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Résumé

Les soins auto-administrés du point de vue des personnes vivant avec le diabète

Shannon M. Spenceley et Beverly A. Williams

Cette étude présente les résultats d'une importante revue intégrative de la recherche sur les obstacles et les facilitateurs des soins auto-administrés selon le point de vue des personnes atteintes de diabète. La réalisation de l'étude a été motivée par un besoin de comprendre les soins auto-administrés selon la perspective des personnes vivant avec cette maladie chronique et d'explorer les implications de cette compréhension sur les politiques de santé au Canada. Des articles et des dissertations explorant les soins auto-administrés du point de vue d'adultes souffrant de diabète de type I ou II et publiés en anglais entre 1993 et 2003 ont été analysés, et des études tant quantitatives que qualitatives ont été considérées. Comme les études s'appuyaient sur différentes définitions des soins auto-administrés, les facilitateurs et obstacles ont été définis en conséquence. Une tension thématique globale était évidente, causée par une vision des soins auto-administrés comme soit tournant autour de la maladie, soit évoluant dans la vie des personnes atteintes de diabète. Cette tension a des implications pour les professionnels de la santé et pour les personnes prenant part à l'élaboration des politiques liées aux soins auto-administrés.

Mots clés : Soins auto-administrés, gestion de la maladie, diabète, revue intégrative de la littérature

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Self-Care from the Perspective of People Living with Diabetes

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This review presents findings from a critical integrative review of research into barriers to and facilitators of self-care from the perspective of people with diabetes. The review was motivated by a perceived need to understand self-care from the perspective of those living with this chronic disease and to explore the implications of this understanding for health-care policy in Canada. Journal manuscripts and dissertations exploring self-care from the perspective of adults with type I or type II diabetes and published in English between 1993 and 2003 were reviewed. Both quantitative and qualitative studies were included. Studies were informed by varying definitions of self-care and facilitators and barriers emerged accordingly. An overarching thematic tension was evident, based on a view of self-care as revolving around the disease or evolving in the lives of people with diabetes. This tension has implications for health professionals and for those involved in policy development related to self-care.

Keywords: Self-care, disease management, diabetes, integrative literature review

The World Health Organization (2005) describes the global rise in diabetes prevalence since 1985 as "epidemic" in proportions. Diabetes is a significant and growing health concern in Canada, with more than two million people estimated to be living with the disease (Canadian Diabetes Association, 2005a). With self-care an essential feature of diabetes management, effective health care and health policy must be sensitive to the self-care needs of these individuals. This paper presents findings from a critical integrative review of research into barriers to and facilitators of self-care from the perspective of people living with diabetes. It focuses on all research that examines self-care from the perspective of adults with either type I or type II diabetes, and concludes with a discussion of implications for health-related public policy, particularly in the Canadian context.

Methods

An integrative literature review examines empirical or theoretical work around a particular topic. It may be narrow or broad in focus, and may employ a broad sampling frame that includes qualitative, quantitative, or purely theoretic literature (Whittemore, 2005). While less focused than other types of synthesis such as meta-analyses or systematic reviews, an integrative review should follow a research protocol that is set up in advance of the literature search. The review is guided by a specific question, terms and variables are defined, search terms and strategies employed are described, criteria for study selection are provided, and the quality of the primary studies is appraised (Whittemore). These elements will now be described as they were implemented in the present review.

Search Protocol

The review protocol addressed the following question: *What are the barriers to and facilitators of successful self-care from the perspective of adults living with diabetes?* Self-care was defined as all health/illness-related decisions and activities carried out by individuals or families related to managing and/or coping with diabetes and/or improving health while living with diabetes. Barriers to self-care were defined as factors that made self-care more difficult and facilitators as factors that made it easier, from the ill person's point of view. Studies had to include a specific exploration of the ill person's perspective. Journal manuscripts and dissertations that explored self-care from the perspective of adults living with diabetes and published in English between 1993 and 2003 were included. There were no restrictions placed on research design, as the aim was to gain an inclusive view of the knowledge about self-care and living with diabetes. The value of exploring the "contradiction and tension between findings generated by different methods" in self-care research, in order to gain a multi-dimensional view of the phenomenon under study, has been noted by others (Meetoo & Temple, 2003, p. 7) and is consistent with the integrative review approach.

