Listening to Patients’ Voices: What Can We Learn?

Susan R. Harris

It is a wonderful honour to have been selected as the Canadian Physiotherapy Association’s Enid Graham Memorial Lecturer for 2006. I would like to thank Dr. Marilyn MacKay-Lyons for spearheading and coordinating this nomination, as well as those of you who wrote letters on my behalf. Because I still feel like a relatively “new” Canadian, having emigrated here in 1990 and become a citizen in 1996, to be honoured as such by my Canadian physiotherapist peers is especially meaningful for me.

Why have I chosen to talk about patient voices in this lecture? Many would have assumed that I would have waxed eloquently on clinical research, knowledge translation or perhaps our journal, Physiotherapy Canada. Patients, clients or consumers are at the very heart of our profession and the reason that most of us entered physiotherapy in the first place: because we cared and we wanted to help others. I frequently tell my physical therapy (PT) students that the most important things that I have learned in my career are lessons that have come from patients and their families.

Three goals will form the outline for this lecture: (1) to define the term patient versus other similar terms; (2) to discuss the importance of listening to the patient’s voice in our various roles as clinicians, researchers, educators and students and (3) to imbed my own personal stories and experiences with patients, as well as what the research literature has to tell us about the importance of incorporating the patient’s voice into practice, research and education.

DEFINITIONS OF A PATIENT AND OTHER SIMILAR TERMS

I will use the terms patient, client and consumer somewhat interchangeably as none of these terms is entirely politically correct. When I did my own PT training more than 35 years ago, before the advent of private practice PT, we dealt solely with patients, which made using the correct terminology a whole lot easier! In defining the half-dozen different terms that include or are somewhat synonymous with the term patient, I will progress from the least to the most autonomous terminology.

The noun patient emanates from an institutional or hospital setting and refers to an individual waiting for or under medical care or treatment; this term implies one who is acted upon. In contrast, a client (one of the most commonly preferred synonyms in today’s health care world) refers to a person receiving services in the community or from a specific health care professional, for example, a physical therapist. A client has also been defined as a person who engages the professional advice or services of another—hence a term that fits better within the private practice realm. The term consumer quite simply means “one that consumes” or one that uses economic goods. In terms of PT, we often think of a health care consumer.

Other terms that I have heard used in both health care and research circles include advocate, stakeholder and customer. These terms seem out of place in the health care arena but will be defined because they are used and likely will continue to be used. An advocate is defined as a person who pleads for the cause of another (used primarily in legal circles). This is a term often applied to women living with breast cancer (perhaps as a preferred descriptor to the outdated and less preferred term, breast cancer survivor). However, this usage appears inappropriate to me as there are many “advocates” in the world of breast cancer, including oncologists, nurses, policy-makers and community and funding agencies, as well as physical therapists. Another business-laden term that seems inappropriate in its lack of uniqueness in applying only to patients is stakeholder, defined as an individual or group with an
interest in the success of an organization in delivering intended results and maintaining the viability of the organization’s products and services.\textsuperscript{1} Once again, I would argue that there are many different types of stakeholders in health care and that this term should not be applied solely to patients. A sixth term that has been used to apply to patients is even more business-related: \textit{customer}. Quite literally, a customer is one who purchases a commodity or service.\textsuperscript{1} In this lecture, I will use the terms \textit{patient}, \textit{client} and \textit{consumer} as these are the terms found most frequently in the literature.

