research falls short in examining existential concerns, psychological and social dimensions, personal capacity, personal and cultural understanding and other cognitive and emotional mediators for learning and acquiring self-management competence (Adams, 2010; Albano et al., 2008; Burke et al., 2014; Formosa et al., 2012; Hibbard et al., 2004; Jones et al., 2013; Sapkota et al., 2015; Serrano-Gil & Jacob, 2010).

The behaviour change models in this review were specifically chosen based on their consideration of cognitive factors. These have also been critiqued for their inability to predict sequencing or transitions among stages of change (Ryan et al., 2011), or inadequate

understanding of cognitive and motivational constructs regulating the participation of less activated patients (Hibbard & Greene, 2013; Smith et al., 2013; Woodard et al., 2014). The emphasis on objectively defined behavioural outcomes does not encompass the cognitive and emotional factors underlying readiness to engage with learning and information. An emphasis on observable interactions and outcomes is also evident in the research around health communication. This has prompted a greater focus on the information content and modes of communication, and less consideration of psycho-emotional issues that may mediate information processing and understanding.

There remains a need to more closely scrutinize learning as a process with more proximal outcomes and cognitive transformations mediating behavioural outcomes. Similar to patient-centred approaches to care, health education needs to be tailored to the patients' needs. This requires consideration of the variations in personal, psychosocial and situational variables and the tensions that arise from personal constructions and appraisals as they are reflected in one's own lifeworld. Previous research recognizes the importance of assessing information uptake and patient receptiveness but has been primarily considered in terms of objective, observable identifiers or markers (Constand et al., 2014) rather than awareness of the cognitive and affective factors influencing the interaction. Without this understanding, there is less ability to address the variables that may mediate and impact the learning process.

A more holistic approach is consistent with adult education principles and theory where learning is seen as a process occurring across the cognitive, affective and psychomotor domains. Learning theories also recognized inner drives, cognitive 'load', interpersonal energy and emotional context. Thus, learning is a more complex process than simply 'depositing' information (Lavie et al., 2004; MacKeracher, 2004). However, cognitive and affective

influences on patient learning have had minimal research consideration. Yet, it is in the healthcare context where negative thoughts and emotions are pervasive and could have significant influence on learning. The idea of being ‘willing and able’ is a notion that seems intuitive yet has not been clearly operationalized in the health education literature. There has been some attention on the related notion of a teachable moment. However this is generally associated with the assumption that a change in health status sharpens one’s focus on the need for knowledge and greater attention to what the knowledge deficits are (Timmins, 2006) but an inability to predict such opportunities (Cohen et al., 2011).

Motivation is an important concept that pervades the problem of readiness to engage in learning. There may also be a number of underlying co-occurring constructs influencing both motivation and mental readiness for learning. In fact, strategies to regulate emotions and emotional turmoil may result in self-regulating information exposure, a reluctance to partake in discussions or information or may limit one’s ability to actively participate, focus attention and assimilate information in the medical encounter. However, this phenomenon has not been explored to determine how it affects education and information uptake and learning capacity more generally. There is a paucity of research literature regarding demotivation or resistance, especially with patients who may be dealing with a complex and precarious health situation. Why people do not seek health information and how to engage people who are not motivated or ready remain challenging unanswered questions (Kim, 2015).

Resistance and engagement are two variables of primary concern in the psychotherapy environment. However according to two reviews (Bright et al., 2015; Holdsworth et al., 2014), there remains inadequate critical exploration or consensus on what engagement means or its determinants (Bright et al., 2015). In particular, the mental aspect is less well-developed than

more objective or behavioural dimensions such as participation and involvement (Holdsworth et al., 2014). The literature generally refers to engagement in terms of the resulting outward behaviours and actions (Bright et al., 2015); a perspective that is also evident in the health education literature (Gruman et al., 2010; Serrano-Gil & Jacob, 2010).

Finally, it is evident in the literature there is limited prominence of the voice of patients and how they specifically and uniquely experience and perceive health education and the self-reported thoughts and feelings that may impact their openness or willingness to engage with health information. The goal of this research focusing on readiness to learn or cognitively engage with health education is to guide a more patient-centred approach for addressing all domains of learning. Holdsworth and colleagues' (2014) review of engagement provides an important example of how the concept of therapeutic engagement has been more frequently considered in terms of clinician and researcher perceptions rather than those of the patients. However where patients provided input, they rated engagement differently (Holdsworth et al., 2014).

This research is guided by coping and information processing theories, which provide a framework to more closely consider cognitive appraisal and personal construal as the mediating process between the stressor and the reaction (Folkman et al., 1986; Lazarus & Folkman, 1984). There is also an automaticity or habitual thinking that must be considered by both provider/educator and patient/learner. With an investigation more focused on cognitive appraisal and personal construal in light of information processing models, this research aims to uncover deep-seated thoughts, assumptions, perspectives and emotions as important and influential elements for setting a learning stage.

This literature review has presented a range of concepts and theories as a foundation upon which to understand the concept and variability of readiness to learn in the healthcare domain.

Indeed, existing theories and concepts within the literature discussed here have shed light on the breadth and complexity of learning and self-management, but have mainly focused on behavioural involvement and outcomes. There is a need to understand the patients' thoughts and feelings underpinning readiness. This may also contribute to the development of theory and educational practices. With the ability to conceptualize and operationalize readiness to learn as part of the health education and behaviour change process, there is greater opportunity to intervene, nurture and enhance engagement as part of the learning process. Addressing the current gap begins with exploring the patients' experiences and the factors they deem to be most influential to readiness to learn and engage with health information.

CHAPTER 3: Research Methodology

The purpose of this chapter is to articulate the research methodology for exploring patients' experiences with health information in the health care setting and the phenomenon of readiness to learn or engage with the information. My research paradigm is based on pragmatism more generally; I do not assume qualitative and quantitative methods are competing or contradictory but offer the opportunity for multi-method, transdisciplinary research strategies to attend to the purpose of the research (Marks & Yardley, 2004; Ritchie & Lewis, 2003). However, the research around patient education has largely targeted content and communication, with less attention to the patients' perspectives or experiences that may influence their responsiveness. Given this deficiency and my own observations of patient's reactions to information in practice, I was interested in a more in-depth exploration of experiences with health information in the clinical setting. Thus, the nature and scope of this inquiry are best suited for a qualitative approach to explore patients' experiences in terms of readiness to learn or cognitively engage with health education.

This chapter begins with the philosophical foundation for this study, including the philosophical origins and key theorists underpinning the methodological choices. Against the backdrop of pragmatism and its origins, an ideological intersection of evidence-based, patient-centred care and education is described and reflects the complexity inherent in the human experience of health conditions. The research design is based on hermeneutic phenomenological inquiry and is well-suited to enhancing understanding of an implicit phenomenon such as readiness to learn. More specifically, the study approach draws from Interpretative Phenomenological Analysis (IPA) and is based on Smith and Osborn's (2003) guidelines for conducting research from an IPA perspective. The study design and methods regarding sampling,

ethical considerations, and the procedures for data collection and analysis are described. The chapter concludes with a discussion regarding rigour and integrity of the research as regarded within the qualitative paradigm.

Pragmatism's Origins

The pragmatist tradition can be traced back to the earlier work of such philosophers as Kant, Emerson, and Holmes (Ormerod, 2006). However, as a doctrine it originated with Peirce, James, and Dewey at the turn of the 20th century and marked the emergence of classical American pragmatism (Cornish & Gillespie, 2009; Kegley, 2014). For Peirce, pragmatism was a philosophy based on meaning as it could be applied in the real world (Ormerod, 2006). James brought pragmatism to the intellectual community but focused on the plurality of personal meaning. This plurality defined truth in terms of beliefs that are shaped by reality, human activity and within a given context. One of James' most important contributions was that knowledge was based on perception and interpretation, with an inherent fallibility in the mind's reflections and uncertainty in the events of the universe. Ultimately, he proposed that reality is based on the limits of what one is able to know and largely based on pure experience (Ormerod, 2006). Dewey followed James and continued to regard pragmatism in terms of experience, while building on this philosophy within the fields of education and politics.

The re-emergence of pragmatism in the late 20th century stemmed from renewed interest in methodologies that prioritized the practical importance of knowledge rather than in pursuit of absolute truths (Johnson, 2007). Pragmatists underscored the importance of focusing on people and their activities. These were the starting points for research which would move beyond abstract generalizations and need not be guided by epistemologies of ultimate truth and knowledge. There was less interest in philosophical debate other than to serve practical

significance (Cornish & Gillespie, 2009; Johnson, 2007) or seeking knowledge that might transform the present and with the intent of generating future possibilities (Rosiek, 2013). Additionally, the complexity of the human condition and the dynamic nature of the world were also presumed to yield fallibilistic theories and only tentatively reveal reality; minimizing uncertainty was considered the best that could be attained (Brouse et al., 2005; Ormerod, 2006).

The human experience as inquiry. Dewey's emphasis on the human experience was a purposeful effort to differentiate pragmatist philosophy from the philosophies of his day, which revolved around metaphysical discussions of the nature of reality or truth. Beckoning to these early epistemologies, quantitative and qualitative research methodologies have been historically aligned with particular paradigms to guide the research process. With the emergence of a pragmatist approach, greater emphasis was placed on why research was being done rather than how it was being conducted. The primary focus was on the research goal, interests and purposes served by knowledge and the meaning and consequences of actions and events (Cornish & Gillespie, 2009; Morgan, 2014). Pragmatism subsequently began to be equated with practicality and problem solving, an emphasis which, Morgan (2014) argues, fails to fully comprehend the philosophical foundations of pragmatism. Although the fundamentals of pragmatism are well suited to problem solving, he urges closer examination of Dewey's process of inquiry rather than the search for an idealized endpoint.

Dewey's process of inquiry centred on the concept of experience. He suggested that experience was a cyclical process of actions and beliefs. This process involved interpretation; beliefs were interpreted as part of initiating action and prior actions were interpreted to generate or reinforce beliefs. This cycle occurs somewhat automatically through habit and Dewey's process of inquiry aimed to examine it more closely and reflectively. It centred on two

inextricably linked aspects of experience - antecedents for beliefs and the beliefs influencing actions (Brouse et al., 2005; Morgan, 2014).

The Deweyian concept of experience was historically and culturally situated and particularly dependent upon the changing nature of one's circumstances (Morgan, 2014). Disregard for context and the role of experience within inquiry is what Dewey referred to as the philosophical fallacy (Kestenbaum, 1977). A contextualist approach to philosophical inquiry is another major tenet of pragmatism, whereby prior experience is related to the outcomes of an action. The world is a context of meaning and described as the horizon or backdrop of all experiences and perceptions that cannot be transcended (Rosenthal, 1980; Rosiek, 2013). As such, the process of inquiry requires reflection due to the habitual nature of actions. History, culture, emotions including language and traditional habits mediate between the inquiring subject and the reality under investigation (Cornish & Gillespie, 2009; Creswell & Plano Clark, 2007; Rosiek, 2013).

To reiterate, pragmatists believe meaning cannot precede experience of an event (Morgan, 2014) and emerges as part of a cyclical process of beliefs and actions. Dewey was rejecting neither positivist or constructivist claims but felt that each were equally important for human existence within the world. "From the pragmatist perspective, *all* human inquiry involves the interpretation, intentions and values which constructivists regard as paramount – but must also necessarily be grounded in the empirical, embodied experience which realists regard as fundamental" (Marks & Yardley, 2004, p.5). In essence, inquiry is constrained by a material and experiential practicality. Experience and knowledge, by extension, are the implicit parameters within which humans investigate, interpret and understand situations and the world.

Ideological intersection. The recent renewed consideration of pragmatism has largely been through frequent association with mixed methods research as a methodology. While considered to be uncommitted to a particular epistemology, mixed methods research focuses on combining the strengths of qualitative and quantitative approaches (Mesel, 2013). This coming together of methodologies has strong parallels to the tension encountered between evidence-based practice and patient-centred health care. With the emergence of evidence-based practice, many health practitioners appreciate the importance of scientific rigor as an important and fundamental building block for providing elements of proof and rationality for the best patient care (Rycroft-Malone, Seers, Titchen, Harvey, Kitson & McCormack, 2004). A quantitatively based evidence hierarchy deems certain approaches as more valuable for informing practice. Certainly, most people would hope for the highest level of predictability and certainty in our own health care treatment and outcomes. However, many individuals do not fit the research situations defined by inclusion criteria or the controls mediating the treatment implementation (e.g., comorbidities that are frequently encountered in practice). Nursing research, for one, has found that empirical knowledge and clinical reasoning are interwoven with subjective knowing based on personal experiences, past patient encounters and clinical experiences (Bonis, 2009; DiCenso et al., 2005; Dopson & Fitzgerald, 2005).

From a pragmatist perspective, practicality requires consideration of the whole person in a broader context. Each individual presents with complexity in relation to managing a health condition, which is further compounded by the range of individual needs, lifestyle and contextual factors. Thus dealing with a wide range of patients requires adjustment to multiple needs, and approaches that are responsive to individualized needs and desired outcomes. Within the health education context, this complexity considers experiential and relational factors (i.e.,

connectedness, caring, trust) or the antecedent motives and emotions that influence outcomes (Brouse et al., 2005). Exploring and understanding this complexity lies at the intersection of pragmatism and phenomenology. The methodological convergence is best described by Rosenthal who stated that scientific method is the pre-reflective root knowledge upon which behaviour is understood while the dynamics of lived experience are the grounding for science (Rosenthal, 1980).

Phenomenological Traditions Informing the Methodology

Phenomenology originated as a philosophy and largely emerged with the work of Husserl and later Heidegger. It centred on the idea of ‘lived experience’ as the fundamental source of knowledge, with an emphasis on the world as lived by a person, not the world or reality as something separate from the person (Lavery, 2003). Phenomenology also rejected the idea of knowledge discoveries or uncovering knowledge that mirrors a universal truth or reality (Dowling, 2007). Further, the distinction between mental and physical phenomena resulted in an act of mind *toward an object* or ‘intentionality’. Husserl posited that there must be a subject to experience a phenomenon or project meaning onto an object and intentionality could not be studied empirically (Dowling & Cooney, 2012). This sparked a critical movement against applying natural science methods to issues of human science and the advent of new approaches to inquiry, particularly in the realm of psychological reality (Lavery, 2003).

Husserl charged that earlier empirical approaches were focused on reactions to stimuli that were contextually isolated and largely ignored human responses based on perceptions of the meaning of stimuli (Lavery, 2003). He further argued that people arrive at certainty in the way things are perceived within immediate experience and their ‘lifeworld’ (Dowling, 2007; Groenewald, 2004). Yet, he felt people immersed in a phenomenon shared invariable parts. As a

result, a level of objectivity could reliably describe a phenomenon through phenomenological reduction or bracketing out the outer world. Furthermore, bracketing would allow one to directly grasp consciousness, the agent that attributes meaning to objects (Lavery, 2003; Sadala & Adorno, 2002). Husserl's scientific idealization of experience and seeking an objectified essence within consciousness seemed to be influenced by a positivist framework despite his intention to depart from this epistemology (Lavery, 2003).

Hermeneutic Phenomenology. Both Husserl and Heidegger were seeking to examine human experience as it is lived and reveal what they believed was lost through the use of empirical scientific explorations (Lavery, 2003). However the need to refrain from judgment by way of bracketing preconceptions marked a difference between the two philosophers (Dowling, 2007). Heidegger's approach acknowledged acting and knowing as part of everyday involvement with the things in our world. Fundamentally, experience is what defined the parameters of human consciousness and there was nothing that could be grasped outside of experience (van Manen, 2007). Heidegger emphasized interpretation of phenomena rather than description, with interpretation being a fundamental means for further understanding (Lavery, 2003). This difference in perspective around interpretation also marked a difference in the way Husserl and Heidegger explored lived experience and resulted in two distinct ideologies - the eidetic (descriptive) and hermeneutic (interpretive) (Lavery, 2003).

Heidegger's existential approach introduced the idea of *Dasein*, translated by many to convey the idea of situated meaning by 'being-in-the world.' This approach involved interpretation influenced by pre-understanding, which he described as the meanings, history, background or organization of a culture that are present before we embark on further understanding. The interaction of pre-understanding and experience was considered a necessary

condition for interpretation and part of the process of understanding, and the formative basis of consciousness. This was a significant point of divergence from Husserl, and initiated the branch of hermeneutic phenomenology (Lavery, 2003).

Hermeneutics has a long history in academic practice and in the interpretation of text. The interpretive movement within phenomenology has drawn from hermeneutic processes to uncover the meaning embedded in life practices and experiences, and which might normally be hidden in human experience (Lopez & Willis, 2004). Hermeneutic phenomenology, while still focused on human experience as it is lived (i.e., one's lifeworld), considers human beings not as passive perceivers of an objective reality but who interpret their world by formulating their own biographical stories in order to make sense to them (Brocki & Wearden, 2006). Heidegger believed every encounter involved interpretation by the individuals who are influenced by their context or 'historicity.' He developed the concept of co-constitutionality which refers to the philosophical assumption of indissoluble unity between the person and the world, which influences the co-creation of understanding based on being constructed by the 'world' as well as constructing the world from one's experience and background (Koch, 1995).

Heidegger's student, Hans-Georg Gadamer, was instrumental in moving Heidegger's work into practical application. He focused on the conditions in which understanding takes place rather than the procedures involved in promoting understanding (Koch, 1995). This further highlighted Heidegger's interpretive process, which he termed the hermeneutic circle. As part of the hermeneutic circle, the interpreter brings a background and a particular frame of reference and meaning which cannot be bracketed and has a bearing on the act of understanding (Koch, 1995). Gadamer used the metaphor 'fusion of horizons' to explain the process of interpretation (Lopez & Willis, 2004). While interpretation is bound by individuals' unique vantage points, it is

at the intersection or fusion of horizons where dialectical and interpretive interaction occurs (Laverty, 2003; Lopez & Willis, 2004). Rather than subjectivity getting in the way, Gadamer proposed that it made the research meaningful to its consumers (Koch, 1995) and, in essence, a shared horizon facilitated shared understanding.

Several schools of phenomenology developed over time, with philosophies evolving from the European (or Continental) branch and emerging within North America. The North American branch focused on applying the philosophy to research and focused on the study of individual's experiences as they engage with the world or a phenomenon, rather than phenomenological reduction and a more objective reality. As such, it was thought to be linked to the pragmatist philosophy and more concerned with understanding the human condition and the reality of experience as people engage with a phenomenon (Caelli, 2000; Dowling, 2007; Dowling & Cooney, 2012). By the 1970's, social researchers were challenging the scientific method, with concern that it is neither possible nor appropriate to control variables when studying human behaviour and the meaning and purposes of behaviour should not be disregarded (Ritchie & Lewis, 2003).

Exploring the lived experience and simply being in the world reflects a practicality comprised of actions, relations and situations as encountered in daily life (van Manen, 2007). This research draws from the hermeneutic-phenomenological tradition of which proponents emphasize that lived experience is captured to the extent it is present in the language used to convey the experience and inevitably requires an interpretive process (van Manen, 2007). Van Manen (2007) further urges consideration of the formative value of phenomenology in its potential to create and bridge possibilities and relations between the present and the future based on how we think, feel and act and the implications for everyday life.

Interpretative Phenomenological Analysis (IPA). Hermeneutic phenomenology seeks to explore and obtain greater understanding of experiences while focusing on the meaning that arises from the interpretive interaction (Laverty, 2003). This is the methodological basis upon which Smith and colleagues (Smith, Flowers & Larkin, 2009) developed Interpretative Phenomenological Analysis (IPA), used most notably in Health Psychology. IPA has drawn insight from three main areas: phenomenology, hermeneutics and idiography (Shinebourne, 2011; Smith et al., 2009). According to Smith et al. (2009), IPA has a strong phenomenological slant which rigorously examines idiographic subjective experiences, and seeks to capture the uniqueness of those who are directly involved with a phenomenon and can provide expert insight (Reid, Flowers & Larkin, 2005).

However the participant's context of cultural and socio-historical meanings limits the capacity for others to understand the world from the participant's point of view (Shinebourne, 2011). The participant's lived experience is part of a subjective process of interpretation requiring an explicit analytical role for the researcher (Reid et al., 2005). The analysis maintains a commitment to the idiographic approach and focuses on a specific situation by specific individuals. Methodologically, this involves intense detailed analysis of accounts from which patterns of meaning and themes are formed (Larkin, Watts & Clifton, 2006). The interpretive process requires a balance of 'emic' and 'etic' positions whereby the researcher moves between an empathic effort to understand the situation as experienced by the participant while critically questioning and speculating around what is being conveyed by the participant and what else might be transpiring (Larkin et al., 2006; Smith, 1996). This also involves a 'double hermeneutic' in which the researcher is trying to make sense of the participant trying to make sense of their experiences (Smith & Osborn, 2003) and further complicated by the

preconceptions of the researcher (Laverty, 2003; Smith & Osborn, 2003). However, the philosophical assumption of IPA is that the researchers' suppositions are valuable for guiding a co-constructed meaning and not overly concerned with biases that need to be eliminated (Smith & Osborn, 2003).

The process of inductively interrogating and analyzing the data to link themes and patterns to theoretical knowledge is done through coding, organizing, integrating and interpreting the data (Shinebourne, 2011). The iterative movement between the emic and etic perspectives contributes to the development of an initial descriptive analysis. However, the inquiry can transcend the simple collection and description of participant narratives by considering the wider social, cultural and theoretical contexts and directly engaging with existing theoretical knowledge. Larkin suggests researchers can draw from considerable 'interpretive range' to make insightful inferences about affective and cognitive phenomena, provided they can relate back to the core phenomenological data. This engagement with other forms of knowledge holds rich possibilities for insightful interpretation (Larkin et al., 2006).

