



*Candace, not
OC evidence
Wait times are long
long wait times are bad.*

Affidavit #1 of Janet Walker
Sworn October 4, 2012
No. S090663
Vancouver Registry

IN THE SUPREME COURT OF BRITISH COLUMBIA

BETWEEN:

**CAMBIE SURGERIES CORPORATION, CHRIS CHIAVATTI by his litigation guardian
RITA CHIAVATTI, MANDY MARTENS, KRYSTIANA CORRADO by her litigation
guardian ANTONIO CORRADO and ERMA KRAHN.**

PLAINTIFFS

AND:

**MEDICAL SERVICES COMMISSION OF BRITISH COLUMBIA, MINISTER OF
HEALTH SERVICES OF BRITISH COLUMBIA AND ATTORNEY GENERAL OF
BRITISH COLUMBIA**

DEFENDANTS

AND:

SPECIALIST REFERRAL CLINIC (VANCOUVER) INC.

DEFENDANTS BY COUNTERCLAIM

**DR. DUNCAN ETCHES, DR. ROBERT WOOLARD, DR. GLYN TOWNSON, THOMAS
MCGREGOR, THE BRITISH COLUMBIA FRIENDS OF MEDICARE SOCIETY,
CANADIAN DOCTORS FOR MEDICARE, MARIËL SCHOOFF, DAPHNE LANG,
JOYCE HAMER, MYRNA ALLISON, and CAROL WELCH**

INTERVENORS

AFFIDAVIT #1 OF MS. JANET WALKER

I, Janet Walker, Adjunct Professor of Nursing, of 830 Braeside Street, West Vancouver, MAKE OATH AND SOLEMNLY AFFIRM THAT:

1. For more than thirty years I have been, and continue to be, a registered nurse in the province of British Columbia. Further, I have conducted research on access to health care issues in Canada. As such, I have personal knowledge of the information stated herein, except where stated to be on information and belief, in which case I believe it to be true.
2. I make this affidavit in support of Cambie Surgeries Corporation's (herein referred to as "CSC") and Specialist Referral Clinic's ("SRC") opposition to the injunction sought by the Medical Services Commission (the "Commission") to prohibit CSC and SRC from providing medical services in contravention of certain provisions of the *Medicare Protection Act* (the "Act") (specifically sections 17(1) and 18(3), which relate to billing practices for benefits under the *Act*) prior to a ruling on the constitutionality of these provisions. I understand that if the injunction is granted, it will prevent patients in British Columbia from seeking medical care at SRC and CSC, even when faced with unreasonable wait times in the public health care system.
3. As I explain below, I believe that if the residents of British Columbia are not able to pay a facility fee for surgeries at CSC or obtain timely medical assessments at SRC, just as residents, for example, of Alberta can lawfully do, it will have a negative impact on the ability of the residents of British Columbia to access timely health care.

My Professional Qualifications

4. I completed a Bachelors of Nursing at the University of British Columbia in 1980. Following this, in 1990, I completed a Masters of Nursing at the University of British Columbia.
5. Since 1991, I have held the appointment of adjunct professor, School of Nursing,

University of British Columbia where I designed and taught both undergraduate and graduate courses on leadership and management. I continue to hold this appointment.

6. I have been an invited author-contributor to two Canadian nursing texts.
7. I am a member of the learned nursing society, Sigma Theta Tau International Honor Society of Nursing.
8. My recent clinical background is in oncology nursing at the BC Cancer Agency from 1988 to 1997 where I held positions of management and provincial nursing chair (pro-tem).
9. I have conducted, authored, presented and/or published a number of academic and research papers.
10. Prior to 1980, I worked as a staff nurse and charge nurse in a variety of acute care areas including medical-surgical, neurology, and intensive care.
11. As I move to full retirement, I continue to teach on an invited basis. Most recently, I have been teaching at Vancouver Community College (2010-2012).
12. Through my professional practice and research experiences, I have direct knowledge of the pain and suffering that the unreasonable wait times for medically necessary services in British Columbia causes patients.

Research on wait times for medically necessary care in Canada

13. I have conducted qualitative research regarding the experiences of Canadians waiting for medical care in the public health care system.

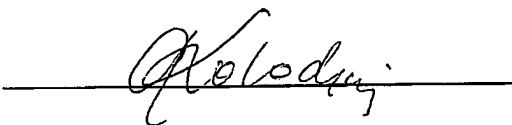
14. In particular, from 2005 to 2008 I interviewed fifty Canadians who endured unreasonable wait times for medically necessary care in the public healthcare system. The results of that research were published in September 2009 in the nursing journal *Canadian Nurse* ("*Canadian Nurse*"), as a peer reviewed journal article titled "*Waiting in Line for Health Care*". *Canadian Nurse* has been published by The Canadian Nurses Association since 1905. Attached as Exhibit "A" to this affidavit is a copy of "*Waiting in Line for Health Care*" as published in the September 2009 edition of *Canadian Nurse*.
15. "*Waiting in Line for Health Care*" studied the experiences, opinions and advice of fifty Canadian participants who faced long wait times for medically necessary care in the public system and included the following observations and conclusions:
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BCP
- a. The participants in my study commonly reported an 18-month wait for diagnostics or a specialist consult, and a further 18 month wait for the medically necessary 'elective' surgery or procedure.
 - b. All of the participants described a feeling that their life was on hold while waiting for care. During these lengthy waiting periods, patients not only felt that they could not lead normal lives, but that their life had 'literally stopped dead'. This was startling to me, as while most Canadians acknowledge that there are significant wait times for medical care, it is assumed that those waiting carry on with their normal life in the interim. This is not the case.
 - c. The participants reported suffering severe and prolonged pain and significant distress while waiting for the care that otherwise would have immediately relieved the medical issues, especially the pain. However, as the patients were unable to obtain timely care in Canada, they continued to suffer unnecessarily.
 - d. The participants often found no relief from pain, despite using medications, or did not like who they became while on these powerful narcotics, so stopped taking the medications in spite of reporting pain levels of 7, 8 or 9 out of 10. Research

participants reported getting addicted to pain medications while they were waiting for care. It was my conclusion that a direct and frequent outcome of waiting for medical care was that patients were getting addicted instead of getting healed.

- e. The number one reason that participants chose private care was because of the pain. They reported that they literally could no longer wait.
- f. The unmanageable and chronic pain suffered by patients while waiting resulted in depression and despair. Many participants discussed this experience. More than a few openly discussed or alluded to thoughts of suicide.
- g. While pain and resulting depression and/or despair were experienced personally, participants spoke at length about the negative impacts on their families. They identified the family's distress to see a loved one in pain and be unable to help. Participants reported feeling like a burden on the family and suffering guilt for the significant stress on family relationships.
- h. Ultimately, forty-four of the fifty participants in the study left their communities or Canada to obtain the medical care they required from the private sector (16% sought and received care in the Canadian private sector, 50% in the United States, 20% in India and 2% in Europe).
- i. The self-reported financial circumstances of study participants ranged from very modest to comfortable. Considering the stated occupations and life circumstances of the participants, they were with rare exceptions "ordinary Canadians". For those participants who sought private healthcare abroad, some of them had to rely on financial assistance from family and friends. Despite any measures taken (financial, personal, travel), the participants were unanimously emphatic that the cost of the private care was "worth it". They reported that, "You are literally buying your life back".

16. I have also provided evidence in another legal proceeding on the effect of wait times for medically necessary services on Canadian patients. In particular, I provided an affidavit that was filed in respect of legal proceedings commenced in Ontario (*McCreith and Holmes v. The Attorney General for the Province of Ontario*, Court File No. 07-CV-339454PD3) (the "Ontario Affidavit"). Attached as Exhibit "B" to this affidavit is a copy of the Ontario Affidavit, which was sworn October 3, 2011.
17. In addition to discussing my study "*Waiting in Line for Health Care*", the Ontario Affidavit also provides my review of the scientific health care literature with respect to the issue of waiting. Included are the devastating consequences of lengthy waiting lists for patients requiring medical services. As outlined in the Ontario Affidavit, these consequences include extreme physical pain, significant disruption of the lives of patients, and profound psychological distress, for both the patients and their families.
18. If the injunction is granted against CSC and/or SRC, patients who are not preferred beneficiaries will not be permitted to obtain their required medical services from CSC or SRC. In addition to compounding and further overburdening the public sector wait lists and therefore harming patients generally, the patients who would otherwise seek timely medical treatment at CSC or SRC will certainly be harmed by this unnecessary and extensive wait for care in the public health care system. In particular, these patients will be at serious risk for profound and prolonged physical and psychological pain, and will undoubtedly experience personal and familial agony and disruption.

AFFIRMED BEFORE ME at the City of)
Vancouver, in the Province of British)
Columbia, this 4 day of October, 2012)

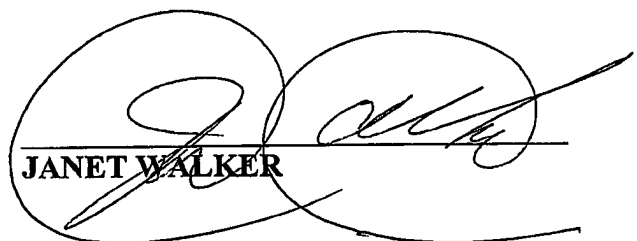


A Commissioner for taking affidavits
in the Province of British Columbia

Ania Kolodziej

HBdocs - 13343207v13

Exp. August 31 2014


JANET WALKER

This is Exhibit "A" referred to in the
Affidavit of Janet Walker
sworn (or affirmed) before me on
10/04/2012

SEPTEMBER 2009 • PEER-REVIEWED FEATURE

Ania Kolodziej
A commissioner for taking Affidavits for
British Columbia

Ania Kolodziej
Exp. August 31 2014



ABSTRACT

In Canada, lack of timely access to medically necessary health care has become well known. Some patients wait in line. Others decide to find their own solutions. Wait-lists represent distress for patients and moral distress for health-care professionals, who feel a shared responsibility for what our health-care system provides. In spite of renewed commitments by the federal government to reduce wait times, little progress has been achieved (Health Council of Canada, 2008). The author outlines a descriptive study in which she documented the experiences, opinions and advice of Canadians who endured long waits for medically necessary care. Forty-four of the 50 study participants ultimately left their communities or Canada itself to obtain medical care. The author calls attention to the value of listening to health-care consumers and promotes collective advocacy on the part of the health-care professions.

A few years ago, I learned some patients' stories that were extremely upsetting to me. None of these people could access the care they needed because of long waits. All eventually found their way to the U.S., where they were successfully treated. I felt responsible for the state of the health-care system I worked in and was part of. I realized that what I was experiencing was moral distress, where one knows what is ethically required (in this case, greater access to care), but is powerless to bring it about. What I decided I *could* do, however, was to describe and document the issue through the experience of patients.