In consultation with a University of Alberta health sciences librarian, nine databases were selected and specific search strategies were developed. Databases searched included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, Medline, HealthStar, and PsycINFO. These databases support controlled search vocabularies, and a strategy was designed to capture published research of all types that focused on self-care, self-management, or self-help in the target period. Keyword searches (self care or self manage or self help) were also conducted in non-periodical databases: the Database of Abstracts of Reviews of Effects (DARE), the Cochrane Database of Systematic Reviews, Medline in Process (current), and Allied and Complementary Medicine (AMED). The online search strategy was supplemented by a manual search of reference lists of articles selected for complete review. Data were managed using Procite™ bibliographic software (version 5) and the outcomes of decision processes were captured using Excel™ (2002 version).

Search Results and Selection Criteria

A review of 461 abstracts against predetermined exclusion criteria (see Table 1) resulted in the selection of 42 papers that explored self-care in diabetes. The majority of the papers focused on type II diabetes, surely reflecting the much greater prevalence of this form of the disease worldwide (World Health Organization, 2005). At this stage of the review, the decision was made to include studies of self-care in both types of chronic diabetes. This decision was premised on our having chosen to

Table 1 *Criteria and Questions*

Exclusion criteria

- non-research items, including editorials, commentary, letters, descriptive articles
- work that relates only to diabetes or health care for diabetes in general or that mentions but does not explore self-care
- work that investigates associations between particular factors or characteristics and the incidence or frequency of self-care behaviours without any exploration of the person's perspective on what made self-care easier or more difficult
- research focused on tool development only
- research focused on gestational diabetes
- program evaluation research that does not specifically explore the impact of the program on perceived barriers to or facilitators of self-care

Questions used to interrogate reviewed papers

- Is the research specifically about barriers/challenges to self-care as related to diabetes management (i.e., self-care or components of self-care as dependent variable or outcome of interest, with research focused on impacts of barriers, facilitators)?
- Do the researchers specifically seek the perspective of participants living with diabetes?
- Is the research about effective strategies for promoting self-care in diabetes (i.e., intervention research with self-care or components of self-care as outcome of interest, with research focused on ways of facilitating self-care)?
- Does the research explore self-care facilitation or impedance as related to outcome measures of related concepts: coping, self-management, self-efficacy, mastery, self-help, empowerment?

focus the review on self-care as well as the observation that the elements of self-care are very similar in type I and type II diabetes (Canadian Diabetes Association 2005a). We believed that we could learn valuable lessons by keeping the focus upon self-care while remaining sensitive to any differences that emerged in terms of the processes of self-care in the two chronic forms of the disease.

All 42 papers were reviewed against a series of questions developed by the authors (see Table 1). We were clear about what we would accept as evidence that self-care is indeed "easier" as a result of particular factors. It was decided that "easier" self-care would be evidenced by an expressed (a) perception of increased ability to assume responsibility for and to direct self-care; (b) feeling of comfort, confidence, or "success" in self-care; or (c) feeling of being supported or reinforced in self-care efforts as a result of particular factors. We excluded studies that simply reported increased incidence or frequency of self-care activity as an outcome, unless a specific attempt had been made to seek the patient/client's point of view about the role of particular factors in increasing personal self-care ability. Any systematic attempt to gain the patient/client's perspective was deemed eligible, including a survey, interview, or questionnaire. At this stage we reached consensus on 22 studies: 13 qualitative, seven quantitative, and two mixed method. These 22 studies were accepted into the next phase of the review process. Manual searching of the reference lists resulted in the selection of eight additional works for review; none of these satisfied all inclusion criteria and all were excluded from the review.

Quality appraisal of primary research is difficult and complex; there is no "gold standard" for assessing quality, particularly when different designs are included (Whittemore, 2005). Such concerns notwithstanding, a consistent method of quality assessment that includes independent appraisal is an important aspect of any integrative review (Whittemore). The 13 qualitative studies were assessed by the first author and an independent rater using a modified research appraisal tool based upon the work of Duffy (1985), Eakin and Mykhalovskiy (2003), and Mays and Pope (2000). The modified instrument was reviewed for content validity by an expert in qualitative health research, and the process of appraisal was guided by the following assumptions: (a) qualitative and quantitative research are methodologically and epistemologically distinct; (b) qualitative research reports must, at a minimum, accurately and completely describe the procedures followed in the research process; (c) procedural correctness alone is insufficient; and (d) a key consideration in appraisal is how the author enables the reader to access the substantive contribution of a study to new or existing knowledge about the topic of inquiry. Therefore, the tool was constructed to assess procedural rigour as well as the study's substantive contribution to our understanding of self-care in diabetes. This approach also facilitated analysis, in that it allowed for the capture of analytic thoughts/questions in the form of memos. This provided the basis for an iterative process of moving back and forth among studies, informing analytic discussions between the two authors, connecting substantive findings, and comparing key assumptions and definitions. This activity also supported the selection of key elements for subsequent data extraction.