Due to the implicit nature of the readiness construct under investigation in this research, IPA was a suitable means for gaining a sense of the human response at the intersection of specialized medical knowledge and the lived, contextualized reality of those living with the health condition (Lopez & Willis, 2004). If the way an individual construes a situation is a factor in determining their response, then a more in-depth examination of their accounts should prove useful in understanding cognitive models and implicit aspects of individual behaviours such as attitudes, triggers and obstacles to health behaviour changes (Smith, 1996; Smith, 2011).

Method

Sample. My research goal stemmed from an interest in understanding readiness to engage with health information among patients who are coping with a chronic condition. To

narrow the scope of this work, I chose to interview adult patients with Type II diabetes due to their experiences with health information and requirements for daily self-management. In order to gain a range of perspectives, I targeted a convenient, purposeful maximum variation sample of participants from two sites: a primary care clinic and a hemodialysis unit within a tertiary care centre. I expected both groups might have different perspectives and accounts based on the point of time within their illness experience. This will add to the range of personal construal I am seeking for this study and was not intended to provide a means for comparison.

In order to gain access to the patients on the dialysis unit, I described my research to the Regional Director for the Manitoba Renal Health Program. I then met with the dialysis unit Nurse Manager and Manager of Patient Care at the Winnipeg hospital where the data was to be collected. The Nurse Manager designated one nurse who was provided with a script (Appendix A) for approaching patients on the unit to inquire whether they were interested in hearing more about the study and the potential for their participation. In addition, a poster (Appendix B) was posted in the waiting area inviting participation. For individuals who expressed an interest, a study-specific leaflet (Appendix C) collected the potential participant's name and contact information (phone number or email address).. I picked up the completed leaflets directly from the Nurse Manager. Alternatively, some patients chose to keep the leaflet, which had my name and contact information in case they preferred to call me directly. It stated clearly on the form that it was not a means for 'signing up' for the study, but for acquiring further study information directly from the researcher.

In the primary care clinic, I described my study to the acting clinic director and also met with the diabetes nurse/educator who then facilitated distribution of the leaflets and information about the research study. A study poster was also posted in the waiting area and included my

name and contact information for further communication. Once the patient's permission was obtained through the diabetes nurse/educator, I followed up with further information. I also received a few phone calls from people who had read the poster in the waiting area.

Among the individuals who provided their names to the nurses introducing the study, I did not reach a total of 14 individuals who expressed interest. I reached saturation prior to contact with five individuals. A further two patients on the dialysis unit declined and I was unable to contact two others as one was transferred to another facility and the other had incorrect contact info. Three other patients on the dialysis unit and two individuals from the primary care clinic agreed to participate and set up appointments but at the time for the interview they were not feeling up to doing the interview, preferred to sleep during treatment or were occupied with other medical procedures. In most cases, more than one appointment was attempted; a subsequent appointment was not made if the second attempt was also not successful as I was trying to avoid having this study become intrusive. The sample size and characteristics of the participants are presented in the results section, in Chapter 4.

Ethical Considerations. The University of Manitoba Education/Nursing Research Ethics Board (ENREB, Ft Garry Campus) approved this study (Approval letter in Appendix D). The dialysis unit and the primary care clinic were affiliated with two separate hospital review boards. Each reviewed and approved the protocol (approval letters in Appendix E). The Manitoba Renal Program Regional Director also reviewed the protocol after the University of Manitoba ENREB approved it.

Once I contacted the interested patients, provided information and answered all of their questions, we agreed upon an interview time and location. At the time of the interview but prior to beginning the data collection, I reviewed the study description and consent form and obtained

written informed consent without bias or coercion (Consent form in Appendix F). I personally conducted all interviews. To respect the participants' rights to privacy, I explained the option of abstaining from questions deemed too invasive or sensitive. Additionally and at the request of ENREB, I prepared a list of resources that could be accessed at each site in case the research study caused undue stress for the participants (Appendix G). The participants were also assured of confidentiality as the consent forms and de-identified interview data were stored on a password-protected computer or in a locked file cabinet at the University of Manitoba, Department of Family Medicine Research office. The individual who transcribed the interviews is a semi-retired medical office assistant and has been transcribing research data for many years and aware of data privacy and protection legislation. She signed a pledge of confidentiality for this study. The data was personally exchanged to ensure protection. I gave each participant a \$20.00 gift card as a gesture of appreciation for the time provided to this study. This was not a sufficient amount to be considered compensation for the anticipated and actual interview durations (most were expected to last 1-1.5 hours) and therefore not likely to have unduly persuaded people to participate.

Data collection. The interviews were conducted at each participant's preferred time and location. Many were most willing to have the interview while undergoing treatment on the dialysis unit. This saved them a trip and also provided an activity during the treatment time. Others preferred an alternate location such as their own homes or a coffee shop. The dialysis unit was not optimal as there were interruptions and background noise. However, this was convenient for the participants and I simply moved aside when medical personnel needed to speak or attend to the participant and resumed the interview once the participant said they were ready. The

interviews were recorded using two devices placed in different areas, which helped to overcome audio challenges.

The first three participants provided an opportunity to pilot the interview. As a result of this pilot phase, I abandoned by my original intent of using the Repertory Grid (RepGrid) Technique (Jankowicz, 2004). The intent was to use this tool as a means for keeping the interview focused on constructs related to receptivity to health information. It became quickly obvious the participants had rich narratives they wanted to share. It was also easier for the participants to begin with a brief biography of their journey with diabetes, from diagnosis to their current status. As they conveyed instances of information exposure in the health care setting, I was then able to engage them in deeper exploration of thoughts and feelings within specific contexts. I felt this introspective analysis and the descriptions provided had to evolve within the narratives and could not be neatly provided as participant generated constructs. The phenomenon under investigation was abstract and much more difficult to objectively describe or define in terms of a developed construct. Further, mapping these constructs required the development of concrete ideas amidst the complexity of ones' narratives, and the means for labeling these constructs 'in the moment.' Seeking these constructs through the RepGrid Technique immediately felt like I was putting limits on what the participants could contribute. It also put me in a position of controlling the conversation and significantly narrowed the discussion. Other researchers have suggested that openness is critical (Jankowicz, 2004) to encourage the interview process to stay close to the lived experience (Lavery, 2003). It was not a natural adjunct to the conversation, particularly on the dialysis unit where participants were in beds and there was little opportunity to participate in the creation of a grid. In all three pilot interviews, I tried using the

RepGrid but within the first 15-30 minutes placed it aside and gave the participants the space within which they could share their stories and respond to questions.

Through this experience, I became more committed to hearing the participant's voice and using an interpretive approach. As I had anticipated, participants had a tendency to describe behavioural or situational aspects due to their more objective nature. To remain focused on the cognitive and affective factors underlying readiness to learn, probing questions were required and urged introspection in ways and on issues participants may not have previously explored or described. Given this challenge of bringing thoughts and emotions closer to the surface, IPA was a valuable approach as it combined empathic hermeneutics with questioning hermeneutics. In other words, there was a need for close examination by trying to understand the participant's point of view by being attentive to what it was like to experience their lifeworld, personal experience and perceptions. But there was also a need to ask critical questions at the time of the interview in order to seek clarification and confront the inherent limitations of an emic perspective (Smith, 1996). The challenges of managing a treatment and diet regimen consistent with managing diabetes is not my area of expertise and I felt I had little choice but to take a modest, unassuming approach and remain open to the challenges as well as successes the participants were willing to share. Many times, I forewarned the participants that I might request clarification as I was hoping to fully comprehend the situation and leave little to my pre-conceived understanding. Throughout the data collection phase, I kept field notes and reflected upon and analyzed participants' data as soon as possible following the interview.

The interview concluded with several open-ended questions asking for the participant's general input regarding the concept of readiness to learn as well as a section documenting basic demographic data (Interview outline in Appendix H). The interviews with study participants

were audio-recorded in their entirety and transcribed verbatim. All data was entered into NVivo Version 10 (QSR International) in order to organize and code the transcribed data.

Determining Data Saturation. Recruitment and interviewing ceased once thematic saturation was reached. I was seeking saturation of themes within both high and low levels of readiness to learn and anticipated doubling the sample size normally reported in the literature (Crabtree & Miller, 1999; Creswell, 2007). However, I soon discovered the participants did not represent one aspect of readiness or the other; rather, all had encountered various reactions and responses to health information. The initial data analysis occurred concurrently with data collection and provided a general sense of the information provided. After interviewing approximately half of the final sample, I began to see theoretical patterns emerge from responses related to “I didn’t know”, “the way s/he talked to me” and “I’m not gonna do that.” While these were central to the final superordinate themes, I continued to interview until the data provided a clearer understanding of the experiences and did not require further explanation (Laverty, 2003). The addition of more participants did not add any further information or suggest alternate or additional themes. The additional interviews provided a richer data set from which I gained clarification and a better understanding of sub-themes and the participant’s perspectives and descriptions. In consultation with my advisor, there was agreement that the 19 interviews demonstrated saturation, and were in fact almost equally divided between patients from primary care and patients on the dialysis unit.

Data Analysis. IPA has a phenomenological emphasis and may be considered as an approach to data analysis rather than a prescriptive method. Generally it involves description followed by an analysis of patterns of meaning that are developed and reported as themes (Larkin et al., 2006). The assumption is that through IPA, the researcher is interested in learning

about the participant's world in terms of their beliefs while constructs are explicated or even suggested through interpretation of their responses (Smith & Osborn, 2003). Unlike descriptive phenomenology and the need for rigorous applications of bracketing, the hermeneutic approach calls for openness and genuine curiosity. The researcher strives to be open, present and willing to listen, see and understand while maintaining a level of humility and respect toward the phenomenon. This also requires a reflexive position of self-awareness (Finlay, 2014). Smith outlines a step by step approach to analysis but further adds that it is a personal process of interpretive work and can be adapted (Smith & Osborn, 2003). My adaptation will subsequently be described as part of the IPA methodology.

Dwelling. The first step was to read the transcript a number of times. Dwelling with or immersion in the raw data is suggested by Finlay (2014) as a more purposeful process for re-examining taken for granted assumptions as well as becoming absorbed in what is being revealed. I conducted the interviews and would often review the audio recorded interview before they were transcribed. Once transcribed, I reviewed the audio recordings to clean the data (e.g., correct spelling errors or add missing words) or add other important conversational features such as a laugh or a sigh. I then transferred the transcripts to NVivo to begin coding the data as soon as possible.

Descriptive analysis phase. The first order of analysis in IPA seeks to describe the participant's view (Larkin et al., 2006). This descriptive phase is the phenomenological aspect of IPA which aims to give voice to the participants in order to identify, describe and understand the 'objects of their concern' and 'experiential claims' (Larkin et al., 2006). The first part of this process involved open coding where I coded single words or concise phrases by breaking the text into meaning units (Dowling, 2007). Where possible, I tried to use the participant's own words to

create a code. I did not adhere to a fixed coding structure or code source but coded according to what each participant was saying. In some of the cases, I used the same codes across participants as they were relevant and did not need to be repeated with a different label. In total, the initial coding resulted in 202 codes. I was also checking on the number of references that were positive and negative instances of readiness to determine if I was taking up more of one aspect than the other and if the interview process needed to be modified. The 459 references of negative instances and 401 positive instances suggested there was almost equal opportunity to express both aspects of readiness. I then reviewed the initial codes to collapse those that were similar, bringing the final number to 137 codes. As an example of collapsing, ‘the influence of others’ was the final code encompassing other codes such as ‘family support’, or ‘receptive to influence of family.’ All of the coding to this point was provided as an NVivo file and audited by my advisor.

Looking for themes. In the next step, Smith suggests documenting emerging theme titles on a case by case basis (Smith & Osborn, 2003). For IPA, the meaning is not in a natural or obvious state within the accounts provided by individuals but is distilled and crystallized through interpretation at various stages of data collection, immersion within the data and throughout analysis (Lavery, 2003). Smith conveys IPA’s theoretical commitment to the participants as cognitive, linguistic, affective and physical beings, with language as a significant medium for channeling thoughts and emotions to the external observer. Some participants may contribute manifest constructs whereas other concepts are simply suggested by the individual’s talk and therefore require the observer to interpret mental and emotional states from what has been explicitly stated (Smith & Osborn, 2003). In fact, it is suggested to look beyond what is said and try to capture what is “between the lines” (Lavery, 2003, p. 19).

While aware of these hermeneutic considerations, I felt there was already an initial layer of interpretation in producing codes during the initial passes through the data. I chose to not begin thematically analyzing within cases as I was concerned that speculating on meanings on a case by case basis might be less insightful and potentially weaker than interpretation based on evidence across participants. Similar to IPA which seeks to understand content and meanings, moving from descriptive to interpretive (Brocki & Wearden, 2006), I chose to focus on the codes that were common and could be grouped together from across all participants. This approach was consistent with Sadala and Adorno (2002), who suggested that information and descriptions provided by the participants stem from their unique experiences and different perspectives at different times and places. But these can cross or intersect with each other and provide common meanings that enable a structure. The convergence of perspectives or the generalities gleaned through this rich data leads to a perception of the thematic structure (Sadala & Adorno, 2002).

Clustering themes. The next step is to look for connections between the themes. It is at this point the researcher is involved in a more analytical or theoretical interpretation in order to contextualize and make sense of the participants' claims and concerns (Larkin et al., 2006; Smith & Osborn, 2003). In IPA, interpretations are expected to seek meaning and commonality beyond the descriptive (the participants' words and conceptualizations) while remaining grounded in the phenomenological account (Larkin, et al., 2006). Interpretation at this stage begins to reveal the gap between an individual's account and underlying cognitions (Smith, 1996). The hermeneutic circle is a key methodological process for interpretation. It is in the researcher's continual movement between the parts and the whole of text that understanding is reached (Polit & Beck, 2012). For this process, I kept the quotes with the codes and theme labels in order to remain mindful of the participants' words. At this stage, I also visually arranged the 'chunks' of data

with the coding using poster boards and written text to organize the thematic framework, rather than the NVivo software. I returned to the original data source to keep the coding and quotes in correct context, in keeping with Gadamerian caution to not separate oneself from the meaning of the text (Polit & Beck, 2012; Smith & Osborn, 2003).

Arranging and re-arranging the codes and themes was a critical process for nurturing insight and participating more fully in the interpretive process. Initially, I had been maintaining themes that aligned with the research objectives and questions. This tended to reflect the interview topics: communication, cognitive appraisal, and emotions. These categories were not truly themes and threatened to structure the analysis before interpretation began (Brocki & Wearden, 2006). In the process of clustering the codes, I realized there were threads of meaning weaving through the initial categories. This was the point at which the final themes and superordinate themes emerged naturally and were retained. According to Smith (1996), an emerging theme is one that underscores a concept introduced by the participant(s) rather than a response resulting from a direct question. Analyzing across the categories that I had constructed for data collection resulted in deeper, more insightful analysis of the underlying meanings associated with the participants' experiences.

Interpretive summary. An interpretive summary involves translating the themes into a narrative account and outlining the meanings from the participants' experiences. While an important stage for reporting, the analysis is also expanded during this time (Smith & Osborn, 2003). I began to re-organize the themes (and their codes) into a coherent explanation of the findings and the evidentiary data extracts. Similar to interpretive memoing, I provided a narrative account of each theme and superordinate theme with a large number of evidentiary quotes. This comprehensive summary was more formalized than memoing but was an effective means for

preserving my initial thoughts, ideas and interpretations. It served as an outline for presenting the results while also providing a comprehensive description of the results and served as an audit trail for my advisor. Smith has suggested the evidence trail presented for audit needs to demonstrate the density of evidence by utilizing quotations from a least three participants per theme (Smith, 2011). This criterion was met although the number of extracts was reduced within the final report in order to provide the most illustrative quotes from the participants. The audit trail was not expected to nor did it provide enough detail to describe the background or rationale behind my analytic decision making. Therefore the various superordinate and sub-themes were also presented and discussed with my advisor.

Relating themes to existing literature or theory. In the final phase, IPA includes a more speculative approach informed by direct consultation with existing theoretical constructs and links to the existing literature (Dowling, 2007; Larkin et al., 2006; Smith & Osborn, 2003). As Finlay suggests, external theory is the lens through which to further consider the analysis (Finlay, 2014). Alongside the emergence of themes, this interpretive phase was equally revealing. In fact, connecting the superordinate themes to psychological concepts or theories provided a wider context within which to consider the findings and build upon existing meaning structures to enhance greater understanding (Pietkiewicz & Smith, 2014).

Rigour and Integrity of the Research. Defining ‘high quality’ qualitative research has generated a great deal of debate among researchers. One of the most contentious issues is the use of terms such as validity and reliability. Such terms have been traditionally associated with quantitative analysis (Polit & Beck, 2012) but differ from the analytic processes used in qualitative research. Researchers within the qualitative community have also argued for specific standards among qualitative methods (Polit & Beck, 2012; Yardley, 2000). I believe the notion

of a standard suggests an objective measure that is difficult if not impossible to apply to the interpretive process. Rather, a framework needs to provide a platform from which to consider the artfulness of insightful interpretation and rich description while conveying authentic and sound scientific work. Essentially, these requirements converge on the need for a rigorous, transparent and coherent process with findings that are authentically and manifestly grounded in the data (Polit & Beck, 2012). I have chosen to draw from the strategies of several critical appraisal frameworks including Yardley (2000) who also informed Smith's criterion specific to IPA (Smith, 2011; Smith & Osborn, 2003), and Lincoln and Guba's framework as described by Polit & Beck (2012).

To prepare for undertaking this research, I have participated in graduate level courses in qualitative methodology, workshops in research methodology and NVivo as well as pursued self-study around much of Smith's writing regarding IPA methodology, and interviewing skills. I attended to ethical considerations, remained respectful of the participants and their preferences including the primacy of their treatment situation, their knowledge of their health condition and the thoughts and beliefs surrounding what they have experienced. I have endeavored to demonstrate my role in the research through presentation of the theoretical context, my philosophical underpinnings and my foregrounded perspective.

An interpretive phenomenological approach was congruent with the research objectives, particularly for exploring patient experiences and seeking a deeper understanding of underlying thoughts and feelings that might influence receptivity to health information. I was actively and thoughtfully engaged with data collection and analysis, which has been evident in the critical analysis of the pilot interviews and efforts to enhance the quality of the data. I modified the initial process of data collection in order to remain close to the participants' voice and

perspectives. Thereafter, I remained open to the participant's full accounts while carefully utilizing the interview guide to provide a dependable source of data within the scope of the research. I also sought clarification in order to avoid an immediate, taken-for-granted understanding of the participants' perspectives.

Reflexivity involves critical self-reflection of the potential influence of the researcher on the research process (Polit & Beck, 2012). Through the use of field notes immediately following the interview, I reflected on the conduct of the interviews and whether I was inadvertently exploring a certain aspect in a preferred manner. I also contributed some preliminary thoughts and ideas around what I thought was being implied. Each field note was associated with a specific interview and is not shared in this report in order to maintain confidentiality of the participants.

Seeking data saturation from the relatively large sample offered clearer meaning for establishing themes and subthemes and was an important element for demonstrating rigour and a commitment to deeper analysis. I have endeavored to transcend a superficial understanding of the data by maintaining a strong connection to the data and presenting multiple nuanced verbatim extracts of data to substantiate an interpretation. Member checking was not carried out as a number of researchers have questioned its role in the hermeneutic process, given there is no ultimate truth seeking or knowing what the 'right' interpretation might be (McConnell-Henry, Chapman & Francis, 2011; Norlyk & Harder, 2010; Sandelowski, 1993). Furthermore, taking the interpretation back to the participants is revisiting concepts which emerged when venturing below the face value of the participants' accounts not their individual experiences (McConnell-Henry et al., 2011). The interview guide also gave the participants room to contribute their

thoughts on the concept of readiness. This was an important aspect that helped guide the analysis and support the findings.

Several stages were reviewed by my advisor including the data coding, thematic development and supporting extracts. Interpretation was further enhanced by discussions of themes. The aim of these checks was to ensure a plausible analysis of the accounts rather than evaluating a singular true account (Brocki & Wearden, 2006).

Credibility also lies in vivid in-depth description (Lavery, 2003). In order to provide a narrative that was clear and complete, I had two readers who were unfamiliar with the topic provide feedback to ensure there was sufficient explanation and illustrative quotes to support my interpretation. I also followed reporting guidelines proposed by Tong, Sainsbury & Craig (2007) in order to disclose all the relevant aspects of the research process.

Finally, I reiterate the tentative nature of the findings and offer it as my interpretation which has endeavored to be transparent and coherent. I expect this research presents my understanding based on my interpretation and does not negate the possibility of other interpretations. However through this research, I hope to offer what I consider to be common experiences around the phenomenon of readiness to learn or cognitively engage with health education. I was cognizant of the need to remain attuned to the explicit and implicit messages of the participants as well as what has been discussed in the literature. Consistent with pragmatist thinking, I believe these are tentative findings. It was my intent to present the patients' voices and I hope there is opportunity to subject these findings to further examination, in particular whether this is a prevalent phenomenon and if there are ways to intervene and enhance the methods in which information is provided.

Yardley (2002) also argues that reliability may not be an appropriate criterion where many interpretations might be possible. However I am also mindful of the interpretive nature of this work and the context or ‘natural attitude’ that I bring to presenting my understanding of readiness, a research study which itself has provided me with a particular learning experience. Given the reflexivity and openness with which I approached this topic, I believe the experience has provoked a new perspective and way of looking at readiness to engage with health information and understanding the patient’s experiences and perspectives. While my interpretation may not move far beyond the hermeneutic circle, together with theoretical constructs from the existing interdisciplinary literature, it brings important elements to the forefront. I recognize the limitations of the findings and highlight the need to consider other aspects such as culture, or terms such as pre-diabetes in future research. Since this is exploratory research, I believe it fulfills the aim of creating a deeper understanding of various aspects of readiness to learn and a platform from which to further investigate the generalizability of these concepts.

