

Sarah, on living well with diabetes, *you really have to take it all in, and embrace it.*

Cooperrider et al, (2003), on the researcher's experience in using Appreciative Inquiry: Imagine letting go completely of deficit-based methods, assumptions and interventions in your work . . . the old paradigms - let go, trust, trust where the new logic and spirit of constructionism is leading . . . The experiment gifted me with many learnings . . . I am not the same person when I am in a discovery mode asking in-depth questions of what leads to "joy, inspiration and hope" as I am when I do an analysis of "low morale" and its causes. Inquiry and change are a simultaneous moment and we ourselves are inescapably "in it" even if the study is "out there". (p. xxviii).

Gergen (n. d.) on moving beyond narrative to relationship: We must ultimately move beyond narrative as the center of our interest to the relational matrix from which narrative understandings emerge . . . Can we envision . . . a condition of pure relatedness . . . in which - like the ocean - all the individual waves are given form by each other, and we must recognize with awe the potential of a singular movement of the entirety? I shall call this condition a relational sublime. We cannot articulate the character of the sublime, for our languages are themselves only local manifestations of the whole; they cannot account for origins, which supersede them in profundity. However, we may with consciousness of the relational sublime perhaps move more comfortably in the world - with less anguish and more tolerance. Rather than charting a singular course for our swim through life - feeling buffeted by the waves, frustrated by our incapacity to make headway, irritated by the squalls that send us helter-skelter - we might, with consciousness of the relational sublime, more properly see ourselves as at one with our surrounds, our bodies moving in multiple directions as we harmonize with the undulations of the grander force . . . When our beings conjoin with a relational sublime, perhaps these are moments in which we most fully approach the sacred (p.12).



**PATIENT VOICE: APPRECIATIVE INQUIRY INTO LIVING  
WELL WITH DIABETES**

by

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M.Ed. University of New Brunswick, 1981

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

**Master of Applied Health Services Research**

in the Graduate Academic Unit of ARTC

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This thesis is accepted by the  
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THE UNIVERSITY OF NEW BRUNSWICK

January 2013

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## **ABSTRACT**

This study explores the question “What factors contribute to successful self-management of chronic disease/diabetes from the patients’ perspective?” It analyses individual interviews with 13 adults with diabetes about living well with diabetes, and their dreams of enhanced conditions for successful self-management of diabetes. The study has two assumptions: 1) patients have unique, particular, and holistic knowledge of their health and self-management practices, 2) Appreciative Inquiry locates and enhances the positive and life-giving forces in individuals and systems. Appreciative Inquiry is thus seen as an appropriate methodology to use in the discovery of the positive, life-giving attitudes, actions, and dreams of the participants. Thematic Analysis of the interview data identifies that positive personal qualities, reciprocal interpersonal support, and experiential expertise are three themes which interact and enable participants to live well with diabetes. Frank’s illness narrative theory is used to frame the quest narrative manifest in the overarching theme, simultaneously embracing diabetes management and life.

## DEDICATION

I dedicate this thesis to my parents, Dr. George Burgess and Phyllis Burgess, who inspired me with their practice of person-centered health care long before that term was used and who supported me unconditionally and materially in so many life projects; to my siblings Ken Burgess, Bill Burgess, Lillian Burgess, and Neil Burgess who showered me with loving moral and material support during this project and who, when I hit the proverbial wall, blessed me with the invitation to freely choose what was best for my well being, to go on or to stop; to those among my family and friends who inspired me with their own thesis journeys; to friends near and far who were there as a network of support, often invisible in the form of silent thoughts and prayers, and sometimes radiantly evident as on the day of my defence; to the participants in this study who shared with me their stories, their wisdom and grace, and their spirit of partnership in this investigation, which is as much theirs as mine; to my two extraordinarily generous thesis advisors, Professor Roberta Clark and Professor Keith DeBell, who gave me the data for thesis, met with me by phone continuously throughout the prolonged data analysis, and were exemplary in their person-centered understanding and patience with the unexpected life commitments that impacted my academic progress; and most of all to my husband Peter deMarsh, my son Luke deMarsh and his friend Jenn Thomas, who lived with the process and my preoccupation for half a decade, unwavering in their belief in the value of this work, accepting and covering for my lesser household contributions, and doubling my joy on completion with their happiness for me and their ever increasing sense of the significance of this area of investigation.

## ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to the Atlantic Regional Training Centre (ARTC) for the full scholarship funding I received to complete the Master of Applied Health Services Research program. I particularly want to thank director of ARTC-University of New Brunswick Fredericton, Professor Ed Biden, and ARTC-University of New Brunswick Fredericton co-coordinator, John Landry, for their support and faith in me as a mature student. I wish to convey my appreciation to all my ARTC professors who provided excellent training in the field and a solid preparation for the thesis work, and to all the other ARTC staff who make this program's unique mix of distance learning and in-person workshops possible.

I wish to acknowledge the Mary Jane White bursary I received from Dalhousie University, which enabled me to attend a workshop offered by its Continuing Education Department, *Appreciative Inquiry: A Process for facilitating positive change*, presented by Dr. Jeannie Cockell. I later consulted with Dr. Cockell during the analysis of my study results; she affirmed the usefulness of an appreciative analytic lens and particularly the identification of the appreciative elements in the participants' stories.

This work is part of a larger project, the *Survey of Patient-Centered Strategies of Diabetes Patients using Appreciative Inquiry*, supported by the Health Promotion Research Fund, made possible by the contributions of Horizon Health Network, Saint John Zone, and the University of New Brunswick Saint John. I wish to express heart-felt gratitude to Professor Roberta Clark of the University of New Brunswick Saint John, and Professor Keith DeBell of Saint Francis Xavier University, for providing an ARTC residency placement with the above-mentioned Survey, for agreeing to my use of the

individual interview data from the Survey for my thesis, and for providing my thesis supervision. Their breadth and depth of guidance have maximized my learning. I wish to thank the other members of my thesis committee, Professor Barbara Campbell, and Professor Bill Morrison, and my external reader Professor Tracy Carr for their encouraging and affirming feedback.

Simon Kneebone, Australian cartoonist and illustrator, gave me permission to use one of his published cartoons (p. 11). A picture is indeed worth a thousand words.

My friend and neighbor, Susan Young, provided formatting and copy editing assistance throughout the ARTC course work and thesis process, embodying an unwavering commitment to see me to the end of this endeavour.

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## **Chapter One: Introduction**

The purpose of this emergent study was to document the factors and processes perceived by patients to be associated with successful self-management of diabetes, and to demonstrate the effectiveness of Appreciative Inquiry as a method for investigating patient experiential knowledge. It explores the question “What factors contribute to successful self-management of chronic disease/diabetes from the patients’ perspective?” Data have been gathered through appreciative interviews with 13 participants, who share their understanding of how they live well with diabetes. Appreciative Inquiry, already proven to be effective in locating sources of success and potential for enhancement, in fields ranging from change management to community development, was found to be effective in producing rich data on patient experiences of successful self-care.

Chapter Two of this thesis presents the relevant literature on patient voice, the conceptual models of Patient Centered Care and Chronic Illness Care, and Appreciative Inquiry (AI) Methodology. In Chapter Three, the application of the AI qualitative method and Thematic Analysis for data gathering and data analysis, respectively, are described. Chapter Four analyzes data under 3 main themes: positive personal qualities, reciprocal support and experiential expertise, and under the overarching theme of simultaneously embracing diabetes and life. In Chapter Five, the results are interpreted in light of the reviewed literature, including the cited health care models and AI philosophy, and through Frank’s (1995) illness narrative framework. Finally, in Chapter Five implications and conclusions are presented regarding potential ways to enhance the health care system’s support of effective patient self-care in the present context.

Chronic illness rates form a rising tide worldwide,<sup>1</sup> which calls for innovative approaches to care and prevention (Strong et al., 2006). Chronic illness, given its long term nature, is largely self-managed; it is the patient and/or personal caregiver who implements the ongoing care plan, adapting it and integrating it into daily life. Over time, patients develop experiential expertise in self-management, a practical and *life ways*<sup>2</sup> resource that they can contribute to the professional body of treatment knowledge.

Patient voice and patient knowledge are significant in the emerging healthcare paradigm, with its patient-centered perspective and population health approach. Particular, holistic patient knowledge on the one hand and generalized disease, treatment, and public health knowledge on the other are two sides of a coin. They are like the yin and yang elements in Eastern philosophy, a paradox combining towards a larger perspective (Chae & Bloodgood, 2005). This combining of experiential and scientific knowledge is part of the larger paradigm shift that synthesizes quantitative scientific and qualitative post-structuralist perspectives<sup>3</sup> and is manifesting in new concepts like holistic and integrative medicine and patient citizens.

Although this study is underpinned by the philosophy and objectives of patient-centered care, it is not an applied intervention. Its purpose is to produce first generation knowledge (Graham et al., 2006) which can serve an enlightenment function, producing conceptual impact over time (Canadian Health Services Research Foundation, 1999).

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<sup>1</sup> Zimet et al., (2001) note that pronounced changes in human environment and lifestyle have accompanied globalization over the last century, resulting in escalating rates of obesity and diabetes.

<sup>2</sup> Leninger (1997) notes the importance of cultural context and practice, in care, and defines culture as “the lifeways of an individual or group with reference to values, beliefs, norms, and practices (p. 37)”.

<sup>3</sup> Reiser (1993) in *Empathy and the practice of medicine* notes “Symptoms that combine patients into populations have become more significant than the symptoms that separate patients into individuals, (p.123-124), thus naming an imbalance inherent in privileging one side of the coin and implying a need for re-balancing.

Findings are preliminary and potentially catalytic, given the underlying project assumption of the value of patient treatment knowledge (Rogers, et al., 2005). This assumption is supported by the work of health informatics investigator and futurist Tom Ferguson, M.D. In his interpretation of the paradigm shift from Industrial Age Medicine to Information Age Healthcare, Ferguson (1996) gives credit to the experiential and general health knowledge of what he calls the *epatient*. In his schema of the paradigm shift, Ferguson places the patient at the top of the healthcare pyramid, an inversion of the traditional, medically dominated hierarchy (See Appendix A Figure). Ferguson's model conveys the central importance of the patient to the production of health and healthcare. It points to the importance of investigating patient self-care knowledge and the need for innovative research methods to capture this somewhat invisible phenomenon.

## **Chapter Two: Literature Review**

Since the underlying theme of this thesis is patient voice and the associated concept of experiential knowledge, what follows is a discussion of the literature on patient voice and its relevance to patient-centered chronic care, and in the case of this study, of diabetes in particular. Appreciative Inquiry is then discussed as a fitting method to explore what patients have to say about their expert part in the care of their chronic condition.

### **Valuing the Patient Voice**

Patient voices can be viewed from multiple perspectives: including as proactive producers of their own care, as holders of credible experiential knowledge, as healthcare citizens with democratic rights and responsibilities, as members of an evolving collective patient culture, as innovative e-patients, and as expert patients with a place at program and policy tables.

#### ***Patients as health care producers.***

The central importance of patient voice/patient perspective to effective and equitable healthcare has been increasingly recognized in the last decade. Some healthcare researchers have come to see patients primarily as health care producers, not health care consumers (Popay & Williams, 1994). Professionals provide a marginal portion of round-the-clock chronic patient care, about 12 hours per year (Barlow, 2008). Patients partly or completely self-manage 19 out of 20 illness episodes (Green, Yawn, Lanier & Dovey, 2001). Patients, with chronic conditions and their carers acquire valuable experiential

knowledge over time, of the particular health circumstances involved and the successful management of these conditions. When patients and carers share experiential knowledge with each other, this more broadly based communal knowledge has been termed *experiential expertise* (Meijer, Rijshouwer & Linse, as cited in Caron-Flinterman, Broerse & Bunders, 2005). When individual and communal knowledge is supplemented by academic reading and discussions with professionals, it has been referred to as *proto-professional knowledge* (Caron-Flinterman et al., 2005). Recognition of the spectrum of patient knowledge varies within the healthcare system.

### ***The credibility of patient knowledge.***

The credibility of experiential knowledge is an epistemological issue. A constructionist perspective of knowledge and truth points to the socially constructed or contextual nature of all knowledge, including scientific knowledge, and proposes an assessment of knowledge based on its usefulness in particular contexts (Rorty, 1999). A pragmatic recognition of the potential usefulness of lay knowledge is exemplified in studies such as an assessment of experiential knowledge of patients as a valid resource for biomedical research (Caron-Flinterman et al., 2005). It is also evident in cases of patient/carer-authored, peer-reviewed, applied health research, which are informed by in-depth and urgent personal familiarity with treatment and quality of life issues (Ferguson, 2007).

Morgan (2008) provides a nuanced discussion of lay knowledge from a sympathetic social sciences perspective. She notes that people, as they experience the phenomena of daily life, are observing and making sense of these phenomena. They convey individual observations or individual case-in-situations that illustrate the large



variability in individual behaviours and the complexity of social and physiological responses. Lay knowledge can contain a powerful level of repeated observation and ideas about associative or causal relationships among phenomena, without the level of conceptualization associated with scientific knowledge. The articulation of this lay knowledge is honed in daily conversation, in contrast to the often inexpressible, tacit craft knowledge of materials and technology.

***Recognizing patient voice — political and ethical issues.***

Social scientists who use participatory observation methodologies are more likely to recognize the credibility of experiential knowledge, as are those researchers committed to emancipatory aims. The latter advocate for the democratic right of citizens to argue, from their social and economic experience, about political, economic, and social arrangements that impact them. Morgan (2008) defines *Voice* as the citizen's articulation of experienced knowledge associated with rights and responsibilities, that is, to be active in democratic decision-making and to be heard. This voice provides a powerful “means to question the framing of issues and thus to contest both the questions and analysis offered in social science research” (p. 28). Morgan contrasts voice with ‘engaging’ the public in one-sided knowledge discussions or projects of educating the public about science (or health). Barriers to knowledge exchange between lay persons and professional experts include issues of trust, power and the lack of a formal institutional base for lay knowledge.

Morgan (2008) acknowledges that expression and reception of voice is impacted by what is acceptable under local civic values, mores and laws – the local civic

epistemology. This civic epistemology is “the way in which democratic societies come to know and make decisions about science and technology (and health) matters” (Morgan, 2008, p. 29). It includes tacit knowledge ways through which communities “assess the rationality and robustness of claims that seek to order their lives” (Jasonoff as cited in Morgan, 2008, p. 29-30).

Civic epistemology and experiential knowledge of citizens are not the same, rather they are complementary. Claims of space for the citizen/patient voice rely on the notion that Western democratic publics are adult enough to determine how and in which manner they wish to engage in decision-making, that citizens possess an effective civic epistemology as well as relevant experiential knowledge (Jasonoff, 2003). Public participation in turn is a way to disseminate both scientific and experiential expertise, producing enhanced civic capacity among scientists and lay persons, and more reflective responses to social change. Public/citizen participation protects democratic rights through public scrutiny. Recognition of patient experiential knowledge clearly has political and ethical significance.

Democracy is rooted in the values of autonomy and equality. Popay and Williams (1994) argue that the principle that all people have equal worth, underlying the standard Western democratic government policy of universal access to health care, points to the need to recognize the worth of patients as health care workers as well as healthcare receivers. This recognition needs to extend to all who do health care work and carry healthcare knowledge, including informal carers, and particularly women, who are traditionally responsible for family health. Popay and Williams note the complexity of experiential health knowledge, a mixture of experience and aspects of past and present

medical practice. This knowledge is largely informal and unwritten, passed on by word of mouth, not codified or taught in universities. Its unstructured nature facilitates creative and innovative thinking, but it does not provide the institutional protection and recognition afforded to academic knowledge (Morgan, 2008). How can recognition and protection be provided to such experiential knowledge, and how has this recognition advanced to date?

***The social development of patient voice.***

Crossley and Crossley (2001) discuss the evolution of a socially recognized patient voice and illustrate with an example from the field of mental health, an area particularly fraught with issues of credibility and power. They note contemporary, rhetorical exhortations in the health system, such as “listen to the voice of the user” and “let survivors and consumers speak out”, and they wonder if the voice referred to is the conceptual, apparently ahistorical ‘other’ who holds a subjugated and genuine discourse that can be recovered through enlightened political measures (as advocated by Foucault, 1965). Crossley and Crossley propose that patient voice, like the voice of medicine, is a historical construction. For them, voice can be defined as:

The articulation of one’s experience and views regarding a specific topic . . . a function of acquired and deeply ingrained schemas and habits, or what phenomenologists (e.g. Husserl, 1972, 1989, 1999) and some sociologists (e.g. Bourdieu, 1977, 1992a) have referred to as *habitus*. [Habitus] includes a collective stock of categories, know-how, typifications, narrative forms, prejudgments . . . taken-for-granted assumptions . . . and rhetorical strategies” which change over time. (Crossley & Crossley, 2001, p. 1478).

Habitus is reproductive in that individual and collective knowledge and action are structured by the sediments of previous experience and will leave their own structuring sediment; habitus is structuring and structured. Individual agents and societies are not

only reproduced through the shaping impact of habitus, but they can be transformed when there is an emergence of a disposition towards resistance and change. The development of an oppositional habitus points to the transformative role of personal agency, social movements, and civil society organizations in the formation of habitus.

The rise of an oppositional patient habitus is illustrated in the comparison of two modern Western collections of patients' stories, one from the 1950s and one from the 1990s (Crossley & Crossley, 2001). The first contains anonymous pleas for attention to individualized accounts of specific oppressive and degrading experiences with certified hospitalization. The second collection, in which all contributors are identified, conveys to the reader a sense of a collective identity as survivors and consumers (Crossley & Crossley, 2001). Associated with this collective identity is a sense of authorial authority, the right to expressive space, and entitlement to a choice of effective and respectful services. There is an emergence of the collective we and the self-definition as survivors of life and the healthcare system. The 1990s patient authors see themselves as persons suffering from mental distress arising from social circumstances such as racism, sexism and abuse. The language of “we survivors” is an example of the categories and rhetorical strategies of which habitus consists. “We survivors” convey a changed patient habitus. The phrase also implies a change in the audience, or at least a change in the conception of the audience/public, the ‘generalized other’ (Mead, 1976), held by patients in the 1950s and in the 1990s. How have these changes occurred?

Social movements are key to changing patient self-concepts and social stereotypes of the sick (Crossley & Crossley, 2001; Tomes, 2006). Social movements begin with critical and excited forms of discourse; taken-for-granted ideas are challenged and taboo

topics are breached (Blumer as cited in Crossley & Crossley, 2001). This process enables a breaking down of conventional patterns of perception and the building up of an opposition habitus (Crossley & Crossley, 2001). The construction of a transformed habitus is a process of struggle with others and with the internalized patterns of thought and behaviour of the activists themselves. It involves a change in the context of *symbolic power* (Bourdieu as cited in Crossley & Crossley, 2001) and in institutional structures that devalue the new or subjugated voice of the patient. The antipsychiatry movement has carried out such a struggle for change and its work has been supported by critiques of health services put forth in other movements such as feminism, black liberation, and decolonization. Patients' rights movements of the last forty years have risen out of and contributed to the larger cycle of contention and counter-culture of the 1960s (Crossley, 1998). These in turn were rooted in the sociopolitical context of post-World War II.

Social movements emerge in social contexts or *fields* (Bourdieu as cited in Crossley & Crossley, 2001) whose dynamics, rules, and power distributions shape their impact. The patients' rights movement has coincided with the development of an ethos of consumerism within the health services field. Consumerism has influenced the delivery of health services and public participation initiatives to include representation of patients and the public on governing bodies, such as regional health authorities. This consumerism ethos and the associated changes in health services policy are related to transformations at larger political and economic levels. These shifts include the emergence of another kind of movement, the New Right, which gained dominance in the late 1970s and early 1980s. The New Right is seen as a response to the break down in the post-war welfare social consensus and to the policy failures and funding crises of the

Western healthcare system (Crossley & Crossley, 2001; Tomes, 2006). Ironically, the New Right's critique of the medical monopoly of healthcare, and the advocacy of consumer rights, has been one of the more powerful forces altering the balance of symbolic power in medicine and facilitating a larger space for patient voice.



Figure 1: Patient opinion cartoon (Kneebone in Newall, 2007).

An example of how this alteration is entering the current habitus is conveyed in a cartoon<sup>4</sup> published in a recent Australian health policy research and action centre journal

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<sup>4</sup> Simon Kneebone<simknee@bigpond.net.au>: Mon, 24 Aug 2009 10:46 to Burgess, Jean [y4ut5@unb.ca](mailto:y4ut5@unb.ca). Dear Jean, I am happy to give you permission to use my cartoon in your thesis. But, yes, please send me a copy of the relevant section that you intend using it in, just to show me the context. Thanks for giving the

article (Newall, 2009). The cartoon scene conveys the space claimed<sup>5</sup> for consideration of quality of life issues in treatment decisions, from a patient perspective.

The neoliberal challenge to medical hegemony has facilitated the rise of complementary therapies and the self help industry, which have fed into the opposition habitus by offering increasingly credible and authoritative alternatives to the medical model, and resources for the patients' rights movements own self-help projects (Andrew & Boon, 2005). The patients' rights movement has used these resources in its transformation of the patient habitus to one of increasing internalization; people are encouraged to reflect on their inner processes of growth and change, as well as reflecting and acting collectively. The focus on internalization is mirrored in the growing interest of the qualitative research community in patient experience. Investigations of patient experience have led to the development of differentiating concepts such as societally defined sickness, professionally defined disease and patient-defined experiences of illness and associated suffering (Aho & Aho, 2008). Understanding and practice of patient voice/patient knowledge continues to unfold in a dialectical dynamic between internal growth and contextual change. This contextual change includes the social impact of the recent developments in electronic communication technology.

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*cartoon an extra life; hope it works well! Best wishes, Simon Simon Kneebone Cartoonist and Illustrator, 70 Strathalbyn Road, Aldgate SA 5154 AUSTRALIA Phone 08 83709152 ABN 53 629 812 679*  
Simon Kneebone<simknee@bigpond.net.au>: Thu, 27 Aug 2009 15:38: to Burgess, Jean <y4ut5@unb.ca>  
*Hello Jean, thanks for the text, a good project. I'll attach the cartoon to this email - if the file type doesn't work I can make it something else. Good luck with it all, Simon.*

<sup>5</sup> MacDonald (2004) notes that broad recognition of patient voice is far from achieved and recommend that professionals make support of collective empowerment of patients central to their work.

### ***Patient voice and the World Wide Web.***

Health informatics theorist Tom Ferguson (2007) suggests there has been a revolution in patient knowledge and power in the last decade with the advent of the World Wide Web. He notes that by 2006, 73% of American adults had access to the Internet and eight in 10 Internet users have searched for information on at least one of 16 health topics (Pew as cited in Ferguson, 2007). Patients also use the net to connect and collaborate with others. Lay-created health websites and on-line support groups can be seen as part of what has been named *disruptive science* (Khun, 1962), the identification of conventional paradigm limitations and contributions to a more sustainable scientific worldview. Ferguson suggests a transformation in the relationship between professionals and patients is needed, if professionals are to truly empower patients as healthcare producers and embrace them as co-constructors of enhanced health knowledge.

Present professional barriers to such a professional-patient partnership are nicely illustrated in medical anthropologist Diana Forsythe's (2001) analysis of a professionally designed web-based patient education system for migraine patients. In discussing the website's limitations, she points to what can make education and communication more patient-centered. Forsythe notes that the website designers made four false assumptions: (i) that patients knew nothing about migraines, (ii) that what they needed to know was what doctors wanted to tell them, (iii) that professionals had not provided such information due to a lack of time, and (iv) that clinicians had nothing to learn from their patients. The professionally-produced web-based education package had five identified limitations: (i) it did not allow patients to raise questions that clinicians habitually ignore, (ii) it forced patients to describe their experience in words chosen from a limited list of



practitioner-defined options, (iii) it did not allow patients to present relevant matters they were aware of that the clinicians were not, and (iv) it did not permit patients to convey information to other patients on topics that patients know more about than doctors and (v) it did not permit patients to give clinicians useful feedback on services or to share with them relevant literature they were aware of. The identified limitations of the migraine education website point to what is needed in the co-construction of knowledge and understanding. Patient-centered education and care needs an *ethical space*<sup>6</sup> of dialogue among the differing perspectives and intentions of patients and professionals (Poole, 1972).

Web system developers failed to address issues of differing forms of knowledge, power, and control among professionals and patients; they did not consider how “most medicine is ten parts culture to one part real science — a good deal of what happens in healthcare is invisible to most clinicians” (D. Forsythe as cited in Ferguson, 2007). Assumptions of medical culture shape the scientific and professional concern about patients distributing inaccurate, potentially dangerous patient culture information through the Internet. Ferguson notes that comprehensive studies of whether e-patients have been injured as a result of bad online postings reported only a single inconclusive case in the 10-year period examined (Crocco, Villasis-Keever & Jaded, 2002; Smith, 2001). This contrasts with the finding of the U.S. National Patient Safety Foundation at the AMA

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<sup>6</sup> According to Poole (1972), when there are two sorts of intentions, e.g., patient’s and provider’s, there are two sorts of space. The intentions structure the space in two different ways. “When the two sets of intentions confront each other, then ethical space is set up instantaneously (p.5)”. This space becomes a bridge when there is an acknowledgment of different perspectives and interests, and then an ensuing dialogue to explore the possible parameters for an agreement to interact, along with appropriate and ethical forms of interaction. Dialogue requires vulnerability, openness to change, equality among the participants, interpersonal skills, and often cross-cultural sensitization (Ermine, 2000; Ermine et al., 2004).

(Harris, & Associates, 1997) that 42% of U.S adults reported that they had experienced a medical error - either personally or to a relative or friend.

Outdated and inaccurate information does exist on the web. However, Ferguson suggests this is not a major concern in an open information system that relies on demand-side quality control measures (as contrasted with the closed system of validated academic knowledge). Ferguson encourages professionals to become aware of the online, lay-run health sites and support groups. He believes the support and collaboration offered there is a significant contributing factor to patients taking more responsibility for self-care. He also suggests that such sites are a useful resource for professional education on patient perspectives.

It should be noted that recent research reports acknowledge that as Internet access accelerates the challenges and risks, as well as benefits, of patient use of the Internet for health information broaden (Benigeri & Plui, 2003; Sass, 2004). With the identification of patient safety issues in professional and particularly hospital care, it should be also be noted that there has been the recent development of effective proactive programs to increase safety for patients and staff (CIHI, 2011; deVries et al, 2009; Jha et al., 2010; Lankshear et al., 2011). This includes initiatives, which recognize the value of patient perspectives and engage patients in safety enhancement design projects (Trew & Flemons, n. d.).

The World Wide Web is a resource for knowledge generation and patient care. Patients have been empowered by direct access to medical information through web-based search engines and online networks. Medical information is no longer the exclusive intellectual property of professionals. Many patients are now more informed, engaged,

confident, and discerning than was possible in the pre-Internet era. These patients desire a collaborative role with professionals. The World Wide Web provides an expanded space for communication among all levels of the healthcare system, from research to self-care. It is a significant factor in the creation of a new health care knowledge paradigm (Appendix A: Knowledge is power figure compares Industrial Age Medicine and Knowledge Age Health Care). This emerging paradigm is congruent with developments in the field of intellectual property in other contexts such as local, traditional and indigenous knowledge systems<sup>7</sup>, where the need to recognize and protect such knowledge is being advanced as part of a larger decolonization, democratization, environmental sustainability project (Appendix B: Comparative strengths of traditional (experiential) and scientific knowledge). The work of health care researcher Leininger (1997) is an example of the application of this democratizing, cross cultural, care-centered trend to nursing in particular (Appendix C, Leininger's Model of Culture Care). It illustrates how as the world becomes smaller in the Information Age, not only do patients become empowered through access to medical information and peer knowledge, professionals can have increasing access to cultural and lay components of care knowledge, which enable them to be more effective health care partners.

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<sup>7</sup> Indian and Northern Affairs Canada (2001) produced *A Community Guide to Protecting Indigenous Knowledge*, one example of recognizing and empowering the legitimacy claims of lay and traditional knowledge. Soto (2006) looks at socio-cultural barriers to be addressed in the case of applying fishers' knowledge to fisheries management, an issue that has bearing on accessible healthy eating options in rural and indigenous communities. Hoppers (2007) argues for recognition and protection of local and indigenous knowledge as a way to support social justice (including equitable access to social determinants of health) and sustainable global development.

### ***Patient voice and expert patients.***

Angela Coulter (2002), a critic of the paternalistic aspects of twentieth-century medicine, proposes that patients be treated as responsible, knowledgeable adults, co-producers of their own health and case-managers when sick. Patients can gather and digest information and learn the skills needed to provide much of their own medical care, with professionals acting as advisors, ready with assistance when needed. Studies (Bodenheimer, Lorig & Halsted, 2002) of such *expert patients* show that they do a much better job of managing their disease, compared to other patients. These patients can be recruited and trained to help fellow patients, as occurs in the Stanford lay-run self-management education workshops for chronic conditions. They can participate as informed citizens in the planning and governance of the health care system (Hart, 2002; Newall, 2009). The effective communication of patient voice in healthcare consulting and decision-making will be impacted by the authenticity and quality of the inclusive processes in place (Brooks, 2008; Health Canada, 2000). Citizen wellness councils affiliated with regional health authorities and a community development approach to community wellness, provide one avenue to integrating patient perspectives into regional health planning and programming, as has been explored in the former River Valley Health Regional Health Authority of New Brunswick (Atkinson, 2007).

### ***Summary of patient voice.***

Patient voice is a phenomenon that has emerged out of several developments of the last century, democratic and civil rights movements, modern education and Internet access, and the epidemic of chronic disease linked to modern lifestyle changes and longevity. There is both an ethical and a resource rationale for recognizing and including

patient voice in health care policy and programming. Citizens have a right to determine the care of their own bodies and they can contribute unique experiential knowledge of what works for themselves and their peers. In section two of the literature review, the patient-centered care approach is explored as a patient inclusive framework and process.

### **Patient-centered Approaches to Healthcare**

Recognizing the value of the patient voice has led to the development of models of care delivery referred to as patient-centered care. A concordance model of patient-centered care, proposed by experts in Canada and the UK, recognizes that the clinical encounter involves “two sets of contrasted but equally cogent health beliefs” (Marinker as cited in Montague, 2004, p. 59). Jo Harkness of the International Alliance of Patients Organizations notes that “patients and health care professionals need to work more closely together, appreciating each others’ expertise, i.e., a health professional is a medical expert, and a patient is an expert in what the condition and treatment mean to them, and interacting to determine the desired outcome” (World Health Organization, 2005, p. 10). The Department of Health in the United Kingdom (2001) has instituted a patient-centered Expert Patient Initiative, a major self-care support program using patient educators; this initiative is based on a recognition that “the knowledge and experience held by the patient has for too long been an untapped resource” (p. 5). A UK Health Department (2001) document notes that the patient has a particular knowledge recognized by the doctor who says “my patient understands their disease better than I do”, and the doctor has complementary general medical knowledge. A patient-centered approach with emphasis on support for self-care is integral to the New Brunswick chronic healthcare policy (New Brunswick Department of Health, 2006). The Stanford model

chronic disease self management workshop *My Choices-My Health!*, with its patient-as-educator approach, is a significant component of the New Brunswick chronic care program (Government of New Brunswick, n. d.).

Several models have emerged to support the implementation of patient-centered care and chronic care in particular. The Chronic Illness Care model (The MacColl Institute, n. d.) provides a comprehensive delineation of the proactive patient-provider healthcare team, supported by the healthcare system and community (Appendix D). The Inter Professional Patient-Centered Practice Model (Health Canada, 2004) illustrates the connection between effective inter-professional patient-centered practice and inter-professional education. This model points to the critical need for respect of diverse views and cooperative autonomy in educational and practice structures, as well as in patient-professional relations (Appendix E). The Transtheoretical model (Prochaska, 1995) is a framework for understanding and supporting the stages and processes of change that are involved in the lifestyle adjustments patients make for primary or secondary health prevention (Appendix F). The Transtheoretical Model emerges from studies of successful, sustained changes in personal health practices (Prochaska, Norcross & DiClemente, 1994). These studies indicate the value of listening to the patient experience. The above three models that guide patient-centered practice provide lenses for identifying the contextual aspects explicit or implicit in the stories and perspectives of the interview participants in this study.

While studies such as those of Prochaska and colleagues have thrown light on patient change processes, much remains to be understood about patient self-care. Narrative literature contains many reports of patient stories of illness and health.

However, it is only recently that patient perspectives of chronic disease management have begun to be recognized as a form of knowledge and evidence relevant to care decisions (Hernandez, 2007; Koch, 1998; O'Neil, Morris & Symons, 2006). The patient-centered care approach assumes that patient knowledge and decision-making capacity are elicited and integrated into patient-professional interactions. Research indicates that a professional-centered approach prevails despite professional self-perceptions of practice change (Rogers, Kennedy, Nelson & Anderson, 2008). Professionals privilege general medical knowledge and marginalize personal patient knowledge, 'the science of one', a product of daily observation and experimentation (Hernandez, 2007). There is a need to document this patient knowledge. This will support a move from patient centered-rhetoric to a more congruent practice, and will empower patients as self-care managers (Winkelman & Leonard, 2004).

### **Valuing Patient Voice in Chronic Care**

Chronic disease requires considerable self-management on the part of patients, and it is an area that benefits from a patient-centered approach that recognizes patient experiential knowledge. Documentation of patient experiential knowledge can contribute to the macro-level considerations of chronic care health planning, grounding them in the realities of daily life. Patient perspectives can address the need for a more effective approach to chronic disease management, in the context of rising rates of chronic disease and rising demands on an already burdened health care system (Public Health Agency of Canada, 2005; World Health Organization, 2005; Health Council of Canada, 2009). A population health approach examines patterns of disease and wellness in order to consider what organization of services is most suitable and equitable to meet healthcare and

wellness support needs. Patients can contribute to this examination, clarifying what will work for them on the ground (Decter, 2000: Public Health Agency of Canada, 2002).

Chronic disease is a significant issue in the Atlantic region and is linked to regional income disparities (Hayward & Coleman, 2003). A small local example: in 2007, 75 newly-diagnosed patients per month were being referred to the diabetes education program of the former New Brunswick Region Two Health Authority, with limited educational impact as indicated by follow-up blood-screening. There were over 4,000 patients in the Saint John area at that time (Barton McPhee as cited in Clark et al., 2007). Graham<sup>8</sup> (personal communication, November 2, 2012) notes that in 2011 the rate of first time referrals had slowed to an average of 35 per month. However the rate of re-referrals for education and counseling regarding diet, foot care and insulin use averaged 40 per month, indicating a lack of educational impact from the first referral. Referrals in 2011 for pre-diabetes education, for persons with slightly elevated blood sugar readings, averaged 9 per month. The rate of no-shows for prediabetes education sessions was considerably lower than those for diabetes education, suggesting the growing openness of the public to prevention education, perhaps linked to the influence of the Internet on public awareness of the risks of diabetes and the positive role of lifestyle changes in prevention. The Public Health Agency of Canada (2005a) reports that nationally diabetes is a factor in nearly one tenth of hospitalizations; 40% of diabetics develop complications “such as heart disease, stroke, kidney failure, amputation, blindness and impotence” (p. 4). A The Public Health Agency of Canada (2011) document notes that annual per capita

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<sup>8</sup> Linda Graham is a certified diabetes educator who is the manager of the adult diabetes education program at the St John NB Horizon Health Diabetes Education Clinic, formerly known as the diabetes education program of New Brunswick Region Two Health Authority.



health care costs are estimated to be three to four times larger in a population with diabetes, compared to one with a zero prevalence of that condition. It states that socio-demographic factors, including lower socio-economic status and living in rural areas, are associated with more prevalent risk factors, higher rates of type 2 diabetes, and higher levels of morbidity and mortality. Persons with diabetes, at every age group, have mortality rates that are at least two times higher than those without this condition. A population health approach, rooted in an understanding of the social determinants of health, points to the importance of addressing these determinants, for example poverty and social exclusion (Raphael, 2004). However, prevention must include secondary and tertiary measures in the case of chronic conditions to prevent or slow down the advance of disease (Rachlis, 2004).

Compliance with professionally prescribed regimens for secondary prevention has been documented as low or declining over time, leading to disease complications that significantly impact patient health and healthcare system usage (Health Canada, 2006; Montague, 2004). Compliance issues are complex. Compliance-influencing factors include: costs, side effects, disruption-of-life-routine by treatments, health beliefs, self efficacy, social support, and the need for a stimulating trigger (Wahl et al., 2005).<sup>9</sup> The literature suggests that patient-centered care, a holistic approach, is critical to the success of patient self-management (Gertais, Edgman-Levitan, Daley & Delbanco, 1993; Health Canada, 2006; Wagner, 2006). However, patient-centered rhetoric may accompany

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<sup>9</sup> There is an increasing acknowledgement that the concept of compliance embodies a hierarchical professional-centered perspective. Alternate terms such as adherence and concordance convey a democratizing response to this insight. Asset-based approaches, such as Appreciative Inquiry are interested in exploring influencing factors that contribute to what is already working.

professionally-centered practice. A professional lens can also narrow the framing of research on patient experience and patient self-management. A review of journals ranging from *The Diabetes Educator* to *Social Science and Medicine* provided me with helpful orientation to issues and current theoretical models in the field of self-care support services. However, it was not until I began to add narrative inquiry to my list of search words, such as “patient voice”, “patient knowledge” and “diabetes self-management” that I began to encounter narrative theorists such as Frank who consider patient experience as part of a life story and who may write from an insider’s perspective. This in turn led me to journals such as *Communication and Medicine*, which are reporting studies of the innovative use of narrative approaches in health communication and education. However, this investigation is new and the literature I found was sparse.

Documentation of patient experience and perspectives can support a patient-professional partnership by addressing a gap in the knowledge of patient-perceived factors in successful, sustained self-management. Appreciative Inquiry has been identified as an effective positive methodology for addressing this knowledge gap, by exploring with patients their stories of what is working in their personal health management. (Montague, 2004; The Valeo Initiative, 2002).

### **Appreciative Inquiry**

Appreciative Inquiry originated in the 1986 PhD work of David Cooperrider. During his study of organizational dynamics within a U.S. healthcare facility, Cooperrider discovered that asking doctors to describe what aspects they valued about their work led them to talk in unrestricted and inspiring ways. This produced data different from studies examining the strains in the healthcare system (Reed, 2007).

Cooperrider, in focusing on the positive factors reported to him by his medical informants, began to think of a new approach to research and organizational development. This approach would identify and build on what is already working. Research, which supports this positive investigative approach, includes studies in the areas of the placebo effect, the Pygmalion effect, learned helplessness, and visualization (Cooperrider, Whitney & Stavros, 2003). These studies suggest that people are significantly influenced by their own expectations and that of others. An early AI change hypothesis proposed that asking positive questions would facilitate positive behavior. It should be noted that the supporting literature referred to above has been challenged by questions regarding its findings or interpretation (Patton, 2003). AI is congruent with the strengths/asset based (versus deficit) model of development that has been adopted by health promotion and community development initiatives worldwide (Elliot, 1999; Fuller, Guy, & Pletsch, 2002; International Institute for Sustainable Development, 2000; Odell, 2002; Patton, 2003). It is also congruent with a resiliency approach to sensitive research issues such as personal health matters (Edwards et al., 2008). AI has been broadly and successfully employed as an organizational tool in business restructuring, urban renewal, international development and more recently the health services sector (Marchionni & Richer, 2007; Reed, 2002). AI studies have begun to address health system issues such as healthy working environments, knowledge translation of best practices, leadership, health promotion, chronic care and whole system approaches to innovation (Kavanagh et al., 2008; Keefe, 2004; Marchionni & Richer, 2007; Moore & Charvat, 2007; Reed, 2007; Wright & Baker, 2005). There appear to be very few studies focused on the patient

perspective (Shiner et al, 2008; Kelm, 2008). This study is modeled after one of these, The Valeo Initiative (2002), which will be described in an upcoming section.

Appreciative Inquiry is rooted in the philosophy of Social Constructionism (Reed, 2007). A Social Constructionist epistemology is one that views the value and meaning of phenomena as historically and culturally defined (Michael, 2009). It is concerned with how meaning/reality is constructed through interaction/language practices and how it embodies power relations. For instance, “without knowing who is determining what counts as fact and what counts as evidence, and which community’s beliefs are being oppressed, it is difficult to interpret the results of any research program” (McNamee as cited in Reed, 2007, p. viii), outside its political context.

A Social Constructionist lens applied to the research process notes how researcher choice of topic, participants and forms of engagement, are central to the construction of a particular reality. Through Appreciative Inquiry, researchers choose to co-construct with participants a reality of potential.<sup>10</sup> They practice a generous listening approach that can receive talk of problems and can frame questions about the values and positive action-directions implied therein. An example of this is posing a question about how gender equity values are already practiced by some people in some ways in a situation where sexism has been identified as a problem. (Positive deviance<sup>11</sup> is another approach to identifying and building on the positive examples of what is working in a problematic context.) Appreciative Inquiry conversations are generative, even transformative,

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<sup>10</sup> AI is congruent with the new positive psychology approach (Pearsall, 2003).

<sup>11</sup> Bradley, E. H. et al. (2009), who review cases of positive deviance in health care organizations, note that the positive deviance approach presumes that the knowledge about ‘what works’ exists in organizations and individuals who demonstrate consistent success.

particularly so if they occur as a form of action research in a ‘whole system’ setting such as an organization or a community, where there is the political freedom to change (Reed, 2007). AI as action research has proven an effective forum for patients to contribute their expertise to program and policy change projects (Reed, 2007).

Cooperrider and other AI authors have enhanced the AI theoretical framework and practice by drawing on the seminal work of social constructionist Ken Gergen. Gergen (1982) proposes a new direction in social theory development that builds on, rather than tries to control, the interaction between research and practice. Attention is paid to how people co-construct ideas and interpretations that influence their behaviour. Gergen’s work helps place the AI organizational development approach in a wider context of theories about the social world in general. AI is now recognized by some as “both a philosophy and a worldview, with particular principles and assumptions<sup>12</sup> and a structured set of core processes and practices for engaging people in identifying and co-creating an organization’s future” (Coghlan, Preskill & Catsambas, 2003, p. 6). In the case of this study the organization that participants could consider co-creating is their country’s healthcare system.