\section*{Patients and People-First Language}

One of my first experiences in the world of disability was my role as a camp counsellor many years ago in upstate New York. In those days (the mid-to-late 1960s), we referred to this setting as a “handicapped children’s camp.” Today, it would be called a “camp for children with developmental disabilities” or a “camp for children with special needs.” Why is people-first language so important, and why do we insist on its use in \textit{Physiotherapy Canada}\textsuperscript{2}

More than a quarter-century ago, I was advised by a very sensitive journal editor (who was somewhat ahead of her time) to change the title of a manuscript of mine that had been accepted for publication. I was asked to change from “\textit{A Transdisciplinary Therapy Model for Down’s Syndrome Infants}” to “\textit{A Transdisciplinary Therapy Model for Infants with Down’s Syndrome}.”\textsuperscript{2} Today, that title would have been edited further to read “\textit{Down} syndrome” rather than the possessive “\textit{Down’s}” as it has been decided that Dr. Down did not own the syndrome but had merely identified it. The same is now true for Parkinson disease, Duchenne muscular dystrophy, etc.

In the mid-1990s, I became a victim of a lack of people-first language myself. I was invited (as a former patient with breast cancer) to participate in a small-group forum of medical students from the University of British Columbia (UBC). One of the students was presenting the results of a study that had included two groups of participants. He described the first group as “breast cancer patients” and the second group as “normal women.” That was my first realization that I was truly “abnormal” (although I am certain that many of my family and friends had been aware of this distinction for some time).

The compelling need to use people-first language was eloquently expressed by the mother of an 11-year-old girl who had been hospitalized frequently for complex medical needs. As Ellen Simpson pleaded, Children on medical units are not “appendectomies”, “craniofacial repairs” or “spina bifidas”. They are small people with medical needs. Their diagnoses do not define them, nor do their procedures explain them. They need to be honoured for the individuals that they are and treated with respect.\textsuperscript{3}

I would like to return to my experiences as a counsellor at the summer camp for children with disabilities, a story from when I was in high school and not yet considering PT as a career choice. One of our youngest campers, Jeannie, was an eight-year-old girl with cerebral palsy (CP) who spent most of her day in a wheelchair. She was very tiny and fragile-looking with beautiful dark brown hair and gorgeous long eyelashes and definitely a camp favourite.

It was dinnertime, and I was seated next to Jeannie at the dinner table. As any who have been camp counsellors can attest, I was exhausted and ravenous, and all I wanted to do was tuck in to that delicious camp food. Jeannie was too small and too disabled to sit on a bench at the table and had to remain in her wheelchair, using a small, four-legged, wooden table that had been designed to rest just above her knees. However, that evening, the table was resting on her knees, and she asked me several times to reposition it for her. This involved folding up several paper napkins and placing them under the legs of her table, which meant that I had to lean down to the floor, wad up various levels of napkins and reposition the table.

On about the third or fourth attempt, when I was becoming impatient and even hungrier, I raised myself up from the floor to get back on my bench. This frail and lovely little girl then looked at me, smiled widely, and with her breathy little CP voice said: “I \textit{love} you.” I was hooked and have been ever since—now almost 40 years later! How could I not become a physical therapist?

\section*{What Can Clinicians Learn from Patients and Their Families?}

So what can we, as physical therapists, learn from the patients and families with whom we are privileged to work? Because much of my clinical career has been spent working with infants and young children, I interact a great deal with their parents and other caregivers. Many of these wise people have told me that although they want me to be honest, they also do not want me to take away their hope. Not surprisingly, I have heard similar comments from my fellow cancer survivors in regard to their dealings with oncologists.
In speaking of the impact that professionals had on her family, Cathleen Moeller, the mother of an infant with Down syndrome, wrote the following:

I feel that we as a family of a handicapped child need more than anything else the security these professionals offer us. We need to believe, to trust in these professionals when they tell us that their physical therapy will enable a child to walk more like a “normal” person, and therefore to be more readily accepted in society. …Most of all, we need to believe firmly that our child will grow to be loved just as he or she loves, and to be accepted as a worthwhile human.4

I was privileged to have been the first physical therapist in this infant’s life, now a young man who has graduated from high school. I was lucky to have learned so much from him and his family and invited his mother to speak to our entry-level students at UBC. In fact, one of my former students told me that Moeller’s chapter was the most important of all of the readings that had been required during her three years in our program.