Summary of the Chapter

In this chapter, I have described my orientation to pragmatism as well as its philosophical origins. Given the complexity of evidence-based, patient-centred health education, exploring patient experiences is an important aspect for determining the factors related to readiness to learn or cognitively engage with health education. While merging qualitative and quantitative methods may provide more comprehensive consideration of the complexity around human experience, the scope and nature of this exploratory inquiry is best suited to phenomenology as described from its philosophical origins, particularly the development of the interpretive branch. Together, the origins of early phenomenologists and the methodologies that followed this philosophy reveal

the foundational principles and concepts upon which Smith (1996) developed Interpretative Phenomenological Analysis, informing the design and method. This has been a useful approach for a more in-depth exploration of experiences with health information in the clinical setting and readiness to learn as a phenomenon that has received little attention in the existing literature. I have detailed the methods used in conducting this research including sampling, ethical considerations, and the procedures for data collection and analysis. I concluded with a discussion of the steps taken to enhance the rigour and integrity of this qualitative research. I reiterated the tentative nature of the findings resulting from this exploratory study, which will be presented in the following chapters, as a tentative, personally contextualized interpretation that links to existing theory and provides conceptual considerations for future research.

CHAPTER 4: Findings

This chapter will describe three themes regarding readiness to engage with health information based on the participants' narratives and experiences. As seen in Table 1.0, the primary theme relates to the *Underlying Incongruence* in knowledge, thoughts and beliefs that are encountered with exposure to new health information. This incongruence also influenced the ways in which individuals tried to cognitively navigate a way forward with diabetes or a diabetes-related complication. Communication was emphasized by study participants in terms of *Relational Talking and Minimizing Interpretation*, further conveying the influence of an interpersonal and person-centred interaction on readiness to engage with health information. The third theme addresses the patients' readiness in relation to *Negotiating Control* as a wavering dynamic between feelings of losing control and fighting for control. A general description of the sample is provided using study pseudonyms to uphold the anonymity of the participants. Table 1.0 summarizes the themes and subthemes, which are further described and supported by excerpts from participants. There is interplay among the themes that cannot be overlooked despite the linear manner in which these results are presented.

Description of the Study Participants

Interviews were conducted with 19 individuals, 12 from the dialysis unit and seven from the primary care clinic. Each provided a brief self-reported description at the beginning of the interview. Eight participants were female and 11 were male, ranging in age from 39-85 years. Among those who reported their education, it ranged from less than high school to post-secondary with professional credentials. The participants had received the diabetes diagnosis anywhere from 2-40 years ago, most (nine of the 12) patients on dialysis had been diagnosed 20

or more years ago. The time in dialysis treatment ranged from 2-18 years however the median was three years.

Main Findings

Table 1.0: Summary of Themes and Sub-themes	
SUPERORDINATE	SUBTHEME
Underlying Incongruence (in knowledge, thoughts and beliefs)	Encountering incongruence between healthy normal and sick diabetic. Processing time and space. Avoiding, to maintain the distance. Navigating around what is different. Navigating between black and white.
Relational Talking and Minimizing Interpretation (Communication)	The exchange of information and voices. A relationship that communicates caring.
Negotiating Control	Loss of control. Fighting for control.

Underlying Incongruence. The primary theme, identified as Underlying Incongruence, refers to an implicit state brought on by information that contradicts or is considered unusual to what one thinks or has experienced. Incongruence is a not a dichotomous state but occurs on a continuum, thus suggesting there are various states of mental distance or sense of strangeness one might feel from health-related information. Incongruence was first encountered in the tension between one's normalized self and the perceived illness or diabetic profile. Navigating incongruence was a complex and individual process influenced by breadth of difference, and the capacity to process in a "grey zone" where prescriptive messages were questioned and resisted as participants needed information tailored to their learning needs and management options.

Encountering incongruence between healthy normal and sick diabetic. The initial diagnosis was a pivotal encounter with incongruence and shifted one's perception of being healthy to being sick. Almost all of the participants explicitly identified feelings of shock:

In emotional shock. Jeez, I have this disease...And there's no cure for it. I could tell you what I would look like; a deer in a headlight...the eyes. Oh my God. (Hans)

And then when I was diagnosed, I was in shock. And then I didn't know what to do. I was totally lost. In disarray. (Nina)

The uncertainty stemming from a poor understanding of diabetes was one of the contributing factors to these acute emotions:

[The HCP said] 'You have diabetes.' And at that point I didn't know what to say. I mean I've never talked to anybody about diabetes. I don't know what diabetes was... I was stunned. I didn't know whether to hit him or, or burst out crying or, you know, like where was my, what should my reaction be with this guy, you know? So I didn't even realize how important, how difficult you could, the difficulties. He didn't say anything. He just said, you've got diabetes. As if I, I knew somewhere in the past that these are the consequences of diabetes. I had no idea what diabetes did to you. (Bogdan)

Participants often did not feel different or sick, which further contributed to the difficulty in comprehending and accepting the diagnosis.

Nothing. Absolutely nothing. I still don't. I don't feel anything. And I don't understand people that say to me, well you must feel something. I don't feel anything. I don't feel any different in the morning. If my blood sugar is eight or nine or 10 or whatever, I don't feel any different than when it's three or four. I don't know what I'm supposed to feel. (Bogdan)

I just didn't feel any different so I just didn't worry about it [chuckle]. (Breanne)

The disconnect between how they felt (i.e., physiological state) and the diagnosis resulted in confusion and disbelief: "I only hear what I want to hear sometimes. I was in denial. I go, this can't be true. ... Yea. I just, this can't be happening. This is not right. They misdiagnosed it." (Josh) Bogdan also explained how the absence of symptoms diminished a desire to hear more about changing his behaviours when he felt fine:

I challenged almost everything they said because none of it made any sense to me. I think they talked about doing things. And why would you do that? It doesn't, you know, it really doesn't make a difference whether you do it or don't do it. And they would just, you know, they just insisted that this was the right thing to do. (Bogdan)

Often shock turned into depression, to varying degrees among almost all of the participants.

I'm not saying I'm going to see the total five stages of Kubler-Ross, but, uh, yea, the first couple of days after I was told I felt bad, I felt very low. Sorry for myself. ... You know, you go through the cycles and the depression and all that kind of stuff. (Hans)

That knocked me down. And it put me in a different, in a different zone in terms of, uh, my personal health. And where I was going to go down the road with this... They're dealing with a pretty, um, a pretty heavy kind of alteration in somebody's life pattern.

(Rolf)

There was also a deep-seated fear that they were no longer like others. The new diagnosis, in particular, changed their normative sense of self. This largely revolved around the label 'diabetic', the constructed meaning associated with a diabetes profile and the perceived differences from one's personal characteristics.

I was always on the go. I was never the type just to sit around like from morning 'til night. Like I worked every day of my life since I was 13 years old. So, I was very active and that's why I was so surprised to find out I was diabetic. (Nina)

I'm pretty fit for a [pause]... you know. I was doing things around here that guys 25 years younger than me couldn't do. You know... I've never been a 'slougher' or a couch potato or a, someone who shirked work and things like that. I do my share and more.

(Rolf)

I didn't want to know about it...I'm not like them. I mean that's not going to happen to me. (Gregory)

There was an underlying desire by the participants to avoid being labeled as diabetic and a described fear of being perceived as different from others:

I felt like, OK, I'm a person with a disease and people are going to look at me like that. I didn't want nobody to know...Like, I hid it. I didn't want nobody to know because I didn't want my friends saying, oh [interviewee's name] got a disease, you know. Like, mocking me or making fun of me...When you're young, you don't want, you don't people to know stuff like that because you don't want people to think you're sick...And that you're not normal. (Nina)

The diabetic profile or sick identity was a notion associated with poor self-control and appeared to be reinforced consistently by others. The participants were advised by HCPs to lose weight but despite their efforts, also experienced guilt, self-blame along with judgment and stigmatizing remarks from others:

People were saying that to me. ...Said like, oh my God, you're on insulin. Oh my goodness...that's bad.... And then I had people come up to me and say like, oh you must

be a bad diabetic... And I'm like, what the hell. I thought I was actually good, like you know. Like, I'm the one that's actually trying to fight this and take care of it. (Nina)

Bogdan had also experienced this very explicitly:

Bogdan: And you know there's a stigma to this stuff too you know... Because, because everybody tells you it's your own fault, you know.

Gayle: Did you actually have...

Bogdan: People say that? Absolutely.

Gregory wanted to be considered normal and therefore rejected any information or help in managing diabetes:

I didn't really want to listen to them because, like I said, I was in denial. Plus, I felt that I was like a different person. ... Like, uh, I wouldn't be recognized as a normal person. Cuz oh this guy has diabetes. This little kid has diabetes. And I'm going to be like pushed away and stuff like that... I was scared and I don't... What I, what, what people would think of me. And it was something I was mad at myself for that. People saying stupid me. (Gregory)

Similarly, downplaying the need or relevance of information was discussed by one participant who felt he was in a less serious situation because he was only diagnosed as pre-diabetic:

I'd say, oh, I'm just pre-diabetic. Let's not get excited kind of thing... so I kind of just lay back in my chair and just listen. And there were some people that had some pretty, uh, acute medical problems which were not even close to what I had. And I, I'd listen to their problems, uh, because I didn't think I had that problem. Not to that extent. So I'm pre-diabetic. I guess everybody can get to be pre-diabetic at one time or another. (Rolf)

Processing time and space. The participants described dealing with initial incongruence as a process of adjustment or acceptance, and therefore needing varying levels or intensity of information or education. Acceptance was a term used by several participants, but to reach acceptance required having the time and space within which to process one's thoughts. In particular, having the diagnosis "soak in" was described as essential by all participants. A range of emotions accompanied assimilating the idea of diabetes into one's life, and many of the participants stated the need for time to deal with these emotions.

It just, a bit of self-pity. A bit of self-pity...Just for a while, uh, not very long. Not very long. 'Til, 'til I was able to assimilate it and just let it soak in that I'm not what I used to be and I can't do what I used to do. It didn't, not a long gradual stretch. Not a lapse of time that it dragged on and on because that's not my style. But things get done. That's my style. And we're, you know, we're not going to self-pity ourselves to death here. Let's go. Let's produce. Let's be effective. (Rolf)

I just, I guess talked myself, 'what the hell am I afraid of,' you know. (Saul)

When offered information, Hans explained how the diagnosis situation made him feel less prepared for the "full meal deal" i.e., "Don't diagnose me in one minute and tell me how to deal with it the next minute." (Hans) Rather, he felt it would be important to have a brief discussion about what one might begin to feel or expect and the emotional support and encouragement the patient could count on from the HCP:

Maybe if she gave me just a three minute talk about, this is the typical emotional cycle that a recent diabetic goes through... like, tomorrow you may feel this. Next week you may feel that. Like, a bit of a, an advanced warning about what I'm going to go through so when I do feel that, I'm going to say, uh, that's normal. If it was like a bit of a pep

talk. ...Like, all is not lost, don't start slitting your wrist quite yet, you know, 'we can get you through it', I think, you know, 'I'll give you a couple of days to, uh, to muddle through it, to process what you were just told. But, you know, we're here to help you,' kind of thing. Yea, I think that would have been helpful. (Hans)

Hans used a humorous anecdote that described how he needed to consider a situation from a distance and analyze it from different angles:

That's a smelly bag of shit on the table and every couple of times a day I'll give it a poke with the stick, you know. I'll start thinking about it and today I'll think about something, write down a note. Tomorrow poke it from a different perspective. Write something else. And maybe in two weeks time I'm ready to actually tackle the problem. (Hans)

The most telling feature of Hans's description is revealed when asked why he refers to the situation as "a smelly bag of shit...you want to poke at it; you don't really want to touch it with your hands." (Hans) The diagnosis of diabetes is not something that he wanted to face head on; he needed the metaphorical space and distance to reconcile a new reality.

Avoiding to maintain the distance. Some of the participants reacted to the diagnosis by distancing themselves from the diagnosis and the information to manage it. Many of the participants explicitly described varying levels of avoidance: "No, I just let her tell but I didn't really listen to her... I didn't really listen to anybody cuz that was my, I say bubble, I guess bubble. That's my bubble." (Gregory) For some, this involved rejecting the medication, mostly the insulin, as a means for diminishing their fears around being 'a diabetic'.

They say you're supposed to have insulin all the time or take pills all the time. But, uh, I didn't really listen to them because I didn't really want to listen to them because, like I

said, I was in denial. There were two different emotions I had. I was like I didn't care and the other part I was scared. (Gregory)

For others, the medical intervention – whether medication or dialysis – became the focus for managing diabetes. However, participants had varying expectations for treatment, which seemed to eclipse behavioural considerations in some cases. The treatment became the means for avoiding the condition and allowed less involvement, suggesting a “take it and forget it” attitude that enabled one to maintain status quo:

With the diabetes, I figured you just take your insulin and forget about it. ... You know they got, they're giving me insulin; it's going to be fine... I'm going to have my beers after work and, you know, I'll take a little bit more insulin. (Jed)

I just took the pills and ignored everything. And then from there I ignored it. I didn't want to hear about diabetes. I kept taking my pills. (Rose)

Peg further explained the difficulty of changing a routine that had not only become part of her lifestyle but also one that she particularly enjoyed and shared with her family. She resolved that the medical intervention would take care of the consequences arising from drinking more than recommended: “I'd go home and first thing I'd say, ‘oh good, you have the coffee on.’ [laugh] ...And I'm still thinking... hmm, they're draining fluid off of me, I can drink as much as I want.” (Peg) From Peg's experiences, she was able to downplay the severity of possible consequences:

I always figure I'm gonna get better fast. Because when I was in intensive care, they told my kids I was gonna be in there at least two months. Within two weeks I was put into a normal room... I was there not even a whole month and then I was home. You know, they'll say, ‘don't cut yourself because you have diabetes.’ Oh, I have so many bumps

and bruises and cuts you know and they would heal faster than anybody else's. So, I think I just consider myself ...nothing bad's gonna really happen. (Peg)

Navigating around what is different. The participants' narratives further described individual differences in terms of their existing knowledge, experiences and exposure to diabetes. One participant advised, "You [HCPs in general] got to put yourself into [our] shoes," signifying the need for HCPs to recognize that everyone deals with diabetes information from a point of individual difference in terms of knowledge and experience. This is the basis upon which people construct further knowledge and understanding. One's lifestyle was their unique way of knowing and operating and new information that contradicts these ways may not be integrated easily.

Many of the participants admitted to having a fairly basic understanding of diabetes. As a result, the participants felt the changes required to manage diabetes would involve giving up their learned lifestyles. This presented them with uncertainty in daily management while denying them the food and lifestyle they had come to enjoy.

You have to change this. He hands me all these forms. Stuff you can eat. Stuff you can't eat. You know how. And I was just like, that's what the...oh no, I can't do this. I can't do this. It's too hard. And so the, the diabetic diet is very specific. You know what I mean? Nothing was, everything that's good is not on there. I go, holy cow, what can I, OK, all right. So. No bread, no bagels, no this, no that. Dah, dah, dah. What's left? (Josh)

It's terrible. You know. And that stuff you used to take for granted, it was so good.

(Dean)

Introducing a new behaviour was sometimes perceived as a big step and seemed foreign to one's current knowledge: "But starting to regiment my intake, something I'm not, wasn't used to... I

said, what do you mean putting needles in my finger tips and checking? I said, [name of HCP], what the hell's going on, you know.” (Rolf) The suggestion to reduce or eliminate a behaviour was also resisted. Jed described the difficulty of having to give up things he considered to be pretty harmless, one of which provided him with a reward for working hard.

Well, you know, I liked my lifestyle. I liked my potatoes... Back then I drank beer. I liked my beers after work, you know....I worked hard and, you know. I got married young. I worked hard. And I didn't gamble...Every time the dietician came around she told me, she told me not to eat my potatoes. I love my potatoes. I was brought up eating potatoes. (Jed)

Rose felt she had made a large sacrifice and couldn't make another as this was taking her away from a lifestyle she knew and enjoyed:

Well I said, well I quit drinking. I said I did a big deed on that. Because I had a problem drinking and coming to dialysis. I said, well I'll quit drinking but I won't quit my smoking. And some of the food I like to eat I don't stop from eating the food I like eating. I just don't want to listen to anybody. (Rose)

Past experiences were frequently influenced by family members or friends with diabetes. These individuals were powerful instruments for conveying messages or modelling a lifestyle that may minimize the need for the suggested changes:

Because of my mom...I lived with her when she had diabetes and she was supposed to not eat potatoes, not eat sweets. And she ate potatoes; she had her desserts – and she said to me one time , ‘I'm going to live to eat, not eat to live,’ And I thought, well – that's a good attitude. And uh, I think that's the attitude I took. I'm gonna live to eat, not eat to live...I figured I knew all about diabetes because of my mom and everybody else having

diabetes I was just, ‘why do I have to be told what to do.’ I know I have diabetes – my mom lives with it and uses insulin. That’s my fate. (Peg)

A few participants suggested that age and culture may be factors that distance one from the information exchange. For example, a more passive approach was conveyed by Tesla, who has difficulty with English and shared: “I’m just waiting to go to dialysis, like that... But I’m still OK with my dialysis.” She remained contently focused on the treatment rather than information around management. Nina shared similar insight about Aboriginal culture: “I think it’s, I don’t know if shy’s the word. It’s not shy. It’s just that, you know ... They’d rather just leave it than ask because they don’t want to impede.” (Nina). Anita also refers to the influence of an age difference: “The younger people who know very little about 80-year-olds tried to tell me, like [name], this one will say, ‘oh we’ll teach the seniors how to eat.’ ...And I think, how could you teach us how to eat?” (Anita)

The turning point in adjusting or even accepting the condition and a more positive attitude toward management sometimes occurred when one’s situation was contrasted with others who, in some cases, may have been perceived to be more seriously affected by diabetes.

But then you kind of pick yourself up. Say, damn it, you know, other people survive and they go on to live perfectly normal lives... And some were on insulin already. So my A1C was 7.0. Some, some of them were in the 20’s. So, so I was the only guy in the room that was actually not on any kind of meds. I felt pretty good about myself there. (Hans)

I was looking at those people. And I said to myself, I’m not going to be like one of those people that just lie there and, uh, people to do everything for me... I saw. That’s why I

changed... I lost my leg. What do I need to do, to get better and, uh, to heal myself.... I had to see everything else around me to get that point. To get healed. (Gregory)

Hearing the experiences of other people with diabetes would sometimes resonate and catch the attention of a few of the participants: “When I began to listen to other people’s stories and I realized, you know, hey, who knows what kind of complications I may have as time goes on.”

(Benjamin) Exposure to others who were viewed as similar to one’s self also helped to diminish preconceived ideas of diabetes:

You know when somebody else had some success, well jeez, they had success, maybe I can too. (Lester)

It’s all relevant to me ... hey, I have the same condition, maybe it’s not as severe as theirs. But it’s, you know, either you’re diabetic or you’re not, right. (Hans)

The participants with co-morbidities processed the information in contrast to their management of other ailments or complications. Having prior experience with other health issues contributed to their confidence to self-manage and they generally described themselves as more open to information that would help them with the added challenge of diabetes. “Maybe because I have had so much go wrong with me it’s just another thing. ...And I don’t dwell on things because I had so much going wrong [chuckle] that I kinda got used to it.” (Donna)

Participants who appeared to have processed and accepted the condition spoke about “getting on” and it didn’t take over their lives but was managed in the context of their daily activities:

You don’t create a fuss where you don’t have to...you know I mean, I make no big do about it. I think positively about it and that’s it... Don’t make any fuss over it. Just like putting your shirt on in the morning. You have to get dressed somehow... just like taking

25 pills a day. If I started thinking, oh no, it's time to take a pills, oh, yi, yi, well then I suppose it could become a problem...I calculate this way here, it's, it's OK... I mean I go to the garage and enjoy myself. Nailing things and cutting things on my band saw, stuff like that. (Alfred)

Considering health challenges as bumps on the road rather than barriers was important for them to maintain a perspective that they were moving forward and living life as normally and as fully as possible:

Like for some people that are here that they're miserable and all that stuff. I mean I can't say, it's what's happened already and I can't change it. I can't change it now so I just got to go forward. (Gregory)

It's done. I take it seriously, you know. It's not going to be to my advantage to buck it and deny it, you know. (Rolf)

Some participants were able to achieve a certain level of ease despite the size of the 'bumps on the road' and looked at in terms of being able rather than disabled:

I said I can do anything. I can be in the Olympics if I lose my limbs. I can, I can do anything. I just, that's just a little lump on the road. I lost my leg. (Gregory)

I'm not really missing that much that I was doing before. So that's how I looked at it, you know, to get over the pressure when I lost my second leg. (Saul)

Looking forward may also have been motivated by having a purpose and goal to strive for:

Gayle: Why did this attitude change from "you only live once"?

Peg: I still have that attitude. Yeah.

Gayle: Yeah. A little bit less of it?

Peg: Little bit...well I've got a little great granddaughter – she's going to be two. And I'd love to see her grow up. She lives in my house. And I just ...aww, it's just so precious to have her around. So I'd like to stay around a little longer.

Navigating between black and white.

“Not everything is black and white. There's usually, you know, dark grey or light grey.”

(Hans)

This quote by Hans reflects what he has learned about diabetes-related information over time. Black and white is how he describes the prescriptive and somewhat over-simplified information for managing diabetes, whereas a 'grey area' signifies the challenges in relating information to one's needs.

There are differences in the types of health information one requires or has the capacity to tolerate and process at various points in time. In the earlier stages, and particularly at the time of diagnosis, several individuals reported a desire for more concrete or 'black and white' approaches to address immediate concerns.

