

AGING AND THE HEALTH CARE SYSTEM:

Am I in the Right Queue?

***AGING AND THE
HEALTH CARE SYSTEM:***

Am I in the right queue?

by

DOROTHY PRINGLE

***NATIONAL ADVISORY COUNCIL ON AGING
OCTOBER 1998***

Table of Contents

What is the National Advisory Council on Aging?	5
About the author	6
Preface	7
Aging and the health care system: Am I in the right queue?	8
Waiting for restorative surgery	12
The burden of waiting for hip and knee replacements in Ontario	15
Cataract surgery willingness to pay to shorten wait	17
Waiting to get into long term care	21
Waiting for assistance	24
Conclusion	29
References	32
Published in the Forum Collection:	34

To obtain more information on this report, please contact:

National Advisory Council on Aging
Jeanne Mance Building
Address Locator : 1908 A1
Ottawa (Ontario)
K1A 1B4

Tel: (613) 957-1968
Fax: (613) 957-9938
E-mail: seniors@hc-sc.gc.ca
Internet: <http://www.hc-sc.gc.ca/seniors-aines/>

The **Forum Collection** is an information series designed to create public awareness and promote discussion on issues of interest to seniors.

Patricia Raymaker
Chairperson
Seniors

Nancy Garrard
Director, Division of Aging and
Seniors

The Division of Aging and Seniors, Health Canada, provides operational support to the National Advisory Council on Aging.

This publication is also available on the Internet at the above address.

1st printing: 1998

©Minister of Public Works and Government Services Canada, 1998
ISBN: 0-662-63864-6
Cat. No.: H71-2/3-6-1998

WHAT IS THE NATIONAL ADVISORY COUNCIL ON AGING?

The National Advisory Council on Aging (NACA) was created by Order-in-Council on May 1, 1980 to assist and advise the Minister of Health on issues related to the aging of the Canadian population and the quality of life of seniors. NACA reviews the needs and problems of seniors and recommends remedial action, liaises with other groups interested in aging, encourages public discussion and publishes and disseminates information on aging.

The Council has a maximum of 18 members from all parts of Canada. Members are appointed by Order-in-Council for two- or three-year terms and are selected for their expertise and interest in aging. They bring to Council a variety of experiences, concerns and aptitudes.

MEMBERS OF THE NATIONAL ADVISORY COUNCIL ON AGING (May, 1998)

Chairperson

Raymaker, Patricia Calgary, Alberta

Members

Duclos, Hortense	Montréal, Quebec
Hodge, Gerald	Denman Island, British Columbia
MacDougall, Bernice	Regina, Saskatchewan
Milette, Yvon	Saint-Georges-de-Champlain, Quebec
Pilon, Juliette	Sudbury, Ontario
Rapelje, Douglas	Welland, Ontario
Sentenne, Yvette	Montréal, Quebec
Skuba, Anne	Winnipeg, Manitoba
Thompson, Joyce	Charlottetown, Prince Edward Island

OOOoOoOo F O R U M oOoOoOoO

ABOUT THE AUTHOR

Dr. Dorothy Pringle is Dean of the Faculty of Nursing at the University of Toronto. She is a registered nurse. She worked as staff nurse, then coordinator of an aftercare program in psychiatry before obtaining her MS degree in psychiatric/mental health nursing from the University of Colorado. She taught psychiatric nursing at McMaster University for four years. She was then employed as coordinator of mental health nursing at the Holy Cross Hospital in Calgary prior to becoming Director of the School of Nursing at Laurentian University in Sudbury. She received her PhD in Nursing from the University of Illinois. She was Research Director of the VON Canada for six years prior to her current appointment.

Her clinical and research interests are in the care of the disabled and impaired older people and in the assistance required by family caregivers of older people. She also studies the effect on health of perceived control on the part of patients and family caregivers. She has developed a scale to measure the impact of respite services on family caregivers. Author of over 20 articles and book chapters, she has made presentations at more than 100 scientific conferences.

OOOOOOO F O R U M OOOOOOO

PREFACE

This **Forum Collection** publication contains the integral text of a keynote address given by Dr. Dorothy Pringle at the 26th Annual Meeting of the Canadian Association on Gerontology (CAG) held in Calgary in October, 1997. The theme of the Meeting was *Aging: Dreams and Realities* and Dr. Pringle had been asked to speak to the realities of seniors with respect to the health care system. She chose to narrow her subject down to the issue of *waiting*, a chronic situation faced by many as a consequence of health care reforms but particularly by seniors, who are considered, it seems, the epitome of patience.

The subject and tenor of Dorothy Pringle's address on the waiting conditions that seniors face within the health care system deeply concern the National Advisory Council on Aging (NACA). The Council takes no position on the opinions expressed in this paper, but hopes it will stimulate debate and reflection on the need to pay special attention, in designing or reforming the health care system, to the particular needs of Canadian seniors.

Patricia Raymaker,
Chairperson

OOOOOOO F O R U M OOOOOOO

AGING AND THE HEALTH CARE SYSTEM: *Am I in the Right Queue?*

The topic that I was invited to address is Aging and the Health Care System. That seemed to have endless possibilities until I read a little farther in the letter of invitation. Despite the fact that the Conference theme is *Dreams and Realities of Aging*, I was asked to speak to the *realities* of aging and health care. That reduced my choices considerably. As I searched for ways that I might conceptualize the topic, I found myself regularly returning to the problem of waiting. While I don't mean to imply that waiting is all there is to the health care system when one is old, it seems to me that waiting plays a significant role in older people's experience. This led me to call my talk: "Am I in the Right Queue?"