In discussing what PT clinicians can learn from patients and their families, I will follow a typical continuum from history and diagnosis through to goal-setting and treatment as a way of organizing this section.

**Diagnosis: What Can We Learn?**

Physical therapists are becoming increasingly involved in diagnosis, a domain that belonged solely to physicians when I received my training in the late 1960s. Recent research has shown PT clinicians to be reliable and accurate in diagnosing musculoskeletal injuries when compared with findings on magnetic resonance imaging (MRI)—in fact, almost as accurate as orthopedic surgeons.5 Whereas orthopedists were correct in their clinical diagnosis compared with MRI findings 80.8 per cent of the time, orthopedic physical therapists were correct in 74.4 per cent of cases compared with non-orthopedic health care providers, who were correct only 35.4 per cent of the time.5 Physical therapists have also been shown to be extremely reliable in hip rating systems for total hip arthroplasty candidates6 and in classifying subgroups of patients with low back pain.7

A recent case report exemplifies how physical therapists listened to a patient in terms of his pain and symptoms, leading ultimately to a diagnosis different from the one for which he initially sought treatment.8 The patient was a 45-year-old man with low back pain and posterior thigh pain on the left, as well as tingling along the anterolateral aspect of his left lower extremity. Although “several components of the patient’s history and physical examination were consistent with a mechanical neuromuscular dysfunction,” the physical therapist also tuned in to the fact that the patient’s most intense pain was in the evening and night and that the restricted motion at the hip had an atypical pattern.8 Despite five PT visits, the patient’s symptoms continued to worsen, leading his therapist to refer him back to his physician for further examination. The patient was subsequently diagnosed with lung cancer that had metastasized to his spine and pelvis.

**One Clinician’s Experience in Listening to Parents to Inform Diagnosis**

In my own clinical work, I take part in diagnosing children with movement disorders or developmental delay. As in all clinical experiences, we need to use our own hypotheses or clinical “hunches” to inform our practice as well as our research. For a number of years, I worked as a physical therapist in the Neonatal Intensive Care Unit Follow-up Program at the University of Washington (UW). Because the initial follow-up assessment of infants at four months’ corrected age was performed by the physical therapists in the program, their parents were understandably anxious to see how their infant was doing.

When I walked out to the waiting room to greet the families, the first informal question I asked was “How do you think your baby is doing?” Invariably, if the parents reported that their infant was doing okay, my standardized tests supported that opinion. Conversely, if the parents had concerns, my assessment usually corroborated those concerns. This pattern caused me to develop a clinical hunch, that is, that parents were usually right in knowing how their infant was doing. Formation of a clinical hunch or hypothesis is consistent with Sackett and colleagues’ definition of evidence-based medicine (EBM),9 one component of which is clinical expertise, or the ability to use our clinical skills and past experience to identify each patient’s unique health state or diagnosis.10

It took me several years to test this hunch, and I used it in developing my own infant screening tool in the early 1990s. In other words, I incorporated into the test four questions to parents asking how they thought their infant was doing in the areas of movement and play. In this way, I was imbedding a second component of EBM,10 patient values (or the concerns and expectations each patient or family member brings to a clinical encounter), into my research question: “How accurate are parents/caregivers in...
determining if their high-risk infant is developmentally on target or developmentally delayed?"

Although I was new to this particular area of research, I knew that there was a prevalent feeling among pediatric professionals that parents tended to overestimate their child’s abilities. Fortunately, others had already contributed to this line of research and had dispelled that myth and found that parents and caregivers were quite reasonable in providing estimates of their child’s development. In fact, my own research, published in 1994, led to similar findings. When comparing parents’ estimates of their high-risk infant’s motor development with standard scores on the Bayley Motor Scale, parents were correct 80 per cent of the time (sensitivity) in believing that their infant was delayed and were also correct 91.9 per cent of the time (specificity) in estimating that their infant’s development was on target.