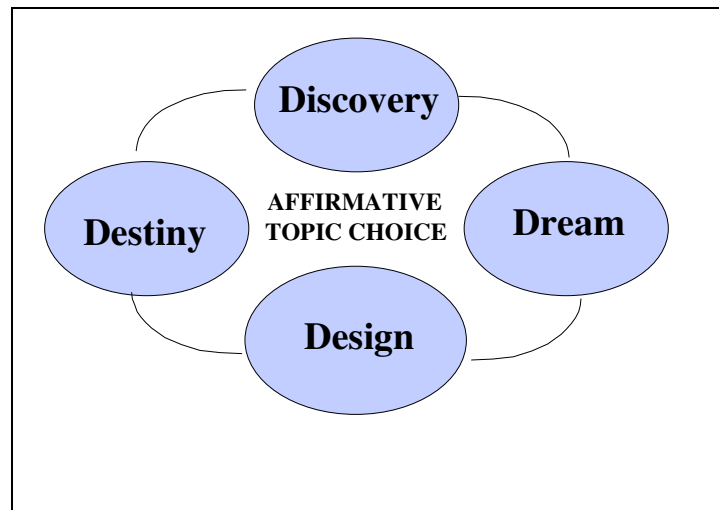
### ***Appreciative inquiry process.***

The process of AI is iterative and cyclic. Questions produce learning and actions, which can be integrated and sustained through ongoing AI reflection. A goal of many AI interventions is to transfer the resource of AI knowledge and practice to the participants and their organizations, for use in a continual learning process.

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<sup>12</sup> See Appendix G for AI principles and assumptions.

The reflective nature of AI work has been outlined in the four phases of the 4-D cycle: discovery, dream, design, and deliver/destiny (Figure 1). It should be noted that the 4-D cycle is usually used with groups but can be adapted for individual interviews (Michael, 2005).



**Figure 2 The 4 D cycle as adapted by Marchionni & Richer (2007).**

*Discovery: Appreciating what gives life.* The discovery phase involves identifying what makes up the positive core of an organization or phenomenon — strengths, values, goals and achievements. This process usually involves participants working in pairs to interview each other and may include other activities such as group discussions and exercises. The intervener/researcher’s challenge may be to encourage the exploration of what gives positive energy, as the negative often seems more vivid and important. Given the AI assumption that knowledge is co-constructed, the researcher doing individual AI interviews is encouraged to take an engaged conversational approach that is flexible, open, and co-operative (Zeldin, 1998; Reed, 2007).

*Dreaming: Envisioning what might be.* In this phase participants brainstorm ideas about what an enhanced future might look like. AI interveners sometimes use what is called the miracle question to stimulate discussion. A classic form of this question is “Imagine falling asleep and waking up five years in the future, to find how the organization or situation has advanced; what changes do you notice?” In the case of the individual interview, the interviewer can ask the participant to dream into the future. However, as in any form of brainstorming, group conversation is usually more generative. Multimedia approaches may also be used. The intervener/researcher may need to remind participants not to be limited by present resources or relationships in their imagining of an enhanced future.

Appreciative Inquiry, in focusing on what gives life to a practice, can elicit from each individual a unique knowledge and wisdom about living well as a participant in a healthcare system community. Such dialogue can produce generative metaphors which can create fresh perceptions of self and other. These metaphors can facilitate revitalized social bonds and individual integration, and heighten individual and collective will to act (Barrett & Cooperrider, 2001; Bushe & Kassam, 2005; Frank, 2004). An example would be the person with diabetes whose metaphor for self-care is skillful driving in stormy weather conditions, committed to keeping himself and others safe.

The third and fourth steps of the 4-D cycle are not used in this study, but are presented below to convey the model in its entirety. These steps are relevant to potential AI applied studies of the role of patient knowledge in health system development.

*Designing: Determining what will be.* In this phase, participants work together to develop ideas for the future. These ideas are then concisely stated in what are called provocative propositions, confident concrete statements like “Everyone will . . .” that contain no caveats or conditions. Provocative propositions challenge and stretch their authors to engage imaginatively<sup>13</sup> with positive possibilities (Whitney, 1998, p. 137). An example would be, “Every person with diabetes will have access to the financial resources needed to purchase diabetic supplies.” Provocative propositions hold promise for catalyzing self-management conversations among patients and between patients and caregivers. Provocative propositions can also stimulate visionary dialogues with other chronic care stakeholders (Marchionni & Richer, 2007; Reed, Pearson, Douglas, Swinburne & Wilding, 2002; Wright & Baker, 2005).

*Delivery: Planning what will be:* In this phase, participants create an action plan, rooted in identified past successes, for implementing their ideas. In some AI Design phase meetings, participants choose one step to implement immediately, to prime the momentum for change (Odell, 2002). For example, “Participants will research successful diabetes supplies subsidy policies in other provinces and meet in 2 weeks to discuss these policies and next steps in adapting them to the New Brunswick context”. This kind of

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<sup>13</sup> Zandee (2008) notes that a narrative mode of knowing including poetic, metaphorical language used in Discovery and Dream phases of AI is often displaced by a more logico-scientific discourse during Design conversations. She argues that narrative dialogue in Design activities can awaken imaginative and relational possibilities needed in the creation of more just and sustainable forms of organizing, in contrast to an often less imaginative modernist managerial approach to design. Simon (1987) who identified the *pedagogy of possibility* discusses the importance of language in enabling a particular ‘not yet’. In doing so Simon (1992) cites Henry Giroux, “A language of possibility does not have to dissolve into reified utopianism. Instead it can be developed as a precondition for nourishing convictions that summon up the courage to imagine a different and more just world and struggle for it (Giroux in Simon, 1992. p.13).”



initiative is more possible in settings where those in authority have agreed to endorse the AI process and its outcomes.

AI focuses on collaboration, integration of whole systems in the AI process<sup>14</sup>, and future thinking; this makes it an effective approach to innovation, which some see as the critical component to healthcare reform (Rachlis, 2008; Reed, 2007). Below is an example of an innovative AI process used by U S. citizens to explore health care reform at the individual and collective level. The AI process used by this group of citizens informed my study.

### ***Valeo initiative model***

*The Valeo Initiative* (2002) is the brainchild of a small group of American innovation leaders (Monnecke, 2009). These leaders were inspired by and wished to apply Dr. Jonas Salk's vision of an epidemic of health. Dr. Salk anticipated this epidemic of health would emerge when "people discover those things they do that make them healthy and share these with as many people as possible" (The Valeo Initiative, 2002, p. 1). The Valeo group created the *Living Dialogue on Health and Care*; it was a one-year national level U.S. project "intended to inspire people to think constructively about their own health and to influence the care they receive" (p. 3). The goal of the initiative was to sponsor 100 workshops in all regions of the country with persons from all backgrounds. The workshop design was based on an Appreciative Inquiry process using the discovery and dream phases. The *Living Dialogue on Health and Care* invited participants to exchange

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<sup>14</sup> AI is congruent with complexity thinking which proposes that in systems the relationship among parts is more important than the parts themselves (Plsek & Wilson, 2003).

stories about exceptional health and care, including positive experiences of taking charge. The goal was for them to discover and dream new possibilities for a) acting on behalf of their own health, b) making decisions about the care of themselves and their families, and c) improving the health of their communities. The idea was that such dialogues could generate actions at the individual and community level, and over time influence the public definition of health. The hope was that this redefinition of health would lead to policy and practice changes in the healthcare system. The Living Dialogue is seen by its sponsors as a good framework upon which to rethink healthcare reform (Munnecke, 2009).

The Valeo Initiative produced an excellent workshop manual that has informed the research design of this study as it is a helpful example of providing a forum for the patient voice and eliciting the positive in the patient's experience. This study will add to the limited methodological literature on the investigation of patient experiential perspectives, building on research work, such as the Valeo Initiative, with its focus on positive experience and how that can be enhanced.

A concern about AI as an organizational development tool or a research method is its restricted focus on the positive (Patton, 2003). Some AI theorists would argue, in response, that AI embodies a critical stance in the sense that it encourages the posing of questions which challenge assumptions about the way things happen (Reed, 2007). AI theorists (Cooperrider et al., 2003) point to the writings of Jung and Einstein, which suggest that problems cannot be resolved by the mental framework or level of consciousness that created them. AI thinkers argue that shifting from a problem to an appreciative focus can precipitate the

needed change of framework leading to generative discussion. This would suggest that Appreciative Inquiry can produce practical knowledge, valued in action research and by adherents of pragmatist philosophy. To quote a famous passage from Rorty (1999), “We cannot regard truth as the goal of inquiry. The purpose of inquiry is to achieve agreement among human beings about what to do . . . inquiry that does not achieve coordination of behavior is not inquiry but simply word play” (p.xxv). For pragmatists, knowledge claims are to be linked to what works in particular contexts or to use a folk saying, “the proof is in the [particular] pudding”. The rise of positive psychology suggests that an appreciative approach works well to facilitate success, not only at a social but also at a psychological level as in the internal change processes at work in the AI focus group and interview interventions (Pearsall, 2003; Kelm, 2008).

Another criticism of AI is that it does not engage with issues of power. In fact there are AI reports which acknowledge how the results of inquiry have not been put into action, due to a lack of support from those in authority (Reed, 2007). Cockell (2006) suggests that AI literature does not explore how differences of power and privilege impact peoples’ ability to appreciate and be appreciated. She calls her AI practice “Critical Appreciative Inquiry”, incorporating critical insights and liberating practices from the realm of transformative education to enhance appreciative possibilities. These include measures which honour differences and support inclusion.

Constructivist thought points to the element of social construction in the distribution of resources, roles and responsibilities; while it is important to not

deny the impact on people of those constructs, their constructed nature suggests their capacity to be altered. AI practitioners report questions and processes that help this change process, including the cultivation of conversation based on genuine inquiry rather than persuasion, viewing conflict as generative, and celebrating diversity (Hammond, 2005; Cockell, 2006; Reed, 2007). Appreciative questions can address matters directly, e.g., “What behavior are you most proud of in yourself in terms of naming elephants in the room?” “What do you most wish this person would learn to do to support the team’s/your goals?” bringing to awareness less visible aspects of a conflicted or oppressive situation. AI’s capacity for conflict resolution and community building, rooted in its philosophical assumption of the fundamental goodness and wisdom of human beings, has been drawn on by figures such as the Dalai Lama and other religious leaders, in the formation of a World Religions Initiative, described as a religious UN (Lefkowitz, 1999). Such examples affirm the potential for use of AI in addressing positive change processes in the complex area of human health and well-being.

In summary, Appreciative Inquiry is a well-tested approach for investigating and supporting the expression of voice at all levels of a system (Reed, 2007). It is an innovative methodology that takes an asset-focused approach to data-gathering that is potentially applicable to examining patient-centered strategies for managing many chronic diseases and to the designing of effective chronic care interventions. Appreciative Inquiry, when used for action research, is an effective form of knowledge translation,

involving participants in an iterative process of formulating questions, data gathering, data analysis, design of the application of results, implementation, and evaluation.

### **Literature Review Summary**

The Literature Review consists of three sections. The first section surveys the general research theme-patient voice/experiential knowledge, their definitions, history, legitimacy, and rising importance in healthcare research and practice. There is a growing recognition in the healthcare field of both citizen-patient rights and patient self-care expertise. The second section presents the changing nature of healthcare practice. In particular it names the rise of patient-centered care and the need to create and disseminate a greater understanding of patient perspectives. Studies indicate that professionally-centered care still prevails in practice, pointing to the need for more investigation and knowledge translation/integration of patient perspectives. This section also addresses the central importance of patient voice in chronic care, the vast majority of which is self-care. Persons performing self-care over time develop an experiential expertise and yet there are few studies of this valuable practical knowledge. Documentation of this knowledge would contribute to the understanding of how to support the self-care work of persons with chronic conditions, including the facilitation of peer exchanges of knowledge. The third section addresses the research methodology chosen for investigating patient knowledge of self-care. It reviews the origins, supporting literature, philosophical framework, and practices of Appreciative Inquiry. AI is identified as an appropriate method for an asset-focused

investigation of the research question, “What factors contribute to successful self-management from the patient’s perspective?”

### Chapter Three: Methodology

This qualitative study is based on 13 single interviews with subjects who self-identified as successful in the self-management of diabetes. Interview questions were designed using an asset-based AI approach, and the results were coded by Thematic Analysis (Braun and Clark, 2006).

The study is Part Two of the *Survey of Patient-Centered Strategies of Diabetes Patients Using Appreciative Inquiry*. Part One consisted of focus groups, and Part Two consisted of individual interviews. Both studies examined the research question, “What factors contribute to successful self management from the patient’s perspective?” The AI Survey parts one and two received Research Ethics Board approval from both the UNB Saint John Research Ethics Board and the Atlantic Health Sciences Research Ethics Board. Data security was handled as follows: Hard copies and digital copies of interview data and consent forms have been stored in locked cabinets and password secured electronic sites, at the UNB Saint John Nursing Department office and my home office.

It should be noted that the *Survey of Patient-Centered Strategies of Diabetes Patients Using Appreciative Inquiry* was designed as one study, not divided into two parts. As the student research assistant on that study, I assisted in the focus groups and conducted all the individual interviews. On completion of my summer internship placement, it was suggested to me by an academic in my family that I ask if I might use the individual interview data for my thesis. Survey investigators, Professors Clark and DeBell, generously agreed to my request to use the individual interview data and also agreed to be my thesis co-supervisors. For convenience I have referred to my thesis as

Part Two of the original Survey study. I conducted four more individual interviews, after switching my role from student research assistant to thesis research student.

Professors Clark and DeBell analysed the focus group data and presented preliminary results in a poster at two conferences in 2010<sup>15</sup>. However, it was agreed that I would focus on developing my own analysis and interpretation of the individual interview data in the thesis before participating in a comparison of the results from the focus group data and individual interview data in a potential journal article, upon thesis completion.

## **Sample**

The sample consisted of 13 patients<sup>16</sup> who considered themselves to be successfully managing the life changes required upon a diagnosis of diabetes. Criteria for inclusion in the interviews were the ability to understand and speak English, and to be at least eighteen years of age. It should be noted that the data-gathering goals of this study regarding patient perspectives could have been met by studying any chronic disease group. The diabetic population was chosen because it is relatively large and contains many individuals who have lived with the disease for an extended period of time. These individuals have amassed experience in the substantial number of self-care activities

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<sup>15</sup> Poster *Self-Management of chronic disease: An appreciative inquiry approach*, authors C.R. Clark, K. DeBell, J. Burgess, J. Barton-McPhee, Partnering in Health Research: Interprofessional Health Research Conference, Saint John Regional Hospital Saint John NB, March 19 2010.

Poster *Patient-centered care: Hearing the patient's voice in diabetes self-management*, authors C.R. Clark, K. DeBell, J. Burgess, J. Barton-McPhee, Fostering a health research culture in New Brunswick conference, New Brunswick Health Research Foundation, Saint John NB, November 1-2 2010.

<sup>16</sup> The sample initially consisted of 14 persons. One interview was discarded for full analysis due to poor audibility of the interview recording. However, I have made a couple of references, in the Results Chapter to data in the audible fragment of the 14<sup>th</sup> interview. (The 14<sup>th</sup> interviewee had presented material similar to that in her interview, in the focus group in which she participated, increasing my confidence in referring to her interview statements).



involved in diabetes self-management. Effective diabetes self-care is complex, increasing the likelihood of obtaining rich data in interviews with participants. Primarily, the diabetes population was chosen out of convenience.

The initial plan was to include as study participants only persons with Type II diabetes. However, given that there is much in common between Type I and Type II diabetes self-care and secondary prevention, interested persons with Type I diabetes and persons at risk of developing diabetes were also included. Referrals were elicited from local senior citizen service providers and diabetes educators throughout the region. Participants were also recruited directly from diabetes mutual help groups and from the AI Survey Part I focus groups. (Focus group participants were asked, if interested, to provide written consent to be contacted for a possible follow up individual interview.)<sup>17</sup> The fourteen interviewees (see Appendix G Participant Profiles) were selected as follows. The research team recommended 10 focus group participants for the follow-up individual interviews based on their informal assessment of individual participants' abilities to add to and deepen the data. Four persons referred by diabetes educators, whose schedules did not permit participation in a focus group, were also selected. Demographic data was not gathered for the interviewees, as this was not part of the design submitted to and approved by the ethics boards concerned.<sup>18</sup> However, as a majority of the interviewees

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<sup>17</sup> Persons were informed of the study in a standardized way. The study was first introduced to potential interested participants, in person by me or the referring professional who had received a written and oral description of the study from me. The study was outlined on the consent form (Appendix H).

<sup>18</sup> At the design stage of the Survey it was assumed that individual follow-up interviews would be entirely with focus group participants. Given the qualitative nature of my thesis, and the small size of my single individual interview group of participants, it did not seem necessary or appropriate to re-apply to the Ethics Board to gather demographic data from the individual interviewees.

had participated in a focus group, the focus group demographic data are roughly representative of the interviewee group (Appendix I: Focus group demographic data).

### **Data Gathering Design**

The AI Survey Part I appreciative design was rooted in the choice of a positive topic ‘living well with diabetes’, which participants endorsed by volunteering to share their experiences in this regard. The interviews first explored the Discovery questions listed in the table below. Dream questions about participants’ visions for an enhanced self-care future were then explored. This included the classic Dream question, “Imagine falling asleep and waking up five years in the future, to find how the organization or situation has advanced; what changes do you notice?”

**Table 1 Discovery questions**

Question 1	Question 2	Question 3
What tells you that you are living well with diabetes? What are your personal signs?	Tell me a story about an experience of managing your diabetes successfully.	What 3 tips for living positively with diabetes would you give to a person newly diagnosed with this condition?
Prompts: Tell me a bit more. Could you describe/explain that a bit more to me?	Prompts: Tell me a bit more. Explain that a bit more to me. Are there people who have helped you in this success?	

### **Interview Protocol**

Interviews were held at participants’ homes, at the research assistant office, and by phone, depending on participant preference and interviewer location. A consent-to-the-interview form was signed before the interview, in person or electronically (Appendix

H). The interviews lasted approximately an hour. They were audio-taped and professionally transcribed. A semi-structured, open interview format was used, guided by the three appreciative questions (see above); participants were also asked about their ideas of what an enhanced future, supportive of expanded self-care, might look like. It should be noted that 8 of the 14 participants had previously participated in AI Survey Part 1 focus group discussions on these same questions. Some referred to comments from other focus group members which they had resonated with or which had stimulated them to reflect further. Appreciative Inquiry principles and assumptions guided the interview process.

### **The Value of the AI Interview Approach**

AI, a qualitative methodology with a positive and inclusive focus, was an appropriate method for exploring patient perspectives and practices. The AI framework includes the following process assumptions: (i) that for every group or individual something works, (ii) that it is more motivating to enhance what is working than to try to dismantle what isn't, (iii) that the language individuals use to describe reality creates that reality, (iv) that what individuals focus on is what they move towards, (v) that there are multiple personal and group realities, (vi) that it is important to value differences, and (vii) that people have more confidence to move into the new and unknown when they carry forward parts of their (successful) known past (Hammond, 1998). The Appreciative Inquiry approach allowed me to address the participant patients as experts without discounting professional expertise, to generate interest and engagement by focusing on what was working for the participants, and to co-construct data around participant aspirations.

The complex and often ineffable reality of lived experience, central to the topic of living well with a chronic condition, was effectively explored through AI. By asking persons with chronic conditions what was valuable about what they did, and what contributed to their success, I took an appreciative, inclusive interviewer stance, open to a diversity of views and definitions of success. Such an inquiry contributed a different or enhanced perspective to findings on the patient voice, the patient journey, and patient forms of knowledge (The Valeo Initiative, 2002).

The AI process challenged participants, and challenges research audiences, to reconsider and experience how people work and learn, how change happens, and how research can contribute. (This process would have increased in reflective power if the AI process had included discussion and plans about how to take achievements and values/visions forward).<sup>19</sup> As the researcher, I was also challenged in this emergent research design, confronted with unearthing my covert and undeveloped ideas underlying intuitive directions pursued in interview conversations and interpretive work. I recorded periodic journal entries as part of my reflective process. An example of this reflective work is two early journal entries considering how my life experience has shaped my focus of interest and appreciation. I also consider aspects of the relationship between researcher and participants. The September 3, 2009, entry reads as follows:

The first year of my life in a coastal village imprinted me with the atmosphere of that ocean-side First Nations community. Immersion in indigenous

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<sup>19</sup> AI was used as a positive form of narrative inquiry in this emergent study. The 13 participants lived in different communities and most did not know one another. This circumstance did not lend itself to use of AI as participatory action research. A next step could be the design of a study which uses all four phases of AI in patient voice and self-care research with groups, communities, and institutions, who have the capacity to reflect and act collectively. AI can also be used with individuals who are interviewed several times to investigate how they plan and implement individual self-care and well being enhancement actions.

culture continued during my childhood in Africa. Indigenous values of community, care, and spirituality have combined for me with a Christian family faith tradition of community service.

Cross-cultural experience has taught me that there are multiple realities, multiple truths, multiple approaches to life and well-being. Growing up in a colony was an early education in the importance of democracy at all levels, as it was practiced in the local church structure and as the impact of its absence was highlighted by a nondemocratic colonial administration.

Work in adult education, community development, and organic vegetable production have educated me in the value of respect, social capital, and environmental health and sustainability, all factors bearing on individual health and well-being.

The Master's of Applied Health Service Research program has introduced me to the tenets of Qualitative Inquiry. Post structural social constructionism is an approach that I find compatible with my personal belief system. Community-based action research and narrative inquiry are forms of research which interest me and for which I seem suited. Memoir work has created for me an awareness of stories as forms of knowledge and 'truth power'.

Synchronicity could be seen to be at work in my summer residency placement with the Appreciative Inquiry Survey carried out with persons living well with diabetes. This experience introduced me to a form of research with a strong communal and spiritual element, one that builds on my understanding of personal and spiritual development and integration, learned through the healing and life-enhancing approach of Psychosynthesis (Burgess).

The September 29, 2009, entry follows:

Nell Noddings (2002) an authority on the Ethics of Care, particularly as it applied in the field of education, suggests that the care that is present in authentic inquiry is rooted in the experience of the parent and vulnerable child, the learning in that earliest relationship to both receive and give. Noddings maintains that if there is no authentic receiving there is no care. Ram Dass and Paul Gorman (1985), in *How Can I Help? Stories and Reflections on Service*, describe the active receiving work of the recipient, through appreciation, sharing of one's life and being present to the life of the caregiver. I would see giving and receiving as a two way street. What do researchers and care providers receive and how do they actively do so? How are interviewees and interviewers actively receiving from one another and giving to one another? Feminist author Tong (1998) suggests caring can only occur in the presence of a social context of mutual respect and consideration. For me, receiving involves a vulnerable openness of heart.

Some writers (Card, 1990) struggle with what they see as maternalism in Noddings' perspective. For instance in a piece on homelessness and social policy Noddings proposes that the homeless be told they cannot live without a home, although at the same time as she challenges controls in shelters, such as restrictions on when and how residents may come and go. Having grown up in a colony during a war of independence, during which my parents, as expatriates

were required to get administrative permission to travel beyond the local town, I am sensitive to the issue of whose interests are served by socio-political policies.

Recently I have been introduced to the work of Marshall Rosenberg, founder of Non Violent Communication, who provides an approach to social and personal issues in which differences of perspective are resolved through a process of authentic inquiry into what he refers to as 'our precious needs'. To convey the spirit in which this needs to be approached he refers to the Sufi poet Rumi who writes about meeting in a space beyond wrongness and rightness. I have encountered the concept of such a place in the work of First Nations researchers (Ermine et al., 2004), who have identified its importance in negotiating research agreements among First Nations communities, First Nations researchers and outside researchers. They recognize this space as a nebulous arena of possibilities that exists when differing cultures, or holders of different kinds of knowledge and different intentions, agree to meet and dialogue in a context bound by ethical parameters of respect and equality. Sinclair et al (2004) cite philosopher Roger Poole (1972) who names the quality of the negotiating arena First Nations seek as 'Ethical Space'.

Discussions on the Ethics of Care and Ethical Space have a bearing on the central component of patient-centered care, the quality and kind of relationships among patients and their care teams. They are relevant to reflexive and ethical aspects of research relationships and provide a lens for locating related themes in the data.

Cockell (2005) reflects on what is the central passion behind her AI PhD thesis inquiry into facilitating collaborative relationships. Reading her work suggests such a question to me. As an active listener in personal and work settings I am drawn to that which supports a connection with one's inner knowing. An example of this inner knowing which is relevant to the healthcare field is one which is discussed by John Upledger (1997), founder of Craniosacral Therapy. He encourages clients to get in touch with what he calls their Inner Physician, a source of intuitive, felt knowing which can guide them on their unique healing journeys. I am more and more coming to appreciate how this process of accessing inner wisdom is as much social as it is introspective. This awareness reinforces a felt sense of the importance of relationship in chronic care and ethical research.

The dialogical aspect of constructing and accessing knowledge is one I am encountering in the thesis project. I wrote a small poem about the need for dialogical relationship in intellectual work, when completing an assignment on the experience of carrying out a mock interview project for a Qualitative course last term:

If an interview is co-constructed  
Where is my partner in this meditation?  
On how we did and what it means?

(Added edit Nov 5, 2012)

The 4-D cycle of Appreciative Inquiry, which combines a positive narrative inquiry with a participatory action approach, includes a cycling exchange between interviewer(s) and interviewees. A 4-D AI inquiry with patients, about living well

with diabetes, is a possible future research project. It would work best if participants belonged to the same existing group, community or program, which would facilitate common collective enhancement actions, supported by bonds of caring and shared values (Burgess).

### **Method of Analysis of Thesis Interview Data**

Appreciative Inquiry provided the conceptual framework and methodology for data gathering of the *Survey of Patient Centered Strategies of Diabetes Patients using Appreciative Inquiry, Part II*. An Appreciative eye informed my analysis of the interviews. I superimposed on this viewpoint an analytic method that can be classified as basic or fundamental Qualitative Description, which attends to the surface of the data (Sandelowski, 2000). Such an analysis is of value in itself and can be the first stage of more theoretically based approaches such as phenomenology. It allows for initial inferences or interpretation and does require an accurate and coherent report of participants' perceptions, experiences, and meanings, conveyed in a proper sequence (Sandelowski, 2000). More specifically, I used Thematic Analysis because of its flexibility and its appropriateness for new researchers (Braun & Clark, 2006).

Thematic Analysis is a foundational qualitative method of analysis, incorporating the core skill of "thematising meanings" (Holloway & Todres, 2003, p. 247). Boyatzis (1998) sees thematic analysis as a tool used across different methods; Braun and Clark (2006) define it as a method "in its own right" (p. 78). They believe much analysis is thematic but is reported as something else, such as content analysis, or simply qualitative analysis.

The flexibility of Thematic Analysis lies in its generic nature and associated theoretical independence. Thematic Analysis can be used as a constructivist method to explore perceptions, experiences and meanings and their emergence from individual and

socio-cultural discourse; Thematic Analysis can also be employed as a realist method (Braun & Clark, 2006). The trustworthiness of the Thematic Analysis method lies in the recording and reporting of what the researcher does, why and how, during the work of identifying patterns and focusing on those that interest them (Braun & Clark, 2006; de Wet & Erasmus, Z, 2005). The flexibility of the Thematic Analysis method can be both beneficial and problematic for the researcher. Despite its frequent usage in qualitative research (Roulston, 2001), there is a paucity of literature on how to apply Thematic Analysis in practice. I relied heavily on Braun and Clark (2006).



To examine the data I began by following the 6 phases set out in the thematic analysis approach as outlined in Table Two:

**Table 2 Phases of thematic analysis (Braun and Clark, 2006)**

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

The table provides broadly defined steps in the analytic work. However, there was a need to clarify how as the researcher I was to spot interesting and relevant features of the data. Reed (2007) recommends drawing on the approaches of Action Research and Narrative Inquiry in the analysis and interpretation of Appreciative Inquiry data. Given the fact that this study involved exploratory data gathering with individual participants but did not attempt any group or organizational intervention, as occurs with action research, it seemed that a preliminary narrative approach to thematic interpretation was appropriate.

This direction was affirmed when I consulted the literature to understand the interview results and found that they fit within a Narrative framing.

In entering phase one of thematic analysis, “familiarize yourself with the data”, I as the interviewer had some knowledge of the interview content. The 14 audio-taped interviews were professionally transcribed. One of these was incomplete, due to audibility, and after unsuccessfully looking for a sound engineer to rectify the problem, I discarded it. I verified the 13 remaining transcripts against the audiotapes and entered the corrections. I read the transcripts several times.

In generating initial codes I drew on the Auerbach and Silverstein (2003) text *Qualitative Data: An Introduction to Coding*. It presents a helpful example of the detailed, iterative work involved in continuous comparison coding. I wrote a reflection after coding each transcript, which evolved over time to include: a) a sentence summarizing the self-report of how the participant successfully managed living with diabetes; b) a listing of all conversation excerpts relevant to each code; c) a note of any links the participant made, e.g., various chronic conditions require similar forms of self-care; d) notes on similarities with other transcripts and anything new or different; e) notes on how the transcript material resonated with AI principles and assumptions; and f) an entitling and listing of all the stories in the transcript. During the coding process I consulted the literature to better grasp issues raised by the participants, such as understanding and working with food cravings and addressing communication with their health care providers. I made notes on these readings and included some of these notes in the reflection documents. As I moved from coding to working with themes, I began to draw on theoretical and applied literature to support my thinking.

Having named over one hundred codes, I first sorted these into instrumental strategies for managing diabetes, such as exercise to lower blood sugar, and process matters, such as mind over matter and natural consequences<sup>20</sup>. I then searched for themes by grouping the codes under potential themes and subthemes. I reviewed the themes by checking them against the codes that fell under them and against the actual pieces of data. (These initial themes were as follows: personal qualities; interpersonal support which had two subthemes, interaction and socioeconomic factors; and experiential expertise which had three subthemes of personal regimen, adjustment process, and results achieved.) I grouped together codes having to do with participants' dreams for enhanced self-management and originally included them under experiential expertise and then I decided to present this material in the recommendations section of the Discussion. Finally, I grouped together codes (e.g., coming out of hiding) that had to do with participant conversations as illness narratives.

In the process of drafting the Results chapter and hearing again and again what the participants are saying in selected quotes, I streamlined my theme structure, dropping the subthemes and creating an overarching theme. The theme of positive personal qualities was expanded to include spiritual experience. The theme of reciprocal interpersonal support does not separate out socioeconomic aspects of support. The theme of experiential expertise does not separate out adjustment process and results achieved. Eventually I integrated some of the Dream results into the report on the particular themes under which they fall, to let their dream recommendations stand with the rest of their

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<sup>20</sup> I did not use any qualitative software. I worked with successive Word drafts of codes, themes and participant statements.

testimony. The 3 main themes were phenomena which worked together in participants' lives to create the capacity to live well with diabetes. The overarching theme, which described the whole formed by the interaction of the 3 themes, I named simultaneously embracing diabetes and embracing life. This overarching theme was the title I assigned to the narrative conveyed by participants. It was inspired by Sarah, who in talking about living well with diabetes, said "You really have to take it all in and embrace it."

Embracing has become the foundational metaphor and narrative line of this study. The Results chapter that follows seeks to convey this narrative through reporting on the dialogue among the participants' stories about the manifestation and interaction of each theme in their lives.

A stronger sense of this study as a narrative inquiry came to me as I moved from coding to interpretation of the participants' stories. Narrative inquiry emerged as a qualitative form of research in the early twentieth century and was associated with the Chicago School of Sociology (Clandinin & Connelly, 2000). Narrative inquiry, among other things, explores how storytelling is used by the teller to create meaning out of life experience and to communicate that meaning. Storytelling can be considered a form of knowledge translation of unquantifiable aspects of experience. Recent studies suggest that the mind most easily forms and receives knowledge in story form (Stephens et al., 2010).

Narrative inquiry is useful as a method of data collection with persons whose perspectives are or have been socially marginalized (Chase, 2011; Clandinin & Rosiak, 2007). This study elicited stories from participants traditionally marginalized in a passive sick role (Frank, 1991; Williams, 2005), and these stories gave voice to participants'

active knowledge of living well with diabetes and participants' understanding of the meaning of simultaneously embracing diabetes and life.

## Chapter Four: Results

In taking a narrative approach to analysing the participants' stories, I experienced their unique, localized, and holistic nature and thus their rich divergence. In an effort to convey this rich information, I produced a first draft of the results that was 75 pages in length. I have since placed most of the stories in Appendix K and will provide a more abstract,<sup>21</sup> synthetic version of the Results in this chapter. I should note that names in stories have been changed to protect the confidentiality of the participants.

First, however, I will discuss the rationale of including such a large appendix of stories, which I anticipate the reader may consult while reading this chapter. This provides the reader with the option of doing what Frank (2010) calls thinking “with” the stories. The Appendix also makes more transparent how I have entered into a dialogical story-telling exchange with the participants by the way I have chosen to group and introduce the participant quotes (Frank, 2010). Readers will observe my dialogical exchange and compare it with their own dialogue with the participant stories. Why is this significant?

This thesis is about patient voice, and these are the voices of the participants. Dorothy Smith (1999) notes how abstraction and generalization make invisible the particular, local, holistic realities of communities and individuals and in doing so, disempower those realities. Ironically, institutions that exclude these realities exclude the

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<sup>21</sup> The Results Chapter is extensively footnoted, to document how aspects of the participants' experiential knowledge are referenced in the professional literature on diabetes and self-care promotion. These scientific references address the associations discussed by participants, such as the association between diabetes and menopause. However these references do not use a patient perspective lens and so were not integrated into the Literature Review. The breadth of patient awareness and experience is a valuable resource in professional encounters, as testified to by the pediatrician who says, “I have learned to listen to mothers”.

very ethical energy which they need to function and learn creatively and authentically (Wicks & Reason, 2009).

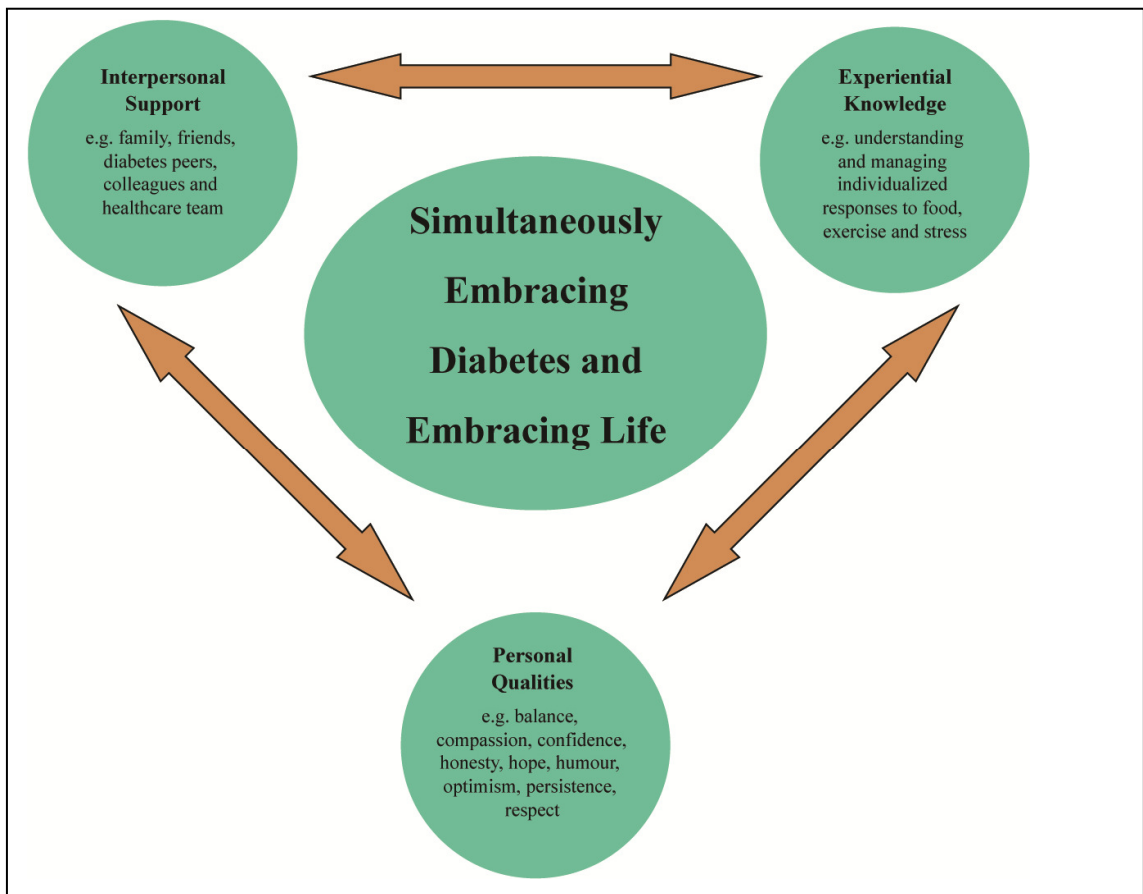
Narrative literature increasingly documents how organizational and personal learning happens most effectively and powerfully through dialogical storytelling (Green & Brock, 2000). Changes in perception and behavior are correlated to immersion in story, whether the learner is a person enhancing self-care or a practitioner enhancing patient-centered practice (Abma et al., 2005, Houston et al., 2011). Such immersion has been demonstrated to reduce cognitive resistance as the listener suspends disbelief while engaging with the story and empathizing with the protagonists (Green, 2004; Green & Carpetner, 2011); Slater & Rounner, 2002). Appreciative Inquiry and other Narrative Methods such as storytelling workshops for health professionals (Abma, 2003) and storytelling by participants in diabetes education workshops (Greenhalgh, 2011) are increasingly used to enhance education, organizational development, and change-management programs. These approaches recognize the complex biographical work involved in learning and change, which storytelling dialogue is uniquely equipped to support.

The participants in this study were well aware of the value of their stories, about positive personal qualities, relationships, and instrumental self-care practices, particularly to peers and practitioners. Direct access to their stories gives the reader an opportunity to think with these stories rather than about them, to resonate with their tone, cadence, drama, and detail. Direct access offers the reader the benefit of enhanced learning and retention associated with information in story form. It is my hope that this appendix can

serve as a repository of these valuable stories, which can be read when relevant and at a convenient time for future readers.

### The Study Model

The study model is a somewhat intuitive construction of a schema that conveys my understanding of major themes in the participants' stories. Given the multiplicity of interpretations possible for any story, or group of stories, I acknowledge the model conveys one of many possible viewpoints, including others I may gain over time. Below is the model in diagram form:



**Figure 3: Results**



## Theme I: Positive Personal Qualities

The participants named or described qualities, values, and personal strengths that were important in the management of self-care, in their reciprocal relationships of support, and in living well. The participants noticed these qualities in themselves and in members of their support networks. The 17 qualities named were acceptance, assertiveness, balance, compassion, confidence, dedication, faith, firm gentleness, gratitude, honesty, hope, humour, persistence, perspective, positivity, respect, and self – acknowledgement.

Appreciative Inquiry supports this attention to qualities and values, seeing them as part of the life force enlivening any successful effort, personal or organizational. Chronic illness expert, Dr Michael Vallis (2009), notes that people are *principle-based* and he sees this ethical base, manifested in positive personal qualities, as critical to long-term motivation for self-care. People will “defend their principles — if health is part of this (set of principles) health behaviours will be protected (p. 13)”.

The qualities named by the participants were ones that infused a moral or spiritual energy into their illness journey narratives. For some, their illness narrative was explicitly a part of their larger spiritual journey narrative.<sup>22</sup> Participants discussed how their spiritual lives guided and sustained their efforts to live well with diabetes. The

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<sup>22</sup> Ferrucci (1982), in *What we may be: Psychological and spiritual growth through Psychosynthesis*, describes exercises to cultivate qualities such as those discussed above as one practice in the journey towards Self-Realization. (Roberto Assagioli, founder of Psychosynthesis, was an Italian psychiatrist and philosopher, and a contemporary of Jung.

following are examples of statements by participants, excerpted from their stories, which support this theme:

Honesty is a key to unraveling the complexities of living with diabetes. Edith said,

*You can fool yourself, but it doesn't last . . . I'll know when I say . . . oh yeah I did do that, and I had that extra and I didn't go for my walk, or I stayed in bed too long . . . For me it's a disease of having to be honest.*

While facing what can be known is important so is being able to live with what is not known and still have faith in the value of self-care. Sarah, who had several chronic conditions, said

*When you have so many different medical conditions, those symptoms can be all symptomatic to any one of them . . . . (Chuckle) So you sort of learn . . . this is possibilities of what's happening . . . so what are we going to do to make you feel better for the day . . . you just do whatever you can to alleviate, one by one.*

Sarah also talked about the importance of humour and dis-identification from her comorbid conditions, in maintaining a balanced perspective, saying, *you sort of put it out there and laugh about it*. Margaret shared how over time she moved from managing her diabetes by sheer determination to *leaving a lot in the Lord's hands*:

*I believe probably about 95 % (of living well with diabetes) has to do with my faith in the Lord . . . I can't say that I take 100% credit for everything, because I do not believe that I deserve that. I believe the Lord deserves it.*

Margaret saw that her faith has changed the way she understood and approached life, and she sensed that she was a channel of practical and spiritual wisdom for others.

*I find that knowing that there is a real God and . . . He has such a much greater love for each and every one of us, that if He can love me that much, then I think I could love Him that much to be able to do His will and to be able to move on with*

*my life and not let it bring me down. Because He wants us to be happy. He doesn't want us to be sad and down. He doesn't want us to be suicidal. He doesn't want us to do anything in any which way or form to harm ourselves. And by having Him in my heart and believing, I believe He has helped me through a great deal . . . it's amazing what you can do when you have that spiritual strength . . . When you give your life to the Lord . . . it certainly changes a lot of ways that you think about things and how you deal with things, right? I sometimes think the Lord is kinda working through me, giving me some answers to give to them [peers] . . . when I'm talking to them. I'm just telling them . . . my [diabetes self-care]) story.*

The participants had a strong awareness of those qualities which were key to living well with diabetes. These qualities had been developed through life experience and were further elicited by the challenge of managing the ups and downs of a chronic condition. These qualities were experienced in reciprocal relationships with those around them, and for some were received as spiritual blessings. The participants' rich resources of personal qualities empowered their application of personal experiential knowledge. This could be seen in stories such as Malcolm's about the sociability of his exercise class (Appendix K, p.173); he emphasized the power of humour in building the kind of connectivity that motivated people to persist in self-care-activities, such as those exercise classes. The participants were keenly aware of the contribution of connection and interpersonal support to their efforts to balance and integrate diabetes management with holistic well-being, which will be addressed in the next theme.

