University of Alberta

Influencing Health Policy: Canadians Living with Diabetes

by

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Dedication

I dedicate this work to the late Dr. Marlene Reimer, my first mentor and an exceptional nurse, scholar and friend. I miss our talks, Marlene, and the gentle way you encouraged deeper reflection and reminded me of what was truly important. I hope you are proud of the work you see here.

Abstract

The overall aim of this research was to understand how nurses can effectively advocate for policy change that supports self-care in people living with a chronic disease. Pursuing this understanding demanded exploration of three areas: (a) self-care in chronic disease as related to policy, (b) what is known about policy advocacy in nursing, and (c) how policy advocacy around chronic disease is achieved. This dissertation is comprised of four papers focused on these areas, all resulting in manuscripts for publication. In this research I focused on diabetes mellitus, a chronic disease that exemplifies the importance of self-care and is described as a global 'epidemic'. The underlying assumption is that nurses have a valuable contribution to make to health policy, largely because of the work we undertake in partnership with our clients, at the place where policy meets life as lived.

The first study is an integrative review of the literature focused on the self-care of people living with diabetes, and the policy roots of self-care issues. The second paper is a critical analysis of the policy advocacy literature in nursing, with a focused discussion of the barriers to policy advocacy, and strategies to develop nursing knowledge further. One such strategy led to the empirical study that is the substance of the third and fourth papers, the findings of a grounded theory case study of policy advocacy in the Canadian Diabetes Association.

The combined findings of these papers illustrate that nurses may be able to participate in policy advocacy in the context of chronic disease more effectively by: (a) bringing critical, interactive and instrumental knowledge of nursing experience with people living with chronic disease to the effort, (b) learning to integrate that knowledge with the knowledge

of others, and (c) maximizing the capacity for leverage by engaging in discourse with others and employing strategic knowing to mobilize nursing knowledge to achieve change. Organizations such as the Canadian Diabetes Association can provide valuable opportunities to learn from seasoned advocates within an advocacy community, and provide access to the ‘machinery’ of advocacy required to target efforts at the policy level.

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CHAPTER 1. Introduction and Overview

Background

> Over broken asphalt, over dirty mattresses and heaps of refuse we went... There were two rooms and a family of seven not only lived here but shared their quarters with boarders... [I felt] ashamed of being a part of society that permitted such conditions to exist... (Lillian Wald, 1893, as cited in the Jewish Women's Archive, 2007)

As a profession, sometimes I think we have forgotten ourselves. Or at least where we came from. Advocacy to influence policy around health is linked to the very emergence of our profession. We should now be able to stand proudly on the shoulders of giants like Lillian Wald, or Florence Nightingale and connect that advocacy heritage seamlessly to the modern practice of nursing. It seems to me however, that somehow the majority of us have allowed ourselves to be distanced from that heritage—with notable exceptions of course, as evidenced by the work of nurses like Cathy Crowe (2007), the "street nurse" who works with Toronto's homeless. Nelson and Gordon (2004) speculated that our profession has purposefully disconnected itself from its humble beginnings out of a drive for social legitimacy and status--a desire to be seen as "new" and as a profession constituted by "practices and knowledge hot off the press" (p. 256). I wonder if it might simply be due to a lack of attention, where front-of-mind and immediate health care problems in a complex system take our attention away from the roots of those problems—an insulating layer of 'busy-ness" that allows us to believe that policy issues must be someone else's concern, because we certainly don't have time to deal with them. This thesis represents my attempt to learn how to deal with them. The products of my learning are represented here, in the output of a comprehensive doctoral program of education and empirical research.

The working definition of policy in this dissertation is provided by Lomas (1990), who defines policy as the decisions and actions taken (or not taken) by governments in a particular area. The area focused on here is the policy domain concerned with decisions and actions related to the protection, maintenance and/or improvement of the health of the population. Advocacy to influence policy in matters of health is an ethical imperative for our profession (Canadian Nurses Association, 2002). My particular interest in policy advocacy emerged from my nursing practice with people living with chronic disease, and from a related small qualitative study of self-care by people living with chronic respiratory disease, undertaken during my master's program in the early 1990's. That study revealed numerous challenges to living with a chronic disease, most of them related to self-care. Many of those challenges were indeed embedded at the individual level, and had to do with specific providers and particular health care relationships. Some of the most difficult challenges, however, had their roots in health policy. I discovered that there was little guidance in the nursing literature about how to engage in advocacy at the policy level, and few opportunities or mechanisms to facilitate such participation.

Two central guiding assumptions of this work are my beliefs that nurses have important knowledge to contribute to transforming the health care system to better meet the needs of people living with chronic disease, and that we are ethically bound to do so (Canadian Nurses Association, 2002). Situated as we are at the interface where policy meets the lives of people, I believe that the place to start is in developing an awareness of the pervasive assumptions in our own practice setting around chronic disease and around policy advocacy. We must also examine the assumptions embedded in research and policy that frame current approaches to chronic disease management, and learn to see the policy roots of the challenges experienced by those whom we serve. We must seek a grounded understanding of these challenges and take that knowledge to policy advocacy. This is difficult to do at the present time, as there is little empirical investigation of advocacy as a process intended to influence policy. Although we are prone to making rhetorical statements about the responsibility of nurses to participate in policy advocacy around health, we seem less inclined to study in this area.

Design

The overall question guiding my work in this area was: how can nurses effectively advocate for policy change that supports self-care in people living with a chronic disease? There were three areas that demanded exploration in order to answer this question:

1. how policy could better support self-care in chronic disease,
2. what we know about advocacy at the policy level in nursing, and
3. how policy advocacy in the context of chronic disease is achieved.

As a result, this doctoral dissertation is comprised of three pieces of work: an integrative review of the self-care literature (Paper 1: Chapter 2), a critical analysis of the policy advocacy literature in nursing (Paper 2: Chapter 3), and a grounded theory study of advocacy processes in a large health charity (Papers 3 and 4: Chapters 4 and 5).

The work has resulted in the publication of two manuscripts (Chapters 2 and 3), and two manuscripts to be submitted for publication (Chapters 4 and 5).

Paper 1: Self-care From the Perspective of People Living with Diabetes

In Paper 1, I address the first area of inquiry noted above: how policy can better support self-care in the context of chronic disease. To understand how policy can better support self-care, I explored what we know about the concerns of those trying to engage in self-care, and the policy roots of those concerns. This first study was a comprehensive integrative review (Whittemore, 2005) of research on self-care in diabetes, a condition that exemplifies the importance of self-care in the successful management of chronic disease (Toljamo & Hentinen, 2001; Sigurðardóttir, 2005; Thorne & Paterson, 2001).

The question addressed in the review was: what are the barriers to, and facilitators of engagement in self-care from the perspective of adults living with diabetes? Barriers were defined as factors making it more difficult to engage in self-care, and facilitators were those factors that made engaging in self-care easier, from the point of view of the person living with diabetes. I included journal articles and dissertations published in the English language between 1993 and 2003. There were no restrictions on research design, as my aim was to seek a more inclusive view of the knowledge about self-care and living with diabetes, and where the research was leading practice and policy. Databases searched included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, Medline, HealthStar, PsycINFO, the Database of Abstracts of Reviews of Effects (DARE), Cochrane Database of Systematic Reviews, Medline in Process (current) and the Allied and Complementary Medicine (AMED). A manual search of reference lists of articles selected for complete review supplemented the online search strategy. A review of 461 abstracts against pre-determined exclusion criteria resulted in the selection of 42 papers that explored self-care in diabetes.

The concept of self-care as the cornerstone of modern chronic disease management has been embraced by clinicians and researchers (Improving Chronic Illness Care, 2007; Kralik, Koch, Price & Howard, 2004; Lorig, 1982; Lorig, Laurin & Holman, 1984; Meetoo & Temple, 2003) for the better part of three decades, and has caught the attention of policy-makers as a “pillar” of health system reform (Health Canada, 1997, 1998, 2002). Self-care in chronic disease has also received a good deal of attention from researchers as an important element of health system reform (Improving Chronic Illness Care, 2007; Shoor & Lorig, 2002; Wagner, 2004; Wilson, 2001).

Picking up the threads of my earlier work, I anchored my thesis in an understanding of what we know from a patient perspective about factors influencing self-care—issues that are experienced at the starting point for advocacy for most nurses, at the level of the individual patient. This initial piece of empirical work provided valuable insights into the assumptions underpinning self-care at the individual care level, and encouraged consideration of the potential implications for policy level decisions regarding how best to support self-care in diabetes. Paper 1 was published in the Canadian Journal of Nursing Research in the summer of 2006 (Spenceley & Williams, 2006), and is included in this dissertation with the permission of that journal.

Paper 2: The Road Less Traveled: Nursing Advocacy at the Policy Level

In paper two, I conducted a critical integrative review of the advocacy literature in nursing, in order to explore the second area of inquiry informing my overall work: what do we know about advocacy at the policy level in nursing, and further, why aren't we effective in doing it? I used a simple keyword search for "advocacy" in the CINAHL database going back to 1980. The search was limited to English language and publication in nursing journals, and yielded in excess of 4500 hits. Papers were selected based on their relevance to the two main purposes of the review: understanding the epistemological foundations of advocacy in nursing, and illuminating factors that influence nursing participation in policy advocacy. I defined policy advocacy as knowledge-based action intended to improve health by influencing policy. The work in this paper helped me identify many challenges to the participation of nurses in policy advocacy that must be addressed within the discipline, in the practice context, and at the interface of the worlds of policy and nursing practice. I also identified many gaps in nursing knowledge about the policy process and how to participate in policy advocacy, and revealed the importance of connecting nursing knowledge and discourse to the larger arena of health policy practice and scholarship. Paper 2 was published in the journal Policy, Politics & Nursing Practice in autumn, 2006 (Spenceley, Reutter & Allen, 2006), and is included here with that journal's permission.

Papers 1 and 2 encouraged me to think about the knowledge that emerges in health care relationships between nurses and people living with diabetes, and the challenges that exist in contributing that knowledge to advocacy for health policy change. I concluded the following as a result of my work on these two papers:

- Knowledge about self-care in diabetes is informed by certain assumptions, and those at the policy level are different than those at the level of the person living with the disease.
- Policy discussions around diabetes would be fruitfully informed by the knowledge generated in partnerships between nurses and people living with this chronic disease.
- Nurses are not generally well informed about policy advocacy, or about how knowledge can most effectively be brought to bear on matters of policy.
- We can learn a great deal by expanding our study of advocacy to other literatures, and by studying the work of others who advocate at the policy level.
- As a profession, we need to seize or create opportunities for nurses to participate in policy-oriented activity with colleagues from our own and other disciplines, policy-makers and members of the public.

Returning to the overarching question guiding this work, these conclusions led me to the third area of inquiry: how is policy advocacy in the context of chronic disease achieved? As a result, I conducted the empirical research which forms part of this dissertation, the output of which is found in Papers 3 and 4. In the conclusion of Paper 2, I suggest one possible way of moving the practice and scholarship of policy advocacy forward in nursing: studying the work of successful policy advocates. This is the challenge I took up in the subsequent empirical study. In papers 3 and 4, I present the findings of an exploratory grounded theory study of an organization recognized for its policy advocacy activities around diabetes (see Appendix A for Health Ethics Forms). The research was guided by these two general research questions:

1. How does the Canadian Diabetes Association attempt to influence government policy?
2. How does the organization use knowledge in the process of influencing government policy?

Paper 3: Leveraging for Policy Change: The Case of the Canadian Diabetes Association

This paper addresses the first research question: how does the CDA attempt to influence government policy?

I was drawn to the voluntary sector to study how to influence government policy because some of the most visible and credible advocates for policy change are voluntary sector organizations (Hall & Banting, 2000; Langille, Lyons & Latta, 2001). A review of voluntary sector contributions to recent health policy initiatives confirms this observation (Canadian Mental Health Association, 2004; Health Charities Coalition of Canada, 2003; Wilson, 2003), as does their visible involvement in supporting policy-relevant health research around chronic disease (Canadian Diabetes Association, 2007a; Heart and Stroke Foundation, 2007, Wilson, 2003). In particular, the large health charities in Canada are active in advocacy around issues that matter to people living with chronic disease (Canadian AIDS Society, n.d.; Canadian Diabetes Association, 2007b; Canadian Mental Health Association, 2006; Langille et al., 2001). I became interested in the CDA in particular, as advocacy around issues of self-care was a major focus for this organization (Canadian Diabetes Association, 2007a).

Method. I undertook a case study of the CDA in order to gain a deeper understanding of *something in particular* beyond the case in and of itself—what Stake (2000) refers to as an instrumental case study. In order to understand how this organization engages in policy advocacy, I chose a grounded theory approach to the case study. Grounded theory is an approach well suited to exploring areas that have not been previously well researched, particularly when the phenomenon of interest is a social process that unfolds over time between people (Glaser, 1978; Glaser & Strauss, 1967). Several different forms of data were collected for the study, including over 1000 pages of narrative data from unstructured interviews with 15 participants and field notes of participant observation in a number of organizational events, as well as over 350 pages of organizational documents. The analytic method of constant comparison commenced with open coding, followed by grouping these codes into higher order categories. As analysis proceeded, the properties of these categories were elaborated and refined. Theoretical coding proceeded when incoming data were readily fit into existing categories, and analysis demanded an exploration of the relationships between and among these categories. Finally, a central category was identified and selective coding was undertaken (MacDonald, 2001) in order to explore how this category related to all the other categories.

Results. Within an increasingly corporatized voluntary sector, the CDA has moved recently to a national corporate structure. The shift to the corporate model brought the evolving processes of policy advocacy clearly to the foreground for both the participants and the researcher. I explained efforts to influence government policy with a conceptualization of "leveraging for policy change", and this process was credible to participants in follow-up interviews. I defined leveraging as a two-dimensional social process of using knowledge, assets and resources to influence decision-making in a particular direction. The two dimensions identified were: the structural dimension--the machinery of advocacy, and the relational dimension—the glue that binds advocates into a community. The efficient deployment of limited resources in an orchestrated approach to advocacy at the national level was the new priority, and was achieved through the structural dimension of the process. I argue that the emphasis on structure at the expense of the relational dimension of leveraging has implications for collective advocacy, and this is explored in this paper. Consistent with my assertion that nursing needs to learn from and participate in a larger health policy discourse, this paper will be submitted to the journal *Social Science and Medicine*.

Paper 4: Knowledge and the New Advocacy

In Paper 4 I address the second research question: how does the CDA use knowledge in the process of influencing government policy?

Most studies of knowledge in policy change have examined the contribution of research knowledge to the process, and some have criticized the implicit supremacy of this form of knowledge in health policy change (Bryant, 2002, 2004; Fischer, 1990; Park, 1993). In this paper, I build on the work of Bryant (2001, 2004) and discuss the contribution of different forms of knowledge, and explore how they are used in particular ways in policy advocacy.

Results. I found that instrumental, critical and interactive forms of knowledge played a role in the newly evolved and more corporate approach to policy advocacy taken by the CDA. These forms of knowledge were filtered through “strategic knowing”, a form of knowing that resided at the top of this organization. Strategic knowing was defined as a cognitive process of continuously evaluating the policy environment for emerging issues, challenges, and opportunities for influence. Strategic knowing further involved the ongoing appraisal of the resources at hand, with an eye to aligning available resources and using them to maximum strategic effect. I concluded that this new emphasis on strategic knowing was perceived to have clear benefits to the effectiveness of national-level advocacy, and potential implications for the commitment of the passionate volunteer base of the organization.

Summary of Dissertation

Once again, I return to the overall question guiding this work: how can nurses effectively advocate for policy change that supports self-care in people living with a chronic disease? The papers in this thesis address the essential components of this question by

1. revealing and challenging pervasive assumptions framing health policy around self-care and diabetes,
2. revealing gaps in our knowledge of policy advocacy and exploring strategies to address them
3. using an empirical strategy to develop an understanding of a process of policy advocacy, and revealing how knowledge can be used strategically to leverage for policy change.

Significance

There are several factors afoot in Canadian health care at this time that few would dispute:

- Not since the introduction of Medicare has there been as much emphasis on health care reform as there is at the present time; the system is transforming beneath us.
- The implications and burden of chronic disease have made its prevention and management the most pressing health care priority into the foreseeable future.
- Health policy makers are struggling to catch up with this epidemiological shift to chronicity, and require knowledge from many perspectives to inform policy.

- There is an increasing emphasis on citizen participation in the policy process, and the voluntary sector is an important mechanism for such participation.

To these assertions I would add that nurses are the most numerous health care professionals, part of every interdisciplinary chronic disease management team and well positioned to contribute valuable knowledge to the policy process. There is, however, little empirical work to guide our participation in policy advocacy. Within these broad-brush strokes of the health policy landscape, I situate the significance of this study: knowledge development in the area of policy advocacy is a priority for our profession.

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CHAPTER 2.

Paper # 1 - Self-care from the perspective of people living with diabetes

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Self-care From the Perspective of People Living with Diabetes

The World Health Organization (2005) describes the global rise in diabetes prevalence since 1985 as epidemic in proportion. 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 and facilitators of self-care from the perspective of people living with diabetes. This paper focuses on all research that examines self-care from the perspective of adults living with either type I or type II diabetes, and concludes with a discussion of potential implications for health related public policy, most particularly in the Canadian context.

Methods

An integrative review of the literature is conducted to review the empirical or theoretical work around a particular topic. It may be narrow or broad in focus, and often employs a broad sampling frame that includes qualitative, quantitative or purely theoretic literature (Whittemore, 2005). While less focused than other types of syntheses such as meta-analysis or systematic review, a quality integrative review should follow a research protocol that is set up in advance of the literature search. A specific question guides the review, terms and variables are defined, search terms and strategies employed are described, criteria for study selection are provided, and an appraisal of the quality of the primary studies is included (Whittemore, 2005). These elements will now be described as they were implemented within this 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 making self-care more difficult and facilitators were those factors that made self-care 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 the English language between 1993 and 2003 were included. There were no restrictions placed on research design, as the aim was to seek a more 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 time 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), Cochrane Database of Systematic Reviews, Medline in Process (current) and the Allied and Complementary Medicine (AMED). A manual search of reference lists of articles selected for complete review supplemented the online search strategy. Data were managed using Procite™ bibliographic software (version 5) and the outcomes of decision processes were captured using Excel™ (2002 version).

Search Results and Criteria for Selection

A review of 461 abstracts against pre-determined exclusion criteria (see Table 2.1) 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 choice to focus the review on self-care, and the observation that the elements of self-care are very similar in both forms of the disease (Canadian Diabetes Association 2005a). We believed that there may be valuable lessons to learn by keeping the focus upon self-care, while remaining sensitive to any differences that may emerge in terms of the processes of self-care in the two chronic forms of this disease. All 42 papers were then reviewed against a series of focusing questions developed by the authors; these questions are also listed in Table 2.1.

It was also necessary to be clear about what we would accept as evidence in the paper that self-care was indeed 'easier' as a result of particular factors. It was decided that 'easier' self-care would be evidenced by: a) an expressed perception of increased capability to assume responsibility for and to direct self-care, b) feelings of comfort, confidence or 'success' in self-care c) and/or an expression of feeling supported, reinforced in self-care efforts as a result of particular factors. We did not include studies that simply reported an increased incidence or frequency of self-care activity as an outcome, unless there was a specific attempt to seek the patient/client's point of view related to the role of particular factors in increasing personal ability to self-care. Any systematic attempt to gain the patient/client perspective was deemed eligible, including survey, interview or questionnaire. We reached consensus on 22 studies at this stage; 13 qualitative studies, seven quantitative and two mixed method studies were accepted into the next phase of the review process. Manual searching of the reference lists resulted in the additional selection of eight other pieces of work for review. None of these additional articles satisfied all inclusion criteria, and were excluded from the review at this point.

Quality appraisal of primary research is difficult and complex; no *gold standard* exists for assessing quality, particularly when differing designs are included (Whittemore, 2005). These concerns notwithstanding, a consistent method of quality assessment that includes independent appraisal is an important aspect of a high quality integrative review (Whittemore, 2005). The 13 qualitative studies were assessed by the first author and a second independent rater, using a modified research appraisal tool based upon the work of Duffy (1985), Mays and Pope (2000), and Eakin and Mykhalovskiy (2003). 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 research is methodologically and epistemologically distinct from quantitative research; 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) assessment of how the researchers enabled the reader to access the substantive contribution of a piece of research to new or existing knowledge about the topic of inquiry is an important consideration in appraisal. Therefore, the tool was constructed to assess procedural rigor as well as the substantive contribution of the study to the understanding of self-care in diabetes. Such an approach also facilitated the process of analysis, in that it allowed the capture of analytic thoughts/questions in the form of memos. This provided the basis for an iterative process of moving back and forth between 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 Estabrooks, Floyd, Scott-Findlay, O'Leary and Gushta (2003), and Cummings and Estabrooks (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 methods studies. Six studies (three qualitative, three quantitative) were excluded on grounds of quality. This review ultimately included 16 research papers (Table 2.2); ten studies explored self-care in type II diabetes, five focused on type I, and one study included participants with both forms of the disease.