You know you're at a point we caught it early, we can probably manage it through diet and exercise. And then I said, thank you very much and I left the office. And then I said, 'now what do I do?'... I didn't have a clue how I was supposed to manage this thing called diabetes... He just said, 'you better lose some weight.' Well that's great. How do I do that? Don't tell me my car's broken unless you're going to tell me how I can fix it I want facts, you know. What should I eat? What should I avoid? What, what's my target number, you know, that kind of thing. (Hans)

Instead, participants received information that was too general and the lack of explanation required interpretation based on what little experience and/or knowledge they had of diabetes.

So I went to the doctor and then he did a lot of blood work and what not. Then they called me back and they told me I was diabetic. And so, [it] was diabetes and then he explained, he explained that a bit here and there. Told me, goes you need to lose weight and you need to change your diet. He said, just cut the junk food out, and blah, blah, blah. And said, but that wasn't just it. You know that's all he did. And then I went home, I said, OK I gotta do this. I lost the weight. And then, but I was still diabetic... I thought that was going to cure me... What?! (Nina)

One individual recounted his difficulty with hypoglycemia because he was trying to cut out sugar as the contributing or even causal factor for his diabetes.

I was flat in bed. I couldn't get up if I wanted to... when you want to eat healthy, you have to make sure there's a certain amount of glucose. You can't cut it off entirely. Your body needs it.... But see, that was new to me. Nobody ever said that to me ... I figured, hey, it would be the best thing in the world if I could cut off sugar entirely. So I tried it. Not the best thing. Causes other problems. (Benjamin)

A 'black and white' approach was evident among others who viewed their condition as stabilized or medically managed rather than impacted by other factors. The following participant explained how he rejected the idea of complications arising while being treated with dialysis. He shared his experience of being diagnosed with blindness and being told the reason was due to poor glucose control. However, this ran contrary to what he knew about his current management and consequently the message was considered inaccurate.

He says, 'well, because you didn't take care of yourself and you're diabetic, uh, you went blind in your left eye.' So I said to him, what do you mean I didn't take care of myself? I couldn't believe that doctor said that I didn't take care of myself. ...' I says, 'No, no, no.'

I says, when I come to dialysis, my sugars are leveled off really well.... I tried to tell him. I said, 'what are you talking about?' I says, 'my specialist, told me that sometimes people get, go on dialysis will control their sugars.' And, uh, he didn't say much after that... (Dean)

Yet another participant dismissed the information provided in a diabetes education class because he felt nothing would make a difference to a permanently impaired bodily function:

So they were trying to get me to use the cereals and the diet to, uh, to get rid of this problem. But I think it was much more than that. I don't think that will, you know, it's not like cutting out bread and a whole bunch of, uh, food types that I think I'm going to start producing insulin again. And, uh, not being diabetic I think I'm stuck with this for good. (Rolf)

Blood sugar measures were the primary focus of management and several participants discussed their dependence on medical treatment to help them reach their target ranges.

When I come to dialysis already I started, my sugars are leveled off really well. I get into the, like this morning, I came in at, uh, I think it was 10. I'll leave here today, it'll be five or six which is, you know, which is good. I don't take no more, uh, insulin. I don't take no more, uh, uh, pills of any kind...And when I seen [HCP] she says that happens sometimes when people go diabetic, go to dialysis, it controls your sugars. So that's what I've been doing... (Dean)

I've got to keep increasing the dosage but I'm going to because I want to get back down. I want to get in that range, in that window. And there regularly, not just as a fluke...A fluke because I ate the right things or did the right things. So all of a sudden my blood

glucose is down. You know I'm going to get it down there because I'm going to take more insulin. (Rolf)

While others explained how the dependence on medication changed with knowledge of the effects of other factors.

With the diabetes, I figured you just take your insulin and, you know, just take your insulin and forget about it. You know. It doesn't work that way. You have to do your blood sugars regularly and play with it, you know. (Jed)

Indeed, becoming more aware of the complexity of diabetes management marked a transition to the "grey area" and also required them to be discerning consumers of information. The participants came upon conflicting messages from health care providers and most definitely in various media messages. One participant shared a newspaper article that reported on current Canadian research suggesting a focus outside of dietary sugar. Such findings made him further question the treatment and the current approach to dealing with diabetes. The inconsistencies and changes occurring in the information created uncertainty and various levels of distrust regarding who they should be listening to and the possibility of inconclusive evidence to support the messages.

I didn't believe anything would help anyway. I mean, try this; try that. Nobody knows what does this anyway. (Bogdan)

Every so often they say well, such and such a food is not good for diabetics. And the next time they say the same food is very good for you. (Benjamin)

Most physicians are saying, 'don't worry about the individual glucose readings, take a broader view; what is your A1C. And if that's a good number, don't worry about a slightly elevated morning reading.' Whereas the diabetes educator is saying, 'no, every

reading counts.’ Who do I believe? Come on guys, get your act together... If I get 10 pamphlets, I would expect that all 10 pamphlets to be on the same wavelength in terms of what is your goal? What is, you know, what are the dos and the don’ts. (Hans)

Similarly, the information participants encountered often came across as prescriptive, which was referred to as being “black and white.” One participant felt that a referral to diabetes education was a “canned” or “go-to” approach that came across as being required rather than tailored to his needs: “They say, oh and we have diabetes education, you should go. This is what you’ve got to do, you know... and this happened to me so many times, I feel like saying, like get that brochure out of my face.” (Saul)

Learning needs varied as individuals were adjusting and integrating diabetes into their particular circumstances. This prompted them to challenge the prescriptive nature of information being presented and at very least expected it would be evidence-based.

I don’t accept things at face value. I would expect somebody to give me a fact and then maybe back it up with more facts or how did they arrive at that fact. And what are, show me your footnotes, show me your references, that kind of thing. Don’t believe everything you read on the internet. (Hans)

What evidence have you got that [a new management approach] is beneficial? (Lester)

Similarly, Josh requests statistics:

I go, what statistically are my chances to live... I could not get a straight answer out of anybody. All I’m asking is, I’m not asking your opinion. I’m not asking you for a thing. I’m asking you for statistics. And they wouldn’t give it to me. None of them would. And that’s because they’re paranoid about liability... Really pissed me off. I want to know my chances right now. Tell me my chances right now to live, to die. (Josh)

However, there was also a tension between efficacy and effectiveness, that is, scientific certainty versus practical flexibility. This once again provided a “grey area” with the challenge of obtaining or interpreting evidence-supported treatment information so it was personally significant and useful. In this ‘grey area’ evidence-based facts and statistics might also be considered “by the book” messages and were met with contempt:

I’d come up, you know, with good things and they couldn’t answer me. And they try and get around. I could tell they were trying to get around just to make sure they sound right.
(Saul)

Their education is based on memorization and association. That’s not thinking...It’s just memorization, resuscitation. That doesn’t impress me, quite frankly. (Josh)

It was suggested that prescriptive messages were related to the ways in which they were delivered:

I’m so sorry but, you know, they just, they’re just, so stuck in it, [and] nothing can change their minds. And yet everything changes all the time. For me because of my personality, my character, I don’t like absolutes. (Bogdan)

One participant provided an example of where his complex health issue made the information less straightforward and felt the HCP refused to adapt it to his situation:

She had to do things her way. Was not much communication between her and I; she just explained the thing away. And I told her what happens when... [She said] ‘Oh well that’s different.’ You know what I mean, she wasn’t there for [my] particular type of situation.
(Alfred)

Several of the participants felt the exchange was confined to a particular message due to the lack of time, regulatory/legal parameters, or simply because the patient’s specific situation was not

understood.

They're just telling me what they have to tell me because their job says that they should say this information to me...Are they understanding what they tell me instead of regurgitating information?...Because that doesn't help me if they're just, you know, saying what they, what they're told to say... Because they come from a more conformist system where they think a certain way. And if you deviate from that, they can't handle it really...I've got a problem trusting these people because they don't have an agenda per se. The agenda's been programmed into them. (Josh)

Rather, they wanted HCPs to consider care beyond "black and white" and the human complexity in managing and learning to manage diabetes:

I needed to feel like that he cared for me as a person, not just as an object that was sort of being given this pill and that pill and so much of this and so much of that. And that'll keep you in shape... I have, I have no, no problem respecting his knowledge that he knows stuff about diabetes that I don't know, but I'd like to learn. And I like to have the chance to learn. Not just run in and out. Oh well, you have the right medication (Benjamin).

Relational Talking and Minimizing Interpretation.

While the intent of this study was to explore thoughts and feelings underlying receptiveness to health information, the role of communication was emphasized in all of the interviews and appeared to be a factor for greater consideration. Communication was not just a mechanism for conveying information, but was felt to be an important interpersonal encounter, and can be described in terms of two subthemes. *'The Exchange of Information and Voices'* relates to the participants' need to be informed, but through an exchange that minimized the need

for interpretation by allowing questions and contributing experiential knowledge for tailoring the information to their unique situations and challenges. The second subtheme, '*A Relationship that Communicates Caring*' suggests there was an interpersonal aspect to communicating and participants felt more open and receptive when being treated "as a person" within a context of caring.

The exchange of information and voices. The participants requested straightforward information. Particularly where objective information or findings were being conveyed, participants wanted black and white information before they started to negotiate the 'grey area' of tailoring information to their needs and personal situations.

First of all I'd say, like you gotta be honest. Very honest to 'em. If you're examining me and you see something that's not right, you know, in my chart or whatever, I'd want you to tell me. You know. I wouldn't want you to be wishy washy about it. (Dean)

I notice that they like to sugar coat stuff. The doctors to make it, they want to spare your feelings. They want to, you know, they want to hit you gently. I don't need that. I need to know the truth. (Josh)

Sparing feelings, as Josh suggested, did not mean that the naturally occurring emotions needed to be ignored but could be addressed as part of the communication process. Hans recommended HCPs acknowledge that:

Yes, this is a disease but all is not lost. There are various strategies to, to manage it. And in a perfect world, everybody would be like a Sheldon Cooper or a Mr. Spock kind of thing where emotions are totally out of the equation. But we're people. We have to, we have to, uh, appreciate and negotiate around those emotions. (Hans)

The participants seemed to value an empathic but honest approach that did not arouse fear unnecessarily: “He was good, you know what I mean? He would, he wasn’t overwhelming. The way he approached it was very, in a casual way...didn’t try to hide it or scare me with it or anything like that.” (Alfred) Yet, many recounted many instances where the HCPs used warning messages or used an “if...then” scenario: “[The HCP] was telling me, ‘the blood sugar is too high... And there’s, what’s going to happen eh. You better get them under control or you’re going to be a double amputee.’” (Saul) These kinds of messages aroused fear and seemed to stir up emotions that were challenging their abilities to adjust to a new diagnosis or change in health status.

There was a particular vulnerability associated with being a patient unaware, and participants reported the need for room to explore their health issue and a comfort level in being able to ask questions and have their concerns addressed. “There’s no, uh, holding back or, or glaring at you if you ask a stupid question or something like this, you know.” (Alfred) Being able to ask questions was part of two-way communication and a means for understanding the patient. But Josh felt questions were not welcomed as there was an expectation the patient receives information rather than being a participant in an exchange: “I feel, I feel they get really defensive when you ask questions. They’re used to, they’re used to zombies... They’re used to telling them, telling people what to do and passively accepting it, without questioning it.” (Josh) One-way instruction or lecturing was a common occurrence and offended many of the participants. It also intruded on their sense of control in how they manage or even live their life:

...if you’re going wagging your finger in their face and, ‘this is what you gotta do and if you don’t do it this way <changed voice to imitate> It just doesn’t work’.... And you’ve got one’ll say, ‘you’re only supposed to drink a litre a day’... one’s ‘ya, ya, ya, ya’-

Yappy.... by the book. One's like a terrier. You know a terrier. Bark, bark, bark. And you just want to get rid of that little terrier dog, don't ya? (Jed)

This approach was considered authoritative and had an underlying message that "I know better and you better listen to what I'm saying." (Alfred) The information came across as simply being patronizing and the participants didn't engage with the information but became defensive and angry.

I think when I was told what I had to eat. I just um... you know they were telling me, 'you can't eat this, you can't eat that you have to eat this' and I'm just, I'm sitting there probably thinking I'll eat what I want. (Peg)

You get angry, and you disregard whatever the person's saying to you. (Jed)

One-way communication when coupled with feedback on test results passed judgment and blame, resulting in a failed opportunity to engage or educate the patient:

There's judgment. Your A1C's off the chart today... And often times that's what you hear. That's why you leave the office you feel badly about the doctor and you feel badly about yourself...and we can't figure out how come these people aren't getting healthy. (Benjamin)

Participants once again raised the importance of experience or 'cultural' knowing for effective communication. The following participant is in her eighties and conveyed:

And I think, how could you teach us how to eat? We brought up your parents. We know how to eat. Yea. But, you know, like thinking that we need to be taught. That they know more than we do? I don't think so... we know about that... And if we do need to [learn] it, it should be taught, taught by people who are our age. Not somebody that is 20 or 25 years old standing there and thinking that they should teach us something. (Anita)

Nina conveyed a similar message with regard to Aboriginal people and which she felt resulted in less optimal learning: “Aboriginal people are so humble, they won’t, some people don’t ask [questions]. That’s why I feel sorry for the elders that, you know, don’t get the proper diabetic teaching.” (Nina) Participants were also inclined to tune out some of the health information when they felt they knew better as their experience enabled them to better judge a personalized course of action.

They don’t know me. So they’re just looking at that mean guy who doesn’t want to listen to us. No, you don’t know my situation. I know you’re busy. You don’t know the situation. I’m telling you that this is the situation. (Saul)

Alfred describes a more positive exchange with his HCP, resulting in an outcome that was more relevant to his situation:

[The HCP] spoke with you. He didn’t speak to you, you know. We had dialogue like. I mean I suggested certain things because I was aware of certain things and uh, you know... he would, he would listen, he would comment. He would accept what was going on. (Alfred)

Participants appreciated educational information tailored to their preferences, based on the personal information they provided to the health care provider:

Yes, I went to a dietitian once... She sat there and asked me what foods I liked and I told her exactly what foods I enjoyed eating and everything. And I said I enjoy bread, I love bread. I still do. And so she allowed me a piece of toast in the morning, I think, a sandwich for dinner and I could have something in between... And I lost weight eating it. (Peg)

I asked if there was some, uh, ethnic food. I'm Jewish So I said, what about, uh, uh, like a couple of Jewish foods ... she came back about a week later with the answers for that kind of stuff. I thought wow, she really like, is interested in helping people. Look what she went through to, uh, get the information I was looking for, you know, It was helpful...I was happy because I could eat the stuff I wanted. (Saul)

They also appreciated an approach that was designed to help them make subtle, manageable changes with the addition of being positively supported. Saul further intimated that tailored adjustments were important to his sense of self and being treated as a human:

...we figured out a plan on how to, like, adjust insulin, you know, according to what I ate, you know... it was almost like a game plan that she, you know, set up with me...dealing with a human not a statistic. (Saul)

Participants reported being more open and receptive to people who took a gentler approach and would advise or suggest information rather than give directives.

I prefer people saying, we think this will work or this is something you should try...For me. I prefer them to say, you know, this is what we think will work for you now. ... Because you're afraid of it. You don't want to not do it but, yea, but you feel resentment when they tell you 'you have to do this' you know. It would be better if they said, we suggest because you need your carbohydrates under control that you keep it to this level and that kind of thing....So it's just a way of delivering the message more than anything else. (Bogdan)

This gentler approach was an aspect of communication that appeared to be significant to all of the participants and a number of examples were provided, including:

He suggested certain things. And he says, ‘you might want to do this or you might want to do that. But, uh, these are the side effects. Do whatever you want.’ (Alfred)

She doesn’t push. She doesn’t push. She just, she just suggests that this is what you should do. Yea, she’s really good at it. (Bogdan)

It’s the way they talked to me, and told me like in a kinder... ‘This is what I’d do it. This is how I’d try.’ (Jed)

One participant advised that information should be given with less authority and with a more tentative approach that is open to change, as progress and further knowledge evolves.

Give the information that you have today. What you know today. But don’t make it sound like it’s the cure all because next week there’ll be something totally different. And it’s, it’s annoying to find things changing when you’ve been told something is the way it is. (Bogdan)

One participant very succinctly summarized: “... you know, if you relate to the person then they listen to you.” (Jed) while another participant suggested “...anybody can give you sheets [of information].” (Alfred)

A relationship that communicates caring. Engaging with information is more than just the information itself; it is steeped within relationship-based communication and interpersonal exchange. Having more interactive and open communication made the participants feel like they were being cared for and treated “as a person.” Participants were most appreciative of the HCPs’ time and opportunities to simply talk. This also generated a sense of openness and a feeling their situations were understood:

She was good for sitting down with me, explain stuff that, whatever I asked her... It just makes you feel, to me, uh, make me feel closer to 'em. And, uh, you're trying to be open to 'em to tell them whatever's bothering you. (Dean)

Last time I went to see him, you know, he really sat down and we started talking and he didn't haul out his prescription pad and stuff 'til we had done some talking. That felt appropriate. (Benjamin)

Exploring further, the participants clearly described the kinds of emotions they were dealing with in managing the diagnosis, the condition and the role of being a patient in a medical system. They also conveyed the importance of communication that was based on a relationship where they felt less vulnerable to these negative emotions.

If there's a kind, understanding person sitting across from me it really helps, you know... you've got to feel sorry for the person. And that's why people need that, regardless of your ego, you still need that... this helps the overall experience because you're going through a lot of pain and shock and trauma. (Josh)

This also had an underlying message of needing to have other aspects of their wellbeing considered, beyond the diabetes.

All he wanted was to see was my numbers. I got pretty fed up with it. I, I would have been ready to leave him if he hadn't changed. I talked to him about it. I said, you know, I don't really like coming to your office because it seems too mechanical to me. (Benjamin)

One participant in particular was angered by the lack of human interaction and understanding:

...isn't a doctor's thing to make the patient feel better in any way. Isn't that the job? The guys I'm talking about did not... [They] don't think that way. Understanding what [the

patient] is going through [rather] than just, you know, mechanically going through it...once the person's more real, that makes me feel better. (Josh)

Overall, there was a clear message that each participant wanted to have the HCP communicate to him or her "as a person" through more casual conversation. "They've learned stuff through textbooks maybe. But you're not dealing with a slab of meat, you're dealing with a person."

(Hans) They desired interactions that were friendly and included discussion that extended beyond providing information. By including a more social exchange, such as talking about the kind of work one did, helped participants to feel they were not just "numbers" or patients in a queue.

...he could chat with you a little bit and stuff like this. It wasn't all medical or anything like that. He, he told us some of his life. (Alfred)

And he, he's not preaching. He sounds like a very down -to -earth kind of guy. Like kind of guy that I'd like to have a beer with... Got a sense of humour. (Hans)

The use of humour was shared by several of the participants as an important way of relating to the HCP. One patient felt a humorous interaction helped to establish that she was easy to talk to – a positive perception that would support a productive doctor/patient relationship. Humour also appeared to be used by the participants as a way to bring a bit of social levity to the encounter.

We have some good laughs sometimes when I, when I rev her up a little bit over there [laughter]. (Rolf)

I use humour to calm me down sometimes. (Gregory)

There was clear distaste for communication that was coming across as being unfeeling. This made the encounter seem like the HCP did not care about them as a person and they, in turn,

appeared to feel disrespected and often referred to feeling like ‘just a number’ or “just a number who was walking through the door.” (Saul) Unfortunately, several patients had experienced negative interactions where the patient was only seen in terms of A1C values: “I had to confront him on it, you know. It was almost as if he didn’t really care as long as I could go ahead and show to him the numbers.” (Benjamin) This kind of communication even resulted in a breakdown in the relationship as one participant demonstrated clear disdain toward the person delivering the message:

...this other idiot who I felt, you know, what’s the point of asking questions because he’s, he’s, you know, he’s like a robot... He told me, ‘well, do this, [or] you’re going to lose your leg.’ You know, type of thing. I goes, well thanks for the information, a__hole.
(Saul)

The downward spiral of declining relationship and deteriorating communication impacted information exchange.

I do it through sarcasm if they’re really pissing me off. (Josh)

When somebody’s being a bitch to you, you just rather not deal with it. (Nina)

Although most of the participants intimated such situations, only a couple described any attempts to address their concerns:

Some of them look like they’re in a hurry to get the heck out of the office, you know, instead of, you know, they’re talking over their shoulder as they’re walking through the door. Hold it, hold it, I’m not finished talking with you. Come back here for a minute.
(Rolf)

Participants repeatedly mentioned their awareness of time constraints and these shut down any opportunities to ask questions or to seek clarification or support for managing their

health. “There are some that come in and it’s almost like don’t tell me too many of your troubles.” (Anita) Such visits are further described as being somewhat pointless: “Well, wasn’t much point in seeing my doctor today, you know, because he didn’t have time for me. He may have given me a new prescription or something but he didn’t really talk to me at all.” (Benjamin) Other participants remarked that it was de-humanizing.

And then they breeze in and they almost give you the impression why are you taking up my time. You know, what you are here for kind of thing. And then they look at you. They watch. Oh your time is up and then they move onto the next person...I’m a person, darn it. (Hans)

A poignant point was made by one participant who referred to the magnitude of dealing with a health issue and valued the providers who:

...don’t put the pressure of time on your, on your shoulders when they’re there.

Especially in cases where they’re dealing with a pretty, um, a pretty heavy kind of alteration in somebody’s life pattern and health record. (Rolf)

Feeling cared for resulted from a HCP who took the time to discuss one’s health care needs. The following participant lamented the fact this is not what could normally be expected. “... a very strict thing of keeping a patient for 15 minutes or so because they have...so many clients that they have to look after in one day so they can’t spend...They don’t have the time.” (Alfred)

An abrupt interaction with a HCP was a particularly negative experience. One participant shared his inability to ask questions resulted in feeling like he simply had to listen to what the authority figure had to say with no ability to seek further information.