The seven quantitative studies were assessed using a modified appraisal tool developed by Cummings and Estabrooks (2003) and Estabrooks, Floyd, Scott-Findlay, O'Leary, and Gushta (2003). Modifications to the quantitative instrument were reviewed in detail with one of its primary authors (G. Cummings, personal communication, July 8, 2004). In order to extend the memoing process to the assessment of the quantitative studies, a further modification of this instrument evolved as the review progressed. Both tools were used to appraise two mixed-method studies. Six studies (three qualitative, three quantitative) were excluded on grounds of quality. This review ultimately included 16 studies (Table 2), 10 exploring self-care in type II diabetes, five focusing on type I, and one that included participants with both forms of the disease (see Table 3).

Findings

The key elements extracted from the studies included the research aim(s), theoretical framework, study design, instruments and sampling procedures, participants, setting, analytic procedures, and identified barriers to or facilitators of self-care. The studies were then carefully reviewed in order to capture key underlying assumptions and explicit or implicit definitions of self-care. To better understand the underlying structure of the existing knowledge, barriers to and facilitators of self-care were coded and thematically grouped by definition of self-care and related self-care assumptions.

Barriers to Self-Care

The most common studies were those informed by a definition of self-care as disease self-management and symptom control based on adherence to the advice of health-care experts. Of the seven studies, five dealt with type II diabetes and two with type I (see Table 3). Barriers described across these studies were similar. The only notable difference was that the studies of type I noted the burdensome nature of frequent injections (Mollem, Snoek, & Heine, 1996) and of monitoring and controlling symptoms related to blood sugar levels (Mollem et al.; Wdowik, Kendall, & Harris, 1997). All seven studies described barriers to

Table 2 ***Studies Included in the Review***

First Author (Year)	**Country**	**Publication**	**Design**
Cagle (2002)	United States	*Ethnicity and Disease*	Qualitative
Cooper (2003)	United Kingdom	*Health Education and Research*	Qualitative
Greenhalgh (1998)	United Kingdom	*British Medical Journal*	Qualitative
Hunt (1998)	United States	*Journal of Family Practice*	Qualitative
Jayne (1993)	United States	Doctoral dissertation	Qualitative
Maillet (1996)	United States	*Diabetes Educator*	Qualitative
Mollem (1996)	Canada	*Patient Education and Counseling*	Quantitative survey
Paterson (2000)	Canada	*Clinical Nursing Research*	Qualitative
Schoenberg (2001)	United States	*Journal of Aging and Health*	Mixed method
Shultz (2001)	United States	*Journal of Health Communication*	Quantitative survey
Simmons (1998)	New Zealand	*Diabetic Medicine*	Mixed method
Thorne (2001)	Canada	*Patient Education and Counseling*	Qualitative
Tu (1993)	United States	*Journal of Community Health Nursing*	Quantitative survey
von Goeler (2003)	United States	*Diabetes Educator*	Quantitative survey
Wdowik (1997)	United States	*Diabetes Educator*	Qualitative
Weiss (1997)	United States	Doctoral dissertation	Qualitative