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 or facilitators of self-care. 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 and facilitators of self-care were coded and thematically grouped by definition of self-care and related self-care assumptions.

Barriers to Self-care

Studies informed by a definition of self-care as disease self-management and symptom control based on adherence to advice from health care experts were the most common. Five of the seven studies dealt with type II diabetes, two with type I diabetes (see Table 2.3). Barriers described across these studies were similar, with the only notable difference being that the burdensome nature of frequent injections (Mollem, Snoek & Heine, 1996) and the burden of monitoring and controlling symptoms related to blood sugar levels (Mollem et al., 1996; Wdowik, Kendall & Harris, 1997) were noted in the studies of type I diabetes. All seven studies described barriers to self-care focused on the rigidity and burdensome nature of diabetes management regimes (particularly dietary restrictions and exercise expectations) within the constraints of limited time, resources, and physical capacity, with motivation to follow restrictions described as difficult to maintain. Challenges to control arising out of anxiety or social expectations (Maillet, Melkus & Spollet, 1996; Mollem et al., 1996; 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., 2003), made self-care more difficult. Lack of understanding and inadequate education related to the complex knowledge and skills required to manage diabetes or prevent complications were described (Maillet et al., 1996; Simmons et al., 1998; von Goeler et al., 2003), as was a lack of confidence in the tools of self-monitoring (Simmons et al., 1998; Tu & Barchard, 1993; von Goeler et al., 2003). Fear of frequent injections and uncertainty about the future were also noted (von Goeler, et al., 2003). The financial costs of diabetes self-care (Tu & Barchard, 1993; von Goeler et al., 2003; Wdowik et al., 1997) and impoverished or unsafe living conditions also created barriers to compliance (Maillet et al., 1996). Conflicting social roles, social pressures and family expectations to put the needs of others first made self-care more difficult (Maillet et al., 1996; Schultz et al., 2001). Competing life priorities and stress also created barriers to the individual's ability to manage diabetes as directed (Mollem et al., 1996; von Goeler et al., 2003; Wdowik et al., 1997). Inadequate support by the family and community, perceived language or communication barriers, and the unrealistic expectations of health care professionals (Maillet et al., 1996; Simmons et al., 1998; von Goeler et al., 2003) were also identified as barriers to self-care. Structural or cultural barriers in the design and accessibility of needed services were also noted in this group of studies (Simmons et al., 1998).

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), and the other on adults with hypertension and either type I or type II diabetes (Weiss, 1997). Adherence to health care advice was identified as an important component of diabetes self-care, but personal factors were also acknowledged as having an important influence on the individual'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 capacity 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, 1997). Other barriers to self-care included feelings of fear and uncertainty about a future life with the diabetes, and lack of confidence in ability to self-monitor and manage the disease (Weiss, 1997). Access barriers to quality health services and a lack of continuity in health care relationships also made diabetes self-care more difficult (Schoenberg & Drungle, 2001).

Self-care as a complex balancing act between decisions related to managing diabetes and fulfilling expected social roles was the basis of three studies, all focused on type II diabetes (Table 2.3). Barriers emerged when cultural beliefs, ethnicity and the demands of social roles clashed with the expectations of the medical culture or the larger societal context. Cultural beliefs that the person with diabetes should take a passive role in health care relationships created conditions where people avoided asking for needed information about diabetes self-care (Greenhalgh, Helman & Chowdhury, 1998). Differing beliefs about illness causation, appropriate therapies and the meaning of symptoms also created conflict in health care relationships (Greenhalgh et al., 1998; Hunt, Pugh & Valenzuela, 1998). Beliefs that taking medication represented worsening disease or weakness created a sense of stigma and social isolation, and perceptions of the negative judgments of others created a reluctance to engage in visible diabetes self-care activities (Cagle, Appel, Skelly & Carter-Edwards, 2002). The belief that diabetes was not really a serious threat to health created a reluctance to follow medical advice. This was particularly evident when following medical advice created conflict with meeting the demands of expected social roles or participating in cherished rituals (Cagle et al., 2002; Hunt et al., 1998). Persistent symptoms and physical limitations further limited self-care abilities and impaired functioning in social roles (Cagle et al., 2002; Hunt et al., 1998). Financial constraints and living in impoverished, unsafe neighborhoods made it difficult for people to access needed diabetes management supplies and engage in recommended exercise (Greenhalgh et al., 1998; Hunt et al., 1998). Language barriers created difficulties in understanding written or verbal communication from providers (Greenhalgh et al., 1998), and people also experienced difficulty understanding health care benefit plans (Cagle et al., 2002; Greenhalgh et al., 1998). Individuals also perceived discrimination in employment settings, and in being able to access needed health services (Cagle et al., 2002).

Finally, four studies were founded on a definition of self-care as an evolutionary process where self-care knowledge develops over time as the individual lives with this complex disease; three of these studies focused on people living with type I diabetes, and one study explored self-care in those with type II (Table 2.3). Barriers to self-care from this point of view included health care professionals who were resistant to working in partnership (Cooper, Booth & Gill, 2003) or who were too “enamored 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 care 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., 2003; Jayne, 1993; Thorne & Paterson, 2001). Also noted were barriers associated with low self-esteem (Jayne, 1993) and with non-supportive social contexts, where self-care activities created a fear of stigmatization if disease-management behavior was visible (Jayne, 1993).

Facilitators of Self-care

Among the seven studies that emphasized diabetes management and symptom control based on adherence to medical advice (Table 2.3), five studies did not describe any facilitating factors. Self-care assistance and support from family were identified as facilitative in one study (Maillett et al., 1996) and assistance from other social networks was identified as facilitative in another (Wdowik et al., 1997). A fear of the complications of diabetes was also described as strong motivation for compliance (Maillet et al., 1996).

Facilitators were noted in one of the two studies that emphasized individual responsibility for positive choices (Table 2.3) and included health care relationships characterized by trust, respect, collegiality and the sharing of timely, relevant diabetes self-care information (Weiss, 1997). Comparing one’s present health with past choices and future risks, and comparing oneself with others who engaged in both positive and negative diabetes self-care behaviors were identified as helpful in achieving effective self-care. The facilitative impact of realizing health benefits from positive self-care choices was also noted (Weiss, 1997).

In the studies conceptualizing self-care within a socio-cultural context (Table 2.3), decisions about managing diabetes were based on a cultural understanding of diabetes self-care. Strong connections to community social networks, the church, 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 2.3) emphasized 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). Key facilitating factors in the health care relationship included acknowledgement of the complexity of diabetes self-care, and of the value of the knowledge gained from living life with a chronic condition (Cooper et al., 2003; Thorne & Paterson, 2001). The importance of creating opportunities for self-care knowledge to evolve and integrate with life experience was emphasized (Cooper et al., 2003; Jayne, 1993). Shared reflection with health care professionals and other self-care partners or peers on what self-care was like in the real world was of great benefit (Cooper et al., 2003; Paterson & Thorne, 2000). 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 achieving diabetes self care (Thorne & Paterson, 2000).

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 emerging 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 included studies, self-care was understood to be disease management and symptom control based upon compliance to medical advice (Table 2.3). In these studies self-care involved following rigid regimens, meeting provider expectations, and following static rules. In the face of life's complexities, the burdensome nature of prescribed self-care and the unrealistic expectations of providers emerged as difficult barriers to compliance, resulting in self-care (according to the definition of self-care operant in these studies) becoming very difficult. These studies described disillusionment with advice that did not work very well, and anger at having to carve cherished activities or traditions out of life. By way of contrast, in studies that defined self-care as an evolutionary, developmental process (Table 2.3), these same barriers to compliance were framed as facilitators of learning. It was the acknowledgement and confrontation of these very barriers to compliance that facilitated an evolution in being able to live with unpredictability and to respond knowledgably and flexibly to challenges as they occurred (Jayne, 1993; Paterson & Thorne, 2000). Indeed, barriers to self-care that emerged from within this definition included the very standardized 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 endeavor 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 prefer to be self-care experts. These assumptions most certainly influenced our interpretation of the findings. As Paterson and Thorne (2000) noted, 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 assume that role are untenable. Underlying assumptions in the included studies were also examined. These assumptions were coded, extracted as data, and then coded again by definition of self-care. While it is obvious that the barriers or facilitators of self-care would be viewed from the perspective of what the researchers perceived self-care to be, we noted that with few exceptions (Thorne & Paterson, 2001; Paterson & Thorne, 2000) the assumptions about self-care underpinning much of the literature were seldom surfaced or questioned. As such, we 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-centered and a life-centered conceptualization of diabetes self-care (Figure 2.1).

In a disease-centered 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 to be a solitary activity. Practitioners were considered to be the self-care experts, and emphasized compliance and control. Self-care education was standardized and based on rigorous scientific evidence. Clearly, self-care was about managing diabetes.

In a life-centered approach to diabetes self-care, individuals were encouraged to listen to and develop trust over time 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 more individually relevant guidelines. Diabetes self-care was considered evolutionary, with constant readjustments based on individual requirements. Practitioners acknowledged self-care as a personal journey for each individual, and the health care practitioner was often considered a trusted partner on this journey. Self-care education was anticipatory and the health care practitioner helped mobilize both internal and external resources with the individual and significant others. The person with diabetes was considered to be the expert on his/her own self-care. It was evident, however, that in studies emphasizing the individual and personally meaningful nature of self-care, self-care was about learning to live a unique life well with diabetes.

It was apparent that this tension was an important factor in the growth in diabetes 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 that varied in sequence and occurrence between people, but that seemed to arise out of the tension experienced between the disease taking control of life, and taking control of the disease within life as lived. However, this tension may go unrecognized from within the persistently dominant view of disease-centered self-care. Indeed, if surfaced at all, such tension seems most likely to be dismissed as the persistent challenge of non-compliance. Much of the diabetes self-care literature continues to reflect notions of self-care as a static achievement, as a compendium of discrete choices focused on restriction, control and adherence successfully accomplished through educative endeavors. It is worth noting that most of the factors identified as facilitative of self-care from the perspective of people living with diabetes were relational in nature, and founded upon a sensitivity to and knowledge of the unique life circumstances of people living with diabetes (Table 2.3).

The emerging role of health professionals as participants in evolving self-care partnerships with people learning to live life with diabetes requires a close examination of the assumptions that inform current patterns of practice. It is essential that this be an important element of nursing advocacy at the level of individual health care relationships. In the area of diabetes self-care, nurses practice at the interface between self-care as taught and self-care as lived. Supporting self-care for people living 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, educate, or simply 'be present' to the experience of self-care, the core value of commitment to use nursing knowledge to assist another in meaningful care for self transects all current worldviews of nursing. At the level of the individual health care relationship, there is increasing acknowledgment that self-care support must start where the client is and be understood as framed from within the perspective of the individual's life experience and meaning (Cicutto, Brooks & Henderson, 2004). The idea that the chronically ill person brings expert life knowledge about living with chronic disease to the health care relationship began to appear in the nursing literature in the early 1990's (Thorne, 1993; Thorne & Paterson 1998), and was an important step forward in reframing health care relationships. While we must proceed cautiously with assumptions that all people living with diabetes are able and desirous of assuming 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 living 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, and what limits there are on access to needed services or treatments. The focus on individually meaningful and useful self-care becomes even more complex at the policy level. Although described as a 'pillar' of health care reform in Canada, discussions of self-care truncate fairly quickly as the discussion moves to the level of 'policy implications' (Health Canada, 1997, 1998, 2002). We have attempted to surface some of the pervasive assumptions underlying how self-care from the perspective of people living with diabetes is understood. We believe that there are similarly pervasive assumptions at the policy level that frame any discussion of self-care. These include 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 conducted from a medical-scientific perspective. In the current Canadian context, policy core values increasingly reflect a belief in individual responsibility for health and a collective responsibility for economic competitiveness driven by the globalization agenda (Chambers & Smith 2002). Attention has focused broadly on disease prevention through better health 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, and yet marginally and inconsistently supporting only the most basic requirements for diabetes self-care. In Canada, provincial jurisdiction over health care has contributed to a patchwork of support; indeed, access and coverage of the medications and supplies needed for many basic disease-management requirements of self-care in diabetes is 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 impacts on diabetes self-care as lived in Canada. The impact of such policy frames upon the development of self-care capacity needs to be more closely examined.

How might policy be made differently if it is founded upon a commitment to supporting diabetes self-care as an evolving, life-centered process facilitated in 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 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 needs to be carefully considered.

Limitations

Learning to self-care is an enormously 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 research that examines the perspective of people living with diabetes learning to self-care, but we are aware that this approach has also introduced a number of limitations to this review. First, we have included studies from both qualitative and quantitative research traditions, along with their differing epistemological assumptions. For this reason the approach taken was that of the integrative review (Whittemore, 2005). This type of review 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, 2005, 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, it is acknowledged that many of these assumptions likely had their origins in the research approach chosen to study the phenomenon in the first place.

It is further noted that 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 U.K. and one from New Zealand, all studies were from North America. We have, however, attempted to focus the discussion more 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 have been inconsistent with our goal of gaining a broader understanding of self-care in chronic diabetes, and 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 and facilitators of self-care. However, it was noted that most of the studies emphasizing the evolution of self-care knowledge were grounded in studies of adults with long-standing type I diabetes. This suggests that further study is warranted about the factors that facilitate self-care over time, and how this evolutionary process might be supported in the context of other chronic diseases.

Conclusions

An important focus of nursing research is the search for understanding health as lived. The goal of this review was to understand the state of the science in self-care from the perspective of those living with diabetes, and to begin to determine potential implications of this understanding for health care policy development. Knowledge arising from this review is valuable in practice and may also be valuable 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 about 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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Table 2.1. Criteria and Questions

Exclusion Criteria

1. Non-research items, including editorials, commentary, letters, descriptive articles.
2. Work that relates only to diabetes or health care for diabetes in general, or mentions self-care but does not explore self-care.
3. Work that investigates associations between particular factors or characteristics and the incidence or frequency of self-care behaviors, without any exploration of the person's perspective on what made self-care easier, or more difficult.
4. Research focused on tool development only.
5. Research focused upon gestational diabetes.
6. 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

1. 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)
2. Do the researchers specifically seek the perspective of participants living with diabetes?
3. Is the research about effective strategies to promote 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 to facilitate self-care?)
4. 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?

Table 2.2. Included Studies

First Author/ Year	Country	Source	Design
Cagle/2002	United States	Ethnicity & Disease	Qualitative
Cooper/2003	United Kingdom	Health Education & Research	Qualitative
Greenhalgh/1998	United Kingdom	BMJ	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 & Counseling	Quantitative: survey
Paterson/2000	Canada	Clinical Nursing Research	Qualitative
Schoenberg/2001	United States	Journal of Aging & Health	Mixed methods
Shultz/2001	United States	Journal of Health Communication	Quantitative: survey
Simmons/1998	New Zealand	Diabetic Medicine	Mixed methods
Thorne/2001	Canada	Patient Education & 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

Table 2.3. Definitions of Self-care and Related Barriers and Facilitators

Reference (First Author)	Self-Care Definition	Barriers	Facilitators
‡ Schoenberg (2001) ♓ Weiss (1997)	An individual's responsibility, and a result of lay-initiated decisions about what is appropriate behavior to benefit health, prevent further illness, limit illness, restore health and maintain independence. Based on rules of adherence, but also factors arising from their personal perspective.	Barriers to positive choices: lack of money, knowledge, skills, time, energy, physical capacity for self-care; lack of support, social isolation; barriers to health care access, lack of continuity of care. Overwhelmed by 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 info; 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 or treatments; synonymous with symptom control and disease management.	Costs; rigid, burdensome regimens conflicting with life priorities and other regimens; unrealistic provider goals. Lack of community support; lack of services or poor access. Sociocultural pressures; belief that cause/cure non-medical; communication barriers. Knowledge/skills: lack of instruction; inability to use tools; lack of confidence in self or in therapy. Environmental, personal barriers to exercise; situational challenges to blood sugar control.	Supportive self-care partners or networks of social support; family support. Fear of complications.

Reference (First Author)	Self-Care Definition	Barriers	Facilitators
‡ Cooper (2003) † Jayne (1993) † Paterson & Thorne (2000) † Thorne & Paterson (2001)	Self-care as an evolutionary, developmental process of developing self-care knowledge through learning to live with the complexity of diabetes in a social context.	Discomfort with public exposure; fear of stigmatization; low self-esteem. Standardized, reactive advice to comply; lack of ongoing education re: regimen modification. Health care professionals "enamoured of the science" and resistant to partnership.	Experiencing, confronting barriers to compliance; losing faith in health professional's ability to manage one's disease; support in learning to live with unpredictability, accepting that perfect control is unrealistic. Recruiting trusted self-care partners. Providers that acknowledge science as limited, patients as knowledgeable and self-care as complex. Education that supports evolution of client expertise and 'real world' self-care. Opportunities to share and reflect with supportive peers. Routinizing self-care; vigilant body-listening, monitoring and tracking.
‡ Cagle (2002) ‡ Hunt (1998) ‡ Greenhalgh (1998)	Self-care as decisions made to manage illness in a sociocultural context and based upon socio-cultural belief systems; balancing disease with fulfilling expected roles.	Cultural beliefs; advice in conflict with cultural values, rituals and with fulfilling 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 2 diabetes †: Type 1 diabetes Ӿ: Both types 1 and 2 diabetes

Disease-centered → Life-centered

Underlying Assumptions About Self-care in Diabetes		
People Living with Chronic Disease	Individual concept	Relational Concept
	Focus on signs, lab markers	Focus on tuning in to body
	Adherence to advice	Sense-making of advice
	Restrictions, rules imposed on life	Seeking normalcy in complexity
	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 Care Professionals (HCP)	Self-care is about the health care system	Self-care is a personal journey
	HCP role is about stewardship	HCP 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 to life priorities
	Certainty	Living well with uncertainty
	HCP 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

Figure 2.1. Thematic tensions identified in reviewed literature.

Running head: POLICY ADVOCACY

CHAPTER 3.

Paper # 2 - The road less traveled: Nursing advocacy at the policy level

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The Road Less Traveled: Nursing Advocacy at the Policy Level

Background

The purpose of this paper is the exploration of a particular terrain of nursing knowledge. Some parts of that terrain are very familiar, and some remain quite foreign from a nursing point of view. The terrain in question: advocacy at the level of public policy, defined as decisions and actions taken (or not taken) by governments in a particular area (Lomas, 1990).

Mention the word *advocacy* and nurses will likely tell you that advocacy is integral to good nursing practice (Breeding & Turner, 2002; Chafey, Rhea, Shannon, & Spencer, 1998; Kieffer, 2000). Indeed, the exploration of the concept of advocacy is not new to nursing (Baldwin, 2003; Copp, 1986; Evans, 1999; Gadow, 1980; Grace, 1998; Rafael, 1995). The literature is replete with references to the concept and normative declarations of its relevance to the profession. In contrast, the word *policy* often conjures up thoughts of policy and procedure manuals, or other necessary administrative evils that operate at a distance from the intimate universe of nursing practice. For nurses, it seems, public policy happens *way out there*, and is of little relevance to nursing practice. Yet there is a persistent and historical belief and expectation that nurses will participate in advocacy beyond the individual level--at both the community and societal level--in matters of health (Ballou, 2000). Indeed, advocacy at the policy level has been regarded as a logical extension of the patient level advocacy role that nurses undertake as part of the health care team (Halpern, 2002). Yet a number of nursing scholars have observed that nursing advocacy at the policy level is virtually invisible (Antrobus, 2004; Boswell, Cannon, & Miller, 2005; Scott & West, 2001; West & Scott, 2000).

While large gaps exist in our knowledge about how to advocate at the policy level, we will suggest that a number of other factors may contribute to the fundamental disconnect between what nurses are expected to do in terms of policy advocacy, and what they actually do. Accordingly, there are two main purposes to this paper: to review the epistemological foundations of advocacy at the policy level in nursing, and to present a discussion of other factors that may limit our participation in policy advocacy. We will discuss challenges emanating within the discipline, in the practice context, and at the interface of the worlds of policy and nursing practice. The paper concludes with a discussion of possible strategies for moving forward. Progress is required both within our own discipline, and, perhaps more urgently, in connecting nursing with the larger discourse about policy advocacy.