Sarah’s Story

In the early 1980s, I was a consultant to a program for young children with special needs in Reno, Nevada. There I was introduced to a two-year-old girl, Sarah, who had been diagnosed with CP, and her mother. The diagnosis evolved out of a prolonged and difficult labour and delivery, as well as the fact that Sarah had profound, generalized hypotonia and significant motor delays. I took one look at this little girl and was certain that she did not have CP. Instead, I suspected that she might have some type of genetic syndrome or muscle disease.

I asked Sarah’s mother if I could share my assessment results and a photograph of Sarah with several specialist physicians with whom I worked at UW. She was delighted at this opportunity and immediately agreed. What complicated this situation even further was that Sarah’s mother was four months pregnant with her second child.

Based on my consultations with several developmental pediatricians, a medical geneticist and a child neurologist, it was strongly suspected that Sarah actually had a muscle disease, likely of genetic origin. I immediately wrote to her mother and explained the opinions of these physicians.

A few weeks later, I received a very terse letter from Sarah’s mother, thanking me for my time and effort but firmly requesting that I do no further investigation. It was clear to me that she was upset, which made me feel similarly so for having “interfered.” Several months later, Sarah’s little sister was born—with profound hypotonia and significant motor delay, as well as facial and other unusual features that were identical to Sarah’s.

Some time later, Sarah’s mother wrote back to thank me for investigating the possible cause of Sarah’s weakness and hypotonia. I asked her to help me to try to be more sensitive in dealing with parents of children with special needs in the future. She wrote back to me with a list of eight suggestions, entitled “Hints for Professionals.” This list appears in Table 1. Pay particular attention to suggestions 2, 5 and 8.

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<th>Table 1. Hints for Professionals from Sarah’s Mother (It was hard to limit this list to less than 1,000!)</th>
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<tr>
<td>1. Try not to make rash judgments about infants. Sarah has been termed both the “most pitiful” case ever seen at the special children’s clinic and the greatest success story. Don’t give up when they’re so little!</td>
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<td>2. If you see behaviours that don’t fit the given diagnosis, MENTION IT! Tell parents your suspicions, so a correct diagnosis can be sought right away. That doesn’t mean parents won’t reject your thoughts or hurl anger your way, but they’ll be thankful in the long run for your honesty.</td>
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<td>3. We appreciate professionals who can look at each child as an individual. Our daughters have the same diagnosis but are very different in capabilities and susceptibility to illness. We love professionals who can say, “In these cases we usually..., but what I think Sarah needs is...”</td>
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<td>4. Put parents in touch with other parents as much as possible. It not only offers support, but seeing another parent’s child with the very diagnosis they fear most will also help rid them of some of their fears. It really helps to see someone who has survived it all.</td>
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<td>5. Don’t underestimate your terrific influence on parents. You may see only our fear and anger, but sometimes you are our only outlet and the child’s only source of help.</td>
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<td>6. Lead parents to other resources. The system is hard to navigate. Whenever possible, be honest about which professionals would be best for the family and suggest second opinions when families are obviously receiving false information or improper care.</td>
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<td>7. Try to be well-informed about the specifics of each diagnosis. Some disorders are accompanied with specific health risks. I’ve seen dangerous things happen because a professional was unaware that a certain procedure placed the child at risk.</td>
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<td>8. Offer hope whenever possible, but be honest at all times. It’s harder to face the truth later than it is sooner, no matter how brutal the truth may be.</td>
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Examination and Goal-Setting: What Can We Learn?

Moving along the continuum from history-taking and diagnosis, the next clinical step is to conduct some form of assessment or examination that will then enable the physical therapist to set goals with the client. Clients and their caregivers should be integrally involved in decisions about what types of assessments they wish to have as well as in developing goals for treatment.