We didn’t care for him too much...he was, um, he was abrupt....He, he sort of looked like he didn’t care. And he was, hated to be bothered with this... It felt like he didn’t

want to be there. That he was annoyed at being there. And because he was annoyed at being there, I felt he was annoyed at me. (Alfred)

This was also evident in a diagnosis situation where there is often need for clarification and questions regarding new information:

I just got the message from the first guy that diagnosed me. Like that, you're dead, why am I even wasting my time with you... You know, like that. It was an attitude thing. Didn't say it but... He just sent me off to the [name of Hospital] to the training session. That was it. (Bogdan)

A number of participants used the term 'God' to describe how they perceived certain health care providers in terms of their manner:

These guys in the medical ivory tower. Yeah, there's a lot of prima donnas in the medical profession unfortunately. The God complex. (Hans)

They're sort of all official and 'I know better' and, you know, 'I have a God given gift' and dah, dah, dah. [We're] not going to be nasty but I think we sort of block. (Alfred)

Other participants provided more detail in terms of how information was communicated by such individuals.

Well when they're answering questions, they get defensive a little bit. And it... their ego, it's all about ego with them... Don't talk to me. Don't bother with, I don't want to talk to you then if you're going to be an ass, you know. (Josh)

A position of authority was heightened when the HCP tried to "... bamboozle you with a bunch of medical speak and jargon." (Hans)

Negotiating Control.

Patients try to negotiate control of their emotions, their health, as well as their roles within the health care system. The imposition of the diabetes condition surfaces at various times – from the initial diagnosis, to times when it is not controlled, to diabetes-related complications, in some cases. All of the participants provided accounts of feeling they had lost control of their bodies and management. To counter, there were various ways in which participants were fighting for control although this did not always mean complying with information or health recommendations.

Loss of control. Many of the participants expressed their thoughts around how the diagnosis was contributing to a sense of loss, particularly the ability to control and manage their own health and body functioning.

It's just this feeling of being alone and helpless. You have no control over it. And that's it. Having no control. Uh. You have no, no say in what's going on. It's happening whether you like it or not. You know what I mean? I had no choice but to rely on them within the system. (Josh)

Diabetes and its management were sometimes described in terms of having to comply with a treatment regimen and participants having little other choice. Rolf explains his reaction: "It's as if I'm no good anymore." (Rolf) while others felt they were "giving in" or at the "end of the road" at the time they were told to begin insulin or for some who had to start dialysis:

I felt I was, I was failing myself. And then when it was, it came to insulin, oh God, that's, that's the last resort man. You don't want to be on insulin because after that you're a dead person. (Bogdan)

I thought that was the end of the road ...Once you're on dialysis then all there is left to do is die. (Nina)

It was evident that participants felt they had limited or no choice in having to take certain steps to avoid problems and comply with a regimen:

I do it anyway even though I resent it...I have to because if I don't, I'd blame myself if it didn't work, if things got worse... I have to at least listen. I may be a jerk but I'm not stupid...I want to be well. And if that's the way to do it, then I'm going to do it. (Bogdan)

I'll get used to the fact that I've got no, uh, no recourse other than medication... That's your situation buddy. Well then, fall in line and carry on, you know. Yea. Oh yea, I wasn't going to fool around. (Rolf)

In particular, the serious prognosis requiring dialysis left individuals with no opportunity to exercise control as decision-making was almost non-existent:

And I asked the doctor how long would it take if I didn't want dialysis. One week. [So] I said, yea. (Rose)

If you don't do what we want you to do, you're going to die. If you don't go, like I was talking about I didn't want to really come here all the time. And he told me ... it's either dialysis or [name of cemetery]. What are you going to do? (Dean)

Participants conveyed the sense of imposition of the diagnosis and in particular their experiences with the health care system. Rolf explains how his control is compromised by the fact that he has to be reporting back to the health care providers and this comes with further instruction:

No matter where I go, I've got to drag that doggone equipment with me. And it takes almost a suitcase just to carry all the pills and the needles and the test strips and, you

know, the log book and I'm not used to being tied down like that... The other thing that, that I find difficult at, difficult, annoying is that I've got to constantly be in touch with the doctor and with the nurse about my medication and about the readings. (Rolf)

Pam also described the effect of dialysis in limiting her daily activities: "I just come to dialysis. Sometimes I go grocery shops and that's it." (Pam)

Within the health care setting, particularly in hospital, several participants described how their self-identity was compromised and the sense of vulnerability became much more obvious as they became dominated by the normative processes of care.

[The central line] was in my neck and I remember, like you know I remember the doctor coming even to change the central line and they had students. Like I felt like I'm not a fuc_ing guinea pig, get the fu__ out of here. But I just lay there and I just, I was thinking in my head but I didn't say it. And they were doing like, he was doing a teaching for them, like. I just didn't say anything because I needed my line cleaned anyway. And then when he, but when he did come to clean it, something happened. He had to end up pulling it out. I had two lines in my, on both sides of my neck. (Nina)

Nina suffered in silence and it was only for the study interview that she shared the anger that was brewing at the time. Other participants also conveyed intense anger at being made to feel like they did not have a choice or a voice in determining how they would be treated. The following is a description of a participant's interaction with a HCP when he found himself unable to transfer himself due to problems with circulation in his legs and open sores on his buttocks:

[The HCP at the] big desk from around the corner, can't even see me, [says] 'oh he looks like a fine strapping guy, he could slide by himself'... I said, 'no, I just said before, I can't do it. I've got sores on my ass, I'm not sliding over. The doctor doesn't want me

doing that type of thing...I said, I can't do it.' And she said it like about two, three more times. And my mom and I were ready to, excuse the language, f__kin tell her... (Saul)

Authoritative providers put the patients in a vulnerable and even fearful position. One participant conveyed how, in retrospect, he tried to be honest and forthcoming but felt what he said enabled the HCP to exercise power and used information against him rather than for his benefit:

Oh, I'd like to punch that guy. Anyways, he said to me, asked me a bunch of questions about. He says, 'are you getting up out of bed yourself? And going to bed yourself?' I says, no, because I couldn't. He says, well why? I says, 'because the doctors and the orderlies say not to get up on your own. Push the button, we'll come and help you.' [The report stated] Mr. [N], needs a longer, uh, longer care and we recommend that he goes to a nursing home instead of going home. So he screwed me around for that. So what are you going to do? I mean they got, they got the power...And the way he was talking was so cut and dry. He had no compassion whatsoever. And to me I felt like he figured he's got me in his hands, and he's just squeezing me and that's it. He doesn't want to let me have anything, uh, good. I wanted to go home. I sure wanted to go home so bad. (Dean)

Having to be tied to medical management, either on their own or in the health care setting, made the participants feel it was unfair.

I got diabetes now. Um. I went blind in my left eye. I got to change my whole life around because I got to go to the dialysis. ...I mean I didn't do nothing to nobody. All my life I treated people good. And I got this stuff to, uh, done to me. (Dean)

Fighting for control. Despite the ongoing and sometimes unpredictable nature of diabetes management, many of the participants were intent on reaching an equilibrium. Although

this state was both precarious and indefinite, it was a satisfying goal that further offered a sense of control and safety that participants didn't want to disturb.

... there is a little bit of comfort in having an absolute where you repeat the diet day after day after day. That routine, you know... I used to have this routine at work. I'd go to work for 7:30. And at 9:30, 10:00 o'clock or so I'd have a break and I'd have... Morning I'd have a banana and some almonds. That was my snack because this is what the dietician told me. And then I'd have lunch and it was always the same thing, you know, just sandwich, this, this this, all within carbs. And afternoon I'd have an apple and a piece of cheese. Everybody knew what time of day it was because they saw me with my banana in the morning and apple in the afternoon. And I did that for years, literally years. (Bogdan)

Having a comfort level and sense of control associated with equilibrium, resulted in less interest in information or suggestions for change that might potentially disrupt the status quo:

Peg: As far as I was concerned, I felt good with it [insulin]

Gayle: So you thought you had it under control?

Peg: Uh hmmm... why do I have to be told what to do?

For some, there was no perceived knowledge deficit, especially when one felt well and what they were currently doing allowed them to feel well:

I was getting letters sent to me, uh, to go to some kind of classes. But, you know, I don't, I thought to myself, well, what more can they tell me? Because, you know, the nurses and the doctor were telling me everything. I already knew. (Dean)

Gregory also described how he couldn't understand why the HCPs were giving information. He felt that as long as he was controlling his diabetes, there was no need for further discussion:

I check my blood work so they tell me, you know that stuff. Then she comes and she starts talking to me. I listen to her. But if my blood work was good, you know, why is she telling me all that stuff? (Gregory)

Experiencing symptoms or more acute situations disrupted equilibrium and one's sense of control. Having numbness or an odd feeling in a limb was a warning sign of potential complications and motivated one to be more engaged with the problem and its management:

I came back [to dialysis] on Monday and I was extra heavy. Oh. And I could feel it in my legs and I could feel it in my arms and my hands, you know...the puffiness. So I got the lecture again [laugh] – cut down on your fluids. I said, 'ok this time I will try. I promise I promise I'll try,' so I did. (Peg)

One participant described his thinking about sustaining a change in his diet. He was willing to deny himself temporarily until his body responded but resumed eating the food item once the readings returned to normal: "I've been having chips for two, three years now. And she says, 'I think you should stop eating chips right now because they're, your potassium is high.' Now I'm going back to eating chips [chuckle]." (Gregory)

Understandably, the participants desired a treatment pathway that would help them feel well. However, the reluctance to use insulin, as previously discussed, was also accompanied by a sense of relinquishing control. One individual discussed a compromised, albeit working, level of control in using medications as a tool for treating diabetes. But getting to this point required a fair amount of time to adjust. His latter comments conveyed the level of resistance he had to overcome:

Bogdan: I'm still not in control myself, but I'm happy to control what I've got. Yea.

Gayle: So you kind of are in control then...just using different tools?

Bogdan: I am, yea. But it's, I'm, I don't feel as if I failed myself anymore. Like that's not the, that's not the feeling I have anymore.

Gayle: How did you get to this point though?

Bogdan: By taking insulin and seeing that it works so I thought, Jesus, what am I? Stupid or what?

Some participants also chose to take control of what information they used, which also meant rejecting some of the information provided by the health care providers.

But I'm open for information and thank you very much...And then I do what I want [laugh]...If somebody suggests something I'm willing to listen and if I like the idea I'll do it, and I don't like it, I won't do it. (Donna)

This highlights the importance of self-determination and the desire to assimilate information in a manner that was suitable to one's self:

You're not gonna rule my life. I'll do what I want. And if I think I'm gonna do better by doing something for myself I will, but nobody is gonna tell me what I can do and can't do. So you can give me information and I'll use it the way I want to...not what you'll tell me to do. (Peg)

[HCP] comes here, she come to see me and she told me you're not supposed to eat french fries and fried chicken and all these stuff and that. Then I said, I'm not going to go along with her, I still think that I could do it on my own. (Rose)

On the surface, this appeared to be a way of avoiding the challenges associated with change.

However, holding on to a lifestyle was also holding onto what was familiar, behaviours that one had grown up with and a lifestyle that became part of their work identity and social identity:

“I just wanted to be out there. And I didn’t want to give up fishing. I absolutely did not because I’d already given up a job.” (Breanne) Breanne further explained how her management was motivated by how she felt and also described how her priority was in maintaining a familiar lifestyle and being able to apply quick fixes such as a shot of juice to manage her symptoms and enable her to carry on:

I was supposed to but I would just take it whenever I felt like it... I was still fishing when I should have been, should have been looking after myself better. But I would be out on the lake and I would be, I would go into a low blood sugar and just take a shot of juice, and keep on going [chuckle]. (Breanne)

Participants provided a number of examples of activities shared by family or friends, which made change difficult.

When I got out of the hospital, I really did try. And then, it was my girlfriend and I, we just, we started eating ice cream but she [laugh] - for my health, she bought diet 7-up [laughing]. And you know, that was funny. And then I started cheating a little more, and a little more. (Peg)

Some chose to continue with a life they knew and were accustomed to, despite any difficulties.

And finally the last time I was out [at work], I was driving [and] hanging over the edge, vomiting like crazy because I was, had so much poison, that’s when I was on peritoneal and [chuckle]... So I would be out there and I would still be trying to do everything.

(Breanne)

Peg suggests some changes are simply too much or too difficult to assimilate into one’s lifestyle.

Such information is rejected as something that others want and not what she wants:

Peg: I just don't wanna remember I guess. I think there's all of the things that you're told but just don't wanna remember.

Gayle: Yeah? Why is that do you think?

Peg: Because you're changing your life too much. You know, like one day you can have this and the next day you're told no – I mean I'm not going to change my lifestyle just to please everybody else. I'll please myself.

The desire for control and independence was sometimes a process that evolved as the participants reflected on their experiences and realized self-efficacy:

The self, the self-coaching that I gave myself, uh, to get out of that lethargy I was kind of, at all cost, wanting to avoid. You know, and I said, 'OK, I've been through other stuff.

I'll get used to the fact that I've got no, uh, no recourse other than medication.' (Rolf)

One individual had an influential individual rally his spirits and urged him to take control:

When I was here on the third floor, my wife came and my brother came. And, uh, I was in; I had given up. I was just lying in bed feeling sorry for myself. And he told me, my brother told me – I get emotional when I talk about this – he, uh, he says, 'you tell those God damn doctors that you're going to walk out of here and you're going to start walking today.' And sure enough, that's what happened. (Dean)

However, others felt a greater sense of control when they were more involved in the process of care and could obtain the information they needed. As mentioned previously, the participants who began to adjust to diabetes and look forward and concentrate on 'getting on' with life activities, were also fighting to maintain control. Thus, information and education were the enabling means:

It has to be me to know what's going on in my body... And it's got to be me to be able to control it. It's all about control. Being able to control your sugar levels. Not letting it control you. It's you that's, it's you that's got to know what you can put in your body that's safe...I say why. You know, every person I go through, it's always like, what for. Like why? Tell me why? Like you're not going to just, I'm not going to, I'm not playing guinea pig here. Like I want to know why. (Nina)

One of the participants summarized the need to be in control as the solution for self-management. He suggests that this responsibility is one's own and HCPs need to be positioned as open, accessible resources to support this:

You say that you're going to take care of yourself the best way possible and you're not, doctors are going to become – the health care system are going to become your ally and your resource. They're not going to drive your health, you're going to make them look after you. Your doctor's not responsible for your health; you are yourself. And your doctor is there as a resource and not a resource that is difficult to get to or extract. I mean a resource that's very willing to be one for you. I think if you stress on those kind of positive views, I think most people would respond. (Lester)

Summary

Three main themes were revealed from the participants' narratives and offered a more in-depth understanding of the thoughts and feelings underlying readiness to engage with health information. Underlying incongruence is the primary theme and reflects the distance that separated the participants from the information or situation they were facing. Many of the accounts exemplified feelings of being healthy and normal rather than a sick diabetic. Navigating incongruence was a process often requiring a reported need for time and space within which to

process the information. Some of the participants reacted to the diagnosis by distancing themselves from the diagnosis and the information to manage it. Many of the participants explicitly described varying levels of avoidance. For others, navigating the difference meant dealing with diabetes information from a point of individual difference. Yet, comparing one's situation to others who appeared to be more seriously affected by a health condition or complication sometimes provided a renewed energy to face health challenges. Integrating diabetes into one's lifestyle required building knowledge and translating it into one's life.

Building knowledge meant navigating between “black and white” as many individuals, particularly in the early experiences with diabetes, desired more concrete and objective information. As individuals in “different shoes” began to tailor and translate the information to their unique situation, they were experiencing the ‘grey zone’ and had to be discerning information consumers.

The participants' accounts also highlighted the importance of communication. Although this had an influence on incongruence and negotiating control, they highlighted the need for information extending beyond the medical condition and communication that conveyed a sense of caring. Also, the participants expressed a desire for talking with their HCPs through an effective interchange based on a relationship. This would facilitate their understanding and minimize how the information needed to be interpreted and tailored to their needs.

Finally, the sense of losing control of one's health and increasing dependence upon the medical system was countered by fighting for control. Control centred on maintaining an equilibrium; this provided a sense of certainty, whereas information about other kinds of management potentially threatened a sense of control. Others also fought for control by disregarding the medical directives and making their own choices. Although some people viewed

their health situation(s) as bumps on the road, they had varying strengths and capacities that enabled them to look forward and beyond the worries of managing diabetes. However this seemed to evolve over time with more knowledge and experience.

CHAPTER 5: Discussion and Conclusion

The purpose of this research is to conceptualize patient readiness to engage with health education and information and the underlying cognitive and affective factors. Coping Theory and Personal Construct Theory were useful frameworks, underscoring cognitive appraisal and individualized constructs activating a particular response. An in-depth exploration of cognitive and affective factors contributed to a more holistic understanding of education and learning within the health care setting. Indeed, the focus on implicit, influential factors broadens health education beyond the traditional foci of behaviour and lifestyle changes (Glanz et al., 2002; Hoving et al., 2010). From the analysis of the in-depth interviews, three themes emerged:

- Underlying Incongruence in knowledge, thoughts and beliefs;
- Relational and Translational Talking; and
- Negotiating Control.

Although presented as three distinct themes, they intersect and converge on the essence of the findings, best described as a gap or a distance between the patient's lifeworld and the disease and its management. The discussion presented in this chapter relates the study findings to the relevant research literature. The findings are then examined through the lens of Cognitive Dissonance Theory and Construal Level Theory (and the notion of psychological distance) to better understand 'distance' as the common integrating factor for the three themes. Implications for the research results, practice and future research are outlined. The chapter concludes with the strengths and limitations of the study and its interpretations.

Theme I: Encountering Incongruence

The primary theme of incongruence emerged from the study participants' narratives. They described how it was encountered and the ways in which they tried to navigate through

uncertainty. The initial diagnosis or a significant change in health status was a pivotal encounter with incongruence and study participants reported shock and denial. The literature also adds that patients report anxiety, fear and worry resulting in feeling overwhelmed, paralyzed and unable to retain or absorb information, or think about next steps (Berry, Anders, Chan & Bell, 2012; Hughes, Keith, Byars & Wiginton, 2012; Longo et al., 2010; Porter, Watson & Bargman, 2013; Stiffler, Cullen & Luna, 2014; Stuckey, Mullan-Jensen, Reach, Burns, Piana, Vallis, . . . Peyrot, 2014). This may also result in less acceptance of the diagnosis or need for management (Stiffler et al., 2014), particularly when personal resources are already stretched (Hinder & Greenhalgh, 2012).

The absence of symptoms also contributes to difficulty in accepting or believing the diagnosis and its seriousness (Johnson, Newton, Jiwa & Goyder, 2005; Troughton, Jarvis, Skinner, Robertson, Khunti & Davies, 2008) and patients are inclined to participate less in diabetes education (Schäfer, Pawels, Küver, Pohontsch, Scherer, Van Den Bussche & Kaduszkiewicz, 2014). The participants' narratives also conveyed implicit efforts to create distance and avoid being considered different, labeled as a sick person (Middleton, LaVoie & Brown, 2012) and potentially altering one's sense of identity within his/her social or work sphere (Aujoulat, Luminet & Deccache, 2007; Persson & Friberg, 2009; Schabert, Browne, Mosely & Speight, 2013; Stuckey et al., 2014). Given diabetes strong association with obesity and preventable risks, patients with diabetes have experienced discrimination, stigmatization and blame from others (Middleton et al., 2012; Schabert et al., 2013). The use of the term 'pre-diabetic' was only used by one of the participants but appeared to enable some distance from a "full blown" diagnosis. Use of this term and its connotations regarding disease needs to be

further considered and whether it influences a particular attitude toward diabetes information and the need for education.

Time and Space. The patient's desire to live as usual and minimize the impact of diabetes has also been found in other studies (Jutterström, Isaksson, Sandström & Hörnsten, 2012). Many of the participants referred to the general imposition of the disease within their lives and life trajectories; they needed time and space to process or negotiate this change. This period of incongruence disrupts one's experience of taken-for-granted body control and a usual orientation to the world is now deflected toward the body (Morse, Bottorff & Hutchinson, 1994). Acceptance is part of the realization that the present and future are irrevocably changed, and patients are faced with having to move beyond the past, reevaluate goals and values, and adjust one's life course to affect the future (Morse & Penrod, 1999; Turner, Goodin & Lokey, 2012). The process of repair is associated with changes in knowledge, from uncertainty, limited awareness, recognition, to acceptance (Morse & Penrod, 1999). A turning point for genuine learning occurs with a shift toward allowing the illness into one's lifeworld without occupying a significant part of daily thinking. However, the patient must also have a willingness to challenge his/her capacity and be open to knowledge and coping strategies for taking on the new situation (Berglund, 2014; Johansson et al., 2015). These kinds of goals for moving forward were made explicit by several participants and appeared to motivate learning. Alternatively, there was a preference to maintain a familiar pre-illness lifestyle, which could trigger resistance to learning. Individuals may reject changes felt to be dictated by a disease and interfering with their goals and expectations of normative development and growth (Berglund & Kallerwald, 2012). This kind of mindset is a challenge that needs to be considered rather than assuming poor glycemic

control is the result of a knowledge deficit (Schmitt, Reimer, Kulzer, Haak, Gahr & Hermanns, 2014).