I want to address waiting under three topics:

1. Waiting for restorative surgery
2. Waiting for a long term care bed
3. Waiting for assistance

Before examining waiting from these three perspectives, let's look at the concept of waiting itself. Waiting is not a preferred state. To better understand it, I turned to one of my favourite philosophers, "Dr. Seuss," who in his wonderful book *"Oh, the places you'll go"* (1990), describes the adventures awaiting you when you strike out on your own. While many aspects of this journey are exciting, and others scary, the only one to be avoided is the dreaded *waiting place*. Dr. Seuss explains how you can end up waiting.

OOOOOOO F O R U M OOOOOOO

*You can get so confused
That you'll start in to race
Down long wiggled roads at a break-necking pace
And grind on for miles across weirdish wild space,
Headed, I fear, toward a most useless place.
The waiting place . . .*

*. . . Waiting for a train to go
Or a bus to come, or a plane to go
Or the mail to come, or the rain to go
Or the phone to ring, or the snow to snow
Or waiting around for a yes or no
Or waiting for their hair to grow.*

Seuss ends this section with the admonition:

*No!
That's not for you!
Somehow you'll escape
All that waiting and staying
You'll find the bright places
Where boom bands are playing.*

If Dr. Seuss considers waiting to be such a bad place, why is it so prominent in the lives of older people when they seek or need health services? Grimley Evans (1996) suggests that we are in a 'moral muddle,' unable to decide whether we think older people should have the right to consume resources and share in the benefit of societies that they helped to make. "Our various systems may merely be using different means of inhibiting consumption of care by older people — gatekeeping and waiting

OOOOOOO F O R U M OOOOOOO

lists in Canada and the U.K., cost control and out-of-pocket expenses in the U.S.”

Waiting is a universal experience. We all know what it feels like. We avoid waiting whenever we can. Who has not had the experience of standing in one of six or seven checkout lines at a supermarket or check in lines at an airport. Inevitably the line you choose moves more slowly than lines on either side of you, so you shift to try to capitalize on the more rapidly moving one only to have it slow down and be passed by the line you just left. Where is the fairness? The move to create a single waiting line in banks, airports, and post offices to feed all the service counters overcomes this sense that the gods are against us by allowing everyone who arrives to be served in turn. We hate waiting and we hate waiting longer than others when we were in line first.

There seems to be at least two ways waiting is experienced. There's the wonderful sense of anticipation as you wait for something grand to happen: children waiting for Christmas, pregnant mothers and dads waiting for the birth of their child, school children and their teachers waiting eagerly for summer holidays to begin. This kind of waiting is very different from waiting for a service man to arrive to repair the fridge — he says he will come first thing in the morning, and arrives at 3 in the afternoon — or waiting to be served in a store when there is not a salesperson in sight. The difference between these two kinds of waiting is the sense of alternative. Christmas will not come before December 25th despite the difficulty excited children have in waiting, pregnancies last 40 weeks (and you want them to), and summer holidays start at the end of June. An individual cannot change this. Furthermore, there are no waiting lists for this kind of waiting, everyone gets to it at the same time.

OOOOOOO F O R U M OOOOOOO

The other waiting is frustrating because we believe there is an alternative. If more resources were made available, our lives would be easier, better and time would not be wasted.

The frustration of waiting when there should be an alternative is linked to our difficulty with wasting time. We are busy people and have important things to do with our time, so we are not happy when someone else's action causes us to waste it. Could it be that we think older people, particularly sick older people, have time to waste and so we are less concerned with keeping them waiting?

Levine (1987) describes waiting as a power game. He states that time is power, and power allows you to control other people's time. Money has become the commodification of time as demonstrated in workers being paid by the hour, lawyers by the minute and advertising sold by the second. Important and privileged people do not wait and in fact create the obverse. The more important you are, the longer people should expect to wait for you. This rule gets played out in dentists' and physicians' offices quite regularly. They are important people and their time is important so they book to capacity or overcapacity so the patient waits for the doctor rather than the doctor for the patient.

However, even important people have to wait at times. Margaret Thatcher probably captures their attitude best: "I'm extraordinarily patient provided I get my own way in the end." (Van Dijk, 1997). There is an interesting paradox around the phenomenon of waiting: while we hate to wait, we tend to value more what we have to wait for, and may dismiss something that is too readily available (Levine, 1987).

OOOOOOO F O R U M oooooOOO

WAITING FOR RESTORATIVE SURGERY

The type of waiting that we hear most about is waiting for surgery. The Canadian health care system has developed a reputation for long waiting lists for common surgical procedures.