self-care inherent in the rigidity and burdensome nature of diabetes management regimes (particularly dietary restrictions and exercise expectations) within the constraints of time, resources, and physical capacity, with motivation to follow restrictions reported as difficult to maintain. Self-care was hindered by challenges arising out of anxiety or social expectations (Maillet, Melkus, & Spollet, 1996; Mollem et al.; Schultz, Sprague, Branen, & Lambeth, 2001; von Goeler, Rosal, Ockene, Scavron, & DeTorrijos, 2003) and the demands of managing multiple chronic disease regimens (Simmons et al., 1998) or chronic pain (von Goeler et al.). Also described were a lack of understanding and inadequate education related to the knowledge and skills required to manage diabetes or prevent complications (Maillet et al.; Simmons et al.; von Goeler et al.) and a lack of confidence in using the tools of self-monitoring (Simmons et al.; Tu & Barchard, 1993; von Goeler et al.). Also noted were a fear of frequent injections and uncertainty about the future (von Goeler et al.). Barriers to compliance were the financial costs of diabetes self-care (Tu & Barchard; von Goeler et al.; Wdowik et al.) and poor or unsafe living conditions (Maillet et al.). This form of self-care was hindered by conflicting social roles, social pressures, and family expectations that the needs of others be put first (Maillet et al.; Schultz et al.). Competing life priorities and stress also created barriers to one's ability to manage diabetes as directed (Mollem et al.; von Goeler et al.; Wdowik et al.). Other barriers to self-care were inadequate family and community support, perceived language or communication barriers, and unrealistic expectations by health professionals (Maillet et al.; Simmons et al., 1998; von Goeler et al.). Also noted were structural or cultural barriers in the design and accessibility of services (Simmons et al.).

Two studies focused on self-care as a personal responsibility and as the outcome of lay-initiated choices about health; one study focused on older women with type II diabetes (Schoenberg & Drungle, 2001), the other on adults with hypertension and either type I or type II (Weiss, 1997). Adherence to health-care advice was identified as an important component of diabetes self-care, but personal factors were also acknowledged as influencing one's ability to make positive choices related to diabetes management. Barriers to making positive choices noted in both studies included a lack of resources such as money, knowledge, skills, time, energy, and physical ability to engage in what were perceived as complex planning and diabetes management activities. A lack of family understanding and support, along with social pressures to put the needs of others first, contributed to feelings of social isolation and created barriers to positive self-care (Weiss). Other barriers were fear and uncertainty about a future life with diabetes and lack of confidence in ability to self-monitor and manage the disease (Weiss). Self-care was also

Table 3 *Definitions of Self-Care and Related Barriers and Facilitators*

First Author (Year)	Definitions of Self-Care	Barriers	Facilitators
‡ Schoenberg (2001) ♓ Weiss (1997)	An individual's responsibility and a result of lay decisions about appropriate behaviour to benefit health, prevent further illness, limit illness, restore health, and maintain independence; based on rules of adherence and on factors arising from a personal perspective	Lack of money, knowledge, skills, time, energy, physical capacity, support; social isolation; lack of access to health care; lack of continuity of care; overwhelming needs of others; stress	Realizing benefits of self-care; mutual trust, respect, collegiality in health-care relationships; support of a self-care partner; timely self-care information; connecting past choices with present health and future risks; comparing self with positive and negative self-care examples in others
‡ Maillet (1996) † Mollem (1996) ‡ Schultz (2001) ‡ Simmons (1998) ‡ Tu (1993) ‡ von Goeler (2003) † Wdowik (1997)	Self-management of diabetes by self-administration of medical therapies; synonymous with symptom control and disease management	Costs; rigid, burdensome regimens conflicting with life priorities and with other regimens; unrealistic provider goals; lack of community support; little or no access to services; sociocultural pressures; belief that cause and cure are non-medical; communication barriers; lack of instruction; inability to use tools; lack of confidence in self or in therapy; environmental or personal barriers to exercise; situational challenges to blood sugar control	Supportive self-care partners or networks of social support; family support Fear of complications

‡ Cooper (2003) † Jayne (1993) † Paterson (2000) † Thorne (2001)	An evolutionary process of developing knowledge by learning to live with the complexity of diabetes in a social context	Discomfort with public exposure; fear of stigmatization; low self-esteem; standardized, reactive compliance advice; lack of ongoing education in regimen modification; health professionals "enamoured of the science" and resistant to partnership	Experiencing and confronting barriers to compliance; losing faith in health professional's ability to manage the disease; support in learning to live with unpredictability and accepting that perfect control is unrealistic; recruiting trusted self-care partners; providers who acknowledge that science is limited, that patients are as knowledgeable, and that self-care is complex; education that supports the evolution of client expertise and "real world" self-care; opportunities to share and reflect with supportive peers; "routinization" of self-care; vigilant body-listening, monitoring, and tracking
‡ Cagle (2002) ‡ Hunt (1998) ‡ Greenhalgh (1998)	Decisions made to manage illness in a sociocultural context based upon sociocultural belief systems; balancing disease with fulfilling expected roles	Cultural beliefs; advice in conflict with cultural values, rituals, and social roles; social isolation; stigma; discrimination; financial hardship; confusion about insurance coverage; language barriers	Strong connections to social networks; role-preserving assistance of caregivers

‡ Type II diabetes   † Type I diabetes   ϰ Both types I and II diabetes

hampered by a lack of both access to quality health services and continuity in health-care relationships (Schoenberg & Drungle).