During the study interview participants were asked to imagine what would enhance living well with diabetes, in relation to emerging themes. While many associated living well with diabetes with being on a journey of personal growth and spiritual development, none talked about what might enhance that journey going forward. It

should be noted that as the interviewer I did not raise the question<sup>23</sup> of what would help enhance the expression of qualities participants name as important to diabetes self-care success and living a good life.

## **Theme II: Reciprocal Interpersonal Support**

Reciprocal interpersonal support is the theme that captures participants' views on formative relationships of reciprocal support. One of the interview probes that elicited this material is, "Are there people who have helped you in this success?" Participants named family, neighbours and friends, diabetes peers and support groups, members of their health teams, and workmates, as sources of support. Some emphasized the importance of supporting themselves, and this notion is explored under the theme of experiential expertise. A few participants highlighted support received by contrasting it with the experiences of lack of support or unhelpful support. This led them to comment on preferred, more effective forms of support. Finally, a number of participants talked about the spiritual support on which they relied.

Participants discussed how they supported others by sharing their experiential expertise in maintaining health and well-being. These others included family, friends, colleagues, and diabetes peers. Participants desired a reciprocal relationship with members of their healthcare team, in which they could contribute their experiential knowledge, insight, and humanity. Some were interested in supporting diabetes

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<sup>23</sup> The role of healthcare providers in supporting the spiritual dimension of persons experience with illness is being investigated (Carr, 2008). The ill person's interest in this kind of support is well documented (Frank, 2004).

healthcare policy and program development by sharing their understanding of the needs of persons managing this chronic condition.<sup>24</sup>

Participants' stories of interpersonal support assist in understanding the complex interactive flow of positive influences that shape successful diabetes self-management and the ability to live well with a chronic condition. The following are examples of statements by participants that support this theme. Ruth described how she enlisted the support of her sister in a strategy to eat healthier by eating together. Ruth was aware of the reciprocal support involved in this arrangement.

*Living alone, if I cook a recipe I have to eat it all week. My sister still works . . . I'm retired and so I said to her, "Are you interested in me cooking supper for both of us and then you could throw a few groceries into the pot once a week? . . . What I'm interested in cooking is all healthy meals so that we're getting our vegetables" . . . She was willing to go along with that. (Sister) works long hours and . . . was just coming home and grabbing a sandwich and never feeling like cooking a meal for herself . . . She says it's just been wonderful . . . to come home and have . . . a healthy meal sitting there waiting . . . It has worked out very well for both of us.*

Andrew talked about management support for timely eating in his work place. He notes his manager's appreciation of the way that Andrew had helped to educate the workplace about blood sugar issues by self-disclosing his experiential expertise.

*We have a new sales manager . . . a very intelligent, young man . . . At the sales meeting he came over by my chair and said "Well it's 5 to 12, Andrew has got to eat so let's break the meeting up." . . . I . . . looked at him and he said "That's a great thing that you've done." Because we had a safety talk about diabetic reactions and things like that and he said "I'm teasing you but it's a good thing for everybody to know.*

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<sup>24</sup> Participant interest in sharing experiential knowledge points to the role patients can play in knowledge translation. They have instrumental and tacit contextual forms of knowledge to contribute to knowledge exchange efforts (Campbell, 2010).

Josephine explained how exchange in a support group served a knowledge translation function and created friendships.<sup>25</sup>

*We . . . talked about what people had to do, or . . . should do and it worked very well, as far as making people feel more comfortable with the information that they were given . . . information that they didn't understand . . . The group could say, "Well, I didn't understand that, what is it?" "Say it in English" . . . They're being sarcastic . . . People that have diabetes can explain it to you much better than the health professionals. They come right down to the nitty gritty . . . They feel less intimidated by somebody that ends up being your friend . . . you're less self-conscious.*

Ruth described a positive experience with a dietician that was a turning point in her ability to practice healthy eating. Her reference to previous experiences of professional lack of respect for patient autonomy highlighted the importance of a person-centered collaborative approach.<sup>26</sup> Such an approach supported resiliency in adapting to the demands of self-care.<sup>27</sup> Ruth had asked to be referred to the dietician for cholesterol management. The dietician suggested considering the diabetes diet that at first Ruth resisted but then became open to trying. Ruth said,

*I walked in there with an attitude because I had been to 2 dieticians before that who both had been very controlling and I really couldn't work with them . . . (One) was a young woman who, when she found out I was taking vitamins, said in this voice . . . "You're taking Vitamin C, well, I'll allow you to continue that for*

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<sup>25</sup> Josephine's support group members are women. Keane et al. (2005) explored the usefulness of women-only diabetes support groups in facilitating more open exchange around gender sensitive topics such as appearance, weight, the diabetes-associated risk of yeast infections and related bladder inflammation, incontinence, and dyspareunia. They, at the same time, explore the usefulness of a specialized women's support group education module, using Kasl's (1992) addiction empowerment model. Keane et al. draw on Kasl's work because they see the similarities between the challenges of managing addiction and managing chronic conditions.

<sup>26</sup> AI theorist Hammond (2005) discusses the positive aspects of 'naming elephants' which creates space for naming what is preferred and what values can be enhanced.

<sup>27</sup> Kralik et al. (2006) note, "Interventions that may foster a sense of coherence, collaboration, competence and confidence are important to the process of developing resilience (p.188)."

*now." . . . She [latest dietician consulted] was so friendly and treated people with so much respect and honor . . . even though I was acting very rude and had this big attitude, she just kept coming back in this very respectful way and saying that's okay and going on from there . . . By the time I went back to the next meeting I apologized to her . . . I said . . . " If you don't mind going over, helping me to choose a diabetic diet . . . I'm ready to give it a try." And so we did and that was the start of me being able to do it [healthy eating]. Because there was nothing that she said I couldn't have. It was just how much of it and how often . . . how to work with my body in a respectful way.*

While participants were committed to being constructive players on the health care team, their support of professionals was perhaps mostly silent, expressed for instance in an internal compassionate awareness of professional stress.<sup>28</sup> Sarah said,

*[Family doctors] They're just time framing. There's just so much being pushed into a day now and they're probably stressed to the max. I mean they not only deal with patients in the office. They've got hospital visits or whatever else they have to do plus their ongoing studies . . . But it's a sin . . . Then again, it's just lifestyle and it makes you wonder . . . how did we get to this stage in life where everything's . . . such a rush. What happened to the good old days?*

Participants acknowledged that support received from many different sources was critical to their self-management success. The meaning of their self-care experience was broadened, and their motivation to continue was reinforced, as they were able to share their hard won awareness, experience, and knowledge with family, their social and work circles, peers, and health services program and policy planning activities.

The experiences of interpersonal support reported by participants are rich in particularities and nuance. These experiences manifested personal qualities such as hope, respect, and compassion. In discussing support received and given, participants continuously made reference to the sharing and cultivation of experiential expertise. For

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<sup>28</sup> Carr (2011) notes that healthcare providers who practice an *ethic of care* recognize their intersubjectivity and shared vulnerability with those they care for, and so are open to receiving expressions of care and connection from the cared for.

instance, Ruth in describing interactions with a helpful dietician spoke not only about the respectful quality of the interaction but also about how the dietician encouraged her in the cultivation of self-knowledge of her bodily preferences. It is this individualized experiential expertise which will be presented in the next section.

When asked about what might be enhanced in their experience of reciprocal support, participants talked about visions of reciprocal support at a societal level. They expressed interest in contributing their experiential perspectives, observations, and creative thinking to health care policy, planning, and prioritizing. A number of participants addressed the need for government financial support for persons with diabetes. Josephine shared her support group's dream of a community-based diabetes prevention and maintenance centre.<sup>29</sup> She said,

*That's one of the things we've been trying to do in our diabetic group, is to get out into the community. Well informing people is one thing, but to have an actual place where you could go and get . . . some support . . . We would need financial support . . . and . . . some help from professionals to set everything up and . . . make sure everything is running properly. But it would be a responsibility from the people that were using the facility . . . I think that's what's happened with a lot of our government programs is the responsibility isn't given back to the community. It's run by people that really don't understand the community . . . That's what I'd like to see . . . along with the information . . . diabetes, in prevention, and if not, in maintenance . . . Then you could get the children interested . . . If you had a program for the kids, that they, instead of just being there with a sitter, there could be someone training them, or helping them with learning things that they could do to avoid.*

Participants' dreams for the future seemed most articulated in terms of peer and policy support.

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<sup>29</sup> Josephine's reference to children's health promotion programs as part of the participants' vision of a community-based diabetes prevention centre points to the possibility of collaboration with health promoting school initiatives, committed to partnering with parents and community (Morrison & Kirby, 2010).



### **Theme III: Experiential Expertise**

Participants had a clear understanding of the importance, and the challenges, of healthy living in the successful management of the stages of diabetes. They also recognized the commonalities in self-care practices for various chronic conditions. The experiential expertise described by the participants covered five areas: knowledge sourcing, healthy eating, exercise, treatment management, and stress management. As the participants discussed their application of many of the standard recommendations for diabetes self-care, they conveyed these experiences in plain language and with personal testimony, both of which serve to make these diabetes protocols accessible to their peers and to lay readers. Participants also discussed knowledge and practices outside the conventional diabetes self-management education programs.

#### ***Participants' knowledge sources.***

Participants learned from health professionals. They particularly credited interactions with diabetes educators, dietitians, and chronic care team specialists as providing relevant, condition-specific, up-to-date counsel. Participants acquired knowledge through reading diabetes and popular press publications. They did Internet searches and used patient e-forums. Participants learned from peers and facilitators in peer support and lay education groups. Participants paid attention to body responses and experimented with lifestyle and medication to find what worked for their unique physiologies and circumstances. Some participants acknowledged their intuition and spiritual practices as sources of knowing.

Participants were discerning in their use of information, understanding the need to cross-reference sources and to adapt information to their individual circumstances. They

emphasized the challenge of puzzling out, integrating, and prioritizing information relevant to managing co-morbid conditions. Participants' experiential expertise consisted of general information they found personally relevant, combined with personal observation and experimentation. They articulated a sophisticated awareness and complex practice of what can be called the mechanics of diabetes management. The following are examples of statements by participants that support this theme.<sup>30</sup>

Martin suggested that practicing body observation and communication was like learning another language.

*Be aware of it [body], and you have to learn how it talks to you. You have to learn a little different language from the ordinary . . . Dealing with diabetes is much like being a linguist . . . you have to listen to what your body is saying to you. And if you can't interpret it, then it's just a bunch of mumbo jumbo and you go along your merry way and it'll be talking but the only trouble is you're saying well that's not talking to me.*

George used the metaphor of a radio channel to convey the importance of tuning into body feedback in sustaining self-management. *Now you wake up thinking, Okay, I have to check my blood sugar . . . You're on another frequency. You've switched radio channels.*

Several participants talked about accessing information in more right brain ways. Ruth acknowledged the informing role of her dreams.

*You're just plodding along, one step at a time, but looking for help and direction and it's given to you. This is crazy, but I've got help and direction from my dreams for the last 30 years and sometimes when I wake up in the morning, something shifts in my head and so I go and I put it in the computer and see what comes of it . . . All things that we dream come in the honor of our wellness and wholeness . . . Because I'm so focused on trying to work with my physical body, I think that's where these things are coming from . . . One of the things that I woke up to one*

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<sup>30</sup> Hernandez (1995) discusses the use of body cues by persons with diabetes, and the importance of encouraging this practice given that personal cues may be different from classical textbook symptoms.

*morning was mindful eating . . . I . . . typed it into the computer and then was amazed to find there were all these sites with just that. It led me to all these sites with . . . different things that I could learn from . . . That's when I picked out a few simple little things and tried them in my own life.*

Participants were proactive and diversified in their approach to knowledge sources. They viewed professional knowledge and the experience of themselves and their peers as complementary.

Participants talked about a future vision of enhanced information accessibility through community-based diabetes drop-in centres, hospitals, and public education campaigns. Participants emphasized the importance of enhanced recognition of peer support groups as a source of practical information and knowledge translation of professional knowledge.

### ***Healthy eating***

Healthy eating is central to self-management, and every participant spoke about growing experiential expertise in this area. Participants discussed the following aspects of eating healthy: positivity and enjoyment, timing to avoid *hypos* and an insatiable hunger, the importance of snacks, portion control and weight control, moderate enjoyment of traditional treats and changing taste buds, dealing with food cravings, and a diabetes-friendly diet. They also discussed the skills and challenges of accessing healthy food. Participants had learned how to locate and choose healthy foods when shopping, how to plan by preparing healthy food ahead for days when they had limited time or energy for cooking, how to locate healthy food when eating out, and how to access fruits, vegetables, and healthy protein when on a restricted budget. One participant referred to the challenges presented by conflicting views on the health value of carbohydrates versus

proteins and fats, and linked it to issues of accessibility to healthy food associated with the unhealthy state of the modern food system. The following are examples of statements by participants that support this theme. Genevieve included a protein in her snack as an effective way to ward off hunger between meals,

*If I eat an apple and I don't have any protein, within 25 minutes, I've timed this, my stomach is ravenous . . . If I put . . . a 1 inch cube of cheese, it's fine . . . (or) any of the nuts . . . You can eat an apple and then half an hour later you're going to want something else . . . an apple or a pear . . . If you're eating an apple . . . a healthy carbohydrate, but even with the peeling and it being a hard apple, it still creates a natural sugar in your body which will . . . in my case, will still spike your insulin, your sugars will go up a bit . . . the protein prevents that.*

Ruth described a mindful eating exercise that helped shift her eating habits,<sup>31</sup>

*I didn't eat until I felt hungry and then I was fully aware of what I chose to . . . put on my plate and when the hunger was satisfied did I . . . stop . . . If I continued to eat, why did I continue . . . I did that for a . . . week . . . never criticizing myself . . . just observing myself . . . becoming fully aware of . . . my patterns . . . and habits . . . Then I found it easier to know how to work with myself.*

Jacob described how he came to adopt a low carbohydrate diet based on exchanges with peers, through his reading on the issue, and through experimentation. Jacob was motivated by the desire to decrease the risk of carrying extra weight and by his health concerns about the quality and quantity of carbohydrates in the modern Western diet.<sup>32</sup>

*We've had . . . discussions on diabetes forums and other forums I belong to about low carbohydrate diets versus high carbohydrate diets . . . on what the correct diet is for a diabetic, whether you're type 2 or type 1, especially one that wants to lose weight or . . . keep off weight . . . Insulin . . . [is] known to have [an impact on] weight . . . After several months of discussion and listening . . . after reading a*

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<sup>31</sup> Framson, C. et al. (2009) developed and validated a mindful eating scale for investigative purposes, indicating there is applied research interest in this nontraditional approach to weight control and healthy eating.

<sup>32</sup> Dr Wortman, a senior advisor with Health Canada, has developed a diabetes-friendly diet based on the traditional Haida diet, which is low carb, high protein and fat. Its apparent effectiveness is being investigated (Accurso et al., 2008); <http://www.cbc.ca/thelens/bigfatdiet/wortman.html>).

*book called “In Defense of Food” by Michael Pollan . . . and some excerpts of another book . . . “Good Calories, Bad Calories” by Gary Taubes and [after I] listened to a number of videos and online radio tapes . . . I’ve become convinced that high carbohydrates, especially high refined carbohydrates, in our diets, are probably the root of the obesity crisis we’re in and the diabetes crisis and heart disease and cancer. I can’t prove that scientifically, but the correlations are so high that it’s not easily discounted . . . I’ve . . . followed a number of people who have dropped the carbohydrates and immediately started dropping weight. So I decided to do the same thing . . . I know carrying excess weight is not good for me in the long run and I’m not clear either that lowering carbohydrates would be good for me in the long run, but I know that carrying the weight won’t be. So I’ve decided to . . . take the plunge . . . In the last 5 weeks I’ve lost just about 10 pounds. . . I’m primarily focusing not . . . just on losing weight but making sure my sugars stay under control . . . I’m feeling fuller than before, I’ve feeling more vibrant than before, and I’m losing weight.*

Jacob described his effort to find healthy low carbohydrate restaurant food. He has learned to ask about the content of dishes. This helped him to see the extent to which the modern North American diet is based on high carbohydrate foods.

*It’s been a challenge finding suitable meals. I’ve been working downtown, and once in awhile I will eat my lunch out. There’s about 10 eating establishments that I walk b y . . . I’ve tried to find low carbohydrate meals . . . 20 or 30 grams of carbohydrates . . . it’s almost impossible to find . . . One place . . . sells salad, but you have to request no pasta and their soups aren’t too bad but they usually have about 20 grams of carbs in a bowl of soup . . . I ask them all the time, “What’s in this food? Are there any carbohydrates?” Because they’re not easy to identify, if it’s home made. Besides that one place, I have not found any low carbohydrate meal, from pizza to sandwiches to pasta . . . That made me realize . . . our whole society is geared toward high carbohydrate foods . . . One suggestion by some scientists . . . is that many people are very sensitive to carbohydrates.*

The participants had considerable competence and confidence in managing the complex task of eating healthy and maintaining blood sugar control. Their interview responses conveyed how in figuring things out for themselves they combined information on physiology, psychology, and the politics of food, with personal experience. They did so while facing challenges such as the availability and affordability of healthy food and

debates about what is the best diet for diabetes control. Participants recognized how other healthy living practices supported and reinforced the positive effects of healthy eating.

Participants envisioned future enhanced control of their eating habits, for some particularly in the area of portion size. For several, finances were an issue. An enhanced future would include public financial support for a diabetes friendly diet.<sup>33</sup> It would include enhanced access to cleaner, healthier foods. Next are presented the participants' experiences with exercise.

### *Exercise*

Participants listed a wide range of exercise-related benefits they noticed. They mentioned the significant lifestyle changes that were involved in integrating exercise into their lives and talked about the importance of taking a step-by-step approach that respected any limits they or their exercise mates had. Participants acknowledged the self-reinforcing nature of exercise and recognized factors that supported their physical activity, such as structured programs and having fun. They mentioned engaging in forms of exercise ranging from walking to playing a musical instrument. The following are examples of statements by participants that support this theme. Josephine realized that she needed to figure out how more general exercise information applied to her particular situation. She needed to listen to her body in setting personal exercise goals, particularly in relation to

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<sup>33</sup> McIntyre et al. (2002), in *Food insecurity of low-income lone mothers and their children in Atlantic Canada*, note that their research participants' diets improved with the infusion of a small amount of cash.

her co-morbid conditions or in relation to other self-care activities such as diabetes-

friendly eating. Josephine learned that she could build up her activity level over time.

*You can't just say everybody exercises a certain way . . . If you're talking about diabetes, there might be a time where you have to eat something in particular in order to feel better. You might not feel right so you can't exercise as much as somebody else, and the same thing goes for a heart condition . . . I go on the treadmill once or twice a week and I do not do the uphill. That's just an example of what I don't do . . . You do have to pay attention to all the information, but make sure it pertains to you . . . When I started at the Y . . . in something called cardiac maintenance program . . . my brain was telling me, this isn't enough exercise. That's not good enough . . . I would do extra . . . and I was too beat. It was too much for me. The cardiac maintenance . . . program . . . is perfect for me . . . Now I've worked myself into doing more but at first when I started, my brain told me . . . I have to keep exercising . . . without exercising for 20 years before that besides walking. That's kind of stupid; you can't just all of a sudden jump at doing things . . . that's when I realized . . . I have to work it to my own liking.*

Jacob described how the refined blood sugar control method he has developed, using diet and insulin, enabled him to play sports without risking a hypoglycemic incident and suffering the associated anxiety.

*Previously say if I wanted to go play a round of golf, I had no idea what my sugars looked like. I knew they were going to go down but then for the next day or two I didn't know if they were going to bottom out in the middle of the night or be really high in the morning . . . It was just a crap shoot . . . Now if I go play a round of golf, or play some hockey, I know pretty much exactly what they're going to do and treat it, monitor it and spend maybe 2 minutes worrying about a game of hockey, where before I would've spent a day and a half worrying about it because of the after effects.*

Genevieve talked about the importance of outdoor activity and exposure to sunlight in keeping in touch with life beyond diabetes and other chronic conditions.<sup>34</sup>

*Get out and don't stay in the house. I really feel for people that do not have an opportunity to get outside, even if it's just out to sit in their yard, or on a deck or*

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<sup>34</sup> Penckofer et al. (2008) note that persons with diabetes have lower serum concentrations of vitamin D; they suggest a regimen that includes exposure to sunlight, foods with vitamin D, and a supplement as necessary.

*anywhere, because if you're not getting sunshine and you're not seeing another part . . . other life, you can become very . . . self absorbed . . . Everything is much more dramatic if you're not looking outside yourself . . . diabetes becomes horrible . . . You can become down very easily without doing that.*

Participants understood clearly the value of exercise in diabetes management and overall health and well-being. They developed experiential knowledge of how to adapt general exercise protocols to their unique circumstances and were aware of what helped them to sustain their practice. They saw how exercise supported, and was supported by, other self-care activities such as treatment management, which is discussed in the next section.

Participants' dreams of enhanced exercise possibilities were focused on increased accessibility. Participants with restricted finances said they would like to use gym facilities if they could be made financially and physically available.

### ***Treatment management.***

Participants discussed treatment of diabetes symptoms and those of co-morbid conditions. The participants combined attention to conventional protocols with experiential self-care expertise developed over time as they responded to their particular circumstances and disease progression. They discussed their experience in dealing with blood sugar testing; oral medication; insulin; and co-morbid conditions, such as pain, heat intolerance, poor sleep, and menopause symptoms. The following are examples of statements by participants that support this theme. Margaret talked about the association she saw between following a diabetes diet and reduced medication use. She noted two benefits of using reduced medication: she had a positive sense of accomplishment and



efficacy, and she delayed the point at which her body would become less responsive to the medication, requiring a switch to insulin.

*Maintaining my diet . . . meant that I can take less medications . . . Before I was on 3 Medforman a day, 500 mg. and I was on 2 Glybride pills a day, which was 25 mg . . . Now I still take the 3 Medforman because that's not really a blood sugar reducing, it's . . . to help your pancreas . . . produce a little bit of insulin . . . The Glybride is the one that drops the sugar. Now I am down to a half a pill in the morning and a half a pill at supper time . . . I have my 3 month blood checks and every time they come back I'm within 5.2-6.2 . . . I . . . contribute that all to the diet . . . watching my carbs.*

*As far as your mental status, it . . . makes you feel good to know that you're doing it, you're getting yourself leveled out without the use of so much medication. The other aspect of it is, it's like any kind of medication, after awhile your body gets immune to it, and then that's when your medications would have to be increased . . . If you can control one aspect of a diet and be able to lower that medication . . . then this medication is going to work for you a lot longer, before you have to start taking the needle . . . Because once you take your medication for so long and you get immune to it, then you're on to the insulin.*

Participants managed symptoms that may be associated with diabetes and other chronic illnesses (such as chronic pain) or aging processes (such as menopause).<sup>35</sup> Management of these symptoms is important to living well with diabetes, for it supports an enhanced quality of life which can increase levels of energy and interest available for self-care.

Sarah protected her mobility by prioritizing foot care. *I am very adamant about inspecting the feet . . . nonslip footwear . . . seeing a podiatrist . . . I've noticed things are taking longer to heal than . . . prior to being a diabetic.* Sarah also managed heat intolerance.<sup>36</sup> *I have a fan on me even in my room all night long.* Genevieve found that following a routine helped to control her fatigue level, which in turn helped her to stay

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<sup>35</sup> Wu et al. (2001) note the association between impaired glucose tolerance and menopause not managed with hormone replacement therapy.

<sup>36</sup> Boulton et al. (2005) recommend, upon diabetes diagnosis, screening for autonomic neuropathy symptoms, which include heat intolerance.

alert and proactive.<sup>37</sup> She was aware that, *when you're tired you just don't . . . sometimes make the right choices.*

Participants with comorbid conditions referred to the challenging complexity of self-management.<sup>38</sup> Sarah dealt with the uncertainties in managing co-morbid conditions by accepting ambiguity and being proactive in self-care.

*So you can't just look at it and go "Well that's my diabetes, today," because that's not necessarily what it's going to be. (Chuckle) So you sort of learn to okay, well this is possibilities of what's happening or what it could be, so what are we going to do to make you feel better for the day, sort of thing. So you just do whatever you can to alleviate, one by one, you know.*

Edith combined natural observing and reasoning abilities with information from her training, to determine that stress is the aggravating factor in her blood sugar imbalance; she then acted to reduce her stress. Her diabetes peer leader trainer, Willow, a fellow study participant, described her observation of Edith's investigative work.

[An example of lay detective work is] *understanding the tests and knowing . . . if their [trainees] sugars are showing signs of increasing . . . being able to . . . problem solve that, and identify what the causation might be . . . in a very methodical way . . . To me . . . it's quite surprising because a lot of people really aren't trained to think that way . . . One of the ladies has been experiencing . . . increased sugars . . . She's [saying] . . . my nutrition hasn't changed. I do very well on the nutrition and I'm taking my medications and they should be working . . . She went through this whole process of elimination and trying to increase exercise and did that help her sugars . . . In the end she discovered that her life was somewhat out of balance and she was experiencing too much stress . . . For her the way to manage that, given that she could identify what the stress was, was to remove herself from that situation for a period of time and try to get her sugars under control, and work on future strategies so that when she's back in the*

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<sup>37</sup> Khutson & Van Cauter (2008) note sleep loss reduces glucose control in persons with diabetes. Sleep disturbances may be a symptom of diabetes. Prioritizing adequate sleep and avoiding a chronic sleep debt is recommended.

<sup>38</sup> Lindsay (2009) notes the stress of the competing demands for care of co-morbid conditions; persons prioritize their conditions according to factors of a) unpredictability b) inability to control with medication and c) setting off other health problems.

*situation she might be able to better manage the stress. And I'm like, Wow, that's pretty impressive . . . She's a very knowledgeable individual . . . very aware and I thought that's great . . . that she has had signs . . . from her body that something's happening here . . . She's been able to step back and sort that out for herself. Apparently . . . that's true with stress; it can really increase your blood sugars and . . . disrupt regulation.*

Participants understood and acted on the need to control blood sugar levels through testing, medication, treatment of other conditions, and healthy living. They recognized the importance of following medication protocols and were committed to sustaining their self-treatment over time. They acknowledged the complexity and stress involved in living with diabetes and discussed how they managed life stress, as presented in the next section.

Participants acknowledged the universal desire for a cure while noting that treatment options were continually improving. They expressed a desire for professionals to have more training in the physiology, psychology, and treatment of diabetes. Some participants said they would prefer that professionals be more open to an integrative approach that combines conventional and complementary therapies. Participants desired a healthcare system with an enhanced patient-centered approach. This approach would include attention to the social determinants of health and government investment in meeting those associated needs.

### ***Stress management***

Stress management is a theme that is related to every aspect of the participants' lives and is a part of all self-care, from healthy eating to treatment management. In order to grasp this phenomenon, for the purposes of investigating it in the participants' stories, I returned to the literature. I have summarized and footnoted this literature, before

presenting my Results, in order to convey the breadth of the stressors the participants were aware of and were addressing.

Stress is increasingly recognized as a risk factor in disease.<sup>39</sup> *Stressors* is a large category that can encompass internal factors such as beliefs and attitudes, and external factors: a) major life events, b) chronic stress related to social determinants of health (e.g., finances, food insecurity, work environment, social environment, social support, gender role/caregiver position, health services), c) hassles of daily life, d) diabetes distress, and e) co-morbid conditions, including depression.<sup>40</sup> Stress management is increasingly recognized as a critical component of diabetes management; this is because stress directly impacts blood sugar levels and indirectly can interfere with the ability to self-manage.<sup>41</sup> Internal and external factors contribute to effective stress management. Internal factors identified as helpful include such phenomena as health beliefs, autonomy/internal locus of control, self-efficacy, goal-setting, motivation, coping skills, problem-solving skills, expressive skills, resiliency, personal qualities and spirituality. External factors include such phenomena as support, assistance, information and skills training, and access to community and institutional resources. Participants discussed what they knew about the stresses of living with diabetes, as well as other stressors, and named the internal and external resources they drew on to manage stressors. They also discussed

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<sup>39</sup> A cumulative burden of repetitive or chronic environmental stress leads to a deregulation of the body's stress system, which in turn contributes to the development of a variety of chronic conditions including diabetes Vanltallie (2002).

<sup>40</sup> Kaissi & Parchman (2009) discuss social determinants of health for persons with diabetes and in particular how the way a health care system is organized can be a stressful barrier to self-care efforts.

<sup>41</sup> Lloyd et al. (2005) explore the pathway of stressors, to diabetes, through physiological mechanisms (involving the nervous, endocrine and immune systems) and behavior (lifestyle and self-care efficacy levels). Chawla et al. (2009) report that the PAID (problem areas in diabetes) instrument has been used to show a link between diabetes distress and poor self-care. Carmen et al (2008) document a connection between positive coping styles, well-being, and self-care.

what they knew about helping others deal with stressors and passing on their stress management knowledge. I should note that, given the comprehensiveness of this self-care activity, this section is much longer than the previous sections on aspects of participants' experiential expertise.

### *Awareness of stress as a risk factor motivates self-care*

Participants described the value of learning about stress as a risk factor for diabetes. This often prompted them to be pro-active in reducing stress and including more relaxation activities in their daily lives.

### *Diagnosis stress and what helps*

Many participants talked about the traumatic shock of diagnosis and what helped or could help to mitigate this stress.<sup>42</sup> Immediate information about the condition and its treatability, particularly in the case of the double shock of a health crisis and diagnosis, was critical. They observed that it was more likely that persons would be able to absorb reassuring information when professionals are immediately available to address potential fears. At the same time participants spoke of the need to pace diabetes information delivery, for the shock made it difficult for them to absorb it. Some preferred to find and absorb more technical information themselves, at their own pace. Persons new to diabetes can be intimidated by the complexity of self-care work.<sup>43</sup> Several participants, including

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<sup>42</sup> Diagnosis trauma is a concept introduced to me by Dr. Carol Look (author and clinical social worker with a PHD in clinical hypnotherapy), in a 2010 audio interview she gave, which was web broadcast at [eftworld.ning.com/](http://eftworld.ning.com/).

<sup>43</sup> Adolfsson et al. (2008) present evidence that an empowerment approach to diabetes education, involving horizontal relationships and participatory learning, increases participants' self-management knowledge and confidence. Rygg et al. (2010) confirm that persons choose to attend diabetes education sessions because

Ron, talked about coming to understand diabetes care as accessible to lay persons. *The bottom line is when it comes down, it's common sense.*

Participants described how peers can mitigate the shock of the newly diagnosed by reassuring them that: it is not immediately life threatening, there are things they can do to be more comfortable and relaxed with their new condition, the self-care tasks involved are not that difficult despite the confusion newly diagnosed persons feel in the face of a flood of physiological information, and self-management mistakes are remediable. One participant noted the value of proactively circulating self-care success stories in communities to promote an awareness of the hope that lies in the efficacy of self-care, and to preempt the intensity of diagnosis fears.

Recognizing the benefits, the silver lining in the cloud of any challenging health event, was an effective stress management response exhibited by many of the participants.<sup>44</sup> The scary experience of diagnosis was described as a wake-up call. This shock/wake-up call was intensified when participants knew family members or neighbours who suffered from diabetes complications. Many participants described making a commitment to their health and life following this wake-up call.<sup>45</sup> They conveyed this commitment through words such as determination, motivation, taking control and being proactive, picking oneself up by the boot strings, and being stubborn and tenacious.

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insufficient information about diabetes led to practical problems and emotional insecurity: these “originated from lack of, or contradictory, information and from lack of contact with other patients with diabetes. This affected the patients’ everyday lives in important areas such as diet, medication, social settings, and lifestyle changes (p.788)”.

<sup>44</sup> Wolever et al. (2010) describe the use of the Benefit-finding Scale as part of an integrative health coaching intervention with persons with type 2 diabetes.

<sup>45</sup> Paterson & Sloan (1994) highlight the initial decision to take and maintain control as the foundation step towards experiential expertise.

Some participants described re-experiencing diagnosis shock with each new progression of their condition. Some acknowledged fear, embarrassment, and a distressing sense of responsibility for causing/aggravating their condition, and they valued professionals who encouraged a more balanced perspective in this regard. Having their health beliefs<sup>46</sup> and knowledge about diabetes updated by both professionals and peers significantly reduced the stress of diagnosis and advancing symptoms.

A couple of participants acknowledged the stress of feeling the stigma of a chronic illness and spoke of the value of talking with others to break their sense of isolation and to diminish negative feelings. They referred to the lingering myths and misinformation around diabetes and emphasized the importance of exchanging emotional support and advice with peers. One participant saw his shame as having roots in social and professional influences<sup>47</sup>; the message he had received was that diabetes was his fault. As his understanding of diabetes grew, he became more open in discussing his condition, breaking his social isolation and feeling better and safer. One participant acknowledged a general tendency in her life to hide from others, and she recognized that developing relationships with people was a necessary part of developing a healthy relationship with food. The participant realized that responding proactively to the shock and shame of a diabetes diagnosis by reaching out to others was part of the larger path of personal growth to which she was committed.

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<sup>46</sup> Brown et al. (2007) document a health beliefs intervention that increases effective self-management and healthier HbA1c levels.

<sup>47</sup> Myers (2004) discusses illness stigma and deciding to *come out*. The strength of an illness stigma is tied to the severity of the illness and whether it is seen as behaviourally caused. *Coming out* has social and psychological risks and benefits to be weighed.

### *Steps or stages in adopting self-management of diabetes*

Participants identified steps they and others experienced as they moved from shock to awareness, from acceptance to action, in responding to a diagnosis or a progression in their condition.<sup>48</sup> In doing so they created a narrative, making meaning as a way to address the stress of losing their pre-diabetic way of life, as will be addressed in the Discussion chapter. One participant, Martin, named three internal stages in the process of embracing diabetes and resources needed to do so: awareness, acceptance, and adjustment. He acknowledged that will power (choosing diabetes self-care actions) and personal desires did not always align well for himself and his peers, and that sometimes seeing one's reality did not translate into *waking up* and connecting the present condition with the risk of future disability.

Martin acknowledged the difficulty and the importance of accepting the reality of any chronic disease. Acceptance could allow an acknowledgement that changes were needed; these required choice-making by the person affected. Martin emphasized that the ability to face reality is critical to the ability to make healthy choices related to long-term health goals. Martin acknowledged the profound inner change that is involved in embracing chronic illness, a change that takes time, that involves dealing with denial and

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<sup>48</sup> Participant's reflections on the process of adopting self-care resonate with the Stages of Change or Transtheoretical model which proposes the following stages: precontemplation, contemplation, preparation, action, and maintenance. Transtheoretical model authors Prochaska et al. (1993; 1994) also identify 5 experiential processes of change: consciousness raising, emotional arousal, social reappraisal, environmental opportunities, self reappraisal, and 5 behavioural processes of change: self-reevaluation stimulus control, helping relationships, counter-conditioning, reinforcement management, and self-liberation. Participants can experience separate processes of change for each self-management task (Parchman et al., 2003).



the stress of grieving one's fate, a grieving journey that is easier for some.<sup>49</sup>

Other participants named some of these inner changes. Sarah talked about the importance of understanding that denial will not halt the progression of disease and that every aspect of life now involves consideration of self-care issues. She recognized that past experience with other chronic conditions enabled her to grasp and accept the chronic nature of diabetes. Sarah emphasized the power of whole-hearted commitment to diabetes self-care to control diabetes progression.

Ron spoke to the importance of consciously choosing what he wanted, taking control, and finding out he could practice secondary prevention. Ron discontinued using insulin, having improved his condition through diet and exercise. He acknowledged ambivalence around taking his prescribed oral medication and periodically checked with his doctor about the possibility of discontinuing; he was constantly challenged with re-assessing to what extent his diabetes could be managed through healthy living. Martin offered a cautionary note about keeping in mind the individuality of each person's condition and stage of disease and the need for an individually tailored response. This awareness of individuality, by self and others, can mitigate the stress of being a *square peg in a round hole*. Ron recognized the difference between disease control and cure, and he acknowledged the ongoing effort needed to maintain chosen self-care practices. George noted the motivational importance of understanding that prioritizing self-care was what made it possible to continue to enjoy well-being in life.

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<sup>49</sup> Kirkham (2003) discusses the stages of grief that start at diabetes diagnosis and cycle towards acceptance.

Andrew said he dealt with the fearful transition to insulin treatment by immediately consulting with a diabetes educator and choosing not to avoid unpleasant aspects of his regimen (injections). Andrew dealt with the stress of his resistance to taking insulin by comparing himself to those who are worse off, feeling gratitude for his own quality of life, having faith in God's power to support him, and affirming the importance of getting over feelings of guilt.<sup>50</sup>

Participants said that diabetes distress, the stress of having an incurable deteriorating condition, was greatly relieved as they experienced success in managing their conditions. Margaret noted how her blood sugar control enabled her to move forward with a positive future outlook.

### ***Managing the stress of adjusting to life with diabetes***

Participants recognized that the life skills and life philosophy developed over a lifetime were invaluable in coping with the demands of the lifestyle change entailed in incorporating diabetes self-care. Malcolm had developed stress management skills during his working life which he applied to the new challenge of diabetes self-management: accepting change, feeling confident and willing to learn new things and to work with new people, interacting with people in a courteous, reasonable, firm way, and being flexible and adaptable. Sarah echoed the importance of continuous applied learning, in avoiding becoming overwhelmed or depressed. Genevieve had learned to relieve her relationship

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<sup>50</sup> Rogers et al. (2009) discuss how persons with chronic conditions often use downward comparisons because feeling better off than others can reduce feelings of insecurity. The authors note that such comparisons may also mask the identification of appropriate needs and of inequalities.

stresses by coming to comprehend what she could and could not change. Ron spoke of how he had learned to reframe a failure, such as the financial setback of having to buy a whole new wardrobe when he lost weight to help control his diabetes, as a learning experience.

Several mentioned the importance of being able to connect self-care with life purpose and goals.<sup>51</sup> Ruth noted that she applied her observational and expressive skills to the enhancement of her relationship with her physical self, as she became involved in physical self-care (transferring skills developed over years of focusing on mental, emotional and spiritual self-care). She was motivated to deal with the threat of physical deterioration not by fear, but by a desire to continue a self-determined path of personal growth.<sup>52</sup> Martin practiced an approach to life based on the parable of the talents that consisted of doing the best he could with the personal resources he had and learning from his life experiences.

### ***Managing the complexity of self-care with the complexity of life***

Participants acknowledged the complexity of responding holistically to the challenge of living with diabetes. Martin described the complex flow between the commitments to daily life and the commitment to self-care, which are impacted by

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<sup>51</sup> Wolever et al. (2010) report that client-centered health coaching with patients with type 2 diabetes, which focuses on patients' values and sense of life purpose, is linked with improved self efficacy, accountability and clinical outcomes, compared to usual care.

<sup>52</sup> Ryan & Deci (2008), in their self-determination theory approach, link autonomous motivation and autonomy support with developing and sustaining competent self-care; they hypothesize that the autonomously motivated person does not experience the internal conflict and division associated with external direction. It is possible that Ruth is resisting not only fear-creating professional messages but also a perceived medicalization of her life by professionals (Conrad, 2007).

internally shifting attitudes, external factors beyond one's control, and the ability to hold to a course of action in the crosscurrent influences of those outside factors. Margaret acknowledged the tensions and fatigue that can be involved in attending to social and emotional needs and commitments while trying to maintain a healthy living regimen, being pulled in two directions at once. She advocated a realistic approach of making the best choices possible under the circumstances. Several participants had co-morbid conditions, which added to the complexity of self-management.<sup>53</sup> Sarah dealt with the uncertainties in managing co-morbid conditions by accepting ambiguity and being proactive in self-care.

***Getting back on track and staying on track.***

Participants acknowledged the stress of knowing when they have strayed from their self-care regimen or have lost control of their blood sugar balance. They emphasized the importance of recommitting to a self-care practice and talked about how to get back on track. George talked about returning to self-care after falling into complacency or attending to a family crisis. He normalized these variations in life priorities, and said what made it easier to resume self-care was the experience he was accumulating about how to resume his regimen. Ruth found that reading about the positive effects of healthy food helped inspire her to take a step at a time in getting back on track with her eating. Genevieve resumed her healthy meals and exercise through careful planning and scheduling. Willow noted that her diabetes education lay-leader trainees had learned to

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<sup>53</sup> Lindsay (2009) notes the stress of the competing demands for care of co-morbid conditions; she finds that persons prioritize their conditions according to factors of a) unpredictability b) inability to control with medication and c) setting off other health problems.

take a long-term approach to self-management. They recognized that a chronic condition can go through acute periods and that they had tools to help re-establish a balance.

### ***Dealing with financial stress associated with diabetes self-care***

Participants acknowledged, for themselves or their peers, the financial stresses associated with the cost of diabetes care. Several described practical approaches to stretching their food dollars. One person, who could retire, chose to continue working to maintain health coverage. Sarah's potential financial stress, as a person on disability insurance, was addressed by good coverage. George dealt with the significant financial stress of his medical costs by focusing on how these treatments kept him feeling well and how he felt his life is blessed. Genevieve drew on spiritual practices to deal with anxiety, including financial concerns.

### ***Specific stress management techniques***

Willow, the diabetes education lay-leader trainer, observed that people learn stress techniques naturally through life experience. They might not recognize a formally taught technique, such as time-out as similar to something they do spontaneously. Edith learned to attend to stress management continuously, and found that she might have to remove herself from stress at times, as a rebalancing step.

Edith acknowledged the discouragement she felt when her blood sugar levels were high despite her self-management efforts. She responded by reviewing her blood sugar management and using stress management techniques; that is, she used meditations and affirmations, chose positive entertainment, had a pet, and exercised to control stress, as well as blood sugars. She recommended daily time for emotional self-care. Genevieve

was aware of the risks of burning out as a caregiver to herself and others. She learned to reduce this risk by regularly taking time to pamper herself, to satisfy her need to continue learning and growing through courses and hobbies, and to express her creativity through making improvements to her home and garden.

Ruth had learned that by recognizing what she had accomplished in self-care instead of focusing on what she hadn't done she could improve her morale. Jacob, who had Type 1 diabetes, preferred to avoid further hypoglycemic incidents and knew that this was not realistic. He used this negative probability to motivate persistence in self-care rather than becoming discouraged and apprehensive.

Josephine had learned assertiveness, from the modeling of others, such as the District Girl Guides Commissioner and community health centre nurse, and from their willingness to problem-solve with her on this issue. She was reducing stress in her life, through learning to say no in the context of her volunteer activities. Volunteer leaders had helped her distinguish between what she was comfortable with and what was too much. Josephine also learned coping strategies from debriefing with her fellow lay diabetes educators who were doing poverty simulation workshops that could be stressful for presenters and attendees. Andrew had learned to be assertive about his need to eat in a timely fashion, even during business meetings. Margaret dealt with the stress of communicating with health professionals who used professional language by assertively requesting a lay translation.<sup>54</sup>

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<sup>54</sup> Margaret's comments about language-related stress in communicating with professionals point to the value of disseminating results of studies on effective professional communication with patients, such as that of Clark (1997) on how to create information messages that reduce patient distress during health care procedures.