Advocacy and Nursing

Advocacy and its relevance to nursing has been the subject of concept analyses (Baldwin, 2003; Davenport-Ennis, Cover, Ades, & Stovall, 2002; Rafael, 1995), integrative literature reviews (Mallik, 1997; Vaartio & Kilpi, 2005), philosophic analyses (Ballou, 2000; Curtin, 1979; Gadow, 1980; Grace, 1998), and a few empirical studies (Breeding & Turner, 2002; Chafey et al., 1998; Hellwig, Yam, & DiGiulio, 2003; Kieffer, 2000; Kubsch, Sternard, Hovarter, & Matzke, 2004; Nahigian, 2003; Segesten, 1993; Sellin, 1991; Snowball, 1996; Warner, 2003). Advocacy has been described as integral to nursing (Baldwin, 2003; Breeding & Turner, 2002; Chafey et al., 1998; Mallik, 1997) and as the philosophic foundation or ideal of all nursing practice (Curtin, 1979; Gadow, 1980). On the other side of the spectrum, some have questioned the appropriateness of advocacy in the context of health care and outlined the paternalistic assumptions that may be operating when health care professionals act on behalf of clients (Hewitt, 2002; Mitchell & Bournes, 2000; Schwartz, 2002). Some have also noted that advocacy can have self-serving professional motivations when advanced as a role unique to a particular profession (Bernal, 1992; Mitchell & Bournes, 2000).

Most discussions of advocacy presuppose the existence of certain conditions. One recognizes vulnerability in another (Baldwin, 2003; Copp, 1986; Harrison & Falco, 2005; Hewitt, 2002; Mallik & McHale, 1995) as well as factors in a hostile context contributing to an unjust response to that vulnerability (Breeding & Turner, 2002; Hewitt, 2002), and then feels a sense of responsibility to act to address the situation (Falk-Rafael, 2005; Grace, 1998; Grace, 2001; Schwartz, 2002;). With this common foundation, a variety of models of advocacy have been advanced in the nursing literature. Fowler (1989) suggested that four models of advocacy inform the role of advocate in nursing: the nurse as protector of rights, preserver of values, defender of personhood and/or “champion of social justice” (p. 97).

Models of Advocacy

It has been noted that the nurse as *protector of rights* is a fundamentally legalistic understanding of advocacy, and influences most discussion of advocacy in the health professions (Dubler, 1992; Foley, Minick, & Kee, 2002; Fowler, 1989; Grace, 2001; Hewitt, 2002; Sanchez-Sweatman, 1997). Clients are perceived as vulnerable (Copp, 1986), factors are in play that are perceived as detrimental to the client or the client’s goals, and the nurse advances client interests or protects client rights by interceding on behalf of the client in the context of the healthcare team (Breeding & Turner, 2002; Grace, 2001; Hewitt, 2002).

The nurse advocate as *preserver of values* (Fowler, 1989) focuses on empowerment, and the preservation of client values and autonomy in decision-making (Pace, 1985; Pullen, 1995). In this view, the vulnerability exists in a temporary inability to engage fully in health decision-making, due in part to inadequate information to make informed decisions. Nursing advocacy, from within this view, becomes a form of “decisional counseling” (Fowler, 1989, p. 98) that draws upon sound knowledge of the client’s situation, current best evidence and effective communication skills in order to support and empower client decision-making (Cary, 1998; Hellwig et al., 2003; Pace, 1985). On these foundations, Gadow (1980) advanced a relational and existential model of advocacy, where advocacy is directed at surfacing and exploring the meaning of the health care experience and preserving the client's right to self-determination in that experience (Corcoran, 1988; Minicucci, Schmitt, Dombeck, & Williams, 2003). Gadow (1980) further emphasized the participation of both the nurse and client as whole people in a relationship focused on assisting clients "to become clear about what they want to do" (Gadow, 1980, p. 85). Other models that build upon this notion of advocacy emphasize the intermediate position of the nurse between the client's world and the perspectives of the health team, and the unique knowledge that comes from such a position (Bishop & Scudder, 1990; Des Jardin, 2001a; Hewitt, 2002). The nurse advocate uses this knowledge to inform a negotiated understanding between these perspectives for the benefit of the client (Jezewski, 1993; Snowball, 1996).

Models of advocacy founded on *respect for persons* treat advocacy as a moral act of shared humanity, acknowledging common human needs and rights and creating an atmosphere conducive to supporting these needs and rights in the context of a moral relationship (Chafey et al., 1998; Curtin, 1979; Sanchez-Sweatman, 1997). This notion of advocacy extends the protection of interests to the client as a human being, with human (not simply legal) rights. Such a frame is less clear about the expectations of the nurse advocate, but it has been noted that it is the "broadest and most demanding interpretation" of advocacy (Fowler, 1989, p. 98).

The *social justice* foundations of many models of advocacy inform a moral and ethical imperative to assertively advocate for the marginalized, address inequities in health care and disparities in health, and insist on change (Falk Rafael, 1999; Falk-Rafael, 2005; Fowler, 1989; Harrison & Falco, 2005). Falk-Rafael (2005) noted that this more political conceptualization of advocacy is present in current Canadian and

American standards of public health nursing practice, but invisible in our theories of nursing. To address this gap, she proposed a mid-range theory of “critical caring” (Falk-Rafael, 2005, p. 212), a theory recognizing the socio-political embeddedness of health and health care, and the privileged location of nursing at “that intersection where societal attitudes, government policies and people’s lives meet” (p. 219). The role of the nurse encompasses both *downstream* care focused on meeting the needs of individuals and families, as well as *upstream* advocacy efforts intended to influence change in the structures and relationships that contribute to the poor health of groups and populations.

On a final note, there are those writing in the area of nursing advocacy that describe the context of health care as hostile and marginalizing to both nurses and clients, with the essence of nursing advocacy residing in nurses realizing that their nursing values about advocacy are inconsistent with the values of the care context (Hutchinson, 1990). From within such a view, effective advocacy for clients may in fact be surreptitious, even subversive (Hutchinson, 1990). Despite these numerous attempts to grapple with advocacy in the literature, many acknowledge that the concept has remained a rather “slippery” one for nursing (Grace, 2001, p. 151) and that the thinking underpinning advocacy expectations for nursing practice has been anything but clear (Baldwin, 2003; Breeding & Turner, 2002; Chafey et al., 1998; Grace, 2001; Hewitt, 2002; Mallik, 1997; Mitchell & Bournes, 2000; Pullen, 1995; Schwartz, 2002). Mitchell and Bournes (2000, p. 204) pointed out that “straight thinking” in terms of advocacy will remain elusive as long as the assumptions underpinning the nature and object of nursing, and how they inform the expression of advocacy in practice, remain unexamined. There are two underlying assumptions that permeate the thinking around advocacy: nursing as a personal relationship, and nursing as ‘doing for’ another in the context of that personal relationship.

Intimacy and Advocacy: Clarifying Assumptions

It has been noted that in the main, nursing has been thought of as a practice that is enacted within the private, intimate sphere of human relationships (West & Scott, 2000). Deeply held assumptions about the personal and relational nature of nursing, and the resulting access that nurses have to 'everyday sorts of patient-care injustices' occurring in the care context (Grace, 2001, p. 153) have led us to claim a privileged stance in matters of advocacy. The traditional, individually-focused view of advocacy fits well with these assumptions. Our feelings of connectedness to individual clients and families often engender feelings of responsibility to take overt action within an immediate context perceived as hostile to the rights and interests of clients (Grace, 2001). When closely examined, however, it can be seen that such a view extends from a set of assumptions about power in health care relationships, and specifically about the weakness and vulnerability of clients. Such a view of advocacy is paternalistic (Gadow, 1980; Mitchell & Bournes, 2000). As Grace (2001) further noted, it is not only paternalistic but also unrealistic to believe that nursing professionals can act solely on behalf of individual clients without regard to risks that may accrue to the nurse as an employee of an organization. Grace (2001) also referred to the professional imperative to balance advocacy action for the individual with the interests of other clients or the larger interests of society at large. The individually-focused view has also had the effect of limiting our assessment of the root causes of injustices or inequities, leading us to pursue short-term, one-off solutions to the individually experienced effects of systemic problems. These underlying assumptions about advocacy are so pervasive that we never question how they might limit our thinking. They have led us to ground knowledge development in the area of advocacy almost exclusively at the level of the individual nurse-client relationship (Ballou, 2000; Breeding & Turner, 2002; Chafey et al., 1998;

Curtin, 1979; Evans, 1999; Gadow, 1980; Jezewski, 1993; Kubsch et al., 2004; Pullen, 1995; Sellin, 1991; Snowball, 1996; Warner, 2003; Wlody, 1993).

Advocacy and Nursing Knowledge: Building on our Foundations

Taking the advocacy discussion to a higher level requires a search for underlying notions in the existing literature that may serve to move us forward. The literature is consistent in suggesting that nursing advocacy seeks change for the good of the client, and is rooted in particular knowledge(s) that nurses possess. Carper's (1978) seminal work on the patterns of knowing in nursing serves as a useful frame for the different knowledges represented in the advocacy literature (Kubsch et al., 2004). *Ethical* knowing was conceived as the moral component of nursing practice, and many discussions of advocacy in nursing are about advocacy as a moral act intended to promote a 'good' (Breeding & Turner, 2002; Chafey et al., 1998; Corcoran, 1988; Curtin, 1979; Falk-Rafael, 2005; Harrison & Falco, 2005; Minicucci et al., 2003; Sanchez-Sweatman, 1997). *Empirical* knowing as a resource for advocacy is embedded in notions of advocacy as thoroughly informing and supporting clients in their health-related decisions (Hellwig et al., 2003; Kohnke, 1982; Rose, 1995). Drawing upon personal knowing, or the individual human qualities and experiences that define who the nurse is in terms of advocacy has also been described as important (Foley et al., 2002; Gadow, 1980). *Aesthetic* knowing as the artful, empathetic act of nursing is seen to inform discussions of relational-existential advocacy as a unique and important role of nursing (Bishop & Scudder, 1990; Breeding & Turner, 2002; Corcoran, 1988; Curtin, 1979; Gadow, 1980). These patterns are eloquently described by Carper (1978) at the human-nurse interface of practice. It has been noted by some that the introspective focus of these patterns has encouraged us to remain relatively inattentive to the larger social, economic and political forces that are altering the human health experience, and shifting the very foundations of our practice (Browne, 2001; Browne, 2004; White, 1995). White

(1995, p.85) suggested adding a dimension of "socio-political knowing" to Carper's framework to address this gap. Perhaps, however, something beyond a discrete addition to Carper's framework is needed. We believe that we need to enlarge our advocacy frame by developing our personal, ethical, empirical and aesthetic knowledge *of policy* and policy processes (West & Scott, 2000). This is not the creation of a new pattern of knowing, but a recognition that we must create opportunities to bring our ways of knowing to bear on a set of processes that are at a completely different level than the individual nurse-client interface. Further, we need to learn to communicate our foundational knowledge—knowledge *for* policy--in a manner that penetrates that larger enterprise.

An important step in enlarging our advocacy frame was provided by Pamela Grace in a thoughtful philosophical analysis of advocacy in nursing, where she asserted that the object of advocacy stems from the profession's purpose and promise to society to engage in practice with the intent of improving health at the individual, health system and societal level (Grace, 1998; Grace, 2001). Grace (2001) acknowledged that while such a conceptualization of advocacy does not solve the problems inherent in balancing the needs of individuals with those of society at large in terms of advocacy, it at least invites a broader discourse on the dilemmas faced by all professionals interested in advocacy for health. Further, such a conceptualization appropriately widens the professional's assessment of the obstacles to achieving health, and increases the possibility that solutions to underlying problems can be found. Such an understanding fits well with how policy advocacy is being considered here.

Policy Advocacy

Policy advocacy is defined here as knowledge based action intended to improve health by influencing policy. The literature on policy advocacy is not well developed in nursing, and it has often been noted that nursing is virtually invisible in terms of influence at the policy level (Antrobus, 2004; Antrobus & Kitson, 1999; Borthwick & Galbally, 2001; Falk-Rafael, 2005; West & Scott, 2000). The literature that exists is replete with normative claims that nurses should engage in policy advocacy (Borthwick & Galbally, 2001; Boswell et al., 2005; Gebbie, Wakefield, & Kerfoot, 2000; Halpern, 2002; Idelson & Bloice, 1997; Jezewski, 1993; Keepnews & Marullo, 1996; Kohnke, 1982; Konkle-Parker, 2000; Krauss, 1996). There are also references to the rich history of public health nursing in advocating for and achieving change in health-focused policy (Falk-Rafael, 2005; Glass & Hicks, 2000; Lasseter, 1999; Nelson & Gordon, 2004; Reutter & Duncan, 2002; Wakefield, 2001). There have been calls to expand the education of nurses to include a greater emphasis on policy advocacy (Faulk & Ternus, 2004; Miller & Russel, 1992; Ortner, 2004; Rains-Warner & Barton-Kriese, 2001; Rains-Warner, 2000; Reutter & Williamson, 2000; Reutter & Duncan, 2002), and recommendations to create policy advocacy as an advanced practice role within nursing (Harrington, Crider, Benner, & Malone, 2005; Maynard, 1999). Nurse scholars concerned with advocacy and social justice have explored the use of critical theory as a framework for policy analysis (Duncan, 2003), and for understanding the politics of oppression and marginalization in matters of health (Dickinson, 1999; Giddings, 2005a, b; Hall, 1999). There is very little empirical work about how to engage in policy advocacy, however, (Wilson, 2002) and very few conceptual models have been developed, studied or used to guide nursing theory, research or practice in the area of policy advocacy (DiGaudio, 1993; Fawcett & Russell, 2001; Russell & Fawcett, 2005).

We have suggested here that nursing knowledge informed by a larger advocacy frame would be a valuable contribution to the policy arena, but that we are hampered by lack of knowledge about how to influence policy. Indeed, the role of knowledge in policy advocacy has not been well explored in the nursing literature, or effectively demonstrated in our participation at the policy level (Hewitt, 2002; Scott & West, 2001;

West & Scott, 2000). Perhaps an exploration of the valuable lessons about the role of knowledge in the policy process in literatures outside nursing is warranted. For example, there is growing evidence that the knowledge brought to bear on policy is of secondary importance to the establishment of relationships with policy makers (Davis & Howden-Chapman, 1996; Feldman, Nadash, & Gursen, 2001; Hanney, Gonzalez-Block, Buxton, & Kogan, 2002; Innvaer, Vist, Trommald, & Oxman, 2002; Lavis et al., 2003; Ross, Lavis, Rodriguez, Woodside, & Denis, 2003), and between and among others interested in policy change (Fischer, 1993; Sabatier & Jenkins-Smith, 1993; Sabatier, 1999; Sherriden, Slosar, & Sherridan, 2002; Weible, Sabatier, & Lubell, 2004). Policy scholars Sabatier and Jenkins-Smith (1993) also studied the role of empirical knowledge and evidence in policy change within an Advocacy Coalition Framework (ACF). In their framework, the value of empirical knowledge is its stimulation of policy-oriented learning by policy actors in competing coalitions via the ‘enlightenment’ capacity of exposure to knowledge over extended periods of time. While the ACF has been criticized for its emphasis on top-down change mobilized by policy and knowledge elites (Bryant, 2001) there are lessons to be learned about potentially effective ways to share knowledge with policy elites, and the power of coalitions in policy stability and change.

More recently, social policy scholar Toba Bryant (Bryant, 2001, 2002, 2004) has built upon the work of Sabatier and colleagues (Sabatier, 1987; Sabatier & Jenkins-Smith, 1993) and proposed a framework of policy change that encourages critical analysis of the ways of knowing used in policy advocacy. In her work, Bryant also explored the strategic possibilities in collaborative advocacy among policy professionals, citizen activists and other practitioners in the advancement of evidence emerging from different ways of knowing (Bryant, 2001). In another example with rich potential for nursing study, Donald Schön built upon his earlier work on the reflective practitioner (Schön, 1983) with colleague Martin Rein (Schön & Rein, 1994) in the study of policy controversy and the related conditions conducive to policy change. Their framework focused upon effecting change through a reflective and critical approach to policy discourse as transacted between people assigning different meanings to policy objects. In a similarly reflective vein, Stone (2002) rejected the traditional, rationally deterministic way of thinking about policy and proposed a framework requiring the advocate to draw upon personal knowledge. In this framework, one must remain aware of personal values and beliefs, unravel the assumptions behind any policy position, and remain sensitive to the paradoxical and situated ways in which the elements of the policy 'story' are strung together. Any of these (and many other) frameworks, although not particularly crafted with nursing in mind, offer fertile ground for advancing our thinking in terms of our contribution to and participation in the policy domain.

Policy Advocacy in Nursing

The moral and ethical obligation of nurses to engage in strategies to effect policy change for health has been described as increasingly urgent (Boswell et al., 2005; Sarikonda-Woitas & Robinson, 2002; Scott & West, 2001), particularly as pressure mounts on health care systems to reform in response to a variety of intersecting influences. The impacts of globalization, pervasive market-oriented ideology and persistent resource constraint (Spenceley, 2004a), combined with the looming challenges posed by an epidemiologic transition in the pattern of illness from acute to chronic (Kopec & Schultz, 2003; World Health Organization, 2005), have had a retrenching effect on social welfare policy in many countries (Haylock, 2000; O'Connor, Orloff, & Shaver, 1999; Rice & Prince, 2000; Scott & West, 2001; Shore, 1998). Increasingly, we hear voices calling for market solutions that are constructed as creating more *choice* (Government of Alberta, 2006; Haylock, 2000), with the correct choice constructed within a health discourse that implies individual responsibility for illness as a result of having chosen poorly, resulting in added costs for the health care system

(Thorne, McCormick, & Carty, 1997). We see health disparities growing, and a reluctance of decision-makers to re-think health policy in light of the powerful social determinants of health (Falk-Rafael, 2005; Raphael et al., 2003). The professional imperative for policy advocacy has increased, and yet our invisibility persists. While a lack of knowledge about advocacy at the policy level has undoubtedly contributed to this situation, we suggest that there are further challenges that bear closer examination.

Challenges to Policy Advocacy in Nursing

If gaps in knowledge constituted the only problem, the potential solutions might be clearer. Although, as anyone who studies the 'research-practice' gap will tell you, singular emphasis on more and better knowledge is inadequate. Further challenges arise within the discipline, in the practice context, and in our discourse at the interface of the worlds of nursing practice and health policy.

Challenges within the discipline. It has already been noted that nurses often see the world of policy as something removed from their scope of influence (West & Scott, 2000), and that this disconnection from the larger world of health policy is reinforced and re-created by the overwhelming, even 'introspective,' focus of our research and practice at the level of the nurse-person relationship. Introspection of another sort also requires mention here—our tendency to be inwardly focused in nursing inquiry (Spenceley, 2004b; Stajduhar, Balneaves, & Thorne, 2001; Thorne, 2001). It can be argued that as a young discipline, we have needed to invest energy in discussions about the components of nursing's metaparadigm (Cody, 1999; Fawcett, 1996; Fawcett, 1984; Monti & Tingen, 1999), appropriate paradigms for nursing (Cull-Wilby & Pepin, 1987; Mitchell & Cody, 1992; Parse, 1999), and congruent approaches to the development of nursing science (Cody & Mitchell, 2002; Johnson, 1999; Mitchell & Cody, 1992). It is important to debate such intradisciplinary issues, but any contribution we might make to the policy arena requires us to build upon our disciplinary strengths and shift our focus outward. We need to think more about designing inquiry to build knowledge of policy advocacy processes, and crafting strategies to support our participation in them.

Others have noted that nursing education does not sufficiently equip nurses to play a role in policy advocacy. Lack of attention to the policy process (Harrington et al., 2005; Miller & Russel, 1992; Rains-Warner, 2000), the development of political competence (Conger & Johnson, 2000; Faulk & Ternus, 2004; Rains-Warner & Barton-Kriese, 2001), or exposure to real-world policy learning opportunities (Harrington et al., 2005; Ortner, 2004) in nursing education have been cited as undermining the ability of nurses to participate in the field of health policy. This reality is beginning to shift at the graduate level, with the development of nursing specialty programs in policy study (Ellenbecker, 2005; Harrington et al., 2005) and calls for a specialized, advanced practice role in policy (Pullen, 1995). While this is one way to proceed, we suggest that we must be mindful of advancing the notion that policy advocacy is for 'those nurses over there', rather than an activity that is relevant to all professional nurses. As Warner (2003) noted in her exploration of political competence, "with only a slight reframing of the lens/perspective, political competence may be within every nurse's skill set" (p. 142).