Self-care as a complex balancing act regarding decisions about managing diabetes and fulfilling expected social roles was the basis of three studies, all on type II (Table 3). Barriers emerged when cultural beliefs, ethnicity, and the demands of social roles clashed with the expectations of the medical culture or of society. The cultural belief that a person with diabetes should take a passive role in health-care relationships caused people to avoid asking for information about self-care (Greenhalgh, Helman, & Chowdhury, 1998). Differing beliefs about illness causation, appropriate therapies, and the meaning of symptoms also caused conflict within health-care relationships (Greenhalgh et al.; Hunt, Pugh, & Valenzuela, 1998). A belief that taking medication represents worsening disease or weakness caused a sense of stigmatization and social isolation, and perceived negative judgement by others brought reluctance to engage in visible self-care activities (Cagle, Appel, Skelly, & Carter-Edwards, 2002). The belief that diabetes is not really a health threat led to a reluctance to follow medical advice; this was particularly evident when following medical advice conflicted with the demands of social roles or one's ability to participate in cherished rituals (Cagle et al.; Hunt et al.). Persistent symptoms and physical limitations further impaired self-care ability and functioning in social roles (Cagle et al.; Hunt et al.). Financial constraints and living in impoverished, unsafe neighbourhoods made it difficult for people to access diabetes management supplies and to engage in recommended exercise (Greenhalgh et al.; Hunt et al.). Because of language barriers, some people had difficulty understanding written or verbal communication from providers (Greenhalgh et al.); some people also experienced difficulty understanding health-care benefit plans (Cagle et al.; Greenhalgh et al.). Individuals also reported discrimination in employment settings and in access to health services (Cagle et al.).

Finally, four studies were founded on a definition of self-care as an evolutionary process whereby self-care knowledge develops over time as the individual lives with this complex disease; three of these studies focused on people with type I diabetes, one on those with type II (see Table 3). Barriers to self-care from this point of view included health professionals being resistant to working in partnership (Cooper, Booth, & Gill, 2003) or being too "enamoured of the science" (Thorne & Paterson, 2001, p. 87) to see other sources of self-care knowledge as legitimate. A related barrier was the propensity for health professionals to provide standardized advice and static rules of self-care, when what was needed was dynamic problem-solving assistance with regimen modification (Cooper et al.; Jayne, 1993; Thorne & Paterson, 2001). Also noted were barriers associated with low self-esteem (Jayne) and with unsupportive social contexts, where visible disease-management behaviour caused a fear of stigmatization (Jayne).

Facilitators of Self-Care

Among the seven studies that emphasized diabetes management and symptom control based on adherence to medical advice (Table 3), five did not describe any facilitating factors. Self-care assistance and support from family members was identified as facilitative in one study (Maillett et al., 1996) and assistance from social networks was identified as facilitative in another (Wdowik et al., 1997). Fear of diabetes complications was also described as a strong motivator of compliance (Maillet et al.). Facilitators were discussed in one of the two studies that emphasized individual responsibility for positive choices (Table 3). These included health-care relationships characterized by trust, respect, collegiality, and the sharing of timely, relevant self-care information (Weiss, 1997). Examining one's present health in light of past choices and future risks and comparing one's self-care behaviour, both positive and negative, with that of others were identified as helpful to the achievement of effective self-care. The facilitative impact of achieving health benefits from positive self-care choices was also noted (Weiss).

In the studies conceptualizing self-care within a sociocultural context (Table 3), decisions about managing diabetes were based on a cultural understanding of diabetes self-care. Strong connections to community social networks, church, and close friends (Cagle et al., 2002) and self-care assistance from a spouse were identified as helpful in maintaining an expected social role or image (Hunt et al., 1998).