Waiting lists are created when the demand for a service outstrips the supply available. If you subscribe to a conspiratory theory then you accept Globerman and Hoyer's definition of waiting lists as a government attempt "to ration health care in the face of rising health care costs in a non-price environment" (Amoko, Madrow and Tau, 1992). There is now an enormous literature devoted to the management of waiting lists; it might in fact be described as a growth industry. There is considerably less information available about the difficulties associated with actually waiting. In a British study (Martin, Elliott and Hart, 1995) people who had been on a waiting list for at least four months awaiting inpatient hospital treatment were contacted and invited to attend a focus group to discuss what it was like to wait. Not surprisingly, the biggest issue for these people was simply not knowing how long they would have to wait. They were concerned about not knowing when the call would come, whether they would be available when the call came, what would happen to them if they could not accept the surgical time made available to them, and if they would go to the end of the line again. If they had waited longer than the waiting time that was proposed to them, then time became a complete unknown; they lost all sense of predictive control and acquired all the symptoms associated with those who do not feel in control of their lives: anxiety, depression, hopelessness. The general practitioners (GPs) in this British study could not help their patients because the waiting lists were under the control of the specialists, and the GPs had to be careful not to antagonize the specialists or to be seen to be doing an end-run around the system by labelling their patient as urgent. These general

OOOOOOO F O R U M OOOOOOO

practitioners were questioned about patients who were in pain and had to wait. Ironically, although a pain clinic was available, the GPs felt that there was no point in referring the patients because these clinics also had long waiting lists. It makes you think that waiting lists have the capacity to reproduce themselves without human intervention! Interestingly, in Britain, a national waiting list helpline is available. In a survey of 2,225 callers, 35% reported that they were in a lot of pain and 12% that their pain was unbearable. Pain is a theme that runs throughout the waiting list literature.

Many procedures for which there are waiting lists are sought by older people in order to restore function. Cataract surgery restores sight and with it more independence and more interesting opportunities. Hip and knee prostheses replace worn out joints and make it possible for people to regain the ability to walk without pain and without the assistance of canes. For some it means no longer needing a wheelchair. Recently, it was reported in the Milbank Quarterly (Bunker, Frazier

“The widespread use of total joint replacement to relieve pain and restore function has been one of the greatest success stories of medical care today”

*Bunker, Frazier
& Mosteller*

and Mosteller, 1994) that “the widespread use of total joint replacement to relieve pain and restore function has been one of the greatest success stories of medical care today.” Pain is relieved in 85-90% of patients and functional improvement gained in 70-80%. Because the prostheses have a life of about 10 years and revisions, i.e., repeat prosthetic replacements are much more difficult than the original surgery, most people are encouraged to find a way to manage the pain and limitations until they are at least aged 60. These types of surgeries are in increasingly popular demand. In Ontario in 1994, the rate of hip replacements per 100,000 adults was 84, up from 44 in 1981; the rates for knee replacements were 80 per 100,000. The fact that they do not require the death or sacrifice of someone else to make the

OOOOOOO F O R U M OOOOOOO

replacement available means they are more easily accessed and guilt is not part of the package.

In a study in Glasgow that involved mainly older people (Roy and Hunter, 1996) who needed hip and knee replacements, patients on the urgent list waited anywhere from 1 to 30 months, with a median wait of three months. Those who were classified as non-urgent waited anywhere from 1 to 78 months, with a median of 23 months. The overwhelming majority of these patients (93%) had pain, including 45% who had significant night pain and 30% who were in constant pain. They had severe mobility restrictions: 84% could not go outside on their own and 77% could not manage stairs. Half (47%) experienced limitations in their ability to get around indoors. Twenty-five percent had been forced to retire. Seventy percent required mobility aides. The investigators identified a high level of psychological distress, particularly among those classified as urgent. A few patients were incontinent, largely due to their inability to reach a bathroom in time. The authors state, "patients on the waiting list were distressed in physical, psychological and social terms. Many were in pain, relieved inadequately by medications; mobility and social activities were severely limited and psychological distress was common." (Roy and Hunter, 1996).

In a recent Canadian study by a group at the Institute for Clinical Evaluative Sciences (ICES) in Ontario, Williams, Llewellyn-Thomas, Arshinoff and colleagues (1997) investigated the burden of waiting for hip and knee replacement surgery. A total of 209 patients were selected from the practices of 20 orthopaedic surgeons from across Ontario who had waiting lists that extended from a few months to more than three years. Patients on these waiting lists were interviewed and their functional ability assessed. The table below lists the lengths of time they waited.

OOOOOOO F O R U M OOOOOOO

THE BURDEN OF WAITING FOR HIP AND KNEE REPLACEMENTS IN ONTARIO

Months waiting	Hip (122)	Knee (87)	Total (209)
1 to 3	18.2%	12.6%	15.9%
4 to 6	20.7%	17.2%	19.2%
7 to 12	25.6%	37.9%	30.8%
13 or more	35.5%	32.3%	34.1%

(Williams, Llewellyn-Thomas, Arshinoff et al.,

1997)

An important finding was that neither their level of pain nor their limitations in function were related to the amount of time they waited. However, 90% of patients said they would not switch surgeons in order to reduce waiting time. Interestingly, the length of time they had waited bore no relationship to the functional outcomes and pain relief they achieved following surgery.

In another Ontario study, Ho, Coyte, Bombardier and colleagues (1994) explored patients' acceptance of waiting times for knee replacement. The 127 patients randomly selected from Ontario hospitals between 1985 and 1990 waited an average of 8.5 weeks to get an initial consultation with a surgeon and another 15.6 weeks for the actual surgery. Over 93% of patients found these waiting times for initial consultation acceptable and 88% found the waiting times for surgery acceptable. The researchers found that patients' acceptance of waiting times had nothing to do with either their satisfaction with surgical results or the time since surgery. This same team

OOOOOOO F O R U M OOOOOOO

(Coyte, Wright, Hawker, Bombardier, Dittus *et al.*, 1994) compared waiting times for knee replacement and their acceptability to patients in Canada and the U.S. While Canadians waited twice as long as Americans for an initial consultation, and eight weeks rather than three weeks for the actual surgery after the consultation, the vast majority of Canadians found the waiting times acceptable and there was little difference between the two countries in the overall satisfaction with surgery: 85% of Americans were satisfied as were 83% of Canadians.