“In a Bubble.” Critical life events categorized as life transitions, failure and trauma are sources of disequilibrium resulting in a reaction to persist, bypass or cease striving toward a goal (Turner et al., 2012). The participants commonly referred to avoidance and denial as well as other related terms, such as being “in a bubble.” Reluctance to engage with diabetes information may range from fear of injections, expectations of a more restricted life (Benroubi, 2011; Nam, Chesla, Stotts, Kroon & Janson, 2011) to more existential issues and a challenged and vulnerable sense of self (Afifi & Weiner, 2004; Berglund, 2014; van't Riet & Ruiter, 2013). According to Frankel and Levitt (2009), individuals disengage from situations to prevent loss of what one knows, their known world and previous patterns of experience. Avoidance and disengagement offer a reprieve from feelings of discomfort or fear, or a sense of weariness with the health issue (Barbour, Rintamaki, Ramsey & Brashers, 2012; Frankel & Levitt, 2009). Exploring avoidance as a polar opposite to readiness, was important for understanding the thoughts and emotions at work in defending and protecting one's self. Significant rates of depression reported in previous research (Harvey, 2015; Nam et al., 2011; Stuckey et al., 2014; Nicolucci et al., 2013) also suggest psycho-social aspects of diabetes management are insufficiently considered or evident in clinical approaches, but may offer considerable benefit (Goering & Matthias, 2010; Schmitt et al., 2014).

Educational information is provided by health care providers with the intent of contributing to an individual's ability to adjust to and manage his/her health. However, what is less often considered are the negative aspects of *more* information. Firstly, information may change the nature of the patient's concerns or even raise new concerns, further complicating

one's understanding (Barbour et al., 2012), and creating a general fear of knowledge (Berglund, 2014). Secondly, inconsistent information, as reported by participants in this study, generates confusion and anger and patients are inclined to avoid trying to manage flawed information. They may also be less willing to try to discern credible from non-credible information, especially if it is not convenient, too technical or requires too much effort to process (Barbour et al., 2012).

Defensive Reactions. Individuals may choose to manage information in a way that restores a level of cognitive comfort. van't Riet et al (2013) defined four types of defensive reactions particularly when information is threatening to one's health or sense of self and perceived to be personally irrelevant. Avoidance involved ignoring dissonance to return cognitive consistency. It is an attractive alternative when an individual is limited in his or her ability or resilience to act upon and be effective toward a threat (Barbour et al., 2012; Johnson, 2014; Frankel & Levitt, 2009). Denial is another defensive reaction whereby individuals refuse to accept information as true - dismissing it or deliberately looking for flaws. A related defense called reactance is motivated by a desire to retain control. Suppressing negative emotions is a third reaction depending more heavily on one's cognitive resources, and may involve aids such as drugs and alcohol to control emotional responses. Finally, cognitive reappraisal occurs when an individual accepts the information as true but constructs additional beliefs to allow one to reduce dissonance by downplaying the relevance and the threat. There is an appreciable logic in these protective reactions for managing turbulent thoughts and emotions. However, when such responses occur in relation to illness management or education, it is perceived as maladaptive and little attention has been given to recognizing these latent influences on health education.

Threatening health messages have been used to try to ignite cognitive processes and stimulate learning, however an opposite effect may occur. Cognitive responses for controlling or

reducing emotions may also disable effective mental functioning. Indeed, emotions have a pivotal role in motivating or catalyzing mental effort. Turner et al. (2012) have explored the intersection of emotion and activation to determine the kinds of emotional responses that precede motivation (Figure 1). According to this model, positive and activating emotions would result in excitement or enthusiasm whereas with deactivating emotions, one might feel peaceful and content. When negative and activation emotions intersect, anger or anxiety would result whereas with deactivating emotions one might have feelings of hopelessness or fear. Notably, negative deactivating emotions creates a situation where it is difficult to move forward and individuals remain motivationally ‘stuck’ (Turner et al., 2012).

	<i>Activating</i>	<i>Low-Activating/Deactivating</i>
<i>Positive Valence:</i>	Excited, Enthusiastic	Peaceful, Content
<i>Negative Valence:</i>	Angry, Anxious	Hopeless, Fearful

Figure 1.0. Emotional Valences and Activations. Reprinted from “Exploring the Roles of Emotions, Motivations, Self-Efficacy, and Secondary Control Following Critical Unexpected Life Events” by J. E Turner, J. B Goodin & C Lokey, 2012. *Journal of Adult Development*, 2012, 19, 4, 215-227. Reprinted with permission.

This intersection also demonstrates the nuanced emotions underlying responses. A similar interplay may be evident among individuals who seek cognitive consistency but also have an obvious desire to feel physically well. Rather than complete avoidance, people may limit the extent to which they avoid or deny information, and defensive reactions may co-occur with behaviours conducive to health management (van't Riet & Ruiter, 2013). A certain level of

cognitive avoidance can be maintained as dependence on medication and medical intervention may enable a satisfying level of management without having to pursue changing other behaviours. This was evident among the participants who were still maintaining effort to manage diabetes, but were less engaged with information. Bogdan's remark: "I'm not stupid...I want to be well. And if that's the way to do it, then I'm going to do it" illustrates how readiness is bound within the delicate balance of distancing oneself from diabetes while participating enough to feel well and maintain a level of management confidence and control.

"Into our shoes."

Following the processing period and the emotions and denial characterizing the time of diagnosis, there is a realization information is needed but it is difficult to identify specific learning and information needs (St. Jean, 2012). Participants had qualitatively different knowledge gaps and were challenged to translate or personalize the information. In this respect, one of the participants advised HCPs to "put yourself into [our] shoes," referring to the patient's limited knowledge, experiences and exposure to diabetes contributing to incongruence. However, learning and openness to learning means daring to trust new knowledge in place of what was previously known (Johansson et al., 2015). This means allowing one's frame of reference, pre-illness way of knowing or being in the world (as reflected in Heidegger's concept of *Dasein*; Lavery, 2003) to be challenged. A patient's frame of reference may be different from the HCPs, separated by a more evidence-based versus experience-based domain of expertise (Persson & Friberg, 2009).

Navigating the Ambiguous and the Strange. According to Berglund (2014) "there is a significant amount of research about patient education but considerably less that describes patients' learning" (p.4). Management is not about a strict plan to be adhered to, but recognizes

there is a learning and change process for self-management (Stiffler et al., 2014) and the process requires patients to navigate information that is “black and white” as well as “grey.” Study participants recommended basic, straightforward information, regardless of levels of education or literacy, and prefer information at an early point following the diagnosis (Longo et al., 2010). Information that was not considered black and white resulted in participants feeling they did not receive concrete directions required to take the initial steps for managing the newly diagnosed condition. Several study participants preferred routinization, which was found to provide a buffer against negative consequences (Newton, Asimakopoulou & Scambler, 2015). Lower diabetes distress and significantly better dietary self-management were associated with clear directions and receiving reassurance (Polonsky, Fisher, Guzman, Sieber, Philis-Tsimikas & Edelman, 2010). However differentiating the “black and white” features requires further consideration.

Patients often report receiving minimal or unclear plans from HCP regarding treatment steps, education and follow up plans (Mulder, Lokhorst, Rutten & van Woerkum, 2015; Polonsky et al., 2010). Ambiguous, vague information or lack of explanation will affect compliance (Elder et al., 1999) and patients are left with questions and general uncertainty about how to manage (Middleton et al., 2012). Information that is more tangible is associated with more positive outcomes in a variety of settings. Patients who meet glycemic targets have more concrete ideas around management than patients who did not, with the latter describing their management in more generalized terms (Brewer-Lowry, Arcury, Bell & Quandt, 2010). In psychotherapy, clients were more likely to do therapeutic homework if they were assigned behavioural skills training (Holdsworth et al., 2014) suggesting this type of approach was easier to work with than more abstract approaches, such as problem-solving. Similarly, Hastall and

Knobloch-Westerwick's (2013) study regarding selective exposure found that respondents preferred and spent more time with messages that featured exemplar evidence.

Changing Information Needs. Patients need strategies to help translate educational programs to real life and cope with the issues that interfere with management (Ritholz, Beverly & Weinger, 2011). Information that builds on the patients' knowledge and experiences will help them attend to education and is fundamental to constructing a workable management plan (Elder et al., 1999), and results in more effective learning (Peyrot, 2009). However patient education based on information from previous change attempts or concerns is seldom evident in consultations (Mulder et al., 2015).

Information needs also differed over time. The nature of support and educational information needed to adapt and change as patients became increasingly familiar with management based on their own experiences. When participants felt that their condition was stable, they sought less information and once again, entered a stage of 'incognizance' where they felt they knew everything they needed to know (Goering & Matthias, 2010). Similarly, self-management was influenced by symptoms (Hinder & Greenhalgh, 2012) and feeling well, which then allowed other life issues to take priority (Ritholz et al., 2011). Overall, patients with diabetes appear to engage with less information over time, and notably, their sources of information also change, reporting more dependence on HCPs initially but increasingly more on other sources such as Internet and support groups (Goering & Matthias, 2010). The information provided by HCPs tends to be more disease related whereas informal sources relate to aspects of the illness experience (St. Jean, 2012).

Theme II: Relational and Translational Talking

Health care providers have a central and valued role in providing health information (Longo et al., 2010; St. Jean, 2012) however the participants also conveyed a desire for a *relational* approach. Firstly, they needed health care providers to *relate to* their individual sense of self, personal autonomy and way of knowing, so health education could be more easily integrated with their personal knowledge and situations. Secondly, the participants appeared to be more open and willing to engage in information exchange when the HCPs could *relate to* their emotions and “as a person,” through a supportive relationship.

Relating to Autonomy and Personal Relevance. The consumer movement in health care assumes individuals are able to understand and interpret health information and turn it into actionable knowledge (Johnson, 2014). However, health care providers have been perceived to be less useful for providing personally relevant information (St. Jean, 2012) and are not seeking patients’ opinions of living with diabetes (Ritholz et al., 2011). Advice and treatment recommendations are considered not worth following when the patient feels his/her knowledge and past experiences are neglected (Berglund, 2014).

Disease management is complex; optimal day-to-day management choices are essential activities which the HCP cannot control (Jutterström et al., 2012). One-way communication centred on metabolic control places the HCP as the authority. In the Newton et al. (2015) study, patients wanted to co-manage their condition through a relationship with the HCP that favoured information exchange. According to their findings, this was reported by only six of the 37 people interviewed (Newton et al., 2015). Education has centred on self-management and personal responsibility however, it is felt to be occurring within a culture of surveillance, compliance and judgment (Jutterström et al., 2012; Schabert et al., 2013; Vallis, 2015). Previous studies have

reported paternalistic approaches causing patients to feel guilt, shame, as well as anger and defiance to information infringing on autonomy and self-identity (Ritholz et al., 2011; Wermeling, Thiele-Manjali, Koschack, Lucius-Hoene & Himmel, 2014). Patients may attempt to conceal information due to fear of negative appraisals, thus compromising potential informational or educational support for their diabetes self-care (Schabert et al., 2013).

Relating to Psychological and Emotional Needs. While HCPs are the most sought after sources for information regarding diabetes, education tends to occur in a stressful, emotional and often anxiety-inducing context (St. Jean, 2012). Participants described the kinds of emotions they were dealing with in managing the initial diagnosis, trying to manage the condition itself and how they felt as a patient in the medical system. There was an expressed need to have the HCP focus more on the emotional aspects of having a chronic illness, with access to psychological supports (Berglund & Kallerwald, 2012; Davies, 2015; Stiffler et al., 2014). The experience of living with the physiological aspects of diabetes and management expectations within the medical and social context are accompanied by feelings of distress and loneliness (Davies, 2015; Hughes et al., 2012; Vallis, 2012). According to Davies (2015), psychological distress is not so much pathological as an emotional burden that needs to be acknowledged as part of the patient experience. Treating distress and enhancing emotional well-being impacts self-management and control. Yet, clinicians seemed to lack knowledge of psychological well-being, the confidence to identify such problems and most interventions are not based on strategies to manage psycho-social issues (Nam et al., 2011; Vallis, 2012).

Patients are expected to implement a facts-based reasoning process to support a problem-focused coping response (van't Riet & Ruiter, 2013). As one study participant angrily stated, there is an expectation for patients to act like fictional film characters such as “Dr. Spock or

Sheldon Cooper” who demonstrate minimal emotion for managing life circumstances. Patients want HCPs to acknowledge the emotions tied to their situations, the hard work of managing a chronic condition and the efforts to change deep-rooted behaviours (Ritholz et al., 2011; Stiffler et al., 2014; Wermeling et al., 2014). Being treated “as a person” within a context of caring would help them feel less vulnerable to negative emotions and more open and receptive to information. The diagnosis situation is a time requiring sensitive communication and in order to be more engaged, patients need to be able to share emotions, tell their story, be heard and understood, and recognized as a person rather than a diagnosis (Bright et al., 2015). In fact, when the patients feel they are not being seen as a person with fears and experiential knowledge, learning is impeded (Berglund & Kallerwald, 2012).

Within this context of empathic communication, the therapeutic relationship is an important, catalytic force for ‘remoralizing’ individuals who often initially perceive themselves to be incapable of tackling their problems. Across different approaches to cognitive change, the provider is in an important position for engaging patients, having them commit to the change process and nurturing coping (Holdsworth et al., 2014; Ryan et al., 2011; Stuckey, Vallis, Kovacs Burns, Mullan-Jensen, Reading, Kalra,...Peyrot, 2015). Engagement is conceptualized as a process or a co-construction through interaction and a trusting connection between the patient and provider, and appears to be a critical facilitator (Holdsworth et al., 2014). In fact, some researchers have suggested that this relationship needs to be established and attended to throughout the therapeutic encounter (Bright et al., 2015).

Cognitive processing is more likely to be affected when tension and anxiety are encountered and uncertainty would further contribute to feeling fearful. A more confrontational approach also results in resistance (Frankel & Levitt, 2009). Study participants shared destructive

scenarios whereby warning or contingency messages were provided. This is also evident in previous research where threats or pressuring techniques occurred when health care providers were frustrated with patients' nonadherence (Ritholz et al., 2011). However, generating fear is associated with maladaptive coping, poor control and quality of life (Harvey, 2015) and may have a counterproductive influence as people limit the extent to which they engage with information (Lazarus & Folkman, 1984). Rather, tailored information that arouses less fear is associated with greater motivation for patients to attend to information (Kessels, Ruiter, Brug & Jansma, 2011).

In general, the provision of support is lacking (Ritholz et al., 2011; Vallis, 2015). Participants discussed the need to have the space within which to deal with emotion and have providers assume high emotions were present and needed to be considered. However they also perceived this to be out of the scope or expectations for the health care interaction as providers do not have time to answer questions but focus on other treatment concerns, such as prescribing medication (Goering & Matthias, 2010).

Theme III: Negotiating Control

Patients negotiated control of the roles they needed to assume as either self-managers or recipients of care within the health care system, and this appeared to be related to readiness to engage with information. *Loss of Control* was encountered when patients felt a diabetes-related health issue was *imposed* on them or with the ways they felt they were treated in the health care setting. They were *Fighting for Control*, particularly when trying to reach and maintain equilibrium, which would provide some reassurance they were adequately managing their condition and would allow them to focus on other life activities.

Levels of Control. Individuals diagnosed with a chronic disease often feel life has become unpredictable and out of their control (Aujoulat et al., 2007). However, various levels or categories of control have been identified, ranging from external attributions of control (such as medical expertise) to internal, autonomous control and self-directing personal actions to obtain outcomes (Turner et al., 2012). Internalized versus externalized control may be associated with varying degrees of willingness and readiness for engaging with information to promote or support a behaviour. Furthermore, readiness may also be a function of various kinds of control related to global conceptualizations versus control of specific tasks, behaviours or situations. In other words, patients may feel less open to information about diabetes as a condition they are unable to control. However, they may feel a sense of control over a particular self-management task and are therefore more receptive to information and education for performing the task.

The variability associated with diabetes management means decisions and ongoing challenges are not static and linear. Beliefs and knowledge about the disease may change and develop over time (Debussche, 2014). The perceived level of control at a given time as well as the risk of losing control when implementing a change in one's management approach or routine may limit the desire for information. A perceived incapacity to address one's issues has an adverse effect on involvement (Holdsworth et al., 2014). Among the participants, low levels of primary control were also associated with fear, depression and ambivalence. Yet, learning to live with diabetes requires the ability to reconcile control over the illness while at other times managing the fear and uncertainty of an unexpected physiological response. The fluctuations experienced in self-management require persistence and perseverance but these may challenge one's abilities and subsequent openness to new information (Johansson et al., 2015).

Managing autonomously was reported as “being normal” (Newton et al., 2015); control and confidence are lost when having to be dependent on others (Aujoulat et al., 2007). There is a greater sense of control when having the freedom to decide whether to avoid, reject or opt out of directives, even temporarily (Wermeling et al., 2014). Reactance may also occur when individuals feel their freedom is threatened and they may refuse what is prescribed simply on the basis that their sense of control may be compromised (Reach, 2012).

Protective Control. Disengagement also offers an unconscious level of protection from losing control and may provide the emotional capacity to prevent being overwhelmed or compromised (Frankel & Levitt, 2009). Petty and Birnol (2015) also found individuals avoided processing counter attitudinal information when there was a desire to maintain happiness. Participants who felt fine and perceived no knowledge deficit, had a sense of satisfaction, control and safety in reaching a state of equilibrium. According to Berglund (2014), balance is considered in terms of the patient’s individual context and feelings or perceptions of health status. This balance may then control the amount of dependence one feels he or she needs to have on others and on the treatment (Debussche, 2014).

A high level of mastery (i.e., general sense of control over the circumstance) is associated with better health among people with chronic disease (Raaijmakers, Martens, Hesselink, de Weerdt, de Vries & Kremers, 2014). It is fostered through greater involvement with the process of care, decision-making, and through a learning process based on personal goals, perspectives and information needs (Peyrot, 2009). Patients’ assessments of powerlessness have not been well researched (Aujoulat et al., 2007) although many have reported a relatively low sense of mastery and recommend autonomy-supporting counseling by providers (Raaijmakers et al., 2014).

Facilitating Control. Vallis (2015) has drawn attention to the need for a required shift in control from HCP to patient, by greater collaboration with patients and HCPs taking a more facilitative approach. However the facilitator role is difficult for HCPs to adapt to (Jutterström et al., 2012) and the shift to a more collaborative approach is complicated by systemic issues and discrepant provider perspectives. Firstly, overstretched providers with the goal of providing comprehensive care are challenged by time, overcome by the patient's psycho-social difficulties and equipped with few treatment options (Ritholz et al., 2011; Stuckey et al., 2015; Vallis, 2015). Secondly, control is a function of both health care provider and patient negotiating the evidence in relation to the patient's preferences and individual situation. This may present a conflict between respecting patient autonomy and the HCP's sense of duty to promote the benefits of certain treatments or management approaches based on sound evidence. Previous research has demonstrated that doctors trying to avoid the paternalistic approach were confronted with the difficulty of integrating the life world and medical world (Wermeling et al., 2014). Caregivers are faced with two different logics regarding the evidence-based knowledge, expertise and trust-worthy information that they are trained to provide versus the complex and experience-based knowledge that is fundamental to patient-centred approaches (Debussche, 2014; Mulder et al., 2015). Patient decision-making requires the capacity and competence to make choices based on values and preferences but it is not as easy to execute (Reach, 2014). Autonomous decision-making is not only based on the here and now but patients are challenged to critically evaluate immediate and future needs.

Summarizing the Interconnected Themes

Rolf's statement that the diagnosis and treatment were "pretty radical from what I've known all my life" exemplified the overarching theme of incongruence while Anita's reference

to “in our shoes” indicated the desire to be understood, with information tailored to one’s needs. Readiness might be conceptualized on a continuum from “radical” to “in our shoes,” representing the breadth of disconnect or distance from a normalized self. Although three themes are presented, they are not distinct as underlying incongruence is interwoven throughout and fundamental to a coherent understanding of readiness to engage with health information.

Varying degrees of incongruence were evident and required the time and space within which to process or adjust, especially following the initial diagnosis as well as at various times when health was challenged. This also required some navigation however the participant narratives conveyed the issues of trying to reconcile the sense of a historical self and experiential knowing with the altered state of health and the uncertainty associated with a future self.

The dynamic process of navigating incongruence was also influenced by communication and impacted one’s sense of control. Communication was encumbered by the degree of incongruence with the informational content, the translational requirements and the perceived sense of disconnect or distance from the HCP and the impositions experienced within the medical system. Being confronted with diabetes immediately provoked a sense of distance. In some cases what they heard and understood was considered “radical,” and also led them to feel autonomous control could be compromised. They fought for control in ways that would be construed as positively or negatively affecting one’s health but which satisfied their needs.

Readiness to engage with health information had a number of factors stemming from emotional responses, existential uncertainty and knowledge deficits. These were encompassed within the three interconnecting themes of underlying incongruence, relational talking and navigating control, and converged on the notion of distance. Existing theories provide a lens through which to more closely examine the meaning of distance as it relates to readiness.

Intersecting with Existing Theory and Implications

Driven by a pragmatist philosophy, the study purpose was to operationalize readiness and gain an understanding beyond abstract generalization (Cornish & Gillespie, 2009; Johnson, 2007; Rosiek, 2013). This approach is also consistent with IPA inquiry (Dowling, 2007; Finlay, 2014; Larkin et al., 2006; Pietkiewicz & Smith, 2014; Smith & Osborn, 2003) where consultation with theoretical constructs transcends collection and description of participant narratives and pursues a more speculative insightful inquiry. Furthermore, consulting additional theories provided a narrower and more in-depth analysis of the essence of the findings. Lazarus and Folkman's Theory of Stress and Coping (1984) and Personal Construct Theory (Ryle, 1975) provided the broad theoretical framework within which to conceptualize readiness as a mediating factor between the stressor (diabetes diagnosis and management) and a coping strategy (engagement with learning and health information). According to Lazarus and Folkman (1984), "psychological stress ...is a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being." A stimulus is therefore defined "only in terms of a stress response. Adequate rules are still needed to specify the conditions under which some stimuli are stressors" (p. 27). This theoretical framework also suggests individual variability in responses, which are not initiated from a general disposition but related to a unique and specific context and changing personal and social dynamics. In fact, cognitive appraisal may not always be an explicit and conscious process but is shaped by an agenda outside of one's awareness (Lazarus & Folkman, 1984). The emergent themes of incongruence and distance from the interpretative analysis of the data is based on the context of education and health information regarding diabetes and can be more specifically understood through the lens of existing theories. The following section introduces

two existing theories related to cognitive dissonance and psychological distance. These theories will be used to inform a discussion of incongruence and distance and allow further hypothesizing around the concept of readiness to engage with educational health information and the implications for practice and research.