Malcolm had a strong awareness of maintaining active mental functioning as a key part of self-care and stress minimization. He noted that an active brain is associated with maintaining other body functions. His strategies included reading, being part of a book club, and taking distance and local university courses, all of which kept his life interesting. Malcolm conveyed his experience that part of the benefit of these activities is the group exchange which can be beneficial to all concerned; he was particularly aware of how such exchanges can provide an opportunity for seniors to make a meaningful contribution.<sup>55</sup>

Martin and others knew the value of staying focused on the present, taking one day at a time. For many this practice was supported by their faith.

### ***All three themes contribute to effective stress management***

Participants talked at length about how gaining and using general and experiential knowledge of self-care empowered them to act effectively, reduced their stress, increased their quality of life, and brought them peace. As has been reported earlier in this chapter, under the reciprocal interpersonal support theme, participants recognized the major contribution that their relationships with family, peers, professionals and other members of their network made to managing the stresses of living with diabetes. Relationships were a source of reassurance, understanding, support, resources, caring, feedback, information, companionship, and solidarity. What participants were able to offer to others was equally valued as a source of meaning, joy, and grounding. The participants

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<sup>55</sup> McMurdo (2000) notes that a healthcare planning focus on care of the rising elderly population can interfere with attention to incentives and opportunities to support a healthy old age. Malcolm advocated for incentives such as tax deductions for gym fees and restoration of free university for seniors.

are aware of the personal qualities they draw on and enhance through the discipline of living well with diabetes. It is these qualities that empower them to work with the tensions of simultaneously attending to life and to diabetes.

The following are examples of statements by participants that support the stress management component of the experiential expertise theme.

*Edith: Well for me I know that the stress is a really big factor, probably more than what I eat. I can control the sugars really well with exercise, and it helps the stress too. But sometimes I'm in that and I don't even realize that I'm in that frame of mind . . . When I'm stressed I am irritable and I'm overwhelmed and I don't think I can do anything, and that's how it affects me. And then that all . . . one thing leads to another . . . I didn't know I was getting that sick in November. I really had got so deep in . . . part of it was depression. And I did go to the doctor and get some extra medication for that to get through this, the winter months are hard . . . Most of my problem was stress at work. It wasn't really a lot that I was doing myself, but I was allowing problems at work to really bother me . . . I did have to take a sick leave from work and I've been really working hard on (stress) . . . If it's {blood sugar} high [on waking] then that negative [feeling] is . . . more apt to be there . . . I find it hard when it's high, but I've done everything I was supposed to the day before, I do get discouraged . . . But I have a lot of things that I use to get out of that negative mode . . . (Sigh) I try to look at what did I eat yesterday, and try to adjust things that way. Also I have a program where I do a lot of positive things with meditation and affirmations. I just pick myself back up I have a program where I do a lot of positive things with meditation and affirmations . . . I read . . . really positive books and watch happy things and go around with people that we laugh a lot . . . And I have my cat.*

*George: When the setbacks . . . come, they slap you upside the head . . . but you have experience to draw on now whereas before I had nothing . . . When your father-in-law has been in the hospital on death's bed, amputated leg, and finally died, I'm sorry . . . [although] your main purpose in life has now become self preservation you had to shut that down because you have a crisis in the family now, that's more important, at that time, than your own self preservation . . . Fall down, at times like that, or even get complacent and slip, but don't stay down . . . Everybody has setbacks, everybody has problems.*

*Genevieve: To be the best person that I can be . . . means [among other things] taking . . . a pampering weekend for me at home, I do that . . . every 4 months . . . spending a weekend doing exactly what I want . . . going to Wendy's and buying a salad with a piece of chicken on top . . . because that's the only thing that's healthy . . . But it's nothing to do with housework or cooking meals. I will have my salad prepared if I decide that I'm going to eat in . . . I will cook something that*



*will last for 2 or 3 days so that . . . I can just heat it up . . . No laundry, no cleaning, lay in the bathtub for an hour if I want to, do my fingernails, do my toenails, maybe do some quilting . . . I don't even exercise. It's just totally focused on me . . . I may decide that . . . all I want to do is read a book . . . 'cuz once I start a book I can't put it down . . . I prepare for that weekend, so that when Monday comes I'm not feeling stressed . . . Everything's done ahead of time. But I don't let anybody know that I'm doing that . . . It doesn't cost me anything, other than maybe an occasional meal out . . . I think it's very important for women to do that . . . Sometimes you can get lost . . . helping other people and just being there for other people . . . we seem to be very good at doing that. So sometimes you have to replenish and give yourself back what you've been giving to other people. And that's time. Do something new every 6 months . . . Explore something new, create something new, even take a course . . . but always keep in mind learning . . . I take courses at Kent's . . . I did my own flower beds with stacking stones . . . The [Kent's store] actually gave a course on that and I did that in front of my house . . . decorating your house, making new curtains, just do something new that gives you pleasure.*

The participants were aware of stress as a risk factor for diabetes and were articulate about diabetes distress in particular. They discussed: how to mitigate the shock of diagnosis, the process of accepting and adjusting to a life of diabetes self-care, drawing on internal resources and life experience to do so, the complexity of simultaneously managing self-care and daily life, getting back on track after lapsing from a regimen of self-care, meeting the financial challenges of self-care, use of specific stress management techniques, and how a combination of experiential expertise in self-care, reciprocal support, and positive personal qualities contribute to effective stress management. Stress management, which is a critical aspect of diabetes self-care, is also foundational to the capacity to embrace life. Much of what has been presented as results under stress management belongs equally under the overarching theme of simultaneously embracing diabetes and embracing life that will be addressed in the next section.

As stress is an all-encompassing part of life, enhanced stress-management is a dream implicit in all the participants' goals, plans, visions, and recommendations for

enhanced diabetes self-care. These included recommendations to publicize diabetes self-management success stories, support diabetes peer-support groups, establish community-based diabetes education and care centres, and subsidize the cost of diabetes self-management. Participants also recognized that life stress is a part of being human and that they had inner resources to draw on and cultivate; they were committed to their ongoing journeys of personal and spiritual growth.

***Overarching Theme: Embracing Diabetes and Life Simultaneously***

The overarching theme of simultaneously embracing diabetes and embracing life is an attempt to name the complex and apparently contradictory process of living well with diabetes by *serving two masters*. Participants achieve this ongoing work of balance,<sup>56</sup> integration, and transformation through the practice of positive personal qualities in interaction with reciprocal interpersonal support and experiential expertise in self-care and life skills. For instance, one participant who was treated with respectful compassion by a health professional was empowered to apply a mindful eating exercise that required her to practice the self-respect modeled for her by that professional.

Participants have described embracing diabetes and their new life as persons with diabetes as a process, a journey. They experienced the shock and trauma of diagnosis, and named steps in their transition to living well with diabetes through growing

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<sup>56</sup> Paterson et al. (2007) explore how finding balance can determine a person's willingness to assume an active role in self-care. Shimizu & Paterson (2007) discuss how values of balance and harmony are important to consider in understanding approaches to diabetes self-management in cross-cultural contexts.

awareness, acceptance and adjustment. They were challenged to reconcile with the reality of their incurable and progressive condition while maintaining their motivation to do what is in their power to slow this progress, and to maintain their quality of life and the meaning of its apparently diminished circumstances. Participants candidly acknowledged the ongoing challenge of managing their uncertain and progressing health condition, while often being pulled in different directions by the opposing demands of self-care and other life commitments. At times they became tired of round-the-clock self-care regimens. Participants also celebrated what one called the apparent paradox of life made easier by self-care work, whereby their diabetes stabilized and daily life was less disrupted by unpredictable responses to eating, exercise, and other activity.

In embracing diabetes, participants faced their suffering and mortality; this confrontation with reality strengthened their awareness of the need for self-care and their motivation to implement self-care activities. Facing reality in this way also clarified for participants what they valued in their lives and were committed to enhancing. In simultaneously embracing diabetes and embracing life they grew in love for body, self, others, and for many, the spiritual as they knew it. The following are examples of statements by participants that support the overarching theme of embracing.

*Martin: If there's something that causes sort of a scare in your life . . . when somebody goes through sort of a life altering situation, reality comes upon you like somebody dropping a water balloon out of the . . . second story or a building as you're walking out the door below . . . Plat. Here it is! You know, you're wet. You're a diabetic and you better do something about it.*

*This is your baby . . . a whole psychological change has to take place within a person's psyche . . . no one wants to admit a lot of times that something is wrong . . . it takes time to allow that to sink in . . . I can see, so many of these things are wrapped up, any disease has a progression and acceptance and then you know, why does it have to be me . . . But you have to accept it and the more you accept it, and the more you try to consciously treat it, if we can use that term, then the*

*better off you're going to be I think in the long run, for it . . . It might beat you in the end, but you might beat it off for a longer period of time if you can do what you should do.*

*Things are allowed to come in order, not to put you down, but that you might grow stronger. And what some people look at as a really negative thing, others then to look at as being something that has a real positive spinoff because none of us are in this teapot alone. We're in there with a lot of other people, so what you learn from it, and what you're able to bring as encouragement to others in spite of it.*

*You take what's given to you and make the best of it . . . that's the parable of the talents, right? To whom much is given much will be required and if something . . . [has] been given . . . [and] you use it, you're gonna get more . . . I found that true throughout all my life . . . I started out as a boy in a fishing village . . . I've been all around the world . . . I've done all kinds of things that resulted . . . [from] leaving yourself open to just think positively. I made a lot of mistakes, made a lot of wrong decisions but learned from them . . . I guess that's where wisdom begins to come into play. You apply the knowledge that you've gained . . . What's that little saying Lord help me, some things I cannot change, and the things I can help to change . . . give me the wisdom to know the difference.*

: *When the Lord said . . . I'll never forsake you, I don't go through any of the stuff alone . . . A lot of people figure they are alone . . . I have Somebody both that cares and understands . . . it's also in the life of those that are around you.*

*Once you reach 50 it's all downhill, but . . . you gotta be in control of the slide . . . You've got to try to get to the end of the whole scheme of things here the best way you can . . . If you view this life that you've been given, as not just your own, as a stewardship, then you will try to do it, not just for yourself, but for the Lord who bought you, for those around you who love you . . . It just makes sense . . . and you feel better about everything.*

*Jacob: I've had . . . quite severe eye problems and quite a number of hypoglycemic incidences . . . It has been somewhat hard on her [wife]. It's scary to have somebody unconscious and convulsing on the floor by your bed as you wake up . . . So I knew that had to change . . . and [that] is what prompted me to go on the pump and seek out more information.*

*[I'm talking online with] . . . other diabetics who are going through the same thing that I am. They're struggling with their sugars, their weight, their energy levels, their health care team . . . Hearing other people's success stories is probably the number one thing that keeps me going . . . All diabetics need to compare what they do to other diabetics, somehow . . . I don't know if statistics tell them what a diabetic does. The only way to get that is to talk to another diabetic.*

*I have heard people say that they are glad they were diagnosed with diabetes. This has lead to weight loss, healthier eating, more energy, more enjoyment of life . . . Its almost paradoxical, the more effort you put into (self-care) the easier life becomes . . . I feel better, physically - more energetic, more focus. I'm more at peace with life . . . Because I have eye problems, I value my eyesight more. I bought binoculars last year and am really enjoying bird watching. I recently bought a high-end camera. I said to my wife, "I need to buy this camera now, because I don't know how long I'll be able to use it.*

*Margaret: Don't go and lock yourself in a closet because it's not contagious and it's not something that somebody is gonna catch off you . . . It's not something you have to be ashamed about . . . It's an every day, known medical problem that's been going on for hundreds of years . . . Talk about it with other people. Find out how other people are living with it and share stories with them . . . hopefully that [talking with peers] would all click in to make them feel a lot better with the fact that they are diabetic . . . You gotta learn to live with it and to deal with it and learn that it's not going to hold you back. You can still do the same things you want to do, that you've been doing.*

*I believe probably about 95 % [of living well with diabetes] has to do with my faith in the Lord . . . I can't say that I take 100% credit for everything, because I do not believe that I deserve that. I believe the Lord deserves it . . . When you give your life to the Lord . . . it certainly changes a lot of ways that you think about things and how you deal with things, right? I sometimes think the Lord is kinda working through me, giving me some answers to give to them (peers) . . . when I'm talking to them. I'm just telling them . . . my story.*

*Ruth: You're just plodding along, one step at a time, but looking for help and direction and it's given to you. This is crazy, but I've got help and direction from my dreams for the last 30 years and sometimes when I wake up in the morning, something shifts in my head and so I go and I put it in the computer and see what comes of it . . . All things that we dream come in the honor of our wellness and wholeness.*

*I remember years ago trying to follow a diet . . . Because I couldn't follow it to 100%, I stopped trying at all and gained a lot of weight . . . If I had continued to follow it, even though I was only doing it 50% or 75%, I would never have gotten so far off track as what I did. So it's being able to accept, and live with, what we are able to do, and focus on that.*

*Since I've started the [healthy recipe] blog, I've come to think differently . . . to realize that I have to take more responsibility for the health of the people that I*

*am cooking for, not just take into consideration what foods that they would love to be eating*

Participants understood and communicated their journey through stories; stories they told about their experiences that referenced stories received from peers and family members and cultural stories such as parables in the Bible. These stories described how they adjusted to their new identities as persons with diabetes, and how they created meaning and purpose out of their new circumstances. Participants used these stories to claim space and recognition and specific kinds of support. These stories suggest the usefulness of narrative analysis as a way to further understand the stories referred to in this Results chapter. The Discussion will describe how Frank's illness narrative theory frames these stories.

## **Chapter Five: Discussion**

Participants described three main factors which enable them to live well with diabetes: the inner strength of positive personal qualities as expressed by themselves and those in their network; reciprocal interpersonal support which nourishes them and gives meaning to their lives, and experiential expertise, which they claim, celebrate, and wish to share. These three factors work interdependently, each present with the other two. For example, practice of stress management skills (experiential expertise), is supported by/participated in by peers, friends, and family (reciprocal support), and motivated by compassion and respect for self and body (positive personal qualities).

Participants express living well with diabetes as a passionate, simultaneous commitment to diabetes self-care and to living their lives, i.e. simultaneously embracing diabetes and life. This double embrace is a personal journey, a process made possible by the three factors mentioned above. Positive personal qualities, reciprocal interpersonal support, and experiential expertise are as key to living a good life as they are to diabetes management. The participants found an underlying unity in living well with diabetes and living well while acknowledging the tensions of these sometimes apparently conflicting, apparently paradoxical commitments.

### **Patient Voice and Study Results**

The study model and its themes are congruent with the recognized health care best practice models of Patient Centered Care (World Health Organization, 2005) and Chronic Illness Care (The MacColl Institute, n.d.), focusing on the centrality of patient voice and patient place. This study's model is based on results that demonstrate patient interest, commitment, and expertise in self-care and an expressed desire for a health care

team approach that serves their individualized needs and recognizes their work. The study model also summarizes aspects of patient experience that are minimally documented in the literature.<sup>57</sup> These are the aspects of patient self-care that can be invisible to healthcare providers: that is the vibrant networks of informal reciprocal help; the autonomous development of expertise through reading, observation, experimentation, and exchange with peers; and the inner strengths and spiritual faith that are invoked and enhanced. The reality of this vibrant patient culture is put into a postmodern context by Frank (2004), who sees it as part of a rising tide of social change.

### **AI and Study Results**

The participants' stories give direct and indirect testimony of how they apply the five AI principles in their lives (Appendix G- constructive, simultaneous poetic, anticipatory, positive). They also show evidence of using these principles in the stories they choose to tell. Participants construct stories that convey their understanding of the importance of telling and hearing stories of hope, of what can be done, of success, of appreciation for available support, of recognition of resources (theirs and others') and of what is working in the here and now. Participants recognize the power of language in creating reality. Language that is accessible and practical conveys a message that lay-persons can both successfully self-manage a chronic condition and live a good life, doing the things they want to do.

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<sup>57</sup> Several reports, which support my results and study model are as follows. They include Campbell et al. (2003) — a meta-ethnography of 10 studies of lay experiences of diabetes and self-care; Thorne & Paterson (1998) — a meta-analysis of 158 reports on chronic-care relationships; Edgar (2005) — a study of the hermeneutic and narrative resources of patients; Vallis & McHugh (1986) —a review of the illness behaviour model which proposes that “The biological, psychological and social contexts (are) equally important dimensions . . . None have a priori superiority in determining human behaviour in health and disease (p.1).”



Participants recognize the power of continually pursuing the question of how they can live well with diabetes. They comprehend how this simultaneously energizes and directs their thoughts and their listeners' thoughts, leading to helpful resources and practices. Participants recognize the poetic power of casting themselves as empowered protagonists in their quest for a balanced life. Participants recognize the anticipatory power of countering the fear of the uncertain trajectory of their life with diabetes, by referencing for themselves and others, the familiarity of past achievements, skills, life lessons learned that are present and accessible resources. The participants are explicit about the value of focusing on the positives in the challenging situations that they face as persons with a chronic and sometimes unpredictable health condition. Participants tell stories of how when they or others interact positively, they naturally and easily turn toward ideas and images that provide nourishment and energy, like plants leaning toward the light (heliotropic principle). They also emphasize the importance of respecting the individuality and diversity in everyone's health and wellness journey.

Participants' stories, when viewed through an appreciative lens, manifested the themes incorporated in the study model. Appreciative thinking supported me in recognizing luminous positive personal qualities as a key part of participants' experience of wellness. Appreciative Inquiry, rooted in democratic values, the right and responsibility for each person to participate, supported my attention to both the reciprocal support and the experiential expertise of participants. The appreciative image of a wave in an ocean of shifting currents (Gergen, n.d.) opened me to the apparently paradoxical reality that participants have recounted of simultaneously embracing diabetes and life, the overarching theme that has emerged in this study. This image of the wave in the ocean

conveys postmodern qualitative research's increasing recognition of the multidirectional, contextually associated nature of relationships; the image itself captures the existential, spiritual journey of the participants. This is a journey explored in the works of illness narrative theorist Arthur Frank. His writings, grounded in his personal encounters with chronic conditions, resonate with, and employ language similar to that in, the participants' stories.

### **Frank's Illness Narrative Work and Study Results**

Frank (1995) identified three intertwining forms of illness narrative in stories, with one form predominating at a particular moment in living with a chronic condition. Where there has been a narrative crash, such as happens with an illness diagnosis, the person loses a sense of continuity, predictability and, security. This is the *chaos narrative* in which a sense of time is strangely altered and persons are buffeted by uncontrollable threats and demands. Some illnesses are curable and persons recover completely; such experiences are the stuff of *restitution narratives*. Modern medicine has been committed to restitution stories, making the development of appropriate care and attention to chronic illness and end-of-life more challenging. Successful chronic illness self-management requires an approach that resolves the initial disruption of normal life and locates insight and meaning in the experience of encountering and living with the thread of mortality. This kind of journey is chronicled in *quest narratives*, which help the storytellers to transform their suffering into experiential knowledge, a source of healing and redemption for themselves and others. It should be noted that experiences of chaos and quest

alternate as persons encounter and adjust to fluctuations in their health.<sup>58</sup> This is consistent with participants' personal journeys as reported in the Results chapter. Frank (2004) sees experiential wisdom as being heart-based, and contrasts it with technical knowledge, and generalizable evidence-based knowledge. Experiential wisdom is the foundation for his (2004) vision of a renewal of generosity in the reciprocal relations of care, whether involving informal or formal caregivers. Frank's vision resonates with the stories and dreams of the participants, who are committed to sharing their hard-won insights with peers, friends, and family and who cherish relations with caregivers whom honour their personhood.

Frank's work falls under the sociological branch of Narrative Inquiry, which attends to the work that stories do (Frank, 2010). Attention to participants' implied and stated motivations for engaging in the study suggests that they told stories to enhance the well-being of themselves, other persons with chronic conditions, and the quality of health services. They claimed a space<sup>59</sup> for their voices, proposed that their self-care work be recognized as socially valuable, and advocated for public participation in institutional program and policy decision-making.

Frank offers a critique of the limits of modern medicine and its impact on the autonomy, expressivity, and efficacy of patients with a chronic condition. He describes how an increasing focus on technology and cure teaches the patient to dissociate from his

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<sup>58</sup> Whitehead (2005) notes that illness narrative type trajectories can vary according to different disease trajectories. For example she found a difference between study participants with chronic fatigue and those who are HIV positive and have been operated on for breast cancer.

<sup>59</sup> Patient voice can be heard when there is created an 'ethical space', based on principles of autonomy and respect, which enables dialogue among those with differing perspectives and interests (Poole, 1972: Ermine, 2000).

own body and attend instead to such external information as blood test results. Yet the patient's own body is the most remarkable 24-hours-a-day source of information, feedback, and motivation to act.

A little used aspect of Frank's (1995) illness narrative framework is his examination of the patient's voice, the patient's story, as told, and lived in an embodied form. Frank proposes four axes of body action problems: 1) Control of the body: from predictable to contingent; 2) Body-relatedness: from disassociated to associated; 3) Other-relatedness: from monadic (focused on self) to dyadic; 4) Desire: from lacking to productive. Frank proposes that a person with a chronic condition who is in a quest phase of his/her illness journey narrative will have embraced the contingency of life with a chronic illness, will be embracing and attending to that ill body, and will be experiencing the productive desire to relate to other. He or she will share the insights and wisdom acquired from facing the fundamental contingency of all life.

In the study reported in this thesis, participants identified their embrace and attention to their bodies as part of living well with diabetes and living their lives. They described learning the language of the body that they likened to learning a foreign tongue or switching radio channels. They valued its subtle cues, slight alterations in perception or mood, which were early warning signs of imbalance. They noted that understanding this language might take months. Such attention brought a new appreciation for the joys of embodiment. Some participants recognized how such an embrace of body experience was part of their continuing life-journey of personal development and integration.

The participants contrasted the experience with professionals who respected and honoured their body experience and those who did not appear to acknowledge it. Frank's

axes of body experience around issues of control, relationship to body, relationship to others, and productive desire, point to areas for professionals to consider. For instance, a diabetes education and treatment approach which focuses on control and attending to blood test results can risk negatively impacting the patient's relationship with his/her body, as the patient needs to accept and identify with a body that can be uncontrollably unpredictable in its illness trajectory. As desire is of the body, a person who is dissociating from his/her body may have weakened motivation for self-care activities or helpful involvement with peers. An understanding of the diabetic body-self (Karas Montez & Karner, 2005) can help professionals committed to patient-centered care hone an approach that can "stimulate productive desires, facilitate deep dyadic relationships, build body-self associations, and potentially replace the emphasis on strict control with integration of control into everyday life" (p. 1102). Such an approach would embody a realization that indeed the patient has the most powerful and effective instrument of diagnosis and care, the body-self. It is that realization that adds credibility to Ferguson's (1995) earlier cited schema, the visionary inverted power pyramid of Information Age Health Care (Appendix A), which places the patient and family caregivers at the top.

### **Patient Voice, AI, and Frank's Attention to Suffering**

AI is democratically committed to including all voices in its investigation of what is working in a particular situation. Critics of Appreciative Inquiry are concerned about how a potentially single-minded positive gaze may make invisible, the more challenging,

oppressed, dark aspects of participant experience.<sup>60</sup> Frank's work gives permission to attend to both the political and healing dimensions of patient experience. His work names the power imbalance which limits and distorts patient-professional partnerships while pointing to the common ground we all stand on, our fragile mortality. Frank (1998, 2004) suggests attending to patients' narratives is healing for the patient and the professional concerned, and it is an activity that infuses health care institutions with the values and qualities which Appreciative Inquiry names as the essence or energetic core of organizations.

Frank (2001) suggests that modern medicine and social science inquiry often miss attending to the suffering inherent in illness. Professionals are trained to diagnose categories of disease, and so can fall into categorizing instances of suffering and prescribing solutions, instead of being present with the tragedy in life.<sup>61</sup> Suffering is a mute, overwhelming experience of loss and disconnection and is hard to research because of that muteness. It is tempting to avoid, as it has the power to disrupt systems and categories. Frank notes how social scientists are at risk of silencing suffering. For instance, they can use fragments of participants' stories as incidences of their academic narrative, losing the integrity and felt sense of a story rooted in a poignant local, particular, holistic reality.

Frank argues that suffering is not to be explained, but to be encountered and responded to. This begs the question of what the researcher is to do in the face of

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<sup>60</sup> For instance, Cockell (2006) uses both an appreciative and a critical lens in an approach she calls Critical Appreciative Inquiry, which help her to identify that which can interfere with the process of appreciation.

<sup>61</sup> Thorne & Paterson (1998) note the risk of ignoring the burden of illness and underestimating the need for support by persons with fluctuating levels of wellness and energy.

suffering. Frank (2001) sees his own work as aiming to explain “social systems to respondents so they can understand the powers in which their lives are embedded” (p. 360). He hopes that his publication platform will amplify the voices of the ill and “offer them previously unrecognized connections and a sense of community” (p. 360-361).<sup>62</sup>

Frank’s reflections allow me to acknowledge a haunting sense of the invisible suffering I sensed in the lives of the study participants.<sup>63</sup> Periodically I feel a pang as I remember intimations of their fragility, and I wonder how they are doing these days. It feels important to honour the participants’ vulnerability in a piece of research about how they live well with diabetes. Part of what participants said about living well with diabetes was that they had learned how to embrace the suffering and the loss of health, activities, and connection. In encountering the truth of their suffering, they honoured the integrity of their life path, and they spoke with reverence of the holy places this encounter brought them to, places of reassurance, comfort, faith, peace, and even joy.

Frank’s work gives permission to take time with participants’ stories, to let them do their work. It provides a balance to the action/modern progress orientation of AI. AI practitioner Zandee (2007) describes an aspect of this orientation in a tendency to fall back into logico-scientific discourse during the design and delivery phases of AI. She advocates for an embrace of poetic language, with its qualities of imagination, ambiguity, touch and holism, throughout the 4-D AI cycle. Ezzy (2002) notes the tendency towards traditional heroic action in the quest narrative. His work with persons with AIDS

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<sup>62</sup> Frank, as an author, chooses to deal with the issue of potentially muting or distorting the voices of persons with chronic conditions by drawing almost exclusively on published stories.

<sup>63</sup> Over the time of writing this thesis I have come to more closely recognize the resonances between the participants’ stories and those of my own body-self journey. The participants’ stories have done their work with me, calling me into a deeper awareness of my precious mortality.

documents stories that focus on the present moment and on *being* more than *doing*, a focus that is also emerging in stories of those confronting the dramatic ecological uncertainties of our time.

In investigating patient experience in the context of our uncertain times what might be added to an Inquiry practice which combines an Appreciative and an Illness Narrative approach? A recently created post-graduate course for physicians offers a continuing education program that combines Appreciative Inquiry, Narrative, Inquiry and Mindfulness Meditation and is reported to enhance attitudes associated with patient-centered care (Krasner et al., 2009). Meditation is a practice that calls for a radical, singular focus on the present moment. Perhaps traditional Eastern phenomenal investigation through meditation would further elucidate patient knowledge of chronic disease management, or contribute to a paradigm shift in our understanding of illness, well-being, and existential existence.<sup>64</sup> It could further illuminate the ways patients are cultivating inner harmony while living with the chaotic uncertainty of their illness and their world.

While participants described their experiences of finding a place of inner balance and peace, many also acknowledged the challenges of living in our changing society and beleaguered ecosystem. Frank (2004), like Crossley and Crossley (2001), as discussed in Chapter Two above, refers to Bourdieu's concepts of habitus and field in addressing the circumstances that influence people in their response to illness and in the stories they

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<sup>64</sup> Wilber (1986), who draws on Eastern and Western philosophical knowledge, has helped lay the base for a transpersonal approach to healing and well-being that is growing in professional acceptability (Bliss, 2009).



create. Frank writes of postmodern society and “the figuration of social forces that has recently changed and keeps changing” (p. 433). Participants were facing change on multiple levels in postmodern society. This included the increasingly recognized impact of accumulating pollutants such as soil, water, air, noise, artificial light, toxic chemicals, and radiation. Persons with chronic conditions can possibly be seen as the canaries in the coal-mine, providing early warning signs of the effects of social and environmental change on human health (Jones et al., 2008). Participants described their efforts to understand the mystery of their physiological responses and the importance of exchanging with peers exercising the same kind of observation and experimentation. This exchange offered mutual support and can be a source of valuable self-management knowledge and support for the larger society facing the same socio-environmental conditions.

The expression of lay knowledge can be seen as the rise of an opposition habitus confronting the modernist scientific paradigm (Crossley & Crossley, 2001). It can also be seen as a cultural claim. Just as there is a call for culturally appropriate approaches to health services for First Nations (Struthers et al, 2003) and other ethnic groups, the participants’ interest in respectful, equal partnership exchanges with health professionals and with each other was a call for a rehumanization of institutional relationships. The inability of modern medicine to cure chronic conditions exposes the imbalance in professional and institutional practices that are not grounded in the lifeworld of relationships and Habermas’ *communicative space* (Wicks & Reason, 2009) (and are often not paying adequate attention to environmental influences on health). Attending to patients’ narratives is healing for the patient and the professional concerned (Frank,

1994); moreover it is an activity that infuses the institution with the values and qualities which appreciative inquiry names as the essence or energetic core of organizations.

The participants demonstrated the efficacy of an appreciative approach to living well with diabetes, and they transmitted that knowledge in a powerful storied form.

Professional educational and treatment practice can benefit from the integration of an Appreciative Inquiry approach, and an attention to the storied nature of lay knowledge.

The use of AI and a narrative/story lens can address the gap for instance between professionally perceived non-compliance and deficient management of chronic conditions, and asset-focused assessments and enhancement support work. I shall quote from my research journal entry, recorded on November 8, 2010.

When diabetes experts were asked to implement their own protocol recommendations they experienced significant difficulties (Warren-Boulter et al., 1982). Why then are persons able to live well with diabetes? They develop experiential knowledge over time by listening to their bodies, doing research, and experimenting to find their own unique parameters of well-being in the area of lifestyle and treatment. In pursuing this experiential knowledge participants are supported by the inner strength of personal qualities and the outer strength that is provided through interpersonal support. Participants who live well with diabetes dance with the tensions of simultaneously embracing diabetes and embracing life. They find meaning, joy and success in living life as it is.

Professionals can access experiential knowledge of living well with diabetes. They can ask appreciative questions such as “What is working for you, what are you proud of/ see as your successes?” Professionals can reflect on their own experience with successfully managing illness or issues such as weight and stress. Finally, professionals can adopt a collaborative relationship with patients, which does not require “the diabetic to redefine his/her life within the narrow ‘sterile’ constraints of ‘the science of diabetes control’ (Hernandez, 2007 p.109)”. In this broader exchange the professional can learn about those underlying success factors such as personal qualities and interpersonal supports which are resources for maintenance and enhancement of successful self-management. They can also broaden their own general knowledge as they are exposed to the nuances and contradictions encountered in its application.

Finally, below is a journal entry I recorded on January 4, 2009, about the participants' interest in dissemination of their knowledge and perspectives. It outlines what they would want highlighted in a knowledge translation of this study.

**Knowledge translation/exchange.** The participants are interested in, talk about, practice, and promote knowledge translation *from* themselves directly as persons who have experiential expertise to pass on to peers, professionals and institutions. In discussing potential researcher dissemination of AI project results participants focus on how the project can support their expertise as well as reach persons in upper levels of the healthcare system relatively inaccessible to themselves as lay persons/patient citizens.

**Participants' concerns/interests in interview** compared to researcher concerns, i.e., exploring the research question in an academically credible way (Aurbach & Silverstein, 2003).

- Advocate for policy changes in health services funding.
- Desire to share experiential knowledge with peers, particularly the newly diagnosed to alleviate or save from suffering.
- Desire to educate professionals, raise awareness of life experience of persons with diabetes.
- Desire to tell one's story, access to an active listener.
- Desire to participate as an expression of gratitude/recognition of diabetes educator, support group, nutritionist.
- Desire to glean something that can be useful in self-care.
- A call for more in depth and broad professional counseling.
- A call for prioritization of respectful empathetic relationship, over regimen/treatment, in the patient professional exchange.
- Desire to support recognition of participant experiential expertise.
- Desire to present self-management as work.
- Celebrate one's success.
- Claim space for autonomy in approaching self-care.
- A call/challenge to awareness and informed commitment.
- Revealing a spiritual foundation to their capacity to live well.

## Conclusion

Listening to the patient voices as expressed by the 13 participants in their stories of living well with diabetes, has been a humbling, affirming experience of the reality of patient experiential knowledge. Such local, particular, and holistic knowledge usefully complements general evidence-based health services knowledge. Appreciative Inquiry

was an effective narrative method for eliciting this knowledge and framing its positive life-giving aspects. Frank's Illness Narrative work contributed an understanding of the storied nature of this knowledge and a frame for interpreting the stories and their significance for patients and health care professionals. Patient experiential knowledge of self-care can be supported, enhanced, and benefited from, through health services policies and practices which recognize its value (Rachlis, 2005).

### **Recommendations**

The following are participant recommendations, made particularly in response to the Dream question (p. 28 of this study), about what would enhance diabetes self-management:

- Invest in primary prevention through supporting active living for seniors and others, public education, and tax incentives which recognize and reward the work of self-care, which benefits society overall.
- Create a first-responder program for the newly diagnosed, as exists for those diagnosed with cancer, to mitigate shock and to provide immediate comfort, reassurance, and hope.
- Prescribe involvement with peers through activities like support and education groups and virtual sites.
- Provide support for such activities.
- Support patient adaptation/individualization of diabetes self-care protocols.
- Support an inter-professional team approach to diabetes care, with priority given to diabetes educators and direct access to specialists for management of chronic symptoms and co-morbid condition.

- Provide material support for diabetes supplies and medications, in order to prevent catastrophic impact on families.
- Create diabetes primary and secondary prevention community-run centres, with a range of lifestyle and health care services.
- Consult patients about their knowledge of factors in living well with diabetes.
- Include patient representatives in planning and policy making forums.

My recommendations are:

- Consider use of an Appreciative Inquiry design in asset-focused investigations of patient experiential knowledge of self-management.
- Assess how consideration of patient experiential knowledge, reciprocal interpersonal support, and positive personal qualities is integrated into patient-centered care.
- Remember that the patient's quest for connection, meaning, and *the good life* permeates health-related activity.

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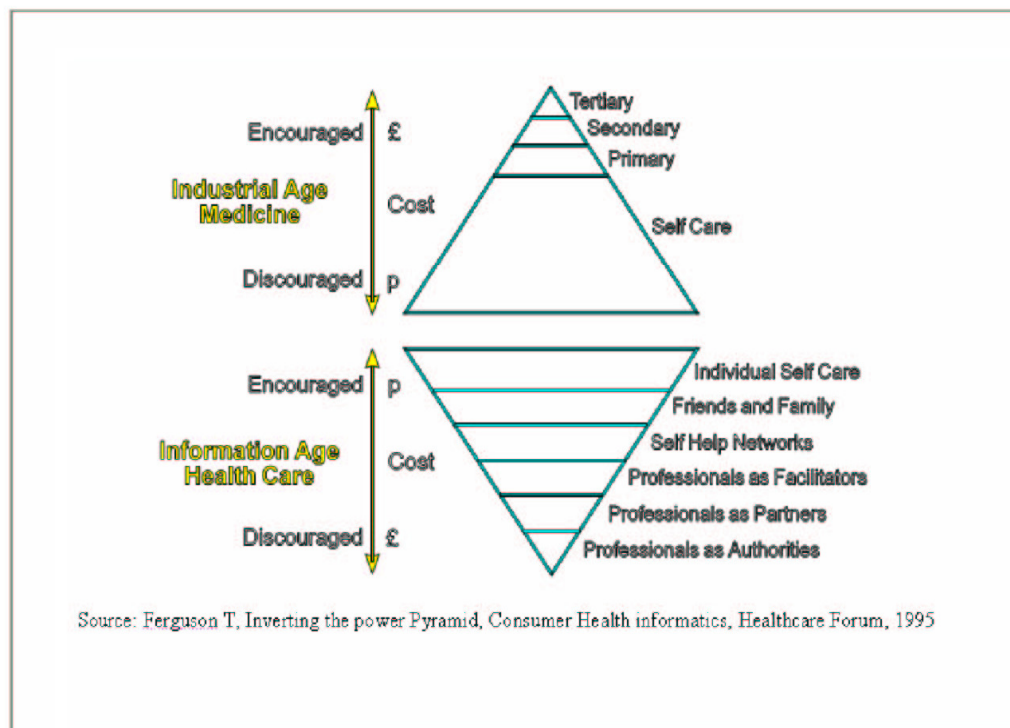
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## Appendix A

# Knowledge is power



Source: Ferguson T. Inverting the power pyramid, Consumer Health Informatics, Healthcare Forum, 1995.

Tom Ferguson, MD, author of the above schema representing the paradigm shift from Industrial Age Medicine to Information Age Healthcare, was an authority on consumer health information and e-patients. He was a senior associate at the Centre for Clinical Computing, Harvard Medical School (Ferguson, T, 1996. [Conference presentation] *A Guided tour of self-help cyberspace*. Retrieved on June 24, 2009 from <http://odphp.osophs.dhhs.gov/confrnce/partnr96/ferg.htm>).

## Appendix B

### Comparisons between experiential and scientific knowledge

Source: National Aboriginal Health Organization (2005). Comparisons between traditional and scientific knowledge styles. *Sacred ways of life: traditional knowledge* (pp. 8-9). Ottawa: NAHO. Obtained from [http://www.naho.ca/documents/fnc/english/2005\\_traditional\\_knowledge\\_toolkit.pdf](http://www.naho.ca/documents/fnc/english/2005_traditional_knowledge_toolkit.pdf) (adapted from charts of The Alaska Native Science Commission. <http://www.nativescience.org/index.htm>).