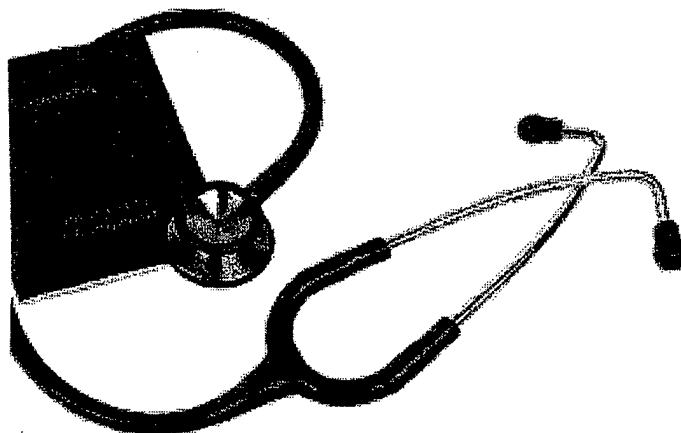
Waiting in Line for Health Care

The evidence of patient access problems is all around us. We read about it in the newspaper, with headlines like "Welcome to Hospital Hell" (Braid, 2009), and view websites devoted to wait times in our home province or territory.

In the literature on patient access, the focus has been on the numbers: estimates of the number of people waiting, estimates of the length of wait times, and discussion of the various methods used to arrive at such estimates (Sanmartin et al., 2000). The Canadian Institute for Health Information used figures from a 2005 Statistics Canada survey to report that 66 per cent of all Canadians who had had elective surgery reported "long wait times as a barrier to access" (2008). This percentage represents the 132,000 Canadians who experienced long waits.

Wait-lists cause patients distress. And when patients are distressed, nurses are distressed. Nurses have a shared responsibility to make the health-care system they work in effective. When the system as a whole is unequal to patient needs, the result can be moral distress for nurses (Heesters, 2009).

The literature offers only a few studies that describe patients' experiences of waiting. One study explored parents' attitudes toward wait times for non-urgent operations for their children; most families waited more than six months. Ninety-four per cent described the wait as emotionally stressful for the entire family (Miller, 2004). In another study, 70 patients waiting for coronary bypass surgery were interviewed for their thoughts and feelings. Results illustrated an experience that was characterized by uncertainty, pain and anxiety (Fitzsimons, Parahoo, & Stringer, 2000). A third study focused on emergency room visits (Wellstood, Wilson, & Eyles, 2005). The majority of patients described their experience negatively with wait times as a principal reason. Finally, in a multi-national examination of patient reports, Schoen et al. stated that "Canadian patients stood out for long emergency room waiting times" (2005).



The value and importance of the consumer perspective to any enterprise is well known. In health care, their involvement is considered essential for the development of effective public policy (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). Analysts conclude that in Canadian health care, consumerism represents a key driver of change (The Change Foundation, 2005). Yet we know little about the consumer or patient perspective regarding access to medically necessary care. Exploring the issue of significant wait times from the patients' perspective can lead to consumer-driven quality improvements, promote new approaches to health-care access and alleviate some of the ethical pressures.

The purpose of my study was to examine and document the experiences of those who are unable to access care. Three questions guided my work:

1. What are the experiences of Canadians who are unable to access medically necessary health care in a timely fashion?
2. What are the experiences of those who choose to find their own health-care solutions?
3. What advice do they have for others waiting for health care and for our health-care planners?

Participants were recruited through referrals from colleagues in my professional networks, from invitations on my website and from snowballing, where those taking part in the study approached others who had similar experiences. Eligibility criteria included the use of English, the language of the researcher. Attempts were made to encourage participation from all parts of the country. I discussed eligibility and informed consent with each prospective participant. Ethical approval for the study was received from Institutional Review Board Services.

METHOD AND SAMPLE

I chose the qualitative method to capture lived experience. I developed a semi-structured interview consisting of 20 questions and conducted the interviews by phone or face to face. Interviews were conducted between 2005 and 2008. Quantitative methods were employed to capture demographics as well as any results best expressed with numbers. Interview data were analyzed using phenomenology (Giorgi, 1985). I studied the transcribed interviews in detail to become immersed in the phenomenon as seen through the eyes of the participants. Then, all salient elements of the reported experience were abstracted. Finally, these elements were iteratively tested against the original data to confirm their accuracy and to develop a coherent

Waiting in Line for Health Care

understanding of the phenomenon.

In qualitative research, the sample size is determined by saturation, or the point where repetition of the information convinces the researcher of its validity (Speziale, 2007). In this study, I determined saturation with 40 participants. I then added a further 10 for purposes of confirmation and validation. These individuals hailed from many parts of the country: 55 per cent (27) from British Columbia, 24 per cent (13) from Ontario and the remaining 20 per cent (10) from Alberta, Saskatchewan or the Maritimes. Sixty per cent were women. The youngest person was a toddler of three; the oldest, 91. The median age was 52 years.

Participants' medical needs fell into the following four groups: joint problems (32%); spine and disc problems (32%); a combination of other conditions and the need for a first or second opinion (20%); and cancer (15%).

RESULTS

My analysis generated a rich volume of information that revealed a number of themes. In this article, I present the major themes, which relate to the experience of waiting and leaving and to the advice participants offered.

"A life on hold..." Participants commonly reported wait times of 18 months for diagnostics or consults and a further 18 months before surgery or treatment was scheduled.

Waiting filled participants with apprehension. Trying to find out when medical appointments and treatments were scheduled and if they were going to go ahead brought anxiety and intensified the level of uncertainty. Answering machines took the calls participants made to medical offices. Those calls were rarely returned.

"I finally wrote a letter and, about a month later, I got a reply saying that there were 900 people ahead of me and that they are only allowed two surgeries a week. He said that it could be another two and a half years. He added that I was free to seek help elsewhere."

Waiting in Line for Health Care

"My referral to a neurosurgeon was three years ago. It still hasn't come up."

"They told me, 'Don't call here anymore!' It was impossible to get hold of a doctor."

Participants also reported that they could not live normal lives. Much had to be put on hold. An electrician couldn't carry his tools. A bed and breakfast owner could not get up the stairs to clean guest rooms. A wilderness officer could no longer manage outdoor terrain. Parents couldn't play with their children.

"My grandbabies would put up their hands to me, and I would have to say, 'Oh, honey, I can't pick you up.' It killed me."

When the diagnosis was life threatening, anxiety increased. One man, who had been diagnosed with borderline aggressive prostate cancer, was told that consults and treatment were still several weeks away: "They said that the wait time was 'acceptable.' Well, it wasn't acceptable to me. Those cancer cells were growing inside *my* body."

The dark world of pain. Ninety per cent of those who left the wait lines did so because of pain. Many used the phrase, "I couldn't wait." They reported severe and prolonged pain — the kind that had to be managed, often not successfully, with powerful narcotics like morphine. Pain drugs were found to be crude medicines, and no one liked taking them. Relief was variable, and many participants said that the drugs changed who they were. Several people stopped taking any pain medications, in spite of pain levels of 8 or 9 out of 10. The kind of pain reported arose from treatable conditions. That is, once the condition is treated, pain is no longer present.

"The pain was so bad that every morning I woke up with murder in my heart."

"The pills [morphine] didn't work all of the time and when they did work, she was more or less someplace else."

Pain took away the appetite for life and ruined relationships. The link between pain and despair arose frequently in interviews. Several people described how at one point they could no longer continue to endure the pain and had contemplated ending their lives. Some implied intentions of suicide; others talked openly about it.

"My partner had as much pain as I did. I could see it in his eyes."

"I tried to fight off depression, but I see now that depression and chronic pain go hand in hand."

"I had not been able to play with my kids. It just crushed me. That's hard on its own. It's been hard on my family."

Mandy, a 30-something mom of school kids, has been waiting for an appointment at a pain clinic for more than two years. Her children want to know when she is going to get better.

"Buying your life back" Nearly 90 per cent of the participants chose to find a health-care solution in the private sector. Some found it in Canada (16%). Most (50%) went to the U.S. Twenty per cent went to India, and another two per cent chose countries in Europe. People used their computers, their medical networks and their family resources to involve themselves in find-it-yourself health care. Once they finally received the care they needed, they found relief and reclaimed their lives.

"I was told that I had to accept being compromised. Now I am back at work and running two miles a day!"

"I had 137 biopsy tests during my surgery, and I saw all of the reports the very next day."

"I am getting around the isolation that I used to impose on myself because I felt so bad and couldn't do anything."

"It was wonderful. You are literally buying your life back."

The costs of private care ranged from a few hundred dollars for a second opinion or a diagnostic test to \$60,000 for a series of life-saving cancer surgeries. Participants described their financial circumstances in terms that ranged from "extremely modest" to "comfortable." Asked if the private care was "worth it," the responses were enthusiastic and positive. The notion of value for money was captured in this comment: "It was either a new truck or a new hip. The choice was easy." However, not all those who had sought care elsewhere were in favour of private care. One man told me that he was saddened to have to leave home. He did not want see a change to a private system in Canada.

PRACTICAL WISDOM

Participants were invited to share what they had learned from their experiences. Specifically, I asked them what advice they had for other Canadians who are waiting for health care and for those who manage the health-care system.

They expressed concern for others in similar circumstances and had words of encouragement for them. Participants wanted their neighbours to be able to get care if they needed it. One young woman said: "My son is special to me, but he is no more special than the son of the woman next door." The need to be proactive and confident of a positive outcome was a common refrain:

"Take responsibility for your own health care. If you don't, no one else will."

Waiting in Line for Health Care

"Do your research and go. It's worth it."

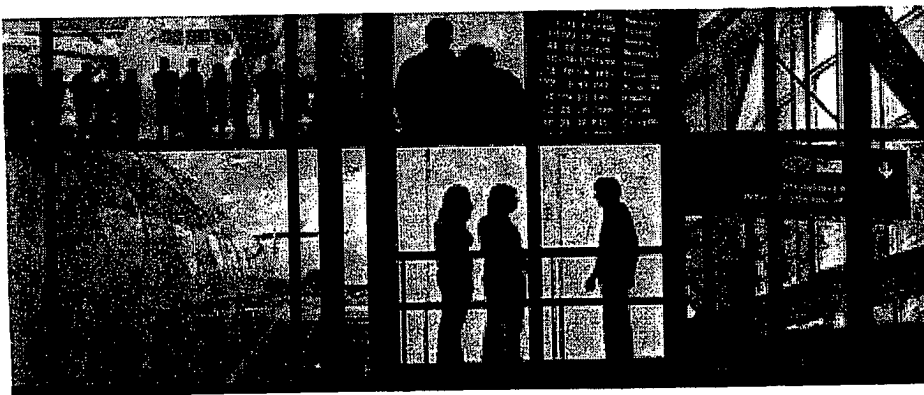
"Know that there is more than just the Canadian system available. I was blown away by discovering what was out there."