I think back in horror to my earlier days as a clinician when I assessed babies with Down syndrome on the Bayley Scales of Infant Development, a norm-referenced test, so I could determine how delayed they were in their motor and cognitive skills. What useful purpose did this serve for families? Did it not further emphasize what a known diagnosis had already provided, that infants with Down syndrome would be delayed?

It was 15 years ago that Cott and Finch stated in our own professional journal that “active participation by the client in the goal-setting process is of primary importance.” How are we actually doing today? Are we “talking the talk” or actually “walking the walk”? What does the research have to tell us?

In 2001, Baker and colleagues described the involvement of elderly clients in goal-setting at the initial PT examination. Initial examinations by 22 physical therapists of 73 elderly patients were audiotaped and then scored by the researchers using the Participation Method Assessment Instrument. Although the therapists believed patient participation to be an important part of high-quality care and that such participation was associated with successful outcomes (“talking the talk”), the study results revealed that patients were seldom involved in the goal-setting process. On only 19.4 per cent of occasions were the patient’s major concerns confirmed by the therapist. Similarly, the PT collaborated with the patient or family in goal-setting only 18.9 per cent of the time. Even more discouraging was the infrequency with which therapists discussed how the patient might participate in goal-setting and treatment planning (6.8 per cent) or how often they asked the patient to prioritize her or his concerns (3.2 per cent).

Treatment Planning: What Do Patients Have to Say and What Does the Research Tell Us?

A 2004 systematic review of 95 qualitative studies involving persons with stroke found that only one study (from Hong Kong) specifically allowed clients to identify their own needs for rehabilitation. This is especially discouraging since qualitative researchers are usually more client-centred than quantitative researchers, especially those who conduct participatory research. According to Bendz, although patients and professionals are similarly concerned about addressing the patient’s physical disability, their priorities for treatment often differ.

This difference in therapist and patient priorities was noted also by Bonnie Sherr Klein, an award-winning filmmaker, in describing her personal experience with having sustained a stroke. When sharing her own treatment plan, which included acupuncture, with her physical therapist, he advised her to stop that treatment: “If you do so many therapies at once, how can you tell which one is working?” Klein’s muttered response to herself was “I don’t give a damn which treatment works. I just want to get better.”

This frustration with differing expectations for rehabilitation between clients and their health care providers was also echoed by a participant with spinal cord injury (SCI) in discussing his own experiences with rehabilitation in a study by Carpenter: “All the things they told me I couldn’t do are proved wrong now. Every time there’s one more thing I can do that they told me was impossible in my life, I realize that being handicapped is a lesser problem than they led me to believe.”

In her implications from the study results, Carpenter noted the following:

The findings of this study suggest that the target of an education program may not be those individuals with SCI, but instead health care professionals. …It is not the actual content of the rehab programs that is inadequate but rather that those interventions must be tailored to capitalize on the individual’s life experience and personality to suit the particular needs identified by the individual.

Professional Power, Decision-Making and Patient Values

Health care professionals, including physical therapists, are often unaware of the tremendous power imbalance between them and their clients. Allan Macurdy, a lawyer who also happens to have muscular dystrophy, wrote about his experience of being placed in an iron lung for a respiratory infection, just when he was in the midst of his bar examinations and job search:
In that hospital experience I learned many things about the medical system that had nothing to do with treating disease or caring, but everything to do with power. Legally, all legitimate power is vested in the patient, providing, of course that he or she is mentally competent and conscious. ...The device best suited to enhance the power of health professionals is their virtual monopoly on medical knowledge. Lack of access to information, except through such a professional, is extremely intimidating and causes the patient to give up a great deal of power. The institutions also coerce the patient through the loss of privacy and scheduling autonomy.

Macurdy went on to describe the power imbalance further:

Even the everyday language is laden with authoritarian nuance. If I as a patient were to decide, for any reason, not to take a given medication I would be described as “refusing treatment”, not “making a decision”. If I were asked if I were in pain and answered in the negative, I would be “denying” pain, as if the pain exists but I just will not admit it. If I were to “deny” or “refuse” too often, I would be labeled “non-compliant”. These few examples are indicative of at least a habit of mind, if not a system of belief, that regards patients as, at best, children in need of parental figures to make decisions for them, and confers superior status on the practitioner.