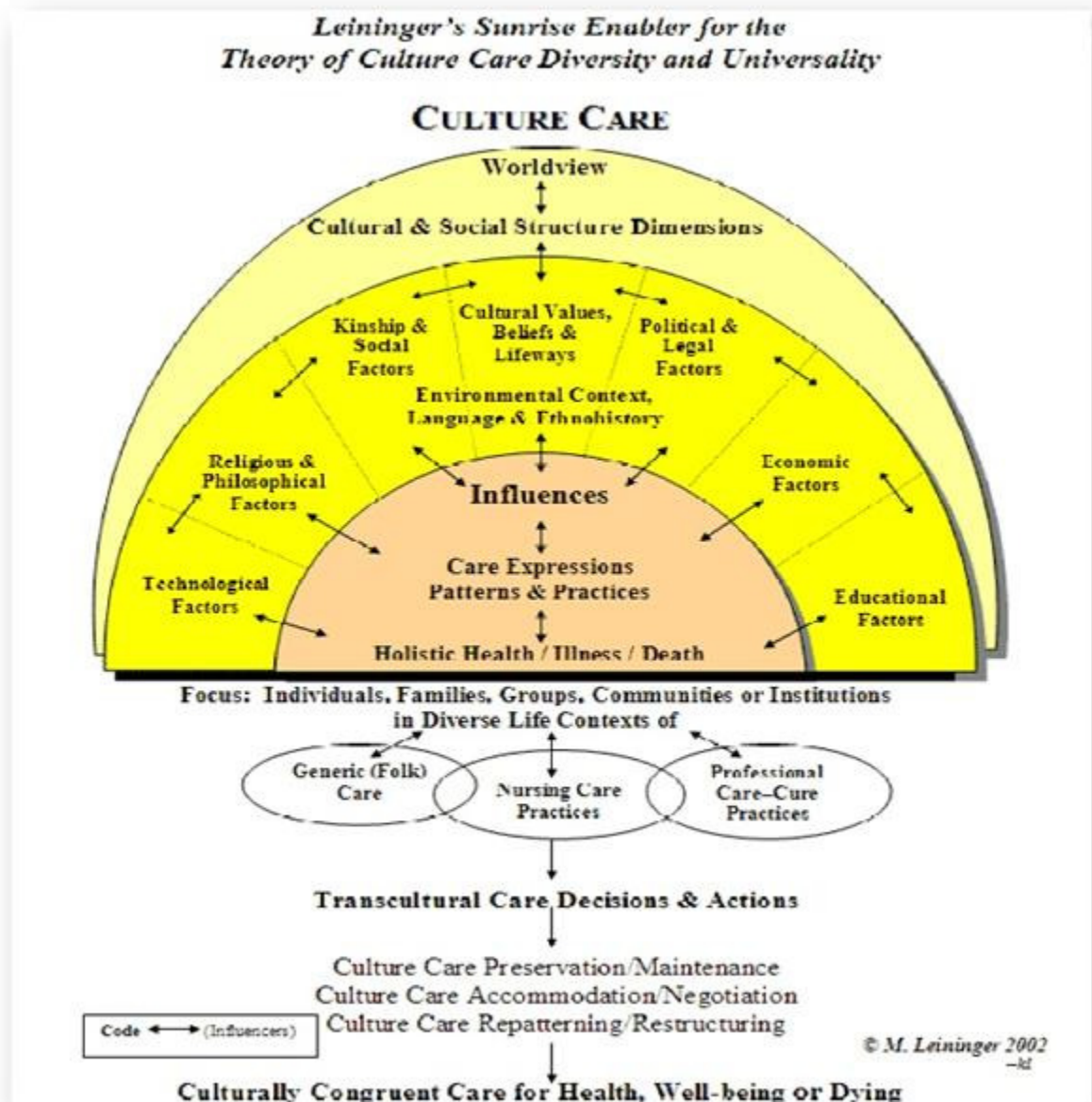
### Comparison between traditional (experiential) and scientific knowledge styles

Traditional (experiential) knowledge	Scientific knowledge
Assumed to be the truth	Assumed to be a best approximation
Sacred and interconnected	Secular (non-religious) segregated
Teaching through storytelling	Formal teaching
Learning by doing and experiencing	Learning by formal education (molding)
Oral and visual	Written
Integrated, based on whole system	Analytical, based on parts of the whole
Intuitive	Model or theory-based
Holistic (based on complete systems)	Reductionist (reduces complex systems to simpler systems)
Subjective (based on personal experience/beliefs)	Objective (not based on personal opinion)
Experiential (based on experience)	Positivist (based on facts)

**Comparisons between traditional (experiential) and scientific knowledge in use**

Transfer of knowledge takes a long time	Transfer of knowledge is fast
Long-term wisdom	Short-term prediction
Powerful prediction in local areas	Powerful predictability in natural principles
Weak in distant areas of knowledge	Weak in local areas of knowledge
Models based on cycles	Linear modeling as first approximation
Explanations based on examples, stories, myths	Explanations based on hypothesis, theories, laws
Classification: -a mix of ecological and use -non-hierarchical differentiation, includes everything natural and supernatural	Classification: -based on phylogenic relationships -hierarchical differentiation excludes the supernatural

## Appendix C



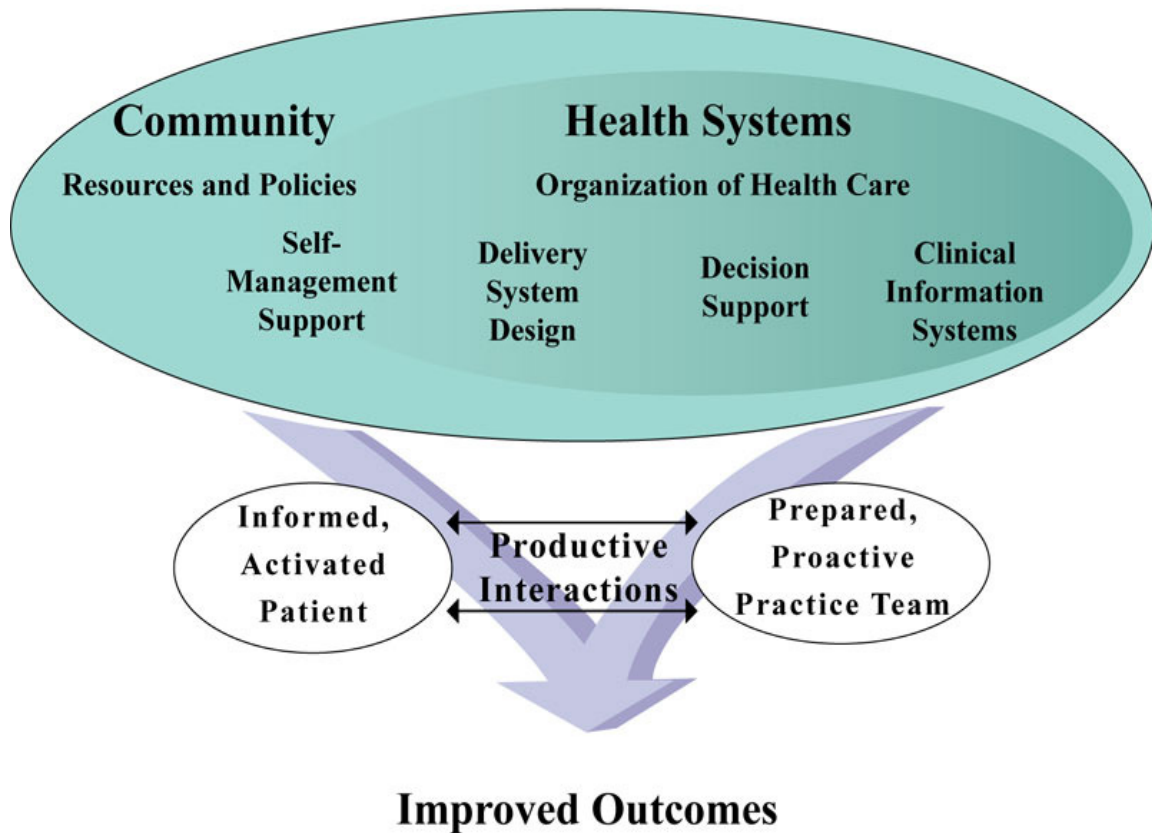
The above is “a CONCEPTUAL MODEL of nursing developed by Madeleine M. Leininger to depict the components of the CULTURAL CARE DIVERSITY AND UNIVERSALITY theory of nursing, named from the form of its graphic appearance. Each culture has a WORLD VIEW and cultural and social structure, which are learned through language and environment contexts. These contexts include technological factors, religious and philosophical factors, kinship and social factors, cultural values and beliefs, political and legal factors, educational factors, and economic factors. All of these language and environmental



contexts influence the care and health patterns and expressions of individuals, families, groups, and institutions; all of the latter participate in diverse health systems, which include both folk and professional systems. The nursing subsystem spans both the folk system and the professional system. To provide culture-congruent care, nurses use knowledge gained through analysis of the components of the model to make nursing care decisions based on cultural care preservation/maintenance (deliverative-assistive or facilitative decisions that include methods of preserving or maintaining lifeways or values beneficial to the client), cultural care accommodation/negotiation (cognitive-assistive decisions that take into account the cultural beliefs, values, and practices of the client), or cultural care repatterning/restructuring (assistive or facilitative decisions that combine several different aspects of the client's culture in a way that is beneficial or meaningful to the client (Miller-Keane & O'Toole, 2003)."

## Appendix D

### The Chronic Care Model

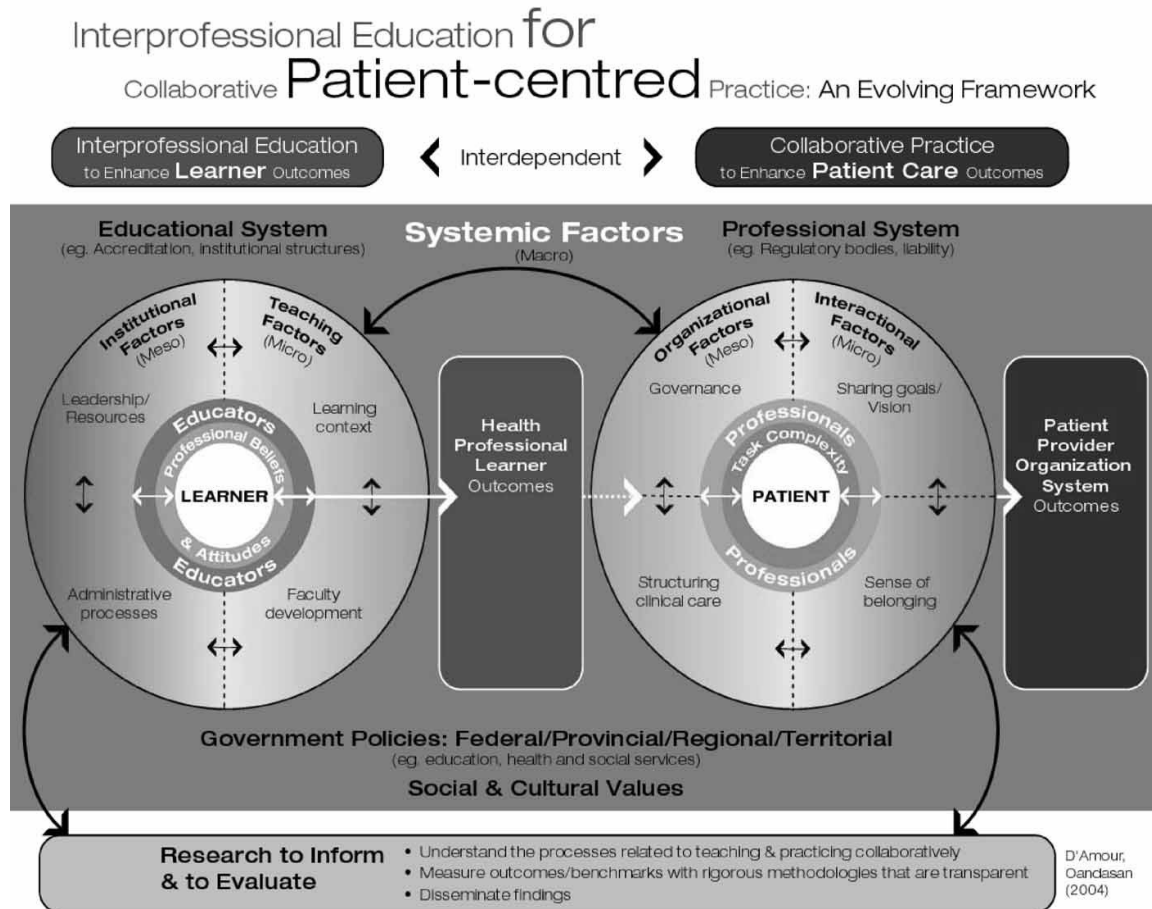


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The Chronic Care Model was first developed in the 1990s by Ed Wagner, MD, director of the MacColl Institute for Healthcare Innovation, Group Health Cooperative of Puget Sound and colleagues, with support from the Robert Wood Johnson Foundation. The model proposes a broadening of the acute focus of the modern healthcare system, in order to provide more effective chronic care and achieve secondary prevention outcomes. The model highlights productive interactions between an informed activated patient and a prepared proactive healthcare team; these interactions are supported by the healthcare system and the community (Mohler & Mohler, 2005). The Chronic Care Model provides a theoretical underpinning for current New Brunswick chronic care initiatives (Health

Council of Canada, 2009). *Getting it right: Case studies of effective management of chronic disease using primary healthcare teams*. Retrieved on July 1, 2009 from [http://www.healthcouncilcanada.ca/docs/rpts/2009/CaseStudies\\_FINAL.pdf](http://www.healthcouncilcanada.ca/docs/rpts/2009/CaseStudies_FINAL.pdf).

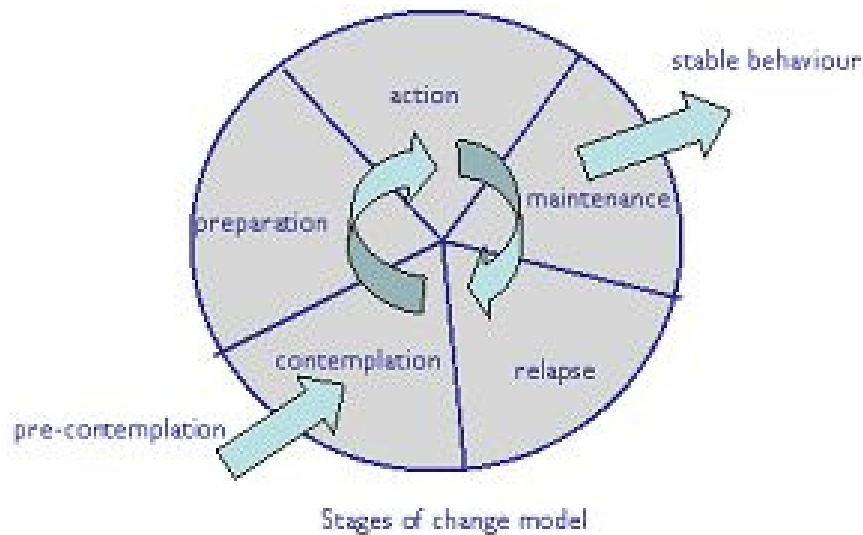
## Appendix E



The Model of Interprofessional Education for Collaborative Patient Centered Practice was developed by University of Montreal nursing scholars D'Amour and Onadasan in the first years of the 21<sup>st</sup> century and crystallizes the work of Health Canada and its associates in the area of interprofessional education and patient-centered practice teams (Health Canada, 2004). The model emphasizes the links between interprofessional education and interprofessional practice, at micro, meso and macro levels. The model also points to mediated learner-patient links, e.g. some training programs use expert patient teachers (O'Neill et al., 2006). The University of New Brunswick is pursuing a

collaborative interprofessional education initiative (De' Bell & Clark, professors at UNB Saint John, personal communications, summer 2008).

## Appendix F



**Diagram of Transtheoretical Model of Behavior Change (Addictioninfo.org, (n.d.)**

The Transtheoretical model of change was developed, starting in 1977, by James Prochaska and colleagues, at the University of Rhode Island. It is a theoretical framework designed to explain generic stages and processes of health behaviour change and is widely used in academic and professional circles, particularly by health educators, to guide them in making interventions tailored to a person's stage in the change process (Prochaska, J., 1995).

## Appendix G

### AI Principles (*Cooperrider, 2003; Reed, 2007*)

- 1) *The constructivist principle* is based on the idea that our thoughts about the world are based on interpretation rather than simple recording and so there are different stories about what is happening that exist alongside one another. AI pays attention to how people construct different stories about the past present and future and the way in which these stories shape and reflect people's attitudes and actions. (Constructivism is the psychological concept associated with the sociological concept of constructionism (Vygotsky, 1978).
- 2) *The principle of simultaneity* refers to the fact that inquiry and change are simultaneous, that is, inquiry is an intervention that stimulates reflection and change at the level of thought and action. Researchers need to maintain an ethical awareness of inquiry as intervention.
- 3) *The poetic principle* acknowledges that people are continuously authoring their world, choosing different parts of their stories to focus on and trying out different plotlines/interpretations of their life poems. AI can support people in this personal and collective process through generous active listening. The AI focus on appreciative story telling links it with narrative methodology.
- 4) *The anticipatory principle* suggests that the way people think about the future will affect the spirit with which they move toward it. AI, in starting off with a focus on what works well, stimulates the exploration of ways present success can be built on, towards a hopeful future.
- 5) *The positive principle* suggests that a focus on asking positive questions engages people because they naturally turn toward ideas and images that provide nourishment and energy, like plants leaning toward the light (heliotropic principle). Capturing peoples' interest by engaging them in appreciative conversations is an effective way to engage them in a change process.

AI principles have been popularized in 8 assumptions.

### AI Assumptions (*Hammond, 1998*)

- 1) *In every society, organization, or group, something works.* This assumption is sometimes expressed as the folk wisdom question about perspective, "Do you see the glass as half full or half empty?"
- 2) *What we focus on becomes our reality.* In drawing attention to achievements and values, reality becomes one in which things can be done well (positive principle).

- 3) *Reality is created in the moment and there are multiple realities.* Reality is dynamic, multilayered and kaleidoscopic (Shotter, 2006).
- 4) *The act of asking questions of an organization or group influences the group in some way.* This assumption is linked to the simultaneous principle and change theory. It applies to individual development and the issue of which among the multiplicity of inner voices are elicited in appreciative exchanges (poetic principle).
- 5) *People have more confidence and comfort to journey to the future (the unknown) when they carry forward parts of the past (the known).* A natural human response to doing new things is to experience fear and anxiety. Approaching change by building on accomplishments affirms peoples' worth, ability, and potential (anticipatory principle).
- 6) *If we carry parts of the past forward, they should be what are best about the past.* This assumption provides direction for the selection of an AI topic and for AI interviews.
- 7) *It is important to value differences.* This assumption challenges AI as action research to respect diversity and not force consensus in interpretation and action design. It also points to the importance of different kinds of reality, as referenced in the recommendations to researchers, by ethnographers Gubrium and Hostein (1999), to "embrace confusion and experimentation with an intermixing of voice, social conditions and authorial aspirations" (p. 57).
- 8) *The language we use creates our reality* (constructivist principle).



## Appendix H



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**And**



### **Patient Consent Form – Individual Interview**

#### **Survey of Patient-Centered Strategies of Diabetes Patients, Using Appreciative Inquiry**

You are being invited to participate in a research study to gather information about how persons with diabetes manage their condition. Too often, health care providers worry about problems that people have in managing their disease. On a more positive note, we are interested in your successes. What is working for you and what helps you to stay on track?

You are being invited to participate in an individual interview with the researcher to gather additional detail about your positive experiences with managing your diabetes. This interview will take a maximum of 30 minutes and will be tape-recorded. The information will be typed, and after the study has been completed the tapes will be erased. Responses will be anonymous. Only group trends and patterns will be reported in data summaries. The data will be stored in a secure office at the University of New Brunswick for five years and will be subsequently destroyed. Only the key researchers involved with the study will have access to the gathered data.

This project has been developed by Roberta Clark (648-5821) and Keith De' Bell (648-5577), both from UNB Saint John, along with Jill Barton McPhee (648-6686) from the Atlantic Health Sciences Corporation. We will use this information to improve programs for diabetics and to educate health care professionals about what is helpful to diabetics in managing their health.

There are no known risks to you and there may be no specific benefit to you personally. Your name will not be associated with any of the information gathered in the

group. You may stop the interview at any time, and your tape will be erased and not included in study data. No information will be shared with your health care providers. Information and results from this project may be used in articles or public presentations; however individuals will not be identified as being associated with specific data.

If you have concerns about the study and wish to contact someone not connected to the study, please contact **Dr David Flagel, Chair, Research Ethics Board, UNB Saint John** or **Nancy Chedore, AHSC Patient Representative, at 648-7614.**



Atlantic Health Sciences Corporation  
Corporation des sciences de la santé de l'Atlantique



## CONSENT FORM

I, \_\_\_\_\_, have read the information presented in the information letter about a study being conducted by Roberta Clark and Keith De'Bell of the University of New Brunswick, Saint John and Jill Barton-MacPhee of the Atlantic Health Sciences Corporation.

I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that my interview will be tape recorded to ensure an accurate recording of my responses and that this tape recording will be transcribed to a written summary.

I am also aware that excerpts from the interview may be included in the articles, conference presentations and other publications to come from this research, with the understanding that the quotations will be anonymous. I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through, the Research Ethics Boards of UNB Saint John and AHSC. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact:

- Dr. David Flagel, Chair, Research Ethics Board, UNB Saint John at (506) 648 5610
- Nancy Chedore, Patient Representative, AHSC at (506) 648 7614.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Yes ☐ No ☐

---

I agree to have my interview tape recorded.

Yes ☐ No ☐

---

I agree to the use of anonymous quotations in any reports (including conference presentations and publications) that come of this research.

Yes ☐ No ☐

---

I wish to receive a copy of the final report on this project.

*(If yes, please provide a mailing address below)*

Yes ☐ No ☐

---

I wish to receive a copy of the written transcript of my interview.

*(If yes, please provide a mailing address below)*

Yes ☐ No ☐

---

Participant name (please print):

**Signature**

**Date**

Researcher Name (please print):

**Signature**

**Date**

If you wish to receive a paper copy of the final report, please provide a mailing address:

Name:

Street:

Apt:

City:

Province:

Country:

Postal Code:

If you wish to receive an electronic copy of the final report, please provide a mailing address:

Name:

Email:

## **Appendix I**

### **Participant Profiles**

**Andrew** is a married, middle-aged person employed in management. He has type II diabetes. Andrew values the support of his spouse, his fellow employees and his diabetes educator.

**Edith** is a married, middle-aged person on sick leave from work, due to a heart attack. She has type II diabetes and bouts of depression. Edith values the support of her spouse, her friends, her cat, and a diabetes prevention lay leadership training group she is a part of.

**Genevieve** is a now single late middle-aged woman who is retired. She has type II diabetes. Genevieve values complementary sources of information on her health issues in combination with information from her healthcare providers. She is guided and sustained by her religious faith.

**George** is a married, late middle-aged person who retired early for health reasons. He has type II diabetes and comorbid conditions. George values the support of his family and his health team, especially his diabetes educator. His religious faith guides and sustains him.

**Jacob** is a married, middle-aged person who is employed as an IT specialist. He has type I diabetes. Jacob values the support of his peers whom he communicates with through the Internet and his diabetes support group, and his health team.

**Josephine** is a now single senior who is retired. She is at risk for diabetes and has other chronic conditions. Josephine values the support of a diabetes prevention lay leadership training group she is a part of.

**Malcolm** is a married senior who retired from management work. He has type II diabetes. Malcolm values the support of his spouse, his diabetes support group, his exercise group, and his health providers.

**Margaret** is a married, middle-aged person who is active in her community. She has type II diabetes. Margaret values the support of her health care providers, and her nutritionist in particular. She is guided and sustained by her religious faith.

**Martin** is a married middle-aged person who is employed in outdoor management work. He has type II diabetes and comorbid conditions. Martin values the support of his wife and health professionals. He is guided and sustained by his religious faith.

**Ron** is a married, middle-aged person employed in management work. He has type II diabetes. Ron values the support of his wife and daughter and his medical team.

**Ruth** is a now single person who has retired from service work. She has type II diabetes, asthma and limited mobility. Ruth values the support of her sister and an empathetic nutritionist. She is guided by her intuition, particularly through dreams.

**Sarah** is a married middle-aged person who has retired early from work for health reasons. She has type II diabetes, asthma and other comorbid conditions. Sarah values the support of her informed family, a team of specialists, and a diabetes support group

**Willow** is a single younger person who is employed as the coordinator of diabetes prevention lay leadership training program. She values the experiential knowing of the persons she works with.

**Fourteenth participant** is a single senior woman who has retired from professional employment and works full time in a voluntary capacity. She has type II diabetes. This

participant values the support of health care providers, particularly the dietician. Her life is committed to her faith.

## Appendix J

### Focus Group Demographic Data

The majority (10 out of 14) of the participants in the individual interviews of the AI Survey Part II were selected from the pool of participants in the AI Survey Part I focus groups. Those 4 interviewees who were not focus group participants were drawn from the same referral sources as the focus group participants. The graph below can thus be assumed to convey some sense of the demographic profile of the individual interviewees.

**Compiled demographic information for 37 participants from 6 focus groups of the *Survey of Patient-Centered Strategies of Diabetes Patients Using Appreciative Inquiry, Part I***

	Number	Percentage
<b>Gender</b>		
Male	11	30
Female	26	70
<b>Age</b>		
18-30		0
31-50	3	8
51-70	17	46
70+	17	46
<b>Live</b>		



Alone	8	22
With a Spouse	22	59
With extended family	5	14
Other	2	5
<b>Affordability of diabetes-related needs</b>		
Comfortably afford	15	41
Have help	13	35
Find it hard to afford	9	24
Note: One person crossed out “comfortably”		
<b>Length of disease period</b>		
Self-described “potential diabetic”	1	3
At risk	1	3
Less than 1 year	2	5
1-5 years	7	19
5-10 years	9	24
More than 10 years	16	43
Type 1, 32 yrs	1	3
<b>Attended education program/classes on diabetes</b>		
Yes	34	92
No	3	8
<b>Have other chronic diseases</b>		
Yes	18	49
No	16	43

No reply	3	8
<b>Most of the time feel well</b>		
Yes	32	86
No	4	11
Replied 50/50	1	3
Note: One <i>No</i> replied “Much of the time when I do not feel well it is not diabetes related”.		

Developed by Jean Burgess, research assistant with the *Survey of Patient-Centered Strategies of Diabetes Patients Using Appreciative Inquiry*, Part I (2011)

## **Appendix K**

### **Participant Stories about Factors in Living Well with Diabetes**

In this appendix I present the voices of the participants (interviewee profiles in Appendix G) through a series of italicized *quotes* that are grouped in the following theme categories: positive personal qualities, reciprocal interpersonal support, and experiential expertise. These themes are aspects of the overarching theme, simultaneously embracing diabetes and embracing life. Participants' stories of living well with diabetes illustrate how these themes are mutually interactive.

I have selected quotations that show the variety of experience among participants. My intent was for the quotations to be long enough to give the reader direct access to the sound and texture of participants' speech and to convey the more evanescent aspects of experiential knowledge. It should be noted that participants are referred to by pseudonyms, for purposes of confidentiality (Appendix G: Participant Profiles).

I reveal how I have entered into a dialogical story-telling exchange with the participants by the way I have chosen to group and introduce the participant quotations (Frank, 2010). Readers will observe my dialogical exchange and compare it with their own dialogue with the participants' stories. While I have used the past tense in introducing participants' statements in the Results chapter, in this appendix I use the present tense, as is used in introducing academic literature sources.

#### **Positive Personal Qualities**

Hope is fundamental. George describes how critical it is during the traumatic shock of diagnosis.

*That was the most panicky time in my life because I thought it was the beginning of the end. And if I could go through that again, and I don't want to, but I would*

*wish that there was somebody that I could talk to . . . if they could come in with some encouragement . . . if you had anything to reassure you.*

Margaret talks about communicating such hope to peers.

*It's good to be able to share experiences with people . . . because . . . it does give them hope to know that it isn't a life and death situation. It can be just as normal as everyday living, as long as you follow your diet and take your medications, you can have a long, long life out of it.*

Other participants mention the hope associated with potential treatment breakthroughs.

Honesty is key to unraveling the complexities of living with diabetes. Edith says,

*You can fool yourself, but it doesn't last . . . I'll know when I say . . . oh yeah I did do that, and I had that extra and I didn't go for my walk, or I stayed in bed too long . . . For me it's a disease of having to be honest.*

While facing what can be known is important so is being able to live with what is not known and still have faith in the value of self-care. Sarah, who has several chronic conditions, says,

*When you have so many different medical conditions, those symptoms can be all symptomatic to any one of them . . . (Chuckle) So you sort of learn . . . this is possibilities of what's happening . . . so what are we going to do to make you feel better for the day . . . you just do whatever you can to alleviate, one by one.*

Sarah also talks about the importance of humour and dis-identification<sup>65</sup> from her co-morbid conditions, in maintaining a balanced perspective. *You sort of put it out there and laugh about it.* Participants share a sense of compassion for themselves and for others, acknowledging the challenge of adjusting to life with a chronic condition. Ruth says,

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<sup>65</sup>Dis-identification is a Psychosynthesis term to describe the action of stepping back from identifying one's sense of self with a partial experiential reality of feeling, thought, or body sensation and then identifying with the observing Self cultivated consciously in meditation and other disciplines (Ferrucci, 1982).

*I really have a lot of understanding and compassion for people who are newly diagnosed and living in denial and just not doing it and just not getting it, because it took me 20 years. And a lot of that time was spent beating up on myself . . . for not being able to do it.*

Martin talks about the value of compassion from personal networks. *It helps a lot if the attitudes of those around you are one of being a fellow suffering human being who realizes that you are not always going to be perfect.* The value of self-respect and respect<sup>66</sup> from caregivers, named by several participants, is articulated in Ruth's story about a helpful dietician.

*She was so friendly and treated people with so much respect and honor, respectful of their very personhood . . . Even though I was acting very rude and had this big attitude, she just kept coming back in this very respectful way and saying that's okay and going on from there . . . the next meeting I apologized to her and told her about the chip I had on my shoulder and why it was there [painful past experience with authoritarian professional conduct] . . . That was the start of me being able to do it [healthy eating] . . . because there was nothing that she said I couldn't have. It was just how much of it and how often . . . how to work with my body in a respectful way.*

Participant and diabetes education lay leader trainer Willow calls for respect for the reality that *clients know best what's going to work in their life.* Sarah talks about the need for assertiveness in communicating with health practitioners.

*I think you have to be just a little bit more aggressive with your family doctors more so than you used to be. I don't know if it's a time issue . . . If I want something I actually have to be a little bit more aggressive . . . You have to be an advocate for yourself. And not be afraid to voice, definitely.*

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<sup>66</sup> Nelson (2001) discusses the significance of respect. "The extent to which our moral agency is free or constrained is determined by our own - and others' - conception of who we are . . . the way in which others identify us establishes what they will permit us to do; if they identify us as morally defective they will perhaps humour us or hospitalize us, or else treat us with suspicion, contempt or hostility . . . If our self conception marks us morally defective we will mistrust our own capabilities and so treat ourselves with suspicion or contempt or exempt ourselves from full responsibility for our actions. (xi)".

For Ruth, respect provides a path to acceptance and self-acknowledgement of what self-care actions she does take.

*I remember years ago trying to follow a diet . . . Because I couldn't follow it to 100%, I stopped trying at all and gained a lot of weight . . . If I had continued to follow it, even though I was only doing it 50% or 75%, I would never have gotten so far off track as what I did. So it's being able to accept, and live with, what we are able to do, and focus on that.*

When professionals, family, and peers are respectful they convey confidence in the individual. Confidence is also a product of experiential learning. Edith describes this as *Knowing I'm doing all the right thing, and if I'm doing the same thing I did yesterday when I did well, then I'm going to be okay for today.* Willow describes the growing confidence of her diabetes education students in the face of the inevitable downswings of a chronic condition; *you'll have ups and downs. It won't be the end of the world because you have tools to bring yourself back.* Many participants recognized the importance of optimism and positivity. Genevieve's mantra is *You can outsmart diabetes.* Margaret says, *everybody . . . it doesn't matter what kind of disease, I guess it's your own way of thinking and your positive attitude that's going to get you through it.*

A key contributor to positivity is gratitude, the ability to appreciate the half full glass.

George says,

*Our finances with the cost of the medical treatment that I have to take . . . its way too close for comfort. But, we get through it . . . That in itself could really make me unhappy, but it doesn't. Because if that's what I have to do to feel this good . . . I've been blessed. And I got to make that my theme. I've been blessed and it's not over yet.*

Persistence and adaptability are recognized by participants as important to successful balancing. George shares,

*You have to be persistent. You can't miss your 7:00 shot if it's supposed to be 7:00. If you have to have a walk at 8:00, you can't put it off and do something else until 9:30 because your body has apparently accepted your new routine . . . And if it's not working the way it should be, then you're going to have to make an adjustment.*

Real life, ranging from the pleasure of family visits to the pain of family illness, and aspects of human vulnerability, what Ruth names *the little kid inside me*, can disrupt the regimen of self-care. Participants talk about the dedication needed to getting back on track and the firm gentleness that enables them to persist, returning through inspirations such as music, meditation, reading, laughter, encouragement of another. Ruth describes an unattached, meditative approach to eating which enables her to move to another level in ease and effectiveness of self-care.

*I took a bit of time to do what I call mindful eating . . . never criticizing myself, just observing myself and becoming fully aware of what my patterns and my habits were. And then I found it easier to know how to work with myself.*

Several participants, towards the end of their interviews, discussed the centrality of their spiritual life, and how that shapes their approach to living well with diabetes. While I have included spiritual life in this section on qualities, which I see as a manifestation of spirit or soul, it speaks to the overarching theme of simultaneously embracing life and diabetes.

Martin says “*My spiritual life is my life . . . God expects me as a good steward . . . you take what's given to you and make the best of it*”. Martin acknowledges the possibility of miraculous healing and at the same time talks about how he does not feel alone in his suffering a deteriorating condition. He rests in the assurances of his faith and the spiritual support channeled through others.

*When the Lord said . . . I'll never forsake you, I don't go through any of the stuff alone*

*. . . A lot of people figure they are alone . . . I have Somebody both that cares and understands . . . it's also in the life of those that are around you.*

Andrew expresses a trust in the adequacy of spiritual sources of support in a referring to beliefs he shares with his sister who has a chronic condition. *My sister . . . says our Dear Savior wouldn't give us . . . any cross that we can't bear and she's right. And that's what I tell people too.* Genevieve speaks of how her faith has provided comfort, calm, and guidance. She says,

*I've always believed in God and Jesus and the Bible . . . I wouldn't be alive today if I hadn't had that to lean on . . . That is one of the main . . . comforts . . . At some point your family is not there and your friends are not there and you still need to have a source that you can . . . feel comfortable going to . . . If I am stressed, I will usually go to the Bible, or if there's things going on that's beyond my control . . . It seems to calm my mind . . . Knowing that God does not want you to worry, that He will take care of it . . . When you . . . feel stressed over financial burdens . . . you can give it to Him to look after or He will give you a thought of how to make additional money or whatever . . . it just seems to work out better that way . . . I still take it back and worry about it maybe for 5 minutes the next day and then I'll say no, you're not supposed to do this and then I . . . give it back.*

Margaret shares how over time she has moved from managing her diabetes by sheer determination to *leaving a lot in the Lord's hands.*

*I believe probably about 95 % [of living well with diabetes] has to do with my faith in the Lord . . . I can't say that I take 100% credit for everything, because I do not believe that I deserve that. I believe the Lord deserves it.*

She sees that her faith has changed the way she understands and approaches life and she senses that she is a channel of spiritual wisdom for others.

*I find that knowing that there is a real God and . . . He has such a much greater love for each and every one of us, that if He can love me that much, then I think I could love Him that much to be able to do His will and to be able to move on with my life and not let it bring me down. Because He wants us to be happy. He doesn't want us to be sad and down. He doesn't want us to be suicidal. He doesn't want us to do anything in any which way or form to harm ourselves. And by having Him in my heart and believing, I believe He has helped me through a great deal . . . it's amazing what you can do when you have that spiritual strength . . . When you*



*give your life to the Lord . . . it certainly changes a lot of ways that you think about things and how you deal with things, right? I sometimes think the Lord is kinda working through me, giving me some answers to give to them [peers] . . . when I'm talking to them. I'm just telling them . . . my story.*

Martin finds spiritual meaning and growth in his experience of a chronic illness. His suffering and his learning make him more able to be there for others, to encourage them.

*Things are allowed to come in order, not to put you down, but that you might grow stronger. And what some people look at as a really negative thing, others then to look at as being something that has a real positive spinoff because none of us are in this teapot alone. We're in there with a lot of other people, so what you learn from it, and what you're able to bring as encouragement to others in spite of it.*

Martin has a clear-eyed awareness of human mortality and both a practical and social sense of responsibility around how he lives with bodily degeneration. He uses a metaphor from winter driving to convey this awareness of a moral duty to be in control of self-care. He practices secondary prevention for the benefit of himself and his family and to honour the gift of life he has received from God. Martin acknowledges the equanimity and sense of meaning he gains by expressing his devotion to God and his loved ones in this way.

*Once you reach 50 it's all downhill, but . . . you gotta be in control of the slide . . . You've got to try to get to the end of the whole scheme of things here the best way you can . . . If you view this life that you've been given, as not just your own, as a stewardship, then you will try to do it, not just for yourself, but for the Lord who bought you, for those around you who love you . . . It just makes sense . . . and you feel better about everything.*

## **Reciprocal Support**

### **Support from family.**

Family response to the diagnosis of diabetes can be helpful in buffering the traumatic disruption of such news. George talks about how he values his wife's reassurance at the point of diagnosis.

*The only person that I had to tell me that (provide encouragement) and I appreciated it, was my dear wife. Because she's never lied to me that I know of . . . She was saying "Honey, you're going to pull through it, like you pulled through your back surgeries. You weren't walking for a period of time. And like, you beat all of that. Don't tell me you can't beat this.*

Family members can be helpful in supporting diet, exercise, and lifestyle changes.

Spouses in particular may participate in the diabetic lifestyle. George expresses his gratitude for this kind of family support.

*When I developed diabetes, B. [wife] acted as if she had too. It was never, "He has it." It was like "We have it." The lifestyle change. When I walked, she walked . . . to have her there with her little hand in mine, it was just worth so much.*

Ron talks about how his wife's established healthy lifestyle supports him in improving his eating and exercise habits. He says *My wife watches her weight and she exercises . . . After [the diagnosis] . . . we would walk for . . . miles . . . she always prepared good foods that are not rich in fats and other things.*

Andrew talks about how his wife is critical to his success, including her support of his medication regimen. He recognizes the effort involved in altering her cooking.

*My wife looks after me very well . . . how good I do is because she does it for me. She looks after the meals with great perseverance and makes sure I do this and . . . that because I can really get up in the morning and leave the house without taking my pills or the insulin . . . she's the best nurse I have. She reminds me of all these things . . . I really didn't want to take this insulin. So for the first 3 weeks she stood right alongside me every time I took it.*

Edith describes the support she receives from her partner around timely eating, to avoid low b.s.

*Well P [partner] is pretty good. He'll say (laugh) before we go shopping, did you eat something? Did you bring something with you? . . . I was having a problem where I'd go out and the stores are so huge now . . . it would get near 4:30 . . .*

*and the low blood sugars just come . . . there's no warning . . . you're okay one minute and then it's there . . . He makes sure that I have some food with me when we go out . . . And eating on time . . . weekends are the hardest because . . . sometimes you're out shopping and you decide well I don't want to go home and get a meal so you . . . go to Subway . . . they have veggies that you can have and it is a better choice.*

Edith's partner gives her feedback on how she is doing with stress and this has raised her awareness of her stress response patterns.

*I don't realize how it's [stress] affecting me, so my partner says, I think you better take a look at things because you're not doing so well, because I'm irritable . . . He's not always that nice about it, but anyway, I get the point . . . quite quickly . . . I find one of the things that I do, I start picking at him, pointing out his flaws. And he says, "Oh, I don't know, I think you better have a look at yourself, here." (Chuckles) . . . I know like pretty fast, now I do.*

Some participants have family members who are health professionals and serve as coaches. Malcolm talks about how his wife helps him keep on track with healthy eating.

*The beast, I mean the dear wife, is a retired nurse, so. Ha, ha. I was told in no uncertain terms, "Don't eat that stuff. It was a guide, more or less . . . She did the cooking . . . so things changed.*

Ronald, whose daughter is his *toughest nurse*, reiterates Malcolm's point about the value of family coaching. *The support of the family . . . sometimes it's hard for people . . . you can do it on your own but . . . you have to get yourself into a routine of doing it and procrastination is one of the worst enemies you have.* Martin talks about how a loving approach to conveying information and guidance is effective in raising awareness and personal responsibility for positive lifestyle changes; his wife is an RN.

*If you have somebody around you that speaks the truth in love . . . through careful guidance [you] may become so self-aware that you will make subtle and positive changes toward the betterment of your health . . . [when you] do have encouragement.*

Sarah discusses how her family members have learned about diabetes through caring for her mother and so can offer more understanding of what she is dealing with.

*My husband, my family . . . is a big support to me. We already have a mum with diabetes and seeing the effects of diabetes . . . it's just nice to be able to talk to someone in the family . . . They . . . have an understanding of what it is you're going through . . . With these conditions you really have to have somebody that understands.*

Sarah notes that support may extend to treatment help. *I teach him [husband] so that he's fully aware of . . . hypoglycemia if I'm having an attack . . . I do carry . . . the glucose tablets.*

Ruth describes how she enlists the support of her sister in a strategy to eat more healthily by eating together.

*Living alone, if I cook a recipe I have to eat it all week. My sister still works . . . I'm retired and so I said to her, "Are you interested in me cooking supper for both of us and then you could throw a few groceries into the pot once a week? . . . What I'm interested in cooking is all healthy meals so that we're getting our vegetables" . . . She was willing to go along with that.*

Ruth is aware of the reciprocal support involved in this arrangement.

*[Sister] works long hours and . . . was just coming home and grabbing a sandwich and never feeling like cooking a meal for herself . . . She says it's just been wonderful . . . to come home and have . . . a healthy meal sitting there waiting . . . It has worked out very well for both of us.*

Ruth is conscious of the support that is available in the example of others' healthy practices. She says, *I have a cousin who has eaten healthy her whole life and I think that she has been a wonderful role example for me.* Ruth and others acknowledge the challenge of eating differently from extended family members and friends and appreciate diabetes-friendly settings.

### **Support to family.**

Sarah notes that cooking healthier family meals is a form of caring for her husband as well as herself. *I cook for us . . . we're both eating a lot healthier . . . It . . . ricochets . . . if you're taking care of yourself you're also taking care of your spouse.*

Ruth articulates a responsibility to serve healthy food to family and others, based on her growing understanding of the importance of healthy eating.

*I've always fed the world . . . cooked for the people I love, my family, and I worked with seniors . . . I always planned my cooking for who I was cooking for and how they liked to eat . . . Since I've started the [healthy recipe] blog, I've come to think differently . . . to realize that I have to take more responsibility for the health of the people that I am cooking for, not just take into consideration what foods that they would love to be eating because 9 times out of 10 the child in them is just as strong as the child in me<sup>67</sup> and would want a kid friendly meal which is not always a healthy meal . . . It's the same idea as that new thing that they're trying to make people aware of is good friends don't make their friends drive home drunk. Well . . . a good friend does not serve one starch on top of another starch on top of another starch and then a big dessert.*

Ruth and other participants recognize the need to accept where family members are at, while gently persisting with skillful encouragement of healthy living. Judith describes her approach with a granddaughter.

*I have a granddaughter that lives upstairs and she buys all this junk food . . . When I cook a healthy meal I always share it with her, "Would you like to try a little of this?" . . . If I have fruit . . . I'll share some of that with her . . . she's pleasantly surprised a lot of the time at the way some of these healthy foods taste.*

Sarah encourages her son and family to go for diabetes screening and she shares her self-care knowledge with them.

*My son and my grandchildren . . . are fully aware that I am a diabetic and I have made them to understand . . . it can be hereditary . . . they are predisposed to it*

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<sup>67</sup> Judith's ability to recognize the different selves she experiences in herself and others helps her to better see how to care for herself and others (Gilligan et al., 2003; Shotter, 2006).

*genetically . . . I ask that they get tested on a regular basis . . . I'm hoping . . . that with what I am learning . . . I teach my son and his family and my grandchildren the importance of what not to do. So that maybe even . . . though they are genetically predisposed to the diabetes . . . they can avert it from occurring.*

Jacob's commitment to self-care comes partly from a desire to support his family by limiting their exposure to stressful diabetes symptoms.

*I've had . . . quite severe eye problems and quite a number of hypoglycemic incidences . . . I'd just need somebody to get me some juice . . . usually in the middle of the night, and probably that affected our [spousal] relationship and is what prompted me to go on the pump and seek out more information . . . It has been somewhat hard on her. It's scary to have somebody unconscious and convulsing on the floor by your bed as you wake up. And my kids have been [affected] somewhat too. I'm not always the friendliest when I go hypo. I don't get violent but . . . I'm very argumentative, kind of like a bull in a china shop wandering around the house, bumping into things. So I knew that had to change.*

### **Support from workplace and social circle.**

Although some people do not understand diabetes self-care, a growing number do.

Andrew talks about management support for timely eating in his work place.

*We have a new sales manager . . . a very intelligent, young man . . . At the sales meeting he came over by my chair and said "Well it's 5 to 12, Andrew has got to eat so let's break the meeting up." . . . I . . . looked at him and he said "That's a great thing that you've done." Because we had a safety talk about diabetic reactions and things like that and he said "I'm teasing you but it's a good thing for everybody to know".*

Andrew's manager affirms the value of disclosure and Andrew, who describes himself as a very private person came to see the importance of disclosure in eliciting support, after having a blood sugar episode during a sales meeting at which he was presenting.

*Someone asked me a question and I told them that they should pay attention because I had already told them . . . The guy I am directly responsible to came over and . . . said "Andrew, how do you feel?" . . . I said, "I feel fine. Why don't you mind your own God damn business?" . . . He said, "Really?" He was one of the guys I had told [about the diabetes] . . . I started to think I wasn't myself and so I said, "I don't feel so good though." . . . He said, "You don't look so good. Whatever is wrong, it's wrong now." So I had something to eat . . . There was*

*some confusion when I changed my medication. I took 2 at the wrong time of the day . . . after that I decided that everybody that I knew, people that I work with and people that I visit should know that I'm diabetic . . . if anything happened to me they'd know . . . give me insulin-*

Support and company for self-care activities are growing as social awareness of the benefits of healthy living grows. Martin walks with a workmate neighbor when they share the same shifts off. Edith, who sometimes struggles with the mood swings and depression that are often co-morbid with diabetes, chooses positive friends to be with, and the company of her cat. *I go around with people that we laugh a lot. We have a lot of fun. And I have my cat.* Malcolm describes the social support and co-operative spirit in his exercise program group.