Participants spoke with empathy about the seemingly impossible task of providing care in the face of current realities in the health system and anticipated future needs. They encouraged health-care planners to listen to patients more carefully and be open to other possibilities:

"People should not have to live in pain."

"Find a way to keep the population healthy."

"While you are fixing the system, allow private care to help. I am all for paying for those who can't afford it."



DISCUSSION

In keeping with the principles of qualitative inquiry, my findings are intended solely to bring greater understanding to a particular phenomenon. As such, they are not statistically

generalizable.

This study represents an early exploration of patients' experiences of having to wait in line for health care. Findings show that when patients are unable to access timely care, they endure significant pain, anxiety and suffering.

In the face of such distress, health-care providers can feel overwhelmed by patient advocacy responsibilities. My own feelings of moral distress have not diminished, but I am heartened by the shared concerns of colleagues. In fact, Welchman and Griener (2005) contend that advocacy related to patient access is best carried out not by the individual nurse, but by professional nursing organizations, where, collectively, nurses can discuss and address the ethical fallout.

I am further encouraged by the actions of my nursing colleagues. For example, a recent CNA document includes examples of nurse-led initiatives across Canada that are reducing wait times (2009).

The participants in this study provided practical wisdom and guidance for others. In simple and eloquent words, they encourage patients, providers and planners to be open to new possibilities and to new and different ways of doing things. We can harness the power of this consumerism by continuing to invite patients to share their ideas for better patient care. In fact, such a dialogue could be the beginning of a grand and ongoing exchange on all aspects of health care. The outcomes will benefit patients waiting for care and treatment and provide new perspectives on fixing a system that is ailing.

JANET WALKER, RN, MSN, IS A COMMUNITY RESEARCHER AND AN ADJUNCT PROFESSOR OF NURSING, UNIVERSITY OF BRITISH COLUMBIA, VANCOUVER, BRITISH COLUMBIA.

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Waiting in Line for Health Care

Social Science & Medicine, 61
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Court File No. 07-CV-339454PD3

is Exhibit "B" referred to in the
Affidavit of Janet Walker
sworn (or affirmed) before me on
10/04/2012

ONTARIO
SUPERIOR COURT OF JUSTICE

BETWEEN:

LINDSAY MCCREITH and SHONA HOLMES

Ania Kolodzie
Commissioner for taking Affidavits for
Columbia
Exp. August 31, 2012
Applicants

- and -

THE ATTORNEY GENERAL FOR THE PROVINCE OF ONTARIO

Respondent

APPLICATION UNDER Rule 14.05(3)(g.1) of the Rules of Civil Procedure

AFFIDAVIT OF PROFESSOR JANET H. WALKER

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**ONTARIO
SUPERIOR COURT OF JUSTICE**

BETWEEN:

LINDSAY MCCREITH and SHONA HOLMES

Applicants

- and -

THE ATTORNEY GENERAL FOR THE PROVINCE OF ONTARIO

Respondent

APPLICATION UNDER Rule 14.05(3)(g.1) of the Rules of Civil Procedure

AFFIDAVIT OF PROFESSOR JANET H. WALKER

I, JANET H. WALKER of the City of West Vancouver in the Province of British Columbia, Professor of Nursing, **MAKE OATH AND SAY:**

I. MY BACKGROUND & QUALIFICATIONS

1. I have been a duly licensed nursing practitioner in the province of British Columbia for more than 30 years. My clinical background is in acute healthcare, most recently in roles of manager and administrator within a tertiary cancer centre.
2. For the past 20 years I have also been an adjunct professor of nursing at the University of British Columbia where I have designed and taught various undergraduate and graduate courses. Currently, I teach leadership and management in the School of Nursing.

3. I have contributed to two textbooks on nursing management. I have authored, presented and published a number of academic and research papers. I continue to conduct research.

4. In addition, I am a member of the learned society, Sigma Theta Tau International Honor Society of Nursing.

5. The full particulars of my education, work experience and publications are set out in my Curriculum Vitae, attached to this affidavit as **Exhibit "A"**.

II. EXECUTIVE SUMMARY

6. This affidavit sets out my findings on the experiences that ill or injured Canadians encounter when they are unable to access medically necessary healthcare in a timely manner. I designed and conducted my own study to describe and document this phenomenon in a scientific manner. The result was published as a peer-reviewed feature entitled "Waiting in Line" in the journal Canadian Nurse, volume 105, number seven, September, 2009, a copy of which is attached as **Exhibit "B"**. I also reviewed the existing scientific literature describing the extent and nature of waiting list problems. The list of publications referred to is attached as **Exhibit "C"**. In the text of this affidavit, I refer to each article by the author's name(s) and the year of publication. I have provided the Applicants' solicitors with a copy of each article, which can be produced upon request.

7. Based on the research of myself and others, the experiences commonly reported by such patients include: (a) extreme physical pain, (b) significant disruption of their lives, and (c) profound psychological distress, both for themselves and for their families.

8. My study also examined the experiences of those patients who opted to seek medically necessary healthcare in the private sector after having experienced the aforementioned stressors. Surprisingly, not a single participant in the survey reported a negative experience with private healthcare. All were enthusiastically positive and described

the cost as "worth it", whether their financial circumstances were extremely modest or comfortable.

III. MY INSTRUCTIONS

9. In preparing this report, I was initially asked to respond to two questions, as follows:
 - (a) What are the experiences commonly reported by individuals who have been required to wait for medical services in a single-payer healthcare system?
 - (b) What are the experiences commonly reported by individuals who have accessed medical services outside of the single-payer healthcare system in their place of residence by obtaining medical services in another jurisdiction?
10. After my initial response, I was asked to answer the following four additional questions:
 - (c) Please incorporate a more detailed discussion of other research, investigations or opinions regarding the issues in question and the reasons for your opinion within any range of opinion that exists.
 - (d) Please draw on your personal experience as a health care practitioner, professor and administrator in formulating your opinion. Does your personal experience confirm your survey findings?
 - (e) With respect to the experiences of those who sought private healthcare in another jurisdiction, do you have any opinion with respect to potential hardship arising from the necessity of travelling and planning for same as opposed to being able to access medical services locally? As well, do you have any opinion with respect to the experiences of individuals, particularly those of modest means, who are required to leave their jurisdiction repeatedly?

- (f) Do you have any information regarding how long individuals tend to wait or how much suffering, etc., individuals are willing to endure before deciding to travel to another jurisdiction?

IV. METHODOLOGY

11. Participants in my study were recruited in several ways. Some came through referrals from other healthcare professionals, both doctors and nurses. Some were found by a "snowball" effect in which existing study participants referred acquaintances whom they knew to have had similar experiences. Some volunteered through my website FindingHealthCare.ca, where the link "Share Your Story" contains a detailed description of the study and invites visitors to contact me if they wish to participate.
12. Eligibility included Canadian adults who were English speaking and who were waiting or had waited in the past for medically necessary care in the public system.
13. Ultimately, 50 eligible participants were interviewed using a standard semi-structured questionnaire, a copy of which is attached as **Exhibit "D"**. Data were gathered between 2005 and 2008. Participants were from various parts of Canada. Approximately half (55%) were from British Columbia, 24 % from Ontario with the remainder from Alberta, Saskatchewan and the Maritimes. All 50 participants were either waiting for care when interviewed, or had previously had the experience of waiting. Forty-four of the 50 participants ultimately chose to leave the waiting lines to find care in the private sector.
14. The data were analyzed using the qualitative method of descriptive phenomenology (Giorgi, 1985). Qualitative research utilizes an inductive process to yield an understanding of the essential features within a particular phenomenon. This method is especially effective in examining the phenomenon of the lived experience.

V. QUESTION ONE: PATIENTS' EXPERIENCES WHILE WAITING

What are the experiences commonly reported by individuals who have been required to wait for medical services in a single-payer healthcare system?

15. Based on my research, the experiences commonly reported by individuals who have been required to wait for medically necessary healthcare include major physical pain, significant life disruption and profound personal and family stress.

(a) PHYSICAL PAIN

16. It is difficult to satisfactorily communicate the depth and breadth of pain described in the accounts of participants. Months or even years after the event, people would become emotional as they recalled their pain and the related issues such as depression and despair. For instance:

- A young man suffering prolonged pain reported "when you are on so many pain killers and in that much pain, you don't think clearly. I couldn't aggressively go after treatment because I was too out of it".
- An avid hiker in her 60s said, "I had absolutely no way to get out of this dilemma. I was in so much pain. I did a lot of crying".
- One woman spent over \$12,000 in her home to try and reduce her bone-on-bone hip pain while she was waiting. She purchased a special bed hoping to reduce the pain and be able to sleep. She had carpets removed and hardwood floors laid so that the walker that she needed before surgery would not catch on the carpet and cause extreme pain.

17. People frequently reported that visits to their physician often ended with yet another prescription for pain medication. The main reason was that the required investigative test or treatment was not yet available.

18. One in five of those suffering prolonged pain reported feeling "abandoned, written off as needing psychological help or being treated as a drug seeker". With the exception of one person, all of these people have had their conditions successfully treated and the pain has disappeared. The person who was still in pain at the end of the study was still waiting for a fuller investigation and an appointment at a pain clinic. She reports that she has become addicted to the analgesic Tylenol #3.

19. Based on this account and others, it would appear that one little-noted consequence of the healthcare system is that it sometimes results in patients becoming addicted before or instead of becoming healed.

(b) LIFE DISRUPTION

20. Individuals waiting for medically necessary care report that they have their lives stopped. They talk in terms of "not being able to have my life; wanting my life back". Life became literally suspended: "We couldn't make any plans because we didn't know when they would phone with a date for my surgery. We waited for two years and then gave up".

21. Employed people sometimes had to stop working, and reported the attendant difficulties that they experienced.

22. The following are some specific examples of life or career disruption:

- Degenerative hip pain meant that one woman needed a custom-measured, raised toilet seat. She thus became restricted to her own house: "Go out and have to use a bathroom? Forget it! You can't get up off the doggone toilet".
- A teenager who was a prospect for professional baseball suffered a knee injury that would not have been treated within the public healthcare system for "18 months to two years". According to the family, "his future career depended on getting immediate treatment" (which he ultimately did, in the private sector).