The final group of studies (Table 3) focused on the importance of health-care partnerships characterized by trust, respect, empathy, and shared decision-making in the development and evolution of diabetes self-care knowledge (Cooper et al., 2003; Paterson & Thorne, 2000; Thorne & Paterson, 2001). Facilitating factors in the health-care relationship included acknowledgement of the complexity of diabetes self-care and the value of the knowledge gained from living with a chronic condition (Cooper et al.; Thorne & Paterson, 2001). The importance of creating opportunities for self-care knowledge to evolve and integrate with life experience was emphasized (Cooper et al.; Jayne, 1993). Shared reflection with health professionals and other self-care partners or peers on what self-care is like in the real world was of great benefit (Cooper et al.; Paterson & Thorne). Assistance from supportive others in building diabetes self-care routines was essential, and developing skills in listening to one's own body, monitoring responses to particular situations, and tracking trends was critical to diabetes self-care (Thorne & Paterson, 2001.

Barriers as Facilitators of Self-Care Evolution

An interesting observation emerged from the thematic grouping of the barriers and facilitators by definition of self-care. Factors that emerged as barriers to diabetes self-care according to one definition were identified as facilitators of self-care evolution according to another. In the majority of studies, self-care was understood to be disease management and symptom control based upon compliance with medical advice (Table 3). In these studies, self-care entailed following rigid regimens, meeting provider expectations, and complying with static rules. In the face of life's complexities, the burdensome nature of prescribed self-care and the unrealistic expectations of providers emerged as strong barriers to compliance, making it very difficult to achieve self-care (according to the definition of self-care operant in these studies). These studies described disillusionment with advice that did not work very well and anger at having to abandon cherished activities or traditions. In contrast, in studies that defined self-care as an evolutionary, developmental process (Table 3) these same barriers to compliance were framed as facilitators of learning. The acknowledgement and confrontation of these very barriers to compliance facilitated an evolution towards an ability to live with unpredictability and to respond knowledgably and flexibly to challenges as they arose (Jayne, 1993; Paterson & Thorne, 2000). Indeed, barriers to self-care that emerged from within this definition included the standard educational approaches that are the hallmark of most disease-management programs; such approaches were identified as offering no creative solutions for self-care puzzles encountered in the course of living life with diabetes.

Discussion

Extending knowledge in an area of scholarly endeavour requires sensitivity to assumptions underpinning the existing research (Paterson, Canam, Joachim, & Thorne, 2003; Shadish, 1993) and an awareness of the assumptions and biases brought to the synthesis of that research. We surfaced and questioned our own assumptions in approaching this review, including our underlying belief that self-care is a desirable outcome of health-care relationships with people living with chronic illness, and that patients/clients would ultimately favour being self-care experts. These assumptions most certainly influenced our interpretation of the findings. As Paterson and Thorne (2000) note, however, until much more is known about the evolution of self-care expertise and the outcomes of assuming the expert role, blanket assumptions about patients/clients wishing to take on that role are untenable. Underlying assumptions in the studies were also examined. These were coded, extracted as data, and then recoded by definition of self-care. While it is obvious that the barriers to or facilitators of self-care would be viewed according to what the researchers perceived self-care to be, we noted that with few exceptions (Paterson & Thorne; Thorne & Paterson, 2001) the assumptions about self-care underpinning much of the literature were not surfaced or questioned. We therefore believed it would be useful to stand back from the synthesis and identify any overall patterns in these assumptions. We identified an overarching thematic tension in the synthesized literature between a disease-centred and a life-centred conceptualization of diabetes self-care (Figure 1).

In a disease-centred approach to diabetes self-care, there was a focus on laboratory markers as a measure of adherence to medical advice. Individual choice was limited to a list of rules and restrictions and self-care was considered a solitary activity. Practitioners were considered the self-care experts, emphasizing compliance and control. Self-care education was standardized and based on rigorous scientific evidence. Clearly, self-care was about managing diabetes.

In a life-centred approach to diabetes self-care, individuals were encouraged to listen to and gradually develop trust in what their bodies were telling them. Self-care adjustments might be made simultaneously in various aspects of diabetes care, and were made according to individually relevant guidelines. Diabetes self-care was considered evolutionary, calling for constant readjustment based on individual requirements. Practitioners acknowledged self-care as a personal journey, and were often considered trusted partners on this journey. Self-care education was anticipatory, and the health practitioner helped to mobilize both internal and external resources with the individual and significant others. The person with diabetes was considered the expert on his or her own care. It was evident in studies focusing on the individual and personally meaningful nature of self-care, however, that self-care was about learning to live a unique life well with diabetes.