Further to this, it might be argued that internal divisions in nursing may discourage collaboration among nurses who do participate in policy advocacy. Advocates for *healthy public policy* (World Health Organization, 1986) have importantly emphasized the social determinants of health beyond health care (Raphael, 2000; Raphael, 2004; Raphael & Bryant, 2002; Williamson, 2001). Nursing voices raised to this broader level have been fewer in number and largely restricted to the area of community health nursing (Glass, 2000; Glass & Hicks, 2000; Rains-Warner & Barton-Kriese, 2001; Rains-Warner, 2000; Reutter & Williamson, 2000; Reutter & Duncan, 2002), as might be expected because of the professional mandate of community health nursing to focus more broadly on population health. Certainly *healthy public policy* is a broader concept than *health policy*, which is focused on the behavior of organizations, institutions and professions involved in the field of health and the provision of health care (West & Scott, 2000). It has been noted that recent health care restructuring and its significant effects has lent a sense of urgency to nursing's participation in this narrower policy domain (Reutter & Duncan, 2002). We suggest that it may be valuable to recognize how these policy foci are linked to each other and to nursing by keeping the ultimate common goal of improving health in the foreground of such discussions. Keeping the goal of health in the forefront may also encourage collaboration among nurse researchers, educators, and practitioners, who each bring different knowledge and experience to an understanding of policy advocacy. More specifically, researchers have greater opportunities to be exposed to policy research literature in nursing and other disciplines, and nursing educators have a clearer understanding of the knowledge/competency gaps and potential strategies to increase the political competence of nurses. Practitioners in hospitals, institutions, and community settings are uniquely positioned to contribute the evidence emerging in their practice about the impacts of policy on the health of their clients. A collaborative approach to policy advocacy emphasizing what we can learn from each other might need to begin here, and it is important to support efforts to create opportunities for such dialogue (Jennings, 2002).

Challenges in the practice context. The influences alluded to earlier in the socioeconomic and political landscape have contributed their own challenges to the participation of nurses in policy advocacy. Boswell et al. (2005) speculated that factors such as heavy workloads, understaffing, powerlessness in institutional settings and lack of time have contributed to the “pandemic” of political apathy among members of the nursing profession (Boswell et al., 2005, p. 3). In a survey of 118 registered nurses practicing in specialty acute care areas in the Midwestern U.S., Cramer (2002) found two significant factors influencing organized political participation--the amount of free time available to the nurse, as well as the sense of personal self-efficacy. DiGaudio (1993) conducted a small grounded theory study with nurses from a variety of practice backgrounds to examine their participation in influencing health policy. This study found that lack of knowledge of policy processes, absence of role models and perceived powerlessness hindered participation (DiGaudio, 1993). Similarly, in a grounded theory study of 22 nurse administrators, McAllister (1997) found that a lack of power over conditions of work, resistance of powerful physician colleagues and resistance to change from other nurses hindered political advocacy. We have noted that policy advocacy is more commonly considered relevant to community health nursing practice, by virtue of its population health mandate. Nevertheless, in a study of public health nurses' perceptions of their roles, MacDonald and Schoenfeld (2003) found that role confusion, inadequate education in matters of policy and leadership, bureaucratic obstacles and lack of autonomy in practice constituted significant challenges to the nurses' perceived ability to fulfill their mandate.

The pervasive socioeconomic and ideological influences in healthcare may have also created a more self-serving (or self-preserving) impetus for policy advocacy in nursing, as the role of the profession in providing front line health services is threatened in the name of efficiency (Cody & Mitchell, 2002). Times of threat to the profession may have caused us to retrench into our professional silos, fragmenting efforts to mobilize for positive change. Others have noted the professionalizing and self-serving nature of advancing the nurse as the logical and ideal advocate in matters of health (Bernal, 1992; Hewitt, 2002; Mitchell & Bournes, 2000). Cody & Mitchell (2002) implied that advocating for a unique role for nursing in health care is, in effect, advocating for the betterment of human kind. We suggest that such assertions can potentially undermine a key strategy for health policy advocacy--building coalitions with others to advocate for change. The ubiquitous notion of the nurse as the *ideal* advocate in matters of health could be perceived as nursing advocating for nursing rather than for health. This may have distanced us from other professions who might fruitfully participate with us in the process of change, and undermined our credibility with policy makers as turf-protecting and self-serving. This is counter-productive at a time when the health care reform debate is crystallizing around notions of inter-professional collaboration and interdisciplinary team-work. Collaborative policy advocacy and coalition building are well developed concepts in other literatures such as the social sciences (Dalyrymple, 2004; Sherriden et al., 2002; Williams, 2004) and the policy sciences (Sabatier & Jenkins-Smith, 1993; Weible et al., 2004; Zafonte & Sabatier, 2004), but rarely have these processes been studied from a nursing perspective (Schorn, 2005).

Finally, it has been noted that there is a risk to the nurse inherent in advocacy at any level (Des Jardin, 2001a; Grace, 2001; Mallik & McHale, 1995; Segesten, 1993; West & Scott, 2000). It has also been observed that nurses are steeped in risk aversion from their earliest socialization into the profession, and that the acculturation to silence and conformity in the face of conflict or confrontation continues even today (Giddings, 2005a; Myrick et al., 2006). These are important obstacles to be considered, and are the pointy ends of advocacy that fuel the argument that advocacy is best done 'under the radar'. As Hewitt (2002) pointed out, however, subversive advocacy may serve short-term goals, but cannot ultimately address the underlying issues creating the need for advocacy in the first place. Subversive advocacy also limits our ability to model and share advocacy knowledge with others by sacrificing an important medium for learning advocacy skills (Breeding & Turner, 2002).

Discursive challenges at the interface of nursing and policy. Fischer (2003) described two dimensions of policy discourse--ideational and interactive. *Ideational* discourse communicates and constructs the substance of policy, and frames the empirical and normative arguments, ideas and knowledge brought to policy discussions. This is what West and Scott (2000) have referred to as the communication of knowledge *for* policy. *Interactive* discourses serve communicative and coordinating functions, and consist of discursive exchanges between and among coalitions, advocacy communities and the broader political system (Fischer, 2003); this is discourse informed by knowledge *of* policy and policy processes (West and Scott 2000). There are challenges at the interface of the worlds of nursing and health policy that emerge from both of these dimensions.

Ideational discourse in health policy has been heavily influenced by the evidence-based medicine movement (EBM). The common and pervasive understanding of what counts as credible evidence in all matters of health, including health policy, has been defined and delimited by the EBM model (Cody & Mitchell, 2002; Evidence-Based Working Group, 1997; Gray & Phillips, 1995; Hess, 2002) . The role of knowledge in policy change received relatively little attention in the literature prior to the late 1980's (Sabatier & Jenkins-Smith, 1993; Sabatier, 1987). These scholars initiated a discourse that privileged evidence of an objective, quantitative nature in advocating for policy change, a notion that quickly found a home in a health sector rapidly constructing its own evidence-based discourse. Voices critical of the singular relevance of ostensibly 'objective' empirical evidence to the world of health policy are beginning to emerge (Raphael & Bryant, 2002; Bryant, 2001, 2002, 2004), but knowledge and evidence emerging from other ways of knowing such as the ethical or esthetic frames (Carper, 1978) or knowledge from qualitative inquiry into the lived human health experience remain largely marginalized by virtue of their low stature in the extant hierarchy of evidence (Cody & Mitchell, 2002; Jennings & Loan, 2001).

The challenge is not merely a matter of producing evidence of a particular type, however. Nurse scholars are well equipped to produce the type of empirical evidence ostensibly valued by policy makers. Important recent examples include investigations of linkages between nursing workplace factors and patient outcomes (Aiken et al., 2002; Aiken et al., 2001; Cummings & Estabrooks, 2003; Estabrooks, Midodzi, Cummings, Ricker, & Giovannetti, 2005; Sochalski, Estabrooks, & Humphrey, 1999). The larger challenge exists in finding ourselves largely ill-equipped to engage in the current policy discourse (West & Scott, 2000) that embeds chunks of evidence within narrative that is steeped in modern neoliberal values of individualism, free enterprise, market competitiveness and economic efficiency (Stairs, 2000; Fischer, 2003). Our discourse, rooted in the humanist and collectivist values of nursing, is discordant with the ideational discourse of the day (Murphy, Canales, Norton, & DeFilippis, 2005). While changing our values is not the answer, we do need to be more astute in how we frame and focus our contributions (West & Scott, 2000). We must build on the successes of recent initiatives emphasizing interdisciplinary health research framed to penetrate policy discourse, such as the work of Gina Browne (2003, 2004) in the System-Linked Research on Health and Social Service Utilization at McMaster University in Canada. Such research has the potential to powerfully influence policy, and perhaps even more importantly, to influence us to *think and talk policy* in our education, practice and research. Evidence of this discursive gap was provided in an interesting study comparing the verbal descriptions of policy activism by baccalaureate nursing students and political science students (Rains-Warner & Barton-Kriese, 2001). It was noted that while nursing students more often engaged in activities of a politically active nature, their discourse reflected a view of policy as a barrier that was largely disconnected from their experience. Political science students were found to be much more comfortable with the discourse of policy, democracy and political action, and yet less likely to have been involved in political activities themselves. While conventional wisdom would have us believe that actions speak louder than words, it may be that in nursing we are undermining our political actions and potential influence with the way we choose to construct and communicate the political in our discourse.

This challenge is compounded by the existence of limited opportunities and mechanisms for practitioners of nursing to observe or participate in policy processes, or to engage in *interactive* policy discourse. There are few tools and fewer opportunities to interact or reflect around issues of policy (Heath, 1998; Wilson, 2002). Opportunities have been mainly limited to participation in professional nursing organizations (Beyers, 2000; Canadian Nurses Association, 2000; Eastwood, 1996; Glass & Hicks, 2000) who, we would argue, have been much more engaged in recent times in advocacy for the profession. Further, structures for engaging practitioners in policy discussions in the practice environment are rare (Carney, 2004). A pressing challenge, therefore, is to find mechanisms and strategies that gain us entry into the world of policy discourse, to listen and learn from the persuasive discursive practices in that world, and to persist in efforts to add a new ideational dimension (Warner, 2003). Discursive policy intervention must stem from the values of nursing, and incorporate the full range of nursing's knowledge of the lived human health experience. It is here that the implications, consequences and impacts of health policy can be deeply explored (Warner, 2003).

Moving Forward

Nursing is well positioned to participate successfully in policy advocacy. Public opinion polls consistently rate nurses as among the most trusted professionals (Jones, 2005; Trust in Nurses Remains High, 2005). Our value base grounds us in the profound sense of responsibility that this trust engenders, a stance that should not be irreconcilable with acknowledging this trust as valuable coalition-building currency for policy advocacy (Curtin, 2001). Our practice gives us access to how policy impacts the individual health experience, knowledge that we can bring to collaborative reflections on deeper patterns and emergent health policy issues in populations over time. We are professionally committed to the goals of improving health, we explicitly acknowledge our role and responsibility in advocacy at the policy level (Ballou, 2000; Canadian Nurses Association, 2002; Community Health Nurses Association of Canada, 2003; Royal College of Nursing of Australia, 2003), we are the largest group of health professionals (Cramer, 2002), and we have a well developed professional infrastructure to support policy advocacy.

Rich dialogues on policy and how nurses participate in the policy process are developing in journals such as this one, and we are just beginning to explore conceptual structures to guide and focus policy inquiry within the discipline (Fawcett & Russell, 2001; Russell & Fawcett, 2005). Such efforts are important in terms of our own knowledge development in this area, and must continue. We can also benefit, however, from the well-developed policy and social science literatures in terms of learning about influencing policy. While a few nurse scholars are bridging the gap between nursing and the larger policy literature (Duncan & Reutter, 2006; Laraway & Jennings, 2002; Odom-Forren, 2006; O'Sullivan & Lussier-Duynstee, 2006; Schorn, 2005; Scott-Findlay et al., 2002), such attempts are rare. Further, a two-way connection to the larger policy scholarship community is important in that it offers the opportunity to contribute a nursing voice and perspective to this larger policy discourse (Warner, 2003).

In conclusion, we have made some progress in coming to a limited understanding of policy advocacy in nursing, but there are a number of valuable perspectives on policy advocacy that remain unexplored, and questions that remain unasked. We have sought the perspectives of nursing students (Rains-Warner & Barton-Kriese, 2001; Rains-Warner, 2000), nurse activists (Hart, 2000; Halpern, 2002; Meerabeau, 1996; Warner, 2003), nurse administrators (McAllister, 1997), nursing organizations (Beyers, 2000; Keepnews, 2005) and nurses in practice (Cramer, 2002; DiGaudio, 1993). Notably, we have not yet explored the perspectives of the people we serve. Perhaps this is one reason that we have not squarely confronted the paternalistic assumptions underpinning much of our knowledge about advocacy. We have not pursued the perspective of other members of the interdisciplinary health team, non-nursing organizations participating in health policy advocacy, and importantly, policy decision-makers. We have inquired about the skills and education required for policy advocacy (Algase, Beel-Bates, & Ziemba, 2004; Brown, 1996; Conger & Johnson, 2000; Davies, 2004; Des Jardin, 2001b; Gebbie et al., 2000; Rains-Warner, 2000; Rains-Warner & Barton-Kriese, 2001; Reutter & Williamson, 2000; Reutter & Duncan, 2002), but are just beginning to explore how to incorporate skills such as assessment of the policy environment into nursing practice (Griepp, 2002; Malone, 2005) Perhaps progress in policy advocacy also lies in pursuing some of the questions we have not yet asked (Table 3.1).

We have rhetorically and repeatedly pondered our invisibility at the level of health policy. White (1995) suggested that we must seek to “lift the gaze of the nurse from the introspective nurse-patient relationship” (White, 1995, p. 85). We would add that we must also take what we have learned from our protracted introspection, and see this familiar terrain with new eyes. Only then can we pierce our veil of invisibility by bringing the best of its lessons to a larger and more collaborative form and forum of policy discourse.

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Table 3.1. Some Questions Still to be Asked

- Who are the visible actors (both nursing and non-nursing) in policy advocacy for health, and what can we learn from them?
- What opportunities can we create to participate in policy discourse with one another, with colleagues from other disciplines, and with policy makers?
- In what ways does the discourse of nursing practice differ from the discourse of policy?
- What knowledge from practice can we build into our policy discourse, and how do we do it?
- Can we collaborate with our clients in policy advocacy? How can we do this?
- What are the desired outcomes for nursing policy advocacy, and how will we measure them?

Running head: LEVERAGING FOR POLICY CHANGE

CHAPTER 4.

Paper # 3 - Leveraging for policy change: The case of the Canadian Diabetes Association

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Leveraging for Policy Change: The Case of the Canadian Diabetes Association

Introduction

On October 9, 1923 the United States Patent Office issued Patent Number 1,469,994 for “extract obtainable from the mammalian pancreas or from the related glands in fishes, useful in the treatment of diabetes mellitus and a method of preparing it” to Canadian physicians Banting, Best and Collip (United States Patent and Trademark Office, 2006), heralding the modern age of diabetes care. Surely these pioneers dreamed of a not so distant day when diabetes would no longer pose a threat to life and health. Unfortunately, the dream has never been so distant. The prevalence of diabetes is described as ‘epidemic’ around the globe (Health Council of Canada, 2007; Rathmann et al., 2005; Steinbrook, 2006; WHO, 2006). Research confirms diabetes prevalence in Canada is exceeding previous projections, with nearly 3 million Canadians now estimated to have the disease (Lipscombe & Hux, 2007). Previous predictions of the economic costs of diabetes care to the Canadian health care system were daunting enough: an increase to 8.14 billion dollars by 2016, from 4.66 billion in 2000 (Ohinmaa, Jacobs, Simpson & Johnson, 2004). It now seems that even this alarming projection was a gross underestimation. The human cost of poorly managed diabetes is equally alarming. Diabetes begets a host of other chronic conditions including cardiovascular disease, kidney disease, blindness, impotence or peripheral vascular disease (Canadian Diabetes Association, 2005a), any one of which greatly influences quality of life and multiplies personal and economic costs. Calls for policy action around diabetes reflect increasing urgency (Picard, 2007), and the skills to participate in advocacy to shape policy in this area have taken on a new importance. Despite a growing realization that influencing policy is best understood as a complex social process (Fischer, 2003; Lomas, 2000; Schön & Rein, 2004; Stone, 2002), there has been little research examining policy advocacy from this perspective. In this paper, we present the findings from a qualitative study of policy advocacy conducted within the Canadian Diabetes Association (CDA)—an organization heavily involved in advocacy around diabetes at the policy level (CDA, 2003, 2004, 2005b, 2007).

Background

Some of the most visible and credible advocates for Canadians living with chronic disease are voluntary sector organizations, particularly registered health charities (Langille, Lyons & Latta, 2001; Wilson, 2003). In Canada, 18 registered health charities have combined their advocacy efforts to focus attention and funding on health policy issues around chronic disease (Health Charities Coalition of Canada, 2006), and are major contributors to research in this area. Advocacy in the sector has been defined as "the act of speaking or of disseminating information intended to influence individual behaviour or opinion, corporate conduct or public policy and law" (Voluntary Sector Task Force, 1999, p. 50). The CDA is a founding member of the Health Charities Coalition of Canada, and is at the forefront of advocacy for policy related to living with diabetes in Canada.

The CDA was chartered in 1949 under the leadership of Charles Best. It was established in a spirit of fierce independence from government and based in staunch beliefs in self-help and lay leadership (Chute, 1974). At that time, as for so many other organizations in the Canadian voluntary sector during the post-World War II era, the primary focus was on providing services for people (Hall, Barr, Easwaramoorthy, Sokolowski & Salamon, 2005). The founders of the CDA also acknowledged the value of providing a means for people with diabetes to gather, support and learn from one another. The CDA also embraced foundational beliefs about educating the public about diabetes, and guiding diabetes care with sound medical advice. The organization maintained these roots in service and education as it evolved over the next five decades to a federation of provincial chapters. The foundations of a more national approach to advocacy existed, however, in an early recognition that a national organization provided "a union with strength enough to bring pressure where pressure is necessary to serve the health needs of all diabetics" (Chute, 1974, p. 11).

The CDA today exists in a radically different context. Rising unemployment, inflation and the pressures of globalization contributed to a resurgence of economic neo-liberalism internationally (O'Connor, Orloff & Shaver, 1999), a now pervasive ideology that favors privatization, deregulation and small government (Basu, 2005). Retrenching of the Canadian welfare state began in the 1990's as economic growth slowed and government funding of voluntary organizations declined (Hall et al., 2005). The rising dominance of market-oriented approaches to governance has influenced the voluntary sector, creating a demand for more centralized and corporate approaches to non-profit work (Roberts, Jones, & Fröhling, 2005). This shift has been called for by governments, donors and the general public in the belief that such approaches create more explicit accountabilities and greater efficiencies (Phillips & Graham, 2000; Phillips, 2006). This new managerialism has been accompanied by professionalization of the voluntary sector (Hall & Banting, 2000) as organizations compete ever more aggressively for dwindling resources, and for the attention of governments to their issues.

It is in this larger context that the CDA has continued to evolve. The organization now has four strategic pillars: service, research, public education and advocacy. A fundamental transformation of the organization began in 2001, when the long-standing federation-style governance model was replaced by a national corporate structure. Budgets and financial processes previously administered by mostly autonomous regional boards were consolidated nationally. Planning of educational initiatives and materials was centralized, and advocacy action previously planned and implemented by regional volunteers and staff shifted to a national strategic model. The involvement of regional volunteers changed from decision-making around local advocacy to a focus on implementing the national direction. A policy governance model was adopted, clearly defining the operational roles of staff and the policy-centric role of the national leadership. The now much smaller volunteer Board is supported by a CEO and national level staff, four of whom are devoted to advocacy and government relations. A National Advocacy Council (NAC) of volunteers remains, although the role has shifted from making national-level advocacy decisions to advising the Board, with NAC activities now reported to the Board through staff. This backdrop of organizational change provided important context to the study, and brought the processes of policy advocacy into sharp relief. The purpose of the study was the exploration of these processes 'on the ground', from the perspective of people engaged in the advocacy effort.

Method

In this study, grounded theory was used to study policy advocacy. The question guiding the research was: how does the CDA attempt to influence government policy? The grounded theory approach is well suited to studying how processes are enacted between people and evolve over time as people try to solve particular problems (Glaser & Strauss, 1967). The theoretic perspective of the method defers to the knowledge of the research participant as expert, by virtue of experience with the phenomenon of interest (Glaser & Strauss, 1967). The underlying symbolic interactionist perspective of grounded theory (Blumer, 1969) guided engagement of the first author with advocates in the organizational context, to gather first-hand knowledge about how they participate in policy advocacy, solve problems and make meaning of their worlds in interaction with others.

Data Collection Procedures

Ethical approval for the study was obtained through the University of Alberta Health Ethics Review Board. Entrée to the organization was achieved through a senior staff member who distributed information about the study, and facilitated the involvement of participants. The study was explained by the first author, and informed consent was obtained from all participants (see Appendices A and B). Hunches and theoretical questions emerging from these initial interviews guided the selection of subsequent participants, and twenty in-depth, unstructured interviews were held with a total of 15 participants representing all organizational levels: national, area (multi-province) and regional (zones within provinces). As advocacy was a collaborative process between paid staff and volunteers, 8 volunteer advocates and 7 staff involved in advocacy activities were selected on the basis of their ability to shed light on the emerging theory. Five participants (2 volunteers and 3 staff) were interviewed twice, in order to confirm perceptions and guide theoretical development.