- One man was in the last few years of his career. Unable to continue working due to knee problems and unable to access treatment, his employer was forced to put him on disability leave. In such circumstances, neither the employee nor the employer can make contributions to the pension plan. This continued for more than a year. As a result, the man's monthly retirement pension was reduced.

23. Many participants reported that hobbies and leisure activities had to be abandoned. For instance:

- A competitive water skier could not ski.
- A motorcyclist could not ride.
- A father could not play with his pre-school children.
- A dancer could no longer dance.

24. For some participants, going anywhere in a crowd meant possibly being bumped and then having to suffer excruciating pain.

(c) PSYCHOLOGICAL DISTRESS

24. Personal and family stress was a constant theme among people waiting for care. The cause appeared to be directly related to the experience of waiting: the loss of one's normal life, pain if it was present and anxiety over an uncertain future and state of health. People commonly reported various levels of despair:

- "I can't move without pain and I can't accept waiting – it's like a brick wall".
- "I just don't think I can live like this".
- "My mother knows how much pain I am in. I promised her I wouldn't do anything. I hope I can keep my promise".
- "I didn't feel good. I couldn't do anything. I took it out on my spouse".

VI. QUESTION TWO: ACCESSING PRIVATE SECTOR SERVICES

What are the experiences commonly reported by individuals who have accessed medical services outside of the single-payer healthcare system in their place of residence by obtaining medical services in another jurisdiction?

26. Forty-four of the 50 participants sought out and obtained their medically necessary care in the private sector. Some went quickly due to the urgent nature of the problem such as the diagnosis of cancer. Others left the wait lines when they could no longer tolerate the pain. Some waited two to three years before they gave up waiting. Destinations for private care included Canada, United States, India and Europe.

27. The experiences commonly reported by those who accessed medical services outside of the single-payer healthcare system were unanimously positive. The two most frequently expressed sentiments were relief and joy. Every person said that faced with the same situation again, he or she would make the same choice. When asked for their advice to other waiting Canadians, they urged them to go.

28. Respondents were not merely positive about their experiences, they were enthusiastically positive. There were no lukewarm responses. Representative comments were:

- I would do it again in a minute.
- They were so good to us – to me and my husband.
- So superior to Canada that it was pathetic.
- The biggest thing I got was peace of mind.
- First class. Doesn't compare. It's like being on another planet.
- They care about you.
- So uplifting. Nothing left untouched.

29. I also asked participants about the cost of private care and whether they could afford it. Costs ranged from a few hundred dollars for a second opinion to over sixty thousand dollars for a series of cancer surgeries. Each and every person reported that the cost was "worth it."

30. Participants described their financial circumstances in terms that ranged from "extremely modest" to "comfortable". Most people appeared to be average Canadians as measured by their work and life situation. A short representative list includes:

- Civil servant, retired
- Homemaker
- Warehouse worker
- Small business owner
- Teacher, retired
- Pipefitter, retired
- Wilderness officer
- Auto plant worker
- Fast food worker

31. Common wisdom has it that only the rich or wealthy seek out and pay for private care. This study clearly shows the contrary to be true.

VII. QUESTION THREE: OTHER RESEARCHERS' RESULTS

Please incorporate a more detailed discussion of other research, investigations or opinions regarding the issues in question and the reasons for your opinion within any range of opinion that exists.

(a) BACKGROUND

32. Patient waiting lists were first recorded in 1982 by the Ontario Medical Association (O'Keefe, 1982). The association wished to (i) document concerns it had been hearing about the time it was taking to schedule surgeries; (ii) establish a benchmark for future reference;

and (iii) compare public perceptions with reality. It therefore mailed surveys to members of seven surgical specialties. Results revealed the average wait times from surgical consultation to surgery. For arthroplasty (a surgical reconstruction or replacement of a joint), the wait was 7.4 weeks. The study also concluded that the public's perception regarding wait times was accurate.

33. Over the intervening 28 years, wait times have steadily increased. By 2009, the median wait time for orthopedic surgery from specialist appointment to surgery ranged from a low of 11.8 weeks in Ontario to a high of 44.8 weeks in Nova Scotia (Fraser Institute, 2009). This wait must be considered a conservative measurement as it does not include the waiting period between the referral by the family physician and the specialist consultation.

34. Patient reports about waiting have only recently begun to appear in the literature. They emerge in a variety of ways, usually paired with another variable being explored. For example, waiting times have been examined for acceptability both from the perspective of the patient and from the perspective of the healthcare provider. Other studies look at the relationship between waiting and clinical outcomes, particularly for specific procedures or conditions. Another relationship of interest is that between waiting and patient symptoms and health related quality of life (HRQoL). Finally and rarely, waiting is studied as a single variable focusing on the patient's lived experience with waiting, its story and meaning.

(b) WAITING AS UNMET NEED

35. One measure of patient waiting can be seen through related and overlapping concepts. One such concept is that of unmet healthcare needs. Researchers looking at possible changes in unmet needs over time reported that the needs are increasing. The percentage of people reporting unmet needs increased from four percent in 1994-95 to six percent in 1998-99 and then doubled to 12% in 2000-2001 (Sanmartin, Houle, Tremblay and Berthelot, 2002).

36. The Canadian Institute for Health Information (CIHI) recently reported that 13% of Canadians who required routine or ongoing care and 21% of those requiring immediate care experienced difficulty obtaining it (CIHI, 2009).

37. In a newly published study (Sibley and Glazier, 2010), researchers examined national data from the Canadian Community Health Survey conducted in 2003. The sample included 111,258 respondents aged 20 or older, representing 69.5% of the Canadian population or some 22.6 million people. The authors reported that 11.7% of the sample group reported unmet healthcare needs in the previous 12 months. The most common reasons for unmet need were due to lack of healthcare availability, with the largest components being "waiting time was too long" (35.6 %); "service not available when required" (16.5%); and "service not available in area" (11%).

(c) WAITING AND ACCEPTABILITY

38. What constitutes a reasonable wait, and from whose perspective? The following studies offer empirical data from both patients and healthcare providers. Boisjoly et al. studied patients undergoing cataract surgery in a Quebec hospital at two different times: 1999-2000 and 2006-2007. Patients were interviewed both before and after their surgery about the acceptability of their waiting time, and the occurrence of accidents or falls. As well, patients were assessed for visual acuity, health status and HRQoL. Findings revealed that 16% of patients in the 1999-2000 group (whose mean wait time was 6 months) reported their wait as "not at all acceptable." By 2006, the mean wait time had been reduced to 4.1 months. Patients in the second group found the waits significantly more tolerable with only 4% indicating a view of "not at all acceptable". Researchers also reported that waiting 6 months or more was associated with more adverse outcomes including falls, accidents, motor vehicle accidents, a reduced quality of life including documented depression. (Boisjoly et al., 2010).

39. Connor-Spady, Johnston, Sanmartin, McGurran and Noseworthy examined patients' perspectives on acceptable waiting times for hip or knee replacement surgery. Mailed

surveys were received from 303 patients who had their arthroplasties performed in Saskatchewan. Researchers reported that "The median waiting time from the decision date to surgery was 17 weeks. Individuals who rated their waiting time very acceptable (48%) had a median waiting time of 13 weeks, compared with a median waiting time of 22 weeks for those who rated it unacceptable (23%). The two most common determinants of acceptability were patient expectations and pain and its impact on patient quality of life." The investigators concluded that "patient views on waiting times are related not only to quality of life issues, but also to prior expectations and notions of fairness and priority". (Connor-Spady et al., 2007).

40. Acceptability studies are also used by healthcare providers to assist with providing appropriate benchmarks for waiting. For example, in a review of 24 studies, Canadian pain specialists provided these results:

Patients experience a significant deterioration in health related quality of life and psychological well being while waiting for treatment for chronic pain during the six months from the time of referral to treatment. It is unknown at what point this deterioration begins as results from the 14 trials involving wait times of 10 weeks or less yielded mixed results with wait times amounting to a little as 5 weeks, associated with deterioration. It was concluded that wait times for chronic pain treatment of six months or longer are medically unacceptable. (Lynch et al., 2008, page 106).

(d) WAITING AND SYMPTOMS

41. Waiting makes a difference because of the relationship between patient wait, patient symptoms, and their possible progression. The following studies shed some light on this relationship. Nearly a thousand patients from six cities across Canada completed a questionnaire about waiting. They did so when they arrived for their consultation with a gastroenterology specialist. Findings revealed that during the waits that ranged from a few weeks to more than a year, 20% reported being very worried about having a serious disease,

with 17.6% and 14.8% respectively reporting that their symptoms caused major impairment of social functioning and with activities of daily living (Paterson et al., 2007).

42. In a study of urban and rural patients having had a total hip or knee replacement, researchers asked them how long they had waited for surgery and the effect of the wait on their health. Charts were examined to determine actual waits. Waiting times for both groups showed that 56% of all patients had to wait longer than nine months. Thirty-eight percent of rural patients and 56% of urban patients believed that their surgical wait contributed to "a lot" or "a moderate amount" of deterioration in their health (Snider, MacDonald and Pototschnik, 2005).

43. Oudoff, Timmermans, Knol, Bijnen and van der Wal studied 176 patients in 27 Dutch hospitals. Patients had waited for and had surgery for one of three conditions: varicose veins, hernia or gallstones. Investigators found that during the wait, each group suffered increased levels of pain and impaired mobility. (Oudoff et al., 2007).

44. Finally, in a study of 153 Quebec patients scheduled for knee replacement surgery, it was found that the longer the wait before surgery, the greater the negative consequences: more pain, poorer function and reduced HRQoL (Desmeules, Dionee, Beizile, Bourbonnais and Fremont 2010). Similar results are reported in a study of 127 Canadian patients waiting for hip revision surgery. Waiting more than six months resulted in significant increases in pain and physical disability (Davis et al., 2008).

(e) WAITING AND CLINICAL OUTCOMES

45. Do long wait times produce inferior clinical outcomes? The relationship is not definitively established in the literature. This is probably due in part to the relatively small number of studies that have been conducted so far on this topic, confounding issues such as how waits are measured, methodological issues, different procedures and the definition and selection of outcome measures that are selected for study. For example, waiting for a hernia repair may have very different effects than waiting for a cataract repair or a knee

replacement. How should outcome measures be defined? Should pain, mobility and HRQoL always be considered outcomes irrespective of the procedure?

46. Arthroplasty or joint repair has the longest wait lines in Canada (Zelder in Garbuz, Xu, Duncan, Masri and Sobolev, 2006). The following studies considered arthroplasty and outcomes. They were all prospective in nature. Further, all of them included the use of the Western Ontario McMaster (WOMAC) Osteoarthritis Index in determining outcomes. WOMAC is a self administered multidimensional index containing dimensions for pain, stiffness and function (Garbuz et al., 2006).