We suggest that the tension between these two perspectives is an important factor in the development of self-care ability. Over time, the nature of diabetes self-care changed. Paterson and Thorne (2000) identified elements or phases of the evolution of self-care ability, which varied from person to person in sequence and occurrence but seemed to arise out of the tension between the disease taking control of life and taking control of the disease within life as lived. However, this tension may go unrecognized within the dominant view of disease-centred self-care. Indeed, if surfaced at all, such tension is likely to be dismissed as the

Figure 1 *Thematic Tensions Identified in Reviewed Literature*

	Disease-Centred	**Life-Centred** →
	Underlying Assumptions about Diabetes Self-Care	
People living with chronic disease	Individual concept	Relational concept
	Focus on signs, laboratory markers	Focus on tuning in to body
	Adherence to advice	Making sense of advice
	Restrictions, rules imposed on life	Seeking normality in complexity of life
	A list of discrete choices	Self-care as a dynamic, fluid process
	Self-care is about disease management	Self-care is about living life
Health professionals	Self-care is about the health-care system	Self-care is a personal journey
	The health professional role is about stewardship	Health professional is part of a trusting partnership
	Providing resources	Working with people to mobilize resources
	Relying on measuring the body, illness	Trusting person to know the lived body
	Standardized advice/scientific evidence	Reciprocity of information and lived experience
	Self-care is uniform, static	Self-care is learned, evolutionary
	Compliance/control priorities	Adjusting, tailoring care to life priorities
	Certainty	Living well with uncertainty
	The health professional is the expert	Ill person is the best expert on self
	Sick role is dominant	Multiple life roles take priority
	Disease as malfunction	Illness as part of life
	Disease management is foreground	Managing the disease is background

persistent challenge of non-compliance. Much of the diabetes self-care literature continues to reflect notions of self-care as a static achievement, a compendium of discrete choices focused on restriction, control, and adherence achieved through educative means. It is worth noting that most of the factors identified as facilitative of self-care from the perspective of people with diabetes were relational in nature, founded upon sensitivity to and knowledge of the unique life circumstances of people living with diabetes (Table 3).

The emerging role of health professionals as participants in evolving self-care partnerships with people learning to live with diabetes calls for close examination of the assumptions that inform current patterns of practice. It is essential that this become an element of nursing advocacy at the level of individual health-care relationships. In the area of diabetes self-care, nurses practise at the interface between self-care as taught and self-care as lived. Supporting self-care for people with diabetes should reflect the philosophical, theoretical, and practical essence of nursing as a discipline. Whether theoretical perspectives on practice guide a nurse to support, facilitate, assist, monitor, or teach self-care, or simply to "be present" during the self-care experience, the core value of commitment to use nursing knowledge to assist another in meaningful care transects all current worldviews in nursing. At the level of the individual health-care relationship, there is increasing acknowledgement that self-care support must start where the client is and be framed from the perspective of the individual's life experience and meaning (Cicutto, Brooks, & Henderson, 2004). The idea that the chronically ill person brings expert knowledge about living with chronic disease to the health-care relationship began to appear in the nursing literature in the early 1990s (Thorne, 1993; Thorne & Paterson, 1998) and was an important step forward in reframing health-care relationships. While we must not assume that all people with diabetes are willing and able to take on the expert self-care role all of the time, some of the findings in this review indicate that there is merit in challenging the assumptions that inform the traditional insistence that people with diabetes must paradoxically and simultaneously achieve compliance and self-reliance (Wilson, 2001). This recognition, we believe, presents interesting implications for those working at the policy level.