Studies that have focused on cataract surgery provide insight into what patients view as acceptable waiting times for this type of surgery. An international team of researchers that included Canadians compared the views of waiting times held by patients who resided in Manitoba, Denmark and Barcelona, Spain (Dunn, Black, Alonso, Norregard and Anderson, 1997). There were 142 older Manitoban patients in the study: 39% of them anticipated they would have to wait no more than three months for surgery while 30% thought they would have to wait 3 to 6 months and 30% were real pessimists and believed they would have to wait more than 6 months. Sixty percent of these patients thought that up to three months was a reasonable time to wait. In terms of their own waits, 57% thought it was shorter than expected or reasonable while 43% thought it was either longer or much longer than they would like. In this study, patients who thought their waits were too long had more visual symptoms and had anticipated that they would not have to wait any more than three months when, in fact, they did. The authors concluded that the anticipated waiting time was the strongest factor predicting their view of what was a reasonable waiting time: patients' dissatisfaction with waiting time increased if they anticipated they would have to wait a long time.

OOOOOOO F O R U M OOOOOOO

In a subsequent study by the same investigators (Anderson, Black, Dunn, Alonso *et al.*, 1997) these cataract patients were asked if they would be prepared to pay either directly or through increased taxes to shorten the waiting times. The patients were telephoned four months after their surgery.

CATARACT SURGERY WILLINGNESS TO PAY TO SHORTEN WAIT

	Manitoba (142)	Denmark (259)	Barcelona (149)
<i>Willing to raise taxes</i>	14.9%	23.9%	12.3%
<i>Willing to pay</i>			
\$ 500	38.2%	16.9%	28.6%
\$1,000	15.3%	11.7%	25.0%
\$2,000	7.1%	11.1%	23.1%

(Anderson, Black, Dunn, Alonso et al., 1997)

The table shows that only 15% of Manitobans were prepared to pay higher taxes to shorten waiting lists and that while close to 40% would be willing to pay \$500 to shorten the amount of time they would have to wait, only 7% would be prepared to pay \$2,000. Should we conclude that the Manitobans' strong Scottish heritage comes through? There were distinct differences across the three countries in these results. About a quarter (23.9%) of the Danes were prepared to pay higher taxes, but only 17% would pay even \$500 and only 11% would pay more than that. Even fewer of the Catalonians from Barcelona would contemplate higher taxes but more of them than either Danes or Manitobans were willing to pay greater amounts to shorten their waiting periods. The investigators found that

OOOOOOO F O R U M oooooOOO

patients' willingness to pay increased as the length of the anticipated wait increased and was higher for people with more education, lower visual acuity and those who were more bothered by their reduced vision.

What can we conclude from these studies? A picture emerges of older disabled Canadians as patient, accepting of waiting lists and waiting times that are several months rather than several weeks in length despite significant pain and limitations in their function. While we do not know how representative Manitobans are of other Canadians, it is difficult not to be impressed with the very few who were prepared to see taxes increase to reduce waiting periods and the relatively small amounts they were willing to pay directly to reduce the time they would have to wait. The authors of this study raise and address the limitations that attend studies that ask patients how much they are willing to pay and they provide a convincing argument of the validity of their results.

Therefore, I offer the following as possible explanations:

1. Older Canadians are really Scottish martyrs in disguise.
2. In a desperate attempt to answer the question "What is a Canadian?", older Canadians have decided the answer is "Someone who waits for surgery."
3. Older Canadians have decided that their unique contribution to reducing the national debt is to wait for surgery.

Seriously, the tolerance for waiting while in pain and experiencing significantly reduced function is remarkable and I believe it has something to do with our definition of being Canadian, valuing our health care system, believing we should not have to pay for necessary treatment and care, and accepting that waiting for these types of surgery is not in and of itself harmful, that is, does not lead to poorer surgical response. This is in

OOOOOOO F O R U M OOOOOOO

contrast to cardiac bypass surgery, where patients have died while waiting for surgery or their conditions deteriorated, leading to complications during and after surgery. These waiting lists are now actively managed to ensure patients are properly assigned based on the urgency of their condition.

Our tolerance for waiting for restorative type surgery does not mean that the waiting times are acceptable or that the wait lists are organized to ensure maximum access to surgery for those most in need. Truly, older Canadians cannot answer the question: Am I in the Right Queue? Waiting lists sound like straightforward devices through which individuals get access to the service they require in an orderly and fair manner. I hate to disillusion you but that is not how the real world works. Let me introduce the concept of a *mortlake* in contrast to a waiting list. I believe this is a British concept and it has a complicated definition involving oxbow shaped lakes, rivers running by and sand piling up. Ignore all that and believe me when I tell you that with respect to waiting for surgery, it should be pictured as a pool of individuals into which the person who controls access to service dips to select the one who will receive the service (surgery) next (Pope, 1991). Perhaps a comparison with how Air Canada handles its stand-by list at Ottawa Airport will illustrate the difference between a waiting list and a mortlake.