Cognitive Dissonance Theory. Festinger's (1957) Cognitive Dissonance Theory introduced the construct of psychological inconsistency as dissonance. It is defined as "the existence of non-fitting relations among cognitions" referring to one's knowledge, opinions, beliefs or feelings about the environment, oneself or one's behaviour (Festinger, 1957, p.3). Festinger posited that dissonance is rarely an accepted condition and individuals strive toward an internal consistency or harmony. It motivates change in order to rationalize, explain away, reduce or avoid the source of psychological discomfort (Festinger, 1957) and has been referred to as a theory about sense-making (Aronson, 1992). Festinger (1957) also refers to Osgood and Tannenbaum who formulated and documented the 'principle of incongruity' where evaluations change in the direction of resolving difference or imbalance within an individual's frame of reference. Some small amount of dissonance may foster curiosity and motivate one to seek out and acquire information that is relevant to an impending or potential future behaviour. Festinger refers to this as the pre-action or pre-decision situation. However, if dissonance is encountered but one's individual reality or capacity remains unchanged, information will be avoided, reduced in importance or alternate information will be sought to reduce or reconcile the magnitude of dissonance (Festinger, 1957).

Construal Level Theory. Construal level theory proposes that individuals have the capacity to transcend thinking about their immediate, current situation by forming abstract mental construals or representations of the future, and of events and objects that are removed and

distinct from direct experience. This is evident in the human ability to remember the past, predict or speculate on future possibilities, understand others' perspectives, and consider hypothetical alternatives (Trope & Liberman, 2010). Psychological distance is the subjective experience of an event or object being removed from one's sense of 'me' and, frequently, in terms of the 'here and now.' However, there are various distance dimensions conceptualized in terms of time (e.g., future or past), space, hypotheticality (likelihood of occurring) and social perspective (e.g., experiences of others). Social distance may be defined in terms of characteristics such as age, gender or culture, and proposes to engage thinking and construal according to situational features or inferring a more dispositional (e.g., higher level, more generalizable) explanation such as traits, values and attitudes (Trope & Liberman, 2010).

In terms of time and 'hypotheticality', a more *distant* perspective is comprised of high level construals which are abstract, schematic and decontextualized and provide a general gestalt rather than specific features. These construals are linked to a superordinate purpose and *why* an action is performed. From a 'near' perspective, construals are considered lower level which means they are more concrete, unstructured and within a context that affords description, specificity and detailed features of an event. It provides more specific information about *how* an action is performed. At a moment of action, people consider lower level, concrete situational factors (Liberman & Trope, 2008). An example provided by Liberman and Trope (2008) is an activity such as children playing basketball in a backyard. While a higher level construal is 'having fun,' a lower-level construal of the activity includes features such as the children's age, colour of the ball and the outside temperature. Specificity is generally afforded in the here and now whereas in the future, there is less certainty of the contextual details.

It has also been suggested that individuals' construals are based on particular mindsets. An abstract mindset in an individual results in a more global perspective (i.e., 'seeing the forest') and relates 'here and now' information to distal goals. A concrete mindset perceives information from a narrower, local perspective focusing on specific features rather relating them to superordinate goals (i.e., 'seeing the trees') (Wiebenga & Fennis, 2014).

Implications for practice and research. The two theories previously described have a meaningful intersection with the research findings, and bring two related but different perspectives to the theme of incongruence. Firstly, Cognitive Dissonance Theory is referenced in relation to *adjustment*, not as an initial outcome following incongruence, but is considered in terms of a re-emerging dynamic throughout the illness experience. This is not unlike many of the assertions from Coping Theory (Lazarus & Folkman, 1984). However, Festinger delves deeper into reactions that are borne from psychological inconsistency, providing further insight into incongruence as an underlying factor for readiness for information (Festinger, 1957). Secondly, Construal Level Theory offers a more nuanced consideration of incongruence and further breaks down the types of distance as factors that influence a process of 'relating to' and the *relational aspect* influencing readiness.

Adjustment time and space. Adjustment is a phase that was presented by study participants. They required processing time and space when faced with a health change, particularly a new diagnosis. Adjustment requires reconciling dissonance, which involves varying levels of engagement including defensive reactions toward health information. Within Cognitive Dissonance Theory, Festinger addressed chronic illness and suggested cognitive change is suspended between having an illness and being ill, and requires adapting, integrating and adjusting to the illness as part of living (Festinger, 1957). Previous research has also

suggested that processing includes accepting the change in one's taken-for-granted biological function and giving the change space within the lifeworld (Johansson et al., 2015). Having the space within which to reconcile dissonance is based on an individual's reality, where experience exerts an implicit influence on knowledge, beliefs and opinions, resulting in an automaticity within one's thinking (Festinger, 1957). Thus, thoughts and feelings when dealing with a chronic health issue are initially steered by a historicity or context (Koch, 1995), much like the state of 'being-in-the-world' or *Dasein* introduced in Heidegger's phenomenological philosophy (Lavery, 2003). This becomes the context within which individuals are trying to adjust to a chronic illness.

Adjustment as a reconciliatory process. Experience-based approaches to adjustment and change have also been examined through post-traumatic growth and the positive changes made by people who have faced adversity or trauma, including stressful events such as a serious health issue or the ongoing stress related to managing a chronic condition (Ruini, Offidani & Vescovelli, 2015). Discrepancy resolution is a component of the affective-cognitive processing and focuses on assimilation or accommodation of pre-existing assumptions related to an 'old self' and the changed status in light of the diagnosis (Joseph, Murphy & Regel, 2012). This resonates with adjustment issues, not simply as a point in time but with every change creating a potential insult to one's given understanding thus evoking uncertainty, fear and loss of control. Participants who were managing other health issues seemed more able to draw upon self-efficacious ways of adjusting. However, other research suggests that the complexity of dealing with more health issues adds to management demands (Ritholz et al., 2011) and means of adjustment.

From the participants and from previous research, it is clear that a diabetes diagnosis has a significant psychological impact and affects one's ability to reconcile dissonance, particularly during an adjustment phase. Psychological assessment has not been a feature of diabetes management in the past but psychological applications are now being considered to help explain behaviours and the critical need for certain behaviours to manage diabetes (Harvey, 2015). Adams (2010) also proposes looking at management competency as a developmental process that must first recognize that the patient's acceptance of the health issue. Other research also suggests that adjustment be addressed within an early phase of learning (Persson & Friberg, 2009) as a lengthy period of poor adjustment may also result in unrealistic fears in patients (Stiffler et al., 2014) as well as coping strategies that are emotion-focused rather than problem-focused.

Adjustment threatened by dissonance. The nature and extent of dissonance needs to be considered carefully. While it may spur curiosity, for some it may provoke more negative reactions. Being faced with a high degree of dissonance also threatens one's sense of control and impacts the degree and selectivity of information. Most study participants had experienced times when educational information was avoided or minimized, particularly when the information is invoking fear or uncertainty. This is consistent with Festinger (1957), who outlined similar responses in order to return cognitive or psychological consistency.

Defensive and biased information processing has clear relevance to health education and information but has not been studied to the same extent as other constructs influencing health information. Few studies have investigated defensive reactions outside of the controlled laboratory setting where participants are requested to exercise certain kinds of emotion-regulation strategies (van't Riet & Ruiter, 2013). The development of or change in defensive

reactions over time is also not clear. Similarly, patient education rarely addresses resistance to learning and assumes that patients have accepted their condition and have a willingness to learn (Berglund, 2014). In fact, Mulder et al. (2015) found that resistance is a notion rejected by some health care providers. Yet, mental defenses are of central consideration in psychotherapy with approaches that focus on acceptance and resistance as primary factors for taking constructive and productive steps toward change (McQueen et al., 2013). Strategies to nurture acceptance-based coping alongside education have resulted in better self-reported management and controlled blood glucose (Gregg, Callaghan, Hayes & Glenn-Lawson, 2007).

The degree of dissonance that invokes fear and defensive reaction represents one end of a continuum of readiness to engage with health information. This provides a more extreme perspective and therefore a step beyond what is described elsewhere (i.e., a continuum from tolerating treatment to being emotionally invested in the therapeutic encounter) (Bright et al., 2015). In all cases, different kinds of support are required and changes can be anticipated over time and supported by the clinician who can sensitively challenge the individual perspective rather than feeling they have to deal with a fixed state or attribute (Bright et al., 2015).

Motivational Interviewing (MI) is a clinical method that elaborates on dissonance and recognizes clients may be experiencing different levels of readiness to change a behaviour, including resistance. The approach focuses on “change-talk” within a supportive and non-threatening context. A recent paper by Miller and Rose (2009) suggests there are possible antecedents to change – including client acceptance, readiness and engagement as well as therapist empathy or therapeutic style, which has already shown to contribute to successful outcomes. The MI approach has largely emerged from clinical success and therefore clarifying the ‘active ingredients’ or cognitive and affective mechanisms of action could contribute to

further theory around MI and help to focus on those components that may increase the efficacy of MI (Miller & Rose, 2009).

Relational challenges as distance. The study findings highlighted a ‘relational’ aspect to communication however this aspect applies more broadly to readiness once critically examined in terms of mental construal and psychological distance. As previously described, Construal Level Theory proposes several dimensions of psychological distance linked to mental construal. The dimensions of temporal distance (e.g., remote in time), hypotheticality (e.g., likelihood of occurring) and social distance (e.g., experiences of others) (Liberian & Trope, 2008) are most relevant to the study findings. From these dimensions, incongruence can be differentiated in ways that shed further light on readiness factors.

The ability to transcend the ‘here and now’ through the human capacity for abstract information processing has implications for health education. Firstly, the patient’s past is not enlarged upon in health education as most of the information is directed toward the future and largely in terms of behaviour change. There has been an increasing awareness of the importance of understanding genuine learning as cognitive change and the intrinsic quality of information processing (Kneck, Fagerberg, Eriksson & Lundman, 2014) rather than directives for patients to do what they are told to do (Berglund, 2014). Development lies in the meeting of the former with the new and patients need to be able to deal with their illness based on past experiences, and in relation to their individual existence, thoughts, feeling and actions (Berglund, 2014). Berglund (2014) asserts that genuine learning “deeply challenges and affects the patient...In the learning process, the whole individual, that is, his/her experiences of and thoughts about the past, present, and future have to be involved. The life conditions and the possibilities have to be challenged and reflected on in order for it to be genuine learning” (p. 8).

Secondly, the patients' narratives were clear that they desired relevant information with several reporting a desire for more concrete or "black and white" approaches to address immediate concerns, particularly immediately after the diagnosis. A recommendation to reduce weight was felt to be useless unless concrete, detailed information was also provided (Wermeling et al., 2014). At times patients were more oriented toward a day-to-day plan or more direct, concrete instruction until they were able to build upon their experiences and could become more discerning and could tailor the information to their needs. There was a learning trajectory that suggested readiness to engage with information was influenced by where one was on this trajectory of navigating 'black and white' (i.e., the concrete versus abstract nature of the information).

'Relating to' as stages of learning. Educational theory around scaffolded learning and Vygotsky's Zone of Proximal Development (Bransford et al., 2000), although largely applied among students, bears similarity in terms of recognizing the distance between what is known and unknown, with learning activities that are supported based on learner capacity. The educational concept of differentiation suggests a learning concept or skill is broken down into parts and instructional assistance is provided in learning each part. Drawing from this idea of breaking down and simplifying learning in the early stages, concrete skills may be required before more abstract learning and management goals are considered. Boström, Isaksson, Lundman, Graneheim, and Hörnsten (2014) concluded that having the ability to control one behaviour or one piece of information may be a necessary part of the management process in becoming autonomous and empowered to take active control. There is also a sense of satisfaction and motivation to be gained from acquiring information consistent with one's thinking and interest and can generate change by addressing the most pertinent issues to the patient (Harvey, 2015).

Progressing according to readiness to engage, may facilitate overcoming the sense of distance and dissonance as well as empowering and restoring a sense of controllability.

This more nuanced consideration of information processing provides a unique lens through which to consider the study findings. It was evident that participants held their reality in contrast to information presented to them. Their information needs can be characterized in terms of concrete (i.e., what is known) versus abstract (i.e., what is hypothetical) and, in most cases, signified the distance individuals were trying to navigate. Readiness to engage with information may be influenced by the nature of the information that is presented at a particular point in time. In other words, learning needs to be tailored to a patient's concrete versus abstract mental construal and is a consideration for how information is structured to meet learning needs and individualized progress from concrete notions to more abstract, problem solving. This allows patients to 'grow into' a position of learning and control. While there is an expectation that being active in the learning process will facilitate change, self-directed, patient-driven learning is an ambitious expectation not normally associated with the early stages of learning (Kneck et al., 2014). There is a need to master foundational information before moving to more creative or abstract thinking and learning (Krau, 2011). Fostering patients' awareness, willingness and attention are fundamental elements for learning to progress within the hierarchy - simple to complex; concrete to abstract; and factual to metacognitive knowledge (Krau, 2011). This kind of patient-centred educational approach has not been considered in the research literature.

'Relating to' is fundamental to common ground. Within the communication literature, the relational aspect has been addressed in the Patient-Centred Care Model (Stewart et al., 1995) and more specifically in terms of finding common ground. Finding common ground has a reconciliatory connotation as Stewart et al. (1995) suggest it requires an exchange and synthesis

of meaning regarding the problem, awareness of causes and defining the goals and roles for health management. It has been associated with better outcomes, adherence to treatment and participation in decision-making (Stewart et al., 1995). However, Stewart et al. (1995) also allude to the challenge at the intersection of perspectives – the physicians’ biomedical interpretation of disease and illness and the patients’ experiential interpretation (Stewart et al., 1995). Once again, a ‘distance’ is apparent; psychological distance and level of mental construal may contribute a more nuanced understanding of the factors fostering a relational approach for finding common ground.

To find common ground, there is a need to bring the voice of medicine together with the voice of the lifeworld (Stewart et al., 1995) and in essence, respond to Anita’s suggestion to “wear our shoes.” In this study and others’ (Boström et al., 2014), patients distanced themselves from HCPs who were setting the agenda, providing normative responses, governing or lecturing about long-term goals and contingencies. Additionally, formal language or medical jargon, as Hans pointed out, was found to signify and create greater interpersonal distance (Trobe & Liberman, 2010). The distance observed between HCP and patient is a result of ways of approaching or thinking about the disease condition. The HCP may have normative biomedical perspective which has significant differences from the subjective experiences and interpretations of the patients, but which are the discernable aspects of the disease that determines its meaning (Debussche, 2014; Friberg & Scherman, 2005). HCP providers focus on the disease and complications, rather than the present-oriented concerns and preferences of the patient (Reach, 2014). Health education addresses the biological perspective, medical outcomes such as hemoglobin A1c at a particular point in time rather than the patients’ perspectives and concerns

and how the disease and its management fit into the bigger existential picture (Berglund, 2014; Johansson et al., 2015).

While abstraction and deduction serve the objectives of medicine by enabling identification, problem solving and developing treatment, it has tipped the scales away from the individual patients, their particular realities and their experiences with disease. In the context of chronic disease and the need to have patients self-managing, there are important implications for having the pre-requisite knowledge, having the information *relating to* the individual's concerns and therefore bridging the distance. This is a fundamental aspect of education that in its absence can affect cognitive readiness to engage with information and feeling uncared for. This is best described by the researchers who have conceptualized the Patient Centred Care Model:

The price we have paid for the benefit of abstraction, is a distancing of doctor from patient. We have justified this to ourselves as objectivity, but to our patients it is often seen as indifference to their suffering (Stewart et al., 1995, p.25).

Future Research. The participants' narratives converged on three themes. Once the primary theme of incongruence intersected with cognitive dissonance and psychological distance, this revealed an interesting perspective and a framework for considering further research. The strength of this research approach was that it centred on the patient experience and revealed his/her 'situatedness' in terms of having diabetes, interacting with HCPs, exposure to various informational sources and a general lifeworld context from which to begin cognitive and emotional processing. The goal of this research was to focus on the cognitive and emotional elements of readiness to engage with health information, which leaves a number of questions remaining and generating new areas to be explored.

The phases of adjustment may be qualitatively different and change according to particular stressors. While psychological assessment has been proposed as an important element for adjustment and coping, little is known of the adjustment time (or processing time), its factors or facilitators that may be integrated into the learning process. Secondly, there is a need to further explore and define the therapeutic relationship and how it might impact the patient's openness to learning and outcomes. This might be further enhanced through empathic communication and the HCP's ability to elicit beliefs, cultural understanding and patient-specific barriers, which could each be examined as factors for health education engagement and *how* patients participate within the educational encounter.

This research has explored readiness to engage with health information, with factors that were further informed by various dimensions of psychological distance as proposed by Trope and Liberman (2010). Goal concordance (concrete versus abstract and immediate versus future-oriented) between providers and patients may be examined as an element of patient-centred education. More recent literature (Fiedler, 2007) has also proposed other dimensions of psychological distance, such as informational distance which relates to the size or density of available information. Based on the research findings, there may be readiness factors embedded within other kinds of distance. Firstly, a couple of the participants alluded to a cultural distance within which a different perspective may influence interactions with HCPs. This was not a focus of the research and would bear further exploration to enhance both communication and education. Secondly, a health literacy distance may further illuminate elements within the cognitive processing gap, not simply as an educational deficit but recognizing certain information may be outside of one's area of expertise or interest. There may also be a need to match informational needs to particular learning style as well as address psychological distance

to mediate patient centered adjustment and foster goal-oriented learning that is relevant to the patient at a particular point in time.

This research has also hypothesized that various factors in relation to concrete and abstract informational needs change in relation to increasing familiarity and greater capacity to tackle more complex learning. A participatory action approach would also enhance development of educational strategies that account for these factors and examine the effects of hierarchical, scaffolded learning on information uptake, coping or defensive responses, and learning outcomes. Through self-observation, thought listing and reflection, patients may be able to provide a better understanding of learning trajectories that are sensitive to psychological, emotional and practical complexity.

Rolf's reference to "pre-diabetes" gave him the metaphorical distance allowing him to minimize a need for information. Rolf was the only one who talked about pre-diabetes however others expressed ways in which they distanced themselves from the diabetes diagnosis and management, which raises the question of how perceived illness severity influences one's readiness for information. While pre-diabetes or having no symptoms appeared to suggest little need for concern, do patients also have a sense of being 'too far gone' or too severely affected to have any kind of influence on physiological response? Furthermore, this also raises the question of whether there is a normalized or normative response that emerged in response to illness, how the patient constructs this response and its overall effect on learning and behaviour.

While the patient perspective was the focus of this research, there is opportunity to seek out the HCPs' understanding and views of incongruence or cognitive dissonance, in terms of how it is perceived in the health care encounters, how it is assessed in relation to defensiveness or pre-contemplation (Prochaska & Norcross, 2010) and how it is managed within the context of

tailoring information. To uncover readiness and ways in which it may influence engagement is still incomplete in terms of how it might be integrated into practice. The discussion of the research findings has also touched on the potential distance between the evidence-based paradigm and patient-centred approaches, particularly as they affect education for self-management firmly within the patient domain. This is an area that may be further parsed out to reconcile difference and distance between the patient and HCP and the influence on information exchange.

Finally, this research focused on readiness to engage with health information regarding a particular health condition – diabetes. The findings would likely resonate with individuals managing other chronic conditions but this would need to be examined further. Continued research into this topic is recommended to further a deeper understanding of the phenomenon and expand the available research evidence around health education readiness for all chronic conditions. Furthermore, synthesizing the factors emerging from these findings with existing measures of cognitive and affective constructs (such as fear, sense of vulnerability, coping, acceptance) would contribute to the development of a scale to assess readiness to engage with health information and ultimately tailor information to address adjustment, empowerment as well as patient-centred self-management.

Educating the HCPs and patients. Most health care professions are well-informed of behaviours and treatments that have a likelihood of beneficial effects to conditions such as diabetes. With the patient-centred approach gaining greater attention, there are still a number of considerations that are not clear and remain as abstract notions that are difficult to translate to the immediate and concrete needs of the patients being seen in practice. Readiness to learn is a concept that may also have implicit limitations and is difficult to translate to practice. However,

understanding the patients' personal challenges in terms of psychological dissonance and distance makes an important contribution in terms of raising awareness of educational limitations that are not normally made explicit. The adjustment needs, and differentiating abstract and concrete education and communication needs may contribute to a scaffolded educational approach that moves beyond depositing information with the assumption of a knowledge deficit.

This research will contribute to patient education, counseling and communication approaches that are currently taught within health professional training programs. Immediate knowledge translation and exchange activities will be through academic endeavours such as primary care conferences and publications targeting an audience of primary care providers. Given the exploratory nature of this work, further research would need to be carried out to determine how the findings could be integrated with existing education and communication models but has potential to inform health education programming for pre- and post- licensure health providers.

Limitations

There are limitations to this research, mostly in relation to the data collection process and caveats to interpreting the results. Firstly, all data was collected via retrospective self-report, which relies on the ability of the participants to accurately recollect implicit thoughts and feelings quite long after the actual experience. The details of one's experiences, thoughts and feelings may only be weakly recalled if at all, and further challenged by having been reconciled. In addition, some participants may be less introspective and not able to readily recognize or describe themselves and convey their thoughts. However, self-report is the only way in which implicit cognitive and affective factors could be gleaned.

Second, the findings are limited to reports from people who were willing to talk to me and may therefore represent individuals who were generally more engaged. While many participants chose the dialysis unit for participating in the interview, being amidst health care personnel may have increased the possibility that information was withheld. However, the participants appeared very willing to convey a range of experiences and were open and forthcoming around both positive and negative experiences. In fact, some of the most emotionally-charged recollections emerged while being interviewed on the dialysis unit.