*There's been 4 or 5 new people come in . . . They [older members] just talk with them and joke with them . . . So they can feel, they can fit right in . . . Everybody helps everybody . . . They support them when they're sick, they send them cards . . . They're a social connection . . . which helps the feeling and the whole group is a group . . . They're from all over, but we're all the same. We work together for the common good, that's the thing I like. It's not the better this one or that one. It's the better everybody and it actually works.*

Josephine describes how volunteering in Brownies has exposed her to a leader who models stress management skills.

*She's a great help when it comes to not stressing about Guiding. She's a very relaxed person and that's the way she behaves . . . I've told her how stressed I would feel about the situation and they don't want me to quit, so she's talked to me about it, and I can tell her just about anything, about the Guiding . . . She has helped me a lot . . . She's always reminding me . . . not to be stressed.*

George talks about social support through networking with friends through the Internet.

He says. *Four or five times a day I check my email. I get a lot of them . . . I've traveled . . . and made friends all over the world, diabetics and non-diabetics. We keep in touch.*

### **Support to workmates and social circle.**

Participants, even those who would describe themselves as private people, experience an irrepressible desire to inform and support others with diabetes or who appear at risk. Andrew acknowledges, *I have a couple of friends that have diabetes and they're not looking after themselves well and I preach to them all the time. I'm not much of a preacher, but I do.* Ronald describes conversations with colleagues and fellow club members.

*At [workplace] . . . other people have been diagnosed with diabetes . . . [They] talk to me about how good they're doing . . . ask me "How are you doing?" . . . There's people in the lodge that I belong to . . . I said you listen to your health practitioner . . . listen to your diabetic nurse . . . they're there to provide you the information . . . they know what they're talking about . . . You need to talk to different people as well . . . There's a lot of great information on the Internet . . . If you get yourself in a regimented program, actually it's not that bad.*

Andrew describes how he avoids upsetting friends who do not understand the restrictions of diabetes self-care by not dining at their homes.

*There are people who really get upset if you're at their house for dinner and you don't have the cheesecake . . . I have friends that I don't, probably don't eat very often with, because [they get] very upset . . . some people don't understand.*

Ruth has created a blog where she posts healthy recipes, a service helpful to persons dealing with various health challenges. Ruth acknowledges the motivation for healthy eating she sustains for herself through this Internet recipe service she offers.

*If I start to fall off track that week then I find I'm not posting any recipes . . . Pretty soon somebody will say . . . "I'm looking for this kind of a recipe" . . . which is a healthy one . . . I'll . . . find some recipes . . . that don't have any flour and sugar or that are low cholesterol . . . say for somebody with kidney disease . . . It helps to get me back on track and stay focused on what I'm trying to do.*



### **Support from diabetes peers.**

Participants are very clear about the value of support received from others with diabetes, individually and through support groups. Sarah talks about how exchanging with peers breaks a sense of isolation.

*I'm . . . in a support group for diabetes and just by speaking with people and listening to other people, you learn. You learn perhaps what not to do, but you also realize yes, that you aren't alone and this is something that's getting high in numbers - the diabetes.*

Josephine explains how exchange in a support group serves a knowledge translation function and creates friendships.

*We . . . talked about what people had to do, or . . . should do and it worked very well, as far as making people feel more comfortable with the information that they were given . . . information that they didn't understand . . . The group could say, "Well, I didn't understand that, what is it?", "Say it in English" . . . They're being sarcastic . . . People that have diabetes can explain it to you much better than the health professionals. They come right down to the nitty gritty . . . They feel less intimidated by somebody that ends up being your friend . . . you're less self-conscious.*

Sarah belongs to a different support group and she values the ongoing diabetes education she receives there from guest speakers.

*I'm one of those that (see) knowledge is power, and so . . . they have guest speakers [at the support group] and an opportunity to learn . . . and grow . . . even if you had that guest speaker before, sometimes they say something a little differently this time.*

Several participants describe the mutual empowerment experienced in lay support and education groups. Edith says,

*I've made some good friends there . . . what it does is . . . you want to go and tell them well I did this . . . I've been working on this . . . where I found this out . . . maybe this will help you . . . It's very supportive . . . we help each other . . . because a lot of times for people with diabetes or any disease like that, you can become very isolated.*

Jacob sees involvement with peers as critical to successful self-management of the complexities of diabetes. He participates in Internet diabetes forums, exercising proper caution, and in a support group. Jacob finds gauging his experience with peers is more concretely helpful than trying to apply statistical generalizations.

*[I'm talking online with] . . . other diabetics who are going through the same thing that I am. They're struggling with their sugars, their weight, their energy levels, their health care team . . . Hearing other people's success stories is probably the number one thing that keeps me going. One thing I've learned is that many diabetics think they know everything but they don't. I've had assumptions crushed many times . . . I thought I knew what was happening and I realized I was off base. All diabetics need to compare what they do to other diabetics, somehow. I don't know if statistics tell them what a diabetic does. The only way to get that is to talk to a diabetic . . . I always tell people, get many opinions, come to terms with it yourself . . . Get opinions from science, from your doctor. You should be talking to your doctor. One thing I'm involved in . . . is a local support group . . . I . . . see some of these ladies really starting to understand what's going on in their lives, what their medication is doing, what they should be striving for, as far as numbers and food and meals. I think we all need to be involved . . . I've often thought that involvement should almost be prescribed by our doctors, our health care teams . . . The doctor . . . should strongly encourage that person to get involved somehow, talk to other diabetics and . . . start caring for your condition and have power over it.*

Willow, the leader of Edith's lay leader diabetes education group, notes the self reinforcing effect of explaining diabetes self-care to others.

*[There is] the feeling that we are helping each other, but we can pass that on . . . to the community which is . . . for this group, very important. The peers that are trained seem to be better able to implement the tools that we talk about . . . it's not the same as . . . going to an information session.*

### **Support to diabetes peers.**

Margaret describes how sharing her weight loss story with peers lets them know successful self-care is possible.

*It . . . inspires other people . . . when I tell them . . . how things went with my mother [who didn't practice self-care] and how things go with me . . . especially when I was first diagnosed with diabetes years . . . ago . . . Back then I watched*

*my fat content to get the weight off and by losing the 120 pounds, that kind of put the diabetes on the back burner for awhile.*

Margaret recognizes the importance of normalizing and even destigmatizing diabetes for peers. She encourages people to deal with depression and shame by talking with other persons with diabetes and by recognizing that the public is more informed now. Her advice is,

*Keep your chin up, don't let it get you down, don't be depressed . . . Find out how other people are living with it and share stories with them . . . Don't go and lock yourself in a closet because it's not contagious . . . It's not something you have to be ashamed about . . . It's an every day, known medical problem that's been going on for hundreds of years. But only now in this day and age more and more is coming out about it, for a more of an understanding. Because years ago people didn't quite understand it.*

Malcolm approaches interaction with peers with an open curiosity. *You have to be broad-minded and understand . . . people are not the same . . . It's interesting, the different approaches.* Genevieve mentions the need to be tolerant and non-judgmental of peers' individual approaches to managing commitments to life and self-care. At the same time she is committed to sharing what she has learned about factors affecting diabetes management. Genevieve believes effective menopause management contributes to effective diabetes self-care for women. She recounts the story of supporting a peer who was overwhelmed with menopause symptoms, by sharing alternative treatment resources.

*She was really upset . . . She said, "Genevieve can't stand this any longer". I had been telling her about what I was doing. And she says where do you get the natural progesterone? . . . I told her . . . I'll bring you up a jar and you can try it for 3 months So that's what I did . . . She said "I would be divorced if I hadn't had it". (Laughing)*

Margaret shares with peers how faith has guided and empowered her self-care efforts.

*There was a fellow . . . he's a diabetic . . . been on pills for years . . . just had to start taking insulin the other day . . . We had been talking about this . . . he said I*

*don't think I could give myself a needle . . . I said D., it's like this, if you have to take the needle, and he's a Christian too, I said . . . the Lord is going to help you and you're going to be surprised what you can do . . . Yesterday . . . he had to take his first insulin needle. He gave it to himself and he was truly amazed how easy it was.*

### **Support from healthcare providers.**

Participants value and appreciate the knowledge and support offered by health care team members. They also express their preferences regarding certain interactions that were experienced as limited in their helpfulness. Sarah emphasizes the importance of access to a team of specialists in obtaining medical guidance.

*I like . . . having what I call a team there for you, because . . . like . . . I never take an over the counter medication without conferring with the pharmacist . . . I want to make sure that it's not going to interfere with anything that I'm doing as a diabetic . . . They're the specialists . . . it's individualized for you because you know each one of them represent a part of what you are going through, whether it be your ophthalmologist . . . optometrist . . . podiatrist, or even your diabetic educator . . . It helps to be able to be able to speak with somebody that you know is specialized . . . you get the results and the answers that you want.*

Sarah faces the complex challenge of managing co-morbid conditions, as do many others, and so this makes her medical team even more important to her.

*I'm very fortunate . . . I have lots of specialists . . . [for] all my other conditions . . . I don't have to go always to my family doctor. I now can go to just my specialists because I'm already set up with them . . . I have an asthma specialist. I have an allergist . . . If things are acting up in any of those areas, I can just go see that individual that's specialized . . . When you have as many things wrong with you as I do, I need to speak to specifics. I need to be very specific in who I see.*

Edith, who suffered a heart attack, notes that her cardiac aftercare program supports her diabetes self-care goal of adequate exercise.

*I'm taking part in an exercise. It's a survey through the hospital to see why men seem to exercise more after their cardiac incident than women . . . I get a pedometer and I exercise . . . and send those results in . . . That sort of keeps me on the straight and narrow for a whole week (laugh) . . . because I want to have good numbers.*

Many participants find their diabetes educators to be most helpful and encouraging in terms of information and approach. George describes how the diabetes educator discerned some of his early fears and addressed them.

*She realized then that my fear was needles . . . She said, “Oh, G, that’s comical because you’re such a big guy.” . . . You’re talking about needles 10 inches long” . . . She showed me a little . . . just a quarter of an inch long and the size of a hair. And she actually let me use that without anything in it, to show (what) it was . . . I was scared of needles . . . And she picked up on that just with a few minutes of our conversation . . . That was her first reassurance. The needles were smaller, the medication is better, “you’re better able to control it from what we’ve learned over the last 30 years”.*

Sarah expresses her appreciation for the accessibility of her diabetes educators. *Even after you’ve done the 3-day training, you have their numbers if you have any questions at all at any time to ask them.* Malcolm mentions the value of conviviality in interactions with professionals. He describes that atmosphere at the local blood testing clinic he visits. *There is a sign out there in the clinic - No Vampires. (Laugh) So I find it much better to deal with people with a sense of humour. You can laugh and joke together and get along better.*

Participants frequently mentioned the life-friendly changes that have been made in the recommended diabetes diet. Ruth describes a positive experience with a dietician, which was a turning point in her ability to practice healthy eating. Her reference to previous experiences of professional lack of respect for patient autonomy highlights the importance of a person-centered collaborative approach. Such an approach supports

resiliency<sup>68</sup> in adapting to the demands of self-care. Ruth had asked to be referred to the dietician for cholesterol management. The dietician suggested considering the diabetes diet which at first Ruth resisted but then became open to trying. Ruth says,

*I walked in there with an attitude because I had been to 2 dieticians before that who both had been very controlling and I really couldn't work with them . . . [One] was a young woman who, when she found out I was taking vitamins, said in this voice . . . "You're taking Vitamin C, well, I'll allow you to continue that for now." . . . She [latest dietician] was so friendly and treated people with so much respect and honor . . . even though I was acting very rude and had this big attitude, she just kept coming back in this very respectful way and saying that's okay and going on from there . . . By the time I went back to the next meeting I apologized to her . . . I said . . . "If you don't mind going over, helping me to choose a diabetic diet . . . I'm ready to give it a try." And so we did and that was the start of me being able to do it [healthy eating]. Because there was nothing that she said I couldn't have. It was just how much of it and how often . . . how to work with my body in a respectful way.*

Martin points out the diversity in individual needs that need to be considered by professionals in order to co-create customized self-care plans.

*For years they tried to put round pegs into square holes . . . in the school system and everything . . . There's a lot of individuality in disease . . . there's a lot of things going to apply to everybody, but it's not just black and white.*

Genevieve notes that health practitioners vary in their openness to helping patients access complementary medicine; in this case a pharmacist is compared to a doctor.

*They will compound natural estrogen and natural progesterone at the drugstore at S. on C. Street, but you need to have a prescription from the doctor. And the doctors do not want to entertain that . . . Estrogen helps your body work in sync. And you wouldn't be losing as much muscle tissue and fat would not be accumulating as much . . . I have been on the estrogen therapy for 2 1/2 years but I had to stop because my breasts were swollen and so painfully sore and miserable . . . I had to go a bra cup size bigger . . . The estrogen therapy just is not a good thing. The chemical one . . . So then I went in search of natural progesterone. And when I did find it, it was through the AIM Company . . . It does*

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<sup>68</sup> Kralik et al. (2006) note, "Interventions that may foster a sense of coherence, collaboration, competence and confidence are important to the process of developing resilience" (p.188).

*make a big, big difference in my experience.*

It appears to Andrew there is good medical information on the physiology of diabetes but less on treatment or self-management psychology. Andrew appreciates and recommends the psychologically informed approach of his diabetes educator.

*It seems like . . . on diabetes . . . there's a lot of very good information, except for the treatment . . . I believe that we have doctors that . . . probably know a lot about the physiology of what it does, but I don't think they understand the psychology of people who have it . . . As soon as the doctor says you have diabetes, go to her [diabetes educator] first, instead of being treated by the doctor first. I think you'd learn a lot more about it. I think people would be more receptive . . . I was particularly . . . moved, isn't the right thing, but when I went to Y . . . I was really concerned about going to someone and telling them about the diabetes. She told me it's not my fault I'm diabetic . . . When somebody does a good job [at work] they're starting something they haven't done before, I give them a lot of positive [feedback] . . . Y [diabetes educator] is very good at that . . . a very positive person . . . So as anybody does when somebody looks at you and explains that you're doing a good job at this, you start to pay more attention right away.*

Josephine describes how some professionals serve as stress management models and coaches.

*They're a model of being calm themselves . . . I've taken a position as coordinator for a poverty workshop we [diabetes prevention education trainee group] do . . . I was stressing somewhat about it but then after speaking with her (nurse educator) . . . it' become much more comfortable.*

Jacob affirms the importance of drawing informational support from as many professional and literature/Internet sources as possible and assessing this information constantly against personal experience and that of other persons with diabetes. He appreciates the encouragement and recognition he receives from his endocrinologist for the results of his extensive research into a blood testing protocol that allows him to better understand his blood sugar response patterns.

*When I presented my basal rates, my [personal blood testing chart] work to my endocrinologist, it was the first he'd ever heard of that, ever seen that done. And it all made sense and he thought it was amazing, thought I'd done a great job and he actually wrote a note to my GP, he didn't know if he could help me anymore, which felt good.*

### **Support to providers.**

When persons with diabetes are responsible, caring and appreciative in their communications with healthcare practitioners, they are providing support to healthcare providers. The participants do not relate many stories of providers acknowledging this kind of team support. An exception would be Andrew's mention of his diabetes educator's appreciation of his consistency in meeting with her.

*She does a good job and she must get discouraged sometimes. I come in and she says thank you for coming in so regularly . . . I kind of smiled at her and I think she knew that I was . . . [thinking] this is what I should be doing and I don't need to be coming back every time. And she says yeah well I know but I have people who don't come for 6 months.*

Participants are very aware of the present heavy work schedules of health practitioners and how that impacts communication possibilities. Participant support is perhaps mostly silent, expressed for instance in an internal compassionate awareness of professional stress.<sup>69</sup> Sarah says,

*[Family doctors] They're just time framing. There's just so much being pushed into a day now and they're probably stressed to the max. I mean they not only deal with patients in the office. They've got hospital visits or whatever else they have to do plus their ongoing studies . . . But it's a sin . . . Then again, it's just lifestyle and it makes you wonder . . . how did we get to this stage in life where everything's . . . such a rush. What happened to the good old days?*

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<sup>69</sup> Carr (2011) notes that healthcare providers who practice an *ethic of care* recognize their intersubjectivity and shared vulnerability with those they care for, and so are open to receiving expressions of care and connection from the cared for.



### **Dreams of enhancing reciprocal support.**

When asked about what might be enhanced in their experience of reciprocal support, participants talk about visions of reciprocal support at a societal level. They express interest in contributing their experiential perspective, observations, and creative thinking to health care policy, planning, and prioritizing. Josephine comments, [Government] *needs to realize ordinary people may have as much information to give about health concerns as the people that work in health professionals*. A number of participants address the need for government financial support for persons with diabetes. Sarah says,

*The Minister of Finance or whatever, I would hope that they would come up with a plan that really helps those that are financially unable to . . . help themselves. Whether it be . . . food or the prescriptions or anything like that . . . Often times they'll . . . have a ceiling of income, but then sometimes there's extenuating circumstances, even though a person is financially okay, but if they have a fairly large family . . . I think they need to broaden the income ceiling and really open some doors . . . There are a lot of conditions, not just diabetes, that you read about that people are struggling, spending thousands of dollars in a year, unable to afford it. They're mortgaging homes and everything, like that's crazy. We shouldn't have to do that, not in our society.*

Josephine shares her support group's dream of a community-based diabetes prevention and maintenance centre.

*That's one of the things we've been trying to do in our diabetic group, is to get out into the community. Well informing people is one thing, but to have an actual place where you could go and get . . . some support . . . We would need financial support . . . and . . . some help from professionals to set everything up and . . . make sure everything is running properly. But it would be a responsibility from the people that were using the facility . . . I think that's what's happened with a lot of our government programs is the responsibility isn't given back to the community. It's run by people that really don't understand the community . . . That's what I'd like to see . . . along with the information . . . diabetes, in prevention, and if not, in maintenance . . . Then you could get the children interested . . . If you had a program for the kids, that they, instead of just being there with a sitter, there could be someone training them, or helping them with learning things that they could do to avoid.*

Willow, the leader of Josephine's support group, elaborates on this community centre concept.

*Just concentrating things . . . to make it easier for people to receive all their care needs, or do their purchasing . . . It could have a little pharmacy, with diabetic supplies and medications and it could have . . . foot care . . . It'd be really cool if they could have little stations . . . that were physically manned by professionals . . . Even a little gym . . . so you can go and do safe activities. Information . . . a borrowing library . . . a testing space, so they could go in and make sure that . . . their bloods are at a certain range . . . drop in, not so much need to make an appointment and get to a place that may be out of your way . . . It'd be great to have either a community kitchen or a cooking class . . . If you really want to go all the way, even a nice little good food corner . . . Really bringing it all together, eh.*

### **Experiential Expertise**

Participants have a clear understanding of the importance and challenge of healthy living in the successful management of the stages of diabetes. Martin says,

*I think people's lifestyle is one of the big hindrances to having somewhat better control of the ultimate results of this [condition] . . . I have found within my own life . . . the benefits of exercise, and so your diet, your attitude and your exercise . . . is key . . . but there's things that you have to realize . . . how to bring various ones into adjustment, some more so at different times during the disease than others maybe. But that's all done pretty well now. That was a transition period.*

Participants recognize the commonalities in self-care practices for various chronic conditions. Josephine says,

*A lot of other things that you may have . . . may resemble it [diabetes] and what you should be doing with your life . . . I have angina . . . high blood pressure . . . arthritis . . . The things that I learned about diabetes also go for helping with arthritis and one of them is . . . try to keep your stress level down . . . That's the same for the heart condition.*

Sarah notes,

*When you have so many different medical conditions, those symptoms can be all symptomatic to any one of them . . . You . . . learn . . . this is possibilities of what's*

*happening or what it could be . . . So you just do whatever you can to alleviate, one by one.*

The experiential expertise of the participants will be presented in the following five sections: knowledge sources, healthy eating, exercise, treatment management, and stress management. As the participants discuss their application of many of the standard recommendations for diabetes self-care, they convey these experiences in plain language and with personal testimony, both of which serve to make these diabetes protocols accessible to their peers. Participants also discuss knowledge and practices outside the common diabetes self-management education programs.

#### **Participant tips about knowledge sources.**

It should be noted that participants have relevant stores of knowledge and experience at the point of diagnosis. Willow (the diabetes prevention education trainer) summarizes her experience of the significant self-care awareness levels of peer leaders and persons she works with, in low-income communities.

*Our messages are certainly not new . . . They focus around areas of nutrition, physical activity and stress management. And to me it's always amazing. First of all that people know that these are the areas they need to work on even before we engage . . . in discussion. That seems to be just a . . . common knowledge across the population.*

Participants acquire diabetes management knowledge from health care providers, reading and Internet searches, peers, self-observation and experimentation, intuitive and spiritual sources. They talk about how this knowledge empowers them

#### ***Healthcare providers.***

Participants find useful both general and process knowledge received from healthcare providers. Ron notes the value of consulting those familiar with one's history. *Talk to*

*your health professional because they know you better sometime . . . than other people . . . I had no reason to question any of the advice or information or counseling that I was given . . .* Following diagnosis George receives professional information as an unquestioned set of guidelines *It wouldn't have mattered if they said [test your blood] 10 times a day, I would've . . . that was the Holy Grail . . . I didn't know anything about it [diabetes]).* Andrew finds his diabetes educator informative and supportive: This leads him to conclude that beginning treatment with a diabetes educator is advisable. *As soon as the doctor says you have diabetes, go to her [diabetes educator] first, instead of being treated by the doctor first. I think you'd learn a lot more about it. I think people would be more receptive.* Andrew adds a contextual dimension to his endorsement of diabetes educators. He notes that 10 years ago he had a different experience. *It's a lot about who you go to . . . My first session with the diabetic nurse, 10 years ago, was not like it was with Y [diabetes educator].* Other participants have noted changes in the field, such as more life friendly diet recommendations. Ruth and Margaret credit consultations with dietitians as providing information that is critical to mastering healthy eating. Sarah emphasizes the breadth and specificity of resources provided to her by her healthcare team: *They're the specialists . . . it's individualized for you . . . each one of them represent a part of what you are going through . . . when you have as many things wrong with you as I do . . . I need to be very specific in who I see . . . You get the results and the answers that you want.* Sarah recognizes how her team can keep her updated *Keeping abreast of the data that all of your team . . . have for you . . . because there is technology and it is advancing.*

### ***Peers, individuals and support groups.***

Participants make many references to experiential knowledge acquired from peers. As mentioned under the Reciprocal Support theme, peers also provide knowledge translation. Ron reports on how discussions in his support group alert him about how to avoid certain problems.

*Diabetes and some of the other fringe things that go with it, you can pick up information from what others have gone through . . . and you don't have to because you can see what fixed it for them . . . There was one of them talking one time about physical trouble sitting . . . I said oh well, I fixed that by going to exercise so I don't have that trouble . . . I see the benefit of staying in shape, where that person isn't. So, I will keep on going.*

Jacob believes that involvement with peers is so essential to mastering the art of diabetes self-care that he wonders if healthcare providers should prescribe it<sup>70</sup>.

*All diabetics need to compare what they do to other diabetics, somehow . . . I don't know if statistics tell them what a diabetic does. The only way to get that is to talk to another diabetic . . . doctors, dieticians, and the diabetes educators almost need to write a prescription to be involved [with peers].*

### ***Reading and Internet.***

Most participants say they read to acquire information that supplements professional input. Margaret refers to the increasingly available popular literature that debunks myths and offers suggestions and hope.

*Just about every magazine has some kind of an article on diabetes . . . it's more apt to catch a person's eye that has diabetes . . . it . . . gives them a little bit more of an*

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<sup>70</sup> Adolsson et al. (2007) quote a woman diabetes education group participant who describes how participatory education with peers supports her learning process. She says, "You walk around with . . . questions . . . way in the back of your head. Then it can be that others in this group ask just this question, and I get an answer to something I actually wasn't fully conscious of" (p. 991).

*outlook and a little bit more information each time they read it and think, "I wonder if that would work for me?" . . . It . . . gives you a good awareness that there's a lot of hope.*

Participants are aware of the need to assess the validity and applicability of what they are reading. Josephine says,

*Read all the information you can . . . not just pay attention and say everything you're reading is true, but kind of diagnosis . . . The information, you've got to see whether it's real or not . . . some things aren't . . . If you go on the Internet, it's not necessarily true for you, and remember that it could be [for] somebody else . . . You do have to pay attention to all the information, but make sure it pertains to you.*

Many participants do online information searches. A few participate in forums. Ruth mentions some of her searches, ranging from adrenal function to healthy recipes.

*Last week . . . I typed in adrenal function to learn what effect different foods had on the adrenal function and how to get that working better . . . I might type in sugar cravings . . . anything to educate myself about what doesn't work well with the body and what does work well with the body . . . I might type in recipes for healthy eating.*

Jacob turns to the Internet to increase his understanding about how to use his insulin pump in the most effective way, drawing on the experience of online peers as well as locating helpful literature.

*I was in a [Internet] chat with . . . a long time diabetic who had very low A1C and was doing very well on the pump and seemed very confident . . . I asked him, "How do I set this [pump] to match my needs properly?" . . . He just said two words, basal testing . . . I asked him what he meant and he said just skip meals and start testing to see what your body does, basically experiment . . . It sounded right, because I've got 2 insulins and I've got basal release and I've got food going in and I've got all this stuff happening and I've got 1 test. How do you figure all that out with one test? . . . It's really a guessing game . . . He said . . . you have to separate your bolus and your basal. So don't eat, don't bolus and just test your basal and see what it does. It should keep you flat. If it doesn't keep you flat, fix it so it does, and then move on to testing your boluses . . . That really struck home with me. I'm a computer programmer and just like computer*

*programming, if you've got a bug what you do is . . . eliminate all the variables one at a time . . . That's basically what this was doing. It made so much sense to me . . . I didn't do it right away. I started researching . . . and found a whole bunch of information on it. It was hard to find but . . . it all made sense. Some groups have developed very scientific approaches to doing this and authors like Walsh who wrote Pumping Insulin, which is the pumper's bible, talks about it in quite detail . . . and Gary Scheiner "Think like a pancreas", does touch on these things . . . also Walsh's "Using Insulin".*

### ***Self observation and experimentation.***

Most participants talk about the value of paying attention to their body experience. Some keep records of body experience, self-care routines, and test results. All participants experiment in a more or less organized way with body responses to food, exercise, and other factors, with a view to balancing their blood sugar levels and maintaining body comfort in areas such as hunger and energy levels. Genevieve notes that each individual is the only one who can sense his/her own body experience.

*You get some information, but as far as you living with it . . . you have to sense what your body . . . that's what I've done, through knowledge of what really works in my body. You have to listen to your body. When you eat different foods, how do you feel? Recognize that and only you can do that.*

Sarah describes how complicated it can be to interpret body symptoms when she has multiple chronic conditions.

*When you have so many different medical conditions, those symptoms can be all symptomatic to any one of them . . . you can't just look at it and go "Well that's my diabetes, today," because that's not necessarily what it's going to be. (Chuckle) So you . . . learn . . . well this is possibilities of what's happening or what it could be, so what are we going to do to make you feel better for the day, sort of thing. So you just do whatever you can to alleviate, one by one.*

Genevieve talks about the importance of recording blood test results in order to monitor one's physical responses over time, of needing to become one's own health provider.

*Record your blood results . . . from your doctor make out a little spreadsheet. Know where your blood levels are. Know what your cholesterol, your triglycerides, your blood pressure [are]. Know that information . . . Every time you go to the doctor, make sure he tells you what it is . . . The doctors do not have*

*the time to talk to you about very much . . . It's in your ball park to know what your body is doing and how it's responding to differing things . . . You are your doctor. So you need to have the tools to work with, which is knowing your test results. And knowing what they were the previous times and what has changed from the previous. Or what has changed in the last 7 years.*

Edith points out the usefulness of recording healthy living activities, which then allows one to detect variations in consistent practice.

*You start writing things down and you see where you didn't . . . you can fool yourself, but it doesn't last . . . I'll know when I said . . . oh yeah I did do that, and I had that extra and I didn't go for my walk, or I stayed in bed too long.*

Martin suggests that practicing body observation and communication is like learning another language.

*Be aware of it [body], and you have to learn how it talks to you. You have to learn a little different language from the ordinary . . . Dealing with diabetes is much like being a linguist . . . you have to listen to what your body is saying to you. And if you can't interpret it, then it's just a bunch of mumbo jumbo and you go along your merry way and it'll be talking but the only trouble is you're saying well that's not talking to me.*

George uses the metaphor of a radio channel to convey the importance of tuning into body feedback in sustaining self-management.

*Now you wake up thinking, "Okay, I have to check my blood sugar." . . . You're on another frequency. You've switched radio channels.*

Jacob goes beyond observation of body responses, in trying to increase his effective use of his new insulin pump. He proceeds to extensive experimentation with food and insulin inputs. Jacob transfers his information management skills as an IT specialist to this investigation and in doing so gives an example of the protoprofessional knowledge some patients develop. Jacob is gratified to receive recognition from his endocrinologist for the successful outcome of this personal applied research, a refined administration of insulin, which reduces his daily dose by 30 units and is associated by him with an increased



feeling of well-being. I include an extended version of this excerpt as a footnote<sup>71</sup> for the benefit of lay readers as it conveys the complexity of factors determining the body's insulin use.

*I developed some spreadsheets . . . to monitor . . . [experimenting with insulin and food inputs] . . . What doing that for each meal has done, is I've understood my behaviour for each meal . . . I know that in my afternoons I have a long, slow curve and in the evenings it's much like my mornings, I have to bolus early . . . I understand my patterns . . . When I take a reading now, I can apply it to that pattern and say am I on the road or not and it means so much more to me . . . I had to do all that experimentation up front to find out what the road looked like before I knew if I was on it . . . I'm down [from 90] to around 60 units (of insulin) . . . a day. And I'm feeling fuller than before. I've feeling more vibrant than before and I'm losing weight. And my endocrinologist says, he can't argue with success.*

### ***Intuitive and spiritual sources.***

Several participants talked about accessing information in more right brain ways.

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<sup>71</sup> *I developed some spreadsheets . . . to monitor . . . [experimenting with insulin and food inputs] . . . I started doing it and . . . found immediately my basal rates were . . . way off. When I skipped breakfast my sugars shot way up. So I started playing with it, doing these basal tastings for 1 meal at a time, breakfast, then lunch, then dinner and then overnight. One night I even stayed up all night to test every half an hour to see how my sugars were doing . . . Once I got my basal rates pretty well flat, then I started working on [the content of] my meals . . . I took the . . . same regimented approach. I decided to eat the same meal every day and then titrate my insulin until I would get it where I wanted it . . . I took my regular breakfast . . . 2 pieces of toast and a glass of milk with maybe a little peanut butter and jam on the toast and I just couldn't get my blood sugars down . . . I finally discovered . . . that I have to employ some other techniques sometimes. I had to take my insulin half an hour early because food impacts me almost immediately. My sugars go up within 15 minutes and when I take insulin my sugars don't start going down for maybe half an hour to 45 minutes. It's a matching game and I had a matching problem. Also in the morning there's something called dawn problem, which makes you very insulin resistant. As you're sleeping in the morning your body decides to release a bunch of hormones that just interfere with your insulin resistance . . . I had to cut back my breakfast. I went down to 1 piece of toast with some honey on it. And I take my insulin when I go in the shower . . . when I get out of the shower and after I'm changed, I eat breakfast and everything works out great. In fact I have to also cut my basals later in the morning or I'll go hypo before lunch. What doing that for each meal has done, is I've understood my behaviour for each meal . . . I know that in my afternoons I have a long, slow curve and in the evenings it's much like my mornings, I have to bolus early . . . I understand my patterns. I don't say perfectly. I don't think anybody does perfectly . . . When I take a reading now, I can apply it to that pattern and say am I on the road or not and it means so much more to me. So I had to do all that experimentation up front to find out what the road looked like before I knew if I was on it . . . I'm down [from 90] to around 60 units (of insulin) a day. And I'm feeling fuller than before. I've feeling more vibrant than before and I'm losing weight. And my endocrinologist says, he can't argue with success.*

Ruth acknowledges the informing role of her dreams.

*You're just plodding along, one step at a time, but looking for help and direction and it's given to you. This is crazy, but I've got help and direction from my dreams for the last 30 years and sometimes when I wake up in the morning, something shifts in my head and so I go and I put it in the computer and see what comes of it . . . All things that we dream come in the honor of our wellness and wholeness . . . Because I'm so focused on trying to work with my physical body, I think that's where these things are coming from . . . One of the things that I woke up to one morning was mindful eating . . . I . . . typed it into the computer and then was amazed to find there were all these sites with just that. It led me to all these sites with . . . different things that I could learn from . . . That's when I picked out a few simple little things and tried them in my own life.*

Several participants mention spiritual practices, which help them perceive differently and think more creatively. Margaret says *When you give your life to the Lord it certainly changes a lot of ways that you think about things and how you deal with things, right?*

### ***Knowledge impact, empowerment.***

Participants speak of how adequate knowledge is linked to psychological comfort and confidence in managing diabetes or its risks. Josephine (diabetes prevention education lay leader) describes how diabetes information reduces her fear about her susceptibility to diabetes.

*At first there was fear when I found out I had all these symptoms, or not symptoms . . . but risks . . . After going to talk with the other people that have diabetes and all the learnings that I've done . . . I feel more relaxed about diabetes . . . My mother has diabetes and I was very nervous about whether I would get the diabetes, but now I feel more confident that I won't . . . I just have to do these things that I'm doing for my other illnesses.*

Sarah says *Knowledge is power . . . Because you can't manage something well if you don't have the knowledge or the power behind you of what you read and what you learn from the various components of the {healthcare} team.* Edith elaborates,

*I can do all these things . . . to look after myself . . . When you just go to the doctor and you think they're going to give you a pill and that it's all up to them . . . you're not very empowered. And it's not very realistic because it doesn't work.*

George tells a story that illustrates how diabetes knowledge has changed his perception of peoples' capacity for self-management and the accompanying responsibility for their health. He says,

*I'm a country and western fan . . . 2 years ago I heard - just right out of the blue, a broadcast. It said Waylon Jennings died this morning at age 63 from complications from diabetes. By his own admission he was on drugs. He was a heavy drinker. He didn't get enough sleep. He overindulged. What killed him? Complications from diabetes, because my hero, Waylon Jennings, did not take charge of his situation . . . He lived to be 2 years older than I am right now because he neglected the most important thing in his life, which was his life . . . That's not going to happen to George. I miss Waylon. I miss his lyrics. I miss he and Willie singing together . . . However, in a part of my mind I'm saying, "Well Waylon, you coulda done better, buddy." Because I know now. I wouldn't have known . . . 7 years ago. I would have said "Poor Waylon, he couldn't help it." But you see, Waylon didn't help it. And I'm not trying to dump on Waylon. He's still one of my heroes. But I know that people can come from right on their back, unable to move, to back up to what I'm telling you right now [about my management success].*

### ***Dreams of enhanced knowledge sources.***

Participants talked about a future vision of enhanced information accessibility through community-based diabetes-drop in centres, hospitals, and public education campaigns. Malcolm says, *There's got to be some encouragement [of healthy living to prevent type II diabetes or its complication] . . . the government is the only one big enough to promote it, the benefits, the lower cost.* Participants emphasize the importance of peer support groups as a source of practical information and knowledge translation of professional knowledge. Jacob envisions doctors prescribing such a group. Ruth's vision of widespread peer support groups grows out of her experience of feeling on her own after diagnosis.

*So if there had been a support group . . . where you could learn more about food and more about how to share with one another, how you were coping with it or*

*how you were cooking that is different from before, you could accept it more easily. Instead you're completely on your own in a family and a world of family and friends who are all continuing to eat a certain way and all of a sudden you've got to learn a new way . . . You don't even know how to do it or what you should be doing, really.*

Participants discuss their knowledge and practice in the areas of healthy eating, exercise, blood sugar management, and stress management.

### **Participant tips for healthy eating.**

Healthy eating is central to self-management and every participant speaks about growing experiential expertise in this area. Andrew says, *The one thing that I'm probably most proud of accomplishing in my life is my diet.* Ruth talks about a disciplined way of eating. *It shows up in the blood sugar levels, in the doctor's office, in the blood tests, but on a day to day basis I know full well whether I am eating in a disciplined healthy manner.* Participants discuss the following aspects of eating healthily: positivity and enjoyment; timing - avoiding *hypos* and an insatiable hunger; snacks; portion control and weight control; traditional treats and changing taste buds: dealing with food cravings; a diabetes-friendly diet; accessing food-shopping skills, planning ahead, affordability, availability of healthy choices when eating out, a reflection on the food system.

Participants discuss skills and challenges in accessing healthy food. They have learned how to locate and choose healthy foods when shopping, how to prepare healthy food ahead for days when they have limited time or energy for cooking, how to locate healthy food when eating out, and how to include some fruits and vegetables when on a restricted budget. One participant refers to the challenges presented by conflicting views

on the health value of carbohydrates versus proteins and fats, and issues of accessibility to healthy food, associated with the unhealthy state of the modern food system.

***Make mealtime a positive experience.***

Martin's experience is that focusing on what you *can* eat is an effective approach.

*The first time I ever started on this . . . the fear was put into you that Man you've got to change, I remember telling the dietician . . . "Do not bother telling me what I cannot eat; tell me what I can eat . . . I know the negative, tell me the positive." "Okay . . . you can have this and this . . . and you've got to watch out for this" . . . I believe that if you can approach things in as positive of a light as possible, you'll have better results.*

Sarah honours the pleasure of eating by focusing on taste and atmosphere. *I really enjoy my food, so I savour . . . I like my meals relaxing and I like the atmosphere.* Ron notes, *I'm eating sensibly now and enjoying it more.*

***Eat meals and snacks at regular intervals.***

Andrew describes his biggest step as developing awareness of the need to eat regularly and integrating this into his work day. *My biggest change is my regularity in paying attention.* He dramatizes this by comparing his old pattern of skipping meals with his present regular schedule.

*If you called me at half past 11 and said did you finish this project, it was a very interesting project, it would be 4:00 before I'd [know it] and I'd start to feel a little bad but then it would go away after awhile. Now I eat . . . The first 25 years of my working . . . I would get up in the morning and have a cup of coffee and a cigarette and at lunch time I wasn't really that hungry and by supper time I was terribly hungry, ate the wrong way, traveled . . . It's hard to turn it around and start eating 3 meals a day. I still don't like to eat breakfast. I do it early so I can get it over with . . . at 6:30 . . . [I] have a couple of crackers at 10:00 . . . I have my lunch as close to noon time as I can. I have my dinner . . . between 5:00 & 6:00.*

Andrew is proactive and assertive about timely eating at work.

*I have been in meetings where I've had to excuse myself because I've got to eat . . . I've brought it back . . . Those people who insist on running meetings too long because they can - I've been with the company 30 years and . . . I'm not scared . . . I know what's right and wrong.*

George talks about the importance of timely eating to avoiding hypoglycemia.

*You have to make sure if your blood sugar is down, which quite often it is in the morning, that . . . you . . . eat your breakfast before you shower, because if not, you're going to feel pretty yucky after your shower.*

Genevieve has learned about the association between feeling hungry or even insatiable, and not eating on schedule.

*If I get really, really hungry, I can't satisfy myself with anything that I eat. If I go more than 5 hours without food, I will want to eat . . . nonstop . . . starving . . . It's like you cannot get enough to eat.*

Participants grow to recognize the importance of snacks in avoiding low blood sugar and hunger pangs. Edith speaks of *having a snack, even if you're not hungry . . . When we go out I always have a carbohydrate snack of some kind and I try to take some fruit and have that with me.* Genevieve includes a protein in her snack, as an effective way to ward off hunger between meals

*If I eat an apple and I don't have any protein, within 25 minutes, I've timed this, my stomach is ravenous . . . If I put . . . a 1 inch cube of cheese, its fine . . . [or] any of the nuts . . . You can eat an apple and then half an hour later you're going to want something else . . . an apple or a pear . . . If you're eating an apple . . . a healthy carbohydrate, but even with the peeling and it being a hard apple, it still creates a natural sugar in your body which will . . . in my case, will still spike your insulin, your sugars will go up a bit . . . the protein prevents that.*

***Utilize portion control and other weight management techniques.***

Participants are aware of weight as a risk factor for diabetes as well as the advisability of reducing intake of foods which spike blood sugar levels. Edith suggests a

gradual approach to portion control. Try having a smaller serving . . . a gradual reduction . . . If you're having 2, have 1.

Ruth describes a mindful eating<sup>72</sup> exercise that helped shift her eating habits.

*I didn't eat until I felt hungry and then I was fully aware of what I chose to . . . put on my plate and when the hunger was satisfied did I . . . stop . . . If I continued to eat, why did I continue . . . I did that for a . . . week . . . never criticizing myself . . . just observing myself . . . becoming fully aware of . . . my patterns . . . and habits . . . Then I found it easier to know how to work with myself.*

Margaret loses significant weight by reducing fat intake. She believes the weight loss has enabled her to manage her blood sugar balance without medication for a number of years.

*I watched my fat content to get the weight off . . . if I was eating a whole bag of potato chips, I'd cut it back . . . By losing the 120 pounds, that . . . put the diabetes on the back burner for awhile . . . As you get older . . . things are bound to start coming back . . . I got so I was 50 before I really had to start taking any major medication.*

Genevieve finds that to lose weight she needs to reduce the recommended amount of carbohydrates in the diabetes diet and increase her protein consumption.

*I was not losing anything on 8 carbohydrates a day. I could exercise my heart out, and it's just not going to work . . . The good books do specify that you should eat protein with each snack and each meal.*

Ron does not deprive himself and loses considerable weight through moderate healthy eating and exercise.

*I don't deny myself a lot of things . . . but . . . I'm more wise . . . I don't eat in large volumes . . . I dropped 45 lbs. within . . . 2 ½ months, but I didn't do it in a crash diet. I did it through exercise and eating properly.*

Malcolm says his diet change, combined with exercise, has reduced his weight. He notes

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<sup>72</sup> Framson et al. (2009) developed and validated a mindful eating scale for investigative purposes, indicating there is applied research interest in this alternative approach to weight control and healthy eating.

the expense of buying a new wardrobe, which would be a financial challenge for some.

*When I got diagnosed with diabetes, I weighed 205. Clothing was extra large. Now I weigh 173.*

The 14<sup>th</sup> participant (audible transcript fragment) notes the importance of knowing the difference between hunger and thirst and drinking adequate amounts.