All interviews were audiotaped and transcribed verbatim. Further data were collected through participant observation and the review of organizational advocacy documents. Over 800 pages of interview data and 200 pages of detailed field notes were collected in three multi-day advocacy events involving over 300 participants, a national professional conference, two full-day meetings of the NAC and one meeting between advocacy staff and an external group wishing to partner around an issue.

Analysis

Data collection and analysis proceeded concurrently, with constant comparison of data segments. Reducing data into substantive codes was followed by higher order coding into conceptual categories. As new data came in, they were compared with existing codes and categories. Categories were developed and refined, altered as new perspectives were revealed, or collapsed into higher order conceptualizations. When categories were well represented by the data, *theoretical* coding facilitated exploration of relationships between and among categories (Glaser & Strauss, 1967; Glaser, 1978). Reflective memos were written during the process, and were often revisited and refined as analysis proceeded. Diagramming the relationships between variables was useful in identifying processes and discussing them with participants. These analytic activities helped to identify theoretical gaps and guide the exploration of hypotheses in subsequent data collection. Finally, selective coding (MacDonald, 2001) was undertaken in relation to the category of “leveraging”, as this category was at the centre of much of what was happening in advocacy in this organization. This core category was framed as a process of *leveraging*, with particular dimensions, phases and strategies to be described here.

Findings

“I am tired of watching my friends and family rot away and die in front of my eyes”. These words were uttered by an aboriginal woman at a volunteer advocacy forum, and brought the room to head-nodding silence. It was at this forum that my first impressions of the organization were formed. Volunteers and staff took turns standing up to explain why they were there. Many related personal and compelling experiences with the effects of this disease on life as lived. They related stories about the financial burdens experienced, how needed medications were inaccessible, or how a diagnosis of diabetes had resulted in stigma and discrimination. Staff members not directly affected by diabetes rose to explain how they had come to feel a deep compassion and enduring respect for those living with these burdens. The driving motivations in the room were deep and diverse, although the goals of policy advocacy were firmly grounded in a desire to improve the lives of all Canadians living with or affected by diabetes.

Over time, it became clear that a basic problem faced by the CDA was how to nurture the passion and commitment associated with these diverse interests, and harness it to fuel orchestrated action for policy change at the national level. The CDA attempted to influence government policy by aligning advocacy structures to secure maximum return from limited organizational resources. It was also necessary for the CDA’s constituency -- Canadians living with or affected by diabetes -- to be perceived as having a legitimate claim on the public interest. Passionate, committed volunteer voices were foundational to this legitimacy, so it was important that these voices were supported and sustained. The main finding of the study was a two-dimensional *process of "leveraging"* that had evolved to deal with both sides of this problem: orchestrating action and nurturing commitment.

Leveraging Defined

Leveraging is a social process of using available resources to try and influence decision-making in a desired direction. There are conditions, or elements that need to be in place before leveraging can occur. Put simply, *one must have knowledge about how to leverage, an intended direction, levers, something leveragable, and a force to apply to the lever to facilitate movement*. Like the use of levers in physics to gain a mechanical advantage, there is a structural element that is positioned to get maximum benefit or lift with the available force; for movement to occur, the force must be connected to the supporting structural element. The term 'leverage' was first used by a staff participant describing the advantages of a business-like approach to advocacy:

> … in the last 3-5 years we have a national board….so we're like any national association, like a franchise….our consistency has been enhanced as a result of that…I'll call it a business approach, and people wrestle with that statement, but business perhaps suggesting greater structure so you can leverage and be more effective and efficient in your message…

These words also communicated a market-oriented understanding of leveraging: strategic investment of capital to gain the best return possible. This perspective on leveraging created the tension referenced by this participant, and he related it to the shift to a more corporate structure. As explored more fully later in this paper, the tension was not a direct result of a more business-like model per se; it arose from the relational consequences of structural change. Indeed, the corporate shift was seen by most as a necessary change in order to leverage maximum benefit from limited resources. The process of leveraging was found to have two interdependent dimensions, one structural and the other relational.

Dimensions of Leveraging

Structural dimension. The structural dimension connected the levers and aligned leveraging efforts in the intended direction. This was the machinery of advocacy:

> …the volunteer who suggested that we do the survey was speaking about one thing, the staff member who would be responsible for actually doing the survey was concerned about the cost and doing it, the time and whether there was the resources to be able to make it happen…the time frame within which it would have to be done and what was to be the deliverable out of it and so on…and for the person who suggested it and for me, who supported the idea, that's not front of mind…(volunteer)

The structures were largely in the purview of paid staff, who enabled advocacy through committee structures, centralized communication structures, and issue-specific working groups. Other mechanisms included advocacy training sessions, centralized strategic planning, and staff-led central budgeting and allocation to advocacy initiatives. This dimension was often communicated by staff as 'paving the way' for advocacy efforts. The structural dimension was focused on creating deliverables, and completely self-interested, from an organizational point of view. It was about harnessing, packaging, and orchestrating advocacy effort to achieve particular objectives.

> Because if you don't have the passion and commitment then you're not going to be a good advocate… I mean, I have been moved to tears by people who get up and tell their story and talk about the impact of what it's like to live with diabetes and its complications on them and what's most amazing is they're more worried about the impact of it on their families…and I just…I look at that and I know it's horrible, but

> part of me thinks, I just have to package that and get it to an MP or elected official. If they heard it they will be as moved as I've been moved and that will make a difference. (staff)

This participant also communicated her sensitivity to tensions in the organization around commodifying the story for leverage when she admitted that it 'sounds horrible'. From the perspective of this dimension, however, everything was capital to be used in advocacy. Relationships were cultivated to gain an understanding of what was valued by decision-makers, and therefore what could be used to achieve advocacy objectives, and to increase the penetration and precision of leveraging strategies.

> And because I know these guys....and because the heart has several strings and some of the guys responded to the endocrinologist because he had a nice suit and more money than they did, and he was at an intellectual level, and some of the MLAs or MPs...really are, you know, more at home with an intellectual...they sit a little straighter, and they really liked listening to him because he was on their level, and others were more concerned about the real common person... (volunteer)

Other external relationships were managed in order to mitigate risks to achieving organizational objectives. For example, relationships were carefully and explicitly structured with pharmaceutical companies in order to leverage the considerable resources they brought to advocacy, while avoiding the message-tainting effect that too close a relationship with "big pharma" might engender. The structural dimension was concerned with maintaining the organizational identity as credible and professional, and protecting this reputational capital. Relationships were also managed through the structural dimension in order to most efficiently meet outcomes. For example, there was a new organizational preference for managing volunteer relationships by engaging these advocates for short periods of time on an issue-by-issue basis. This was consistent with the new corporate lens, where ad hoc engagement was viewed as a more efficient and effective way to leverage limited volunteer resources and match the talents of advocates to the demands of particular issues for limited periods of time.

> They're really busy and to get them to do something you want to really be strategic because you don't want to take their valuable time… to come and do something that's not going to have a big bang for its buck, so you've got to identify specific things for them that you can use them at that really, really does bring us up a notch. And you have the volunteers who are also really busy in various lives, all over the place, and so they want to come and do something but they want it kind of time specific because they've got family lives and all sorts of things going on. (staff)

Relational dimension. This dimension was more about *being and becoming* an advocate within an advocacy community. The relational dimension connected people to one another, nurturing commitment to a shared cause and a community goal. This dimension connected people to a higher purpose than their own self-interest, and motivated them to act in concert out of a deep sense of moral commitment to acting for the greater good. Volunteers at advocacy forums talked about staying involved because of the people, the cause, the fun, and also the responsibility they felt to make a difference for people who were unable to advocate for themselves.

> …I realize that there are a lot of people for whom access to their necessary medications and supplies is an issue and…ironically, those same people are probably the people least able to identify that…and bring about positive change. They're too busy trying to survive from day to day…because I don't face that issue I have the time to be able to go out and represent the people for whom it is an issue. (volunteer)

In the relational dimension, relationships were the "glue" of advocacy; they developed over time and nurtured the force behind leveraging—commitment to a shared cause. Mechanisms such as advocacy committees, forums or training sessions served as relational infrastructure, as ways to connect and share local knowledge and lived experience.

> …I had a new volunteer contact me just the other day…she had moved here from another province and was looking to connect with those of us here that were involved with advocacy. She wasn't looking for a task or an issue, she was looking for a meaningful connection…just connecting with others is so important… (volunteer)

Balancing the dimensions. A balance between these two dimensions was critical to leveraging. The structural dimension ensured that manifested passion was reigned in and used as a targeted and sustained force for change. On the other hand, the relational dimension nurtured this same passion, fostered learning in relationship and supported engagement in a shared pursuit. One senior staff participant described it this way: "it's a creative art…it's not a science and its not something that's ABCD and then do…you're working with people who aren't textbooks…you've got to go with the flow and figure out, OK, how do we position this best?" This participant also shared an observation that there was an intangible quality, an emotion that was crucial to the effort that couldn't be manufactured or purchased, a quality without which, an advocate became just another lobbyist—she noted that without the feeling side it might be organized and professional, but "it just wasn't real".

The importance of dimensional balance was brought into sharp relief for both the participants and the researcher in the context of organizational change. As the CDA recognized the need for more coordinated action at the national level, the focus shifted to structure—the organization moved away from supporting longstanding regional advocacy groups, and towards creating a lean and nimble staff-led advocacy structure to ensure efficient, orchestrated national action. Mechanisms in the organization that had previously been used to draw the membership into a discussion about the advocacy direction now featured communication heavily weighted in the other direction. The structural dimension educated volunteers on *'how we do advocacy here'*. Advocating appropriately was taught and reinforced by teaching the power of the sound bite and the scripted message, and the importance of centrally prepared and vetted communications. Effects of this structural focus on the relational dimension were observed by a volunteer participant, who advised that advocates seeking to “make a serious investment of their time, energy and commitment” balked at the one-way nature of this communication. Another volunteer related that “the process must be balanced…communication has to be genuine and two-way…without balance it's broken”, speaking to the advocates' search for what another volunteer described as “authentic, meaningful participation” and relationships that exceed the boundaries of short term commitments to specific issues. Another experienced volunteer observed that while all this attention to structure had many positive effects for the organization as a whole, there had also been some negative consequences for advocacy:

> …but I think one of the fallouts has been …the importance of engagement in terms of motivating volunteers is not high on the radar screen because those kinds of contributions and those kinds of capacity building endeavors are difficult to quantify and aren't readily recognized in…you know, in many traditional business model approaches to governance…

Phases and Strategies of Leveraging

Leveraging happened as a two-phased process over time, and was squarely focused on a chain of decisions leading to advocacy action. There were key leverage points where it became possible to influence the decisions of others with particular strategies. A move to more centralized decision-making at the national level illuminated a phase of leveraging aimed at internal decision-making. This internal phase preceded an external phase focused on the decision-making of government policy makers. A number of leveraging strategies were identified in the analysis, where some form of capital was used to its greatest advantage (see Table 4.1) and will be discussed as they were used in each phase.

Internal leveraging. The CDA has branded itself as *the place to turn to* about diabetes. Many people contact the organization to ask questions, raise issues or share personal struggles. Recognition of the need for advocacy often arose from this grass-roots contact, or out of opportunities recognized by senior staff scanning the larger socio-political context. When issues arose from the ground, individuals related the urgency of their situation to front line staff through their stories. Staff were deeply moved by what they heard, and gained a perspective on issues unavailable to those making decisions higher up in the organization. This was *making it real*, or trying to give someone a deeply personal understanding of what it's really like to face these issues. A front-line staff participant shared this observation:

> …front line people, we get it, we cry, we feel sad…but when you're kind of a decision maker at the top of the line, you don't have that one on one with people to really understand the scope of the problem, right?

The person hearing the issue would decide on some type of advocacy action, often focused at the individual level to address the problem. After assessing the complexity and reach of the issue, action may also have included using strategies to move the issue up in the organization. This was the first step in connecting the issue to the advocacy machinery. Staff and volunteers talked to each other and to expert advisors about the issue and its implications. Front-line staff *weighted* the issue by communicating the number of times the issue had arisen and the number of people affected, and tried to get the issue noticed. One participant related an example of putting her own credibility on the line by championing an issue she felt very strongly about, using her reputational capital to move an issue forward. Staff also tried to *elevate* particular issues over others by highlighting positive outcomes such as good public relations or favorable media attention as a result of pursuing or sticking with an issue. All efforts focused on getting an issue on the organization's 'advocacy radar'. Alternatively, issues jumped the queue and landed directly on the radar screen when senior staff recognized an emerging opportunity in the larger context.

> The staff group are quite tuned in to...policy issues and in particular are quite tuned in to opportunities for influence so the result of that knowledge on their part means that sometimes sudden shifts take place in the organization's direction... (volunteer)

However issues emerged, once they reached the top of the organization there were efforts focused on getting the organization to commit at the national level to one issue over others. Senior staff had direct access to the structures of decision-making, and used strategic knowledge of the policy horizon in terms of issues, challenges or opportunities to advise decision-makers about which issues were best to commit to at particular points in time. Issues were presented in terms of internal, organizational priorities, but also *translated* in terms of the larger political context and external stakeholder relationships.

The next focus was to secure the commitment of the entire organization to the national advocacy direction. Staff and members of the Board embarked on 'advocacy road-shows' to secure regional buy-in and *activate* regional staff and volunteers to own the selected issue and move it forward. There was sensitivity to maintaining internal relationships by respecting regional differences, although any 'tweaking' of the national message to reflect local priorities was only allowed within narrow limits. This was a *calibrating* strategy to ensure that the message stayed consistent and focused on the desired outcome, and also part of *translating* the national direction into regionally meaningful terms:

> …but then we look at what that means in a local provincial area, so we'll go out to BC and say, you know, here's the issue that we're positioning around, access and financial burden, what's your tweak on the Ask in BC? And if your tweak on the Ask is we just need one more drug on the formulary, then go for it… because it's within the umbrella of the issue… and in the Maritimes…we know there's an opportunity that they may position some extra money for low income people. Great, go for it…
> …but we're still staying within a theme (staff)

As advocates gathered and prepared for the external phase, efforts focused on decisions around 'fine-tuning' the message, and its delivery. There was final tweaking of 'the Ask', and efforts were made to *calibrate* the message with the messengers and intended audience by fine-tuning stories to fit the opportunity at hand, and practicing the message for consistency and clarity. There was a focus on *making the issues real* and resonant for policy decision-makers, and advocates practiced delivering messages in both personal and more policy-oriented economic terms. *Weighting* occurred in the background as advocates were equipped by staff with the evidence behind 'the Ask'. The outcomes of internal leveraging included a clear, achievable goal with national reach, commitment from all segments of the organization to a plan of action, and advocates prepared to act in concert in the next phase.

External leveraging. This phase commenced at the interface with policy decision-makers. Opportunities to bring issues to the attention of the media were seized upon, and events like "Diabetes Day on the Hill" featured an orchestrated march of advocates to Parliament Hill to 'create a buzz', an *agitating strategy* to stir up public dialogue about diabetes. In planned meetings with policy makers, advocates rose and told their stories about living with diabetes, *personalizing* the consequences of policy. Experienced advocates *elevated* the exchange by clearly acknowledging the fit between their message and the politician's desire to do the right thing.

> So one of the first questions I ask them is why they got involved in politics, and they often say, 'Because I want to make a difference.' I'm like, 'Great. Here's how you can.' It's pretty simple. (volunteer)

These experienced advocates also emphasized the importance of strategizing and adapting their efforts based upon an understanding of the ideology and perspective of those they wished to influence:

> Yeah...The cowboys are in town and they will do things differently. So I guess that's kind of where we've got to go in terms of advocacy...

Advocates also pointed out the common ground with policy makers, and emphasized their relationship as *reciprocal*:

> ...we need to be able to understand what their position is and figure out ways to assist decision-makers with whatever they have to deal with. If the Health Minister has to deal with Treasury Board then a good advocate should be thinking about it in talking to the Health Minister...how can I help you with Treasury Board, if...you know, you say you want to help us, well, let's figure this out...(volunteer)

A final leverage point occurred as staff heard back from decision-makers and communicated the outcomes of the action. *Elevating* to sustain momentum was visible as organizational staff shared photographs of advocacy events with government staff, highlighting the participation of politicians in this worthy cause. Volunteers and staff at the highest level of the organization also reinforced the *reciprocal* relationship by helping to flesh out the logistics of any resulting policy change. *Activation* of the membership base continued as staff updated them on progress, and encouraged them to maintain pressure and focus on the issue. Success of advocacy activities included short and longer-term achievements. Initially, any indication that efforts had been noticed or heard by key decision-makers was considered a successful outcome. Such things as attendance of an event by senior ministers, good media coverage, and further requests for information from government were celebrated. In the longer term, success entailed solidifying relationships with decision-makers, receiving invitations to participate in future policy processes, and seeing incremental policy change in a desired direction. Successes were in themselves precious capital to be fed back into the leveraging process to keep advocates engaged and enhance the organization's reputation externally.

Discussion

The purpose of this study was to explore how the CDA attempted to influence government policy. The findings illustrate that organizational advocates engaged in a process of leveraging for policy change. Beginning inside the organization and moving outward to the interface with government decision-makers, they harnessed and aligned their available resources and strategically aimed them at key points in the decision-making process in an attempt to maximize their influence on policy. The mechanistic and investment-like metaphors in this model seem out of step with the thinking of policy scholars such as Shalom Glouberman (2001), who suggested that such metaphors failed to capture the complex, non-deterministic nature of policy-making and the unpredictability of outcomes. Glouberman suggested the organic metaphor of "sowing seeds" as more accurately reflective of the unpredictable nature and process of policy development (p. 44). This organization is also trying to sow seeds of change by engaging in a process intended to use its resources to increase the probability of policy movement in a desired direction. To extend Glouberman's metaphor, the structural dimension encourages the coordinated and concentrated sprinkling of seeds in a particular part of the garden to try and increase the chances of germination, while the relational dimension encourages an ongoing and shared commitment to tending the crop. We would argue that the leveraging model presented here does not belie the complexity of the task at hand, but tries to address the challenges inherent in influencing the direction of the very complex and unpredictable policy making process.

In the following discussion of leveraging, we describe the model's contribution to the current understanding of policy advocacy. Despite the fact that this is early work, its contributions lie demonstrably in three areas: a) the focus on *the perspective of the advocate*, b) the importance of *relationships within an advocacy community*, and c) the *interaction between structure and relationships*.

A Matter of Perspective

A good deal of knowledge developed around policy advocacy has taken one of two perspectives: a high-level system view of a policy domain (Kingdon, 1994; Sabatier & Jenkins-Smith, 1993), or a more mid-level view of how the world of policy change appears from the perspective of policy-makers, analysts and/or producers of policy-relevant knowledge (Lomas, 2000; Schlager, 1999; Schön & Rein, 1994). A few have taken their work closer to the ground, examining the idea of collaborative policy practice between citizens and expert policy analysts (Bryant, 2001, 2004; Fischer, 2003).

Some of the earliest and most influential work was that of Sabatier and Jenkins-Smith (1993). The high-level perspective from their Advocacy Coalition Framework (ACF) brings to mind a lengthy chess game, with competing coalitions of advocates making small and calculated moves that eventually result in a change in the game's direction. Critics of the ACF have mostly focused on its top-down, rationalistic approach to policy change (Bryant, 2001; Fischer, 2003), arguing that its scope is limited to the activities of policy elites (Bryant, 2001). Others have noted the failure of the ACF to account for motivational factors, such as why people act collectively, or stay connected to particular coalitions (Schlager, 1999). Even critics of the ACF, however, build on its insights around how deep-seated ideologies, policy core values and interests influence how groups of policy actors respond to policy change efforts (Lomas, 2000; Bryant, 2003).

A more mid-level perspective was proposed by Schön & Rein (1994), who advocated a critical reflective approach to policy dialogue between those with conflicting policy positions—a dialectic that penetrates policy stalemates by facilitating the construction of a metaframe within which common ground can be found and controversy can be resolved. Their model encouraged mutual understanding and frame-reflective discourse, but limited its application to those in the roles of policy analysts, decision-makers and academics. Another perspective is provided by Lomas (2000), who contrasted the perspectives of researchers and policy makers on the process of policy change. Lomas likened policy change to a 'sausage machine' (p. 142) that rarely runs predictably. He broadened the understanding of inputs into the policy process, and acknowledged the roles played by many purveyors of knowledge including the media, interest groups, advocates and pollsters. He further advised those attempting to influence policy to attend to the institutional structures of policy decision making, and the beliefs of the decision makers that inhabit them. The particular value of his work lies in his efforts to make the process more accessible to those outside the policy world. These frameworks are useful in lifting the gaze of those involved in the messy, organic world of policy practice to a level that reveals why others act as they do. The guidance to erstwhile advocates, however, is quite high level: encouraging reflection on the basis of one's own policy position as well as the motivations of other policy actors, building relationships with those other policy actors, and taking a collaborative approach to participation in the policy process.