47. Mahon et al. (2002) examined 99 people waiting for total hip arthroplasty (THA) for health-related quality of life (HRQoL) and mobility at the point of referral by the general practitioner and every 3-6 months until at least 3 months after surgery. Results included:

- At referral, patients with short waits (< 6 months) had poorer HRQoL and were less mobile than those with long waits (> 6 months).
- Throughout the wait, anxiety increased among all groups
- The length of wait for elective THA is not correlated with postoperative HRQoL and mobility. However, patients who undergo the procedure within 6 months after referral have greater disability at referral, and realize greater gains in HRQoL and mobility after surgery than patients waiting more than 6 months.
- Clinically important losses in HRQoL and mobility occur in patients waiting more than 6 months.

48. Garbuz et al. (2006) hypothesized that longer waiting times were detrimental to achieving the full benefit of surgery. They followed 147 patients requiring primary THA from the time of the surgical consultation to one year after surgery. The results included:

- Longer waiting times are detrimental to achieving full benefit on functional outcome of surgery

- Waiting longer than 6 months results in a 50% decrease in the odds of achieving a better-than-expected outcome compared with those who waited less than 6 months
- Each additional month spent waiting was associated with an 8% decrease in the odds of a better-than-expected functional outcome
- Waiting longer did not impair the probability of achieving a better than expected pain or stiffness outcome.

49. Davis et al. (2008) examined patient disability in relation to candidates waiting for a revision of a THA. One hundred and twenty-seven patients were followed from the time of the surgical consult to surgery. The investigators reported that "Wait times > 6 months for revision of hip arthroplasty resulted in significant pain and physical disability". (p. 92)

50. Finally, Desmeules et al. (2010) focused on those patients waiting for a knee replacement. They examined 153 patients from the time of surgical consult to surgery. Investigators measured changes in pain and function related to the affected knee; changes in HRQoL; and changes in the contralateral knee (the good knee). They reported that "pre-surgery wait time has a negative significant impact on pain, function and HRQoL at the time of surgery" (p. 946). And in some further commentary, these researchers stated:

"We did retrospectively find that the mean wait between the physician's referral and the initial orthopedic consult was 89 days. Therefore, we believe the total combined wait time could result in a worse deterioration of patients." (p. 953)

51. Cataract surgery is another procedure for which Canadians commonly wait. Hodge et al. wanted to understand the relation between wait time for cataract surgery and patient outcomes and the variables that modify this relation. They conducted a systematic review of 27 empirical studies involving cataract surgery. They found that patients who waited 6 weeks or less had better outcomes than those who waited 6 months or more. These latter patients experienced more vision loss, a reduced HRQoL and an increased rate of falls. The outcomes for patients waiting between 6 weeks and 6 months were not clear (Hodge et al., 2007).

52. Toronto surgeons (Braybrooke et al., 2007) prospectively examined the impact of surgical wait time on patient-based outcomes in posterior lumbar spinal surgery. They used four timeframes of waiting: from initial symptoms to surgery, from primary physician to surgery, from the referral from the primary physician to the surgical appointment and time spent on the waiting list following surgeon-patient informed consent. Seventy patients were enrolled and 53 completed the follow-up assessments up to one year post-surgery. Statistical measures were used to evaluate the pre- and post-surgery baseline scores. Findings revealed that: "A longer wait time to surgery negatively influences the results of posterior lumbar spinal surgery for degenerative conditions as quantified by patient derived functional outcome measures. The parameters of pain severity and physical aspects of function appear to be the most significantly affected." (p. 1,832)

53. Finally, in British Columbia, Sobolev and colleagues worked with patients undergoing coronary artery bypass grafting (CABG) surgery. In a sample of 7,316 patients, researchers studied whether hospital deaths were increased for those patients waiting longer than the recommended time. Results determined that delay in admission for elective CABG was associated with increased hospital mortality. The risk of death was 33% lower if you had CABG within the recommended time frame. The authors concluded, "We found a significant survival benefit from performing surgical revascularization within the time deemed acceptable to consultant surgeons for patients requiring the treatment on a semi-urgent or non-urgent basis." (Sobolev et al., 2008, page 1)

(f) THE ACTUAL EXPERIENCE OF WAITING

54. Studies focusing on the actual experience of waiting as described by participants (similar to the research which I myself performed) are few in number and fairly recent in appearance. Five such studies have been located and are presented here in chronological order.

55. The earliest study that was found took place in Ireland in the year 2000 (Fitzsimons, Parahoo and Stringer, 2000). Researchers prospectively studied people waiting for a coronary artery bypass surgery (CABS). Seventy randomly selected patients were interviewed at three intervals in the first year on the waiting list: at the time of referral for surgery; after six months; and finally after one year. Attrition occurred through: having the surgery performed (36), refusals to continue participating (2) and deaths (4). The authors state that theirs was the first known qualitative study which specifically examines patients' perceptions of the waiting period prior to bypass surgery. Interview data were examined using content analysis. Three central themes were revealed: uncertainty, chest pain and anxiety. Uncertainty caused many people to feel that their lives were "on hold" and that they could not make plans for the future as a result. Chest pain was another regular feature of waiting. The meaning of the pain was captured with these representative statements:

- I can't do anything, you know. I couldn't get up on a chair to change a light bulb if the light went out.
- You hope you don't take another heart attack – that's the dread – you're on your own, and you take the pain and you always wonder – Is this going to be the Big One?

Anxiety was a predominant feeling expressed by participants. The anxiety was rooted in their heart problem and the possible imminent surgery:

- You would be so worried when you're out there for a walk. What would make me worried is that I have three brothers and a sister died with heart trouble, and they were all found outside – one of them was only 26 years of age – I often think of that whenever I get those pains.

Powerlessness was reported when patients were uncertain about their waiting time and when they could not lead their lives the way they wished:

- Your life's on hold – there's a restraining force that you can do nothing about. You've got to accept it – And I think for a man, that's the hardest part.

- I just feel that my life is not my own since then (being put on the CABS wait list). It's on a roller coaster sort of thing: I've been swept along – I wasn't in control like.

Many expressed feelings of anger and frustration at the long queue for surgery and the lack of information that they were being offered:

- I feel let-down, I think that's the biggest problem. Now when I was told, within 6 months – within it, not around it, or about it – I thought 'Well OK! I can battle on to such times as it comes', but then as it passed and another month came and went ... like I understand that there are other people waiting, but at the same time, I was promised that date, and they still haven't had the decency to apologize – you're just another number.
- I feel it's wrong that there should be waiting lists for treatment, but nobody listens, nobody cares.

56. The second study, (Sjoling, Agren, Olofsson, Hellzen and Asplund, 2004), took place in Sweden and used the interpretive (as distinct from the strictly descriptive) phenomenological method as described by Benner (cited in Sjoling et al.) "Using this approach, lived experience was understood as the ways people encounter situations through their embodied intelligence, in relation to their personal concerns and understanding of the situation." (p. 541) The researchers examined the lived experience of waiting for arthroplastic surgery of the hip or knee and its impact on daily life. Nine patients who had undergone hip or knee arthroplasty after waiting for 30-40 weeks were interviewed one week after surgery. A further nine candidates for arthroplasty were also interviewed. These patients had been on the waiting list for 30-65 weeks and were still waiting. The thematic analysis revealed "six themes which illustrate aspects of commonality among the study participants.", (p. 542). Excerpts are set out below:

- (i) "Pain restricting life activities – A common problem among the respondents is that pain restricts activities, which they consider important and meaningful." (p. 542)

(ii) "A life on hold – A continuous struggle against a faceless system. Most of the respondents had been on the waiting list for longer than 1 year... Most often, they waited months before they went to their general practitioner, followed by several months waiting for an appointment with the orthopedic specialist (OS) and X-ray. What they find most annoying is not being able to obtain information from the orthopaedic clinic about when surgery is due to take place.... In their struggle to obtain information, they contact the clinic, sometimes on a daily basis and this leads to even more frustration and feelings of being misunderstood and a sense of being neglected by the health service." (p. 542)

(iii) "Living an undignified, meaningless life due to pain and disability. Some of the respondents share the experience of life not being worth living. Pain and disability ruin their self-image, and they feel as though they are not longer a part of their own world. The meaning of being is absent." (p. 543)

(iv) "Caring needs met – obtaining and establishing a trusting relationship with health-care representatives. Establishing a trusting relationship with health-care representatives can help the person endure the wait for surgery more easily." (p. 543)

(v) "Living a full life in spite of pain, disability and the uncertainty of waiting for surgery. There are respondents who are able to preserve the sense of living a full life by contenting oneself with what they actually can do, or finding alternative interests." (p. 543)

(vi) "Living in a supportive world. Having a sense of underlying support (from family, relatives and friends) can preserve continuity and meaning in life and prevent a bodily breakdown." (p. 544)

57. The third study took place in the United States (Brown, Sorrell, McClaren & Cresswell, 2006) and opened in part with this introduction:

Out of the silences and repetitions of their time on the waiting list, an occasional voice was heard. It was at times an articulate plea for recognition of the uniqueness of their experience; more frequently, it was the moaning of a soul that we clinically

recognized as depression. (James Sorrell, psychiatrist and initiating researcher of the study, "Waiting for a Liver Transplant," page 119)

This study used the qualitative method of phenomenology to explore the meaning that people with liver failure ascribe to the experience of waiting for a transplant. The guiding question was, "How is waiting experienced"? Nine open-ended interviews were conducted with six patients waiting for liver transplant at a university medical center. Findings revealed a variety of themes that traversed the experience. A representative list of core ideas or feelings expressed by participants included:

- Waiting is felt when it interferes with goals
- Feeling forgotten
- Waiting becomes a job
- Depression is devastating

58. In 2010, a Canadian team of researchers (Choiniere et al., 2010) published a study entitled: "The Canadian STOP PAIN project — Part I: Who are the patients on the waitlists of multidisciplinary pain treatment facilities (MPTFs)?" This study is, according to its authors, the first to document the burden of illness associated with chronic pain in individuals on waitlists of MPTFs across Canada. Seven hundred and twenty eight participants were recruited from the waitlists of eight university-affiliated MPTFs. Subjects completed validated questionnaires to 1) assess the characteristics and impact of their pain; and 2) evaluate their emotional functioning and quality of life (QoL). Follow up questionnaires were completed by a subgroup of 271 patients three months later. Results of the study are quoted here:

"Close to 2/3 of the participants reported severe pain (7 or greater on a 10 point scale) that interfered substantially with various aspects of their daily living and QoL. Severe or extremely severe levels of depression were common (50%) along with suicidal ideation (34.6%). Patients aged over 60 were twice as likely to experience severe pain as their younger counterparts. Patients with frequent sleep problems were more at risk of reporting severe pain. Intense pain was also associated with a greater

tendency to catastrophize , severe depressive symptoms and higher anger levels. Small but statistically significant changes in pain intensity and emotional distress were observed over a three-month wait time.” (pages 539-540)

59. Sometimes, researchers ask one particular question, but surprisingly, receive answers to another. Such was the case for investigators in Toronto (Mulcahy, Parry and Glover, 2010). They set out to discover whether Gilda’s Club (an organization that supports people affected by cancer) increases opportunities for the cancer patient to resist the role of the “patient patient”. Twenty one women and five men at Gilda’s Club were interviewed on this topic. In the process, people revealed the trauma of waiting. As a result, researchers expanded their study purpose to include “a better understanding about how cancer patients cope with the long wait times in Canada’s time-crunched health care system”. Results identified three themes that are developed with greater discussion: 1) waiting (during diagnosis, treatment, post treatment, 2) resisting the wait (during diagnosis, post diagnosis) and 3) Gilda’s Club as a space for resistance. Researchers provided this summary of the reported experience of waiting:

“Waiting was described by many as the worst part of the cancer experience: waiting for diagnosis, waiting for treatment, waiting for remission, and waiting for relapse. This waiting process was accompanied by a loss of control: patients described feeling as though they were always on someone else’s schedule. Consequently, waiting became the hallmark of the cancer experience, compounding the ever-present fear of the unknown experienced at each stage of the cancer journey.” (pages 3-4)

Some typical responses about waiting included:

- It took six weeks to identify what my difficulty was. That was like an eternity.
- My problem with cancer was that there was a lot of trauma between the time that I found the bumps to the time of my surgery...It took them four months to tell me that I wouldn’t need radiation...It took four months before I knew.

- That was the first time I had a bit of depression...I think what made it worse was all these months of waiting for the results, waiting for appointments, not knowing what's happening, not being able to sleep...you're going according to their schedule, when they can fit you (in), and you can spend hours sitting in the waiting room.

(g) CONCLUSION ON QUESTION THREE

60. Comparing my research to the broader research, one can see a widespread consistency. With respect to the specific literature area of waiting as the lived experience, one sees an almost complete overlap. Commonly, the same experiences with waiting for treatment were reported in spite of country of origin, type of condition, source of pain or type of procedure. For example, patients reported debilitating pain that restricted the normal activities of their lives including work, personal life and relationships (Choiniere et al.; Fitzsimons et al.; Sjoling et al.; and Walker). Another widely reported experience was that one's life was put "on hold" (Brown et al.; Fitzsimons et al.; Sjoling et al.; and Walker). Finally, waiting brought with it emotional trauma that was characterized by fear, anxiety and depression (Brown et al.; Choiniere et al.; Fitzsimons et al.; Mulcahy et al.; Sjoling et al.; and Walker). The two latest Canadian studies (Choiniere et al., 2010 and Mulcahy et al., (2010) not only confirm but underline my opinion regarding the devastation of waiting.

VIII. QUESTION FOUR: MY OWN PROFESSIONAL EXPERIENCES

Please draw on your personal experience as a health care practitioner, professor and administrator in formulating your opinion. Does your personal experience confirm your survey findings?

61. My personal experiences do confirm my survey findings. In fact, it was personal experience that initiated my research. Hearing accounts of patients waiting and suffering, I determined to begin exploring the actual nature of this phenomenon through scientific investigation. Since then, my personal experience continues to confirm what patients in my study reported. Daily life is filled with personal accounts of waiting and its hardships. For example, within the past year, the salesman from whom I was purchasing some household appliances communicated that he would not be at work because, after a very long wait, his

surgery date has finally come up. The topic of healthcare and/or waiting arises serendipitously in life and I frequently hear someone share a poignant story of someone they know who is waiting, and living the effects of waiting.

62. The full realization of the breadth and depth of waiting caused me to try and assist Canadians in being able to access the healthcare that they needed – anywhere. In 2008, I founded a website, www.findinghealthcare.ca. The purpose of the website was to provide information to Canadians trying to access medically necessary care. The website offers information on access and wait times in Canada, private clinics in Canada and elsewhere, and Canadian medical tourism services. There is also information on my research and an open invitation for people to share their stories. The website is 100% independent and accepts no advertising of any kind.

63. Through the website, Canadians regularly contact me with accounts of their particular health care difficulties. For example, Carol, a nurse in her 40's who works in the field of disability, e-mailed me. In 2008, Carol suffered a late diagnosis of breast cancer (8 months late and only after she insisted on a biopsy). With the late diagnosis and misdiagnosis (subsequent discovery of more and different tumors), Carol used her own money to fly to the Mayo Clinic where, after appropriate clinical investigation, surgeons removed both of her breasts. Carol states that the Mayo Clinic saved her life. This story has not been included in my research. However, she is public about her story and has been working on a website and a petition related to it.

64. Most people who contact me through the website are still waiting for care and are searching out ways to find care. I have found that people in these circumstances very much want to tell their story to me, but that they are not willing to have the stories made public. They report that they can't "take a chance" of being identified or risking the relationship and current access to their healthcare providers. This risk appears to be real as I have received several accounts where the relationship with the local healthcare provider was damaged and ultimately severed over issues such as the patient asking for another opinion, or asking for

help in finding another jurisdiction for immediate care. Thus, these people remain vulnerable and silent.

65. In both my personal and professional life, I find people who are strongly opposed to private healthcare. Yet, they choose private healthcare for themselves when they are in need. One example is Dr. Tom Koch, a Canadian and an ethicist. Although publicly and adamantly opposed to any sort of private healthcare, Dr. Koch 'went private' in his own case. This story appeared in BC Business magazine (Cornwall, 2006) with the relevant passage quoted here:

"Tom Koch, 57, is a Vancouver-based ethicist and the author of a score of books about medical and journalistic issues of a moral nature. He describes himself as a democratic socialist. And when it comes to B.C.'s health-care system, he says, "It remains my belief that nobody should receive what everybody can't." This placed him in an exquisite dilemma when the private Copeman Healthcare Centre – Canada's first private, primary health-care centre - opened in downtown Vancouver last November. His GP of several years, Peter House, announced he was leaving the Seymour Medical Centre to become medical director at the new, private clinic. Koch, who has arthritis, has been very vocal in his opposition to the privatization of health care. But, he admits, 'That opposition paled before the need to have a physician who I knew thought like I did about things like pain control. The relationship I have with my physician who I respect out-weighed my concerns about private health care' ... It took Koch nine months to decide what to do, but in the end, he paid his \$3,500 and joined the clinic."

66. Dr. Koch subsequently became a member of the board for a private medical clinic in Vancouver (Walker, personal communication with Dr. Koch, 2008). Currently, Dr. Koch lives and works in Toronto. This account dramatically illustrates how basic is our need for physical and mental security such that even personal moral beliefs will be sacrificed. He is not alone. I have spoken with many people who are torn between waiting and suffering in our medicare system and leaving in order to find care in the private sector.

IX. QUESTION FIVE: TRAVELLING TO OBTAIN HEALTHCARE

With respect to the experiences of those who sought private healthcare in another jurisdiction, do you have any opinion with respect to potential hardship arising from the necessity of travelling and planning for same as opposed to being able to access medical services locally? As well, do you have any opinion with respect to the experiences of individuals, particularly those of modest means, who are required to leave their jurisdiction repeatedly?

67. My opinion is based on two sources. The first is the research that I conducted with the 50 participants of my study. One area of questioning was specifically focused on financial means. The questions were:

- What did your procedure or treatment cost?
- Could you afford that?
- Would you call yourself rich?

The answers (along with participants' stated work and life situations) led me to conclude that most people were in the "ordinary" category financially. That is, they were not struggling; yet they were not rich. No one who chose to travel complained about any of the costs (money, time, energy, anxiety) associated with leaving their home to get the needed care. It was my sense that these people were in so much pain and life difficulty that the costs, whatever they might be, seemed small compared to the costs of waiting. I did not ask specifically about hardships related to leaving for care. As the interviews consisted of open ended questions, participants shared much information that was collateral to the interview questions. In spite of this, I heard no words or stories of hardship related to the medical travel. The only possible exception might be the reports from people who went to India for care. All of these individuals made comments about the impact of the different culture (intensity of the numbers of people and noise and traffic etc), but no one identified this as a hardship. In fact, several people who went to India spoke of the "beautiful and calming" environment in their medical facility and among their medical team.

68. The other source for my opinion is the contact (professionally and personally) with people who find themselves unable to access care in the public system and are now searching for private solutions in other jurisdictions. One such example is a woman in her thirties from Kamloops, British Columbia. She was in a great deal of pain owing to the fact that she needed a hip replacement. She was told that she would be waiting between one and two years for the surgery. She was exploring costs for private care when her doctor called her to say that he had "moved her to the top of the list because of her young age". Happily, this woman got her arthroplasty. But in our conversations, she had indicated that if she went private, she would be paying for it by taking out a second mortgage on her house. She had no qualms about this, indicating that the need was great enough to justify such a financial plan.

69. Based on the above sources, it appears that people who are in need of care are readily willing to pay for the costs. The participant statement from my research that captured this idea best was, "It was either a new hip or a new truck. The choice was easy."

X. QUESTION SIX: HOW MUCH WAITING WILL PATIENTS ENDURE?

Do you have any information regarding how long individuals tend to wait or how much suffering etc. individuals are willing to endure before deciding to travel to another jurisdiction?

70. I do not have an opinion on this question due to limited information. As some researchers point out, acceptability of waiting is related to a number of things including personal expectations about waits and ideas about fairness and priority (Connor-Spady, et al., 2006). Participants in my study illustrated a variety of wait times and a variety of levels of suffering. What was clear was that the number one reason for leaving the wait lines was unendurable pain. What was also clear is that when a person is suffering significant pain, the other components of their life are also severely compromised (sleep, activities of daily living, family relationships, etc.). These related ripple effects may also figure in the decision to leave the wait lines and find private care. For those who did not leave the wait lines, the reasons given were: 1) too frail to travel and 2) could not afford the cost.

XI. RESEARCH ON MEDICAL TOURISM

71. I took the liberty of perusing the scientific literature for information regarding medical tourism. My search indicates a dearth of such information. For example, researchers who studied the citizens of the European Union reported that "Hard empirical findings pertaining to out-of-pocket medical tourism are rare. Findings relating specifically to mid-life and ageing populations and medical tourism are non-existent." (Lunt and Carrera, 2010). The situation appears similar in Canada. In discussing the state of existing knowledge on medical tourism, researchers at the university of Saskatchewan concluded that "data collection, measures, and studies of medical tourism all need to be greatly improved if countries are to assess better both the magnitude and potential health implications of this trade." (Hopkins, Lebonte, Runnels and Packer, 2010).