*The key is to eat small meals, make sure you get enough and pay attention to your body, when you're hungry or when you're thirsty and to know which one it is . . . I take my liquids . . . maybe 1/8 of glass of cranberry juice with the rest full of water.*

Martin talks about eating moderately, while acknowledging that the desire to do so varies. He indulges his love of eating with little treats while still achieving weight control.

*I try to eat sensibly, but not always being able to do that, or not always even wanting to do that . . . To know what to do good, and to do what is good, is two different things . . . that's where you get into the psychology of mind over matter, the will . . . There's some days you know you shouldn't eat things and I don't care, I'm going to have it anyway . . . That's where I try to hold the horses back and give myself the little treat . . . That way I won't go hopefully on a binge . . . If am in control [in charge at work] then your mind is not so much involved with eating . . . I used to eat for the love of eating, so when you cut back . . . that helps your weight.*

***Enjoy treats in moderation.***

As Martin mentioned above, he and other participants find they are more successful in maintaining healthy eating habits if they give themselves permission to be flexible in following diabetes diet guidelines. Martin describes his traditional treasured treat while on a work break. He notes that treats help him avoid the risk of bingeing.

*I give myself a little treat if I go on the mainland. I always have . . . I've got them trained when they see me coming over at the shop . . . I want my treat . . . that is 7 . . . or less, or maybe a few more, but mostly around 7 of those chocolate covered*



*almonds . . . So far it has worked out pretty good . . . Those are one of the things that I like and I guess the lesser of 2 evils . . . That way I won't go hopefully on a binge . . . [because of] the monotony . . . the pressure of responsibility.*

Malcolm enjoys baked desserts and fruit in moderation. He does not feel deprived because his desire for sweets has decreased over time, with his diabetes diet.

*You can, a couple of times a month have banana cream pie . . . but not every day. You have to be aware of the fruit situation and don't overdo it . . . That's not a great big deal because after a bit . . . you adjust . . . Candy . . . doesn't interest me anymore; I don't know whether the taste buds are shriveled up or what it is, but certain things I used to eat 30 years ago, I don't any more.*

***Take steps to avoid triggering food cravings.***

Participants talk about how they learn to deal with food cravings. These include becoming aware of eating patterns and emotional eating, avoiding certain foods, finding healthier recipe ingredients, keeping healthy foods on hand, using outside support to establish limits, and satisfying oneself with 3 bites of a treat. One participant discusses food cravings as a mysterious addiction, which she continues to research.

Ruth has become aware of emotional aspects of eating. *I have discovered the little kid in me is alive and well and sometimes stronger than me.* Ruth has also learned through observation that refined ingredients such as sugar and white flour trigger cravings.

*I have noticed that I can go . . . 2 weeks eating healthy food and then if I'm out somewhere and I'm offered and accept one thing that's full of sugar, the next day . . . I had sugar cravings all day long . . . I began to realize . . . no wonder I've had such a hard time getting myself on the right path. There's a physical reason. There's something happening inside my body.*

Ruth discovers unbleached whole wheat flour, which relieves her cravings. Ruth uses her knowledge of healthy food ingredients to create dessert recipes that limit cravings.

Edith says that eating fruit helps avoid sugar cravings. *I find days I don't have enough*

*fruit then I crave sugars, because I'm not getting that from the fresh fruit.* Sarah finds that she can manage food cravings by allowing herself a taste. *When you are craving something it actually only takes 3 bites. Savour those 3 bites and you get the same satisfaction.* Malcolm acknowledges the stress of withdrawal from a high sugar diet and notes that it helps to have a “coach” in the family who can support limits until they become natural.

*It was sort of irritating at first . . . You have to force yourself . . . You really need . . . somebody there to keep watching. Otherwise, your tendency - oh that doesn't matter . . . you'll slip right out of it . . . If there's someone there who understands the business, and can keep an eye on what you're eating, especially, you're much better off . . . It's just a matter of your psychology and physiology changes . . . your taste buds change . . . I find after you have established your limits you live within them no trouble.*

Some participants deal with food cravings by not bringing the addictive items into the house and by having healthy food available Willow says *Make sure you freeze . . . a leftover . . . That way you'd have it on hand so that if you needed to have something fast you won't . . . grab . . . a bag of chips.*

Genevieve wonders if food cravings are an addiction with emotional and physical components. She has observed her craving for potato chips and noticed an association with stress. However she also wonders about the physiological impact of the fat or salt content. She would like more information on this puzzling experience of being out of control.<sup>73</sup>

*I cannot control myself around potato chips. I am addicted . . . If they're in the house, I*

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<sup>73</sup> Kessler (2009) combines an academic literature review with interviews in seeking to understand why he and others cannot resist certain foods. His resulting theory is that foods high in fat, salt and sugar alter the brain's chemistry in ways that compel people to overeat.

*cannot leave them alone . . . It has nothing to do with hunger . . . I cannot rest, I cannot stop . . . it's when I'm stressed . . . I don't know, I can't get my head around the potato chips . . . Am I getting too much omega 6 and its causing . . . that craving? . . . I've even mentioned it to the dieticians and they're no help.*

***Find an individualized diet which balances health and enjoyment.***

All the participants discuss individual alterations in their eating habits; these include limiting consumption of less healthy foods, increasing consumption of healthier foods, noting changes in what they enjoy and appreciating a sensible eating approach that includes a judicious quantity of treats. Ron avoids items such as fatty beef, uses substitutes such as veggie burgers, eats more fruit, and prepares food from scratch.

*Stay away from anything white . . . sugar, salt and white flour . . . I use lean ground beef . . . I enjoy more vegetable hot dogs now than regular hot dogs, and vegetable hamburgers more than regular hamburgers, which I couldn't believe . . . I drink water and I still drink coffee, but I don't drink juices. I'll eat fresh fruits all the time . . . I did before but I enjoy it more now . . . I'm very careful how I cook things . . . I still cook things sometimes that . . . have . . . grease . . . I do a lot of things from scratch . . . it's . . . much healthier. I don't go to McDonald's or any of those places, maybe once a year.*

George mentions steps to eliminate sugar from his diet.

*We very carefully sorted out the jam . . . double pieces of pie, and the foolishness . . . [In the morning] B's [wife] . . . got half a grapefruit, ooh, I don't like that Splenda, but anyway . . . and there's my cereal, oh more Splenda.*

Ruth does not serve fruit after meat, for effective healthy digestion.

*I don't eat fruit at the end of the meal because fruit on top of meat causes it to stay in the stomach longer . . . ferment and take longer to digest . . . Little changes like that I find I'm trying to make in my family.*

Diet changes are more likely to succeed if they are adopted by the whole household.

Andrew acknowledges the effort involved for his partner in making diabetes friendly cooking changes.

*How good I do is because she [wife] does it for me. She looks after the meals with great perseverance . . . She's dedicated to making great food . . . She's cooked with Splenda . . . for 10 years. It was hard for her to do but she never batted an eye.*

Margaret tells of how learning from the diabetes clinic dietician about the diabetes carbohydrate diet provided knowledge critical to managing her diabetes.

*I believe the turning point [in successful blood sugar management] was . . . my diet . . . Years ago they [dieticians] said you couldn't eat this . . . you couldn't touch that . . . This time around when I went to the dietician, she explained things more outright . . . They used . . . the carbohydrate diet . . . you count your carbs. If you're allowed 2 carbs for your breakfast, well you had your 2 pieces toast, or you had a bowl of cereal . . . By sticking with that, that gave me a better outlook on how a person should be eating their meals without overdoing it or under doing it. So that you'd have a balanced meal . . . I think that was the big basic turning point for me, was getting to the understanding of the diet.*

Edith says, *The diabetic plan has changed so much over the years . . . it's just so user friendly now. You really don't have to do without anything, you just have to be . . . a little bit sensible.* Some participants find that a more protein-based diet works better for them.

Jacob describes how he has come to adopt a low carbohydrate diet based on exchanges with peers, through his reading on the issue, and through experimentation. Jacob is motivated by the desire to decrease the risk of carrying extra weight and by his health concerns about the quality and quantity of carbohydrates in the modern Western diet<sup>74</sup>.

*We've had . . . discussions on diabetes [web] forums and other forums I belong to about low carbohydrate diets versus high carbohydrate diets. There's much discussion . . . on what the correct diet is for a diabetic, whether you're type 2 or type 1, especially one that wants to lose weight or . . . keep off weight . . . Insulin . . . [is] known to have [an impact on] weight . . . After several months of discussion and listening . . . after reading a book called "In Defense of Food" by Michael Pollan . . . and some excerpts of another book . . . "Good Calories, Bad*

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<sup>74</sup> Dr Wortman a senior advisor with Health Canada has developed a diabetes friendly diet based on the traditional Haida diet, which is low carb, high protein and fat. Its apparent effectiveness is being investigated. (<http://www.cbc.ca/thelens/bigfatdiet/wortman.html>; Accurso et al., 2008).

*Calories” by Gary Taubes, and [after I] listened to a number of videos and online radio tapes . . . I've become convinced that high carbohydrates, especially high refined carbohydrates, in our diets, are probably the root of the obesity crisis we're in and the diabetes crisis and heart disease and cancer. I can't prove that scientifically, but the correlations are so high that it's not easily discounted . . . I've . . . followed a number of people who have dropped the carbohydrates and immediately started dropping weight. So I decided to do the same thing . . . I know carrying excess weight is not good for me in the long run and I'm not clear either that lowering carbohydrates would be good for me in the long run, but I know that carrying the weight won't be. So I've decided to . . . take the plunge . . . In the last 5 weeks I've lost just about 10 pounds . . . I'm primarily focusing not . . . just on losing weight but making sure my sugars stay under control . . . I'm feeling fuller than before, I've feeling more vibrant than before, and I'm losing weight.*

The 14th participant (audible fragment of interview) discusses the importance of distinguishing hunger from thirst, drinking healthy liquids, and avoiding aspartame.

***Read labels when shopping.***

Participants describe shopping for food with increasing awareness and skill.

Malcolm avoids sweets, reads labels and acknowledges the growing variety of food choices.

*It's just a routine. When you go down to Sobeys, you go by the candy stuff . . . You pick up the different groceries . . . read the label thing to tell you what's there and the high sugar . . . It's just a matter of being aware of what you should not be involved with . . . The selection of groceries now . . . there's food there that was never there 10 years ago . . . You really gotta look and see what's in them before you try them . . . You get Thai food and Chinese food and Vietnamese stuff. You get them from all over . . . sugar is not a big deal in the Asiatic things.*

Ron is very selective in his shopping; he reads labels and avoids canned goods, salt, sugar and white flour.

*I'm very picky when I go grocery shopping now . . . I do a lot of research . . . I'm very careful . . . I read those labels and I don't eat canned foods or canned products . . . I look at grain products, I mean whole wheat. I make sure I look at salt content . . . stay away from . . . sugar, salt and white flour.*

***Plan ahead so there are healthy choices on hand.***

Participants talk about the extra planning involved in ensuring they have access to healthy food during times when their daily schedule is altered or they are unwell.

Genevieve describes the work involved in preparing healthy food for herself and her summer company which can be frozen for use as a quick meal after returning late from an outing.

*I know there'll be an upset [in my routine] because I'm going to have 5 extra people here . . . I'll be planning and preparing and . . . have 2 or 3 meals prepared ahead of time and then just put them in the freezer, so that I can pull them out . . . I usually like to prepare all my own meats and sauces . . . so I know what's in them . . . how much salt is there. I'm using extra lean ground beef to make my pasta sauces . . . to cut back on fat and . . . it's just healthier . . . I add a lot of vegetables . . . Those things I can do ahead . . . if we're late getting back then I can heat them up and just cook the whole wheat pasta and put a meal together really quickly.*

Edith talks about using days she is feeling well to prepare and freeze meals for her *bad* days.

*With any condition, you have your good days, you have your bad days . . . On my good days I then take that opportunity to do a lot of advanced prep work . . . I do food up and I freeze it. I cook . . . up, my vegetables and that, so then on a bad day, and I really don't feel like doing much, but I know I have to eat properly, I just have to go in and grab a bag and I put it in the microwave or whatever and heat it up. And I've got my meal there, within minutes.*

***Find inexpensive vegetables and fruit to fit low budgets.***

Some participants want to eat healthy but are challenged to so with limited finances. Willow discusses how this is true for the lay diabetes education leaders she trains. Persons on tight budgets watch sales and choose less expensive forms of healthy food such as frozen vegetables.

*When I [as an educator] say "Look at nutrition" that might be a tip for somebody who is . . . perhaps overeating or just . . . not paying attention to the balance.*

*Many people, at least in our group . . . know what the balances are, but it is an affordability issue . . . It's still very hard for people on budgets to get fresh . . . foods . . . Oftentimes people will make sure they have some frozen vegetables on hand . . . Other . . . strategies would be like freezing stuff during the summer . . . You might have to have some Kraft dinner, but try to have a piece of meat with that . . . Look at the flyers and when you do see sale items pick those up . . . some fresh grapes or . . . broccoli.*

***Be aware of food choices in restaurants.***

Participants remark that it is a challenge to find healthy choices when eating out. Edith says (*When we eat out*) *we do go to Subway and they have veggies . . . it is a better choice.* Jacob describes his effort to find healthy low carbohydrate restaurant food. He has learned to ask about the content of dishes. This has helped him see that the modern North American diet is based on high carbohydrate foods.

*It's been a challenge finding suitable meals. I've been working downtown, and once in awhile I will eat my lunch out. There's about 10 eating establishments that I walk by . . . I've tried to find low carbohydrate meals . . . 20 or 30 grams of carbohydrates . . . it's almost impossible to find . . . One place . . . sells salad, but you have to request no pasta and their soups aren't too bad but they usually have about 20 grams of carbs in a bowl of soup . . . I ask them all the time, "What's in this food? Are there any carbohydrates?" Because they're not easy to identify, if it's home-made. Besides that one place, I have not found any low carbohydrate meal, from pizza to sandwiches to pasta . . . That made me realize . . . our whole society is geared toward high carbohydrate foods . . . One suggestion by some scientists . . . is that many people are very sensitive to carbohydrates.*

***Be aware of the health issues associated with our industrialized food system.***

The participants have an awareness of the issues with our industrialized food system which then informs their eating choices. Jacob reads scientific and social critiques of the North American food system, which give him a sense of its potential contribution to the rising rates of chronic disease.

*It's being shown over and over that societies that eat Western diets end up with massive problems . . . Much of [carb food] is laced with corn syrup . . . additives . . . preservatives . . . lasts longer . . . takes less time to prepare . . . is much more affordable than the healthy food.*

Jacob's developing analysis energizes the considerable effort involved in consistently accessing healthy food. Ruth takes a course in healthy cooking, which includes an introduction to the health value of unrefined foods as well as practical information on local sources of such foods.

*I had taken a course in healthy cooking and learned about flour from Speerville Mill . . . near Woodstock . . . made without chemicals . . . wasn't put through any bleaching process . . . I started cooking with it . . . that was the first time in my life that I experienced a freedom from craving.*

After our interview Genevieve discusses with me the difficulty of obtaining *clean* organic food in her community and how she periodically travels to another community to shop for organic products. Like Jacob and Ruth, Genevieve reads extensively about food system issues and how to address them.

*I was just looking around at the magazines . . . the Prevention<sup>75</sup> one that said Outsmart Diabetes . . . and the title clicked in . . . Then there was 2 or 3 books that came out and I found them to be even more helpful . . . I really feel knowledge is key and you're not going to get it from a diabetic clinic. You get some information, but as far as you living with it, you have to find out.*

The 14<sup>th</sup> participant (audible fragment) has learned to avoid artificial sweeteners.

*Diet drinks are foolish . . . Aspartame is poisonous . . . It's made from formaldehyde and the toxins settle in your hips and . . . thighs. When I used to go for massage [for back pain], the massage therapist had me feel those toxins . . . the nodes . . . Our systems don't get rid of them . . . He [massage therapist] used a rolling pin and soaking in hot water . . . I had all kinds of pain in through my back because the nerves were going over those lumps . . . [The pain is] . . . gone . . . I read this article that Aspartame and NutraSweet, Sugar Twin and those things, they're garbage and dangerous.*

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<sup>75</sup> In 1942, Rodale began publishing the *Organic Farming and Gardening* magazine which taught people how to grow good produce without using chemicals. It is the most highly read gardening magazine in the world. In 1950, Rodale Press began publishing [Prevention](http://www.rodaleinc.com/about-us/brief-history), a best-selling health and wellness magazine, which has the same chemical-free standards for consumption as well as production of food. (<http://www.rodaleinc.com/about-us/brief-history>)



### ***Dreams of enhanced healthy eating.***

Participants envisioned future enhanced control of their eating habits, for some particularly in the area of portion size. Andrew says, *What I eat in the run of a day would scare you . . . I can't lose any weight on this . . . She [diabetes educator] said she's going to help me.* For several participants, finances are an issue. An enhanced future would include public financial support for a diabetes friendly-diet. Willow says,

*With our group there are a few individuals on social assistance . . . They would definitely say that the rates need to be increased . . . just to cover current living prices . . . If they did have the money most of our group indicated they would totally . . . eat the way they know they're supposed to.<sup>76</sup> So I'd say social assistance increases. Personally in my dream I'd like to even see like a decent food allowance for diabetics.*

### **Participant tips about exercise.**

Participants list a wide range of exercise-related benefits they notice. They mention the significant lifestyle change that can be involved in integrating exercise into their lives and talk about the importance of taking a step-by-step approach that respects any limits they or their exercise mates have. Participants acknowledge the self reinforcing nature of exercise and recognize factors that support their physical activity such as structured programs and having fun. They mention engaging in forms of exercise ranging from walking to making music.

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<sup>76</sup> McIntyre et al. (2003), in their article *Food insecurity of low-income lone mothers and their children in Atlantic Canada* found that diets improved with the infusion of a small amount of cash.

***Notice the benefits of exercise.***

The participants are aware of the broad benefits of exercise. They name the following positive results: more balanced blood sugars, more regulated blood pressure and cholesterol, increased energy, tone, and flexibility, better weight control and pain management, improved emotional balance and perspective. Exercise is associated for some with the well-being that comes with enjoyable social interaction and social support. Martin and Ron note the impact of exercise on blood sugar balance. Martin says, *You can tell when you don't get the exercise the sugars are up. If I do get the exercise, they are far more [balanced]*. Ron adds

*If I don't exercise, my blood sugar goes up . . . not much, but I can see the difference . . . I'm able to, through historical tests . . . [to] correlate them to . . . my activities . . . If I do very little and I still eat my diet, my blood sugar stays still well within the range, but it goes a little bit higher . . . I find that you can't live without the exercise . . . it's a regular component.*

Malcolm observes the health improvements over time in his exercise classmates. *When they get their joints going . . . they become more flexible . . . lose weight . . . feel better.*

Edith finds that the exercise improves her energy level and thus her sense of self -worth. It also helps with weight and blood sugar control *Exercise is very important, not just for weight, or sugars, but just overall feel better about yourself. Because it gives you more energy.*

Malcolm believes that being fit contributes to healing more quickly, *What you'll save on medication, you get sick, everyone gets sick, but if you're in shape, you're out of it pretty quickly, or an awful lot quicker than if you're not in shape.* Sarah describes how walking

helps her manage chronic pain by releasing endorphins and shifting her focus; it also helps her keep mobile.

*Walking . . . releases endorphins and they make you feel better. . I take something that's going to calm the pain . . . If I have to I'll ice . . . Then I like going for a walk . . . It reduces my pain . . . It does allow you to refocus because you're concentrating on the walking . . . If you stay . . . in the house, in pain, you're going to dwell . . . on that pain. You need to keep mobile and refocus, whether it's reading or . . . I found . . . walking is my best avenue.*

Edith believes that exercise has been a key to recovering from a health crisis.

*I've got my blood sugar levels back down . . . to a healthy range. My cholesterol is almost at a normal range . . . my blood pressure is down below where they wanted it - by just following the diabetic plan and exercise and taking my meds on time.*

***Commit to regular rigorous exercise.***

Integrating exercise into daily life may require a significant lifestyle change.

George describes shifting from long hours of physical shift work, interspersed with sedentary breaks of 2-3 weeks, to his present practice of 45 minutes fast paced walking three times a day.

*I worked 12, 18, 20 hours a day at brute manual labour and then I did nothing for 2 and 3 weeks at a time. I had to learn that I have to walk now, 45 minutes, 3 times a day at a fast pace with all my arms swinging.*

Ron describes becoming physically active after his diagnosis.

*When I came out (of the hospital) I bought a treadmill . . . I worked my way up to 4 or 5 miles a day on the treadmill and I still do that today – not . . . on the treadmill . . . I'll walk 5 miles, at a very fast pace, just to keep my weight down.*

Ron notes that the critical personal factor of commitment *But it's something that . . . you commit [to]*. Genevieve mentions it may take persistence over several months to see the benefits of exercise for managing diabetes, managing weight, and increasing overall well-

being.

*And you don't get to know (how to exercise) until you have lived with it (diabetes) for awhile and experienced how exercise affects your body and how you feel. In the first 3 months you're not going to like it, if you're not an exercise person, but you keep going back. You keep doing what makes you, and you actually do feel better and you lose weight. Exercise is key.*

### ***Individualize an exercise program.***

Participants understand the importance of a step-by-step transition into an exercise program and the need to respect their limitations and those of others they may exercise with. Josephine realizes that she needs to needs to figure out how more general exercise information applies to her particular situation. She needs to listen to her body in setting personal exercise goals, particularly in relation to her co-morbid conditions or in relation to other self-care activities such as diabetes-friendly eating. Josephine has learned that she can build up her activity level over time.

*You can't just say everybody exercises a certain way . . . If you're talking about diabetes, there might be a time where you have to eat something in particular in order to feel better. You might not feel right so you can't exercise as much as somebody else, and the same thing goes for a heart condition . . . I go on the treadmill once or twice a week and I do not do the uphill. That's just an example of what I don't do . . . You do have to pay attention to all the information, but make sure it pertains to you . . . When I started at the Y . . . in something called cardiac maintenance program . . . my brain was telling me, this isn't enough exercise. That's not good enough . . . I would do extra . . . and I was too beat. It was too much for me. The cardiac maintenance . . . program . . . is perfect for me . . . Now I've worked myself into doing more but at first when I started, my brain told me . . . I have to keep exercising . . . without exercising for 20 years before that besides walking. That's kind of stupid; you can't just all of a sudden jump at doing things . . . that's when I realized . . . I have to work it to my own liking.*

Sarah juggles her need for exercise with managing her asthma. She exercises inside during the winter, to avoid falls, which she fears, knowing person with diabetes heal more slowly from injuries. She says, *In the winter, because of a fear of falling we [she*

and her partner] *walk inside and perhaps I do maybe more strengthening exercises during that time.* Edith talks about easing into physical activity by breaking up exercises into 5 minute sections and gradually increasing exercise time.

*[Set] a small goal . . . If you're not used to exercising, just do a 5 minute burst. They've done studies where someone on a bike . . . was [doing] . . . a minute, 30 second . . . bursts of speed and then to slow down . . . You can take those exercises and you can break them up, 5 minutes at a time. If you can't sit down and do something . . . for 30 minutes . . . start out in little segments . . . Start slow and do a little bit each day.*

Malcolm is part of an inclusive lawn bowling program, which bends the rules to accommodate team members' physical ability; the focus is on social enjoyment and the well-being that brings.

*The bowls . . . they're weighted on 1 side, so they don't go straight. They bend, depending on which side is weighted . . . We make up the teams by who appears. Nobody cares who wins. You do 3 or 4 good shots in the game, you're doing great . . . And you get to meet . . . different people. A number . . . are . . . from England or Scotland . . . There's about 30 . . . members, men and women . . . You have fun at it — because the damn thing doesn't go where you want it to go . . . so you laugh at it . . . You have fun at it, which means it's good for you. You can play a game and you don't have to be physically strong . . . The people that go . . . Tuesday and Thursday afternoons, they're . . . retired, or widows . . . they're not working . . . We do have them . . . who have trouble bending over or moving . . . They can move ahead . . . 5 or 6 feet if they don't have the strength and throw from there . . . We adjust to a person's physical problems . . . Nobody makes a big deal of it because we want them to have some fun at it.*

***Consider a range of physical activities.***

Most participants mention walking as a physical activity. Several use gym facilities and programs. One uses a bicycle. Ron, who walks 5 miles a day, describes needing to maintain a vigorous pace for 30 minutes to obtain benefits. In explaining this point he draws on his high school sports training knowledge.

*I do a lot of golfing and I walk and golf and I enjoy that, but still its start and stop . . . I find that I feel better only after I do a minimum 30 minutes of a good pace.*

*We used to have a rugby coach when I went to F high school, BT used to say, "When you guys start sweating, you're ready to exercise." . . . By the time you get your heart muscle going . . .*

Malcolm describes his gym exercise class with its emphasis on flexibility and strength building.

*You have a half hour of aerobics that's a stretch, stretch and step, step . . . You walk around and do this and breathe . . . For the second half of it, you get dumbbells and you do curls and for the back of the arm and the abdominal exercises . . . It's a whole body type thing . . . squats and stretches and curls, turn the head . . . it's very good. It's not a test to see how much weight you can lose . . . its more geared to . . . flexibility . . . You trim down the weight a bit over time, not in 3 weeks . . . you gradually become more flexible and the muscles tighten up a bit when you use dumbbells.*

Andrew mentions his daily bicycle exercise practice. *I have a bicycle I ride almost every day.*

George notes that his singing and playing guitar have been a form of exercise.

***Appreciate the self-reinforcing nature of exercise.***

Several participants talk about how, over time, exercise becomes a self-reinforcing activity. Edith describes a shift from obliging herself to exercise to enjoying it and seeing its benefits.

*If you can make yourself, or find the time . . . usually I start out with "Oh, I gotta do this", and by the middle of the program . . . I'm starting to enjoy myself in spite of myself . . . I was doing my program . . . walking . . . in the house . . . having fun, and I thought . . . this is great, because then I'll want to do it again tomorrow . . . It's really nice when you start to see some of the results . . . just doing the 30 minutes a day . . . It's very heartening.*

Josephine sees how her increasing stamina has increased her desire to walk in mild weather.

*I know that I can do more walking, because I have done more walking . . . I don't do as much in the winter, but now again, it's starting to be better, and that's what I noticed last year, is that I would walk more places and not even want to take the*

*bus.*

Ron speaks of developing a positive addiction to vigorous daily walking. He notes that walking with its outward focus can mean one forgets one is exercising.

*I make sure I exercise every day . . . I walk to work . . . My daughter lives about a mile and a half from me and I walk to her place and back . . . I walk now about 13 minutes a mile . . . When I finish working, I go home, I usually hook up my computer at home and just run my VPN so I can access all my files again. But I find that I have to exercise. You get to the point that it becomes an addiction, which is fine. I love to walk . . . You don't even realize you're doing it . . . I think that's key.*

Edith finds keeping a record of exercise is self-reinforcing.

*Keep a record of it and then you can say, "Oh, I did that." . . . Have a calendar and mark on it . . . it doesn't have to be anything fancy, just a little check mark or . . . number. If it was 15 minutes . . . just write 15. And then when a week goes by and you look at it and gee, I did that 4 times. So small, just small and steady.*

### ***Add in exercise friendly factors.***

Participants mention a number of factors that make it easier and more pleasant to exercise and thus maintain their motivation. Malcolm talks about the mental, physical, and social benefits of his gym exercise program. The social interaction increases motivation to attend classes and the gradual improvement of each member, as flexibility increases and weight gradually reduces, increases the overall positive feeling in the group.

*I go up to this (gym) exercise group . . . that's been . . . a big plus for everyone who goes there . . . They start out . . . going "Ugh" and after a couple of months, excellent. It's an excellent way of keeping in shape and psychologically, if you're in better shape, your mind is more positive . . . You're better off with a sounder body, better thinking . . . and a sense of humour. You have to have a sense of humour to survive . . . The gym . . . I went 3 times a week . . . [For a while], I was the only man there with a pile of women . . . It was interesting, but they have a sense of humour. You can laugh and joke with them . . . so you look forward to going . . . I think that improves your performance because you like it. . . . Gradually . . . the weight goes down, so you can actually experience the good*

*results . . . Every 3 months they got to go out and eat [together] . . . You see everybody improve after a few months. When they get their joints going . . . they become more flexible . . . lose weight . . . feel better. And so everybody feels better and you like going.*

Malcolm finds that a structured and flexible exercise program with a diverse membership provides the stimulation, mutual affirmation, and fun that sustain activity.

*It's relaxed . . . there are 3 or 4 different trainers. You get a different one Monday, Wednesday and Friday. At times they goof up and you get a laugh out of that and they laugh . . . it's fun . . . the people needle others and carry on a bit and laugh . . . it's good, the group can socialize and they do . . . You meet people from . . . we had a woman from China . . . one from Japan, one from India. We get them from Newfoundland, Cape Breton . . . they're from all over, but this is the point . . . we're all the same. We work together for the common good . . . It's the better [for] everybody and it actually works . . . They support them when they're sick, they send them cards . . . They're a social connection and a support . . . which helps the feel and the whole group is a group . . . In this last month or so there's been 4 or 5 new people come in . . . It's open. The minimum age is 50, although one time they let in a younger one who was pregnant, due in a month or so and she wanted to keep in shape . . . They asked if she could come in – sure . . . no trouble at all . . . you have to be understanding and flexible. People go regularly because they like going. They like meeting the other types . . . everybody helps everybody.*

Edith participates in an exercise study and finds that the measurements motivate her.

*Right now I'm taking part in an exercise; it's a survey through the hospital to see why men seem to exercise more after their cardiac incident than women . . . I get a pedometer and I exercise whatever I do for a week . . . and send those results in . . . That . . . keeps me on the straight and narrow for a whole week. (Both laughing) Because I want to have good numbers.*

Ron measures his blood pressure before and after exercise to give himself reinforcing feedback on his workout. *I check my blood pressure and I check it after exercise. I do all these things that I never thought about before . . . just to give me some feedback on how I'm doing.*

Martin benefits from the walking company of his wife or his workmate when their work



shifts schedules coincide with his.

*We usually get . . . a moderate amount of exercise . . . We . . . walk at night and go a couple of miles, 4 or 5 times a week . . . M [wife], and a friend down the road . . . We work together on the ferry and he and I sometimes will go walking . . . if we're free in the afternoon.*

Jacob describes how the refined blood sugar control method he has developed, using diet and insulin, enables him to play sports without risking a hypo incident and suffering the associated anxiety.

*Previously, say if I wanted to go play a round of golf, I had no idea what my sugars looked like. I knew they were going to go down but then for the next day or two I didn't know if they were going to bottom out in the middle of the night or be really high in the morning . . . It was just a crap shoot . . . Now if I go play a round of golf, or play some hockey, I know pretty much exactly what they're going to do and treat it, monitor it and spend maybe 2 minutes worrying about a game of hockey, where before I would've spent a day and a half worrying about it because of the after effects.*

Ron keeps up his exercise routine even when he travels to meetings for his work. He benefits from hotel gym facilities as well as walking.

*Most hotels have exercise rooms, which I use, or I go out for a walk . . . I was in F for a couple of days of meetings. One day after we finished I went out and walked about 5 miles . . . you don't even realize you're doing it . . . I think that's key.*

Genevieve talks about the importance of outdoor activity and exposure to sunlight as ways to keep in touch with life beyond diabetes and other chronic conditions.<sup>77</sup>

*Get out and don't stay in the house. I really feel for people that do not have an opportunity to get outside, even if it's just out to sit in their yard, or on a deck or anywhere, because if you're not getting sunshine and you're not seeing another*

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<sup>77</sup> Penckofer et al. (2008) note that persons with diabetes have lower serum concentrations of vitamin D; they suggest a regimen that includes exposure to sunlight, foods with vitamin D, and a supplement, as necessary.

*part . . . other life, you can become very . . . self-absorbed . . . Everything is much more dramatic if you're not looking outside yourself . . . diabetes becomes horrible . . . You can become down very easily without doing that.*

### ***Dreams of enhanced exercise.***

Participants' dreams of enhanced exercise possibilities were focused on increased accessibility. Participants with restricted finances would like to use gym facilities if they can be made financially and physically available. Willow notes that while the trainees she works with understand the importance of paying attention to their weight, exercise has not been a focus of this group because affordable, accessible, safe facilities are limited.

*People watch their weight . . . and understand that there's importance in managing that. Exercise hasn't been a big one because I don't think people have been able to get out and do too much . . . walking outside and what not.*

When asked to dream about circumstances that would enhance diabetes self-care

Josephine describes a family-friendly community-based centre,

*To have an actual place where you could go and get . . . some support. If you had a program for the kids . . . instead of just being there with a sitter, there could be someone training them.*

Willow adds *A little gym . . . so you can go and do safe activities.*

### ***Summary of exercise tips.***

Participants understand clearly the value of exercise in diabetes management and overall health and well-being. They develop experiential knowledge of how to adapt general exercise protocols to their unique circumstances and are aware of what helps them to sustain their practice. They see how exercise supports, and is supported by, other self-care activities such as treatment management, which I will discuss next.

### **Treatment management.**

Participants discuss treatment of diabetes symptoms and those of co-morbid conditions. The participants combine attention to conventional protocols with self-care expertise developed over time as they respond to their particular circumstances and disease progression. Below are presented the participants' experiences in dealing with the following: blood sugar testing, oral medication, insulin, and co-morbid conditions such as pain, heat intolerance, poor sleep, and menopause.

#### ***Blood sugar testing.***

All participants value the information and feedback that daily and quarterly blood sugar testing provides. Knowing when blood sugar levels are not balanced enables them to be proactive by appropriately altering (in consultation with professionals) their self-care activities.

#### ***Use daily self-testing results to provide feedback on diet, exercise, and general health.***

George accepts the importance of self-monitoring his blood sugar control through a daily blood test and has learned to be attentive to details such as varying the testing site.

*You have to check your blood, 4 or 5, it wouldn't have mattered if they said 10 times a day, I would've . . . I found out the needles were painless . . . I play the guitar — and I found out not to take my blood samples on the end of my guitar fingers . . . I was taking my blood . . . on that little finger because it likes to bleed . . . this was interfering with my guitar playing.*

Ron says he maintains his blood testing routine, even when away from home. The historical record of his results allows him to see the impact of activities on his blood sugar levels. Ron also regularly measures his blood pressure, another source of feedback.

*When I go away to conferences . . . I still measure my blood sugar . . . I correlate historical test [results] to . . . my activities . . . I check my blood pressure and I check it after exercise. I do all these things . . . to give me some feedback on how I'm doing.*

Participants balance various needs in choosing how to act on blood sugar readings Martin has discovered a blood sugar level *comfort zone* in the 6s and 7s (above the recommended level); he can maintain this level by moderate eating, which helps him avoid serious hunger sensations and accompanying irritability or the risk of low blood sugar symptoms.

*For me, my normal, which I accept as being normal, is in the 6's and the 7's . . . To be down at a 5.4, I'm liable to take your arm and eat it . . . I don't allow myself down there . . . Maybe I should, but I'm not going to because it is uncomfortable and I get irritated and I don't like being irritated and neither does anybody else around me . . . My comfort zone, I do know by feel, it's sort of like your hunger level, I can almost tell by my hunger level . . . where the lower parts of the blood sugar are at. Not so easy to tell if it's high, that's why, like the silent killer, blood pressure . . . because if it's [blood sugar] high you're not hungry anyway . . . I don't want it to go high, but yet I don't want it to go low either, so I seek a comfort zone in there and try to eat right.*

Edith self-tests once daily or more frequently if she gets a high reading at the start of the day. In that circumstance she combines frequent monitoring with proactive steps such as decreasing her food intake at breakfast and exercising for half an hour.

*If it's that high [on waking] then I have less for breakfast and I do my exercise . . . I'm very careful and I check my sugar . . . at every meal. Usually I just check once a day at a different time each day . . . If I do have a . . . sugar that's unusually high for me, I check it each meal, just to see which foods . . . are causing the sugar to increase . . . When my sugars are high . . . I . . . try to do is get out for a walk, or I have a walking tape or CD that I use here . . . If I do exercise, within 30 minutes my sugars are back to a reasonable level.*

Edith observes that her vulnerability to hypo episodes is increasing. She makes sure to carry a snack with her, especially when shopping, and attempts to eat on time.

*I'm finding that I'm having the low blood sugar, it doesn't even have to go as low as it used to . . . I would get a low blood sugar when it went away down to 3.9, but now it's like anything under . . . and I'm already starting to have the reaction . . . I don't know if that happens with the longer you're diabetic . . . I was having a problem where . . . we'd go . . . to the stores . . . and . . . near 4:30 . . . the low blood sugars just come . . . There's no warning . . . you're okay one minute and then it's there . . . So I always have a carbohydrate snack of some kind. And I try to take some fruit and have that with me . . . We try to keep meals on time.*

Edith is aware of the impact of illness on blood sugar levels; when self-care measures do not lower her blood sugar readings she consults her doctor.

*The only time you really don't have an effect [with self-management] is if you're ill . . . I know when my sugars are that way for a number of days that I must have an infection of some type . . . I know that if I'm watching what I eat and they continue to be high, then I make an appointment and go to the doctor . . . Usually we find out it's . . . a cold or something that's causing it. That's why the importance of checking your sugar every day.*

Interpreting blood sugar readings is made complex by all the factors that impact blood sugar balance. Willow talks about lay problem-solving abilities and gives the example of the work of one diabetes education lay leader trainee; Edith combines natural observing and reasoning abilities with information from her training to determine that stress is the aggravating factor in her blood sugar imbalance; she then acts to reduce her stress.

Willow says,

*[An example of lay detective work is] understanding the tests and knowing . . . if their [trainees] sugars are showing signs of increasing . . . being able to . . . problem solve that, and identify what the causation might be . . . in a very methodical way . . . To me . . . it's quite surprising because a lot of people really aren't trained to think that way . . . One of the ladies has been experiencing . . . increased sugars . . . She's [saying] . . . my nutrition hasn't changed. I do very well on the nutrition and I'm taking my medications and they should be working . . . She went through this whole process of elimination and trying to increase exercise and did that help her sugars . . . In the end she discovered that her life was somewhat out of balance and she was experiencing too much stress . . . For*

*her the way to manage that, given that she could identify what the stress was, was to remove herself from that situation for a period of time and try to get her sugars under control, and work on future strategies so that when she's back in the situation she might be able to better manage the stress. And I'm like, Wow, that's pretty impressive . . . She's a very knowledgeable individual . . . very aware and I thought that's great . . . that she has had signs . . . from her body that something's happening here . . . She's been able to step back and sort that out for herself. Apparently . . . that's true with stress; it can really increase your blood sugars and . . . disrupt regulation.*

***Use AIC quarterly testing as a more comprehensive measurement.***

George understands that a more comprehensive picture is provided by the quarterly AIC test. George learns the AIC can be an objective indicator of whether he has maintained consistent self-management, serving him at times as a prompt to return to that disciplined self-care practice.

*They don't put enough emphasis . . . on this AIC . . . the 3 month blood check. You can fool your little glucometer . . . because you know the times of the day your blood is going to be at a better level . . . If you want to, you can go right ahead and check your blood only at those times. If you have chocolate cake for supper you sure don't check it after supper. But you cannot fool the AIC because it shows that over the 3 months your blood sugar has elevated from 7.1 which is quite normal and it's up to almost 8 now. So you've really blown this guy . . . You're only fooling yourself. The doctor and the diabetic educator, they can read your little machine because it has a memory. It's a little computer. And they can look on this and say oh, well this was 7.7 in the morning and 6.2 by lunch time. But you can't fool the AIC. That's your blood telling on you. And so if that just happens then you've been negligent. You're letting down. So you really have to crack down on yourself. You've become, as I said earlier, complacent.*

Ruth notes that blood tests effectively show the link between blood sugar balance and eating patterns.

*I think all of us know what we should be eating and how much we should be eating and so we all know when our eating is off or when our portions are too large and things like that . . . It shows up in the blood sugar levels and it shows up in the doctor's office and it shows up in the blood tests.*

Jacob uses his A1C and other quarterly tests to assess the impact of changing to a high protein diet.

*So I've decided to . . . take the [protein diet] plunge, and follow closely with my quarterly blood work to see what my numbers are doing and my cholesterol and liver numbers and kidney numbers and make an assessment each quarter on how I'm doing . . . I'm primarily focusing on, not only just losing weight, but making sure my sugars stay under control . . . Dropping the number of carbohydrates in my diet and dropping some weight has changed my sensitivity and it's thrown me into a bit of a precarious situation, so I need to pay closer attention.*

Willow notes that trainees who cannot afford diabetes supplies for self testing understand the importance of having medical check-ups and accompanying blood work, *that they need that medical supervision to be good managers of their own health.*

#### ***Oral Medication use.***

While blood sugar monitoring and healthy living may suffice to manage blood sugar balance in the early stages of diabetes, over time most participants are prescribed oral medication.

*Use effective self-care to reduce oral medication levels.* Margaret finds she is able to reduce medication use for a period after losing considerable weight. She says,

*Losing the 120 pounds . . . put the diabetes on the back burner for a while. So from that time on, right up until last year, I never was on anything . . . I always kept an eye on it . . . every 3 months I would check my blood sugar. It was doing fine until last year . . . when I checked it, it was up to 14 and I thought . . . feedback . . . I got back in with the doctor and got pills to get straightened around . . . As you get older . . . things are bound to start coming back . . . I was 50 before I really had to start taking any major medication [which] would be the Glyburide because before I was only on the Metformin.*

Margaret elaborates on the association she sees between following a diabetes diet and reduced medication use. She says,

*Maintaining my diet . . . meant that I can take less medications . . . Before I was on 3 Medforman a day, 500 mg. and I was on 2 Glybride pills a day, which was 25 mg . . . Now I still take the 3 Medforman because that's not really a blood sugar reducing, it's . . . to help your pancreas . . . produce a little bit of insulin . . . The Glybride is the one that drops the sugar. Now I am down to a half a pill in the morning and a half a pill at supper time . . . I have my 3 month blood checks and every time they come back I'm within 5.2 - 6.2 . . . I . . . contribute that all to the diet . . . watching my carbs.*

Margaret notes two benefits of using reduced medication; she has a positive sense of accomplishment/efficacy and she delays the point at which her body will become less responsive to the medication, requiring a switch to insulin.