Fischer (2003) described a more grounded approach to policy analysis and deliberation in his post-positivist analysis of public policy development, advocating an approach that facilitates the active participation of citizens at all stages of the policy process. A number of strategies are advanced, including the lay consensus conference, citizen juries, and participatory policy analysis and action research. Although he provides a compelling argument for involving lay citizens in activities to influence policy, his analysis takes the perspective of policy makers, researchers and analysts, challenging them to adopt these approaches. Taking a perspective closer to the front lines of policy advocacy, Bryant (2001, 2003) analyzed the different forms of knowledge evident in policy advocacy efforts in both the health and housing sectors in Ontario, Canada. Bryant proposed a general framework outlining how these different forms of knowledge are brought to policy advocacy through collaboration between citizens and policy analysts, although a subsequent application of the framework led Bryant (2004) to suggest an overriding role for political ideology. She described neo-liberal ideology as a filter that favored some inputs over others, but did not explore how advocates might adapt their strategic approach in the face of such obstacles.

The model of leveraging for policy change proposed here is consistent with a basic premise of these other models, i.e. that policy, and activities to influence it are value-laden activities. The advocate must be aware of the interests, values and beliefs informing policy; one of the conditions for leveraging, in fact, is an understanding of the values and beliefs of policy decision-makers. The leveraging framework, however, encourages exploration of such factors at the ground-level, so that knowledge gained can inform specific leveraging strategies. The next step in this exploration would be proposing and testing hypotheses around leveraging strategies. For example, the leveraging framework would predict that the more contentious the issue, i.e. the more an issue directly challenges the values of the policy decision-maker, the more leveraging strategies must be employed by the advocate in order to give the issue any lift.

The Power of Relationships

Literature exploring the contribution of relationships to the process of influencing policy has focused on the importance of relationships between policy makers and those outside the policy world. Many have focused on the positive value of relationship building between researchers and policy decision-makers (Feldman, Nadash & Gursen, 2001; Hanney, Gonzalez-Block, Buxton & Kogan, 2002; Lomas, 2000). Others have spoken in sweeping, high-level terms about the importance of a healthy and reciprocal relationship between the voluntary sector and government (Voluntary Sector Task Force, 2001; Voluntary Sector Initiative, 2002a 2002b). There is substantial literature on the influence of coalitions (Sabatier & Jenkins-Smith, 1993; Warleigh, 2000; Zafonte & Sabatier, 2004) and social movements (McCarthy, 1987; McCarthy & Zald, 1977; Minkoff, 1997) on policy change, but the analysis of collective action in this literature focuses on the contribution of structure in consolidating and mobilizing resources, and not the essential power of the relationships within an advocacy community. In the model of leveraging presented in this paper, structure is also important as the machinery behind orchestrated action. What the leveraging model proposed here demands, however, is attention to the quality of relationships between and among organizational advocates in an advocacy community--this was at the heart of advocacy, and fueled the advocacy machine.

Similarly, Stone's (2002) thoughtful discussion of political decision-making frames all policy activities as activities of a community. Social action in Stone's *polis* is enmeshed in a complex web of human relationships characterized by cooperation, competition, loyalty, and a myriad of other influences, and is governed more by the *laws of passion* than the rational laws of matter. The laws of matter (or economics) would dictate vigilance to the efficient use of resources given that they are finite, and gone once used. In an observation that has particular relevance to the discussion here:

> One of these laws is that passion feeds on itself. Like passion, political resources are often enlarged or enhanced through use, rather than diminished. Channels of influence and political connections, for example, grow by being used. The more people work together and help each other, the more committed they become to each other and to their nominal goal (Stone, 2002, p. 30).

Just as the laws of passion suggest that the whole is greater than the sum of its parts (Stone, 2002), the model of leveraging presented here predicts that the concerted action of a committed collective means something more than the aggregate sum of contributions of individual advocates.

Structure and Relationship: Inextricably Linked

There was a natural experiment of sorts underway at the CDA, a structural overhaul that was undertaken to achieve greater efficiency and a higher profile, amid contextual pressures to adopt a more business-like and professional approach to operations (Fyfe et al., 2006; Phillips, 2006; Roberts et al, 2005). With this backdrop of corporatization, it is not surprising that the conceptual distillation of advocacy was found to be a process of 'leveraging', a mechanistic concept that is quite at home in the business literature. Conducting this study at this point in time, however, brought to light a dimension of leveraging beyond the mechanistic, by revealing the implications to a relational dimension when structures are realigned to accommodate corporate governance.

Corporate governance and its underlying neo-liberal belief system have been criticized as inconsistent with non-profit work, largely because of their dissonance with the value system of a civil society that supports the pursuit of a larger social good (Basu, 2004; Murphy, 2005; Roberts et al., 2005). Adherents of neoliberal ideology look to the free market to determine efficiency, and place high value on individual productivity, efficiency and economic competitiveness. In this view, societal welfare is defined as an aggregate of individual choices made to maximize individual self-interest (Fischer, 2003; Stone, 2002). Mechanisms do not exist to account for the contributions of community membership, social cohesion or camaraderie to the welfare of a society (Stone, 2002), or the health of a democracy (Phillips, 2006). In this study, corporate reorganization to a national model required a realignment of structures, and resulted in the dissolution of more local structures, including those connected to advocacy. From the perspective of the advocacy community, however, this did more than realign structures—it eroded infrastructure for relationships in the community and removed points of connection for sharing experience and knowledge. It was in this infrastructure that passion was fueled, and where volunteers were prepared for leadership roles within the community. The quality of relationships and their intrinsic value to advocacy surfaced repeatedly, along with an observation that this value may go unrecognized in an uncompromising emphasis on national advocacy outcomes and “return on investment”.

Undoubtedly, the CDA is an organization in evolution. Barbot’s (2006) study of AIDS advocacy associations in France revealed an ongoing evolution in collective advocacy organizations. “First generation” organizations helped individuals become better illness managers, while “second generation organizations” decried the invisibility that such an approach maintained (Barbot, 2006, p. 542) and pursued a more sophisticated “packaging of organized resistance” (Landzelius, 2006, p.532). Similarly, the CDA has evolved beyond grass roots advocacy and local issues and is seeking a higher national profile. Minkoff (1997) asserted that in order to succeed in their mandates, most advocacy organizations are destined to evolve to more national models of governance. As a direct result of broad system factors such as globalization and the rise of neo-liberalism, it is similarly inevitable that such organizations will continue to evolve along more corporate lines. In terms of the leveraging model, it is logical that an organization would align itself in ways that connected its diverse policy levers to lift a larger issue a greater distance. Participants in this study agreed with this logic—they recognized the inherent necessity of the corporate shift and shared this sense of inevitability. However, the model also predicts that such a shift requires close attention to the relational consequences, and participants believed that the shift had created an imbalance between the relational and the structural dimensions of leveraging.

Conclusions

This study was focused on understanding the process of advocacy from inside one organization. Bounding a study in this way introduces limitations to its theoretical reach. Although the model resonated with participants as verified in follow up interviews, additional work is required to fully develop the model. The role of a community of advocacy in collective social action was a central theme in the study. Theoretic extension could be facilitated by further analysis of the linkages between the model of leveraging and the concept of social capital (Looman, 2005; Putnam, 1995, 2000; Shortt, 2004) as well as some aspects of health social movement theory (Brown & Zavestoski, 2004). Mechanisms to surface and measure the 'intangible' contribution of the relational dimension are certainly required, as is further critical analysis of the role of governance on collective action for policy change. Although further research is required to refine this conceptualization of leveraging, the work adds important new insights, particularly around how successful advocacy hinges upon supporting both the structural and relational dimensions of leveraging for policy change. In the literal sense of "research" as a process of taking another close look, this study rediscovers and emphasizes the wisdom of CDA founder Charles Best, who stated his intention in 1947 to create an organization that would take action to improve the lives of people living with diabetes—an organization that valued and maintained a 'true sense of community' (Chute, 1974, p. 11).

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Table 4.1. Leveraging Strategies

Strategy	Definition	Leverageables
Weighting	Adding weight, mass, volume to the message.	Knowledge/evidence of many types; constituency; credibility/stature with policy makers.
Elevating	Creating the opportunity for a policy maker to be seen doing the right thing, and have an organization of high stature applaud the action publicly. Also involves elevating the message above self-interest, to 'the right thing to do' for all people.	Knowledge/evidence to support the legitimacy of the cause and the related claim on the public interest; credibility/stature of organization; strategic knowledge of the competitive nature of politics
Calibrating	Standardizing the message to be clear, and consistent, and adjusting/aligning its delivery: right message, right messenger, right opportunity.	Strategic knowledge of the policy environment; insider knowledge of how government works; communications expertise.
Making it Real	Projecting 'what an issue really means' in terms of consequences from a particular perspective.	
	Personalizing: projecting consequences of policy decisions on a life as lived.	Deep knowledge of living everyday with the disease; passion
	Translating: projecting consequences in terms that policy makers can readily grasp from their perspective.	Strategic knowledge of government priorities; economic knowledge
Activating	Organizing, empowering and mobilizing others to own an issue and take it forward.	The trust of those you are mobilizing; knowledge/resources to support their efforts.
Agitating	Stirring up public discussion in a way that gets the attention of policy makers; 'creating a buzz'.	Relationships with media sources; amicable but arms-length relationships with more activist groups; strategic knowledge
Reciprocating	Demonstrating common ground with policy makers, that you are a concerned colleague trying to assist in solving a common problem; being part of the solution.	Stature/credibility of the organization; knowledge of the policy process; strong, mutually respectful relationships with policy makers.

Running head: KNOWLEDGE AND ADVOCACY

CHAPTER 5.

Paper # 4 - Knowledge and the new advocacy

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Knowledge and the New Advocacy

> Surely there is no more important way to use knowledge than to use it to help each other—imagine what a world we could create if we always remembered that. (volunteer)

The words of this participant set the stage for this paper, and in many ways set the stage for the question: how is knowledge used in policy advocacy? The focus of this paper is the presentation of findings that address this question, arising from a grounded theory case study of advocacy in the Canadian Diabetes Association.

Introduction

Internationally, voluntary sector organizations have been identified as influential advocates at the policy level, and as important mechanisms for citizen participation in the policy process [1-4]. It is this connection at the place where policy meets the citizenry that is at the heart of the sector's perceived legitimacy in the advocacy role [1-5]. Charitable organizations in particular have been described as essential threads in the fabric of civil society, adding vibrancy and balance to policy debates through their efforts in policy advocacy [6]. Advocacy in the voluntary sector has been defined as "the act of speaking or of disseminating information intended to influence individual behaviour or opinion, corporate conduct or public policy and law" [1, p. 50]. What this definition does not account for is what kinds of knowledge inform these actions, or how knowledge is used to influence policy change. Indeed, the forms and uses of knowledge in policy advocacy have not received a great deal of research attention. Following a brief review of particularly salient literature in this area, we present findings that focus on the forms of knowledge, and specific ways knowledge was used by this organization to influence policy decision-making.

Background: Existing Frameworks

Advocacy Coalition Framework

The first framework to examine the role of knowledge in the process of policy change was the Advocacy Coalition Framework (ACF) [7-9], and it has been used to examine policy change in many policy fields [10-12]. In the ACF policy change results from influencing the values and beliefs of policy makers. According to the framework, policies are founded on deep core beliefs (fundamental values), policy core beliefs (policy positions and strategies to achieve fundamental values) and secondary beliefs (instrumental decisions for policy implementation). The role of knowledge is confined to the contribution of technical information to policy-oriented learning, by influencing the beliefs of policy actors over time via an 'enlightenment' mechanism of action. The framework emphasizes the value of expert, empirical knowledge and the power of dominant, ideologically based coalitions in policy communities. Deep and policy core values are predicted to be resistant to influence, with the most potential for change existing in secondary belief patterns. The ACF has been criticized for its emphasis on top-down change mobilized by policy and knowledge elites, its overly rational approach to policy change, and its reliance on a one-dimensional view of evidence [13-15]. In addition to these criticisms, are the practical difficulties imposed by its portrayal of policy advocacy as an elite activity, essentially beyond the reach of ordinary citizens.

Lomas Framework

Lomas [16] directly challenged the rationality of models like the ACF and outlined policy decision-making as a messy social process, rather than a single event. Although focused on the contribution of research knowledge, informational inputs into the process were envisioned as multiple and inclusive of anecdote, experience, propaganda and "common knowledge" that has become "common" through the activities of the media, advocates and special interest groups [p. 143]. Building on the ACF [7-9], Lomas noted that interacting beliefs, ideology and interests underlie policy positions, with ideology (deep core beliefs) being virtually impossible to change. Interests (secondary beliefs) were the most easily influenced by context and other policy decisions. Beliefs were based upon how a decision-maker thinks the world works, and amenable to change over time in the face of new knowledge. Moving beyond the ACF, Lomas emphasized that policy advocates should not only understand the beliefs of policy makers, but maintain engagement with those in the formal and informal institutional structures for decision-making. The policy context is such that the purveyor of knowledge is always in competition with many other sources of persuasion, and this relational work increases opportunities for influence. Although the observations provide valuable insights into the world of policy making, Lomas' framework offers little understanding about how policy advocacy unfolds as a process at the front lines of advocacy, in response to this 'haphazard' and 'somewhat volatile' world [16, p. 140].

Knowledge Paradigms Framework

Social policy scholar Bryant [13, 14, 17, 18] is one of the few researchers taking a wider view of the contributions of knowledge to policy change. Building upon the work of Sabatier [7-9] Hall [19] Habermas [20] and Park [21], Bryant proposed a framework of policy change [13, 14, 18] that accounted for the contribution of different forms of knowledge to policy advocacy (Figure 5.1). In the framework, civil society is the context for policy change, and the contribution of two distinct politically engaged groups is outlined: professional policy analysts and citizen activists. The former brought specialized authoritative knowledge and credibility to the process, while the latter brought knowledge about personally experienced issues [13, 14]. The framework built on what Bryant dubbed the Habermas-Park typology [13, 14, 18] of instrumental, critical and interactive forms of knowledge [20, 21]. Instrumental knowledge was defined as the empirically derived, objective knowledge of experts. Critical knowledge reflected an understanding of power and its influences, evident as people question social conditions, challenge policies that influence their lives, and choose political action to effect change. Interactive knowledge arose in relationship, in the sharing of experiences between members of a community [13, 14]. Professionals and lay citizens presented different forms of knowledge in different ways to influence the policy process. Bryant's framework [13, 14, 18] spurred theoretical sensitivity [22] to the opportunities to view the contributions of knowledge to policy change in a voluntary sector setting where different actors, with different knowledge, unite in collective action to influence policy. The framework makes a valuable contribution in broadening the conceptualization of policy-relevant knowledge, and gives some examples of ways that different advocates used knowledge in their efforts to influence policy. The framework did leave unanswered questions, however, about how to mobilize that knowledge to craft specific strategies to achieve policy change. Consequently, it was this aspect of the framework that provided the focus for the current study (Figure 5.2).

The Study

The Organization

The CDA is a large organization with a constituency of nearly three million Canadians affected by diabetes. It has a long history of grassroots advocacy and federation-style governance. Decisions about advocacy direction, until recently, were made and implemented by mostly autonomous regional boards with local and regional advocacy volunteers, with the assistance of paid staff. Realignment to a national corporate structure began in 2001, in the belief that a unified constituency with national reach could wield greater influence on public policy. It has resulted in a much smaller, policy-oriented governance board of volunteers, supported by a senior management team. It also resulted in the dissolution of long-standing local volunteer advocacy structures, and a new organizational preference for engaging volunteers on an issue-by-issue basis. Planning for advocacy initiatives is now led by staff, and focused on issues deemed to have national scope. A formal volunteer advocacy structure remains in the form of a National Advocacy Council, although their mandate has shifted from advocacy decision-making to providing advice to the Board through senior staff.

Method

In this study, grounded theory was used to address this research question: how does the CDA use knowledge in its efforts to influence government policy? The theoretic perspective of the method leads the researcher to enter the social world of participants, and defer to their knowledge as expert by virtue of their experience in the social context with the phenomenon of interest [22, 23].

Data Collection Procedures

After gaining ethical approval for the study through the University of Alberta Ethics Review Board, entrée to the organization was achieved through a senior staff member who distributed information about the study and recruited initial participants. As analysis proceeded and theoretical hunches arose, other participants were selected and approached directly by the first author. Over the course of 18 months of experience with the organization, 20 in-depth interviews of 1-2 hours in length were conducted with 8 volunteer advocates and 7 staff involved in advocacy at multiple organizational levels. In order to confirm perceptions and guide theoretical development, five participants (2 volunteers and 3 staff) were interviewed twice. Interviews were audiotaped and transcribed verbatim, and further data were collected through participant observation in three advocacy events involving over 300 participants, the national CDA conference, two full-day meetings of the National Advocacy Council and one meeting of advocacy staff with an external coalition. These activities culminated in over 800 pages of interview data and 200 pages of detailed field notes, supplemented by review of organizational advocacy-related documents.

Analysis

Consistent with the methods of grounded theory [22, 23], data were analyzed concurrently with data collection. Data segments were constantly compared as open coding proceeded, and these substantive codes were then grouped into higher order categories. As comparison with new data proceeded, the properties of these categories were elaborated, refined and sometimes collapsed into even larger conceptual groupings. Higher order, theoretical coding proceeded when incoming data were readily fit into existing categories, and analysis demanded an exploration of the relationships between and among these categories. Finally, a central category was identified and selective coding was undertaken [24] in order to explore the relationships between this category and all the other categories. Theoretical memos and conceptual diagrams were integral to the entire process, and served to document and guide analytic activity and shape follow up discussions with participants [22, 23].

Findings

When structures and processes are in the midst of change, they are at their most visible. When asked about advocacy, participants reflected on its processes and structures as they were experienced before the 2001 organizational restructuring, and compared this to what happened now. Participants observed that what one needed to know to be an advocate in the past was now quite different, and several worried about the continued relevance of what they knew in this new approach to advocacy. One volunteer participant of long tenure reflected on the more local and "hands on" knowledge she brought to the advocacy table, and wondered out loud if that still fit:

> At the last meeting...I was really wondering if the group can tell me where it's going over the next year…do you really want me sitting at this table or not or would somebody else be better placed?...I'm not sure how I fit…now I find that a lot of the advocacy work is more centralized at a staff level so a volunteer role is

> more cursory I think…it's much more efficient…but you know that's just a new reality in the Association, if you want to grow…and attack bigger issues.

It became evident that the structural shift at the CDA provided important context to understanding how knowledge was used in advocacy. Knowledge had always been viewed as a resource in the organization, but in "the new reality", it was clear that different forms of knowledge were used and valued in different ways. Participants observed that knowledge was now valued more in terms of how it promoted a greater strategic return on investment at a higher system level. The different forms of knowledge as outlined by Bryant [13, 14, 18] were evident in this study, but participants observed that the knowledge they brought to advocacy was now received and used differently. Their knowledge was streamed through a strategic cognitive process, a way of knowing employed by those with a view of the 'big picture'. *Strategic knowing* now occupied a place of prominence in policy advocacy at the CDA (see Figure 5.3) and enabled the organization to craft strategies intended to get maximum benefit from the knowledge of advocates. After more fully defining *strategic knowing*, we present the different forms of knowledge evident in this study using the Habermas-Park typology from Bryant's framework [13, 14, 18]. We also discuss how these forms of knowledge are now used as a result of their trajectory through strategic knowing. We conclude with a discussion of how the new context of advocacy has influenced the voluntary sector and encouraged a more national, corporate approach to policy advocacy. We argue that the privileged place of strategic knowing fits with this new approach to advocacy, and has potential implications for how such organizations remain connected to the volunteer base.

Strategic Knowing

Strategic knowing is defined as a cognitive process of continuously evaluating the policy environment for emerging issues, challenges, and opportunities for influence. Strategic knowing also involves the ongoing appraisal of available resources, aligning those resources and using them to maximum strategic effect. This made strategizing possible, and allowed the organizational leadership to maintain a handle on how to quickly mobilize organizational resources:

> but we have to...we have to be watching those constantly...and they all have an impact...I have to be aware of the balls (in the air) and if one's shifting faster than another then we have to be prepared. So part of the challenge becomes keeping a national organization ready to move... and that's a huge challenge...but if we're not watching constantly, we'll just be way out there and we'll miss the boat. (staff participant)

Strategic knowing conferred the ability to 'see' available resources and knowledge and match their leverage potential to the situation at hand. This was a way of knowing that was developed through experience in the world of policy and politics, and was demonstrated by those with a big picture view of all the factors in play, such as senior staff and some members of the Board. This way of knowing enabled one to stand back from the situation, reflect on the strategies most likely to be effective and with whom, and be realistic in assessing the potential for success. One volunteer with experience inside government observed:

> Logistics, be realistic ...you can't just ask for something and say, you know, Catastrophic Drug Plan, no one should pay for drug costs. If you ask for something like that, yeah, maybe you can convince...probably can't even convince the politicians at that point, but when it gets into the civil service it's like, "Well, we can't do that. I mean, we just can't"...so what's realistic? How can we make this work?