72. In an article appearing in the Canadian Medical Association Journal exploring medical tourism and Canadians, Hinds (2010), using a number of sources, discussed the incomplete information available about this phenomenon. She cites the Canadian Medical Association's "informal canvas of provincial health departments" which reported that over the past three years, 160,000 medical services or treatments were performed on Canadians outside the country. The survey further revealed that "some Canadians choose to go to the United States, others are sent by their physicians or provincial health systems for reasons ranging from capacity to wait times". Hinds further notes that according to the Canadian Institute of Health Information, official or national data on medical services obtained out-of-country is at best incomplete for the following reasons:

- Provinces don't all collect the same information about out-of-country spending
- Some provinces do not distinguish between out-of-province and out-of-country claims.

Hinds added a further reason:

- Some provinces only record information about treatments received with prior approval applications. (2010)

73. Finally, Esmail (2010), using the Fraser Institute's annual survey data on waiting, reported that the estimate for the number of Canadians leaving the country for healthcare in 2009 was 41,006. He stated that this represents a significant increase in the overall number of patients receiving treatment outside Canada between 2008 and 2009. In 2008, the estimate was 33, 492. Increases in the estimated number of patients going outside Canada for treatment were seen in British Columbia, Manitoba, Ontario, Quebec and Prince Edward Island.

74. This completes my information and opinion.

West SWORN BEFORE ME at the City of
Vancouver, in the Province of British
Columbia on the *3* day of *October*,
2011

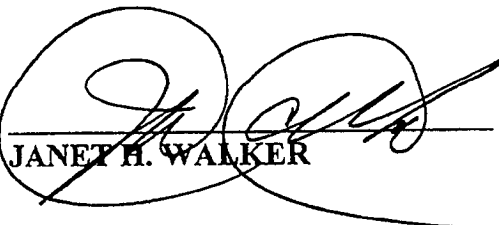
Notary Public

A Notary Public in and for the Province
of British Columbia

KENNETH SHERK
NOTARY PUBLIC
STE. 301 - 1497 MARINE DR.
WEST VANCOUVER, B.C.
V7T 1B8 922-5972

CANADA

PROVINCE OF BRITISH COLUMBIA
PERMANENT COMMISSION


JANET H. WALKER

This is Exhibit "A"
referred to in the
Affidavit of Professor Janet H. Walker
affirmed before me, this 3 day of October 2011.

Notary Public

KENNETH SHERK
NOTARY PUBLIC
STE. 301 - 1487 MARINE DR.
WEST VANCOUVER, B.C.
V7T 1B8 922-5972

JANET H. WALKER

CURRICULUM VITAE

830 Braeside Street
West Vancouver
British Columbia, V7T 2K8

Home/office: 604.926.3506
Cell: 604.862.0922
E-Mail: janw@telus.net

EDUCATION

University of British Columbia, Vancouver, BC <i>MSN – Specialization in Administration</i>	1990
University of British Columbia, Vancouver, BC <i>BScN (honors)</i>	1980
St. Paul's School of Nursing, Vancouver, BC <i>RN</i>	1965

PROFESSIONAL EXPERIENCE

Adjunct Professor, Nursing University of British Columbia, Vancouver, BC	1991- Present
Teaching area – management and leadership Research area – patient experience and access to healthcare Clinical supervisor, Master students Invited second chair, Master's thesis committees Designer and teacher, undergraduate and graduate courses; campus, distance and online	
Consultant, System Redesign Sierra Systems, Vancouver, BC	1997-1998
Advisor, guide to multidisciplinary teams of tertiary care centers on matters of process redesign	
Senior Manager BC Cancer Agency, Vancouver, BC	1988-1997
Manager of special oncology patient care and a variety of support services	
Patient Services Administrator and Provincial Chair Nursing, Pro-Tem BC Cancer Agency	1994

Professional Experience Cont'd on Page 2

Student, Graduate Studies University of British Columbia	1985-1988
Assistant Coordinator, Learning Center Lecturer University of British Columbia	1982-1985
Independent Nurse Practitioner, Gerontology Student, undergraduate studies University of British Columbia	1980-1982
Staff Nurse Surgery, neurology and intensive care	Prior to 1980

PUBLICATIONS & PAPERS

Walker, J. (2009) Waiting in line. Canadian Nurse, 105 (7), 26-30.

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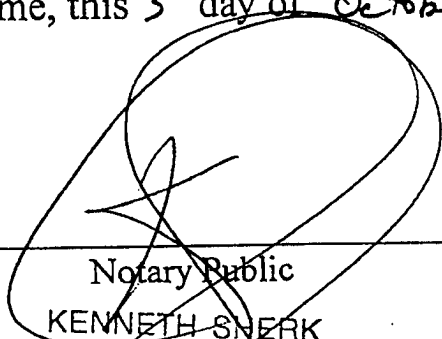
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Walker, J.H. (1988). Philosophical and Ideological forces: Their impact on the female profession of nursing. Paper presented at the International Nursing Conference, University of Saskatchewan, Saskatoon.

PROFESSIONAL ACTIVITIES & DISTINCTIONS

- Recipient and Project Liaison, Nurse Retention Initiatives Project and grant sponsored by the BC Ministry of Health and the Registered Nurses Association of BC
- Principal investigator and project leader on various clinical research initiatives
- Invited author contributing to two Canadian textbooks
- Recipient, Excellence-in-Teaching prizes
- Invited faculty speaker, keynote addresses
- Past President, North Shore Chapter of the Registered Nurses Association
- Member, Sigma Theta Tau International Honor Society of Nursing

This is Exhibit "B"
referred to in the
Affidavit of Professor Janet H. Walker
affirmed before me, this 3 day of *October* 2011.



Notary Public

KENNETH SNERK

NOTARY PUBLIC
STE. 301 - 1497 MARINE DR.
WEST VANCOUVER, B.C.
V7T 1B8 922-5872

PEER-REVIEWED FEATURE

WAITING IN LINE FOR HEALTH CARE



JANET WALKER
RN, MSN

ABSTRACT

In Canada, lack of timely access to medically necessary health care has become well known. Some patients wait in line. Others decide to find their own solutions. Wait-lists represent distress for patients and moral distress for health-care professionals, who feel a shared responsibility for what our health-care system provides. In spite of renewed commitments by the federal government to reduce wait times, little progress has been achieved (Health Council of Canada, 2008). The author outlines a descriptive study in which she documented the experiences, opinions and advice of Canadians who endured long waits for medically necessary care. Forty-four of the 50 study participants ultimately left their communities or Canada itself to obtain medical care. The author calls attention to the value of listening to health-care consumers and promotes collective advocacy on the part of the health-care professions.

A few years ago, I learned some patients' stories that were extremely upsetting to me. None of these people could access the care they needed because of long waits. All eventually found their way to the U.S., where they were successfully treated. I felt responsible for the state of the health-care system I worked in and was part of. I realized that what I was experiencing was moral distress, where one knows what is ethically required (in this case, greater access to care), but is powerless to bring it about. What I decided I *could* do, however, was to describe and document the issue through the experience of patients.

The evidence of patient access problems is all around us. We read about it in the newspaper, with headlines like "Welcome to Hospital Hell" (Braid, 2009), and view websites devoted to wait times in our home province or territory.



In the literature on patient access, the focus has been on the numbers: estimates of the number of people waiting, estimates of the length of wait times, and discussion of the various methods used to arrive at such estimates (Sanmartin et al., 2000). The Canadian Institute for Health Information used figures from a 2005 Statistics Canada survey to report that 66 per cent of all Canadians who had had elective surgery reported "long wait times as a barrier to access" (2008). This percentage represents the 132,000 Canadians who experienced long waits.

Wait-lists cause patients distress. And when patients are distressed, nurses are distressed. Nurses have a shared responsibility to make the health-care system they work in effective. When the system as a whole is unequal to patient needs, the result can be moral distress for nurses (Heesters, 2009).

The literature offers only a few studies that describe patients' experiences of waiting. One study explored parents' attitudes toward wait times for non-urgent operations for their children; most families waited more than six months. Ninety-four per cent described the wait as emotionally stressful for the entire family (Miller, 2004). In another study, 70 patients waiting for coronary bypass surgery were interviewed for their thoughts and feelings. Results illustrated an experience that was characterized

by uncertainty, pain and anxiety (Fitzsimons, Parahoo, & Stringer, 2000). A third study focused on emergency room visits (Wellstood, Wilson, & Eyles, 2005). The majority of patients described their experience negatively with wait times as a principal reason. Finally, in a multi-national examination of patient reports, Schoen et al. stated that "Canadian patients stood out for long emergency room waiting times" (2005).

The value and importance of the consumers' perspective to any enterprise is well known. In health care, their involvement is considered essential for the development of effective public policy (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). Analysts conclude that in Canadian health care, consumerism represents a key driver of change (The Change Foundation, 2005). Yet we know little about the consumer or patient perspective regarding access to medically necessary care. Exploring the issue of significant wait times from the patients' perspective can lead to consumer-driven quality improvements, promote new approaches to health-care access and alleviate some of the ethical pressures.

The purpose of my study was to examine and document the experiences of those who are unable to access care. Three questions guided my work:

1. What are the experiences of Canadians who are unable to



- access medically necessary health care in a timely fashion?
2. What are the experiences of those who choose to find their own health-care solutions?
 3. What advice do they have for others waiting for health care and for our health-care planners?

Participants were recruited through referrals from colleagues in my professional networks, from invitations on my website and from snowballing, where those taking part in the study approached others who had similar experiences. Eligibility criteria included the use of English, the language of the researcher. Attempts were made to encourage participation from all parts of the country. I discussed eligibility and informed consent with each prospective participant. Ethical approval for the study was received from Institutional Review Board Services.

METHOD AND SAMPLE

I chose the qualitative method to capture lived experience. I developed a semi-structured interview consisting of 20 questions and conducted the interviews by phone or face to face. Interviews were conducted between 2005 and 2008. Quantitative methods were employed to capture demographics as well as any results best expressed with numbers. Interview data were analyzed using phenomenology

as seen through the eyes of the participants. Then, all salient elements of the reported experience were abstracted. Finally, these elements were iteratively tested against the original data to confirm their accuracy and to develop a coherent understanding of the phenomenon.