Picture this. It is a Tuesday afternoon and you have a full fare ticket to return home after a meeting. The meeting ends early so you have a chance to get the 3 o'clock flight instead of waiting till 6 for the flight on which you are booked. At the airport, you check in at stand-by. There are only three of you waiting and the 3 o'clock flight has three empty seats. You are called on a first come first serve basis and you get on the plane. No problem. You were on a waiting list and based on a system that was transparent to all, all received equitable treatment.

OOOOOOO F O R U M OOOOOOO

Now change the scene to Friday afternoon, same airport. You have a seat on the 7 o'clock flight but reach the airport at 4:30, hoping to get on the 5 o'clock plane. There is a huge group of people on stand-by because the 4 o'clock plane was cancelled. The time you arrive at the airport now plays only a small role in determining if you will get access to the 5 o'clock or even 6 o'clock plane. The type of ticket you have, i.e., full fare or reduced rate, whether you have prestige or elite status as a frequent flyer, if you are an MP — that is an important person, whether you had a confirmed seat on the cancelled flight, all play a role. Here, the concept of mortlake is more appropriate than a wait list because the most powerful person in the world in your life at that point, the Air Canada desk attendant, is going to dip into that pool and you have no idea if your name will be selected.

People awaiting hip and knee or cataract surgery find themselves on waiting lists that are affected by many variables of which they are not aware: the number of people already on the list, those who are considered more urgent in the judgement of the surgeon, the amount of operating room time allocated in the hospital in which s/he does surgery, how often that block of time is reduced or expanded by the hospital, how many important people (however that is interpreted — rich, famous, occupying an important position) are on the list and how the list is managed between the surgeon and his or her secretary. The secretary is to the list what the Air Canada desk attendant is to stand-by. Can we do better? Of course.

The ICES research group (Naylor, Williams and the Ontario panel on hip and knee arthroplasty, 1996) has indicated that the waiting lists for hip and knee surgery can be made to function in a more predictable manner. Reliable measures have been developed so that surgeons can identify the relative urgency of presenting patients. This does not handle the problem of patients wishing to be operated upon by particular surgeons who may have

OOOOOOO F O R U M OOOOOOO

very long waiting lists, but these patients can at least be treated more fairly if they make the deliberate choice to enter one of these long queues. In many communities it is possible to offer patients the choice of being operated on by a surgeon with a shorter list. This is a manageable problem that we have chosen not to manage.

WAITING TO GET INTO LONG TERM CARE

Let's move on to a second kind of waiting that a significant proportion of old people go through every year, those waiting in an acute care hospital bed for a bed to become available in a long term care setting. These people frequently have to bear the burden of being labelled a '**bed blocker**,' a highly pejorative term that allows the health care system to transfer the blame from system inadequacies to the patient (Aronson, Marshall, Sulman, 1987). Hall and Blytheway (1982) define a blocked bed as, "a bed that is occupied by a patient who, in the consultant's opinion, no longer requires the services provided for that bed but who cannot be discharged or transferred to more suitable accommodation." There are less punitive labels: patients awaiting placement, placement problems, inappropriately placed patients and ALC patients (alternate level of care patients) and although the label is better, the actual care delivered is not.

We know a lot about people who are awaiting placement because studies have been conducted all over the world, New Zealand, Sweden, England, Scotland, the U.S. and several in Canada. These studies have described the characteristics of patients who remain in hospital after their acute treatment needs have been met. The Swedish study (Styrborn and Thorslund, 1993) found that while these patients had a mean age of 81.6 years, the majority (84%) were over 75. More than 70% had four or more diagnoses, 14% experienced impaired vision, 5% had a serious hearing

OOOoOOO F O R U M oOOOOOO

deficit but only 10% were demented. Even though these patients were declared ready to be discharged, 50% percent of them experienced a significant medical symptom or event within two weeks of the time the application for placement was sent. Among the problems were falls, new decubitus ulcers (bedsores) or an exacerbation of existing ones, deterioration that led to 14 deaths and severe confusion. The lesson here is that these patients may not require an acute medical or surgical bed but they are far from stable.

A team of investigators at the Montreal General Hospital (McClaran, Tover-Berglas and Glass, 1991) followed 115 patients declared chronic and requiring placement for two years between 1987-1989. These patients occupied 19% of the beds at the Montreal General and they were found in all hospital wards. While their age ranged from 23-93, the mean age was just over 73 and many were very old. This study reminds us that not all people who require placement in long term care facilities are old, but the vast majority are. These 115 patients were hospitalized a total of 101,585 days, of which only 8,880 could be classified as acute care. This worked out to an average of 77 days of acute care each. Therefore, 92,705 days were spent as chronic patients awaiting placement, or an average of 811 days per patient. This represents over 91% of their total hospital time. This is a very long time.

A third study was conducted by Evelyn Shapiro, Robert Tate and Ellen Tabisz (1992) in Manitoba. They followed 366 patients in four Winnipeg hospitals for a year. Seventy-seven percent of them were 75 or older and their mean age was 80.3 years; 40% were cognitively impaired and 33% had behavioural problems. During the year they waited, 68 of these people died. A significant finding from this study was the influence that the patient's or family's choice of a nursing home had on the length of time they

OOOOOOO F O R U M OOOOOOO

ended up waiting. If they were prepared to move to a for-profit secular home, the median waiting time was 115 days; this increased to 195 days if they were waiting for admission to a not-for-profit secular nursing home. If they wanted a particular non-profit ethnoreligious home, the median wait was 344 days.