An understanding of strategic knowing was shared in unapologetically purposive terms, as a way of thinking that enabled, for example, the "packaging of passion" (staff participant) for maximum effect. This way of thinking facilitated a view of knowledge as a valuable commodity, which fit well with the move to a national corporate culture. It was clear that participants believed it was valuable to stream the knowledge of advocates through the filter of strategic knowing, as this was critical to speaking with one clear voice and to focusing organizational resources on issues of national import. Filters, however, also keep things out of the mix. As explored more fully later in this paper, it became evident that the new emphasis on strategic knowing was creating a perception in many volunteer advocates that their contributions were not as valued or relevant as they once were. This perception was having unintended and potentially corrosive effects on the volunteer base of the organization.

Instrumental Knowledge

Instrumental knowledge is objective, empirically derived and technical, and constituted by theories of causation derived under controlled conditions [21]. The instrumental knowledge of diabetes was brought to advocacy through the voices of educators, researchers and medical practitioners. Instrumental knowledge was apparent as advocates with professional backgrounds in science and medicine shared their perspectives, often bringing awareness of recent medical breakthroughs and ongoing research. This was most evident in advocacy forums and in meetings of the Professional Sections of the organization. Others have noted that this form of knowledge is usually given privileged access to discussions of policy change [13-15, 21]. In the CDA, the value of instrumental knowledge was taken as self-evident, and this had not changed as a result of the new approach to advocacy. Indeed, the structural shift had little impact on the “Sections”; their contributions were of obvious value, both before and after the shift.

> …so I think we lost some people on the volunteer side and you know, I think there was concern that we were losing our grassroots and we were losing our real reason for being because we were…the perception that staff had the ability to drive things more strongly…it didn’t happen as much on the professional side

> because the volunteer contribution on the professional side is so obvious …there'll be change regardless of what the organization structure is but on the lay side it did because it was so community based… (staff participant)

From the perspective of staff, the shift enabled the more targeted and appropriate use of this specialized form of knowledge:

> …we use professional co-chairs that run (the conference) with the staff…they bring…now, these are the topics, this is what we should be talking about, you know, they help position that…so they're feeling a sense that they're bringing their expertise, they're bringing their networks, they're bringing their information to help the Association position itself versus you know… 'I'll buy a ticket, but I don't have time to go out and sell raffle tickets…and that's probably not a good use of my time'.

Instrumental knowledge also bestowed a considerable measure of credibility on advocacy messages. Indeed, a great deal of effort was invested by the organization in maintaining a credible and professional image, an image projected in the balanced tenor of all organizational advocacy documents. Perhaps the clearest example of the use of instrumental knowledge in advocacy was evident in the high profile Diabetes Clinical Practice Guidelines, developed by the CDA in 2003, and currently being revised by an expert panel led by members of the Scientific Section of the organization. These guidelines are widely accepted as the state of the science in diabetes management, and give weight to advocacy efforts to make the medications, health services and supplies noted in the guidelines available and affordable for Canadians living with the disease. In the hands of someone with high levels of strategic knowledge, such instrumental knowledge became even more valuable as a way to credibly translate the consequences of policy decisions into terms a policy maker could readily grasp:

> ...the real answer is we understand, Mr. Premier, or Mr. Prime Minister, that you have all kinds of people that are saying you should spend money on this or that...what we're saying is you should invest money in this in order to reap a pay-off of...you know as...the investment outcome, so its not a spending model...it's an investment model. (volunteer)

One application of strategic knowing to the use of instrumental knowledge was visible in the organization's evolving approach to the "Diabetes Report Cards [25-27] which began in 2001 with a comparative research investigation of diabetes programs and policies across Canada. The first Report Card attempted to objectively grade the progress of the provinces and territories, with results ranging from a B+ to a D [25]. One participant shared her observation of how this information had been received by policy makers:

> ...some provinces just went wild on it. And I mean, they were just not pleased at the grade that was assigned...to the point where they were saying, "We have worked with CDA supporting different projects in the past and now our Deputy Minister is saying you need to be off all those committees right away".
>
> ...you look at a subsequent report card and suddenly some of those areas that were having the problems get nice extra sheets highlighting what they've done...well, I think the squeaky wheel got greased... (volunteer)

Through the lens of strategic knowing, this exemplar demonstrated the influence of an evolving strategic sensitivity in the organization, a sensitivity that framed how knowledge was presented and the implications for highly valued political relationships.

> So it is about gauging what's going on here on the ground, not only with the public, but with the medical community and what they're advocating... and what the mindset of the government is...and where they want to go. So it is about ...that connection. We're now sharing information and we're going to try and

> move something forward. That seems to be the approach ...but there are still some that believe that we need to be out there hammering the government, you know, we need to embarrass the government...our diabetes report will embarrass them into action. It won't embarrass them into action. (staff member)

Critical Knowledge

This form of knowledge comes from reflection and action, and facilitates the deliberation of questions about what is right and just [21]. Park [21] noted that the pursuit of such knowledge has been deemed almost trivial in the new intellectual order. Critical knowledge was brought forth by the voices of both volunteers and staff, and was referred to repeatedly as the underlying passion that fueled advocacy.

> ...it's personal, too...so I think it's a much more natural fit than for me to lobby for better roads or something...it's not my street, you know...okay, I might want to help somebody but I'm not going to be as passionate about it. I'm passionate about it because I live it and I also see it...I see what...you know...how people with diabetes are challenged...(volunteer)

> (I stay involved because) the person with diabetes is first and foremost...helping more people rather than a few is always a priority. I absolutely believe in fighting for the underdog...and doing lots of it. (staff member)

In the new strategic order at the CDA, critical knowledge was something to be harnessed and leveraged for change at the national level. Strategic knowing helped to mobilize critical knowledge for policy change, and informed strategies intended to make the struggle more visible to policy-makers:

> We had about twenty or twenty-five MLAs... and we brought in four people...and they told a story that would make you cry...they couldn't eat, they couldn't feed

> their children, I mean, it was just awful…they had to make a choice, insulin or breakfast, it's insulin, so that certainly got everybody's attention... (volunteer)

In this way, action or inaction on such issues was translated into personal, lived consequences, something that policy makers are often insulated from by layers of bureaucracy.

In the new approach to advocacy, streaming critical knowledge through the filter of strategic knowing produced a more scripted and controlled approach to sharing this type of knowledge with policy makers. Great effort was expended teaching advocates *how we do advocacy here*. Volunteers were given media training and practice in delivering key messages. The new emphasis on the influence of social disparity at the national level led to more education at advocacy forums around, for example, the national picture of how supplies and medications are made available and funded in different provinces. Many observed as the emphasis moved to national issues more removed from the individual-level struggles encountered by people living with diabetes, however, that it was more difficult to keep volunteers engaged,

> …if your volunteers are people who are directly affected by the disease…you cannot…equal their passion, their commitment….they're living it…you need to be able to respect that…that sometimes is difficult when you're asking for something that is very national, countrywide in scope…because that's not really where they're living and breathing. (staff member)

and that something important was being lost:

> … there's always the return on investment, I suppose…but…I think a lot of the smaller items we don't address…or we don't have the resources to address…because we have to look at the big picture, the 'access to medications and supplies' and you know, working on that big issue, and some of the smaller issues that are just…forgotten… that's hard… (staff member)

Interactive knowledge

Interactive knowledge is defined as knowledge that comes of sharing a common "life-world", where people speak and exchange knowledge and actions "against the background of common experience" [21, p.6]. This is knowledge that has relationship at its core. Interactive knowledge was brought forth in this study by the voices of advocates and staff connected around a shared cause. Staff and volunteers alike spoke of how important it was to come together as a community to share knowledge and lived experiences of this disease. They also shared knowledge gained from participation in advocacy, including tips and "best practices" for delivering the message. One volunteer shared this observation:

> Probably the most important thing about advocacy is… to believe what you're doing right to your core and then share that with others…that's a real motivator…

It was in this shared, community endeavor that an advocacy identity was forged and the knowledge of individuals was developed. Here, people were engaged over the longer term, and meaningful commitment to a community goal was cultivated. Interactive knowledge is about community discourse and engagement. Many volunteers of long tenure worried that the new structure of the organization diminished the opportunities for such engagement, observing what they saw as relational consequences to the structural change:

> …the volunteer network needs to be engaged and it seems to me that ultimately what a cohesive structure would allow us to do…is to engage volunteers and provide them with a way of being involved in a meaningful way. And that's where I think there's been a problem with the transition in the volunteer structure of the organization, because a lot of people used to get their empowerment, their engagement, their meaningful participation through involvement in the various

> regional areas and that sort of thing, (and now) they may or may not use volunteers… they need a creative structure to keep volunteers involved.

The dissolution of more local advocacy structures was seen to diminish opportunities for volunteers to share and contribute their considerable knowledge to the organization, and there was a perception that the organization was "losing the conduit to the base of the organization" (staff member).

In the new approach to advocacy, knowledge developed as a result of relationships was more about the strategic and efficient use of volunteer resources than it was about fueling engagement. Relationships developed between the organization and its volunteers, for example, were now structured to be more ad hoc, time-limited and issue-focused.

> …part of the difficulty is that volunteers need to feel valued, they need to feel that they have…an important role to play… and they do play an important role, but it's not always as consistent… and so sometimes they feel like maybe they're not contributing… and certainly on the advocacy front with the champions, it might be once a year they actually get asked to do something…that's very difficult because we're not really engaging them…

Relationships were, however, cultivated and managed strategically over time with policy-makers and external stakeholders to achieve particular objectives. Staff developed knowledge of the values, beliefs, priorities, personal connections to diabetes, preferences and interests of individual policy makers. This knowledge, when viewed from the perspective of strategic knowing, paved the way for advocates to use their resources in a much more precise and informed way, emphasizing those aspects of the message that carried more weight with a particular policy maker. This relational work also helped CDA advocates claim a privileged location 'inside the tent', positioning the organization on common ground with policy-makers as part of the solution to a shared problem. Participants spoke of keeping policy-makers ‘in the loop’ on initiatives, inviting them into success stories, and not surprising or attempting to embarrass policy-makers into action.

Discussion

The findings of this study illustrate that knowledge in many forms plays an important role in policy advocacy at the CDA, and that these different forms of knowledge are used in particular ways when strategic knowing is used as a filter and frame for action. The forms of knowledge identified by Bryant in the Habermas-Park typology [13,14, 18] were visible in this study. They were useful in advocacy by filtering them through a lens of strategic knowing--a way of knowing that has taken precedence since the organizational shift to a national, more corporate structure. This is perhaps not surprising given that the organizational shift was fueled by recognition that the CDA was not influential enough in a national context with competition from many other causes. The new emphasis on strategic knowing in the CDA needs to be understood in relation to the evolving socio-political context of policy advocacy, and the implications of some of the potential tradeoffs made to achieve change in this context.

The New Context of Policy Advocacy

In the new approach to advocacy, instrumental, critical and interactive knowledge constitute valuable capital to be invested in strategies to achieve policy change. That investment is targeted to achieve maximum return by applying strategic knowlege of the policy context—a context increasingly shaped by market-sensitive forces such as the globalization of world economies [28]. Such forces provide the impetus for corporatization in all sectors, although their influence on the voluntary sector is often overlooked [29]. Corporate approaches in the voluntary sector have been introduced in response to demands from government, donors and the general public for a more business-like approach to non-profit work, in the belief that such approaches support greater accountability and transparency [30]. Critics note the potentially negative implications of the neoliberal beliefs underpinning corporate governance for endeavors intended to support a larger social good [29, 31, 32]. Those subscribing to neoliberal views trust the free market to determine efficiency, and seek knowledge that enhances a competitive return on investment. The welfare of the whole is seen as an aggregate of individual choices made to maximize individual self-interest [33-35]. In the current study, this was seen in the efforts to use volunteers more efficiently: there were efforts to 'add up' the impact of individual volunteer efforts within short term, ad hoc engagements and orchestrate these disparate activities to achieve a larger aggregate good. Indeed, the logic is so pervasive in the modern context that it becomes difficult to argue with the efficiency of this approach to leveraging limited resources for maximum gain in a competitive environment. The logic is further confirmed by recent studies showing that in many voluntary sector organizations volunteers are becoming scarcer, and are looking for more time-limited and focused opportunities to contribute [36]. It becomes an empirical question then, about whether the prevalent logic is a good fit for the CDA, or whether there is something fundamentally different about health charities where most of the volunteers are personally connected to the issues.

Many participants in this study sensed that the centre of gravity had shifted, and acknowledged the 'new reality' of a more corporate approach to advocacy. They saw the new deference to strategic knowing as inevitable, and recognized the value of the new professional structures around policy and government relations. Indeed, there was an overall consensus that the organization had been missing opportunities for influence by not having these structures in place. Simultaneously, however, there was a sense of loss expressed by many participants in the advocacy community—loss of connection to one another and to the shared cause. There was a sense that other forms of knowledge previously sought at more individual and local levels was now of less relevance, a sense that was confirmed for many advocates of long tenure as they witnessed the erosion of local advocacy structures and mechanisms. Strategic knowing now resided at the top of the organizational structure, and knowledge of all forms and from all levels had to stream to the top before being infused into the structure to orchestrate action. Many felt that although strategic knowing added real value in the coordination and orchestration of advocacy, the unrelenting application of the strategic filter had created a troubling distance between those at the base of the organization and those at the top. There was a perception that the organization was running the risk of alienating the very people that were the essence of their legitimacy in policy advocacy—those at ground level, who lived at the place where policy meets life with diabetes.

Conclusion

The findings of this study deepen the understanding of the contributions of different forms of knowledge to the process of policy change. While most literature in this area focuses on the contributions of research knowledge to the process, the findings of this study suggest important roles for different forms of knowledge. The study reveals a prevalent view of critical, instrumental and interactive knowledge as valuable commodities, made possible through the use of strategic knowing. Engaging in strategic knowing means looking for the tangible, seeking deliverables, and seeing the greatest value in knowledge as capital. It is a way of knowing that is at home in a more market-oriented worldview. Like all worldviews, however, it has a blind spot. There are no mechanisms in such a worldview to account for the contributions of community membership, social cohesion or camaraderie to the welfare of a society [35], the health of a democracy [4, 5] or the relational fabric of an advocacy organization.

The role of the voluntary sector in civil society has long been valued for its emphasis on connecting citizens to one another, and adding the lay knowledge and voice of the community to the policy process [37, 38]. The findings of this study illustrate that the value of knowledge in policy advocacy extends beyond how it is 'brokered' [39], 'leveraged' [40] or otherwise 'exploited' for policy innovation [41]. In an increasingly corporatized context, it is important to be reminded that knowledge as social process arising in human interaction is valuable in its own right, and important in creating and maintaining communities that advocate for a just society.

The advocacy work to be done at the CDA is important work, and how knowledge is used in that work is deserving of the close attention it has been paid here. How knowledge is used in this organization to influence policy and to what effect remains an empirical question, but the findings of this study suggest that how knowledge is used communicates what is valued. Recalling the words that began this study, knowledge used in particular ways creates a chosen world. The man who spoke them died a few months later at age 47 from the complications of type one diabetes. Choosing to use our combined knowledge to benefit others, is perhaps the finest definition of advocacy that could be crafted.

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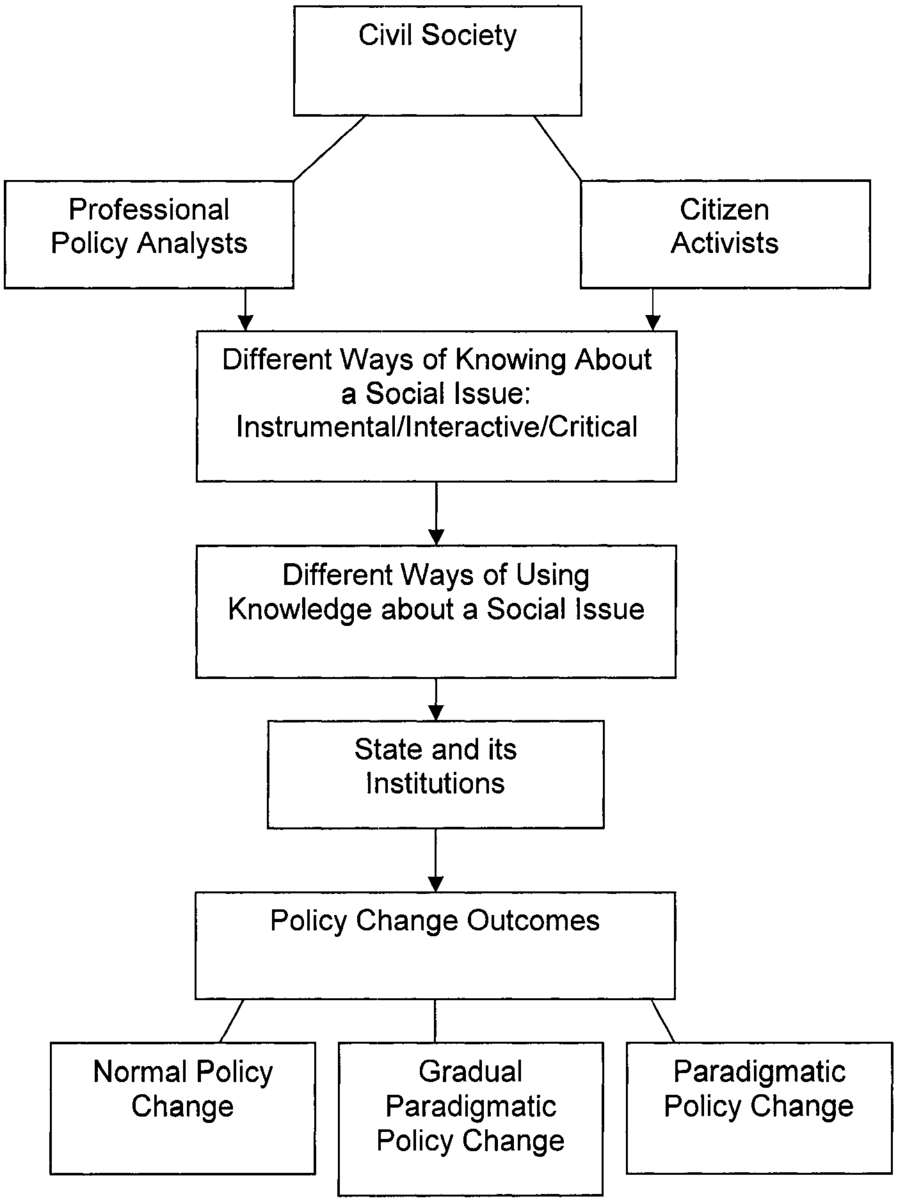

Figure 5.1. Knowledge paradigms framework

Note. From *The social welfare policy change process: civil society actors and the role of knowledge,* by T. Bryant, 2001. Unpublished doctoral thesis, Faculty of Social Work, University of Toronto, Ontario, p. 31.

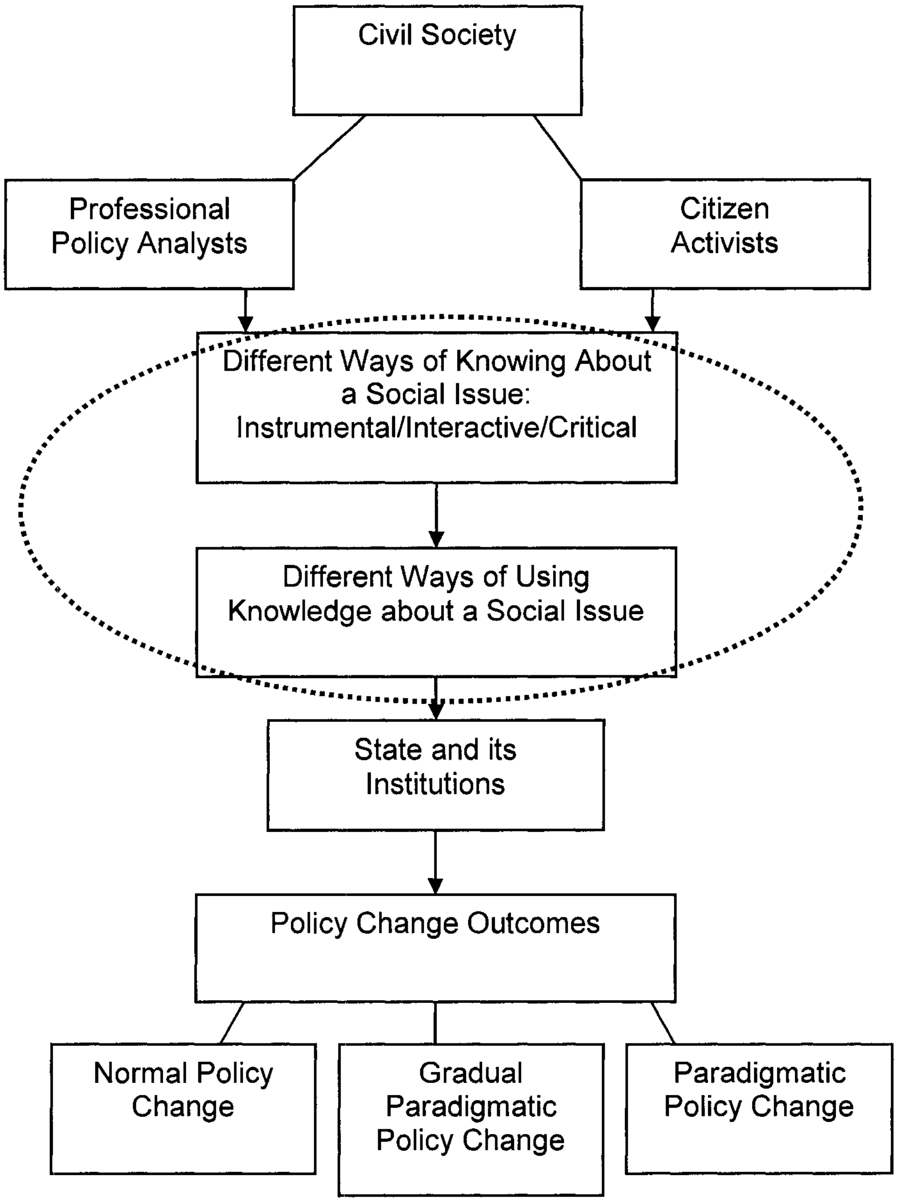

Figure 5.2. Focusing on how knowledge is used: The knowledge paradigms framework.