In qualitative research, the sample size is determined by saturation, or the point where repetition of the information convinces the researcher of its validity (Speziale, 2007). In this study, I determined saturation with 40 participants. I then added a further 10 for purposes of confirmation and validation. These individuals hailed from many parts of the country: 55 per cent (27) from British Columbia, 24 per cent (13) from Ontario and the remaining 20 per cent (10) from Alberta, Saskatchewan or the Maritimes. Sixty per cent were women. The youngest person was a toddler of three; the oldest, 91. The median age was 52 years.

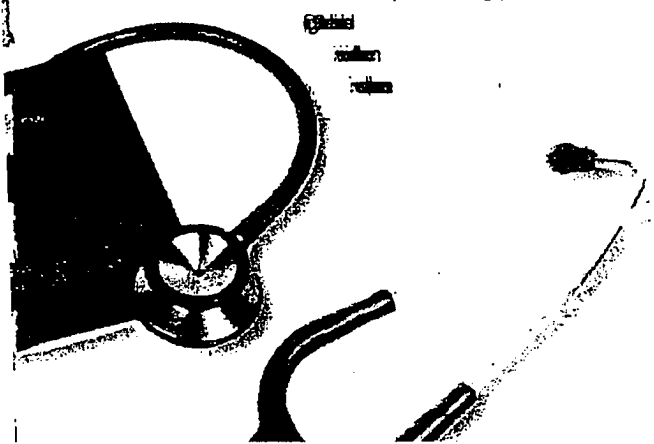
Participants' medical needs fell into the following four groups: joint problems (32%), spine and disc problems (32%); a combination of other conditions and the need for a first or second opinion (20%); and cancer (15%).

RESULTS

My analysis generated a rich volume of information that revealed a number of themes. In this article, I present the major themes, which relate to the experience of waiting and leaving and to the advice participants offered.

"A life on hold..." Participants commonly reported wait times of 18 months for diagnostics or consults and a further 18 months before surgery or treatment was scheduled.

Waiting filled participants with apprehension. Trying to find out when medical appointments and treatments were scheduled and if they were going to go ahead brought anxiety and intensified the level of uncertainty. Answering machines took the calls participants made to medical offices. Those calls were rarely returned.



"I finally wrote a letter and, about a month later, I got a reply saying that there were 900 people ahead of me and that they are only allowed two surgeries a week. He said that it could be another two and a half years. He added that I was free to seek help elsewhere."

"My referral to a neurosurgeon was three years ago. It still hasn't come up."

"They told me, 'Don't call here anymore!' It was impossible to get hold of a doctor."

Participants also reported that they could not live normal lives. Much had to be put on hold. An electrician couldn't carry his tools. A bed and breakfast owner could not get up the stairs to clean guest rooms. A wilderness officer could no longer manage outdoor terrain. Parents couldn't play with their children.

"My grandbabies would put up their hands to me, and I would have to say, 'Oh, honey, I can't pick you up.' It killed me."

When the diagnosis was life threatening, anxiety increased. One man, who had been diagnosed with borderline aggressive prostate cancer, was told that consults and treatment were still several weeks away: "They said that the wait time was

One man told me that he was saddened to have to leave home. He did not want see a change to a private system in Canada.

'acceptable.' Well, it wasn't acceptable to me. Those cancer cells were growing inside my body."

The dark world of pain. Ninety per cent of those who left the wait lines did so because of pain. Many used the phrase, "I couldn't wait." They reported severe and prolonged pain — the kind that had to be managed, often not successfully, with powerful narcotics like morphine. Pain drugs were found to be crude medicines, and no one liked taking them. Relief was variable, and many participants said that the drugs changed who they were. Several people stopped taking any pain medications, in spite of pain levels of 8 or 9 out of 10. The kind of pain reported arose from treatable conditions. That is, once the condition is treated, pain is no longer present.

"The pain was so bad that every morning I woke up with murder in my heart."

"The pills [morphine] didn't work all of the time and when they

did work, she was more or less someplace else."

Pain took away the appetite for life and ruined relationships. The link between pain and despair arose frequently in interviews. Several people described how at one point they could no longer continue to endure the pain and had contemplated ending their lives. Some implied intentions of suicide; others talked openly about it.

"My partner had as much pain as I did. I could see it in his eyes."

"I tried to fight off depression, but I see now that depression and chronic pain go hand in hand."

"I had not been able to play with my kids. It just crushed me. That's hard on its own. It's been hard on my family."

Mandy, a 30-something mom of school kids, has been waiting for an appointment at a pain clinic for more than two years. Her children want to know when she is going to get better.

"Buying your life back" Nearly 90 per cent of the participants chose to find a health-care solution in the private sector. Some found it in Canada (16%). Most (50%) went to the U.S. Twenty per cent went to India, and another two per cent chose countries in Europe. People used their computers, their medical networks and their family resources to involve themselves in find-it-yourself health care. Once they finally received the care they needed, they found relief and reclaimed their lives.

"I was told that I had to accept being compromised. Now I am back at work and running two miles a day!"

"I had 137 biopsy tests during my surgery, and I saw all of the reports the very next day."

"I am getting around the isolation that I used to impose on myself because I felt so bad and couldn't do anything."

"It was wonderful. You are literally buying your life back."

The costs of private care ranged from a few hundred dollars for a second opinion or a diagnostic test to \$60,000 for a series of life-saving cancer surgeries. Participants described their financial circumstances in terms that ranged from "extremely modest" to "comfortable." Asked if the private care was "worth it," the responses were enthusiastic and positive. The notion of value for money was captured in this comment: "It was either a new truck or a new hip. The choice was easy." However, not all those who had sought care elsewhere were in favour of private care. One man told me that he was saddened to have to leave home. He did not want see a change to a private system in Canada.

PRACTICAL WISDOM

Participants were invited to share what they had learned from their experiences. Specifically, I asked them what advice they had for other Canadians who are waiting for health care and for

those who manage the health-care system.

They expressed concern for others in similar circumstances and had words of encouragement for them. Participants wanted their neighbours to be able to get care if they needed it. One young woman said: "My son is special to me, but he is no more special than the son of the woman next door." The need to be proactive and confident of a positive outcome was a common refrain:

- "Take responsibility for your own health care. If you don't, no one else will."
- "Do your research and go. It's worth it."
- "Know that there is more than just the Canadian system available. I was blown away by discovering what was out there."

Participants spoke with empathy about the seemingly impossible task of providing care in the face of current realities in the health system and anticipated future needs. They encouraged health-care planners to listen to patients more carefully and be open to other possibilities:

- "People should not have to live in pain."
- "Find a way to keep the population healthy."
- "While you are fixing the system, allow private care to help. I am all for paying for those who can't afford it."

DISCUSSION

In keeping with the principles of qualitative inquiry, my findings are intended solely to bring greater understanding to a particular phenomenon. As such, they are not statistically generalizable.

This study represents an early exploration of patients'

experiences of having to wait in line for health care. Findings show that when patients are unable to access timely care, they endure significant pain, anxiety and suffering.

In the face of such distress, health-care providers can feel overwhelmed by patient advocacy responsibilities. My own feelings of moral distress have not diminished, but I am heartened by the shared concerns of colleagues. In fact, Welchman and Griener (2005) contend that advocacy related to patient access is best carried out not by the individual nurse, but by professional nursing organizations, where, collectively, nurses can discuss and address the ethical fallout.

I am further encouraged by the actions of my nursing colleagues. For example, a recent CNA document includes examples of nurse-led initiatives across Canada that are reducing wait times (2009).

The participants in this study provided practical wisdom and guidance for others. In simple and eloquent words, they encourage patients, providers and planners to be open to new possibilities and to new and different ways of doing things. We can harness the power of this consumerism by continuing to invite patients to share their ideas for better patient care. In fact, such a dialogue could be the beginning of a grand and ongoing exchange on all aspects of health care. The outcomes will benefit patients waiting for care and treatment and provide new perspectives on fixing a system that is ailing. ■

JANET WALKER, RN, MSN, IS A COMMUNITY RESEARCHER AND AN ADJUNCT PROFESSOR OF NURSING, UNIVERSITY OF BRITISH COLUMBIA, VANCOUVER, BRITISH COLUMBIA.

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This is Exhibit "C"
referred to in the
Affidavit of Professor Janet H. Walker
affirmed before me, this 3 day of *October* 2011.

Notary Public

KENNETH SHERK
NOTARY PUBLIC
STE. 301 - 1497 MARINE DR.
WEST VANCOUVER, B.C.
V7T 1B8 922-5372

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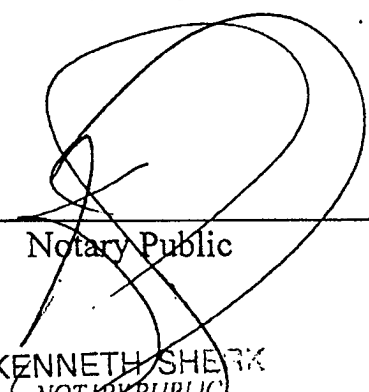
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This is Exhibit "D"
referred to in the
Affidavit of Professor Janet H. Walker
affirmed before me, this 3 day of October 2011.



Notary Public

KENNETH SHERK
NOTARY PUBLIC
STE. 307 - 1497 MARINE DR.
WEST VANCOUVER, B.C.
V7T 1B8 922-5972

Interview Questionnaire – Finding Healthcare

1. Reaffirmation of consent to participation and recording.
2. Name and mailing address so that a copy of the consent information and contact information of the researcher can be forwarded to them for their records.
3. Demographic information.
4. What was the medical problem that you needed to get fixed?
5. Tell me the story.
6. Tell me about waiting.
7. What is the experience of waiting for a medically necessary procedure?
8. Tell me about any pain that you were or are experiencing.
9. Were pain medications necessary? (kind or name, dose etc)
10. What was or is the impact of waiting on your life?
11. Did you ever consider leaving the wait list? Why or why not?
12. For those who left the wait list, what made you decide to do so?
13. How long did were you told that your wait would be?
14. How long did you actually wait before leaving?
15. In searching for private healthcare, how did you know where to look?
16. What was the deciding factor in choosing to go private?
17. What was the exact treatment or procedure that you completed in private care?
18. What was the experience like – having healthcare in the private domain?
19. What did your treatment or procedure cost?
20. Could you afford that?
21. Many people think that only the rich choose to pay for healthcare. Would you call yourself rich?
22. What would you say to other Canadians considering finding private health care?
23. What advice to you have for other people who are waiting for healthcare?
24. What advice do you have for the folks who manage the health care system?
25. How do you feel about use of names? My practice is to use first names only. Would you like your real name used or a fictional name or?
26. Thank you for this interview. I will keep you informed about the findings, the publication or presentation of the results.

Interview Schedule © Janet Walker

Filed: Finding Healthcare: Interview Questionnaire