Third, I recognized at the earliest stage of the research process, that obtaining implicit thoughts and feelings around an abstract concept such as readiness would be challenging. Coping Theory also questioned whether people know what they are doing as part of their individual coping strategies. Thus, gaining a better understanding of coping requires interpretive inference and moving beyond observable measurement (Lazarus & Folkman, 1984). As mentioned in the methodology section, I had initially intended to conduct interviews facilitated by Repertory Grid Technique but very shortly into the pilot interviews, I chose to forgo this method in favour of an interview that allowed the participants to tell their story. I did not seek out member checking as I only conducted a single in-depth interview to obtain patient narratives. I did, however informally engage in member checking as I very explicitly informed participants that I would be frequently asking for clarification, which I did throughout the interview. While the analysis and synthesis maintained a close association with verbatim extracts, my approach involved a double hermeneutic with the potential to introduce bias. Member checking wouldn't have provided participants with a concrete description of the data. Thus, the synthesized data would have been less identifiable to the participants as it may not directly convey their specific experiences. Each narrative was part of a larger abstraction as I consulted theoretical constructs to transcend simple

description. I also did not assume to be revealing an objective or ultimate reality or obtaining generalizable outcomes (Sandelowski, 1993). Rather, I approached this topic with the intention of properly representing the aggregate patients' experiences and drawing attention to and prompting further inquiry around the concept and factors underlying readiness to engage with information.

Fourth, readiness to engage with health information and in particular, the thoughts and emotions underlying the process, is a complex issue and this research does not profess to encompass a comprehensive examination of all factors. For one, this research focused on only one aspect of patient-centred communication: finding common ground. The intention of this research was to take a narrower perspective and therefore the results are not to be interpreted as a specific approach to patient-centredness.

Fifth, there are a number of confounding variables that are not specifically considered in the inquiry. This includes the actual visit or personal characteristics such as race/ethnicity, relational factors (including levels of trust and dependence upon the person providing the health information), or social determinants that may incapacitate patients to fully engage with particular content or learning processes. I had encountered two occasions where I became more aware of potential cultural factors. Having conducted the interview in English and not inquiring specifically about cultural factors narrowed the focus at the expense of certain cultural factors. Two of the participants did not speak English as a first language and less in-depth information was obtained regarding their thoughts and feelings. They generally conveyed a more passive approach which cannot be considered a generalizable finding but requires further examination. This study does not intend to disregard or minimize the potential of such confounding variables as they are fundamental to the larger picture of relevant and meaningful patient education.

However, my research purpose was limited to self-reported emotional and cognitive factors underlying readiness to learn as an initial step toward understanding the patients' experiences, perspectives and the issues often overlooked in the patient care environment.

Conclusion

Health education literature has focused on the delivery of information and advice-giving, concentrating on patient behaviour change and management regimens for controlling glucose measures. There is less concern with the capacity for patients to be cognitively engaged in educational health information and the psychological, emotional and practical complexity of managing diabetes. But the perception of non-compliant, resistant and even difficult patients is a common occurrence with little understanding of the factors underlying this condition and impacting on one's learning and information processing capacity or willingness. The literature supports the need for understanding the thoughts and emotions underlying the concept of readiness to engage with health information. There are assumptions that patients have a fundamental desire for information and learning as pre-requisite for self-management, which are countered by the fact that some patients may refuse or selectively attend to health information. Within the context of literature regarding patient-centred care and communication, there is increasing awareness of the patient's experiences and perspectives but much more to be understood about the thoughts and feelings that moderate readiness to engage with health information.

This inquiry was seeking to better understand these circumstances as experienced and described by the patients themselves. Using an approach informed by Interpretative Phenomenological Analysis, the goal of this research was to conceptualize and describe readiness to learn or cognitively engage with health education. More specifically, this research

aimed to gain a better understanding of patients' educational experiences; explore the situations where they felt more or less ready to learn; and examine the patients' self-reported cognitive and affective factors related to readiness to learn. Interviews with patients diagnosed with diabetes were guided by Coping Theory and Personal Construct Theory which focused on the idiographic and experiential perspective for an in-depth examination of the participants' cognitive appraisal of encounters with health education.

From the analysis, three main themes emerged regarding underlying incongruence in knowledge, thoughts and beliefs; relational talking; and negotiating control. The participants' accounts of self-reported readiness and willingness to engage with health information were consistent with existing theory and literature. Furthermore, these themes converged on the essence of the findings, best described as 'distance' between the patient's lifeworld and the disease and its management. This overarching theme, when considered in relation to cognitive dissonance and psychological distance theories, revealed the importance of psychological adjustment and relational challenges underlying readiness to learn. Firstly, adjustment was a phase requiring the patients to reconcile difference and dissonance. The diabetes diagnosis and its ongoing management presented participants with a situation that was strange and unfamiliar. Furthermore, the situation felt imposed upon them and they required the space and time within which to engage in a reconciliatory process. However the degree of dissonance also threatened adjustment and in some cases generated various kinds of defensive reactions. This also suggests a more focused effort is needed to facilitate adjustment or health management transitions and greater consideration of these constructs to provide the foundation upon which autonomously-motivated learning can begin.

Relational challenges were conceptualized in terms of dissonance and psychological distance. Considered together, it was evident that ‘relating to’ could be facilitated by strategies that stage or scaffold learning. Differentiating the message according to concrete and abstract information and educational needs may be more conducive to a learning process. This approach may also contribute to a more tangible and practical understanding of ‘finding common ground’ as a component of the patient-centred communication model.

Recognizing the underlying factors of incongruence, relational communication and personal control is a key point of departure for learning, described here as *readiness to learn*. Considered within the context of existing theories, in particular constructs of psychological dissonance and distance, adjustment and relational challenges have a bearing on the early stages of the learning process. These factors underlying readiness to learn have been reported by patients with a range of experiences with diabetes and require further consideration for tailoring communication and education that supports person-centred care and self-management.

This research was exploratory and seeking to gain an understanding of patient education experiences to draw out the factors underlying cognitive readiness to engage with education or information. These findings need to be further examined to determine the prevalence of various factors and ways in which educational interventions and interactions can be enhanced. In particular, the participants raised awareness around the importance of psychological adjustment and the sense of strangeness or distance they felt from what they knew and how they needed to manage diabetes. This supports the need to consider patient education as truly interdisciplinary, and benefiting from the synthesis of counseling, communication and educational approaches in both research and practice, and to characterize patient education in a way that considers the more intrusive role of negative thoughts and emotions. Finally, the concrete versus abstract nature of

information can provide a lens through which to consider the patients' information needs thereby informing a more customized, patient-centred approach and a foundation upon which to build knowledge through a process of engaged learning rather than one-way delivery to fill a knowledge deficit and expect behaviour change.

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Appendix A: Recruitment Scripts

Information about Your Diabetes: Have you been “Tuning In” or “Tuning Out”?

SCRIPT for PATIENT INQUIRY (Dialysis Unit)

Student Investigator: Gayle Halas

This research study is being conducted as **part of my PhD** thesis (University of Manitoba).

I am exploring the concept of **readiness to learn** among patients who have been diagnosed with **Type 2 diabetes**.

My study requires **40 participants** who have **Type II diabetes** and are currently in **dialysis treatment**. They must be willing to participate in **one interview during their dialysis treatment**.

My interview questions will ask questions about:

- **reactions** to different situations where diabetes information was made available.
- reasons for **feeling more or less receptive** to diabetes information.
- experiences of **feeling “tuned in”** and **feeling “tuned out”** to diabetes information
- kinds of thoughts or feelings were related to **feeling ready, willing and able** to discuss diabetes?

Filling out the form: This form is **not a “sign up”** for the study.

This form provides contact information and permission for me to contact the person so I can **provide more information** about the study, answer questions and ask if they would be interested in participating in the study.

OR

The form also has my name and phone number in case the person **prefers to call me**.

What would be involved by agreeing to participate?

During one of the dialysis treatments, I would sit with the person and conduct **one interview** that would be **audio recorded**. It is being audio recorded for my purposes only, so I can listen to it over again to ensure I have the correct information. All participants will be mailed a gift card once the interview is complete.

Information about Your Diabetes: Have you been “Tuning In” or “Tuning Out”?**SCRIPT for PATIENT INQUIRY (Diabetes Class)**

Student Investigator: Gayle Halas

This research study is being conducted as **part of my PhD** thesis (University of Manitoba).

I am exploring the concept of **readiness to learn** among patients who have been diagnosed with Type 2 diabetes.

My study requires **40 participants** who have Type II diabetes. They must be willing to participate **in one interview** after they have completed all of the diabetes classes.

My interview questions will ask questions about:

- **reactions** to different situations where diabetes information was made available.
- reasons for **feeling more or less receptive** to diabetes information.
- experiences of **feeling “tuned in”** and **feeling “tuned out”** to diabetes information
- kinds of thoughts or feelings were related to **feeling ready, willing and able** to discuss diabetes?

Filling out the form: This form **is not a “sign up”** for the study.

This form provides contact information and permission for me to contact the person so I can **provide more information** about the study, answer questions and ask if they would be interested in participating in the study.

OR

The form also has my name and phone number in case the person **prefers to call me**.

What would be involved by agreeing to participate?

After the diabetes education sessions have been completed, I would conduct **one interview** with the participant. This would be at a mutually agreeable time and place, lasting for approx 1 hour. The interview would be **audio recorded** for my purposes only, so I can listen to it again to ensure I have the correct information.

All participants will be mailed a gift card once the interview is complete.

Appendix B: Recruitment Poster

The poster is titled "Invitation to Participate in a Study" and "Information about Your Diabetes". It asks if the reader has felt like "TUNING IN" or "TUNING OUT?". It states that the researcher is a doctoral student from the University of Manitoba. The purpose of the study is to hear reactions to diabetes information, listen to experiences of feeling "tuned in" or "tuned out", and understand thoughts or feelings related to discussing diabetes. It needs 20 volunteers for one-time interviews during dialysis treatment. Contact information for Gayle Halas is provided, including a phone number and email address. The poster has a decorative border with a repeating geometric pattern and a dark wood-textured top and bottom.

Invitation to Participate in a Study

Information about Your Diabetes

**HAVE YOU FELT LIKE "TUNING IN"
OR "TUNING OUT"?**

I am a doctoral student from the University of Manitoba and conducting research with patients who have diabetes.

The purpose of my study is:

- To hear your reactions to different situations where diabetes information was made available.
- To listen to your experiences of feeling "tuned in" and feeling "tuned out" to diabetes information
- To understand the thoughts or feelings you had that were related to feeling ready, willing and able to discuss diabetes?

**I need 20 volunteers who are willing to be interviewed one time during dialysis treatment.
Would you like to know more?**

Please ask the unit nurse

OR

Contact me:

Gayle Halas 204- Gayle.Halas@

Appendix C: Study-specific Information Leaflet

Invitation to Participate in a Study

INFORMATION ABOUT YOUR DIABETES HAVE YOU BEEN "TUNING IN" OR "TUNING OUT"?

I am a doctoral student from the University of Manitoba and doing a research study with patients who have diabetes.

This would require 1 interview during your dialysis treatment.

The purpose of my study is:

- To understand the reasons why people may be more or less receptive to diabetes information.
- To know more about why people are "tuned in" to the information and other times need to "tune out."
- To uncover underlying thoughts and feelings enabling a person to feel ready, willing and able to discuss diabetes?

If you want to know more about this study, please complete this form, seal it in the envelope provided and place it in the study container:

Name: _____

I prefer to be contacted by:

☐ Phone: _____

☐ Email: _____

OR if you prefer:

Contact me for more information:

Gayle Halas

Phone: 204-_____

Email: Gayle.Halas@_____

Once you have heard more about the study, you can decide whether or not you would like to take part.

Thank you!

Appendix D: University of Manitoba Education/Nursing Research Ethics Board (ENREB, Ft Garry Campus) approval



Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Fax +204-269-7173

APPROVAL CERTIFICATE

May 9, 2013

TO: Gayle Halas
Principal Investigator (Advisor B. Temple)

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2013:038
"Patients' Experiences of Emotions and Cognitions that Moderate
Receptiveness to Educational Health Information"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix E: Approvals from Affiliated Hospital Review Boards



Hôpital St-Boniface Hospital

409 Taché Ave, Winnipeg MB Canada R2H 2A6

Research Review Committee Approval Form

Principal Investigator: Ms. G. Halas

RRC Reference Number: RRC/2013/1307

Date: July 5, 2013

Protocol Title: Patients' Experience of Emotions and Cognitions that Moderate Receptiveness to Educational Health Information

The following is/are approved for use:

- Protocol Submission Form, Version reviewed at RRC meeting held on May 1, 2013
- Research Participant Information and Consent Form, Version 3.0 dated May 28, 2013
- Description Leaflet, Version reviewed at RRC meeting held on May 1, 2013
- Interview Outline, Version reviewed at RRC meeting held on May 1, 2013
- Repertory Grid Outline, Version reviewed at RRC meeting held on May 1, 2013
- Recruitment poster in the Dialysis Unit, Version reviewed at RRC meeting held on May 1, 2013
- Recruitment poster in the Primary Care Clinic, Version reviewed at RRC meeting held on May 1, 2013
- Scripts for Patient Inquiry for Dialysis Unit and Primary Care Clinic, Version reviewed at RRC meeting held on May 1, 2013
- Scripts for Study Introduction for Diabetes Class/Primary Care, Version reviewed at RRC meeting held on May 1, 2013

The above was approved by Dr. B. Ramjiawan, Co-Chairperson, Research Review Committee (RRC), St. Boniface Hospital, on behalf of the Committee. As the recommendations by the Research Review Committee have been met, final approval is now granted.

As a reminder any changes to the study Protocol and/or Informed Consent Form must be reported to the Research Review Committee along with any other documents required as per Standard Operating Procedures for Clinical Investigators. The Research Review Committee must be notified regarding discontinuation or study closure.

Should you require assistance during any stage of your research project, please do not hesitate to contact the St. Boniface Hospital Office of Clinical Research (204-258-1044).

saintboniface.ca

Espoir et guérison
Hope and Healing



Hôpital St-Boniface Hospital

409 Taché Ave, Winnipeg MB Canada R2H 2A6

The Research Review Committee wishes you much success with your study.

Sincerely yours,

A redacted signature, indicated by a blue rectangular box with the letters 'XX' inside.

Dr. B. Ramjiawan
Co-Chairperson, Research Review Committee
St. Boniface Hospital

Please quote the above reference number on all correspondence.

Inquiries should be directed to the RRC Secretary

Telephone: (204) 235-3623 **Fax:** (204) 237-9860

N1004 – 409 Taché, Winnipeg, MB, Canada R2H 2A6

BR/ar

saintboniface.ca

Espoir et guérison
Hope and Healing



**Health Sciences Centre
Winnipeg**

Office of the Director of Research

Dial Direct 204-787-4831
Fax 204-787-4547

May 10, 2013

Gayle Halas
Principal Investigator
P228

Dear Gayle Halas

**RE: PATIENTS' EXPERIENCES OF EMOTIONS AND COGNITIONS THAT
MODERATE RECEPTIVENESS TO EDUCATIONAL HEALTH INFORMATION.**

ETHICS #: E2013:038 RIC #: RI2013:062

The above-named protocol, has been evaluated and approved by the HSC Research Impact Committee.

The Department of Research wishes you much success with your study.

Sincerely

A blue ink handwritten signature, likely of Karen Shaw-Allan, over a horizontal line.

Karen Shaw-Allan
Research Protocol Officer
Health Sciences Centre

cc: Director of Research
Ancillary Services, Finance Department

M57 - 820 Sherbrook Street, Winnipeg, Manitoba Canada R3A 1R9

www.hsc.mb.ca

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Winnipeg Regional
Health Authority
Office régional de la
santé de Winnipeg

Affiliated
with the



UNIVERSITY
OF MANITOBA



Appendix F: Consent form

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: “Patients’ Experiences of Emotions and Cognitions that Moderate Receptiveness to Educational Health Information”

Principal (Student) Investigator,

University of Manitoba, Interdisciplinary PhD Program

Gayle Halas

Ph: 204-_____

Email: Gayle.Halas@_____

Research Supervisor:

Dr. Bev Temple

Ph: 204--_____

Email: Bev.Temple@_____

You are being asked to participate in a research study. This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of Study

This research study is being conducted to explore the idea of readiness to learn among patients who have been diagnosed with Type 2 diabetes. This research will aim to:

- 1) define the idea of “readiness to learn” from a patient’s perspective
- 2) explore the situations encountered by patients where they felt more or less “ready to learn”
- 3) identify, describe and rank the patients’ self-reported thoughts and emotions related to “readiness to learn”

A total of 40 people will participate in this study.

Study procedures

If you take part in this study, you will be interviewed by the student investigator, who will ask about your thoughts and feelings regarding your experiences with encounters where health information was being presented to you. You may request to skip over some questions that you feel are too difficult for you to answer. The interview will take approximately 1-1 ½ hours and will be audio recorded.

You can stop participating at any time; please discuss this with the student investigator. A brief summary of results will be sent to you by mail or email within 6 months of the study being completed.

Risks and Discomforts

There are no anticipated risks associated with this study, however the questions will ask about your experiences, which may cause some anxiety related to the sensitive nature of the information.

Benefits

There may not be direct or immediate benefit to you from participating in this study, however the information learned from this study may be of benefit as researchers further investigate or develop health education programs.

Costs

There are no costs related to participation in this study.

Payment for participation

A \$20.00 gift card will be mailed to you when the interview is completed, as a gesture of appreciation for the time you have provided for the interview.

Confidentiality

Information gathered in this research study may be published or presented in public forums; however, your name and other identifying information will not be used or revealed. The interview will be audio recorded but the interview transcripts will not contain your name or any other names mentioned during the interview. Only the student investigator, the research advisor and the transcriptionist will see the study data, all of whom will abide by regulations to maintain privacy and confidentiality and in accordance with the Personal Health Information Act of Manitoba.

All records will be kept in a locked secure office within the University of Manitoba for seven years and no information revealing any personal information such as your name will leave the University. All study data and records will be permanently removed and destroyed seven years (June, 2021) after the study is complete.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may stop participating at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If you decide to stop participating, your information will be removed and not used in the study.

You are not waiving any of your legal rights by signing this consent form or releasing the student investigator from her legal and professional responsibilities.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, contact the student investigator: Gayle Halas at (204) _____ or her advisor Dr. Beverley Temple (204) _____.

For questions about your rights as a research participant, you may contact The University of Manitoba, Education/Nursing Research Ethics Board at (204) 474-7122.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. St Boniface Hospital may also review research-related records for quality assurance purposes.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I agree to be contacted for future follow-up in case I am unable to complete the interview in one visit:

By signing this consent form you agree to the described collection, review, use and storage of your research records.

Participant's Signature _____ **Date** _____

Participant Name [please print]

Researcher and/or Delegate's Signature _____ **Date** _____

Researcher/Delegate Name [please print] _____

I would like to receive a copy of the study results: **Yes** **No**

Please provide your email or mailing address:

Appendix G: Participant Resources



ABORIGINAL SERVICES

cultural and spiritual services
Ph: 204-204-787-2467

**ABORIGINAL
TRADITIONAL WELLNESS
CLINIC**

The Health Sciences Centre runs an Aboriginal Traditional Wellness Clinic for patients of the hospital. The clinic runs two days per month and services include:

- Prayer
- Psychosocial and spiritual counselling
- Life-style counselling
- Liaison and access to community healing supports prior to discharge
- Individual and family ceremonies for healing

To register, phone:
204 940 2556

SOCIAL WORK SERVICES
Ph: 204-787-1287 Adult Medicine; 787-2480

**ADULT DIABETES
EDUCATION CENTRE**
Ph: 204-787-7852

**PASTORAL (SPIRITUAL)
CARE SERVICES**
PH: 204-787-3884

**RENAL HEALTH
OUTREACH SERVICES**
Ph: 204-787-7382

Health LINKS/INFO SANTÉ
-a 24-hour, 7 day a week telephone health information service. Health Links is staffed by registered nurses with the knowledge to answer your health care questions and guide you to the care you need. Call anytime 204-788-8200 or toll-free 1-888-315-9257

Patients share their stories online at:
<http://www.kidneyhealth.ca>

Patients Like Me:
www.patientslikeme.com



**Supports at
Health Sciences
Centre**



Enclosed are supports available at Health Sciences Centre.

Please consider speaking with your health care providers.

Appendix H: Interview Outline

1. Demographic Data

- Age
- Year diagnosed
- Year dialysis started (if applicable)
- Education

2. Introduction

- *I am interested in finding out more about people's attitudes toward health information and how that might change depending on different situations.*
- *Do you remember a visit where the information was not getting through?*
- *Do you remember an occasion when...?*
- *As you look back on your visits with health care providers, are there any events that stand out in your mind where the information was not getting through?*
- *Did you attend a diabetes education class?*

3. Description

- *What happened?*
- *What did you experience?*
- *Can you tell me about that?*
- *Can you describe in as much details as possible a situation in which...?*
 - Include:
 - Primary purpose of this visit?
 - Stress level?
 - When- (how soon after dx)?

4. Clarification

- *Could you say a bit more about that?*
- *Can you give a more detailed description of what happened?*
- *Do you have further examples of this?*

5. Operationalizing

- *How did you feel then?*
- *What was going through your mind at the time?*
- *What was your reaction to the information or advice?*
- *How did you respond to ____?*
- *What was that like?*
- *Why do you suppose you reacted this way?*

For greater construct specificity:

What do you mean by....?

Is this the same as [insert parallel construct]? If no, how is it different? If yes, which one is better and why?

Using Dyadic Comparison: What was going through your mind in [instance A] versus [instance B]?