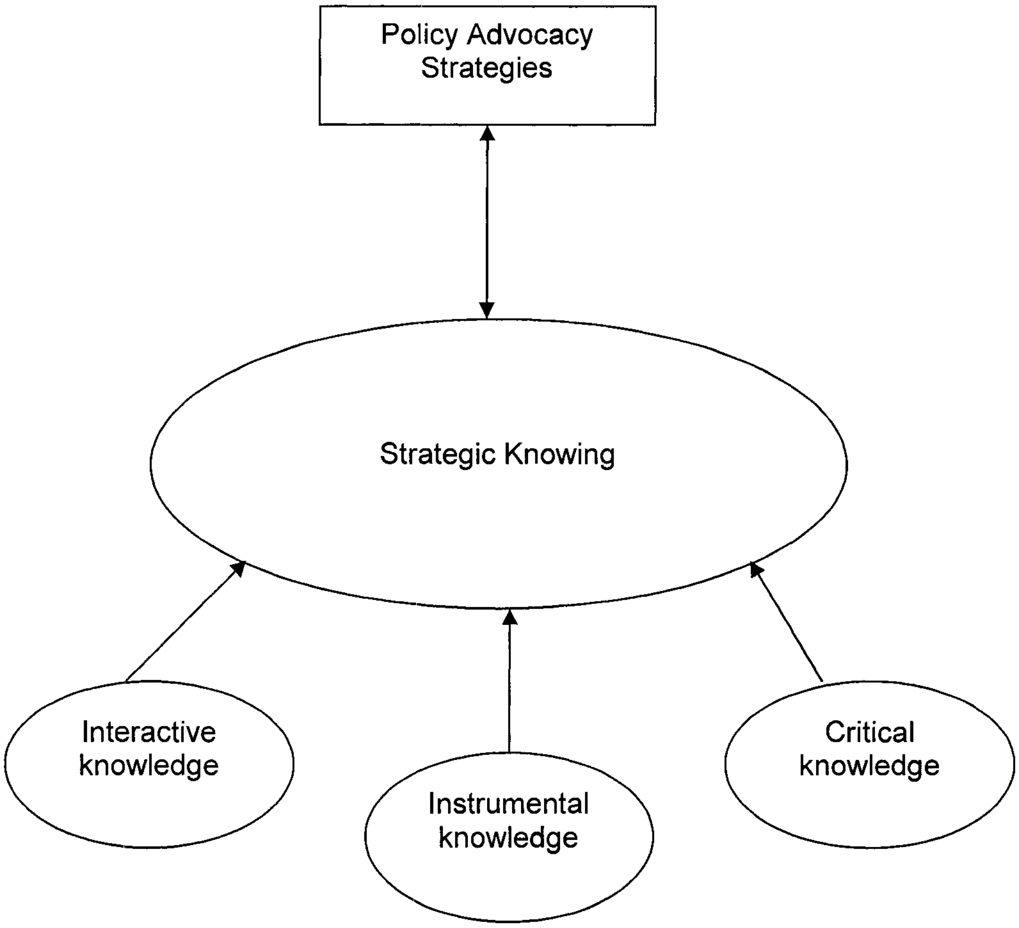

Figure 5.3. Strategic knowing and policy change.

CHAPTER 6. General Discussion and Conclusions

Nurses have a valuable contribution to make to health policy, largely because of the work we undertake in partnership with our clients—in this case, with people living and self-caring with a chronic disease. This leads me back to the overall question guiding this dissertation: how can nurses effectively advocate for policy change that supports self-care in people living with a chronic disease?

The question frames the contribution of this cumulative work in three areas of inquiry:

- policy support for self-care in chronic disease
- advocacy at the policy level in nursing
- processes of policy advocacy in the context of chronic disease

Following a summary of the work conducted in these three areas, the contributions of this dissertation to the broader literature on policy advocacy, as well as to the knowledge base of nursing will be presented.

Policy, Self-care and Chronic Disease

Policies are crafted by governments in order to guide action on problems. The selection and definition of what constitutes the problem meriting the action, however, often rests on pervasive and unchallenged assumptions. As I approached the study of policy advocacy in the context of chronic disease, I chose to focus on one chronic disease and surface some of the pervasive assumptions underlying how self-care in is understood in the literature, and how it is framed at the level of health policy. In the case of diabetes, the prevalent assumptions reinforce beliefs at the policy level that self-care is mainly about the health care system, that diabetes is a disease of life-style choice, and that the most problematic barriers to self-care lie in individual non-compliance with medical advice, not in policy. In Canada, these beliefs and a backdrop of provincial jurisdiction for health care have resulted in a patchwork of marginal and inconsistent support for only the most basic requirements for diabetes self-care. The review in Chapter 2 crystallized my thinking about the 'what' of policy advocacy, the substantive contribution that nurses could potentially make to health policy that is more responsive to the needs of people trying to live well with diabetes. Advocacy at the policy level requires nurses to be able to 'see' the policy roots of issues encountered in practice, and to be able to challenge the prevalent assumptions influencing practice and health policy. Nurses are at the front lines witnessing the struggles encountered by those trying to live well with diabetes in the current policy context. In partnership with those living with the illness, I concluded that 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 the evolution and progression of diabetes self-care.

Policy Advocacy in Nursing

The next step in building knowledge about policy advocacy in nursing was to explore what was already known, and what factors were getting in the way of knowing more. In doing the work for Chapter 3, I discovered that there were many gaps in nursing knowledge of policy advocacy. Most of the existing knowledge focused at the individual client level, and was founded on assumptions that individual level advocacy was logically linked to advocacy at the policy level—the activity only differed in degree. I found there had been little inquiry into policy advocacy, although barriers to achieving (Faulk & Ternus, 2004; Miller & Russel, 1992; Rains-Warner, 2000; Rains-Warner & Barton-Kriese, 2001) and exercising (Boswell, 2005; Cramer, 2002; DiGaudio, 1993; MacDonald & Schoenfeld, 2003; McAllister, 1997) political competence had received some empirical attention. I noted factors within the discipline, in the practice context and most notably at the interface between the world of nursing practice and the policy arena that had acted as barriers to our discipline's development and participation in policy advocacy. I argued that moving forward required asking different questions and pursuing different perspectives on policy advocacy, and concluded that there was much to be learned from literature outside nursing, and inquiry in settings where policy discourse and advocacy were well understood.

Policy Advocacy in the Context of Chronic Disease

Studying with the Canadian Diabetes Association was a privilege, and provided a view from the perspective of advocates who are expert at influencing the policy process. As an organization responding to the changing demands of an evolving voluntary sector and seeking a higher national profile, the CDA had recently undergone a significant structural shift to a more national, corporate model of governance. Studying the organization at this time of structural change made processes more visible to me and to the participants as they reflected on how advocacy used to occur, and how it had changed. This perspective allowed me to view a process of *leveraging* for policy change, as explored in Chapter 4. Leveraging was found to be a social process of using available resources to try and influence decision-making in a desired direction. In the CDA, the leveraging process began inside the organization and moved outward to the interface with government decision-makers. A structural dimension to the process allowed the organization to harness, align and target available resources at key points in the decision-making process in order to influence decisions in a desired direction. I was to discover the equivalent importance of a relational dimension to leveraging in nurturing an advocacy community, and how leveraging for policy change depended upon a unified community connected and mobilized through a cohesive structure.

A closer examination of the role of knowledge in the process of leveraging is presented as Chapter 5. I discovered that instrumental knowledge (from empirical, scientific inquiry), critical knowledge (arising from critiquing power and its influences, questioning unjust social conditions, and choosing political action to effect change) and interactive knowledge (from living and sharing experiences in a community) (Bryant, 2001, 2003; Park, 1993) played important roles in policy advocacy in the CDA. These different forms of knowledge were used in different ways since the structural shift, as a result of filtering these forms of knowledge through a process of strategic knowing. Strategic knowing was defined as a cognitive process of continuously evaluating the policy environment for emerging issues and opportunities for influence, and appraising available resources in order to align and use them to maximum strategic effect. This was a way of knowing engaged in by those at the top of the organizational structure who could see the 'big picture'; knowledge of all forms and from all levels had to stream to the top before being infused into the structure to orchestrate action. Many felt that strategic knowing was essential to framing, coordinating and orchestrating organizational advocacy efforts. There was also a sense, however, that other forms of knowledge previously sought at more individual and local levels were left out of the frame, and of less relevance and value. There was concern expressed by participants that such a perception could have potentially disintegrating implications for the volunteer advocacy base of the organization.

Contributions to the Policy Advocacy Literature

This work makes a valuable contribution to the broader literature on policy advocacy in two main areas: a) by providing a perspective from the 'front lines' of policy advocacy, and b) by making explicit the importance of cohesive structure and community relationships in policy advocacy.

Perspective

The model of leveraging for policy change proposed here is consistent with a basic premise of other models in the literature (Lomas, 2000; Sabatier & Jenkins-Smith, 1993; Schon & Rein, 1994) that policy, and activities to influence it are value-laden activities. One of the conditions for leveraging, in fact, was an understanding of the values and beliefs of decision-makers. In contrast with much of the literature on influencing policy, however, this study took a ground-level perspective on the process. I explored how resources were combined and used in specific strategies, fine-tuned based on knowledge of the context and values and beliefs of decision-makers, and then aimed at particular points in the decision-making process. Many have criticized existing models of policy change for being top-down, and limited to the activities of policy elites (Bryant, 2001, 2004; Fischer, 2003). The contribution of the bottom-up perspective of this model is in the possibilities it creates for ordinary citizens to contemplate and participate in processes of policy change.

Structure and Relationships

Literature exploring the contribution of relationships or structure to the process of influencing policy has mostly focused on the strategic importance of relationships in creating opportunities for influence (Feldman, Nadash & Gursen, 2001; Hanney, Gonzalez-Block, Buxton & Kogan, 2002; Lomas, 2000), or in creating structures that facilitate the consolidation of resources (McCarthy, 1987; McCarthy & Zald, 1977; Minkoff, 1997). In the model of leveraging presented here structure and relationships are also important. Structure is the machinery that aligns resources behind orchestrated action, and paves the way for advocacy by strategically cultivating relationships and learning what 'buttons to push' with particular policy makers. What the leveraging model proposed here contributes, however, is an understanding of the essential power of relationships between and among organizational advocates in an advocacy community.

The relational dimension of leveraging is, like social action in Stone's (2002) *polis*, governed more by the *laws of passion* than the rational laws of matter or economics. And just as the laws of passion tell us that the whole is greater than the sum of its parts, the model of leveraging contributes an understanding that the concerted action of a committed community means something more than the aggregate sum of contributions of individual advocates.

Contributions to Nursing

The main contributions of this work to nursing knowledge and practice relate to the role of knowledge in policy advocacy, and the concept of community in advocating for policy change.

The Role of Knowledge

Perhaps the most seminal work around types of knowledge in the nursing literature resides in Carper's (1978) typology of knowledge, including aesthetic (the art of nursing), empirical (the science of nursing), ethical (the morality of nursing) and personal knowledge gained through reciprocity in the "I-thou encounter" (p. 18). In White's (1995) thoughtful review and critique of Carper's work, she used the 1998 work of Jacobs-Kramer and Chinn (cited in White, 1995) to examine and extend the dimensions of Carper's typology. These dimensions were focused on how the particular knowledge was created, expressed and identified (through a critical question), as well as in what context or process it was revealed and judged in terms of its credibility. It was her assessment that the original typology focused nurses so much at the level of the individual relationship between patient and nurse, that it limited the possibilities around using knowledge for policy level change. Her response was to add 'sociopolitical knowing', a concept she also explored in terms of its dimensions (Table 6.1). She suggested sociopolitical knowing as foundational to nursing participation in policy planning and decision-making, although a review of the dimensions of this form of knowing left me with unanswered questions about how to use sociopolitical knowing to mobilize nursing knowledge to effect policy change (Table 6.1).

In the current study I went beyond the nursing literature to learn from the policy and social sciences (Bryant, 2001, 2002, 2003, 2004; Fischer, 1993, 2003; Lomas, 2000; Sabatier, 1987, 1999; Sabatier & Jenkins-Smith, 1993; Schön & Rein, 1994; Stone, 2002). This informed my exploration of the role of knowledge in policy advocacy, and revealed the contributions of critical, interactive and instrumental knowledge in this context. This knowledge typology (Bryant, 2001, 2004; Park 1993) also addressed the gap in Carper's framework that was identified by White (1995), and the dimensions of sociopolitical knowing (Table 6.1) are consistent with the contribution of critical knowledge outlined here. A central contribution of the current work lies in the concept of strategic knowing as a mobilizing frame for policy advocacy. Strategic knowing allows one to take a step back, and view what is available to in the current context in terms of its capacity for leveraging change. When viewed through White's (1995) dimensional lens, it becomes clear that strategic knowing is 'terra incognita' from a nursing perspective (see Table 6.2). As nurses, we can more easily accept being strategic and purposive in advocacy at the individual level, subverting rules (Hutchinson, 1990) or playing 'the game' to get what patients need (Stein, 1968; Stein, Watts & Howell, 1990). We are, however, quite unfamiliar with and lack confidence in such maneuvering at the policy level. Some have suggested that a political agenda around disease or the determinants of health is a poor fit for nursing, and best left to those in the political sciences (Pilkington & Mitchell, 2003). It is true that strategic knowing is not unique to the nursing discipline any more than interactive, instrumental or critical knowledge are, unless turned to the study of nursing phenomena. However, as a frame for action informed by critical, interactive and instrumental knowledge, strategic knowing may assist nurses in effecting change that furthers the goals of the profession with regards to health, or what Grace (1998, 2001) referred to as ‘professional advocacy’.

The other finding of significance to nursing is around advocacy as a social process pursued in community. Successful advocacy in this study was contingent upon having an engaged community of advocates committed to a shared purpose, supported by a structure that facilitated ongoing connection and reciprocal relationships. Those who do examine nursing collectivity in advocacy most commonly iterate the ‘power in numbers’ notion of collective action (Abood, 2007; Artz, 2006) that is consistent with the ‘weighting’ strategy articulated in the study. Grace’s (1998, 2001) philosophic analysis of advocacy is one of the few treatments of the concept that coherently broadens its scope to the policy level. She briefly addressed the notion of collective action by all professions committed to health as important and appropriate, and as a responsibility within nursing when obstacles arise to fulfilling the profession’s promise to further health. Collectivity as social fuel for advocacy, however, is missing from existing nursing conceptualizations of advocacy.

Others have noted and I would concur that factors in the professional evolution of nursing have ruptured our connections to our shared history and to each other. Nelson and Gordon (2004) noted how the profession’s incessant search for social and scientific legitimacy has effectively led us to continually reinvent the profession, turning our backs on the more traditional conceptualizations that have connected us historically, traditions that we once shared as a nursing community. This is echoed by Falk-Rafael (2005) who reminded us of our historical legacy as policy advocates, a legacy in decline as we fail to pass it along to new practitioners of the profession. This study suggests that we as nurses must ask how to sustain and nurture a modern ‘community of nursing’. There may be an important role here for professional associations, particularly as related to the structural dimensions of the proposed model. Those that discuss the role of professional associations in advocacy, however, more often emphasize the notion of collectivity as strength and leverage (Rains-Warner, 2003; Rieger & Moore, 2002), rather than any notion of community. Further, it has been observed that nursing involvement in professional associations is low and consistently declining (Cramer, 2002). It must also be asked, is a 'community of nursing' even seen as relevant in the current age of interdisciplinary health reform? Is there value in reestablishing such a community, or is there a need to reconstitute a community of health care professionals and others around health issues rather than disciplinary lines?

This study suggests that voluntary sector organizations such as the Canadian Diabetes Association can provide valuable opportunities to join an advocacy community, and also provide access to the 'machinery' of advocacy required to target efforts at the policy level. The nurse brings critical, interactive and instrumental knowledge of nursing phenomena to the advocacy table of such organizations, and can learn to integrate that knowledge with the knowledge of others and maximize the capacity for leverage by engaging in strategic knowing with experienced policy advocates. The lesson in this study for all policy advocates, however, is this: relationships in an advocacy community fuel collective action and sustain commitment. This is different than time-limited coalition building around individual issues (Clark et al., 2006); this is a community of policy practice (Wenger, 1998) where advocacy experiences, stories and knowledge are shared, legacies of action are sustained, policy discourse about health is welcomed, and 'batteries are recharged'.

I look forward to continuing work on the model of leveraging, extending the study of the concepts into other advocacy settings and encouraging discussion among nurses of the developing model. To start, I anticipate further publication of findings from the case study that space did not permit. For example, findings illustrated four degrees of leveraging that varied based upon the nature of the relationships between the advocate and others, and the depth of knowledge brought to bear on the process. For example, “naïve leveraging” was engaged in by advocates who had little connection to the advocacy structure or community; it consisted of individual, “one-off”, ad-hoc advocacy efforts like signing petitions, writing letters or participating in “advocacy-on-line” and sending electronic messages to policy-makers. This was leverage by the masses, inferring the sheer number of votes connected to a particular issue. There was little knowledge shared or preparation involved, the process was one-way with the advocate simply delivering a message within a particular frame. These individual efforts were aggregated by others and used to weight advocacy messages. I would argue that this level of participation in policy advocacy is the one most familiar to nurses, and one that does not bring the value of our shared knowledge to bear. I look forward to sharing such findings with the goal of precipitating a nursing dialogue about our “community of policy practice” and its role in helping us achieve what the public expects of us: to lead health policy change in the future (Villeneuve &MacDonald, 2006).

Concluding Thoughts

I conclude with a response to those genuinely curious and well-meaning nurses who have asked what this study has to do with the caring profession of nursing. Are leveraging and strategic knowledge at odds with the caring traditions of nursing, even ignoble and vaguely distasteful? These are the questions that cause me to ponder the ruptured connection to our advocacy roots. I would challenge that true ignobility lies in complacency, or worse, in the blind trust that others are better suited to influence the policy decisions that shape the system in which we practice, and within which our clients receive care. Further knowledge development in the area of policy advocacy is a priority for our profession. It is what we do with this knowledge, however, that is of ultimate significance.

I think one's feelings waste themselves in words; they ought all to be distilled into actions which bring results. (Florence Nightingale as cited in Woodham-Smith, 1951).

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Table 6.1. The Dimensions of Sociopolitical Knowing

Dimension	Characteristics
Creative	Exposing and exploring alternate constructions of reality
Expressive	Transformation Critique
Assessment: critical question	Whose voice is heard? Whose voice is silenced?
Process-context	Critique and hearing all voices
Credibility index	Shared governance, enlightenment Movement toward equity

Note. From “Patterns of Knowing: Review, Critique and Update,” by J. White, 1995, *Advances in Nursing Science, 17*(4), p. 83.

Table 6.2. The Dimensions of Strategic Knowing

Dimension	Characteristics
Creative	Engaging in policy discourse Participating in policy advocacy
Expressive	Through orchestrated collective action; leveraging strategies.
Assessment: critical question	What do I have, and what do I need to build a convincing case for change in this context? How and when is the best time to deploy?
Process-context	Leveraging; getting the maximum lift in the current context
Credibility index	Legitimacy in policy context