While we know a great deal about the characteristics of patients who end up spending a long time in acute care hospitals and something about why that happens, we know very little about what life is like for them and their families. Research that was carried out in an acute care hospital in Toronto helped fill in some of the gaps (Rosenthal, Sulman and Marshall, 1992). The 84 family caregivers in the study found these circumstances very difficult and reported a range of problems: tension between the caregiver and other members of the family, feeling torn between their own needs and those of the patient, and uncomfortable when visiting.

When asked open ended questions about problems they were experiencing, almost half reported difficulties with medical and hospital care. These were broadly classified as problems with delayed, insufficient or inappropriate care, or communication. These family members complained that their elderly relative was not getting enough physiotherapy, the nurses were not sufficiently attentive and left the relative waiting, there were too many doctors and none of them explained what was happening. This may sound like any hospital stay these days, but the difference is that most of us feel we can survive these seemingly intractable components of hospital stays because we will get home soon. These patients have no home. They have given up their own homes and they are in transit to what will be their home. They are not shelterless, but they are homeless. An acute care hospital was not designed to be anybody's home and you should not have to wait in this transient environment for months and years.

OOOOOOO F O R U M OOOOOOO

I believe that being an ALC patient is being in the black hole of hospitals. The physicians are mad at you for occupying a bed for which they have other patients with acute care needs. In these days of reduced hospital beds, every bed is precious and the pressure to admit, treat and discharge patients is enormous. The nursing care these patients receive can be dreadful. Nurses work in specific areas because they like delivering the kind of care these types of patients require. When patients no longer require this care and require largely hygienic and supportive care and much tender loving care, they can lose interest in the care and in the patient. And the reality is, nurses on acute care floors are busy and taking the time to help elderly, very disabled patients do as much for themselves as possible is time consuming. So is toileting every two hours when the patient requires two people to transfer from bed to wheelchair to toilet.

Patients trapped in these predicaments have no idea how long they are going to be in these environments; it may be weeks, or months, or years. They are in queues, although the term tends not to be applied to these waiting problems. However, the decision about who gets available long term care beds is about as straightforward as who gets a knee replacement. These patients should not be called ALC, they should be called TIN, for trapped in no-man's-land. Perhaps, they truly are in Dr. Seuss's dreaded "waiting place."

WAITING FOR ASSISTANCE

Let me now turn to the third kind of waiting and what I think is the most invisible kind of waiting that many older people experience: the wait for assistance when they reside in long term care environments of all kinds. I am referring to the very disabled who must signal their need for help in getting to and from and off and on the toilet, for help in having their meals

OOOOOOO F O R U M OOOOOOO

arranged in a way that allows them to eat independently, for help to get out of bed and back into it when they wish to. We take our independence so much for granted that it is hard for us to imagine what it is like to require assistance to do any of these functions. The need to ask for help would seem to be a sufficient penalty for anyone to bear but when we add in waiting to receive that help, it truly becomes too much.

It is with some ambivalence that I have discussed the problem of waiting for a transfer to a long term care facility. While I absolutely believe that acute care hospitals are not homes and cannot be, I also know what life is like for many, many old people in long term care. Dr. Seuss says that when you escape the waiting place, “you’ll find the bright places, where boom bands are playing.” Not so! At least not for many people.

The extent of the waiting that institutionalized older people sustain surfaced when Dr. Gail Mitchell and Christine Jonas undertook a study of the quality of life of 80 residents in a chronic hospital in Toronto. Half of these people complained of waiting and described it as “frustrating, irritating, maddening, destructive and harmful.” (Mitchell, 1997). A second study by Kolodny (1996) in another long term care facility in Toronto revealed similar experiences. Here are some examples from these studies:

“Having to wait. You know ... if you’re sitting on the toilet for instance, or left longer than you want to be left. You know, they get called away someplace else that needs them more. And sometimes I have sat in there for nearly an hour. That’s nearly driven me out of my mind.”

(Kolodny, 1996)

OOOOOOO F O R U M OOOOOOO

“It’s really frustrating. Some will tell you they’ll be back in a minute and to go to your room and wait. You know darn well they are not going to be there in no minute, so why do you want to go sit in your room like a dummy? I am not going to sit there for half an hour. It’s like sending a kid who’s been bad up to his room.” (Kolodny, 1996)

“Most of the nurses come in to see how I am and if they can help me. . . I have had problems with some nurses. . . I felt I had to report one. Because I had her for ten weeks one time and every time I had to go to the washroom she would always say she was going off to coffee or she was going to lunch, or she was doing this or that. She never said once she wouldn’t take me, she just said I am doing something else. I just thought I had to say something about being that cruel.” (Mitchell, 1997)

Gail Mitchell is a member of the Long Term Care Research Consortium and heads up the program of research that focuses on quality of life. This consortium is comprised of Baycrest Centre, Sunnybrook Health Science Centre, the Rehabilitation Institute of Toronto (formerly Queen Elizabeth and Hillcrest hospitals), Providence Centre and the Faculty of Nursing at the University of Toronto. We are trying to do studies that will have a direct impact on how we care for residents. Because of the recurrence and powerful impact of the findings related to waiting in these previous studies, Mitchell and her colleagues are undertaking a series of studies that focus specifically on what residents’ experiences are of waiting and the effect it has on them.

OOOOOOO F O R U M OOOOOOO

Any of you who has ever worked in long term care knows that waiting is part of life there, but what we have not appreciated is the effect it has on the people who live in these environments. It is one thing to cause someone to wait, it is another to be the “waitee.”