And from the voice of an 11-year-old girl who described her medical history to be “as big as a football field”:

I think parents should always listen to their kids, and if they refuse the test parents should not agree to do the test. They should start letting children be part of the medical decisions at age 9 because they are able by that age to make good decisions. There was a doctor who would wake me up at 5 o’clock in the morning just to ask how I was doing. I said, “I was doing just fine until you came in here and woke me.” I thought the guy looked like a chipmunk, so I put a sign on my door that said, “No chipmunks allowed until 8 a.m.” He never came back early in the morning again.

In his chapter, Allan Macurdy outlined four principles that governed his interactions with health care professionals (Table 2). To exemplify the fourth principle, he described having had a tracheostomy, with increased susceptibility to respiratory infections, and being advised by his health care team to eliminate all sources of risk and protect himself at all costs:

But that could happen only if I were willing to live apart from other people in some kind of bubble. I would not be able to teach, represent clients, see friends, have an intimate life with my wife, play with my nephews and godchildren, or hug my dog. In other words, all those things that gave my life value, purpose and meaning would be sacrificed in order to protect me from infections that might kill me. Who would want to have such a barren, empty life? ...So instead we take reasonable precautions, in the context of the life I choose to lead, and accept the risks and consequences of a meaningful existence. I am fully aware of the dangers, and my choices are the result of a rational decision-making process, but even if these choices are arbitrary and irrational, they are my choices and may not be gainsaid.

What Can Clinicians Do to Listen to Patients to Ensure Their Involvement in Goal-Setting and Treatment-Planning?

There are a number of reasonably simple steps that physical therapists can take to ensure involvement of their clients in setting collaborative goals and planning treatment. Listed in Table 3 are just a few sequential steps to get you started.

**Table 2. Macurdy’s Principles to Govern His Interactions with Health Care Professionals**

1. As the person with the greatest stake in my health care, I make the decisions and no health professional can overrule my preferences.
2. I am the only legitimate decision-maker and no one else is permitted to speak for me.
3. I must have complete information about my medical situation (including access to my medical chart).
4. I must have a meaningful life and a life that I desire, even if that conflicts with best medical opinion.

Adapted from Macurdy AH.
Examples of credible websites aimed at informing both clients and practitioners include StrokEngine (www.medicine.mcgill.ca/strokengine/), the CanChild Centre for Disability Research (www.fhs.mcmaster.ca/canchild/) and the Center for Evidence-Based Practice (www.researchtopractice.info).

**WHAT CAN EDUCATORS AND STUDENTS LEARN FROM PATIENTS AND THEIR FAMILIES?**

In reviewing the Centre for Evidence-Based Medicine components of EBM, I believe we are doing an excellent job of contributing to the “best research evidence” in rehabilitation, the first of the three components included in the EBM definition. As well, PT has always been a strong profession and physical therapists are highly regarded by our professional colleagues and our patients with respect to our “clinical expertise,” the second of the three components of EBM.

What is sadly missing from much of our own literature, our teaching and perhaps also our clinical practice is our willingness to embrace patient values, the third component of the definition, as a central theme of evidence-based practice. As educators for the physical therapists of the future, we need to incorporate patient voices and patient values into our teaching and learning endeavours.

What can educators do to model the importance of patient voices for their students? Table 4 includes a few suggested activities, many of which are likely already being incorporated into entry-level PT programs in Canada.

**WHAT CAN RESEARCHERS LEARN FROM PATIENTS AND THEIR FAMILIES?**

Certainly, qualitative researchers have been the most effective in incorporating the voices of patients and families into their research:

The inclusion of the patient’s experiences and values is an integral component of qualitative health research. By including patients or clients as participants or co-researchers, rather than as subjects to be studied by others, qualitative research directly encompasses patient values into the design and execution of those studies.