*As far as your mental status, it . . . makes you feel good to know that you're doing it; you're getting yourself leveled out without the use of so much medication. The other aspect of it is, it's like any kind of medication, after awhile your body gets immune to it, and then that's when your medications would have to be increased . . . If you can control one aspect of a diet and be able to lower that medication . . . then this medication is going to work for you a lot longer, before you have to start taking the needle . . . Because once you take your medication for so long and you get immune to it, then you're on to the insulin.*

*Adhere to the oral medication regimes as prescribed.* George has learned the importance of consistently taking medication on the recommended schedule. He says,

*You have to learn to take your medication at exactly the same time each day . . . You have to reschedule your thinking. You don't [just] think about, I must get up at 6:00 and I must have my shower and have my coffee by 7:00 . . . its persistence, you're on another frequency.*

Margaret knows the importance of taking medicine in the doses prescribed and she acknowledges that some persons do not have an understanding of the associated safety issues.

*If you're on meds, make sure you take the medication and not to abuse it . . . Some people . . . especially in the older generation (have the idea) . . . if one pill does good, what will 2 pills do? Will it drop it down and make it go away? To me that is a kind of abuse of medication . . . in that sense they could put themselves in serious situations.*



### ***Insulin use.***

*Overcoming fears of initiating insulin use.* A number of participants share a common belief that switching to insulin is a sign of entering a more critical stage of diabetes and often they are not comfortable with the idea of injections. When insulin is recommended to Edith she refuses; she greatly increases her self-care activities and succeeds in bringing her blood sugar levels down. She says, *I have avoided the needle . . . My sister just went on it in the fall . . . She said if you can avoid this avoid it at all costs, because she's on 4 needles a day.* Several participants have begun to use insulin. Andrew acknowledges the anxiety he experiences in shifting to insulin use. He says *I was pretty nervous because my perception, and I think a lot of people's perception is when you have to start taking insulin, Oh my God, you're close to being tragic at that time.* Andrew notes that his family doctor tried to motivate self-management by encouraging him to avoid reaching a stage where he needed to begin insulin use. *For 10 years she threatened me with insulin, like if you don't (take care of yourself), you're going to have to take insulin.* Andrew now senses that he would have benefited from starting insulin treatment earlier to relieve oral medication side effects. He says,

*My feeling is that had I taken insulin a few years earlier, 5 years ago, I wouldn't have had to live with that discomfort . . . terrible stomach cramps almost every day . . . Insulin is not a bad thing . . . Y [diabetes educator] says there are no ill effects . . . you can take as much as you need. So, I'm still trying to get my head around that too.*

One participant describes how peers can help reduce anxiety about initiating insulin use. Margaret talked extensively with a friend who didn't believe he could inject a needle. She

said, *The Lord is going to help you and you're going to be surprised what you can do.* Shortly after, the peer self-administered his first needle. Margaret reports, *He was truly amazed at how easy it was . . . it didn't even hurt.*

*Learn the complex process of insulin regulation.* Participants who use insulin need to calculate their dosage and timing needs. Andrew is learning to regulate his doses based on an increasingly confident interpretation of his blood sugar readings. He, like others, needs to watch out for his instinctive reluctance to take medication. Andrew says,

*I take insulin 4 times a day. I've only been taking insulin for 3 or 4 months . . . I'm still learning how to control it, but today my blood is up . . . Yesterday my blood all day was 6.1; this morning it was 6.3 . . . Part of my problem is I do not like the big dose. I don't like to take the insulin. For whatever reason that's in my psyche that doesn't want me to do this. This morning when I got up . . . I said I'm doing a really good job and I'm going to cut my insulin back today . . . to 25 instead of 30 units . . . At lunch time my blood wasn't as good. Which I've also learned isn't a tragedy. I'm getting used to it . . . I've . . . learned what blood sugar really means and where it goes and how to control it and not to panic if it's 11 because it'll be down to 7 or 8 and then it's fine.*

Andrew and other participants learn to accept mistakes and keep them in perspective.

They value the increasing sense of control, freedom and well-being that active self-management of medication brings. Andrew says,

*I don't think I'm where I should be yet but I think its coming. I have my days when I get disappointed. I don't like making bad decisions and yesterday I'm sure I made a bad decision. Oh, it's a learning curve and I've also found that I can control this myself now and that makes a guy like me feel pretty good. It also gives me . . . a little bit more freedom. My blood sugar isn't such a concern to me anymore . . . I feel quite healthy. I feel better now than I did when I was taking a whole bunch of pills.*

Participants constantly balance the need to focus on daily life commitments with the need to maintain their medication regimen. Andrew says. *Even with taking the insulin, my struggle is to stop and take the time to do it. I really regret the time it takes, but I know*

*there's nothing more important than looking after yourself.* George emphasizes the importance of sticking to the prescribed frequency of insulin. He says, *It's got to be a routine. It's got to be orderly. You have to be persistent. You can't miss your 7:00 shot if it's supposed to be 7:00.* Understanding the factors that affect insulin use in the body is a complex process. One participant is stimulated to do so when he acquires an insulin pump. Jacob describes the enhancement of his insulin dosing skills through online consultation with peers, reading, and personal experimentation. He says that experimentation has enabled him to better match his insulin needs to reduce his overall insulin use without precipitating hypo incidents, and to achieve tighter blood sugar control.

*I understand my patterns and when I take a reading now, I can apply it to that pattern and say am I on the road or not and it means so much more to me. So I had to do all that experimentation up front to find out what the road looked like before I knew if I was on it . . . Those of us that have discovered our patterns, discovered how we behave and have adjusted our basals to meet our basal requirements, pretty well all have AICs . . . 6.0 or less . . . at least the low 6's . . . Not only do I have a very low AIC at 5.9% but I have a very low rate of hypoglycemic incidences. If I had previously gone for low AIC like this, I'd have been passed out all over the place.*

Jacob adds that he has learned to alter the conventional formula that matches carbohydrate intake to insulin dosage to accommodate his high protein diet.

Some participants are prescribed insulin, upon diagnosis of type 2 diabetes with life-threatening blood sugar levels. Over time, with lifestyle adjustments, they are able to self-manage with little or no medication. George mentions his experience. *The medical community here had never heard tell of anybody that went from 75 units a day of insulin to none. And then to stop taking the oral agent.*

### ***Manage symptom and comorbid conditions.***

Participants manage symptoms, which may be associated with diabetes, and other chronic illnesses, (e.g. chronic pain) or aging (e.g. menopause).<sup>78</sup> Management of these symptoms is important to living well with diabetes as it supports an enhanced quality of life which can increase levels of energy and interest available for self-care. Sarah protects her mobility by prioritizing foot care. *I am very adamant about inspecting the feet . . . nonslip footwear . . . seeing a podiatrist . . . I've noticed things are taking longer to heal than . . . prior to being a diabetic.* Sarah also manages heat intolerance.<sup>79</sup> *I have a fan on me even in my room all night long.* Genevieve finds following a routine helps to control her fatigue level, which in turn helps her to stay alert and proactive. She is aware that, *when you're tired you just don't . . . sometimes make the right choices.*<sup>80</sup> Participants with co-morbid conditions refer to the challenging complexity of self-management<sup>81</sup>. Sarah deals with the uncertainties in managing co-morbid conditions by accepting ambiguity and being proactive in self-care.

*So you can't just look at it and go "Well that's my diabetes, today," because that's not necessarily what it's going to be. (Chuckle) So you sort of learn to okay, well this is possibilities of what's happening or what it could be, so what are we going*

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<sup>78</sup> Wu et al. (2001) note the association between impaired glucose tolerance and menopause not managed with hormone replacement therapy.

<sup>79</sup> Boulton et al. (2005) recommend screening for autonomic neuropathy symptoms, which includes heat intolerance, upon diagnosis.

<sup>80</sup> Khutson & Van Cauter (2008) note sleep loss reduces glucose control in persons with diabetes. Sleep disturbances may be a symptom of diabetes. Prioritizing adequate sleep and avoiding a chronic sleep debt is recommended.

<sup>81</sup> Lindsay (2009) notes the stress of the competing demands for care of comorbid conditions; persons prioritize their conditions according to factors of a) unpredictability b) inability to control with medication and c) setting off other health problems.

*to do to make you feel better for the day, sort of thing. So you just do whatever you can to alleviate, one by one, you know . . .*

***Dreams of enhanced diabetes testing and treatment.***

Participants dream of enhanced accessibility to testing and treatment. Some participants have insurance coverage for blood sugar testing supplies and many do not. Sarah advocates financial support where needed for the costs of diabetes supplies. She says,

*The supplies are not cheap that we need to take care, manage the diabetes well . . . you need to have those supplies at hand . . . There are a lot of people out there that don't have the financial support to be able to do that and yes that does need to be readily available for those that need it.*

Some participants envision community-based centres, which combine treatment and wellness activities. Willow describes such a centre.

*Just concentrating things . . . to make it easier for people to receive all their care needs, or do their purchasing . . . It could have a little pharmacy, with diabetic supplies and medications and it could have . . . foot care . . . It'd be really cool if they could have little stations . . . that were physically manned by professionals . . . Even a little gym . . . so you can go and do safe activities. Information . . . a borrowing library . . . a testing space, so they could go in and make sure that . . . their bloods are at a certain range . . . drop in, not so much need to make an appointment and get to a place that may be out of your way.*

Participants mention looking forward to the discovery of a cure for diabetes. Sarah says,

*I'd love to see a cure. (Laughing.) I think is what any diabetic would like to see (one). Bill says, I read recently that they're determining which DNA . . . causes diabetes . . . Then they can eliminate it . . . What the future holds is much better handling of it and preventing it.*

## **Stress management.**

### ***Awareness of stress as a risk factor for diabetes.***

One participant describes how she learns about the connection between stress and diabetes in a lay leader's diabetes education training session.<sup>82</sup> Josephine says,

*The nurse (at the community health centre) . . . talked to our group about stress . . . I had no idea that stress had anything to do with diabetes . . . That was a light bulb moment . . . I was trying to reduce my stress anyway because of my angina . . . I was told that not only was (it) important to not have stress with diabetes but also with arthritis because she's a nurse and she knows that . . . I was kind of aware of the other things about diet and exercise . . . but the stress I was shocked.*

Edith, a fellow lay leader diabetes education trainee talks about how her experience of stress at work, combined with a tendency to depression and seasonal affective sensitivity, is associated with a recent mild heart attack and aggravation of her diabetes.

*Well for me I know that the stress is a really big factor, probably more than what I eat. I can control the sugars really well with exercise, and it helps the stress too. But sometimes I'm in that and I don't even realize that I'm in that frame of mind . . . When I'm stressed I am irritable and I'm overwhelmed and I don't think I can do anything, and that's how it affects me. And then that all . . . one thing leads to another . . . I didn't know I was getting that sick in November. I really had got so deep in . . . part of it was depression. And I did go to the doctor and get some extra medication for that to get through this, the winter months are hard.*

### ***Steps or stages in coping with the stress of integrating self-care.***<sup>83</sup>

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<sup>82</sup> Bruce et al. (1992) link psychological stress and the activation of the sympathetic nervous system to deregulation of glucose metabolism. Surwit et al. (2002) document how a stress management intervention improves glycemic control.

<sup>83</sup> Participant's reflections on the process of adopting self-care resonate with the Stages of Change or Transtheoretical model which proposes the following stages: precontemplation, contemplation, preparation, action, maintenance. Transtheoretical model authors Prochaska et al. (1993) also identify 5 experiential processes of change: consciousness raising, emotional arousal, social reappraisal, environmental opportunities, self reappraisal, and 5 behavioural processes of change: self-reevaluation stimulus control, helping relationships, counter conditioning, reinforcement management and self liberation. Participants can experience separate processes of change for each self-management task (Parchman et al., 2003).

Participants identify steps they and others experience as they move from shock to awareness, from acceptance to action. In doing so they are creating a narrative, making meaning as a way to address the stress of losing their pre-diabetic way of life, as will be addressed in the Discussion chapter. Martin names what he sees as 3 internal stages in the process of embracing diabetes — awareness, acceptance, adjustment — and the resources needed to move through these stages.

*Awareness, acceptance, adjustment, in that order . . . You can be aware of something . . . you can accept it, some people more than others, but adjusting to it and adapting to it, takes willpower, determination and a reality check.*

Martin acknowledges that will power (choosing diabetes self-care actions) and personal desires do not always line up and that sometimes seeing one's reality does not translate into *waking up* and connecting the present condition with the risk of future disability.

*In the realm of having the willpower, for you to know what you ought to do and want to do it, to know what you ought to do and what you want to do, might not always be in the same mixture at the same time. And the reality check sorta comes in there when you realize that if you don't do what you ought to do, there's no way you're going to be able to do the least of what you would like to do, because it is going to completely debilitate you. I've seen it, and seeing it, does not even sometimes hold the weight of somehow waking up in your brain and realistically realizing this is your disease.*

#### ***Awareness of diagnosis stage.***

Many participants talk about the traumatic shock of diagnosis and what helps to mitigate this stress. George experiences the double shock of a health crisis and diagnosis and talks about how immediate information about the condition and its treatability can cushion this shock. George notes that when professionals are immediately available to address potential fears it is more likely persons will be able to absorb the reassurance.

*That (health crisis/diagnosis) was the most panicky time in my life because I*

*thought it was the beginning of the end . . . When I got diabetes I ran into a brick wall. I was going wide open, life is great . . . I've been laid up for 12 years of my working life with back problems and with whiplash problems . . . I could fight all of those things but I didn't know I could fight diabetes . . . And so I laid in there . . . hopeless and helpless and useless . . . for this whole 3 day thing until Y. (diabetes educator) got in there . . . She realized then that my fear was needles, not my only fear but one of my big fears . . . She picked up on that just with a few minutes of our conversation . . . That was her first reassurance. The needles were smaller, the medication is better. You're better able to control it from what we've learned over the last 30 years. But none of that was available for like 36 hours or more. And my attitude was so . . . so negative by the time she got there that I couldn't really accept what she was telling me. Like I had gone down for the third time, kind of . . . There should be a pamphlet or a tape or a person that can go to the bedside of someone that ends up in that mess that I was in . . . A hospital should have . . . It doesn't matter if it's clergy, a nurse, a PR person, a candy striper, but if they could come in with some encouragement and tell you . . . "This is not the beginning of the end" . . . My parachute didn't open. And like I hit the ground and I lived through it, but I just wasn't ready for any of it . . . It's so important that [as] more and more people are getting diabetes now . . . that the information is there for them immediately . . . that, no, no, this isn't the beginning of the end as long as you treat it seriously and listen to the help that we have for you and take charge of your own. It's a deadly disease but we'll help in any way we can and there's medication available and all of this, but like, you're the bottom line.*

George believes that when persons with diabetes spread success stories in communities they can raise awareness and hope, which may help mitigate the diagnosis shock for others in the future.

*There are only diabetics here [at the focus group] but they all know non-diabetics. And we . . . are going to tell other people, "Hey man, did we ever hear some good success stories there." And this will slowly, but surely, or maybe even quickly, like keep the ripple on the water.*

Josephine talks about what is important for peers to communicate when people are first diagnosed, to facilitate their embracing diabetes; this includes reassuring them that it is not immediately life threatening, that there are things they can do to be more comfortable and relaxed with their new condition, that the self-care tasks involved are not that difficult despite the confusion newly diagnosed persons feel in the face of a flood of



physiological information, and that mistakes are remediable. Josephine says,

*Well, first . . . one of the things you can tell people is there's lots of things you can do for yourself to live more comfortably, without being fearful of you're just going to die immediately, and that's what some people think when they get diabetes . . . I tell them my mother is 87 and she was 62 when she was diagnosed and she has 2 needles a day, and she's fine . . . She's been handling it and it's actually not that hard to handle, as some people might think in the first place. When you're first diagnosed with diabetes . . . you learn a lot of things that you don't want to know. It's very confusing for people . . . things that maybe you have not a clue about - your blood and what your blood does is very complicated. So to be relaxed about the whole thing . . . I would tell people, "There's lots of people that live with diabetes and other things. And they're just fine" . . . I would probably tell someone, "Everybody makes mistakes and then they correct them later and they'll be fine."*

One participant points to the importance of balancing timeliness and pacing in the delivery of information to the newly diagnosed. Genevieve mentions how diagnosis shock interferes with her ability to absorb professional teaching. She is an avid reader and locates materials that help her make sense, at her own pace, of diabetes and what she needs to do to manage it.

*When you're first diagnosed with diabetes, you cannot absorb [clinic diabetes education information]. By giving everything [complications] up front . . . all you come away is being really scared and really depressed . . . [Six months later] I was getting groceries and I was just looking around at the magazines and the Prevention one that said Outsmart Diabetes . . . the title clicked in.*

Being able to recognize benefits, the silver lining in the cloud of any challenging health event, is a resilient response exhibited in the remarks of many of the participants.<sup>84</sup>

Martin notes that the scary experience of diagnosis can serve as a wakeup call.

*If there's something that causes sort of a scare in your life . . . when somebody goes through sort of a life-altering situation, reality comes upon you like somebody dropping a water balloon out of the . . . second story or a building as*

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<sup>84</sup> Wolever et al. (2010) describe the use of the Benefit-finding Scale as part of an integrative health coaching intervention with persons with type 2 diabetes.

*you're walking out the door below . . . Plat. Here it is! You know, you're wet. You're a diabetic and you better do something about it.*

Sarah responds to the fear and shock of diagnosis by committing herself to self-care; she is motivated by the cautionary example of her mother.

*Being diagnosed was quite a shock for me but at the same time, I'll do everything I can to keep myself very healthy . . . I watched . . . my mom was dying from complications of diabetes. I've seen the gangrene before my very eyes on a daily basis. That's what empowers me really today (Sniff) . . . That's on the rise, not just the diabetes but this amputation thing . . . It's scary . . . I'm doing everything I can now to take care of myself, to prevent that . . . I'm hoping I can learn as much as I can about that.*

Margaret responds to the stress of her family history of diabetes, the cautionary examples of those not practicing self-care, and public information on risks, by choosing a proactive path. Margaret conveys her determined response through an anecdote about her diagnosis and associated exchanges with her family doctor.

*I believe that is a lot of it [is] . . . the determination . . . on top of that seeing people that had it . . . not looking after themselves . . . what they have gone through. When you see that and plus all the other things that's being advertised that can do it, gives you a lot of motivation to be able to say well I can do this. I'm not going to give up and die just because its sugar diabetes . . . My mother is a diabetic . . . My grandparents, on my father's side, were both diabetic . . . My grandmother on my mother's side was a diabetic . . . it just keeps coming down each generation . . . With my mother . . . she didn't follow nothing, when they first diagnosed her . . . Within a year she was put on insulin . . . Then it happens to you, you kinda have an idea . . . I don't want to be like her and be on insulin at the age of 42 . . . I remember my doctor . . . saying to me that I'm putting you on Medforman now, but by the time you're 45 you're going to be on insulin . . . I looked at him and I said, "Eh, wrong answer." . . . I was taking my Medforman and then I started just watching my fat content . . . I had lost 120 lbs . . . when I went back to my doctor a year later for my check up, He couldn't believe it was me walking in . . . He said, "What can I do for you?" Well, I said, "It's like this, I stopped taking my diabetes medication because I found my blood sugars was down to 5.2 and they've been staying there for the last 3 months" . . . He checked my blood sugar. He said, "It is perfect." So he went out and he said to his secretary . . . "She made a liar out of me." . . . His secretary said, "What do you mean?" "Well for one, she lost 120 lbs., and two, she hasn't been on any of her*

*diabetic medication for the last 3 months and her blood sugars have been normal." . . . I'm 51 now and I'm not on insulin. I'm just on the pills.*

Ron talks about responding to fear by deciding to take control and be proactive.

*[Diagnosis] scared the living hell out of me . . . I decided then and there that I was going to take control and I was going to do what was necessary to get me down to where I should be.*

George acknowledges the tenacity needed to confront the challenges of self-care.

*Because once you're released up there [from hospital] . . . you pick yourself up by the boot strings and become stubborn and tenacious . . . and you make it work. And it can. It's been proven. And I'm just another bit of proof.*

Participants can re-experience diagnosis shock as each stage of progression of their condition. Andrew talks about the helpful professional reassurance he receives at the time he is prescribed insulin and referred to a diabetes educator. He describes how she helps relieve his fear, embarrassment and distressing sense of responsibility for causing his condition, and encourages a more balanced perspective.

*I went to see Y [diabetes educator] I was pretty nervous because my perception, and I think a lot of people's perception is when you have to start taking insulin, Oh my God, you're close to being tragic at that time . . . I was particularly, particularly, ah, moved, isn't the right thing, but when I went to Y to start doing these things . . . I was really concerned about going to someone and telling them about the diabetes. And she told me it's not my fault I'm diabetic . . . I like the positive reinforcement that Y does . . . I think she also taught me not to take myself so seriously.*

Andrew and others acknowledge how having their health beliefs and knowledge about diabetes updated by professionals and peers significantly reduces the stress of diagnosis.<sup>85</sup>

***Stress of diabetes stigma and breaking isolation through talking with others.***

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<sup>85</sup> Brown et al. (2007) document a health beliefs intervention that increases effective self-management and healthier HbA1c levels.

A couple of participants acknowledge the stress of feeling the stigma of a chronic illness and speak of the value of talking with others to break their sense of isolation and disperse negative feelings. Margaret acknowledges lingering myths and misinformation around diabetes;<sup>86</sup> she emphasizes the importance of exchanging emotional support and advice with peers.

*Don't go and lock yourself in a closet because it's not contagious and it's not something that somebody is gonna catch off you . . . It's not something you have to be ashamed about . . . It's an every day, known medical problem that's been going on for hundreds of years . . . Years ago people didn't quite understand it . . . now in this day and age . . . there's a lot more information and a lot more history of sugar diabetes that people can understand what it is . . . Talk about it with other people. Find out how other people are living with it and share stories with them . . . hopefully that would all click in to make them feel a lot better with the fact that they are diabetic . . . You gotta learn to live with it and to deal with it and learn that it's not going to hold you back. You can still do the same things you want to do, that you've been doing.*

Andrew sees his shame as having roots in social and professional influences;<sup>87</sup> as his understanding of diabetes grows Andrew is more open in talking about it; the more he talks the better he feels, as he breaks his social isolation.

*For years the health care professionals do stress that it's your fault if you have diabetes. And I don't think in a malicious way. I think they're trying to scare the bejesus out of you to get you to do the right thing . . . I really had a hard time when I first got diabetes. You shouldn't talk about it, you know. It's kind of your fault type of thing, you know, you ate too much, you didn't eat too much . . . Diabetes is really not a disability; it's a medical condition that you should look after. So it's a private thing but the more I talk about it, the better I feel about talking about it.*

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<sup>86</sup> Margaret's awareness of traditional patterns of response to diabetes in her community is an example of how practice of what might be called popular ethnography can be a step towards change by an individual and a community (Gubrium, 1999).

<sup>87</sup> Myers (2004) discusses illness stigma and deciding to come out. The strength of stigma is tied to the severity of the illness and whether it is seen as behaviorally caused. Coming out has social and psychological risks and benefits to be weighed.

Ruth acknowledges working on a general tendency in her life to hide and recognizes that developing relationships with people is intrinsic to developing a healthy relationship with food.

*I have spent the last year coming out of hiding. Because that was one of the other things that I've learned about myself is that I have spent my life . . . hiding who I was from the world. [As] long as I continued to do that I was always going to have a problem with food. So for me, part of developing a healthy relationship with food was learning how to develop a healthy relationship with the world, which means developing a healthy relationship with people.*

***Acceptance stage.***

Martin acknowledges the difficulty and the importance of accepting the reality of any chronic disease. Acceptance can allow an acknowledgement that changes are needed; these require choice making by the person affected. The ability to face reality is critical to the ability to make healthy choices related to long term health goals.

*Number 1, the hardest thing for anybody to do is to accept it . . . There's a natural progression, that doesn't change for anything, whether it be cancer, or diabetes . . . it's hard to accept the facts. Once you've accepted it, it is a fact. You've got to acknowledge that something's got to change and then you've got to do something to make a change . . . the choice is yours. Nobody else is going to live your life but you. How long do you want to live it? And what do you want to live it like? And from what I can see, this diabetes can be an awful, awful thing . . . right now you have to be aware that everything you do is . . . you'll have an immediate fulfillment and then there's a long term fulfillment. So how immediate and how long-term do you want it to be? And the more you overlook and don't deal with it, that long term becomes short term real quick . . . Well this is one thing you can't make differently, it is there, it is a fact, it is reality and you have to deal with reality. This is not Hollywood. It is not make believe. You have to deal with it.*

Martin emphasizes the profound inner change that is involved in embracing chronic illness, a change that takes time, that involves dealing with denial and the stress of

grieving one's fate and that is easier for some.<sup>88</sup>

*This is your baby . . . a whole psychological change has to take place within a person's psyche . . . no one wants to admit a lot of times that something is wrong . . . it takes time to allow that to sink in. Some people can do it; I suppose it's like people quitting smoking. Some people will never quit and some people will quit cold turkey and some people will have to have all sort of manner of manipulation to help them. I've never had that problem in my life . . . I can see, so many of these things are wrapped up, any disease has a progression and acceptance and then you know, why does it have to be me . . . But you have to accept it and the more you accept it, and the more you try to consciously treat it, if we can use that term, then the better off you're going to be I think in the long run, for it . . . It might beat you in the end, but you might beat it off for a longer period of time if you can do what you should do.*

Andrew acknowledges that acceptance is an ongoing task. He describes how he deals with the stress of his resistance to taking insulin by comparing himself to those who are worse off<sup>89</sup>, feeling gratitude for his own quality of life, having faith in God's power to support him, and affirming the importance of getting over feelings of guilt.

*Change your attitude, or attitude has to change, but get on with it, get over it. I know, I was watching the news the other night before I left home . . . and I had been thinking about taking this insulin and how much I don't like it and I watched on the news little children at the IWK hospital and I really don't have anything to complain about. So people who complain about it, you don't always like to hear that but get over it. I have the best of everything in my life and always have and my sister is in England and she has xxxxxxxx for many years and she has rheumatoid arthritis, and she has accomplished a lot in her life. And she says our Dear Savior wouldn't give us anything, any cross that we can't bear and she's right. And that's what I tell people too. That's just the way it is. If you're diabetic maybe your lifestyle has something to do with it, of course it does, but you're going to have it one way or the other, so it's not your fault. And that was good to hear. I was glad to hear that it was not my fault because I know people think of it that way and I've talked to people about it too. And they've said yeah, well you kind of feel like that but you have to get over it.*

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<sup>88</sup> Kirkham (2003) discusses the stages of grief that start at diabetes diagnosis and cycle towards acceptance.

<sup>89</sup> Rogers et al. (2009) discuss how persons with chronic conditions often use downward comparisons as feeling better off than others can reduce feelings of insecurity.

Sarah talks about the importance of understanding that denial will not halt the progression of disease and that every aspect of life now involves consideration of self-care issues.

*Denial is not going to stop anything from occurring. So you need to accept your condition, learn as much about it as you can, do everything that you can to make yourself, like the eating, just every aspect of your life now revolves around the fact that you're diabetic. And there's no sense in sitting back and going "Huh I'm not", because it's not going to work. Denial is not going to get you anywhere. I think it probably opens some doors to trouble more than anything else.*

Sarah recognizes that past experience with other chronic conditions have given her practice in accepting the chronicity of diabetes.

*I had a lot of medical conditions, so . . . you can't be ignorant to the fact that once you are diagnosed . . . you can't change it. I mean you can change it, don't get me wrong. You can change the numbers. But you can't change the fact that you are a diabetic. You can be a very well-controlled diabetic, but you are still a diabetic and always will be. You can't change that. Not at this point. Maybe someday we can.*

Sarah emphasizes the power of whole hearted-commitment to diabetes self-care to control diabetes progression. She says,

*So you really have to take it all in, and embrace it. You really have to embrace it. And by doing so, then you do have much better control and you perhaps stop or halt or slow down the progression of the other things that can occur from diabetes, like your high blood pressure, the neuropathy.*

Ron also speaks to the importance of consciously choosing what he wants, taking control and finding out he can practice secondary prevention. He says,

*I'm also trained in reality therapy and it's either you're in control or somebody else is in control, and I don't like somebody else to be in control . . . I've found that yes I can do those things. You know if you're playing catch up to what you have, then you're not in control. You're just trying to address the cause . . . the result of what is happening. But if you're in control and become proactive . . . it's key . . . the person has to ask themselves, what do I want? What can I do about it? And what are some of the things that I need to do in order to get there and stay there? . . . But unless you're willing to do it, and make a decision as such, well,*

*it's going to be tough.*

Ron recognizes the difference between disease control and cure and he acknowledges the ongoing effort needed to maintain chosen self-care practices. He says,

*The condition is never going to go away. But you can control it . . . between you and your health professionals . . . you can develop something that you can use successfully towards improving your quality of life . . . The other thing is maintaining. It's easy upfront to-[say]-I'm going to do all these things and be gung-ho. It's down the road where . . . you say, oh gee now I'm there and oh, there's no problem . . . I'll just slack off. Well if you slack off . . . you're going to have . . . problems again, more than you have now. I'm sorry but you can't go back. You have to maintain.*

Andrew deals with the stress of adjusting to insulin treatment by immediately consulting with a diabetes educator and choosing not to avoid unpleasant aspects of his regimen.

*I really wanted to get a good start and look after it and take it seriously . . . I went to her 2 or 3 times and she started out . . . I'm the type of person if I'm going to do it, today is the first day of the rest of my life, let's get it done now. So if I need to start with 10 units, I'll start with 20 . . . she smiled and said, we can do that, because she doesn't like to scare people away . . . I'm no braver than anybody else. It's just the way I think my mindset. So you have to do it whether you like it or not . . . I take great pains to do things I don't like right away and get them behind me. She does a good job and she must get discouraged sometimes. I come in and she says thank you for coming in so regularly and I kind of smiled at her and I think she knew that I was [thinking], this is what I should be doing . . . And she says yeah well I know but I have people who don't come for 6 months.*

George sees that prioritizing self-care is what makes it possible to continue to enjoy well-being in life. He says, *The most important thing in my day being, I've got to get better, so I can keep enjoying life.* Martin adds a cautionary note about keeping in mind the individuality of each person's condition and stage of disease and the need for an individually tailored response. This can address the stress of being a round peg in a square hole. He says,

*The trouble is when people discover this, they are at various stages . . . They might be further down the road than what I am and consequently what I would be saying right now . . . it's not a true guideline for that individual, but right now it's*



*the way I'm dealing with it, where I'm at, at this stage in the game . . . That's like everything, in the school system . . . For years they tried to put round pegs in square holes to hold the water back . . . You're dealing with individuals . . . When you study things out, when you look at things there's a lot of individuality in disease. There's a lot of things that are the same. There's a lot of things going to apply to everybody, but it's not just black and white. There's all kinds of shades of grey.*

### ***Adjustment stage.***

Participants recognize that the life skills and life philosophy developed over a lifetime are invaluable in coping with the demands of the lifestyle change entailed in incorporating diabetes self-care. Several mention the importance of being able to connect self-care with life purpose and goals.<sup>90</sup> Ruth notes that she applies her observational and expressive skills to the enhancement of her relationship with her physical self involved in self-care.

Ruth is motivated to deal with the threat of physical deterioration not by fear but by a desire to continue a self determined path of personal growth.<sup>91</sup>

*Over the years I have done a lot of work on myself, personally . . . trying, got in tune with who I am and how I act and how I want to change that . . . Now . . . I'm working on the physical level and putting my energies into observing what's going on inside and finding words for it to express it . . . Fear was not going to help me make different choices. I had to find my own way and want to learn to eat healthier and want to share that with the other people in my world. That is what motivates me to do that.*

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<sup>90</sup> Wolever et al. (2011) report that client-centered health coaching with patients with type 2 diabetes, which focuses on patients' values and sense of life purpose, is linked with improved self-efficacy, accountability and clinical outcomes, compared to usual care.

<sup>91</sup> Ryan & Deci (2008), in their self-determination theory approach, link autonomous motivation and autonomy support with developing and sustaining competent self-care; they hypothesize that the autonomously motivated person does not experience the internal conflict and division associated with external direction. It is possible that Ruth is resisting not only fear but also a perceived medicalization (Conrad, 2007) of her life.

Malcolm has developed stress-management skills during his working life which he applies to the new challenge of diabetes self-management. These include an acceptance of change, confidence, and willingness to learn new things and work with new people, interacting with people in a courteous, reasonable, firm way, and being flexible and adaptable. As an aside, Malcolm throughout his interview addresses stereotypes particularly about aging and cultural differences. Here he challenges stuffy stereotypes about his line of work. Perhaps this ability to challenge the stereotypes of others and himself is one of the strengths that Malcolm applies in living well with diabetes.

*Some people don't adapt to changes, which is one thing we learned on the job . . . I was an income tax auditor . . . you go out and audit a pulp mill . . . You start at the top, bringing the logs in, the debarker, the chipper, the acid baths and down comes the paper . . . you learn how things go on and it's quite interesting. And people you deal with . . . at times . . . people get real ugly . . . other types you help them a bit and they're quite happy about it . . . You have to be polite, courteous . . . reasonable . . . firm . . . it depends on the circumstances . . . To be flexible, adaptable, that's the key . . . Nothing stays the same so you have to be prepared to change and adapt because on the job you'd be [at] this stuff for 2 or 3 years, then you'd go to another group for 2 or 3 years . . . You have to learn to adapt to all the change and circumstances, which I think is good for people maturing . . . they learn to go through this. It's the same with watching your diabetes. You've got to adapt to this . . . and that. It's all different. But you can do it.*

Sarah echoes the importance of continuous applied learning, in avoiding becoming overwhelmed or depressed. *For me, I don't suffer depression . . . at this point. I'm very fortunate. But I think it's learning as much as you can and doing the best that you can to take care of yourself.*

Participants draw on their life philosophies in coping with the stress of diabetes.

Martin practices an approach to life based on the parable of the talents that consists of doing the best he can with what he has and learning from his life experiences.

*You take what's given to you and make the best of it . . . that's the parable of the talents, right? To whom much is given much will be required and if something . . .*

*[has] been given . . . [and] you use it, you're gonna get more . . . I found that true throughout all my life . . . I started out as a boy in a fishing village . . . I've been all around the world . . . I've done all kinds of things that resulted . . . [from] leaving yourself open to just think positively. I made a lot of mistakes, made a lot of wrong decisions but learned from them . . . I guess that's where wisdom begins to come into play. You apply the knowledge that you've gained . . . What's that little saying Lord help me, some things I cannot change, and the things I can help to change . . . give me the wisdom to know the difference . . . that comes into it. I've had open-heart surgery, I've had prostate surgery and I just finished the other day on a . . . hernia . . . it could be life threatening, but . . . everything takes on a different realm, according to how it's approached and how it's affecting you.*

Genevieve has learned to relieve her relationship stresses by learning what she can and cannot change. *And realizing that I can't change other people. I can only change me. I can't fix other people. I can only fix me.*

Persons new to diabetes can be intimidated by the complexity of self-care work.<sup>92</sup>

Several participants including Ron talk about coming to understand diabetes care as accessible to lay persons. *The bottom line is when it comes down, it's common sense.*

Martin acknowledges the complexity of responding holistically to the challenge of living with diabetes. He says,

*We are fearfully and wonderfully made and everything interacts with every other thing in our life. But a lot of people don't realize that. They think you can just departmentalize everything. No, everything is overlapping with everything else. You know. It's just sort of like a giant octopus, those tentacles are involved everywhere.*

Martin goes on to talk about the complex flow between daily life commitments and commitment to self-care, which is impacted by internal shifting attitudes, external factors beyond one's control, and the ability to hold to a course of action in the crosscurrent influences of those outside factors.

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<sup>92</sup> Adolfsson et al. (2008) present evidence that an empowerment approach to diabetes education, involving horizontal relationships and participatory learning, increases participants' self-management knowledge and confidence. Amoaka et al. (2008) document that a telephone intervention designed to reduce uncertainty among person with diabetes improves psychosocial adjustment as well as self-care activity.

*There is a flow and there is a continuity to all of these things, though at times you might act . . . as if you're not aware or don't care . . . So . . . things that the dietician has said, things you've learned through going to conferences, things that you read . . . you program these things in your brain . . . There's times when . . . you know what you ought to be doing . . . and you just can't find the time to get it done . . . There's so many factors that change throughout the run of a day, there's sometimes when you can . . . be in control but yet don't take control, and there's other times it doesn't seem like anything is in control, but yet you do have control of it and you're aware of it, and you're able to do something about it. You purposely do . . . I think there's a tremendous amount of psychology involved in the treating, or handling diabetes as well as there is you know physical thing.*

Margaret acknowledges the tensions and fatigue that can be involved in attending to social and emotional needs and commitments while trying to maintain a healthy living regimen. She advocates a realistic approach of making the best choices possible under the circumstances.

*You can have all this information, but to keep implementing it day after day after day, sometimes you just get tired of doing that . . . Like when you're entertaining and you're busy . . . you're not in your . . . normal space and time . . . I find it very hard . . . to be on any program . . . If it's out of your daily routine, you're not as apt to be as successful at being and doing the things that you need to do . . . You're kind of in this awkward position that pulls you in two directions at once . . . that is what I call real life . . . I'm not eating at the regular times I normally eat. I'm not exercising the way I normally would do . . . everything is not like the norm . . . Those times come in your life and you just deal with it and make the best choices that you can.*

Participants acknowledge the stress of knowing when they have strayed from their self-care regimen or have lost control of their blood sugar balance. They emphasize the importance of recommitting to a self-care practice and talk about how to get back on track. George talks about returning to self-care after falling into complacency or attending to a family crisis. He normalizes these variations in life priorities and says what makes it easier to resume self-care is the experience he is accumulating.

*You can't fool the A1C. That's your blood telling on you . . . You've become . . . complacent . . . And I've had setbacks . . . when the setbacks . . . come, they slap you upside the head . . . but you have experience to draw on now whereas before I*

*had nothing . . . When your father-in-law has been in the hospital on death's bed, amputated leg, and finally died, I'm sorry . . . [although] your main purpose in life has now become self-preservation you had to shut that down because you have a crisis in the family now, that's more important, at that time, than your own self preservation . . . Fall down, at times like that, or even get complacent and slip, but don't stay down . . . Everybody has setbacks, everybody has problems.*

Ruth finds that reading about the positive effects of healthy food helps her take a step at a time to get back on track with her eating.

*What helps me to get back on track is I start reading about healthy food and the effects it has on your body. And then once I start reading it and reinforcing that in my brain, then I start making 1, 2, 3 little healthy choices and pretty soon I'm making more headway with making healthier choices and then I'm okay until the next time.*

Genevieve describes how she gets back on track with meals and exercise through careful planning and scheduling. She says:

*I'm going to do . . . a weekly schedule, for myself as to when I want to go to the gym. And I'm booking the time in. And then I'm going to sit down and do my meal plan too.*

Willow notes that her diabetes education lay-leader trainees how they have learned to take a long term approach to self-management. They recognize that a chronic condition can go through acute periods and that they have tools to help re-establish a balance.

*[They have developed] the ability to approach this as something they have to deal with . . . and manage . . . understanding that it's not going to be something that's fixed overnight. That it's going to be a chronic condition. You'll have ups and downs. It won't be the end of the world because you have chosen to bring yourself back. So I do hear that . . . "I'm glad I know some things to do . . . And that I've been in the project because I now have these tools."*

Participants say that the stress of having an incurable deteriorating condition is greatly relieved as they experience success in managing their conditions. Margaret notes how her blood sugar control enables her to move forward with a positive future outlook.

*I'm not being held back because my sugars are out of whack . . . I got them under control and I feel like I can do just about anything I want to do without it holding me back . . . it is a good feeling because then that way there you're not bogged*

*down with, Oh, am I ever going to get this straightened out, or what's ever going to become of me . . . It's just push on and move forward.*

### ***Dealing with financial stress associated with diabetes self-care.***

Participants acknowledge, for themselves or their peers, the financial stresses associated with the cost of diabetes care. Andrew, who could retire, chooses to continue working to maintain health insurance coverage. Sarah's potential financial stress is addressed by good health and disability insurance coverage from her former place of employment. She says, *I'm fortunate. I do have good coverage at this point for my supplies.* Several describe practical approaches to stretching their food dollars. George deals with the significant financial stress of his medical costs by focusing on how these treatments keep him feeling well and how he feels his life is blessed.

*Our finances with the cost of the medical treatment that I have to take, and so on, it really gets bad sometimes . . . way too close for comfort. But, we get through it . . . That in itself could really make me unhappy, but it doesn't, because if that's what I have to do to feel this good, and this wonderful . . . I got to make that my theme. I've been blessed and it's not over yet.*

Genevieve draws on spiritual practices to deal with anxiety, including financial concerns.

*If I am stressed, I will usually go to the Bible. Or if there's things going on that's beyond my control and it seems to calm my mind . . . from knowing that God does not want you to worry, that He will take care of it. And when you get into financial difficulties or you feel stressed over financial burdens or anything like that, that you can give it to Him to look after or He will give you a thought of how to make additional money . . . it just seems to work out better that way. Now I still take it back and worry about it maybe for 5 minutes the next day and then I'll say no, you're not supposed to do this and then I do that all over again - give it back. So that's played a part in my life, a big part in my life.*

### **Simultaneously Embracing Diabetes and Embracing Life**

The participants identify three main interdependent contributing factors to living well with diabetes — positive personal qualities, reciprocal interpersonal support, and experiential expertise. These interact in a way that facilitates the apparently paradoxical approach of the participants, which I have named as the overarching theme of simultaneously embracing diabetes and embracing life. Sarah first names this phenomenon when she said *You really have to take it all in, and embrace it*. Martin and other participants talk about their enjoyment of life and how embracing their chronic conditions can enhance that enjoyment. While diabetes is *a pain in the butt*, devotion to self-care paradoxically is integral to the participants' quest to live their lives well. Facing diabetes as a degenerative condition can also inspire them to seize the joys in the present. Jacob describes this enhancement of life for peers and himself.

*I have heard people say that they are glad they were diagnosed with diabetes. This has lead to weight loss, healthier eating, more energy, more enjoyment of life . . . I feel better, physically — more energetic, more focus. I'm more at peace with life . . . Because I have eye problems, I value my eyesight more. I bought binoculars last year and am really enjoying bird watching. I recently bought a high-end camera. I said to my wife, "I need to buy this camera now, because I don't know how long I'll be able to use it."*

Martin speaks of the value of staying focused on the present, taking one day at a time.

*If it gets worse because of things due to my . . . lack of control, or just natural circumstance and the natural progression of the disease itself, then there's a lot of other things you're going to have to learn to deal with. But we take that one day at a time; I'm not worrying about that part now. I am taking today for what today offers and making the best out of it.*

## **Curriculum Vitae**

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