You may ask: Why is waiting so intractable? I believe there are at least two explanations: workload and power. Linda O’Brien-Pallas and several of her colleagues from the University of Toronto and McMaster University (O’Brien-Pallas, Charles, Blake, Luba, McGilton *et al.*, 1995) conducted a study for the Ontario Ministry of Health Long Term Care Division to identify factors that influence care delivery. Twenty-two representative for-profit and not-for-profit nursing homes and homes for the aged from across Ontario that housed 2,200 residents were involved. Workload sampling was done and the direct care providers were interviewed about their work. The workloads were very high. On day shifts, the average health care aide was assigned to care for 19 residents. This rose to 39 residents on night shifts. For those of you who have not been in a residential long term care facility lately, you may not appreciate the level of dependency the residents have. It is simply not possible to have responsibility for 19 residents and not cause them to wait. The average amount of direct care residents got on a day shift was 20 minutes.

In order to understand how aides organized their work, Bowers and Becker (1992) studied three nursing homes in Wisconsin for a five month period. They worked alongside the aides, observed them over other shifts and interviewed them to understand how they made decisions about their workload. They learned that a fundamental principle of worklife was: there is not time to get everything done. In order to survive, you must cut corners. The aides who survived — and they were not usually the best of the new recruits — learned how to cut corners without being detected either because

OOOOOOO F O R U M OOOOOOO

no one was there to notice except the residents or the aides on the next shift would do what they left out. When workloads are too high, waiting lists form in order to control the work flow to give the worker a sense of control. Dependent individuals usually do not know they are on a waiting list, i.e., in a queue, and they do not know how many people are ahead of them. In Bowers' study, the aides had a carefully worked out queueing system, in fact, it would rival the cardiac surgery waitlist in Ontario.

“More experienced NA's (nurse's aides) often increased the efficiency of rounds by sequencing patients according to a plan that did not (could not) take account of individual patient needs. The rooms were entered in a patterned sequence, and residents were fed, bathed and put to bed in a preplanned, predictable order, often regardless of individual preference. Usually this style of organization meant that call lights would not be answered while “rounds” were being conducted.” (Bowers and Becker, 1992, p. 363)

I have often ranted about the pace that most long term care facilities maintain on their day shifts. I am teaching a fourth year elective undergraduate course on long term care this term. All my students have placements in residential facilities. Several of them are having difficulty coping with the workload. They find they cannot get everything done that needs doing. They are concerned they are leaving some residents waiting while they respond to the calls of others. They are assisting Mrs. Smith to get washed and dressed, when Mrs. Jones calls because she needs to go to the bathroom. Do you leave Mrs. Smith undressed by her bed to go and help Mrs. Jones, or do you tell Mrs. Jones to wait, you will get there as soon as you can, knowing that Mrs. Jones cannot wait and she will wet herself. One or the other ends up in a queue.

OOOOOOO F O R U M OOOOOOO

There is also a very visible clock ticking and expectations are laid on all the staff including the students to get their residents up, polished and buffed and ready for breakfast, get medications out within a magical time period or fill out an incident report which, by the way takes time, and then get the various residents ready for physio, a doctor's rounds, or most frequently, to sit for hours. Isn't it rather perverse that we require incident forms to be completed when medications are late, but not when the staff are late getting to residents to help them in all the other ways that make a day either pleasant or frustrating, meaningful or demeaning.

While I believe that most of the waiting that residents endure can be attributed to workload, some is due to power, the power that staff have over residents. The people who care for residents of long term care facilities are the lowest on the totem pole of the health care providers. The only people who have less power than them are the people they care for. Foner (1994) reported that in a year-long ethnographic study of a large non-profit nursing home in New York City, she did not see a lot of abuse and she saw a lot of kindness. When mistreatment did take place, it was usually in the form of yelling, swearing at and insulting residents, taunting and teasing them, and ignoring residents' calls for help. The confused patients' requests were most often ignored. Deliberately making residents wait for assistance is nothing less than cruel. It is also cruel, for both resident and care provider, when workload makes it impossible or impossibly difficult to respond in a reasonable time.

CONCLUSION

I have talked about three kinds of waiting: waiting for surgery, waiting for an appropriate placement and waiting for assistance. The most troubling

OOOOOOO F O R U M OOOOOOO

of the three, I believe, is the third, because it is so pervasive and so invisible.

The queues or mortlakes for restorative surgery are not well managed currently but we know how to do a better job of this so that those people who are in most pain and are most disabled go to the head of the queue.

Trapped in no-man's-land in an acute care hospital can also be made much more liveable if not a home. Hospitals need to create day programs for their long-stay patients so they have someplace to go and something to do while they wait. Volunteers can make an enormous contribution to these programs although they cannot be run entirely on volunteer help. I do not underestimate the challenge of trying to cope with one or several cognitively impaired patients on a surgical unit particularly if they are inclined to wander or to disturb other patients with yelling; they will be restrained physically or pharmacologically as a way of managing them. I don't know why they are not in day care programs designed for them while they wait. These programs exist in a variety of settings. Patients would need to be transported to the programs that are located in other facilities, but we transport patients between acute care hospitals all the time for MRIs, special tests, and to have access to equipment not available in every hospital. It would cost money. Yes. But if the problem is who will pay, let's work it out.