For example, the patient’s (or family’s) voice has been reflected in qualitative studies exploring a variety of situations: the identification of rehabilitation needs after stroke, parental adjustment to having a child with CP and participating in home therapy programs, the experiences of adults with SCI in rehabilitation settings and adaptive choices for a middle-aged adult with CP.

Although inclusion of patients’ or consumers’ values and experiences has been integral to the design and execution of qualitative health research through their roles as participants or co-investigators, consumer involvement in quantitative research has more typically been in the traditional role of subjects. However, recently, consumers’ voices have been used in designing quantitative research trials. For example, consumer input was used to assist in designing a randomized controlled trial (RCT).

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<th>Table 4. Steps for Educators in Modelling the Importance of Patient Voices for Students</th>
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<td>1. Invite patients and their caregivers to be (paid) guest speakers in the classroom. Ask students to prepare several questions in advance of the class.</td>
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<td>2. Include required readings of qualitative studies that will inform students about what clients or families value in rehabilitation.</td>
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<td>3. Include a book written by a patient as required reading and development of a book review (for publication in <em>Physiotherapy Canada</em>).</td>
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<td>4. Have students interview a patient about his or her personal values concerning what the patient hopes to gain from physical therapy.</td>
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<td>5. Develop case scenarios in which a client values/preferences a treatment for which there is no good scientific evidence or one that could potentially cause harm. Have students review the existing evidence for the treatment and develop strategies to share with the client.</td>
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to examine the risks and benefits of thrombolytic treatment for acute ischemic stroke. The consumers contributed to refining the study’s consent procedures and developing an ethically appropriate study design.

Fortunately, involvement of consumers in research development appears to be a growing trend. In 2001, the results of a national survey of 62 clinical trial centres in the United Kingdom demonstrated that 37 per cent of the centers had involved consumers in designing, conducting or interpreting RCTs and 27 per cent planned to involve them in the future. This study’s authors concluded that “consumer involvement in the design and conduct of controlled trials seems to be growing and seems to be welcomed by most researchers. Such involvement seems likely to improve relevance to consumers of the questions addressed and the results obtained in controlled trials.”

WHAT CAN RESEARCHERS DO TO INCLUDE PATIENT VOICES IN THE DESIGN AND EXECUTION OF THEIR STUDIES?

PT researchers, whether they are quantitative or qualitative in their approach, need to involve clients in developing research questions that are important to the clients themselves. Clients should be involved in study design from the onset. Using client-centred goals as outcome measures in clinical trials or single-subject designs provides another effective means for ensuring that client goals and values are embedded into the study. Finally, clients could also be involved in contributing to the research article and in translating the knowledge gained from the study to other clients.

My dream is to see Canadian PT researchers take the lead in involving clients in the design, development and conduct of future rehabilitation studies.

CONCLUDING REMARKS

As I hope is clear from the foregoing comments, I firmly believe that we have much to learn from the voices of our patients and their families, not only as clinicians but also as educators, students and researchers. In Enid Graham’s obituary, her “personal warmth and interest in others” was specifically mentioned (Figure 1). Although I never had the good fortune of meeting her, I strongly suspect that that warmth and interest in others extended to her patients as well.

Most of us entered this wonderful profession because we wanted to help others. Unfortunately, that was a somewhat paternalistic (or, perhaps, maternalistic) goal, albeit a well-meaning one. Rather than helping patients by assuming our traditional position of power, we need to work in partnership with them to develop goals and treatment plans and to evaluate the effects of those interventions together. Further, we need to model the importance and inclusion of patients’ voices and values into our teaching so that future physical therapists will understand the collaborative role we share with patients or clients. Finally, we need to lead the PT research world by involving clients in the development of research questions that are important to them, as well as in the design of those studies and the translation of their results.

REFERENCES