Health policy frames what self-care choices are considered appropriate and are supported for those living with diabetes. Supporting self-care in practice requires an awareness of health policy structures that serve to define what constitutes appropriate self-care and appropriate support from the health-care system as well as the limits on access to services or treatments. The focus on individually meaningful and useful self-care is even more complex at the policy level. Although self-care is described as a "pillar" of health-care reform in Canada, discussions of self-care truncate quickly as they move to the level of "policy implications" (Health Canada, 1997, 1998, 2002). We have attempted to surface some of the pervasive assumptions underlying our understanding of diabetes self-care from the perspective of people living with the disease. We believe that similarly pervasive assumptions frame any discussion of self-care at the policy level. These include the assumptions that health policy relating to living with diabetes is mainly about the health-care system, that diabetes is largely preventable, that self-care is a resource-saving device for the system, and that the most relevant evidence to support health policy is generated from a medical-scientific perspective. In the Canadian context, policy core values increasingly reflect a belief in individual responsibility for health and collective responsibility for economic competitiveness driven by the globalization agenda (Chambers & Smith, 2002). Attention has focused broadly on disease prevention through education about healthy choices. Prevention is an extremely important policy focus, but in terms of meeting the needs of those already living with diabetes it seems that policy-makers have proceeded based on a very static, disease-oriented understanding of self-care. Policy has *encouraged* self-care by placing disease in the foreground, yet it has marginally and inconsistently supported only the most basic requirements for diabetes self-care. In Canada, provincial jurisdiction over health care has resulted in a patchwork of support; indeed, access to and coverage of the medications and supplies needed for basic self-care in diabetes are highly variable and uneven across the country (Canadian Diabetes Association, 2005b). There is currently little discussion at a national policy level about how such an approach affects diabetes self-care in Canada. The impact of such policy frames upon the development of self-care capacity needs to be more closely examined.

How might policy differ if it is founded upon a commitment to supporting diabetes self-care as an evolving, life-centred process facilitated within knowledgeable, mutually respectful primary care partnerships? Policy-makers would need to access and act upon the input and expertise of people living with diabetes and to create space in policy dialogue for the discussion of how policy impacts upon self-care and how it might more effectively and consistently support self-care efforts. For example, new team-based approaches to chronic disease management are being enthusiastically undertaken across the country (Calgary Health Region, 2002; Chinook Health Region, n.d.; Government of British Columbia, 2005; Health Quality Council, n.d.; Wong, Gilbert, & Kilburn, 2004). The results of this review indicate that the impact of such reform on the establishment and development of consistent health-care relationships with trusted providers should be carefully considered.

Limitations of the Review

Learning to self-care is a complex human health experience that has been researched from a variety of perspectives. We have attempted to be systematic, thorough, and inclusive in our approach to examining the perspective of people with diabetes learning to self-care, but we are aware that this approach has introduced into the review a number of limitations. Firstly, we have included studies from both qualitative and quantitative research traditions, along with their different epistemological assumptions. For this reason the approach taken was that of the integrative review (Whittemore, 2005). This is a synthesis approach aimed at discovering the broad landscape of an area of inquiry, with a purposefully broad sampling frame intended to capture "a comprehensive portrayal" of the topic (Whittemore, p. 57). Such an approach, however, limits the analysis to a narrative synthesis of broad themes and limits the depth of the conclusions that can be drawn from the work. While we did closely examine the assumptions made about self-care in each of the studies, we acknowledge that many of these assumptions likely had their origins in the research approach chosen to study the phenomenon in the first place.

Further, the search strategies and exclusion criteria employed have limited the international relevance of the work, given that, with the exception of two studies from the United Kingdom and one from New Zealand, all studies were from North America. We have, however, attempted to focus the discussion on the Canadian context.

Finally, extending the review to both chronic forms of diabetes may be considered a limitation, as they are quite different in clinical course, etiology, and pathophysiology. Limiting the synthesis based upon these medical criteria, however, would be inconsistent with our goal of gaining a broad understanding self-care in chronic diabetes and would be incongruent with a focus on seeking the perspective of people living with diabetes (Campbell et al., 2003). Further, this inclusive approach did not appear to generate different descriptions of barriers to and facilitators of self-care. However, most of the studies emphasizing the evolution of self-care knowledge were grounded in research with adults living with longstanding type I diabetes. This suggests the need for further research on the factors that facilitate self-care over time and how this evolutionary process might be supported in the context of other chronic diseases.

Conclusion

An important focus of nursing research is the search for understanding health as lived. The goal of this review was to examine the state of the science in self-care from the perspective of those living with diabetes and to attempt to determine the implications of this understanding for health-care policy development. Knowledge arising from the review may be valuable in practice and in extending policy discussions beyond the limits currently placed upon them by largely unchallenged assumptions related to chronic disease management. Public policy discussions in Canada would be fruitfully informed by evidence on how diabetes self-care evolves and how it can best be supported. In partnership with those living with diabetes, nurses have an important role to play in bringing to the policy table an understanding of the implications of health policy for how self-care is lived and of how rigid policy or service structures may inadvertently create barriers to effective diabetes self-care.

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