The problem of patients not being willing to go to long term care facilities that are not their first or only choice while they wait for their location of choice is not uncommon. Many jurisdictions have simply established policies that require them to take an available place until their preferred place has a bed. This is efficient and necessary if somewhat heartless. It would be less distressing for these patients and their families if they

OOOOOOO F O R U M OOOOOOO

believed they would get the care and assistance they need in a loving and timely way while they waited.

This brings me to “waiting for assistance.” The abuse of power that may keep old, frail, dependent people waiting is much easier to manage than waiting caused by excessive workloads. It is not acceptable. It should be viewed as any other type of abuse and the people perpetrating it should be disciplined.

I don’t believe that we can ever overcome “waiting for assistance” entirely. I do believe it is possible to reduce it so that care providers can meet their residents’ requests for assistance more often than they have to deny them or keep them waiting an unconscionable length of time. Residents should be able to have confidence that their care providers will come and know that when it does not happen in a reasonable length of time, it is an exception rather than the rule. We are not going to be able to do that with workloads at the levels that were found in Ontario.

The economy is getting better. I have a suggestion for where we should spend more money. Forget the debt, forget a tax cut, let’s take care of our old people and not keep them waiting any longer.

OOOoOOO F O R U M oOOOOOO

REFERENCES

Amoko, D.H.A., Modrow, R.E., Tan, J.K.H. (1992). Surgical waiting lists I: Definition, desired characteristics and uses. Healthcare Management FORUM, 5(2), 17-22.

Anderson, G., Black, C., Dunn, E., Alonso, J., Christian-Norregaard, J., Folmer-Anderson, T., Bernth-Peterson, P. (1997). Willingness to pay to shorten waiting time for cataract surgery. Health Affairs, 16(5), 181-190.

Bowers, B., Becker, M. (1992). Nurse's aides in nursing homes: The relationship between organization and quality. The Gerontologist, 32(3), 360-366.

Coyte, P.C., Wright, J.G., Hawker, G.A., Bombardier, C., Dittus, R.S., Paul, J.E., Freund, D.A., & Ho, E. (1994). Waiting times for knee-replacement surgery in the United States and Ontario. The New England Journal of Medicine, October 20, 1994, 1068-1071.

Dunn, E., Black, C., Alonso, J., Christian-Norregaard, J., Anderson, G.F. (1997). Patients' acceptance of waiting for cataract surgery: What makes a wait too long? Social Science Medicine, 44(11), 1603-1610.

Evans, J.G. (1996). Health care for older people: A look across a frontier. JAMA, 275(18), 1449-1450.

Foner, N. (1994). Nursing home aides: Saints or monsters? The Gerontologist, 34(2), 245-250.

Hamilton, B.H., Hamilton, V.H., Mayo, N.E. (1996). What are the costs of queuing for hip fracture surgery in Canada? Journal of Health Economics, 15, 161-185.

Levine, R. (1987). Waiting is a power game. Psychology Today, 21(4), 24-33.

Martin, M. (1995). Life in the slow lane. Health Service Journal, May 25, 1995, 24-26.

OOOOOOO F O R U M OOOOOOO

McClaran, J., Tover-Berglas, R., Glass, K.C. (1991). Chronic status patients in a university hospital: Bed-day utilization and length of stay. Canadian Medical Association Journal, 145(10), 1259-1265.

Naylor, C.D., Williams, J.I., and the Ontario panel on hip and knee arthroplasty. (1996). Primary hip and knee replacement surgery: Ontario criteria for case selection and surgical priority. Quality in Health Care, 5, 20.

O'Brien-Pallas, L., Charles, C., Blake, J., Luba, M., McGilton, K. (1995). The nursing and personal care provider study. Final Report. University of Toronto.

Rosenthal, C.J., Sulman, J., Marshall, V.W. (1992). Problems experienced by families of long-stay patients. Canadian Journal on Aging, 11(2), 169-183.

Roy, C.W., Hunter, J. (1996). What happens to patients awaiting arthritis surgery? Disability and rehabilitation, 18(2), 101-105.

Shapiro, E., Tate, R.B., & Tabisz, E. (1992). Waiting times for nursing-home placement: The impact of patients' choices. Canadian Medical Association Journal, 146(8), 1343-1348.

Styrborn, K. (1995). Early discharge planning for elderly patients in acute hospitals - an intervention study. Scandinavian Journal of Social Medicine, 23(4), 273-285.

Styrborn, K., and Thorslund, M. (1993). Delayed discharge of elderly hospital patients - A study of bed-

blockers in a health care district in Sweden. Scandinavian Journal of Social Medicine, 21(4), 272-280.

Van Dijk, N.M. (1997). To wait or not to wait: That is the question. CHANCE, 10(1), 26-30.

Williams, J.I., Llewellyn-Thomas, H., Arshinoff, R., Young, N., Naylor, C.D., the Ontario Hip and Knee Replacement Project Team. (1997). The burden of waiting for hip and knee replacements in Ontario. Journal of Evaluation in Clinical Practice, 3(1), 59-68.

OOOOOOO F O R U M oooooOO

Published in the *Forum Collection*:

1. Consumer fraud and seniors. March 1991
2. Elder Abuse: Major issues from a national perspective. March 1991
3. Seniors' independence: Whose responsibility? April 1992
4. Are we spending our children's inheritance? March 1994
5. The social contract for seniors in Canada. March 1994
6. Aging and the health care system: Am I in the right queue? October 1998